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SUPPORTING BUDDHIST IDENTITY
IN LONG-TERM CARE SITUATIONS

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DOCTOR OF PHILOSOPHY

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The Triratna/FWBO Buddhist movement has been associated with younger people and a lifestyle in which single sex residential communities and work projects (TBRLs) have been prominent. There is now a trend towards a wider range of lifestyles including fewer people living communally. Demographic changes include 50+ average age for ordained members and some people developing Long-Term Care (LTC) needs, with limited family and financial support. This raises questions as to the extent to which 'Buddhist identity' can be supported in LTC situations, with informal care, mainstream LTC services and possible care-based TBRLs all relevant.Data-gathering was initially on the basis of a general investigation of LTC issues in Triratna/FWBO using an eclectic, primarily qualitative design which had features of both a case study and a cross-sectional survey. 17 interviews included participants with current LTC needs, others asked to anticipate future care preferences, and people with relevant expertise. A questionnaire was formulated to explore attitudes to possible care-based TBRLs, with 107 participants and numerous additional comments. There was a strong consensus that Buddhist-based LTC services would, for example, provide better vegetarian diets and have an understanding of Buddhist names taken at ordination. These features were included in a conceptualisation of Buddhist identity which contrasted 'Buddhist' and 'Non-Buddhist' life, and noted 'Dreams' and 'Nightmares' as to LTC. Effective basic care was seen as essential to the general level of well-being needed for Buddhist practice, whilst a higher level of support might facilitate access to Buddhist 'life goods', and assist people in self-verifying themselves as committed Buddhists through ongoing practice. Informal support from fellow Buddhists was available in many contexts, but not at levels of intensity and duration characteristic of some family-based care, and it was seen as modulated by perceptions of burden, 'busy-ness' and other factors. There was a 'legacy of suspicion' of mainstream LTC, mainly focussed on residential care, with acknowledgement of some good/respectful carers and care services . TBRLs in LTC were generally welcomed, being seen as suitably altruistic work which might feature an atmosphere of 'mutuality' between staff and clients who were Buddhist or of Buddhist sympathy. Comparative material was used here from Methodist, Jewish and Lesbian/Gay/Bisexual/Transgender (LGBT) communities in LTC contexts, with the last of these conceptualised as comparable to the Western Buddhist community as a currently emerging identity in terms of later life services. Practicality and feasibility were discussed with reference to existing TBRLs, and experience of paid-for care input between Buddhists. The latter appeared supportive of Buddhist identity and readily linked to the personalisation agenda in social care. Buddhist-friendly services were seen as a possible context for generativity, and the concept of 'a natural part of life' was explored in terms of the emergence of LTC in the Triratna/FWBO movement,and of Buddhism as a gradually more familiar identity which might be encountered in the sphere of LTC.

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PART ONE – INTRODUCTION

CHAPTER ONE: INTRODUCTION TO THE STUDY

Overview Of Structure And Content

This study arose from some practical questions in which I became especially interested from 2001 onwards. From explorations of these emerged an initial title, and later the present one, with the research questions modified along the way. I believe it to be a contribution to knowledge in that I am not aware of any other studies that consider the general long-term care (LTC) of *Western* Buddhists, by which I mean people who have become Buddhists after a predominantly Western upbringing. The study is mainly concerned with the UK and with one specific movement, the Triratna Buddhist Community (known as the Friends of the Western Buddhist Order-abbreviated as FWBO- from 1967 until May 2010). The primary focus is on older people in the present and the future, although the experience of younger people is often drawn upon in relation to care systems. In this introductory chapter I first discuss the beginnings of the research with reference to what prompted my specific interest, some personal aspects of this inquiry and early considerations in formulating a research approach. Next, I review my first proposal and discuss progress made and difficulties experienced. Third, I outline how the study was refocused and given the new title *Supporting Buddhist Identity in Long Term Care Situations.* Lastly, I present the revised research questions which have latterly guided the study and offer some preliminary remarks about key literature and reference points.

The thesis is arranged as follows: Part One consists of Chapter One (Introduction to the Study) only; Part Two comprises Chapters Two to Five and reviews the literature and other background material. The review addresses the key terms in the title in the following order-

- Chapter Two considers some central aspects of Buddhism, presenting first general features and then elements more specific to the Triratna/FWBO movement. The central concern throughout is to elucidate the concept of Buddhist identity, which is seen as likely to be closely linked to the lifestyles and levels of commitment of individual Buddhists.

- Chapter Three examines identity in more detail and explores the idea that the FWBO's foundation in 1967 was linked to an era when identity politics began to develop and 'Western Buddhist' could be viewed as what I call here an emerging identity. Some parallels in care contexts with another emerging area of identity – lesbian,gay,bisexual and transgender (LGBT) people – are noted plus some evidence in relation to what are here termed traditional identities. The latter are drawn from research with a Christian (and mainly Methodist) group, and from a study of services for frail elderly Jewish people. Key reference points are Taylor's work on the self, Kitwood's on personhood and relevant themes from developmental psychology approaches applied to ageing.

- Chapter Four considers material relevant to the main forms of LTC available in the UK, primarily regarding frail older people.

- Chapter Five concludes the literature review under the overall title of *Supporting Buddhist Identity in Long Term Care*. There is a summary of material from the previous chapters and further attention is given to Buddhism, frailty in later life, and LTC. In Chapter Two the Triratna/FWBO tradition of Buddhist work projects have been introduced. These were originally known as co-operatives and are now called Team-Based Right Livelihoods (TBRLs). At this point the possible application of TBRL principles and practices to LTC is explored with reference to the part they might play in supporting specifically Buddhist identity in relevant situations.

The study's methodology is considered in Part Three, which comprises Chapters 6-8

- Chapter Six looks at the choice of a primarily qualitative methodology and the selection of methods appropriate for the study.

- Chapter Seven gives an account of data collection and data analysis. A group of six people ordained into the Triratna/FWBO – henceforth called Order Members – were interviewed about their current care needs and another six Order Members gave interviews about their anticipated care preferences if they should need LTC in the future. Next a series of interviews was conducted with people considered to have expertise relevant to the study. The final phase of data collection involved a questionnaire on LTC filled out by a wider group of Triratna/FWBO respondents. All of the interviews but two were with Order

Members. It is important to note the distinction between the Order and the movement: the former refers to people *ordained* into the Triratna/FWBO and the latter to everyone involved with Triratna/FWBO. The different levels of involvement are explained in Chapter Two. The verbal data, from the interviews and the 'additional comments' of questionnaire participants, were analysed using an NVivo-7 software programme.

- Chapter Eight reflects on key methodological issues, with sections on ethical aspects of the study, its validity and reliability and the perceived strengths and limitations of the research approach.

Part Four continues and concludes the study as follows;

- Chapter Nine gives an account of key themes and sub-themes in the research findings.

- Chapter Ten discusses the findings with reference to the relevant literature and background material.

- Chapter Eleven presents the conclusions reached by this study.

Beginnings

In July 2001 I completed a four-month retreat in Spain during which I was ordained as an Order Member within the FWBO. Shortly after returning to the UK in I attended the International Order Convention, a large biennial event to which all Order Members worldwide are invited.

In the methodology section below I give more detail of how, at the Convention, I noticed the deteriorating mobility of an Order Member, then in his seventies and here given the pseudonym SA. I talked to him about his health problems and asked if we could maintain contact. My subsequent visits to him followed his move into more intensive LTC situations, from his home to hospital and then to a care home.

What prompted my visits and general interest? One aspect was my professional involvement in care. In the 1970s I trained to work with people with learning disability in a large old hospital/'asylum', and then as a registered general nurse. Later my career

took me into mental health nursing in London and Canada, followed by ten years working in higher education teaching a range of health-related courses. In 1999 I left my university job, primarily to focus on my Buddhist life, and have returned to hands-on care as a livelihood. This has included part-time staff nurse posts in a dementia care unit and since 2004 in a specialist nursing home for people disabled with neurological conditions, a minority of whom are past retirement age.

Observing SA's difficulties thus activated elements of what I had learned over the years as well as some concerns for the future, as I sensed that he would need increasing levels of support as time went on. It also sparked off some anxieties even closer to home. I am unsure how much I reflected on this in 2001, but in retrospect I believe I was also worried in some measure for myself. In middle life I had left a relatively secure and well-paid job. I am a single and childless man. Increasingly my time and energy were focused on Buddhist activities and shared with Buddhist friends. If at some future time I needed support and/or care I would be most likely to look to people in the Triratna/FWBO. What could I expect? If informal support proved insufficient I might need care from mainstream services. LTC is often said to be variable in quality, with financial resources a factor, and I had elected to live on a considerably lower income than before.

Subsequent informal discussion around the Order and movement indicated that others share a measure of this anxiety about LTC, with lifestyle apparently a key factor. In fact, SA had been ordained when already in his seventies and had some family support and financial resources. If anything, people's concerns seemed more centred on those who have worked in Triratna/ FWBO full-time from a relatively early age. An example might be someone who has worked for the movement as a gardener at a rural retreat centre for many years and has not built up any financial security or close family links such as with a live-in partner, spouse and/or children.

Nonetheless, SA was amongst the first Triratna/FWBO people to live in a care home. I had been aware of a female Order Member who became involved in Buddhism in her seventies after an active life in other spheres, including having a family. Her final years were spent in a care home in the north of England. From people who knew her well, I understood that she appeared to have developed a measure of cognitive impairment and it seemed that interviewing her would be problematic. I never met her, and she died in 2008.

Whatever people's family and financial circumstances, SA's admission to a care home began to throw up questions about how a Buddhist might fare in an LTC situation. Triratna/ FWBO Order Members are given a Buddhist name at the time of ordination and some, like SA, prefer to be known by this name at all times. Would people at a care home respect and understand this? What about his vegetarian diet and practice of meditation? Would anyone take an interest in his Buddhism as part of his identity? However well-intentioned, staff might not know where to start talking to him about a way of life that is relatively rare in the UK. Also, although the elderly woman Order Member mentioned above played no personal part in the study, informal information about her apparent cognitive decline prompted further reflection. What are the implications for Buddhist practice where dementia is seen as a key factor in a Buddhist's need for LTC? For example, someone might have had many years of strong identification with Buddhist principles and practices, but cognitive impairment might render her/him less able to initiate and maintain Buddhist activities. A mentally frail individual may gradually become less able to look after a personal Buddhist shrine which has always been an important feature of her/his daily spiritual life. In a residential context, would care staff be able to offer suitable support?

Another aspect came to mind at quite an early stage of the research. I lived in Buddhist residential communities for 13 years from 1995, sharing houses usually with three or four others. In the early days all my co-residents worked in a gift shop in Ipswich in the UK, which was and remains a specifically Buddhist TBRL –*Team-Based Right Livelihood*-project. As discussed in Chapter Two, TBRLs are closely associated with the Triratna/FWBO vision of Buddhism. Right Livelihood is part of the Noble Eightfold Path which a Buddhist takes up to make spiritual progress (Bhikkhu Bodhi 1994). Whilst some occupations are ruled out ,for example working in a slaughterhouse, many forms of livelihood are acceptably neutral, although ideally Buddhists earn their living through altruistic activity. This can take many forms, with traditionally the greatest benefit to others seen as coming from spreading the Dharma (the Buddha's teaching). TBRLs such as gift shops, vegetarian restaurants and wholefood outlets emerged in Triratna/ FWBO as a way of funding Buddhist activities and a means for Buddhists to earn a living and work together as a form of spiritual practice.

Although I was in a minority of one in my community as a non-TBRL worker, my work in the care sector *is* a Right Livelihood, albeit not in a team with explicitly shared

values beyond professional and legal requirements and local philosophies of care. Many Buddhists, Triratna/FWBO or not, are comparably employed in the care sector; for example, in the men's wing of the Order I am aware of at least seven other registered nurses. In the 1990s there was an attempt to found a care-based TBRL with a learning disability community service in the north-west England. For various reasons this project stalled at the planning stage. There now might be a case for revisiting these ideas to see if LTC provision could be developed on a TBRL basis with a service offering care to people from a range of backgrounds whilst remaining particularly sensitive to the needs of Buddhists.

On a further personal note, this research period has coincided with my parents increasing health needs. Both are in their eighties: my mother recovered well from a mild stroke in 2003 but my father has required domiciliary personal care for some years and during a five-month hospital admission in 2008 he was diagnosed with idiopathic normal pressure hydrocephalus (see Gelling 2007). He is now unable to walk and has other health problems, and is supported by domiciliary care four times a day. My parents' experiences have illuminated a number of aspects of LTC from the care recipient/relative's perspective.

In this and other respects the study has prompted personal reflection and brought to mind some of my own experiences, some of which have seemed relevant and appropriate enough to be included in this thesis.

First proposal

After many informal conversations and some searching of the literature I registered for an MPhil research degree in 2004. Within the movement I had received a number of suggestions about 'people you should talk to', typically people with care needs of various kinds, several of whom I had never met. I believed that studying for a research degree would provide a structure for what I wished to do, and that when meeting people with relevant experience I would be able to take along a reasonably systematic outline of areas to explore. Notwithstanding wanting to be as systematic as possible I had little interest in a quantitative survey of care needs and was keen to find an approach within which personal narrative and individual experience were valued.

I had friends in various situations in Triratna/ FWBO, but my day-to-day knowledge of the movement was largely based on activities in two ***medium-sized*** towns, one where I began attending classes in 1990 and a second less than 20 miles away where I had done much of my preparation for ordination and then contributed as an Order Member. I knew much less about bigger situations such as the large urban setups where the Buddhist Centre dwells amidst what is sometimes termed a ***Buddhist village*** of associated residential communities and TBRLs. I also was less familiar with what I call ***outposts*** of the Triratna/FWBO, where classes are offered in rented rooms and features such as TBRLs and communities are usually absent. As many activities in the Triratna/ FWBO operate on a single-sex basis I also knew considerably less about the women's wing of the Order, never having visited a women's residential community or the two UK women's retreat centres. It was not that I had any grand notions of 'perfect' sampling, but in contemplating this project I had a strong sense of having much to learn and of needing to broaden my horizons in relation to Triratna/FWBO, to LTC issues and to areas such as research design. I was intrigued by the prospect of academic research on a subject to which I had a strong personal commitment. Also as someone who loves good writing in its many forms I wanted to see if I could eventually produce something that was readable as well as effective from a research perspective.

Further work yielded an MPhil research proposal that was accepted by the university, with the working title *LTC Issues in a British-founded Buddhist Movement.* By the latter part of 2004 I was more aware of people who might be willing to participate in the study and had identified three groups of people that I wished to interview. First, a group with current care needs, for which SA was clearly a candidate and had signalled his willingness to help. Although I had been focusing on age as a factor, several people were mentioned to me whose illness/disability was not specifically age-related.

The second group I wished to interview would be people over 50 years of age who would anticipate their care preferences and whose exposure to LTC issues to date might be through relatives (typically mothers) with such needs. A fellow researcher suggested that this was an unusual form of Vygotsky's 'proximal development', a concept more usually applied to childhood, where much of a child's everyday knowledge of adult-world processes and tasks is acquired through being around the adults involved in them (see Chaiklin 2003). Whilst the Vygotsky parallel should not be extended too far, it had some salience. Here the grown-up offspring were introduced, via the parent's experience as a care recipient, to various spheres of LTC which might include informal

care, paid domiciliary care, residential care homes and hospitals. Often exposure to these is extensive. I hoped that this group would help me to develop views about LTC in general and that their input might in turn be applied to their *own* preferences if they had comparable care needs in the future.

Semi-structured interview schedules were developed for these two groups. I adopted a more varied and generally less structured approach for the third sequence of interviews with a group of 'experts' in the field of LTC. One participant in this group, Padmasuri, had been a nurse and midwife and then worked for many years in the movement's TBRL gift business and had written a book about this project. I wondered how she might apply the latter experience to the prospect of care-based TBRLs and other issues. Also included in this group were two people I met during my visit to San Francisco Zen Center, with our interviews looking at various aspects of Buddhist practice in relation to care.

Completing the interviews and contemplating the use of a questionnaire for the next stage, I noted my mixed feelings. Certainly there was a positive sense of being considerably more immersed in what I was investigating, but this was blended with a general sense of disquiet. The data collected thus far was rich, stimulating and suggestive of a number of areas for further inquiry. But I had yet to identify the main focus of my interest. Perhaps linked to this tension about my aims, I noticed a change in my ideas for the proposed questionnaire.

Re-formulation

On page 7 above I refer to the provisional title *Long-Term Care Issues in a British founded Buddhist movement* to which I had been working. The research questions focused on Triratna/FWBO Buddhists' experiences and views of mainstream LTC services and informal care and support and their views of possible LTC services with a Buddhist/TBRL foundation. Linked to these was a theoretical/conceptual framework that I had devised with reference to three key cultural themes; diversity, values and community. In due course this framework proved unsustainable, and problems arising from this were doubtless surfacing as I planned the questionnaire for the next phase of data collection.

I wrote at the time in my journal that: "I get the feeling that FWBO Buddhists experience mainstream LTC as good, bad and indifferent… like everyone else!". Also, of course, many people might have no experience of relevant forms of LTC, and any

questionnaire items that assumed exposure to some form of LTC might cause potential participants to opt out. In due course I realised that the questionnaire approach should be less concerned with seeking out actual experience than with participants' views. In line with this I determined to use an attitude scale centring on TBRL-type LTC services or what could be termed **_Buddhist-based care services (BBCS)_** which do not presently exist in the UK. On this basis the questionnaire was formulated and it was completed by 107 people around the movement (62 of whom were Order Members). An unexpected feature of the responses was the emergence of extensive additional comments and these greatly enriched the data set.

In the autumn of 2006 I started attending meetings of the Buddhist Healthcare Chaplaincy Group (BHCG). This initiative stemmed from a Department of Health commitment to extend and develop multi-faith chaplaincy in healthcare settings, and it brought me into more contact with Buddhists from other traditions, including the Samatha Trust, the Amida Trust and Rigpa Spiritual Care (UK). On an informal basis I was certainly learning a lot from this involvement, and considered seeking more data from Buddhists outside Triratna/FWBO. However, my supervisors advised me to focus on the material I had already gathered and on reflection I realised that this was the right approach.

During 2007 I decided to try to take the research onward towards a PhD, and at around the time of my Confirmation of Candidature panel in November 2007 I began to wonder if a new focus and a new title were needed. At the panel meeting I was challenged about the wide-ranging nature of the inquiry thus far. Some notably Buddhist material had emerged along the way (e.g. in relation to vegetarianism in LTC) and I have already mentioned the unsatisfactory nature of my theoretical/conceptual framework.

In the week after the panel meeting an idea duly came to me. Reviewing some of the data, particularly the additional comments on the returned questionnaires, suggested that many people's hopes of a positive experience of LTC (if such is needed) and their concerns about possible negative situations could be represented under the heading of 'identity'. Sometimes this was expressed in terms of individual or personal needs being respected and understood and sometimes it was linked more explicitly to Buddhist and spiritual factors. It also seemed to link readily to the Dignity in Care Campaign which the Royal College of Nursing (RCN) was promoting at the time (2008)-see also Birrell,

et al.(2006). The RCN's perspective that dignity was something that can be supported or undermined in a care situation was particularly salient and seemed equally applicable to Buddhist identity.

As the research went on, intriguing aspects of my participant observer status and questions about objectivity came to the fore. My reflective journal contains the observation that a number of Triratna/FWBO people seemed (erroneously!) convinced that I was determined to open a Buddhist residential care home. The study *is* intended to have some practical outcomes. I acknowledge that it would be difficult to convince me that Buddhist identity would be given optimum support in every LTC situation, and this implies a range of ameliorative initiatives with which I might be able to help. Such initiatives might include the establishment of Buddhist/TBRL-based care services, although again decision-making on this would have to include scrutiny of the desirability and feasibility of a number of different models of care. I hope that at least the study would help in making decisions as just detailed.

After some further work on the new focus on Buddhist identity it now was possible to reformulate the research questions.

Research Questions (Revised)

The data set was reviewed with the study's new focus in mind. It appeared that notwithstanding the change of emphasis, little of the existing material had been rendered irrelevant. Concern with Buddhist identity linked most readily to the individual level, where people share their personal experiences and views. For example, people might speak of their Buddhist identity being potentially vulnerable in certain situations, including LTC contexts, and participants' data might concern actual occurrences or relevant hopes and fears. These contributions might typically reflect aspects of identity and personhood which are closely linked to their Buddhist practice.

Nonetheless, a participant might for example take the view that her Buddhist identity would be best supported if she could 'age in place' at the rural retreat centre where she has lived for some years. In the event of severe frailty key questions would then centre on the availability of informal support and care, with her co-residents probably the first resort for this and other friends and family potentially also assisting. If a residential care home is unavoidable, questions asked of SA such as 'What about the vegetarian diet?' would arise and have a bearing on the maintenance and support of Buddhist practice and

identity. Finally, I have already mentioned my interest in TBRLs and the data included hopes that if established they might support Buddhist identity. Some of the organisational issues of TBRLs could seem remote from the individual client's experience e.g. would such projects be financially viable? The counter-argument here was that exploration of practical feasibility was essential and relevant, because all discussion about such services was predicated on their viability, and, to coin a summarising phrase; "They will not support anyone's identity if they cannot be established in the first place".

The new research questions were identified as follows:

1) How might identity and personhood be conceptualised in relation to people involved with Triratna/FWBO?

2) Within the Triratna /FWBO Sangha, what factors would influence the level of informal support which someone with care needs receives?

3) How do Triratna/FWBO people experience and/or view mainstream LTC services in relation to support for Buddhist identity?

4) How do Triratna/FWBO people view the possible application of Buddhist TBRL principles to the LTC sector and its implications for the support of Buddhist identity?

My task was to consider the above with reference to a range of literature and background material, the selection of which is discussed in the introduction to Part Two.

Triratna/FWBO Order Members are described as neither monks/nuns or lay people. (Sangharakshita,1988a). They are not unique in this respect, with Shinran in 13th century Japan a historical example (Kulananda,2000,p.223), and the priests at San Francisco Zen Center providing contemporary parallels (Chadwick,1999,p.271). However, such a stance can reasonably be said to be unusual and the ensuing lifestyles are of key interest here. A crucial question is how this type of Sangha copes with informal care needs, which gives rise to a series of interlinked questions which demographically will grow increasingly salient in future years.

Where formal mainstream care is needed there are ongoing concerns about quality of care, again raising questions about Sangha members' responsibilities to one another. Lee-Treweek (2000) gives a grim picture of a particular LTC setting where any form of valued identity appears highly vulnerable, and some of Kitwood's work on dementia and personhood is also relevant here. Can comparable services offer acceptable care and

respect to Triratna/FWBO Buddhists if needed, and beyond this, can they in any sense meet the spiritual needs of these Buddhists?

A final literature/background section summarises the key points and considers some additional aspects. It shares its title with the overall study title and reviews material on Buddhism and the Triratna/FWBO movement in relation to LTC issues. A particular reference point here is the possible development of TBRLs/BBCSs for frail older people: if this is feasible they may prove relevant in the support of Buddhist identity.

PART TWO- REVIEW OF LITERATURE AND BACKGROUND MATERIAL

Introduction to Part Two

As the study's title is 'Supporting Buddhist Identity in Long-Term Care Situations', literature and background material on key aspects will be reviewed in succeeding chapters as follows:

- Chapter Two will consider some central aspects of Buddhism. It begins with three sections on general features, followed by four sections which are more specific to the Triratna/FWBO movement. The central concern throughout is to elucidate the concept of 'Buddhist identity', with this seen as likely to be closely linked to the life-styles and level of commitment of individual Buddhists.

- Chapter Three examines identity in more detail and explores the idea that Triratna/FWBO's foundation in the 1967 was in an era when identity politics began to develop and Western Buddhist could be viewed as what I have called an 'emerging identity'. Some parallels are noted in care contexts with another 'emerging' area of identity, lesbian,gay,bisexual and transgender (LGBT) people plus some evidence in relation to what are here termed 'traditional identities'. The latter are drawn from research with a Christian (and mainly Methodist) group, and from a study of services for frail elderly Jewish people. Key reference points are Taylor's work on the self, Kitwood's on personhood and relevant themes from developmental psychology as applied to ageing.

- Chapter Four considers material relevant to the main forms of LTC available in the UK (primarily for frail older people).

- Chapter Five concludes the Literature Review under the overall title of *Supporting Buddhist Identity in Long-Term Care Situations*. There is a summary of material from the previous chapters and further attention is given to Buddhism, frailty in later life, and LTC. In Chapter Two the Triratna/FWBO tradition of Buddhist work

projects will have been introduced. These were originally known as co-operatives and subsequently termed Team-Based Right Livelihoods (TBRLs). At this point the possible application of TBRL principles and practices to LTC will be explored, with reference to the part they might play as BBCS (Buddhist Based Care Services) in supporting specifically Buddhist identity in relevant situations.

Note on Literature Searching

The literature for this study was inter-disciplinary and potentially very extensive. Internet searches indicated three general areas which linked Buddhism and LTC issues. One area in the professional literature offers general guidance on Buddhist preferences as to diet, practices associated with death and attitudes as to pain management (Smith-Stoner, 2003) and similar matters. A second area applies Buddhist practices such as mindfulness and the cultivation of positive emotion to health issues, with an increasing application to frail elderly people. A third strand refers to populations of Buddhists with a range of health problems, often age-related, and in my experience these journal articles are exclusively focussed on people of Asian ethnicity, either resident in Asia or as migrant populations elsewhere. A recent Internet search for updating purposes, using 10 databases including CINAHL, Medline, Assia and Social Policy and Practice indicated over 37,000 results for 'Buddhism and long-term care', with the majority belonging (it would appear) to category three as above. My sampling of these confirmed previous impressions that Buddhism was mentioned only in passing in most cases, often with reference to the cultural background of older people.

Other material was sourced through databases such as the British Humanities Index, with the online *Journal of Buddhist Ethics* proving particularly useful for applied aspects of Buddhism and the Ethos/British Library system giving access to academic theses. I have also had access to a range of general Buddhist literature linked to my leading of classes at my local Centre. A particular interest have been books and articles about San Francisco Zen Center, which illustrate some of the opportunities and difficulties faced by Western Buddhists in a different, but in some respects comparable, context to that of Trirtna/FWBO.

Much of the material about Triratna/FWBO has been written by its founder, Sangharakshita, with many Order Members also publishing through its

journals/magazines and its publishing house, Windhorse Publications, and other imprints.

Triratna/FWBO has featured in a number PhD studies, two of which have formed the basis of books. Bell (1991) and Bluck (2006) offer comparative studies of the movement in relation to other Buddhist groups active in the UK. Inaba (2004) studied the development of altruism in people involved with what he termed New Religious Movements, comparing aspects of Triratna/FWBO with a Christian evangelical group. More recently Smith (2008), who was herself a Triratna/FWBO Order Member before her death in 2011, completed a comparative study of the involvement of ethnic minority people in East London in Triratna/FWBO and another Buddhist group Soka Gakkai International (SGI).

When the study was re-focused with reference to 'identity' Charles Taylor came readily to mind. Since my teenage years I have had a personal interest in cultural conceptions of 'authenticity' and the self, and on this basis had read his *The Ethics of Authenticity* (1991) and had some familiarity with *Sources of the Self* (1989) also. I was aware of his interest in dimensions of faith (he is a Catholic convert), his concern with community cohesion and the acclaim with which 'Sources of the Self' was received.More recently I had found how often he is drawn upon in applied contexts, including discussions of dementia where philosophic reference points as to selfhood are needed. Further literature searching, for example using the British Humanities Index database, reveals a much broader scope of influence, including articles on conceptions of the 'good death' in palliative care (Thoresen,2003), on the nature of nursing expertise (2004) and on the ethics of organ transplantation (Surman and Cosimi 1996) amongst many others.

Thus Taylor's work appeared promising for the current study, as did Kitwood's work on personhood and dementia. Although Tom Kitwood died in 1998 he is notably the most quoted author in a recent major book on dementia (Downs & Bowers 2008) and the subject of a retrospective evaluation (Baldwin & Capstick 2007), with much progressive work in dementia deriving from him. Some of this work is readily applicable to Long-Term Care (LTC) in general, and personhood is closely related to identity, as will be explored below.

Some attention to dementia was appropriate, as cognitive changes were mentioned by a number of participants and it will feature in the increasing LTC needs of people in Triratna/FWBO. However, there was a risk of equating later life unduly with 'decline'

and literature which took a developmental approach to old age proved valuable. Coleman and O'Hanlon (2004) gave a detailed account of much relevant material and re-introduced me to Erikson's lifespan psychology and guided my conceptual focus on 'generativity'.

Literature searching on the databases already mentioned, and others such as *Social Policy and Practice* revealed extensive material on identity and LTC, and valuable material specifically on spiritual identity.

Key journals used included *Ageing and Society*, the *Journal of Aging Studies*, *Nursing Older People* and *Aging and Mental Health*. Comparative material from Jewish, Methodist and Lesbian, Gay, Bisexual and Transgender (LGBT) communities was located from a range of sources. Other literature on the social history of the 1960s and Identity Theory (Burke &Stets, 2009) was found through general reading and use of the university book-stock and Digital Library.

CHAPTER TWO: BUDDHISM AND THE TRIRATNA/FWBO MOVEMENT
Preliminary comments

The aim of this chapter is to contribute to the exploration of Buddhist identity by providing an outline of key features of Buddhism in general and the Triratna/FWBO in particular. Any introductory remarks on Buddhism have a potentially vast remit. The tradition stretches back two and a half thousand years with, for example, Gombrich (2009,p.2) stating that the Buddhist spiritual community is "the oldest institution in the world". Globally there are said to be approximately 376 million Buddhists (Adherents.com, 2007), with a huge range of cultural variations and approaches to practice. The brief generalisations required in the present piece of writing can thus seem problematic indeed.

This sense of difficulty does not entirely disperse when I turn to the Triratna/FWBO tradition, in which I have been involved for 20 years and ordained for 9 years. For example, I will need to convey something of the movement's focus on what was once called 'The Three Cs' (see Subhuti,1983, p.133), these being:

- Centres (urban Buddhist Centres and rural retreat centres)

- Communities (single-sex residential communities)

- Co-operatives (work projects now known as Team-Based Right Livelihoods or TBRLs).

The Three Cs provide a context in which people can commit themselves to practising and spreading the Dharma (the Buddha's teachings) whilst living and working alongside others on a comparable spiritual quest. They feature prominently in literature on the FWBO per se, but TBRLs and residential communities have a somewhat lower profile in what was renamed as the Triratna Buddhist Community in 2010. Equally I will need to explore the idea that Triratna/FWBO Order members are neither monks nor lay people, and to give a sense of the Order's remarkably non-centralised way of organising itself.

Three priorities emerged in relation to this chapter;

- All material must be relevant to the concept of ***Buddhist identity.***

- When considering long-term care (LTC) issues people's ***lifestyles*** are a major factor, and lifestyle in Buddhism and the Triratna/FWBO will be discussed

- Other aspects of Buddhist LTC need to be considered, so this chapter will provide some foundations for material in later chapters which is specific to LTC.

At this stage it is crucial to note the distinction between the ***Order*** and the ***movement:*** the latter refers to everyone involved with Triratna/FWBO. The different levels of involvement are explained below. As with other faith groups, ordained people are in the minority in most Triratna/FWBO contexts, so, for example someone visiting a class at an urban Triratna/FWO Buddhist Centre might meet two or three Order Members and 15-30 people who are not ordained.

More material on Triratna/FWBO follows below, but firstly I explore some key aspects of Buddhism in general.

The Three Jewels of Buddhism

The Three Jewels (which translates as 'Triratna' in Sanskrit and thus provides the FWBO's new name) are ***the Buddha***; his teachings, which are known as ***the Dharma***; and the community of practising Buddhists, ***the Sangha***. A committed Buddhist is often said to be "going for refuge" to the Three Jewels" (Sangharakshita,1988a,p.17)

Following his enlightenment at the age of 35 the Buddha has occupied a unique place in our historical era, being neither god (or God) nor man but an enlightened being (Armstrong 2000). After six years as a spiritual seeker Siddhartha Gotama sat down beneath a bodhi tree on a full-moon night in the place now called Bodhgaya. By the morning he was fully enlightened, and from then on was known as the Buddha ("He who is awake"). Tradition indicates that no definitive description can be given of enlightenment, although accounts suggest that the three key elements are great compassion for all beings, pure, clear, radiant awareness or wisdom, and perfected use of energy (Sangharakshita 1994).

Born in about 410 B.C.E in the Nepal/Northern India border region, Siddhartha (the future Buddha) is said to have abandoned a privileged, sheltered life and set off on his quest after encountering what are known as the Four Sights. The renowned existentialist Simone De Beauvoir begins her book *Old Age* with the story of the young Siddhartha going against his father's wishes and venturing out from their opulent home only to see:

A tottering, wrinkled, toothless, white-haired man, bowed, mumbling and trembling as he propped himself along on his stick. (De Beauvoir,1972,p.1)

Siddhartha is disturbed by seeing this old man, and by succeeding sorties in which he meets a sick man (the second sight) and some people carrying a corpse (the third sight). He realises that his youth and health are impermanent and that the meaning of his current life is thus called into question. The fourth sight, a wandering Holy Man, prompts him to go forth and seek some answers amongst the many spiritual paths available at the time. The story has the colourful hyper-reality of a folk tale, and there is a danger of over-literalism. Some versions say that he had been protected from *any* contact with older people, whilst other commentators suggest that he found himself confronted with old age and infirmity *as if* for the first time; for a typical account see Durden-Smith (2009). A key point to note is that Siddhartha's spiritual quest began not with some supernatural vision but through a sudden receptivity to the apparently ordinary phenomena of ageing, sickness and death.

The Buddha began to communicate his experience with the aim of assisting others to move away from suffering and towards spiritual development. One formulation of his teachings is the Threefold Way (Prebish & Keown,2006,p.53). This consists of the following:

Ethics means avoiding harming all beings and seeking opportunities to practise generosity and other ***skilful*** action. The Buddhist precepts can be rendered in proscriptive form, with the first a resolution not to kill or harm living beings. Equally it can be seen as expressing an intention to do deeds of loving kindness as far as possible. The First Precept can be interpreted as making vegetarianism a desirable option. Although it is reported that, for example, in the Theravadan Buddhism of Thailand, Sri Lanka and Burma people do not usually take this up (Walshe,1995,p.572), many Buddhists, West and East, are vegetarian today (Bodhipaksa 2009). Buddhist ethics encompass many other areas including environmental responsibility, truthful and

harmonious speech, avoidance of sexual exploitation and the seeking of *mindfulness* rather than intoxication by excessive use of alcohol and recreational drugs.

Meditation includes the development of mental states which are calm, concentrated and kind. Such is the aim of *Samatha* meditations taught at Triratna/FWBO Centres , see below.

Wisdom is beginning to see the true nature of phenomena. This can be associated with the Three Levels of Wisdom, namely listening to, reflecting upon and then meditating on Dharmic teachings (Ratnaguna,2010), plus study in various forms, *Vipassana* practices (meditations which build on *Samatha* practice and seek 'Insight') and many other features.

The divisions of the Threefold Way, above, should not be seen as entirely discrete. Ethics can be seen as the foundation of practice, but Buddhist vegetarianism, for example, can be seen as going beyond personal preference and as expressing a world view that Buddhists might consider relatively informed by wisdom. Thus Gregerson (1994,p.2) draws on Eastern traditions when averring that to participate in the meat industry "is to fragment reality and sunder the wholeness of being".

It is said that the Buddha guided his disciples away from metaphysical speculation and rigid dogma and towards active participation in spiritual life, and such principles are reflected in Batchelor's (1997) book *Buddhism Without Beliefs*. Sangharakshita (1997) signals agreement with some of Batchelor's arguments whilst questioning the absolute distinction he appears to make between action and belief. Sangharakshita cites the Buddha's first disciples taking on some of his teachings because they had come to *believe* that he was enlightened, although they could not be sure of this. It might be added that in Triratna/FWBO, as in many other Buddhist movements, claims of enlightenment and overemphasis on this as a goal are seen as foolhardy and unhelpful. A more modest aim would be to seek a sense of spiritual progress (e.g. "A few years ago I'd have got really aggressive in that situation") with aspirations to be a *Stream Entrant,* when the progressive flow of Dharma practice is said to become irreversible (see Subhuti 1994).

The Sangha appears to be the least celebrated of the Three Jewels. Nonetheless it is crucial. Sometimes the term is used to mean the Arya Sangha, the assembly of Buddhas and others who have gained enlightenement, and in an Eastern context it can signify

those who have been ordained as monks or nuns. However, seen as the spiritual community of Buddhists its part in the development of friendship and communication is usually indispensable, and it is highly relevant to this research in relation to areas such as informal care. More broadly we can note the Sangha's part in creating conditions for practice. It is a core Buddhist teaching that anything which exists or comes into being only does so when the conditions necessary for its support are in place, and that all such phenomena are liable to disappear when the supporting conditions disperse (Snelling, 1991). To take one example from my own experience, I had a revelation about vegetarianism when I began to spend time with Sangha friends, some of whom can cook very well. Renouncing meat and fish had been an ethically compelling but sometimes gastronomically disappointing course of action; under these new conditions it came to seem entirely natural and very pleasurable.

Lifestyles in the history of Buddhism

Along with the establishment of Buddhism as an integral part of life in numerous societies came the great monasteries and temples of Asia. The Theravada Buddhism characteristic of Sri Lanka, Burma and Thailand was followed by the Mahayana schools, which focused on the Bodhisattva as the ideal Buddhist who strives to assist all beings to enlightenenment. Mahayana influence spread into China and Japan, with Zen, Pure Land and other schools developing within it. Finally, Vajrayana or Tantric Buddhism emerged in Tibet (see Novick,1999). Lifestyles varied, with for example, Tibetan lamas of the Nyingma school often marrying (Kulananda,2000,p.261), and Zen priests frequently having families (Chadwick,1999,pp 4-5) – see also page 11 above. However monasticism has been a feature of many, arguably most, traditions and remains a core aspect of the Theravada.

In an influential book Ray (1994) argues that the high status accorded to Buddhism in many Asian cultures and its association with monastic life has been problematic regarding substantial spiritual practice. As Buddhism became 'respectable' it was the monks (bhikkhus) who came to be seen as the true Buddhists, at the expense both of practitioners amongst the lay people and the forest renunciants – wandering, often hermit-like devotees of meditation. The dying out of the bhikksuni (nuns) Sangha in many places meant that over the centuries there were few women in the Buddhist

spiritual life full-time (Falk,1980). Thus the male monastics came to dominate this sphere of life and often were keen to retain their control, with conventional moral observance and scriptural knowledge reportedly valued above practices such as meditation (Ray,1994,pp.17-18)

In the context of this study the term lifestyle is used to signify key aspects of someone's life conditions. A celibate monastery-dweller clearly has a different lifestyle to someone who is married with five children and who spends much time working to earn money. Similarly the Buddha's way of life was markedly different to that of the troubled King Ajatasattu, who set off one night with his entourage of wives, attendants and elephants to seek teachings from the Enlightened One in a forest glade (Walshe, 1995,p.92).

Horner (1951, cited in Sangharakshita 1991,pp.68-69) talks of conditions in Buddha's in a narrative. The Buddha is visiting some of his disciples. Sangharakshita points out:

> *We must not imagine the Buddha going his rounds of a large, palatial, well-furnished monastery. The lodgings in question were probably just clusters of thatched huts scattered over an area of park-land just a few miles outside the city gates. (Sangharakshita, ibid,p.69)*

A situation that the Buddha finds in one of the lodgings is of major relevance to this study. One of the brethren is on the floor lying in his own excrement, having contracted dysentery. The Buddha and his companion Ananda assist and wash him. They discover that the other monks have been neglecting him because, in his own words, "I am useless to the brethren". The Buddha gathers together the other monks and gives them some unambiguous instruction:

> *Brethren, ye have no mother and no father to take care of you. If ye will not take care of each other, who else, I ask, will do so? Brethren, he who would wait on me, let him wait on the sick. (Sangharakshita, ibid,p.63)*

As Sangharakshita (ibid:64) comments, this story "deals with a significant episode in the collective life of the early Buddhist spiritual community". He goes on to say more about the spiritual community of that time, and to draw parallels with how practitioners need to support one another now as then (the chapter is based on a talk given to Order Members in the early 1980s).

The starting point is what Sangharakshita (ibid,p.64) calls "a dreadful picture". The neglectful monks seem to see no connection between whatever spiritual aspirations they might have and the condition of their sick brother. Even if they have failed to

understand the Buddha's message about the cultivation of compassion it is disappointing that they offer no ordinary human kindness or basic practical help. We never find out in what sense the sick monk is "useless", but his unpopularity seems to be a factor. Wijayaratne (1990) tells us that many of the Buddha's early disciples were young men from relatively wealthy families, so perhaps immaturity and lack of exposure to the unpalatable realities of life contributed to their collective failure of will and action.

Sangharakshita (1991,p.71) points out that they are viewing others in terms of their usefulness rather than treating each other as persons. Even in an aspirant spiritual community we can fall into valuing such "talents and capacities as a bricklayer, accountant or lecturer" and end up withdrawing the value we place on someone if they are no longer willing or able to contribute in the way we have come to expect. This has some parallels with Kitwood's (1997) ideas on personhood in people with dementia ,see Chapter Three.

The story also contains a strong example of friendship, with the Buddha and his companion Ananda embodying the two "principal aspects to persons treating others as persons" which Sangharakshita (ibid,p.71) sees as "communication and taking delight". If we communicate regularly with someone and find the contact enjoyable we have the start of a friendship. If we can have dialogue about deeper values and emotions we may have the start of a spiritual friendship. And, in turn, spiritual friendship is seen by Sangharakshita as the basis of the spiritual community (Subhuti,1994,p.153).

The latter part of the chapter might shock some readers, as Sangharakshita (1991,p.77) insists on the "absolute discontinuity" between the spiritual community and the wider world. Such a divide seems to have existed in the Buddha's time as regards practical arrangements As indicated by the phrase "Ye have no mother and no father", becoming one of his disciples entailed leaving behind the usual network of family ties (Wijayaratne,1990,p.104) which was the main source of personal support at the time and indeed remains so in most human societies. The implication is that bhikkhus were neither expected to do much to help their relatives nor could they count on assistance from family members in the event of illness, disability or other difficulties. So the onus is on fellow members of the spiritual community and where this is characterised by strong friendship we can hope that people happily look after one another. Where it is weak, what might happen if "some-one is ill, or depressed, or experiencing

psychological difficulties, or not finding the spiritual life very enjoyable?". Sangharakshita (1991,p.75) suggests that it is likely that the person may drift back to the family for "comfort and consolation". This comment might be interpreted as Sangharakshita being hostile to family links. Although he often argues that a spiritual community supports Buddhist practice more fully than most families can, he consistently encourages disciples to aim for a good relationship with their parents (Sangharakshita 1983,p.304). His audience for the original talk were Order Members, and his main point was surely to ask them to check that they were taking sufficient responsibility for the welfare of their Sangha brothers and sisters; and if not, to consider making this more of a priority. The implications of this in the changing demography and lifestyles of the Triratna/FWBO movement are further explored below.

Buddhism arrives in the West

The history of Buddhism in the Western world is short. According to Bluck (2006,p.7) the Buddhist Society of Great Britain and Ireland was formed in London in 1907 and the following year hosted a mission from Burma by Ananda Metteyya (born Allan Bennett in 1872), one of the first Englishmen to be have been ordained as a Theravadan bhikkhu. He had a number of difficulties during his visit, with Bell (1991) noting the challenges he faced in living by the *Vinaya* (the monastic rule-book). For example, accommodation was problematic because he was not permitted to live in a house where a woman slept, and the proscription on handling money meant that he could not travel alone. After five months he returned, "disappointed", to Burma (Bluck,2006,p.7).

Such instances illustrate some of the questions that arose when Buddhism first came to the West and which in some measure persist today. To what extent does being a committed Buddhist necessitate following strict monastic rules or wearing saffron robes, which Ananda Metteya experienced as making him an object of ridicule (Bell, 1991,p.39)? In societies where there is little knowledge of Buddhism full-time spiritual life can also seem economically impossible, as begging monks are unlikely to be able to cover their living expenses and there is no monastery at the heart of the local community.

The Buddhist Society was reorganised in the 1920s and continued to offer a platform for Theravada, Zen, Tibetan and other teachers. The Society and its long-standing president, Christmas Humphreys, unquestionably did much good work. Criticism

sometimes centred on the 'evening class' atmosphere at some Buddhist Society events, which according to Batchelor (1994,p.333) "Seemed to promote Buddhism as a kind of spiritual pastime rather than a fully committed engagement with the Dharma" . Perhaps this was understandable: in the USA, Prothero (1995,p.4) suggests that apart from some Asian-American communities, "Buddhism remained for the most part a literary and intellectual enterprise until the sixties and seventies". I argue below that larger-scale and even much full-time practice of Buddhism in the West were in some measure reliant on the cultural changes associated with these decades.

Whilst the Buddhist Society was made up of lay members, there were efforts to establish a monastic tradition in the UK and in 1962 the English Sangha Trust opened the Hampstead Buddhist Vihara as "the first (monastery) intended for Western-born monks" (Walshe 1963,p.172). Two years later an invitation was extended to Sangharakshita, London-born but long resident in the East, to return to Britain and head this Vihara.

Sangharakshita founds the FWBO

Sangharakshita was born Dennis Lingwood in 1925 and grew up in Tooting in south-west London. Largely self-educated, he discovered Buddhism from books read as a teenager and travelled to India as a young army conscript towards the end of the Second World War. He remained in the East, and amongst other activities lived as a homeless spiritual wanderer or mendicant; took Theravadan *bhikkhu* ordination; established himself as a writer in 1957 with a major text *A Survey of Buddhism* ;had vital encounters with Tibetan lamas as they gravitated to India in the wake of the Chinese invasion; and had contact with Dr Ambedkhar, the leader of India's ex-'untouchables' and catalyst for many of his followers' conversion to Buddhism (see Subhuti,1995).

He seems to have been well received on his return to the UK by 1964, but at times found a gap between his behaviour and some people's expectations. To give just one example, he caused surprise at the Buddhist Society Summer School by sitting to eat with lay people, going against strict Theravadan formalism (Sangharakshita,2003). He also found problems in working with Maurice Walshe, an academic and translator who chaired the English Sangha Trust (Sangharakshita,2003,pp.173-74). Whilst on a visit

to India in 1967 Sangharakshita received a letter terminating his tenure at Hampstead, and immediately he decided to start a new Buddhist movement in the UK.

This seems to have been an auspicious time for such a project, as 1967 featured "the summer of love" and the emerging hippie lifestyle which included some interest in Eastern religions (Green,1988,pp.296-7). In fact there were no hippies as such in the small FWBO movement which commenced that year, nor in the Western Buddhist Order established with the ordination of 12 people in 1968- see the film *A Circle of Friends*(1993). But one influential historian of that time argues for a Long Sixties of cultural change stretching from about 1958 to the oil crisis of 1974 (Marwick,1998). Long before this latter date there were idealistic young people around the movement, some of whom were looking for a lifestyle that would support and enhance their spiritual and creative aspirations.

Numbers were relatively small, and even in 1980 the Order only had 150 Members (Goodman,1981), although the entire movement, including people at various levels of involvement, was appreciably larger. But while young people might be interested in Buddhism, relatively few were attracted by formal monasticism. Equally, the Buddhist Society might then have seemed staid (Nagabodhi,2004) and for all his contribution to Dharmic understanding in the UK, Christmas Humphreys could appear a decidedly 'establishment' figure. Such perceptions often derived from his professional life as a barrister, appearing in many Old Bailey trials and acting, for example, as prosecuting counsel in the case of Ruth Ellis, who in 1955 was the last woman to be executed in Britain (Hancock,2000).

Sangharakshita guided the movement's gradual growth and began to establish what he later called "the six distinctive emphases of the FWBO" (Sangharakshita,2002). Buddhists in Western societies had faced all manner of dilemmas and conflicts; he now identified key principles which could be expressed in practical action. These are reviewed below in the order of presentation adopted by Sangharakshita in his 2002 talk.

Sangharakshita refers first to the movement's ecumenical approach. There was no exclusive focus on Tibetan, Theravadan,Zen or other traditions, and the movement sought out teachings across all schools of Buddhism which supported ***Going for Refuge*** and ongoing practice.

Going for Refuge to the Three Jewels has been crucial in Sangharakshita's teaching. His experience was that all too often following the formalistic monastic lifestyle is mistaken for authentic practice. Sangharakshita (1987,5) argues that commitment to

Buddhist ideals and practice are the central feature, and that lifestyle, whether monastic, lay or neither, is secondary. Thus for example the robes worn by Ananda Metteya were seen as inessential, and a kesa, a white stole/ scarf worn around the neck at Triratna/FWBO events became the only external sign that someone is ordained. The specific term Going for Refuge derives from the Buddhist perspective that people tend to seek refuge from reality in all manner of activities, distractions and forms of pseudo-security, whilst the Three Jewels provide 'true refuge'.

Nagabodhi (1988,p.8),one of Sangharakshita's early disciples, writes that he has a sense of the "all consuming commitment" his spiritual teacher has made: for Sangharakshita "life has no other Refuge than the Three Jewels of Buddhism". This can emerge in and be expressed by people with a wide range of lifestyles, so the monastic way of living may be unsuitable and irrelevant for many. Based on such considerations Triratna/FWBO Order members have come to be known as Dharmacharis (male) and Dharmacharinis (female), signifying a practitioner of the Dharma without any reference to the lay/monastic distinction (see Sangharakshita,1988a,p.112). In seeking and accepting ordination, Order members are aligned with a vision of spiritual life whereby:

> *" We commit ourselves to whatever helps us to develop spiritually – to whatever helps us to grow into Enlightenment, into Buddhahood"*
> *(Sangharakshita, 1983,p.13)*

Thirdly the Order is unified, with its women's and men's wings based on the same ordination. Sangharakshita personally ordained all Order members until the late 1980s, but as this responsibility was handed over, women Preceptors emerged and ordained new female Order members (Srimala,1996). A Preceptor is a senior and experienced Order member who provides ongoing spiritual friendship to the people s/he has ordained.

Fourthly TBRLs are work projects in which Buddhists collectively aim to make their livelihoods as much of a spiritual practice as possible whilst also ensuring that they are suitably productive. These have the potential to resolve some of the economic and lifestyle difficulties outlined in relation to Ananda Metteya, which I discuss further in the next section. In its earlier days, unemployed Triratna/FWBO people sometimes worked full-time for the movement (Bell,1991,p.173), but ethical issues and changes in benefit regulations have made this increasingly non-viable. Diski (2009,pp.15-16) comments on her own experience of a lenient dole system subsidising many in the

counter-culture of the Sixties and well into the Seventies, and for Triratna/FWBO the TBRLs played a key role in moving away from such dependency.

A fifth aspect is that the Triratna/FWBO movement celebrates the arts, for which Sangharakshita (1988b) argues as a means of expressing and refining emotion and of celebrating the joys of spiritual life, the natural world and much more. As Bell (1991,p.175) remarks: "Artists, designers, musicians and writers are well represented within the ranks of the FWBO".

Spiritual friendship has been consistently emphasised in the movement. The fact that Sangharakshita mentioned it sixth and last in 2002 should not be seen as diminishing its importance, and a vital part of his talk concerns the friendship between Sangharakshita and one of his Tibetan teachers, Dhardo Rinpoche. Friendship is the subject of a famous dialogue between the Buddha and Ananda (Bhikkhu Bodhi 2000,pp.1524-5), but does not appear to be a major element in many schools of Buddhism. Sangharakshita (2000,p.227) argues that experienced spiritual friends are vital to spiritual progress and more helpful than guru-disciple relationships in which there is much inappropriate dependency and a

> *...fantasy world in which whatever happens is seen to do so on account of the guru's 'grace' and the guru's will (Sangharakshita 2000,p.180).*

People seeking ordination can affirm such friendship in a ceremony with two experienced Order members, who are then known as her/his **Kalyana Mitras** (which can be translated as 'spiritual friends').

Controversial aspects

Whilst I recognise all the above emphases in my own experience of the movement, critics have drawn attention to other features. Limitations of space and time preclude a full account here of these critiques or of the Triratna/FWBO's response to them. However, such controversies are relevant to people's Buddhist identity and how the movement is perceived from within and without, so a brief outline is necessary.

Although reluctant to label himself gay, Sangharakshita (2005) writes of finding males sexually attractive from an early age. This was one of many factors which contributed to his critical view of Christianity. His identification with his Theravadan monk/*bhikkhu* ordination decreased over the years and he eventually abandoned it

(Rawlinson,1997). Over a period of years he was sexually involved with a number of male disciples, usually much younger than him, as were the great majority of Order Members of the time. This has at times prompted debate within the movement, and well beyond it, about Sangharakshita's ethics and judgement in this respect (Bluck,2006).

Wider ramifications included a disaffected former Order Member instigating a critical article in the *Guardian* newspaper (Bunting,1997). The article also highlighted problems at the Croydon FWBO Centre some years earlier when allegations of bullying and 'cult-like' behaviour culminated in the resignation of the Centre's Chair in 1988 (Vajragupta,2010). Since 1998 material of this kind has appeared on *The FWBO Files,* an unremittingly hostile web-site which consistently questions Sangharakshita's legitimacy as a teacher and portrays him and the movement in a wholly negative light-(see Bluck,2006). For example, the historical rarity of teachers from other Buddhist schools being invited to contribute to Triratna/FWBO events is represented as outright sectarianism. People in the movement usually explain this in other ways, including the practical difficulties ensuing when a Zen teacher reportedly made extraordinary claims to spiritual attainment whilst working alongside Order Members in the early days (see Subhuti, 1995) .The Internet campaign continues to the time of writing, and Vishvapani (2001) offers some reflections on it from within Triratna/FWBO.

This raises some questions for the present study. Has people's Buddhist identity been affected by the criticism, or indeed by the alleged negative influence of the Triratna/FWBO culture? Would other spiritual groups and official bodies be reluctant to help or collaborate with LTC projects if they were associated with the Triratna/FWBO legacy?

The Croydon debacle occurred in a setting known for its active Centre, communities and TBRLs. It is helpful now to go back to the origins of the Three Cs to consider how they came to be seen as integral to the movement's spiritual vision.

'The Three Cs'

The communal, hippie aspect of the early movement seems to have been linked to features such as the stock of short-life housing around Pundarika, its centre in Archway, North London. This was the first and only centre throughout much of the 1970s, with Order members going to other cities including Glasgow and Manchester to start

Triratna/FWBO activities in the latter years of that decade and the main London centre moving to a renovated former fire station in Bethnal Green in the East End. The heroic building work done by Buddhist volunteers on this site established a pattern that was repeated in many other places as urban Buddhist centres and rural retreat centres came into being (Vajragupta,2010). Bell (1991) has some material on an Order member, Devamitra, and his work initiating activities in Norwich in 1976-80;

> *I had no money of course, but I came to find out there were some short life premises held by the council that they were willing to let out for two pounds a week. (Bell,1991,p.172).*

Initially he subsidised the rent from his own savings along with money earned from organising yoga classes and other fund-raising. Public classes and meditation retreats began and a residential community and TBRL vegetarian café were started. Perhaps the "strong anti-family feeling" found by Bell (1991,p.294) in parts of the movement during her research had some of its roots in such idealistic commitment and the logistics of establishing a viable movement. Certainly anyone with dependants or a demanding career would have found it difficult to take on this pioneering work. Thus an 'anti-conventional' bias, doubtless spiced at times with the youthful arrogance discussed by Vishvapani (2001), may have emerged in some places and alienated some people.

Around this time Order members also began work in India with people inspired by the late Dr Ambedkhar and established Triratna/ FWBO in the USA (see Subhuti,1995). Overall the development of the Three Cs approach was linked to the movement's evolving culture, described by Nagabodhi (2004,p.3) as "highly idealistic and semi-monastic".

Centres

The Centres offered instruction in meditation and different levels of Dharma teaching, with Order Members other than Sangharakshita gradually taking more responsibility. Two meditations are taught at public classes. One of these is the Mindfulness of Breathing (Paramananda 1996,p.63), intended to develop a calm, mindful and concentrated state of being. The second is Metta Bhavana (Kamalashila 1992,p.23) intended to promote warm-heartedness and loving kindness towards all beings, with stages in which the meditator focusses on him/herself; a good friend; a neutral person

(some-one we see often but rarely consider as an individual); a 'difficult' person; and finally all beings in the universe.

These are both traditional Buddhist meditations, and Sangharakshita often comments on the tradition from which his Dharma teaching springs (Subhuti 1994,41). In almost seven decades of writing and lecturing he has covered a vast range of Buddhist subjects, often drawing on his extensive knowledge of the arts and humanities to illustrate key points. Where relevant, his talks and seminars refer, for example, to psychology, sexuality, social trends and the evolution of reflective consciousness. He also emphasises the importance of devotional pujas (ceremonies) done as a collective practice. These have often featured the Bodhisattva figures of Mahayana Buddhism, though a recent development has re-emphasised the historical Buddha (see page 18 above, and Subhuti,2010). Pujas are seen as crucial in engaging the emotions as well as the intellect in the spiritual life (Sangharakshita,1990).

When someone firstly attends a Centre to learn meditation and/or find about Buddhism, she or he is firstly known as a Friend, and some people continue as Friends for many years. However, if people come to see themselves as Buddhists they can request, after some months and subject to certain criteria, to become a Mitra (a Sanskrit word for 'friend'), thus strengthening involvement with the centre and enabling access to dedicated study groups. Beyond this s/he may wish to be ordained, and although someone asking to do this is usually referred to as a 'man/ woman who has asked for ordination', I have adopted the less commonly used but briefer term Postulant. To be ordained takes a number of years (1994-2001 in my case) and involves going on specific retreats, having ongoing contact with Order Members and, in terms of the Threefold Way, working on strengthening one's practice in ethics and meditation and seeking wisdom in reflection and the study of Buddhist texts. Notwithstanding the value placed on *spreading the Dharma*, Inaba (2004,p.71) considers that the movement is not "fiercely evangelical", with relevant effort often put into publicising events and creating a welcoming atmosphere for newcomers. Street-level proselytising would be unthinkable in the Triratna/FWBO and an Order member's comments from over 20 years ago is still valid in this respect:

> *A Buddhist genuinely wishing to spread the Dharma learns that he or she has no alternative but to appeal to the independent judgement and natural aspiration for growth of people he or she meets. (Ratnaprabha 1987,p.64)*

Communities

As the movement grew, so did the number of residential communities. The typical FWBO set-up became a single-sex urban household, with retreat centres also developing for men and for women only, although there were some variations such as the family-based community described by Srimala (1996). Female (Sanghadevi,2003) and male Order members (Maitreyabandhu,2001) write that communication and spiritual friendship can be enhanced in a predominantly single sex environment. Sanghadevi seems conscious of the limits of arguments for and against such arrangements and the strong assumption in Western cultures that mixed environments are usually preferable. She concludes that the lifestyle of a single-sex community is;

> *...essentially an esoteric experience. In other words, one needs to try it out, and then one will find out the benefits for oneself at first hand*
> *(Sanghadevi 2003,p.60)*

I place a high value on my 13 years in communities. Certainly my meditation practice seemed to move forward through sitting regularly with like-minded friends. For the majority of this time we were an open community, offering hospitality to female visitors, although quite a number followed the Vajrakula men's community in Norwich which in 1977 decided "to refuse entry of women onto its premises" (Oliver,1979,p.169).

In this respect the Triratna/FWBO seems at its most **semi-monastic** (Nagabodhi, 2004). However, it is worth recalling that only a minority of Order Members have ever formally committed themselves to celibacy for any length of time, with Inaba (2004,p.110) mentioning 5 per cent, and this has probably decreased since he wrote. Many of the Order members, Postulants, Mitras and Friends who have lived in communities have had partners/ lovers elsewhere. This 'living apart together' (LAT phenomenon within the movement is discussed below (see page 69). Finally there is debate about whether lesbian/gay relationships in single sex communities are unduly problematic (Subhuti 1990). Opinions vary, but such relationships in this context seem fairly rare.

TBRLs (formerly co-operatives)

These typically originated from modest beginnings such as a market stall that grew into a substantial retail business (Padmasuri,2003,p.26). There were a number of

vegetarian restaurants and ventures in cushion-making, printing, building and gardening, amongst others from the 1970s onwards (Bluck,2006,p.169) . In the 1980s the Windhorse:Evolution gift business emerged with a chain of shops known as Evolution and a wholesale division. TBRL principles were identified whereby the business would sell ethical products, raise money for local and movement-wide FWBO (now Triratna) projects and offer opportunities for people to make their livelihood a form of spiritual practice. This last included an emphasis on communication and (as far as possible) spiritual friendship, and ongoing efforts to keep the business's broader purpose in mind. Thus team members would start the day by 'tuning in' together to establish how people are faring and to plan for the day, whilst the weekly Right Livelihood meeting might for example feature training on how to improve communication with customers or a *puja* to Ratnasambhava, a Buddha figure associated with generosity and abundance. Two team retreats take place each year (Buddhasiha, 2010).

Much of this persists in the shops such as the one in Ipswich. However, for several years other shops have had a manager (rather than a team emphasis) and the TBRL focus has sometimes been modified in the face of economic strictures and social change. Formerly all employees received a support package which allowed for "a simple Buddhist lifestyle" and included six weeks of paid-for spiritual retreats (Tejasvini 2007,p.5). In contrast, today an increasing number of people work on a wages/salary and annual leave basis and are in a pension scheme which was not previously available.

The general trend away from traditional TBRLs might appear retrograde. Talks by Sangharakshita in the mid-1970s and later emphasised such projects as a key feature of an economically and practically viable potential **New Society** based on Buddhist values.However, Tejasvini (2007,p.4) links some of the changes to growing professionalism and practical necessity. The employment of sympathetic non-Buddhists in key posts is an example of this, along with a more open relationship between the movement and the wider world. Nonetheless, people in Triratna/FWBO continue to work together in familiar contexts and new areas, which I briefly discuss in Chapter Five.

Other aspects of lifestyle

Although Sangharakshita insisted that ***lifestyle is secondary*** (Subhuti,1994,pp.145-146) there could be a perception that the Three Cs *was* the Triratna/FWBO lifestyle and that a family situation would always tend to be seen as less favourable for spiritual practice. Some flavour of this debate is given by Srimala, an Order Member who became one of the first female Preceptors. She is looking back here to the retreat on which she was ordained in 1975. She was pregnant with her second child and married to an Order Member at the time, and was taken aback by comments that came up in a study group:

> *one Order Member, married with a family, commented that there seemed to be no place in the Order for someone like him. I was shocked to hear him say such a thing. Shy as I was, I had to object. How could that be true when I was about to be welcomed into the Order? (Srimala,1996,p.42)*

Srimala's book is frank about the challenges of combining her family and spiritual life. The disillusioned man from the study group is reported to have later resigned from the Order (a number of people choose to leave the Order each year and this is referred to as a ***resignation***). For many people, full-time commitment to the spiritual life influenced their major decisions about family and lifestyle. Padmasuri's account of her life includes the following:

> *By choice, though not always an unequivocal one, I never got the husband, children, house or garden I had envisaged as a teenager. I have spent many of the last twenty-five years living in Buddhist communities with other women, though I now live simply and alone…I have a livelihood that is meaningful, and an intelligent and warm network of friends who are a great source of inspiration to me, including a long-standing lover… (Padmasuri,2003,p.20)*

Around the movement there can be encouragement to talk over significant life-choices with spiritual friends and Preceptors, but in my experience there is also a very high measure of personal autonomy. If for example someone wishes to move out of a community to live with a partner, stop leading meditation classes at the Centre or leave a TBRL to train in another livelihood, very often this is what they will do, usually accompanied by the good wishes of spiritual friends. There is no system for allocating Order members to centres or other settings, and very often people's re-location is based on having spiritual friends in the new place or other personal reasons. Padmasuri's choice not to live communally is not unusual for a long-standing Order Member. I have noted my own appreciation of community life, but in its latter years I was the only Order Member and in my fifties while the other residents were Mitras, Postulants or

Friends in their thirties. Occasionally I felt I was being perceived by one or two co-residents as a representative of the whole Order, for example when someone had had a setback with their hopes to be ordained. This could be especially unwelcome when I came home after a long nursing shift! Thus Lokabandhu's (2009) evidence of Order Members increasingly living alone or with a partner seems not entirely surprising to me.

The Triratna/FWBO vision of the Three Cs could and did go badly wrong in some locations. Croydon's problems over 20 years ago remain a much-cited example, with by all accounts a gifted, dynamic Chairman who attracted acolytes but also had a strong tendency to dominate. Vishvapani writes about his time at the vegetarian restaurant which was then a key TBRL at Croydon:

> *That wasn't a good experience…behind the youthful idealism was a strong emotional pressure to conform to quite a narrow lifestyle and outlook. Some people suffered quite badly as a result (Vishvapani,2004,p.30)*

Today much has changed, and the Three Cs are lived out by a smaller proportion of Triratna/FWBO people. There are safeguards such as a senior Order member taking on the Presidency of Centres to keep in contact with local situations and to help to maintain centres' spiritual health (Vajragupta, 2010). Vishvapani's restaurant work took place in a gap between school and university, and few very young people are involved to that extent in 2010. If such changes sometimes equate to a perceived loss of intensity of spiritual practice it can only be hoped that this is recreated elsewhere, and that people are respected and well-supported in all activities. Few would deny the benefits of the Three Cs, but if they become linked to a narrow lifestyle in people's minds this runs the risk of limiting their growth and could eventually be self-defeating.

No doubt the different types of practitioner outlined by Ray (1994) are expressive of variations in temperament, talents and needs. Ray, Sangharakshita and others make it clear that Buddhist practice (or indeed Buddhist identity) can never be equated with one lifestyle. Indeed Sangharakshita has stressed the emergence of the 'true individual' as crucial to any conception of spiritual progress; he sees such a person as capable of reflecting on his or her experience independently of the groups to which he/she might belong Subhuti (1994,p.119). Vajragupta's (2010) picture of the contemporary movement indicates a combination of individual practice, with, for example "a number of Order Members [undertaking] long retreats of a year or more" (2010,p.69), and collective endeavour, and his biographical sketches of Triratna/FWBO people consistently emphasise the importance of the Sangha context and spiritual friendship.

Lifestyles and interests are varied in the movement. We might not be surprised to find meditation teachers, artists and broadly middle-class people fairly well represented (Schoch 2007,p.107). However, Inaba (2004,p.106) refers to examples of people from more difficult backgrounds such as 'John', who came from a "very poor…working class family where alcohol and drug abuse were common", and who had nine years of heroin addiction and associated offending behind him. Bell's (1991) interviews with Triratna/FWBO people included a joiner, a retired insurance salesman and a man who was long-term unemployed, plus 'housewives', a hospital doctor, people with business skills, and so on. Increasing numbers of Order Members work in the wider world and the restricted budgets of many Triratna set-ups would in any case limit the number of full-timers working, for example, in a Centre. Many people in the movement work in the caring professions. It seems reasonable to speculate about whether this could be a factor in the direction of future TBRLs (see Chapter Five).

The Triratna Buddhist Community in 2010

In May 2010, as proposed by Sangharakshita, the former FWBO changed its name to the Triratna Buddhist Commmunity, with Order members now belonging to the Triratna Buddhist Order. The main reason for this was the need for a single name for the whole movement, which had been known in India as the Trailokya Bauddha Mahasangha Sahayaka Gana (TBMSG). However ,the name change could also be seen as signalling some differences between the FWBO as people had known it in its earlier forms and the movement today. It is larger, with approximately 1,800 Order members and activities across 20 countries (Triratna News,2010) . Statistics are less available for non-Order members, but Bluck (2006,p.156) suggests at least 5,000 people in regular contact. Bluck states that the movement is one of the three largest Buddhist groups in the UK, the others being the New Kadampa Tradition (NKT) led by the Tibetan teacher Geshe Kelsang Gyatso, and Soka Gakkai International (SGI), a lay tradition deriving from the 12th century Japanese teacher Nichiren. Bluck also notes that the 2001 census indicated a growth in the UK Buddhist population to approximately 150,000, adding:

> *There are about 60,000 ethnically European people in Britain who have converted to Buddhism rather than coming originally from an Asian*
> *Buddhist background (Bluck 2006,p.16)*

The Order and the movement manifest in a range of UK contexts. For example, notwithstanding evidence of an ageing Order, summer camping festivals and retreats known as Buddhafield are organised by the movement, often attracting younger people with an eclectic programme. It continues to be possible to lead an intensively Buddhist life within Triratna/FWBO. For example, someone might live at a retreat centre, either contributing directly to retreats or on the support team that provides catering, maintenance and other services. There are seven such centres in the UK. There is some variation in remit, so their programmes might mainly emphasise meditation, Dharma study, preparation for ordination or retreats for a relatively wide public, with for example, the retreat centre in Scotland running retreats which combine introductory meditation with hill walking. Certainly in such a setting much of resident Buddhists' daily interaction is with people who also practise Buddhism or are sympathetic to it. An urban equivalent is what are sometimes referred to as the **Buddhist villages** that have developed around some larger city Buddhist Centres with a number of residential communities and TBRLS. On the other hand, some Triratna/FWBO activities are offered in what might be called **outposts,** smaller situations where, for example, classes take place in premises rented for the night. It appears that these set-ups can develop their own intensity where people get to know each other well and support one another's practice.

Sangharakshita began handing over day-to-day responsibility for the movement in the 1990s, and some senior Order members formed the College of Public Preceptors (CPP). It was agreed that leadership of the movement would be invested in whoever took on the Chairmanship of the College for a five-year term, although in 2003 the College renounced the idea of a "headship" (Inaba, 2004,p.83) and focussed on issues such as ordination and other specific tasks. The responsibilities of the current CPP chair, Dhammarati, include "building and maintaining links with other Buddhist sanghas" (Vajragupta,2010,p.146). Manifestations of such initiatives include Triratna/FWBO Buddhists' involvement in chaplaincy work in prisons and increasingly in healthcare settings (Munnings,2007), and the movement's membership of the Network of Buddhist Organisations (NBO) to which most UK traditions are affiliated.

Sangharakshita had incapacitating health problems some years ago but has been active again recently. He will be 86 years of age in August 2011. The recent name change as proposed and taken forward by him underlines the fact that Sangharakshita

remains by far the most influential person in the movement and is its guiding spiritual teacher.

Sangharakshita is often referred to in the movement as ***Bhante***, a traditional term of address for a Buddhist teacher approximately equivalent to calling someone 'Sir'. Whilst Bhante/Sangharakshita brings much continuity, change continues apace. To take some examples, Lokabandhu's survey of the Order (2009) includes material from about a third of the Order members outside India and he notes some of the changes which were signalled. Whereas nearly all Order members ordained for 20 years or more have some experience of TBRLs and single sex residential communities, of those ordained for less than 2 years 54 per cent have no experience of TBRLs and 46 per cent have never lived in a community.

These newer Order members are increasingly likely to be living with partners (63 per cent of men and 61 per cent of women). Approximately 40 per cent of Order members support themselves through professional work in the wider world, compared to 20 per cent who are supported in some way by the movement (e.g. in a TBRL or a centre/retreat centre, or fulfilling an Order/movement-wide job). Broadly, the semi-monastic aspect of the Order, and by extension the movement, appears to be in gradual decline, at least as a proportion of a larger total number of people involved. In 2007 the movement's publishers, Windhorse Publications, produced a book by Sara Burns (Buddhist name Karunagita),. A Path for Parents, about a single mother's efforts to make her relationship with her children a form of Buddhist practice. The book reflects the lifestyle of an increasing number of Triratna/FWBO people and changes in the movement's culture and outlook.

Recalling the other part of Nagabodhi's phrase (see page 30 above) we might ask if the Order and movement continues to be 'highly idealistic'. Some Order members resign, some are disaffected, some seem inactive, and this, of course, is their privilege. In contrast, Moksananda concludes his book with these comments looking back to his ordination nearly 20 years earlier;

> *Sitting in the stillness of the shrine-room after the ceremony I felt I had set the direction of my life…the simple act of expressing that commitment before my Preceptor had etched that allegiance deep into me and made it more complete.*
> *(Moksananda 2004,pp.118-19)*

So it is arguable that there is a high level of idealism in many parts of the movement, and ordination is certainly a key element in this. Personal identity is profoundly

involved here, as a new, Buddhist name is given which is intended to reflect qualities which the person has in some measure or which s/he might strive to develop. The ordainee also receives a *vipassana* (insight) meditation practice related to a Buddha or Bodhisattva figure. This might be for example Tara, who is associated with compassion, or Manjusri, who embodies wisdom, though there is a current re-emphasis on the historical Buddha (see page 18 above and Subhuti, 2010). And whilst the goal can be seen in terms of (usually!) far distant enlightenment, many also find inspiration in the everyday practice of ethics and meditation, and the mysterious quest for wisdom.

Concluding comments

This chapter has referenced the Threefold Way and other frameworks within which Buddhist identity can be viewed. Buddhist practice includes individual and collective elements. If we relate this to personal and social identity, Burke and Stets note that the former can involve "seeing oneself as a unique and distinct individual, different from others" (2009,p.124), whilst the latter "is based on a person's identification with a social group" (2009,p.118). Going on a long solitary meditation retreat might seem predominantly personal, whilst a life spent in TBRLs, residential communities and Buddhist Centres can appear a relatively social way of living. Many Triratna/FWBO Buddhists have combined both of these elements. Some spiritual practices encompass both personal and social aspects.Thus taking a Buddhist name at ordination is a strongly individual matter although much of its impact arguably requires a social context in which the name is at least accorded a measure of respect, and at best is well understood.

However it is conceptualised, Buddhist identity can be an important factor in the lifestyles people adopt. As LTC needs begin to be more pressing, related questions about lifestyle can acquire increasing salience. Buddhists may recall the future Buddha's encounters with the Four Sights, but to really see old age, sickness and death is uncomfortable, and even in a supportive Sangha it seems possible that frail people are sometimes moved to the margins of people's concerns. Historically many Triratna/FWBO Order members appear to have fewer family ties and more modest financial resources than comparable people in the general population. Notwithstanding the Buddha's exhortation to the neglectful brethren of the monk with dysentery, or Sangharakshita's decision to make this neglect the subject of a talk, we can ask how much impact such narratives might have on the availability of informal care within the

Sangha. There is evidence of greater prevalence of Buddhist practice in the UK, but we can wonder whether this will equate with a gradual growth of understanding of Buddhists' specific needs in the mainstream LTC sector. And if TBRLs are such a distinctive emphasis of the Triratna/FWBO, it seems reasonable to speculate on the desirability and feasibility of care-based Buddhist projects.

Before fully engaging with such questions, it is essential to explore the concept of identity further, as follows in Chapter Three.

CHAPTER THREE: IDENTITY

Identity and Self

The previous chapter included reference to personal and social identity, and key terms related to these are now explored further. Atchley (2009) offers an outline of what he means by 'self' and 'identity', initially dividing the former into self as experiencer and the reflective self. These he links to Mead's 'I' and 'me' respectively. 'I' consists of the "bare experience of being…and experience of self as the centre of action", whilst the more complex "me" comes from "the person's own perceptions of self…and messages about the self which come from others" (2009,p.47).

Atchley outlines various categories for thoughts about the self as follows:

> *Self-concept (what I think I am actually like), ideal self (what I think I should be like), feared self (the self I am afraid I might become), self-evaluation (my assessment of the fit between actual and ideal self), and self-esteem (how much I like or dislike myself, often based on my self-evaluation). (Atchley,2009,p.47).*

He proposes a self-system which processes information and participates in the development of self-schemas, of which his examples include 'I am a spiritual person' and 'I am a frail old man'. Atchley outlines his view of identity as:

> *The unique set of characteristics and qualities considered collectively and regarded as essential to a person's self-awareness…identity is a holistic self-concept, a sort o metaconception of self created by synthesizing multitudes of specific attributes capabilities, life experiences, motives, habits and preferences.(Atchley 2009,p.50)*

Thus he emphasises reflexivity and draws a useful distinction between the terms self and identity. His approach is eclectic, drawing on Mead's symbolic interactionism and sharing terminology with Rogers' person-centred approach to counselling in his reference to the "self-concept", and with the information-processing/meaning-making focus of cognitive models when invoking "self-schemas" (see Atkinson et al 1996,pp.529-530). There is also acknowledgement of psychodynamic perspectives with mention of Jung and his emphasis on

> *"the importance of bringing aspects of the self that exist in the unconscious into consciousness". (Atchley 2009,p.47).*

Applying Atchley's definition of identity to people involved in the Triratna/FWBO with an exploration of their "attributes, capabilities, life experiences, motives, habits and preferences" would surely reflect the fact that they have typically grown up in a Western culture and have become Buddhists in adulthood. Thus their development will often have been influenced by a wide range of relevant ideas, emotions, practices and attitudes.

The next section reviews some Buddhist ideas about the self, whilst the succeeding one considers spiritual identity in relation to a range of theoretical perspectives. I explain my decision to focus discussion around three areas explored by key writers. The influence of socio-cultural change on perceptions of identity is discussed in succeeding sections on identity politics and traditional and emerging identities in the applied context of LTC. Examples of the former are drawn from Methodist and Jewish experience in the UK, whilst the latter focuses on lesbian,gay,bisexual and transgender (LGBT) people and on Westerners who have become Buddhists. Some key features of the latter in relation to identity and LTC are brought together in a final section.

'Self and non-self' in Buddhism

Buddhism is sometimes represented as 'denying the self', with the term *anatman* often translated as 'no-self'. Sangharakshita is clear, however, that this does not "mean no soul in the sense of no psychic life at all. It means no *unchanging* soul, not *unchanging* self" (1994,p.117). Harvey comments that whilst newcomers to Buddhist studies can misunderstand *anatman* teachings as a "denial of *any* kind of self, metaphysical or empirical", further study will show that this "is plain wrong". (1995,p.7).

A number of areas of Buddhist teaching are relevant here. Firstly, Williams notes the Buddha's focus on a Middle Way between eternalism's belief in a permanent self and nihilism's certainty of extinction at the end of this life, with the latter sometimes linked to denial that we exist in any meaningful sense, even in the here and now:

> *This middle is that we do exist in some sort of dependence upon dynamic, causally generated psychophysical bundles. (Williams, 2000,p.61)*

These 'bundles' or aggregates are the five *skandhas,* (sometimes translated as 'heaps') which are said to collectively constitute the whole of our being and which comprise our material form plus the mental attributes of "feelings, perceptions, formations (e.g. intentions/volitions) and consciousness". (Williams,2000,p.58).

If this begins to sound unduly theoretical, the key point is straightforward. We can identify elements of 'self' in terms of functional and experiential phenomena, but an overriding or underpinning 'selfhood' and any unitary entity associated with this tends to elude investigation. This aspect of Buddhist thought seems to have parallels with cultural processes described in Martin and Baresi's (2006) *The Rise and Fall of Soul and Self.* These authors, a philosopher and a psychologist respectively, offer a historical

review of Western thought in which the soul becomes a marginal concept amidst the secularisation of knowledge, whilst the twentieth century sees the self not only "demoted…but dismantled…as a unitary object of study" (2006,p.297). At the same time the authors acknowledge the indispensable nature of the term 'self' in everyday usage. Referring back to the Atchley quotation on page 41 above raises questions about how we might replace the term 'self-awareness' or indeed the litany of other compound words, "self-image…self-confidence…self-esteem" and many more) quoted by Martin and Baresi (2006,p.297). These authors seem justified in their joke that the self may have suffered the death "of a thousand hyphenations" (2006,p.297) and their implication that the empirical self remains a pragmatic necessity in a wide range of human discourse.

So it is arguable that Buddhism's 'deconstruction' of the self has some parallels with prominent contemporary strands of thought. In contrast, when we read a well-known psychologist stating that "Buddhists believe in a cycle of reincarnation" (Gilbert, 2009,p.5) this can sound like an unscientific piece of dogma which Buddhists unquestioningly accept and which would surely have curious effects on their ideas about identity. Sangharakshita explicitly rejects the notion of reincarnation, seeing it as implying "an unchanging essence of yourself that pops into one body after another" (1998,p.45).

In contrast the preferred term *re-birth* suggests instead that there may be connections between the various lifetimes of various beings with no implication that an 'unchanging essence' is being transmitted. Ideas about rebirth and reincarnation are prominent in many Eastern spiritual traditions (Smart,1998) but are certainly not articles of faith. Intriguingly, Sangharakshita comments that in his experience:

> *Western Buddhists seem to remain resolutely uninterested in karma and unimpressed by the whole future prospect of life after life after life. (Sangharakshita,1998,p.40)*

Such issues might reasonably be seen by many practitioners, East and West, as unduly abstract, but it is to be hoped that Buddhists *are* consistently interested in putting the Buddha's teachings into actual practice. Opening ourselves to teachings on the impermanence and fragility of the self can be a valuable method (as opposed to doctrine) of 'softening' the divide we make between self and other. This process may be supportive of considerate and compassionate action (Collins,1982), with the additional

point that the aspiration to extend *metta* (loving kindness) to all beings includes seeing oneself as worthy of kindness and care (Salzberg,2002).

Spiritual and Buddhist identity

Identity and self are central themes in many areas of inquiry and debate, including the humanities, arts and biomedical sciences. In my own field of practice, nursing, a growing interest in identity and self has accompanied attempts to provide a stronger theoretical basis for care-related activity, with, for example, a phenomenological approach often seen as suitable to exploring the lived experience of patients or clients (Mackey,2005).

In a health service context our information about specifically spiritual identity is often limited to a descriptor such as 'Church of England or 'no religion' in the person's file, and frameworks for seeking more information may be useful. Thus Harrington discusses the HOPE acronym as a model of spiritual history-taking in relation to elderly patients/clients. Adapted from Anandarajah and Hight (2001) the interview involves enquiring about general sources of "**H**ope, meaning, comfort, strength, peace, love and connection"; then any contribution from **O**rganised religion; independent **P**ersonal spiritual beliefs and practices, and finally the "**E**ffects of medical care, or how illness has affected spiritual practice" (Harrington,2010,p.186). Atchley (2009) also seeks as full a picture as possible. The following are examples of statements that he has utilised in research on spirituality in relation to self or identity.

> *I am a person who has spiritual experiences…I feel separated or alienated from my spiritual self…I feel attracted, drawn, or called to a spiritual journey…I am a person on a spiritual journey, I am a spiritual seeker…I experience some degree of detachment from worldly joys and sorrows. (Atchley,2009,pp.54-68)*

It seems that for many people, spiritual identity can be explored with reference to such interview items, although its precise definition may be problematic. The explicitly theistic perspective of some writers can limit the applicability of models of spiritual identity to a Buddhist context. This may be true of Poll and Smith (2003), although their conclusion to a review of psychotherapeutic evidence appears salient;

> *The supposed power of spiritual identity to promote resiliency and change in individuals corresponds with research indicating that similar benefits are derived from a strong sense of personal identity. (2003,129)*

Koenig et al. (2001) argue the case for active participation in religion being associated with positive mental health. They acknowledge the hostility of Freud and Albert Ellis, the founder of Rational Emotive Therapy, and quote the latter's nostrum that "the less religious people are, the more emotionally healthy they will be" (2001,p.67). Nonetheless, they point to the potential benefits of having meaning and purpose in life and social support amongst other factors.

In the UK the relationship between religious faith and the well-being of older people is historically reported to have attracted little research interest. (Howse,1999). Coleman and O'Hanlon make the general statement: "Religion and culture are important sources of existential meaning that may grow in importance in later life" (2004,p.143), and a recent major British book on depression in the elderly lists religious affiliation as a protective factor (Chew-Graham & Baldwin 2008,p.4). Krause's (2010) recent American study focusing on health benefits linked having a close companion at church with relatively better self-reported health and fewer outpatient attendances in a sample of 'oldest-old' people (85 years plus). The close companionship in Krause's study is considered with reference to factors such as self-disclosure, self-expression and a sense of belonging in the church congregation. Such work seems salient to the present study, bringing in dimensions of social and personal support associated with involvement in a faith and reflecting some of the Triratna/FWBO emphasis on spiritual friendship and Sangha connections.

The term ***Buddhist identity*** appears to have some currency in the literature and is commonly defined, implicitly rather than explicitly, with reference to certain features. These are mainly a person's self-reported sense of connection with Buddhist ideals and observed and/or self-reported level of participation in Buddhist practice and related activities. For example, Henry's (2006) study of people associated with the Network of Engaged Buddhists in environmental and social activism includes a refutation of another scholar's position that members of such groups are often only nominally Buddhist. Whilst the Network is not aligned to any particular school of Buddhism, Henry's evidence suggests high levels of involvement in observance of the precepts, meditation, Buddhist study, devotional *puja*, going on retreat and other practices. It appears that many of Henry's participants were following the Threefold Way and had a robust and substantial Buddhist identity. In other literature the term 'Buddhist identity' is characteristically used as a counterpoint to perceived 'non-Buddhist' behaviour. For example, McCargo's (2009) report of Thai Buddhists implicated in sectarianism against

a Muslim minority population. Buddhist identity is explored with reference to Buddhist ideals, as represented by key words such as "peaceful…*metta*…harmonious" (2009,p.12); the actual behaviour of the relevant Buddhists in a *realpolitik* context; and the author's contention that Western commentators are prone to interpreting the political dimension of Thai Buddhism with undue emphasis on the former and naïvety about the latter.

Tweed (1999,p.81) notes that in the USA "some folks want to claim Buddhist identity",even where they have never had any connection with Buddhist classes or groups and, in the case of his vignette of 'Margaret', attend a Christian church. Tweed attributes Margaret's continued Episcopalian affiliation to her wish that her children have some form of faith-based upbringing. The local Buddhist group does not offer this and she is concerned that her attendance there would elicit ridicule from her extended family. Nonetheless she is mostly vegetarian, meditates intermittently, reads Buddhist and New Age books, and so on. White and middle class, Margaret might be seen as exemplifying the trend away from committed religious observance towards a more personal spirituality, as described in Heelas and Woodhead's (2005) UK studies. Tweed (1999,pp.71-72) emphasises the complexity of religious identity and argues that often it is not adequately captured with reference to either "certain defining beliefs or practices" or to the joining of a religious organisation and participation "in its ritual life". He concludes: "Ambivalence is the norm" (1999,p.73).

Poll and Smith (2003) explore the influence of systems theory on spiritual identity. External expectations from a family might unduly influence someone towards a substantial external religious observance. In such a case, internal spiritual identity may prove inadequate in crisis situations. This might not be seen as salient in relation to Trirtana/FWBO people, especially to Order members, who have taken the external and culturally anomalous step of declaring themselves Buddhists (usually in a Western context), in whom it is reasonable to assume a strong internal commitment. However, family influence may not be entirely irrelevant. Moksananda (2004) notes that his father:

> …*always considered my dedication to Buddhism to be something of a waste of my life.* (2004,p.107)

This and other background factors may remain latent as a person's Buddhist life goes on, but they also could be a source of influence as circumstances change over the years. Ordination takes place when a person's Going for Refuge (i.e. practice of Buddhism) is

considered effective, although inevitably this is subject to impermanence. Order Members' internal and external connection to Buddhist practice is modulated by all manner of situations in their spiritual development and life events. Although ambivalence may not be the norm, it is certainly not unknown and indeed, a total absence of it might bring with it the dangers of unreflecting complacency.

Whilst my research process included enlarging my general awareness of identity-related discourse, my next step was to focus on specific themes and particular writers whose work appeared relevant to the evolving conceptual framework. The writers in question are Taylor, Coleman and O'Hanlon, and Kitwood, and a section on each follows.

Charles Taylor and Sources of the Self

Taylor is a Canadian philosopher and political scientist with a longstanding interest in faith-related questions and the expression of values in societies and systems of thought. His *Sources of the Self* (1989) has been described as "magisterial" (Wohrmann 2004,p.xiv) and "seminal" (Sorabji 2006,p.3) and has influenced many subsequent explorations of the topic indicated in its sub-title: *The Making of the Modern Identity*.

Taylor makes central to his argument "facets or components of a good life", to which he gives the collective term **life goods** (1989,p.93). He goes further in relation to certain central values which he calls **hypergoods**. A hypergood is an element of life to which I might apply:

> *...a 'strong evaluation' and find that my orientation to it is essential to my identity, so the recognition that my life is turned away from it, or can never approach it, would be devastating and insufferable. (Taylor 1989,p.63).*

In contrast:

> *The assurance that I am turned towards this good gives me a sense of wholeness, a sense of fullness of being as a person or self that nothing else can (ibid)*

Taylor gives a number of examples of 'hypergoods' and the evaluative frameworks with which they are associated. Someone (perhaps a traditional warrior) might have a strong attachment to ideas of honour, whilst for another person rationality is a hypergood, and for an artist much of human activity would be evaluated in relation to creativity and expressive power.

The claimed benefits of religious affiliation in later life have been outlined above. Frank (2005) indicates that a sense of 'home', including key associations with connectedness/belonging, control/autonomy and other valued ways of being, is crucial to many people with Alzheimer's Disease. Thus *faith* and *home* could be seen as hypergoods that are highly salient to well-being and which may be especially important to older people's sense of self.

In a Buddhist context we could characterise the opportunity to practise the Threefold Way (ethics, meditation and wisdom) as a hypergood, or (in more specifically Triratna/FWBO terms) we could describe conditions conducive to Going for Refuge to the Three Jewels in a comparable manner. Thus 'faith' would be of relevance, with the Buddhist term being *sraddha* ('that which we set the heart upon'). This might be closely linked to associations with 'home', especially if someone has lived in a specifically Buddhist retreat centre or residential community, or with a Buddhist partner or friend.

Hughes' (2006) book *Dementia: Mind, Meaning and the Person* has references to Taylor in three separately authored chapters. For example McMillan (2006) outlines the story of 'Mr D', whose Alzheimer's disease seems to have damaged aspects of his personhood, with memory loss and behavioural problems contributing to the deterioration in his marital relationship. McMillan characterises Taylor as attempting to establish that 'selves' are necessarily tied to frameworks of value. McMillan adds that:

> *He (Taylor) argues for a deep connection between selfhood and conceptions of the good. Taylor believes that frameworks that allow a consciousness of value are the result of culturally produced ways of life and that living within such frameworks constitutes the self. (2006,p.66)*

Mr D seems now to have a different relationship to the "frameworks of value" that have guided most of his life, and his wife reportedly comments that he is no longer "the man I married". McMillan notes another aspect of Taylor's thought whereby:

> *Knowing, forming, and articulating a sense of self is a discursive or narrative process. (McMillan 2006,p.66)*

McMillan equates this with the concept of 'webs of interlocution' that he has developed with a co-author. Webs of interlocution are seen as:

the networks of interpersonal relations that we are immersed in, which play an important part in our formulation of a sense of self. (ibid)

Poll and Smith (2003) see narrative approaches to the self as highly relevant to spiritual identity. They are a familiar part of activities in the Triratna/FWBO in which,

for example, people often give talks on 'Why I am a Buddhist'. Telling one's life story from time to time is seen as a form of spiritual practice. Associated with psychologists such as McAdams (2005), narrative constructions of identity also have a key part in progressive approaches to dementia. These are outlined, for example, by Surr (2006), and I return to them in the discussion of Kitwood below. More broadly, Taylor's approach seems to signal the crucial importance of hypergoods and frameworks of value in the support of the self. The value which Buddhism places on Sangha is closely related to the need which most Buddhists seem likely to need in maintaining and developing their practice. We might ask whether Buddhists in long-term care have sufficient access to the webs of interlocution of spiritual friendship, or the hypergoods of Buddhist practice in general, or experience their frameworks of value as being sufficiently understood.

A literature search indicates that Taylor is widely quoted in academic work beyond his specific field (see for example Thoresen,2003, on concepts of a good death in palliative care); that his interest in religion is increasingly central to his writing and includes more comment on Buddhism; and that there is a growing secondary literature (see for example Abbey, 2000). Fraser (2007) focuses on Taylor's abandonment of humanist Marxism, a perspective which these authors apparently once shared. Fraser also details Taylor's unease with many aspects of modernity, especially individualism, and the prominent influence of his Catholic faith in recent writing. In the context of the present study Fraser (2007,p.40) notably criticises Taylor for equating Buddhist views of the self with the Christian faith's reported call "for a radical decentering of the self, in relation to God". Although there are good arguments for the relevant Christian and Buddhist positions being seen as very different on this (see Gethin 1998), Taylor has certainly incorporated a concern with Buddhism in his recent work. Whilst metaphysics are largely beyond the scope of the present study, brief discussion of one aspect of Taylor's view of Buddhism may be useful. He comments that *anatta* teachings posit that:

> *The way to Nirvana involves renouncing, or at least going beyond, all forms of recognizable human flourishing. (Taylor,2007,p.17)*

He also acknowledges that most faith traditions encompass on the one hand "a mass religion of the social sacred" where "ordinary" flourishing is the aim of most people, and on the other "dedicated minorities of religious 'virtuosi'" (2007,p.154). Although dedicated practitioners within Triratna/FWBO are indeed likely to become Order

Members, and many sustain their practice long-term, it is arguably a mistake to award all ordained people the Weberian accolade of spiritual 'virtuosi'. The evidence from autobiographical writings suggests a perspective whereby the Threefold Way/Going for Refuge are seen in terms of work in progress (see for example Maitreyabandhu, 2001). I have referred to ambivalence in spiritual identity and the wide variety of personal trajectories within the Dharma. Thus whichever elements of ordinary flourishing – the economic, the sexual, the familial, the psychological – are emphasised there will be examples of Buddhist practitioners working, even struggling, with them. Using Atchley's (2009) terminology, it might be posited that effective Buddhist practice involves an individual with a realistic *self-concept* (including awareness of what aspects of 'ordinary flourishing' are important to her/him) and an *ideal self* strongly informed by the Dharma and thus highly conscious of the impermanent and provisional nature of all aspects of self.

It is notable that Fraser's critique of Taylor elicits from the latter a declaration of his own framework of values within humanist Marxism. Fraser also offers a succinct summary:

> *For Taylor, we define a self or identity by the way things have significance for a person (2007,p.9).*

This suggests some parallels with work by Burke and Stets (2009) on what they call Identity Theory. With its intellectual roots in Mead's symbolic interactionism, its stance has been characterised as follows:

> *The core of an identity is the categorization of the self as an occupant of a role, and the incorporation, into that self, of the meanings and expectations associated with that role and its performance. (Stets& Burke,2000,p.224)*

The term 'role' can have the unfortunate implication that someone is playing a part, raising questions about personal authenticity. In Triratna/FWBO parlance we speak more of, for example, a Centre Chair taking this on as a particular responsibility. Nonetheless, the work reviewed by Burke and Stets (2009), typically undertaken in the border territory between sociology and psychology, does appear to augment some of Taylor's concerns and (unusually for this discourse) includes some empirical evidence. Of particular interest is **self-verification**. We typically have an 'identity-standard' which we attempt to verify through our actions. Applying Atchley's terminology, this identity standard might be seen as an aspect of the *self-concept,* with elements also of the *ideal self.* Thus someone who believes him or herself to be a good driver may have a

reasonable level of relevant skills plus some overconfidence that these will show through in all driving circumstances. These authors propose:

> *Identity behaviour is a function of the relationship between perceived meaning of the self in a situation and identity-standard meanings. (Burke & Stets,2009p.54)*

Thus people tend to create a 'verification context' for themselves, with stress emerging when identity standards fail to be verified in evaluation of the self and others. Reverting to Taylor's terms, someone whose life goods are largely centred on Buddhist practice may experience the stress of non-verification in a care situation where, for example, there is a high level of noise and no accessible quiet areas. The person finds the identity standard "I am an effective meditator" under threat, with this possibly augmented if the person also perceives that: "No-one else here has any interest or understanding of meditation".

Coleman/O'Hanlon and the developmental psychology of later life

As LTC needs are often associated with older people it is important to include here some developmental perspectives on later life. The Buddha continued to teach the Dharma up to his eightieth year. He spoke about his physical decline, comparing his body to "an old cart held together by straps" (Walshe,1995,p.245), but his spiritual vision was undiminished and continued to evolve. Thus to present old age simply in terms of decline is as absurd and unacceptable in a Buddhist context as it is in many other spheres of life. Coleman and O'Hanlon (2004) cover much material in this area, and their exposition on ***generativity*** and associated themes is especially salient for Buddhists. Kotre defines generativity as "A desire to invest one's substance in forms of life and work that will outlive the self" (1984,p.10).

Several areas that Coleman and O'Hanlon discuss seem likely to be more relevant to a Triratna/FWBO context when there is a larger cohort of older people in the movement. Thus, for example, Tobin's (1999) work on survivor-type personalities and the finding of meaningful activities (including some forms of psychotherapy) will gain in relevance as the movement ages further.

However, one chapter covers the developmental themes of "wisdom, generativity and reminiscence", which, the authors acknowledge, are "closely interrelated" (2004,p.80). Of these, generativity has the most immediate relevance for the present study, although links to the other two themes can also be readily made.

The concept of generativity was developed in the context of Erikson's stages of the life-span, and its originator describes it as "The concern in establishing or guiding the next generation" (Erikson,1977,p.249). The most obvious manifestation of this is having children or, more specifically, giving one's offspring the psychosocial and material support they need for their well-being in the present with a view to a positive future. Erikson initially visualised generativity in relation to midlife (see Zender,2008), whilst subsequently seeing later life as another stage in which it is crucial. Kotre's (1984) own development of the concept has four categories (biological, parental, technical and cultural) and somewhat eschews its being bound to certain life-stages. Instead Kotre sees it as appearing "on and off in different guises through fifty or sixty years of adult life" (1984,p.264).

Thus it may emerge in situations from childhood onwards, and to these Kotre applies the term 'moments'. Gombrich (2009) gives an example from the Buddha's life at the beginning of his time as a spiritual teacher (in his mid-thirties) when he speaks of his insights to a group of potential disciples and realises that one of them, Kondanna, *had understood* at some level what he had just said. In Kotre's terms this would seem to be cultural generativity.

We can ask how this relates to the present study's primary concerns. Taking Erikson's binary 'life-stage tasks', people who fail to achieve generative activity are in danger of stagnating. Orthodox Eriksonian theory also indicates that if this stage conflict is not resolved, the person concerned will be unable to move on to the final conceptualised goal of "ego integrity". Erikson (1977,p.241) is frank about the difficulties of definition here, giving instead "a few constituents of this state of mind" including the ego's awareness "of its proclivity for order and meaning". At the opposite pole is the possibility of despair. Certainly stagnation and despair seem inimical to any conception of an ongoing Buddhist identity. In Triratna/FWBO terms one might wonder if a stagnated person's practice can remain effective, even if s/he continues to self-identify as a Buddhist. Dark and desperate mental states might still be seen as impermanent, and as possibly providing stimulus for deeper reflection, as in one Order Member, Nissoka's (2006) account of the impact of Huntington's Disease on himself and his family. Nonetheless, outright and prolonged despair would be highly problematic for sustained effort and faith in Buddhist practice.

Buddhist practice appears to have a strongly generative aspect, especially for those who seek ordination. As noted above, until well into the 1980s Sangharakshita

personally ordained all newcomers to the Order, and these were typically much his junior (Nagabodhi 2004). Today the chronological age of those being ordained and the Preceptors conducting the ordination are closer, with the ordainee older in some cases, although Preceptors are invariably long-ordained and considered to have the appropriate experience and personal qualities to be a spiritual mentor to new Order members. This principle also applies to the formalised spiritual friendship arrangements *(Kalyana Mitra)* which people seeking ordination are encouraged to make.

Erikson (1977,p.240) states that a mature person "needs to be needed", and it is arguable that this is potentially more possible in Buddhism than in many other spheres of activity. Erikson et al (1987,p.158) relate the poignant narrative of an older pharmacist who found himself facing "professional obsolescence" with the advent of new products, and De Medeiros (2009,p.99) describes an 85-year-old man who talks of his daughter's success in the retail world and concludes: "So how can I teach her anything?".

True generativity requires receptivity on the part of other, typically younger, people, and technological and cultural change can of course greatly compromise this. In Buddhism, although there are developments in how the Dharma might be communicated there is arguably a timeless aspect to many teachings and practices, so the insights of experienced people can be genuinely valued whatever their age. In the Triratna/FWBO Sangharakshita is unquestionably still the most influential individual in his mid-eighties, and whatever criticisms have been made of him few would question the depth and range of his experience, practice and Dharma knowledge.

De Medeiros (2009,p.98) seems to see not being needed as a form of suffering along with ill-health and some aspects of old age. She links suffering in turn to a "loss of self", and suggests that the 85-year-old man of her narrative was counteracting his feeling of "fading away" through the "generative acts" (2009,p.101) of writing poetry and creating a wood carving. Charmaz's (1994,p.54) study of chronically ill men found some participants disturbed by a perception that their lives were shrinking, whilst an award-winning work initiative gave another man a sense of an expanding identity and a "developing self". Some Triratna/FWBO people might be able to find similar activities and thus repair their selfhood in some measure if it becomes vulnerable. However if the validation of others (De Medeiros,2009) is a key aspect of this, one might enquire to what extent Buddhist wisdom and reminiscences about a Buddhist life would be validated by others who have no relevant experience. Perhaps the crucial factor is the

Buddhist's ability to communicate such aspects to others, with considerable variation likely in this respect.

Tom Kitwood and Personhood in Dementia

Whatever their other difficulties, the 85-year-old featured in de Medeiros's article and the pharmacist described by Erikson et al (1987) emerge as fully able to express themselves clearly. Tom Kitwood had an academic post in psychology and counselling when he became interested in dementia. Before his untimely death in 1998 he founded a research and training group at the University of Bradford which continues to play a very prominent part in progressive approaches to dementia and, by extension, to other areas of LTC. Kitwood (1997) ruefully recalls his first encounter with dementia in the person of Mrs E, an older woman he had got to know when she was still relatively well. Following the deterioration of her memory and concerns about her safety she was admitted to a residential home, and Kitwood's retrospective analysis is that he nihilistically assumed that nothing significant could be done to help her and that dementia "is a death that leaves the body behind". He sees such views arising from what he terms "malignant social psychology" (1997,pp.46-47) and to counteract this, one word came to be at the heart of his approach. This was ***personhood,*** defined as:

> *A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. (Baldwin et al 2007,175).*

The definition thus focuses primarily on social being and as such has been criticised for its perceived over-emphasis on the responses of other people to the person with dementia (O'Connor et al 2007). Sabat (2008) reviews the way in which scores in tests of cognitive function and a diagnosis of dementia can contribute to unduly pessimistic assumptions about someone's abilities and inner world. Baldwin et al (2007,p.177) note some evidence that: "One's private sense of self persists into the late stages of the illness".

Surr's (2006) article is an example of the ongoing work of the Bradford group with its focus on a socio-biographical approach in the maintenance of self for people with dementia living in residential care. Of particular interest in the present context were findings that for some participants:

> *Epiphinal or turning point moments appeared particularly significant in explaining present circumstances and self (and)…value and belief systems and personality. (Surr,2006,pp.1728-9*

We can speculate on how much Buddhist content there might be in a future Triranta/FWBO cohort discussing turning-points and values, and what extra contribution a facilitator with a Buddhist background might bring to such a situation. As we will see in Chapter Four on LTC, personhood is often seen as vulnerable in many care situations, with Surr's informants arguably facing the double jeopardy of being in residential care *and* having a diagnosis of dementia. Approaches to the maintenance of self are thus crucial, as is work on care-givers' attitudes and actions regarding this and other, comparable groups of vulnerable people.

Kitwood is reported to have had an interest in Buddhist and Taoist philosophy (Baldwin & Capstick 2007) and his later writings include approaches to both the ethical framework that care-givers bring to their work and the personal development of these workers (1998). For the latter, he nominates meditation as the most feasible method, although he seems to see this only in terms of developing a calm, mindful state of being.

This, of course, has its place, and Kitwood's interest somewhat prefigures the major application of mindfulness as a therapeutic tool in many areas of health and well-being (Kabat-Zinn,1990). It is tantalising that he does not appear to be aware of the *Metta Bhavana* type meditations, which are intended to develop warm-heartedness towards oneself and other beings (in stages including focusing on a good friend, a 'neutral' person and a person with whom communication can be problematic, as mentioned earlier). It seems that Kitwood values meditation as a general approach, but (for whatever reason) there is no evidence of him connecting this to the inspiration he gained from Martin Buber, to which he often refers (Baldwin et al.,2007). Buber, a Jewish mystic and writer, upheld the 'I-Thou' relationship (1937) between persons, contrasting this to the 'I-It' stance which can all too readily take its place. 'I-Thou' relationships based on acknowledgement of shared humanity, whereas an 'I-It' approach reduces others to entitities who may intermittently share my sphere of being but whose well-being, or even existence is of little or no concern to me. Dependency can be a risk factor for an 'I-It' response, as the monk with dysentery discussed in Chapter Two sadly discovered. To a Buddhist, the *Metta Bhavana* immediately recommends itself in situations where the I-Thou relationship may need development and reinforcement (Kamalashila,1993). The implications of this for care-based TBRLs are discussed below. Notwithstanding the ideas that Kitwood did *not* develop, his work on personhood remains an essential resource for everyone concerned with the support of

valued identities in LTC situations, with its influence especially strong in dementia studies but, I would argue, stretching well beyond this specific field.

Identity Politics

It is often argued that the social changes associated with what is now termed identity politics originated in the much reified era broadly known as 'the Sixties'. Where identity issues relate to sexuality and certain aspects of gender there is the contemporary term LGBT (Lesbian, Gay, Bisexual and Transgender). There are problems with the use of this umbrella term in encompassing a wide range of individuals and groups, though it has some utility in this study where I am aware that people from all these 'communities' participated including, for example, two transgender people.

More specifically the politics of gay male sexuality offer an example of a change in UK legislation that signalled an evolutionary stage in public policy rather than a full-scale revolution in social attitudes. Weeks (2007) notes that the 1967 Wolfenden Report, which recommended the legalisation of male homosexuality (with certain restrictions) saw same-gender sexual activity as "a problem that needed to be dealt with" rather than a "valid life choice". This is relevant to the Triratna/FWBO in that, as Inaba puts it:

> *It seems that there are a number of gay and lesbian people in the FWBO, as interviews make plain. (2004,p.120)*

Also in 1967, the Triratna/FWBO movement was founded and gradually emerged as a more confident and forthright form of Buddhist movement than had existed in Britain in the past. Sangharakshita (1996a) writes that the 'old style' UK Buddhists of that era were often anxious to say that they were:

> *...just like everyone else. Personally I found this frustrating because I felt that people were not taking Buddhism seriously..(Sangharakshita 1996a,p.40)*

There seemed to be a hegemony of majority values in the pre-1960s era (see Booker, 1969) which arguably persists in other forms today, but which was notably monolithic and at times oppressive. It should be acknowledged, especially with reference to this section's title, that Triratna/FWBO has historically been cautious of aligning itself with explicitly political causes, and many Buddhist narratives relate finding the Dharma after disillusioning experiences in more political spheres (see, for example, Maitreyi,2003). The social identity work of Tajfel and others (see Worchel & Coutant,2004) highlight

the potential in identity politics for over-identification with one's 'in-group' and projection of exaggerated hostility and suspicion onto people outside it. According to Harvey (2000,p.429), Sangharakshita has been critical on this basis of highly politicised attitudes to sexual orientation, as, for instance, narrated in Clune's (2003) account of her difficulties as a member of radical lesbian groups in the 1980s.

Overall there appears to be a valid parallel between LGBT politics and the Western Buddhist identity, with both arguably having become what I term emerging identities. Indeed, recent research by Yip with Smith (2010) considers over-lapping areas here with its focus on Western Buddhists from LGBT communities . As explored in the next section, this has implications for LTC services and other aspects of social policy provision.

Traditional and emerging identities

The essential contention of this section is that some traditional identities are in apparent decline, at least numerically, whilst others are emerging. As my overall concern is with LTC issues, it is unsurprising that such services (usually geared to older people) tend to reflect more traditional aspects of identity. Thus I was interested in Kellaher's (2000) report 'A Choice Well Made', which looks at residential care provided by what was then called Methodist Homes. In 2004-5 the organisation changed its name to MHA Care, reflecting the more secular foundation of the relaunched charity and the availability of its services to a wider public .In Kellaher's study "over two-thirds of the informants said they were now Methodists" (2000,p.3) with others members of other (predominantly nonconformist) churches and a few who "said they 'supposed' they were Christians"(*ibid.)*. Kellaher notes that the organisation:

> *...commenced in 1943 at least a decade in advance of those local authority initiatives to provide residential care for older people which moved away from poor law philosophies and practices. (2000,p.78)*

At the time of her study, residents' evaluations of the service were generally positive. Shared Christian values were seen by many as contributing to the atmosphere of mutuality, defined as "a mix of friendliness, respect and support" (Kellaher 2000,p.82), with autonomy and being able to "be myself" (2000,p.74) also emerging as valued features.

The changes in MHA Care also doubtless mirrored the general secular trend in UK society, which is often linked to the 1960s. A social historian quotes evidence that at the beginning of that decade:

> *Just over two million people were members of a Nonconformist sect, of which the Methodists and Baptists were the most popular [and] as the appeal of traditional working-class thrift and vigour declined their numbers fell by as much as a third. (Sandbrook 2006,p.464)*

In Valins' (2002) report on LTC issues amongst older Jewish people in the UK there appears to be a more complex cultural background. Valins notes an apparent reduction in the UK's Jewish population to 25% lower than 50 years previously, but acknowledges difficulties in accurate estimation with, for example, some people classifying themselves as ethnically but not religiously Jewish. Amongst synagogue affiliates there is considerable variation from reform/liberal at one end of the spectrum to strict/conservative orthodox traditions at the other. Valins (ibid:pp.127-128) considers the residential homes run by the organisation Jewish Care, noting that many Jews are not religious and may choose a Jewish home notwithstanding their past lack of involvement in Jewish ways of life. He says that their decision about care appears:

> *Really important as they wish to 'return to what they know' [and] spend the latter part of their lives with other Jews. Valins quotes a care home manager: Sometimes it's obvious, they want kosher food, access to a synagogue etc etc, but in other cases kosher food is irrelevant, access to a synagogue is irrelevant, so one can only conclude that it's cultural reasons. Somehow they feel they can relax more and feel more comfortable with people who come from a similar background.. (Valins 2002,p.127)*

One difficulty in maintaining a Jewish ethos in these care homes is that very few of the care staff are Jewish themselves. Valins (2002,p.222) acknowledges that in the Jewish community there is currently a "low level of interest in…working in the social care sector".

Of course this does not imply that Jewish people, if available, should be preferentially employed, or that non-Jewish staff should be in any way undervalued simply by virtue of their ethnic or religious background. However, Valins (2002,p.181) offers a striking and seemingly unarguable example of the need for particular types of staff training, quoting a care home manager as follows:

> *There is a big cultural divide between the carers and the cared for. We run a series of lectures, for example on the Holocaust, but many of the staff had either never heard the word 'Holocaust' before; or didn't know what it meant. One staff member at a recent training session thought the Holocaust was a drug for Alzheimer's disease. It is incumbent on us to provide as much training, education input as possible.*

(Valins 2002,p.181)

Valins (2002,p.34) notes also the policy trend towards mainstreaming, which he defines as:

Encouraging the provision of services in general settings rather than by religious or ethnic minorities for their own communities. (2002p.34)

With reference to the quotation about the Holocaust above it seems reasonable to ask whether staff in another setting would receive equivalent training if there were just one or two Jewish clients.

If identity in the examples above is explicitly linked in some measure to religious affiliation, a quite different source of identification is explored in Heaphy and Yip's (2006) and Knocker's (2006) work on older people's services. The latter is an Age Concern resource pack for professionals, with the title *The Whole of Me: Meeting the Needs of Older Lesbians, Gay Men and Bisexuals Living in Care Homes and Extra Care Housing.* In its preface the Director General of Age Concern lists a number of related initiatives which the organisation has steered, beginning with a previous resource pack in 2001.What is noticeable is the recent nature of all such targeted work It seems that a discourse of this kind has only become possible in the twenty-first century, with the civil partnership legislation passed in December 2005 a watershed in official recognition of same sex relationships.

Looking at Methodist, Jewish and Lesbian/Gay people in an LTC context, themes emerge about each group's relationship with wider UK society and narratives about possible oppression and the practical ramifications of this. The fact that the great majority of MHA Care staff have no connection with Methodism is mentioned by some resident-participants as a matter for regret. With the decline in Methodists numbers some members of this faith doubtless feel marginalised, and staff who feel hostility or incomprehension in relation to Christian belief at least need to give careful consideration to how to handle conversations with clients on this subject.

Historically the oppression of the Jewish people is of a different and terrible order of magnitude, with recurring persecution and anti-Semitism in its many forms probably factors in the community's tradition of developing separate and specialised services. Homophobia is likely to be commonly experienced by LGBT people in LTC, with, for example some older fellow service-users at times reflecting the intolerant attitudes that were the norm until relatively recently. Knocker (2006) offers guidelines for best

practice in residential and Extra Care housing including, for example, encouraging managers and other staff to challenge homophobic comments.

On a more positive note Knocker (ibid) highlights heart-warming instances of staff acknowledging people's sexual orientation in an affirming manner, of same-sex partners being fully involved in care and care planning, and of a generally LGBT-friendly ethos in some services. Although there are instances of care facilities specifically geared to the older LGBT community in the USA (Concannon,2009), I have not found evidence of any plans for these in the UK, although it seems reasonable to predict that services known to be friendly to minority sexualities might attract increasing numbers of people from those groups. Heaphy and Yip (2006) surveyed a total of 266 from LGBT communities over the age of 50 about their views on receiving support in sheltered housing and residential care homes if required in the future. Categories offered for the respondents' valuation of such provision in general included 'desirable' and 'highly desirable', which scored 46% and 8% respectively. However, these same hypothetical facilities, if posited as run by people from LGBT communities, scored 61% and 45% respectively. So this study supports the general idea that in making choices about LTC, factors linked to identity, shared experience, understanding, and so on can be highly influential. It is notable that Knocker (2006) uses *The Whole of Me* as the overall title for her resource pack, implying that services may make what Heaphy and Yip (2006) term hetero-normative assumptions about people, and that such mindsets on the part of others can make it more difficult for people to be themselves as fully as they might wish.

It seems that specialist services for traditional minorities face notable challenges with both MHA and Jewish Care working with a culture gap between residents and staff, who are predominantly non-Methodist and non-Jewish respectively, and with the need to broaden their remit beyond their initial community. However, just as some MHA and Jewish Care residents report that key aspects of their identity are well-supported by the shared values and/or culture of the organisation that cares for them, so a comparable mutuality of experience might be supportive to emerging minorities. The examples used are LGBT people and Western Buddhists as exemplified by the Triratna/FWBO. As noted above, there are both overlaps – Inaba (2004) notes that a number of Triratna/FWBO people are lesbian or gay – and distinctions to be made here. About the latter, Western Buddhists may sometimes experience being seen as eccentric or even "weird" (Moksananda,2004,p.107) but are less likely to have experienced the gross

oppression suffered by many in the LGBT community. Nonetheless, where some measure of shared values and culture is perceived evaluations of care seem to be boosted and current personalisation agendas in care policy need to take this into account.

Specialist services are always open to the accusation that they are socially divisive, echoing debates about faith schools (see Cairns,2007) but probably evincing less trenchant positions. At the very least an older person could be seen as exercising a freer choice in opting for a faith-related care service than a child going to a school selected by her/his parents. In any case, the pragmatics of organisational viability and the need to avoid sectarianism appear to coincide. Thus a Buddhist-friendly LTC service might encompass clients who are explicitly Buddhist or sympathetic to Buddhism along with others who have no particular affiliation but have made it their choice. Mather (2006), reviewing the work of Carstensen et al. (2000), offers a perspective on people choosing a culturally familiar service. While not denying that older people often seek out new experiences, this strand of research suggests that emotional closeness and familiarity are major factors in the elderly's decisions. Thus older people's 'nearest and dearest' can become ever more crucial, and for many from a Triratna/FWBO background these may be fellow Buddhists.

Concluding comments

This chapter first discussed Buddhist perspectives of the self and then considered the Buddhist identity in the wider context of spiritual identity, with key elements such as faith affiliation's claimed benefits about meaning and purpose and social support noted. Buddhist identity is discussed in the literature in terms of both observable practice and `internalised values. Thus being in a situation where it is possible to practice the Threefold Way can be seen as having access to Taylor's 'life goods' and as offering opportunities for self-verification as a committed Buddhist. Generativity is seen as highly relevant in Buddhist practice but appears to require a spiritual context in which it can occur. Kitwood's work on personhood appears salient in relation to supporting the identity of those with LTC needs, with a specific Buddhist practice, the *Metta Bhavana* meditation, beneficial in many situations. Traditional and emerging identities have been considered in relation to LTC. Whilst social divisiveness is relevant, there is a rationale

for the maintenance and/or development of services known to be 'friendly' to specific minority identities.

Further application of these concepts is explored in the next chapter, which considers mainstream LTC.

CHAPTER FOUR:LONG-TERM CARE AND SUPPORT

Preliminary comments

My reflective journal for this study (2005) notes that informal discussion of LTC for older people quite often elicited assumptions linking this to a single model of care, namely the residential care home, and this in turn was sometimes linked to assumptions that I was already personally committed to opening a Buddhist care home. These tendencies seemed especially strong in Triratna/FWBO people who had little or no connection with the care sector in the sense of having care needs themselves, having relatives or friends receiving LTC, or working in the sector. There are other approaches to LTC, of course, which include domiciliary care in people's own homes, sheltered/assisted housing, and extra care housing. Equally central is the ongoing implementation of what is sometimes known as the ***personalisation agenda*** in social care whereby:

> *Every person who receives support, whether provided by statutory services or*
> *funded by themselves, will have choice and control over the shape of that support*
> *in all care settings. (Department of Health,2008).*

It is well-known that informal LTC provided by relatives and friends dwarfs all statutory provision. In the sections that follow I consider the concept of ***ageing in place*** and other care trajectories, and then focus further on informal support and care in the next section. Some material follows on formal LTC, with sections on residential care and other models of LTC beyond the care home. Finally there is a section on personalisation and progressive approaches and a brief conclusion. Throughout the chapter the aim is to keep at its centre the issue of Buddhist identity and its support in LTC situations.

LTC is a more prominent political and policy issue than it has ever been, both in the UK and elsewhere. It was an arena for impassioned debate in the 2010 general election, with the Personal Care at Home Bill that aimed to make care free defeated in the House of Lords and no cross-party consensus on funding for such proposals. *The Times'* headline five weeks before the Election seemed to capture the current situation;

> *Free care for elderly: just don't ask how or when (Lister,2010,4)*

With the political debate a number of Department of Health documents appeared, including:

- *National Service Framework for Older People* (2001).
- *Our Health, Our Care, Our Say* (2006)- A White Paper setting out aspects of personalisation.
- *Putting People First* (2007)- a concordat between key public bodies as to the implementation of the above White Paper.
- *National Dementia Strategy* (2009).
- *Care, Support, Independence* (2010)- White Paper with the (now former) Government's proposals for a National Care Service in relation to the social care of older people.

All such work reflects the move of LTC from the margins of public discourse, along with pension deficits and other issues related to the rising age profile of Western populations (Magnus,2008). Such reports often set benchmarks for best practice, with, for example, the *Dementia Strategy* emphasising earlier diagnosis and the *National Service Framework*, concerned with the care gap for people who are medically well enough to be discharged from hospital but cannot yet manage at home offering development guidance regarding intermediate care. As reviewed below, specific policies such as the piloting of individual budgets as an aspect of personalisation are highly relevant to the present study. Further examples are cited in the next and succeeding sections.

Ageing in place and other trajectories of care

If a Triratna/FWBO Buddhist has a living situation that is supportive of her/his spiritual practice in relation to ethics, meditation, wisdom and other features and subsequently becomes frail, the best option might be to remain there. Support systems could include informal input from friends and family and the statutory services, including domiciliary care and other community-based provision. In this context the support of Buddhist identity might be in some measure reliant on the availability and effectiveness of such systems.

If someone opts for housing with more support, there is a continuum from traditional sheltered housing to very sheltered provision,through to Extra care housing where round-the-clock support is provided. Choosing this type of housing may mean losing

some of the advantages of ageing in place in a familiar environment, but compared to residential care there are some relative benefits in terms of retaining autonomy and independence, one's own space where preferred activities can be pursued, food prepared and so on. Such features may be closely linked to individuals' valued sense of self and identity, and may be relevant to Buddhist practice where a quiet place for meditation and opportunities for vegetarian/vegan cooking may be required.

The residential care sector is large, and inevitably facilities and standards vary considerably. The concept of person-centred care has achieved general currency, often applied to dementia care but with evident salience for other frail residents. Fossey refers to key principles of person-centred care including:

> *Treating the person as an individual…Ensuring that a positive social environment exists in which the person can experience relative well-being [with assessments which] …identify activities that reflect individual preferences. (2008,p.340)*

These principles explicitly emphasise environmental factors, in common with much progressive work in this field developed by Kitwood and others. Retrospective evaluations of earlier work in this field can sometimes be critical, as for example, Kitwood's ideas about 'rementia', which involves the cognitive "recovery of powers that [have], apparently, been lost" (1997,p.36). Baldwin and Capstick see his presentation of this as "somewhat optimistic' and comment that it is a concept that 'has not been taken up in any significant way in the literature of dementia." (2007,p.17).

Nonetheless, few today would doubt the importance of environmental factors in frail people's quality of life (Brooker,2008), their influence on the communication and relationships of people with dementia (Allan&Killick 2008) or in the prevention or amelioration of depression (Choi et al., 2008).

In the interactions between our embodied selves and our environment we often experience key aspects of identity such as 'home', 'job' and our relationships with others, which in Taylor's (1989) terms might be seen as life goods or even, in the case of crucial elements of the self, hypergoods without which life cannot be imagined. Links to such key aspects and life goods can become more tenuous and vulnerable with the onset of frailty. Daily tasks become more difficult, more assistance is needed and there may be doubts as to whether it is possible to continue living in our current home. Cognitive deterioration, physical illness and pain and depressed mood may compound such difficulties and, to quote De Medeiros's interviewee (2008,p.101), there may be a subjective feeling of "fading away".

This in turn may worsen with a move to a new environment such as residential care. In relation to specifically Buddhist identity, it is hoped that people giving support have some understanding of, or at least respect for, Buddhist practice and that suitable facilities for requirements such as vegetarian/vegan food exist. More broadly, to begin Buddhist practice people typically need a reasonable level of well-being (Sangharakshita,2004), and if this is lost it is arguable that practice may be compromised (see also Epstein,1993,on the complex relationship between Buddhist meditation and depression). Certainly untreated physical or mental ill-health or the general effects of being in an unstimulating or objectionable residential environment can undermine general well-being and hence the ability to undertake spiritual practice as an aspect of Buddhist identity.

The discussion of the above that follows is based on the experiences of people using existing services. Some material on possible TBRL work projects in relation to LTC is included in a final literature review section under the title *Supporting Buddhist identity in LTC situations.*

Informal support

It is well-documented that identity and environment can be closely linked, and that such connections can be especially vital for older people. A sense of 'home' is often crucial, and in the concluding part of their large study of later life Peace et al note:

> *The importance of maintaining a place of comfort from which to direct life seems to be crucial to the maintenance of identity. (2006,p.160)*

The research participants here were generally able to articulate the value they placed on aspects of their environment. Even where such articulation is compromised, as in advanced dementia, there is evidence (to quote Baldwin et al 2007,p.186) "that a sense of home is strongly associated with selfhood", and Frank's (2005) work relating 'home' and 'personhood' has already been quoted in Chapter Three.

These concerns have formed the basis of some very well-known studies such as Langer and Rodin's (1983) experiments whereby enhancing personal responsibility and by implication a perceived sense of control in nursing home residents improved activity levels and general well-being. The environmental manipulations seemed modest enough, such as asking a group of residents to look after plants, but had the notable effects mentioned. On the one hand such studies could be seen as giving some support

to a reformist agenda whereby personal responsibility is deliberately enhanced in comparable settings. On the other, commentators with major concerns about residential care, discussed below, may feel that significant loss of control and of other valued aspects of active selfhood may be intrinsic to the social situation of nursing home residents to a greater or lesser degree, and that the main point of policy, as Timonen (2008,p.140) argues, should be to make all efforts to avoid the use of such care settings.

However well-intentioned the staff, the design and the general regime of a particular residential care setting might be and whatever the drawbacks of an individual person's home, it is reasonable to conclude that in many instances home is best as regards support for valued identity. Ageing in place thus emerges as the favoured option of both older people themselves and policy-makers in the field (Alber& Kohler 2004). Dalley (2002,p.10) sees independence and autonomy as what she terms "the twin peaks of ideology" in the relevant discourse, and argues for the benefits of residential care for some frail people if they can find an affinity group centred on shared interests, with one example being a care home for retired actors.

Ageing in place is the obvious course of action for the high proportion of people who go through later life with little or no diminution of health and functional capacity, or in whom such changes emerge relatively late in their lifetime (see Peace et al.,2006). Where frailty does emerge, staying in familiar surroundings remains an option for many, with relatives a major source of support. Pickard (2008) summarises some of the evidence as follows:

> *Most informal care for older people in England is provided either by spouses or adult children…Around 85 per cent of disabled older people living in their own homes in England receive informal care and, of these, over 80 per cent receive care from either a spouse, an adult child or both…Of those receiving care from either a spouse or a child, approximately half receive care from a spouse, and half from a child. (2008,p.2)*

Pickard makes a key distinction between these two main sources of informal support. Taking into account that women predominate in these late life cohorts of people requiring care, she makes the notable observation that:

> *Care by spouses is likely to increase in the future, primarily because projected improvements in male mortality are likely to lead to a fall in the number of widows.(2008,p.2)*

In contrast, care by adult children is said to be "particularly important for those aged 85 and over" (ibid) and appears likely to diminish in availability due to smaller family sizes, growing childlessness in the population, the increasing rarity of the co-residence

of older people with children and the ongoing growth of women's participation in the labour market.

There are possible influences of other trends, with for example migration and the general mobility of children tending to place some relatives much further away than would once have been typical (Phillipson,2005). There is also the question of family solidarity, with intergenerational ambivalence emerging as a result of phenomena such as high levels of divorce, blended families and paternal absence (Lowenstein,2005). All these are linked to contemporary Western living patterns and to a reduction in people's 'automatic' sense of intergenerational obligations.

Intense informal care is usually defined in terms of 20 hours or more of care per week (Hirsch,2006), and typically involves personal care such as assistance with washing, dressing, toileting and other intimate tasks. Duration over the years of care-giving can also be a factor, although Martin et al. (2006,p.104) quote evidence that the morale of care-givers can improve as time goes on, perhaps as the role becomes more familiar (see Gilhooly,1984). However, these authors also write about care-givers' feelings of entrapment and shame, sometimes leading to depression. Informal carers may feel trapped and unable to progress with their lives whilst committed to care-giving, and have feelings of being "inadequate, flawed and inferior" as regards the care they are able to provide (Martin et al. 2006,p.102). These and other stressful aspects of informal care are often grouped together under the term 'burden' (Zarit&Zarit,2008).

In the Triratna/FWBO context, childlessness and single lifestyles appear the most salient variables in relation to informal care. As to the former, Kohli and Albertini (2009) acknowledge the complexity of research outcomes in relation to social isolation amongst the relevant population but conclude:

> *The findings on social support are less equivocal. Childless older people are less able to receive [care] from their informal support network than those who were parents, and consequently they are more dependent on public-sector and private-market care services. (2009,p.1178)*

In parallel with this, Lowenstein's (2005) review of evidence on informal care notes the following:

> *Data revealed that the input of caring for frail elderly from anyone outside the family is marginal, in terms of the total volume of informal care. (2005,p.406)*

As outlined above, Triratna/FWBO developed from the late 1960s onwards, eschewing the lay-monastic distinction which has characterised much of Eastern

Buddhism whilst also having an ethos which was at least cautious about some aspects of traditional family life. In 2010 (again as indicated above) the movement has changed considerably, as have many features of family life in the wider world. Today many people already have children when they first arrive at a Triratna/FWBO Centre and it is far from unusual for established Order Members to become parents (see Nagabodhi, 2004,p.3). At the same time, a relatively high level of childlessness exists amongst people who have been ordained for many years, especially those who have worked full-time for the movement, Overall, Lokabandhu (2009) concludes that of the Order members he surveyed,

About 20% of men seem to have children, and about 24% of women.

One aspect of this tendency to childlessness might be some people's commitment to their particular spiritual life and caution at any prospect of this being compromised by the emotional and financial pressures that can accompany family life. Another factor might be LGBT factors, reported as well-represented in the Triratna/FWBO. Concannon (2009,p.409) notes evidence from the USA that compared to the general population "LGBT people are four-and-a-half times as likely not to have any children" (see Kaelber,2002).

Finally there are narratives, usually from earlier phases of the movement, in which people seem to have been in conflict regarding family and spiritual life. For example, Inaba (2004,p.121) narrates how an Order member, 'Jeff', decided to leave his wife, children and family home to live in a men's residential community. It is a complex story, with Jeff's wife later ordained herself and Jeff seeing his sexuality as a factor in what happened, as he came to see himself as predominantly gay. So whilst many Order members who are parents are in good contact with their children, it is possible that socially unconventional decisions such as that made by Jeff might contribute to a situation of intergenerational ambivalence as referenced above (Lowenstein,2005). The availability of informal care in the future might also be affected in such cases.

Similarly, whilst it appears that only a minority of Order members have been celibate at any given time in the movement's history, there seem to be a fair number of single people. Order Members who are in relationships (heterosexual or lesbian/gay) quite often do not live together. Thus for example a couple might meet on a regular basis whilst living separately in single-sex communities or retreat centres. Whilst the trend within the Triratna/FWBO appears to be for more couples to be co-resident (Nagabodhi 2004,p.3) the Living Apart Together (LAT) life-style is still to be found in the movement and there is evidence of its growing popularity in the wider world especially

amongst 're-partnering' people in middle to later life (see de Jong Gierveld,2004) and see page 32-33. Both in Triratna/FWBO and the general population it appears unclear how current LAT arrangements might change in the event of care needs arising in either or both partners, and the implications in relation to informal care. Issues as to loneliness are also sometimes mentioned, as several older Order Members known to me live alone, and a recent Mental Health Foundation report has reviewed contributory factors including a 'Cult of Busyness' whereby people may have less time to support others (Griffin 2010). In contrast, Victor et al. (2009) emphasise the subjective nature of loneliness and question whether it is necessarily more widespread. Triratna/FWBO people potentially may have larger social networks than average, with the movement's emphasis on spiritual friendship an aspect of this, though anecdotally there are stories of people experiencing isolation in a way they find problematic.

It is reasonable to conclude that compared with the general population, Triratna/FWBO Order Members are less likely to have informal support from adult children if care needs emerge in their later life. Generalisations about future levels of support from partners/spouses are perhaps more problematic, but the social structure of the traditional Triratna/FWBO suggests that this may be relatively limited, and in any case a good number of Order members do not have partners. This in turn raises questions about other sources of informal support. For example, if someone lives in a Triratna/FWBO residential community or retreat centre, what resources will be available for informal support in the case of future care needs? Such questions take the movement into relatively uncharted territory.

Much of the existing literature on the movement still suggests a relatively youthful population for whom care needs are but a marginal concern. Nonetheless, warnings have been sounded and Lokabandhu's survey of the Order encapsulates the situation well:

> *There's not yet many Order members who have really reached old age yet – but they're coming. (2007,p.14)*

'Elders' are beginning to emerge, and there are few reference points of sufficient cultural relevance for their care needs or even retired life-styles. In Chapter Two I noted the Buddha's exhortation to the neglectful monks, but this was in a vastly different society and in response to an acute care need rather one entailing LTC. One approach is to look further at Buddhist traditions in relation to LTC. Contemporary examples are of particular salience, and are reviewed in Chapter Five.

At the time of writing some relevant plans are emerging in Triratna/ FWBO. One of these is a Welfare Fund, founded in 2008 and intended to alleviate the effects of ill-health, disability and poverty amongst Order Members (Abhayaratna Trust,2008) by, for example, helping with the costs of going on retreats. This is a small-scale project, but the emergence of some dedicated funding is a positive development since, as noted above, the resources of Triratna/FWBO urban centres and retreat centres are often limited and commonly have to be devoted to keeping current core activities going (Bloyce,2010). Order Members may have relative advantages in terms of general contact with people (if they wish for this), since links to a local Buddhist Centre can equate with a relatively large social network, and the movement's emphasis on spiritual friendship (Subhuti with Subhamati, 2004) may translate into ongoing links with friends. In contrast, future prospects for the 20 hours or more per week of intense informal care required by some frail older people is a less likely scenario for Order Members than for the general population, mainly by virtue of childlessness and single status being relatively common. The need to find out more about this area and to link it to the support of the Buddhist identity provides the basis for this study's second research question.

Residential care

Residential LTC is a relatively unpopular option for older people themselves (Timonen,2008), for people over 50 asked to express preferences if care needs arise in the future (CSCI/MORI,2003), and amongst policy-makers (Dalley,2002). Dalley notes this consensus but, as quoted above, points to its potential benefits for people such as those for whom an affinity group is important. In my relatively recent time as a peripatetic agency nurse (2000-2003) I saw good standards in a number of the care homes in which I worked. Whatever the wider debate, such homes are likely to remain a significant part of the LTC sector for the foreseeable future, and presently care for over 400,000 people in the UK (Froggatt et al. 2009,p.10).

Whilst the positive contribution of care homes should not be overlooked, there is what Goodman and Redfern (2006,p.82) call a "legacy of suspicion" associated with residential care. Some care homes can be seen to do more harm than good and their good faith can be questioned for a number of reasons. As an agency nurse my sense was that admission to one or two of the places I saw could have imperilled any valued sense

of identity with which a new resident might arrive. Sheila Payne, a professor of hospice studies, suggests that "we are hugely influenced by what we witness" in relation to end-of-life care (Moorehead,2006,p.3). Comparably the quality of LTC that what we see relatives or friends receiving may stay with us throughout our life and in some measure shape our expectations and emotions if we become potential LTC recipients ourselves.

One very critical portrayal is presented here in some detail. Lee-Treweek (2000) discusses aspects of her sociological research on the work of auxiliary care workers in two private care homes for the elderly. One of these, under the pseudonym 'Bracken Court', is described as:

> *A horrible place to be, physically cut off from the outside world and not pleasant inside. (Lee-Treweek,2000,p.121)*

Her alienation was compounded as she noticed the "grinding routine and the mistreatment of patients by the auxiliaries". The regime included demeaning staff attitudes whereby older people were perceived as wilfully childish, always "trying it on" and attempting to manipulate staff emotionally through crying and exhibitions of distress. Such emotional needs were resisted and staff focussed on basic bodily care. Lee-Treweek adds some disturbing perceptions of the characteristic staff approach;

> *They also used threat and fear to control behaviour. For example, because all the patients were frail and/or unable to walk, it was possible for even the smallest auxiliary to use her physical size to indicate threat or emphasise her power(ibid).*

The author gives an account of an interaction between Rosie, a resident, and Vera, an auxiliary. When the former made a mildly critical comment about the quality of care, Vera leaned over her wheelchair "very close to her face" and in effect brow-beat her into replacing her complaint with manifestly inauthentic compliments, including "You're lovely girls to me". (2000,pp.121-122).

Lee-Treweek's chapter appears in a book on the emotional, psychological and physical dangers that researchers can face. Observing the grim round of everyday 'care' at Bracken Court made the author "feel intensely guilty". Being unable to rescue residents was one aspect, and the way the elderly people "identified me with the negative activities of staff" was even worse. One resident wanted to go home and asked Lee-Treweek to take her:

> *When I said I could not she replied, 'A big strong girl like you could, you're just like them, no better, a collaborator'. Unsurprisingly I found this very hurtful. The last thing I wanted was to be associated with the uncaring behaviour I witnessed in the home.*
> *(ibid,p.123)*

Such narratives from Bracken Court appear to fully justify suspicion of LTC, though it could be argued that Lee-Treweek had found an unusually negative setting. LTC is a problematic area in which to establish and maintain good standards, with staff recruitment difficulties, low pay and inadequate training all conspiring against positive outcomes (Pollock,2005). Lee-Treweek acknowledges the pressures under which staff work, and that the other care home in her study was better. In my experience it is unusual to find a setting in which none of the staff exhibit more positive attitudes to clients. Nonetheless, sadly the general picture painted by Lee-Treweek is all too believable, even if some might question how typical it is. Two further points will be made. Bracken Court's owner lived locally and was prepared to give Lee-Treweek full research access, and it is arguable that the increasing corporatisation of LTC, with large firms increasingly predominant (Pollock,2005), might make such an open door policy for researchers less likely. Also, the Residents' and Relatives' Association (2009) raises the question of advocacy for care home residents with few family contacts, and promises a project on this. Such input might help with a range of issues; for example Cooney and Murphy's (2009) study includes the comments of an elderly lady who wishes she could have a bath more often than fortnightly. Advocacy may be of particular relevance for Triratna/FWBO people who are more likely to be single and childless.

More generally, Timonen states that many residential settings assume that clients have uniform needs, with much emphasis on routine tasks and physical needs and a marked lack of privacy. Personal identity is not prioritised, so "care plans are frequently not individualised" and often overlooked are people's:...social and higher level needs (such as the need to influence their surroundings and have a say in decisions concerning them). (2008,pp.139-140)

Equally, Timonen reports that little attention is given to:

> *...social activity, education or creative activities…[the activities available] can be highly unimaginative and overly structured (prayers on Sundays, bingo on Tuesdays, and so on).(ibid,p.139)*

She also comments on the indignity involved in staff using pet names or endearments with residents (Timonen 2008, p.139).

Much of what Timonen says is true of some care settings, although my disappointment in her approach is highlighted when she concludes:

> *While there will probably always be some older people who want and need 'medicalised' and institutional long-term care… (2008,p.149)*

Going on from this point she presents the future challenge as very much in the spheres of domiciliary and community care. Research shows an ongoing and relatively high level of usage of care homes, especially amongst the very old, with 16.9% of people of 85 years-plus resident in them (Laing & Buisson 2007).

Unlike the old psychiatric hospitals there is no current prospect of root and branch re-provision. Timonen's coverage of residential care contains no clear agenda for change, no examples of good or better practice, and refers to just one piece of research, published a decade before her own. Such an approach can surely leave residents, relatives and staff even more marginalised, with the sector seen as so flawed that attention must be placed elsewhere and is directed at people with lesser needs.

The dangers of this can be illustrated by drawing parallels with mental health service changes from the 1980s onwards. Along with the growing unfashionability of the old hospitals came a reported reluctance in some of the burgeoning community workforce to focus on the seriously mentally ill, with policy changes later having to redirect staff to the clients most in need of provision (Patmore& Weaver,1992).

The National Care Homes Research and Development Forum (NCHRDF), established in 2003 to facilitate contact between researchers and practitioners involved in care home work (Froggatt et al.,2009), works against any such tendency. Froggatt et al. review a range of initiatives and situations in this numerically large but easily overlooked area of work. Projects have included founding and evaluating active Friends of the Home groups in a number of settings, involving residents, relatives and staff in developing the services provided (Furness& Torry,2009), and facilitating connection with nature at the "edge spaces" of care sector buildings, finding that engagement with this "seems undiminished by even advanced levels of cognitive impairment" (Chalfont,2009,p.133). Brown Wilson et al.(2009) give a full and moving account of their work in a chapter entitled *The use of narrative in developing relationships in care homes*, in which the importance of ongoing life-stories is emphasised and linked to identity factors, as referenced in Chapter Three. Some approaches have a strongly practical, even commonsense aspect to them, such as:

> *Introduce residents who may have shared interests to each other. (Brown Wilson et al., 2009,p.88)*

Notwithstanding the apparently straightforward process this involves, activities are a vital and sometimes overlooked aspect of life in residential care. Brown Wilson et al.

reflect in their chapter on issues of quality and real engagement with individual needs where activities are concerned (see also Mozley et al., 2007).

So there are positive initiatives in the residential sector, and any care-based TBRL could learn much from them. Perhaps the main anxiety surrounding such work is how integral it can be made in the eyes of managers, purchasers and regulators of care, so that therapeutic approaches are seen as crucial to the service and not just as optional add-ons which prove fragile when public service costs come under even greater scrutiny (Dunning,2010).

'Costs' include the part that care users' personal finances play in the type of LTC they receive. This is not to argue that people who self-fund will consistently receive high quality care (see McDonald,2010,p.90), but the approximately 257,000 care home residents funded by local authorities (Hirsch,2007) have less choice of LTC. As noted on page 4 above some long-standing Order Members have very limited finances. Family legacies can be a factor here. While Lokabandhu's (2007,p.16) survey included people's expectations to inherit money and property, the majority of his participants "were not expecting anything", although they did include some people in professional-type jobs. Thus personal finance is an aspect of LTC, and is an area where a proportion of Triratna/FWBO people may be relatively disadvantaged.

Much of the above raises questions about what determines 'a good life' for older people in care homes. Interviews by researchers from the Joseph Rowntree Foundation (Smith et al., 2009) identified the following key areas:

- People knowing and caring about you;

- The importance of belonging, relationships and links with your local and chosen communities;

- Being able to contribute (to family, social, community and communal life) and being valued for what you do;

- Being treated as an equal and an adult;

- Respect for your routines and commitments;

- Being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with;

- Having and retaining your own sense of self and personal identity – including being able to express your views and feelings;

- Feeling good about your surroundings, both shared and private;

- Getting out and about. (2009,p.4)

These are valuable reference points for life in residential care and can also be salient in other models of care, as discussed in the next section.

Beyond the care home: Other models of care

As noted above, Timonen (2008,p.140) urges that development be focused on domiciliary care, as this appears to be the model of formal support that meets frail people's characteristic wish to age in place. Cost pressures apply in this sector, with a BBC Panorama documentary highlighting poor practice in local authority purchase of services from care agencies and featuring very brief and ineffective care visits to highly dependent and isolated people (see Samuel,2009). A report by Wainwright and O'Brien (2009,pp.5-6) notes the "downward pressure" on fees that local authorities exert and the tendency for state-funded care to be less available to people classed as having "lower level needs". Finding suitable domiciliary care can be problematic.

Extra care housing has been put forward as a positive alternative to residential care homes. According to Fear and Boddy:

> *It offers purpose-built housing for older people in either a flat or bungalow, or in part of a retirement village complex, where care can be provided in situ. (2009,p.49)*

From 2003 onwards the then community care minister, Stephen Ladyman, prompted a debate on resource availability, predicting that extra care housing would become the

dominant model of long-term care in due course (Harrison,2003). Although there are several references to extra care housing in the Department of Health's White Paper *Care, Support, Independence* launched in March 2010 and heralding the prospects for a National Care Service, no detailed information on projected costs or current progress are given. Peace et al (2006) refer to about 20,000 older people living in extra care housing.

My parents' home area, Oxfordshire, is reported to have a population of 635,500 people and the local strategy estimates a need for 7,832 extra care housing flats by 2025 (Oxfordshire County Council, 2009). And yet when Oxfordshire County Council's website information was last updated in October 2009 it was acknowledged that across the entire county there was "just one scheme with 20 flats with 24-hour care on site".

It is reasonable to conclude that at the current rate of development the prospects for Ladyman's predicted advent of extra care housing as the dominant model of LTC are remote indeed. It also appears that much of the political/policy attention is now on the personal care issues outlined above on page 63.

Extra care housing housing has been associated with higher-level needs, including the support of people with dementia, and, increasingly, end-of-life care (Dutton,2009). It can thus be seen as a development which potentially goes beyond very sheltered and traditional sheltered housing, although with some additional costs.It might be thought that the services offered by the last of these would remain consistently available, with newer developments building on this type of support and offering more input to an ageing and probably frailer population. However, traditional sheltered housing has been surrounded by a strong debate about the withdrawal – proposed and in some cases carried through – of resident wardens in many places, with the campaigning lawyer Yvonne Hossack seeking judicial reviews in relation to about 50 schemes located in 20 authorities (Stothart,2009). Parry (2010), of the sheltered housing representative consortium the Essential Role of Sheltered Housing (ERoSH), defends some of the changes in terms of improvements in practice such as reducing warden visits if they are unnecessary and institutionalising. In contrast Silverman (2010) attributes the introduction of more 'floating' wardens to politically-based cost-cutting and points to surveys indicating very high (90 per cent and above) levels of opposition from tenants.

Personalisation and progressive approaches

At the beginning of this chapter I quoted a Department of Health statement about the principles of personalisation in social care. Official policy has taken this forward, with direct payments (DPs) available to service-users since 1997 and individual budgets (IBs) being piloted in certain areas from 2005 onwards (Rabiee et al., 2009,p.919). The former empowers users to purchase their own care with due autonomy as to who they employ as a personal assistant (PA), the PA's work schedule and other aspects. Individual budgets go further, bringing together each user's finances from a number of funding sources. This means, for example, that someone might decide to reduce input from PAs and reallocate that money for leisure or education. A Social Care Institute for Excellence (SCIE) (2009) evaluation of these pilot schemes across a number of client groups found that "younger disabled people gained the greatest satisfaction" (2009).

In contrast, older people reported lower psychological well-being than those in the comparison group of people using more conventional services, and the evaluation adds some details about how older people utilising IBs were then given further support. Mandelstam (2007) voices concern that such policies can potentially be:

> *..a means of running down further public sector provision of services, and of capping the amounts of money made available to individual service users.(2007,247)*

He notes anecdotal evidence at the time of writing of people being inappropriately allocated such budgets, and sees health needs often rebranded as social care requirements as a form of cost control. Mandelstam's overall thesis is well captured in the following extract from the publisher's book jacket summary:

> *He outlines how humane care, particularly for older people, is compromised by the ruthless determination of NHS management to increase patient throughput and government-set targets. (2007)*

So personalisation is certainly not a panacea. However, the explicit commitment to individual needs and preferences in social care may offer advantages to Buddhists regarding aspects of their spiritual identity.

Another potentially progressive factor is that more attention is now paid to spirituality as an aspect of holistic care. The exploration of spiritual identity through the HOPE questions was discussed in Chapter Three, and it is notable how broadly-based definitions of spirituality in a nursing context can be. Sessana et al.(2007,p.258) include features such as 'art, music [and] literature' (2007).

Certainly a dialogue with people about their spirituality, where appropriate, can be valuable when offering them care, and handbooks giving basic details of world faiths can be a useful starting point for some staff (e.g. Mootoo,2005). There are dissenting voices on such matters and under the title *Keep the NHS Secular* Paley (2009) argues against some notions of spiritual care:

> *I am appalled by the suggestion that they be incorporated into nurse education. (2009,p.27)*

One response might be to ask 'What about care planning?' Individuals' spiritual interests may be of major significance to them, especially in the face of illness and death, and Paley fails to explain how nurses and others can respond to these if they have had no relevant preparation or training.

He is also concerned that the "ancient wisdom traditions" (Paley,2009,p.27) are sometimes seen as relevant in contemporary care practice. Many other workers seem happy to draw on these. For example McBee's (2008) book *Mindfulness-Based Elder Care* explores her years of work with residents in a New York care home and psychologists Balint and Ralph (2006) discuss working with positive emotions in people with dementia, and in both cases the Buddhist roots of the interventions are acknowledged. For frail Buddhist elders, now and in the future, there are at least some signs of convergence between Buddhist perspectives and some mainstream approaches to care and treatment.

Concluding Comments

LTC has become more prominent in political, policy and professional debate. There are many progressive and positive features of contemporary LTC, and at times these have come to the fore as levels of need have increased, so that, for example, 2009 saw the first ever *National Dementia Strategy*. However, a Triratna/FWBO Buddhist concerned about her/his LTC prospects or those of a friend in the movement might not be reassured by a detailed study of the current situation. Limitations on informal care could make ageing in place less feasible than for someone in the general population. Extra care housing is an attractive option, but its growth is limited by financial pressures. Today in 2010, the greater stringency in public spending means that generalised standards in residential and domiciliary care are unlikely to be driven upwards, and the challenge will be to maintain current levels of quality.

For a fuller picture, I consider further aspects of Buddhism and LTC in the next chapter.

CHAPTER FIVE: SUPPORTING BUDDHIST IDENTITY IN LONG-TERM CARE SITUATIONS

Preliminary comments

Concluding the literature and background review, this chapter summarises some of the previous material and brings together additional aspects, some of which are then considered in the wider context of Buddhism and its relationship to LTC issues.

Some of the key points made thus far can be summarised as follows:

- Buddhists have particular needs regarding their practice of the Threefold Way of ethics, meditation and the seeking of wisdom.

- Meeting these needs includes the availability of a vegetarian/vegan diet and suitable conditions for meditation, and interaction with others with comparable spiritual interests.

- Such life goods can be seen as constituting Buddhist identity, an emerging identity in a range of social contexts, including LTC, which can be supported or undermined.

- More broadly, there is concern about the general quality of LTC, and the fact that aspects of valued personal identity may be vulnerable in settings in which care is poor.

- Some Triratna/FWBO people, especially long-standing full-time practitioners whose minimal financial and family support may compromise choices of LTC, may be relatively at risk in this respect.

- This raises questions about the availability of informal support within the movement, and about Triratna/FWBO people's views and experiences of LTC.

- The movement has a tradition of work projects (TBRLs) and a proportion of people working in various caring professions and jobs. TBRLs might therefore be developed in the LTC field to offer various forms of support to the wider public whilst having a particular sensitivity to the needs of Buddhists, and thus supporting their Buddhist identity. These can also be termed BBCS (Buddhist-based care services). The personalisation agenda in social care is relevant here.

A range of material has already been reviewed in relation to the above. Below I place the previous work in a wider Buddhist context.

Buddhist History

The future Buddha's encounter with the old man related in Chapter Two does not appear in the Ariyapariyesana Sutta, a key source of biographical material (see Sangharakshita 2009a). However, it has wide currency in Buddhism, although this may signal a general concern with impermanence rather than a strong and specific focus on the difficulties faced by the frail elderly. The Buddha's response to the neglected monk with dysentery (discussed in Chapter Two and elsewhere) is the main canonical source regarding the spiritual community's responsibilities in caring for one another in the event of sickness (Sangharakshita 1991).

We can consider two contrasting references in subsequent Buddhist traditions. From 18th century Japan there is the story of the great Zen practitioner Hakuin, who as a young man hears that the man who taught him the Dharma is now ill and has no-one supporting him (Waddell 1999). Hakuin takes on the caring role for a number of months; interestingly, the narrative emphasises that Hakuin maintains his meditation practice during this time. However, if this prompts too benign a picture of traditional community obligations in operation, a famous biography of Padmasambhava, who established Buddhism in Tibet in the 8th century, includes a grim portrait of ageing. Incontinence is graphically described in relation to an archetypal frail old man, with the conclusion that:

> *The human heart not being kind, young people despise him. (Douglas and Bays 1978.,p.721)*

Contemporary Contexts: East and West

It is worth briefly considering some contemporary situations, although there is little detailed research. Kariyakarawana (2010) discusses a Sri Lankan tradition whereby certain monks take on the designated role of care-giver to frail monastic elders, with juniors often supporting their Preceptor. Monks also care for their parents at times, suggesting that today the boundary between monastic and family care arrangements is now less pronounced than the attitude implied by 'Ye have no mother and no father' as presented above-see page 22.

In Asia monks are involved in health and social projects such as the Thai Sangha Metta organisation, which offers education and support for people with HIV/AIDS (Sangha Metta,2010).

However, this is a less prominent part of the monastic remit than has historically been associated with some Western orders of monks and nuns (see Horner 1951).

In the West, research on the care needs of Buddhists has focussed on Asian migrant groups (see for example Lee et al.,2005). Handbooks giving information on care are widely in use (see Mootoo,2005), with a typical focus on:

> *...what one eats and how one disposes of the dead and so on. (Neuberger,2004,p.2)*

The authors of such works are in a difficult position, as the concise format demands broad generalisations about large and varied populations, although most recommend drawing as much information as possible from the individual client/patient.

However, as previously stated, I am not aware of *any* research focusingon LTC issues amongst Buddhists primarily of a Western cultural background. This seems to be mainly a matter of demographics, as larger-scale, full-time practice of Buddhism in the West is a relatively new phenomenon with many of the original cohort from the 'baby boomer' generation. Also Buddhist practice is often associated with the middle-classes and thus other minority groups may be seen as more in need of investigation and support. In fact there are many Triratna/FWBO people from less privileged backgrounds, and the full-time Buddhist life is often linked to very modest financial resources. However, other minority groups may face bigger challenges in negotiating with the care system: Triratna/FWBO Buddhists, even if financially poor, are typically native speakers of English and often well-educated. Many have extensive social/personal networks, and overall can reasonably be seen as people with useful assets when it comes to having care needs assessed and met- see also page 100 below.

However, as this study indicates they also can have actual and potential difficulties. As a minority group there may be a concern with being able to 'be myself' as much as possible in later life, and this may mean ensuring ongoing contact with other Buddhists. A retirement project for older Buddhists has been developed in Devon by a group of 'non-aligned' Buddhists including Richard and Diane St Ruth (Golden Buddha Centre, 2010). I visited their property in 2003, but their web-site now confirms that it has since been sold and that there are plans to develop sheltered housing in the same area.

San Francisco's Zen Center is a well-known reference point for Western Buddhists. Its founding teacher was Shunryu Suzuki, who arrived from Japan in 1959. The centre's development, including the establishment of an organic farm, renowned food outlets

and a monastery that is also a hot-springs tourist resort, has been much documented-see Chadwick (1999) and Downing (2001). These work projects have been associated with Zen students working for modest levels of support. In 1983 a dispute erupted at the Zen Center resulting in Suzuki's successor as abbot, Richard Baker (Baker-Roshi), being in effect deposed. At the same time issues in the local Sangha began to include longer-term health needs, and Issan Dorsey, a leading priest, was reportedly very disappointed when his request for funding for a new hearing aid was turned down by the centre's board (Schneider,2000). The situation was complicated by his pending departure from the Zen Center, but it highlights pressing care-related issues for people who have lived on a basic support package rather than a salary as part of their spiritual life. Reading about this interested me in learning more about the Zen Center's response to LTC needs, and I visited it in 2006. With one of the largest and most long-standing Western Buddhist Sanghas it seemed likely to offer some points of comparison between care systems in the USA and the UK.

A leading figure at the Zen Center, Lewis Richmond, has produced a book, Work as a Spiritual Practice (1999), with particular reference to his information technology business. This contains useful material on work-related stress, anger, generosity, gratitude and other key Buddhist themes. However, compared to Padmasuri's (2003) book on TBRL it is geared to individual practice with no particular emphasis on spiritual friendship and communication with co-workers. There seems something distinctive about the Triratna/FWBO approach to TBRL which is no doubt also linked to the type of livelihood being undertaken.

As to the altruistic dimension of livelihood, the Zen Center is well known for its work in palliative care, with a small hospice nearby in the past, and presently a project to support volunteers in two palliative care units. These are discussed in the next section.

Hospice and Palliative Care Work

Collett (2002) outlines the personal and spiritual impact on him of working as a volunteer at the small hospice formerly adjacent to the Zen Center. This mainly served people with no specific Buddhist connections, with AIDS and poverty/homelessness often part of the picture. Palliative care has become associated with a number of other Buddhist groups, including Sogyal Rinpoche's Rigpa group (see Longaker,1997), the Karuna Hospice Service in Brisbane, Australia and the UK's Buddhist Hospice Trust.

The latter was founded in 1986 and originally aimed to have its own building(s). However, there was a change of direction some years ago prompted by fund-raising problems, hospice-at-home developments and recognition of the fact that there was unlikely to be a critical mass of people seeking care from a Buddhist Hospice in any one geographical area (Goble,2007). The aim has always been to offer services to a wider public, and the Trust's website is headed with the statement *Meeting the Spiritual Needs of Seriously Ill and Dying People*. Volunteers are involved in palliative care settings on this basis, with the Trust contributing to wider debates in this field.

Two general points can be made about Western Buddhist involvement in palliative care. The first is that it is often geared to non-Buddhists, reflecting Buddhist aims to offer support for the general public where appropriate and feasible as well as Buddhists' minority status in Western cultures. Thus, for example, the Brisbane-based Karuna Hospice Services has developed around Pende Hawter, an Australian-born physiotherapist who is an ordained Buddhist in a Tibetan tradition. Karuna, meaning 'compassion' in Sanskrit, provides professional staff and volunteers who offer palliative care to people in their own homes. Although some of the workers are Buddhists the service is available to all eligible people:

> *The spiritual component of the support is not explicitly Buddhist unless the patient so desires (Bucknell 2000,p.472)*

A second general point is that books and other material offering a Buddhist perspective on death have entered the cultural mainstream in the West. Thus Sogyal Rinpoche's The Tibetan Book of Living and Dying (1992) is reported to have sold 1.6 million copies and has been translated into up to 30 languages (Rigpa 2010). Several other books (Lief,2000; Lama Shenpen Hookham,2006) are well-known, as are relevant films such as that by Mori and Hayashi (1994).

There is much less material about ageing in relation to Buddhism, although Maitland (2004**)** gives an elegiac account of his mother's Alzheimer's disease with Buddhist perspectives on impermanence and the elusive nature of the mind and the person. There are other contributions by Jones (2003) and Barzaghi (2010). In relation to the Four Sights experienced by the Buddha (see Chapter Two**)**, while some of his spiritual heirs may be prepared to engage with death (the third sight), focussing on frailty and old age (traditionally the first) may be more difficult. No doubt the well-documented general aversion to the prospect of old age (Kitwood 1990) is all too often extended so that the

elderly themselves become a relatively unpopular group (Bytheway,1995). This doubtless applies in Buddhist circles as well as the wider world. However, Inaba (2004) finds some evidence that involvement with two faith groups, one of which was Triratna/FWBO, helped to develop people's altruism, so it is to be hoped that Buddhists are able to bring a due amount of awareness and help to the difficulties of the frail elderly when they arise.

Overall, Buddhist involvement in palliative/hospice care appears a positive trend for all concerned, and it may be a mistake to see this type of care as strongly distinct from the LTC sphere. As Froggatt (2007,p.235) points out, up to 25 per cent of the deaths of people over 65 in the UK occur in care homes. Watson et al (2009) note the importance for Buddhists of a person's state of mind at the time of death, also noting that

> *Some patients may want help to find quiet for meditation, and others may welcome Buddhist chanting to influence their state of mind (2009,p.796)*

Support for this may be provided by Sangha friends, family or hospice volunteers, or by one of the small but growing number of Buddhist chaplains in the UK (see Chapter One). A service with an explicitly Buddhist foundation could appeal to some Buddhists approaching the end of their lives. If a residential TBRL facility for LTC proved viable, staff of a similar spiritual background rather than a specialist palliative/hospice setting might provide end-of-life care for increasing numbers of Buddhists and/or people of Buddhist sympathy.

The Triratna/FWBO Context

As noted, it could be seen as surprising that care-based TBRLs have not been developed already. Lokabandhu (2009) found that 40 per cent of the Order members who responded to his survey had professional livelihoods, and a proportion of these are certainly involved in health and social care work. The practice of TBRL is a central distinctive emphasis of Triratna/FWBO and LTC might be a new area for this. Care linked to spirituality might arouse the suspicions of some secularists, see Paley (2009), and would go somewhat against the mainstreaming trend referred to by Valins (2002,p.34).Nonetheless, 'faith' as an aspect of caring vocations has a long history (see Ardern,2005) and there is evidence of Buddhism being well-thought of by the public in some Western contexts (Wuthnow& Cadge 2004). So it is arguable that a wide range of people might find the prospect of care from a Buddhist service acceptable.

Characteristic livelihoods within Triratna/FWBO are increasingly therapeutic and care-related. Several centres have developed projects with local councils and carer organisations to offer weekend retreats for informal carers with yoga, meditation and other activities in a rural setting (Roberts, 2007). Vajragupta (2010) comments on thriving developments around the London Buddhist Centre and in Manchester which involve:

> *...teaching mindfulness meditation techniques to help those suffering from depression,addiction, chronic pain, or stress. (2010,p.63)*

As mentioned in Chapter One, the only care-based TBRL proposed that ever reached the advanced planning stage was a community-based learning disability project in North-West England over ten years ago. This project, originally known as Metta Unlimited, was unable to establish a viable team. The TBRL content would have been based on the work's intrinsic potential for altruism, with aspirations to positive communication amongst staff but no explicitly Buddhist discussions with the client group.

In contrast, it seems that in 2010 there are opportunities for supporting Buddhist identity where appropriate as well as for offering a service to a larger, non-Buddhist public. The personalisation process in social care (see Chapter Four) may mean that eligible Triratna/FWBO people are increasingly able to shape their own care packages, and it seems likely that personal assistants will be recruited from networks of people known through the local Sangha. The rising age demographic means that growing numbers of people will need some level of care. Lokabandhu (2007,p.4) notes that in 1976 male and female members of the (then much smaller) Order were on average 29.7 and 35.1 years old respectively, with current equivalent figures 49.3 and 51.7 and a growing number of people in later life (by 2010 the average Order Member age was over 50 for both sexes-Lokabandhu 2009). In the late 1980s Bell (1991) found that Triratna/FWBO had a predominance of people in their twenties and thirties, with attempts reported to appeal to a broader public. In November 2008 the movement's Development Team launched a project called Inspiring Young People in the Dharma (Triratna News,2010). Whilst some younger people attend most centres and events such as the Buddhafield camping festivals and retreats often have a youthful constituency fewer young people are seeking ordination. Lokabandhu (2007) has been quoted above

regarding the future with a growing cohort of older Order Members, and he points out that:

> *The 20-somethings have all disappeared…the 30-somethings are fast going…50- year-olds are rapidly becoming the norm. (2007,p.5)*

Even since many of the 50-year-olds were ordained there have been notable changes in the Order and movement's relationship to the wider society. Inaba (2004) states that Triratna/FWBO tends to be world-affirming rather than world-rejecting. Although Buddhist values can be linked to a critical stance regarding consumerism, political decision-making and many other areas, Triratna/FWBO organisations typically aim for harmonious relations in local situations. Buddhist Centres offer resources to their neighbourhood communities, and many people come to learn meditation as a life skill rather than for any specifically spiritual purpose. Centres contribute to education programmes on Buddhism in a world-faith context. These and other examples are relevant to discussion about social solidarity in relation to LTC (see Sutherland,1999). Trirtana/FWBO people are not a group apart from their local communities and can make significant contributions to the economy, such as the Windhorse:Evolution warehouse in Cambridge (see Padmasuri,2003). Thus it is reasonable to ask for specifically Buddhist needs to be taken into account in general LTC practice and policy development.

Finally we can note two recent statements by Sangharakshita. In 2009 he wrote about care for dying friends becoming more of a "natural part" of the life of the Order (2009,p.14). In 2010 when speaking at the Ipswich Buddhist Centre he mentioned issues of loneliness and encouraged visiting of frail older people if they wished it (this seemed to refer to people known to the Centre). So there was some sign of informal support becoming part of the Order and movement's everyday life, and an extension of principles of spiritual friendship to those who might otherwise be 'at the margins'.

PART THREE – METHODOLOGY AND METHODS

Part Three of this thesis considers the methodology of the study. It comprises the following chapters:

- Chapter Six discusses the change of focus in the research in late 2007 and some issues arising from this. Philosophical and political aspects of the methodology are also explored.

- Chapter Seven reviews the data collection and analysis, with material from interviews with three sample groups and a questionnaire with a larger sample of Triratna/FWBO people.

- Chapter Eight concludes this part of the study with commentary on the ethics involved and the study's validity, aspects of the research instruments in view of the refocusing of the research, and the general strengths and limitations of the thesis.

CHAPTER SIX: ASPECTS OF METHODOLOGY AND THE SELECTION OF METHODS

Preliminary comments

As outlined in Chapter One, this study began as a general study of LTC issues in the Triratna/FWBO movement with the working title *LTC issues in a British-founded Buddhist movement.* In late 2007 a number of factors contributed to my decision to refocus the research under a new title *Supporting Buddhist identity in long term care situations*. In this chapter I discuss how I developed a methodology in relation to the first working title, and how I adapted this when I refocused the research. I argue that although the research instruments were designed to suit the study's first set of research questions, the majority of the data remained relevant. The study's focus on a particular Buddhist movement indicated that a case study design would be suitable.

First set of research questions and associated framework

Following early work carried out in 2003-4, two research questions emerged:

1. How do Triratna/FWBO Buddhists experience LTC as offered by a) formal mainstream care services, and b) friends and relatives?
2. What are the views of Triratna/FWBO Buddhists on the possible development of long-term care services with a Buddhist foundation?

With these two questions in place I began work on schedules for semi-structured interviews, and having gained the necessary permission I began the first phase of data collection. This involved interviewing one group of people with current care needs and another group asked to anticipate their care preferences if LTC needs arose in the future. Next I conducted five interviews with people considered to have expertise relevant to the study's remit. The data collection was completed with a questionnaire completed by 107 people around the movement and focused on possible Buddhist-based LTC services.

It was evident that there was a danger of producing an overly descriptive piece of writing and the inquiry thus needed a wider conceptual/theoretical context. A framework was developed whereby the questions would be considered in the context of three cultural themes: diversity, values and community. Diversity was linked to question

1a) in view of the apparently strong contemporary focus on cultural variations (e.g. diet) and how these can be respected and accommodated in care situations. Question 2 related more to community, defined in terms of people who have some level of shared experience, with a range of care-related questions such as: What measure of responsibility are Triratna/FWBO people prepared to take for one another? Values were seen as relevant across all areas of inquiry, sometimes as *features to be responded to* (as with vegetarian/vegan diets) and sometimes as *espoused aspirations that may or may not be seen in action* (for example, Buddhists may be associated with compassion, but what are participants' experiences of this?

Initially the 'diversity-community-values' framework appeared to have some advantages for relating Triratna/FWBO LTC experiences to broader patterns and themes and thus helping to develop some theoretical constructs about key processes. By late 2007 I had a substantial data set comprising material from the interviews and the questionnaire, where participants' additional comments had proved more fulsome than I had expected. But the existing framework appeared to lack a unifying relationship to the data, and feedback from a research review panel prompted me to find a new focus. Some reflection on this produced the idea of making Buddhist identity the central theme. This would need to be explored in relation to general Buddhist tradition and some specific aspects of Triratna/FWBO. The idea that valued identities can be vulnerable in LTC situations, for example in residential care homes, seems to have a wide currency linked to key themes such as respect, dignity, understanding of individual and spiritual needs, the quality of the care environment and other factors. Informal care and support within the Triratna/FWBO Sangha would also be relevant.

The possible development of Buddhist-based LTC services has already been noted, and this is linked to the movement's history of TBRLs. If any LTC-based TBRL were to develop it is assumed that its services would be open to a wider public whilst having a particular sensitivity to the needs of frail Buddhists, so supporting Buddhist identity. Once this change of focus was agreed, four revised research questions emerged:

1. How might identity and personhood be conceptualised in relation to people involved with Triratna/FWBO?
2. Within the Triratna/FWBO Sangha, what factors would influence the level of informal support available to someone with care needs?
3. How do Triratna/FWBO people experience and/or view mainstream LTC

services in relation to support for Buddhist identity?

4. How do Triratna/FWBO people view the possible application of Buddhist TBRL principles to the LTC sector and the implications for the support of Buddhist identity?

Identifying a Methodology

After deciding on the first set of research questions it was necessary to identify a methodology. When I first resolved to research LTC in relation to Triratna/FWBO I had a fairly broad aim in mind which can be summarised as follows;

> *I want to find out a lot more about anything which is relevant and then find some practical approaches that may help.*

This sounded more like the basis for a fact-finding report than for a piece of academic research, and further reflection was needed. The questionnaire as planned would provide some numerical data, and so there was already an element of mixed methods in the design, but my emergent thinking was that the quantitative contribution to the study would be relatively minor. I felt increasingly sure that the study should draw on interpretivist and qualitative approaches. Robson (2002,p.549) states that in interpretivism, "the focus is on an analysis of the meanings people confer on their own and others' actions". Creswell (2009) echoes this in his definition of qualitative research. He adds that there is a "focus on emerging questions and procedures", an inductive approach to data, "building from particulars to general themes" and a concern with "making interpretations of the meaning of the data" (2009,p.232).

Denzin and Lincoln (2008,p.128) emphasise experiential knowledge as the "essence of qualitative understanding". This emphasis on personal experience can include the researcher's own narratives and reflections where appropriate, and in the first section below I draw on a personal experience of research from over 20 years ago. I continue on from this to outline key factors in the decision to choose a qualitative/ interpretivist approach. I will argue that I used an eclectic methodology, which had elements of case study and of survey research to it, and to which ethnography, participant observation, and mixed methods approaches have relevance. Studying aspects of a spiritual movement in which I have been long immersed prompted me to wonder how "thick" a description I could produce, and to reflect on any tensions between my status as a researcher and my on-going membership of the Order. This took me into theoretical

territory explored by Geertz (1973) and others, whilst I remained clear that I was not attempting an ethnographic study. The general culture of Triratna/FWBO, to which an ethnographer might gravitate, certainly was salient, especially with the emerging focus on Buddhist identity .However there was an at least equal concern with LTC issues, for the investigation of which other methods were needed which were non-ethnographic.

The Qualitative/Interpretivist Approach

I first heard the term *qualitative research* in 1989 from a psychology lecturer at the University of Surrey where I had just started working towards a teaching certificate in order to work in nurse education. The previous year I had completed a BSc. degree in Psychology, and in that University of Surrey teaching room I realised that all my research training had been in *quantitative* approaches. My final BSc. project had included five people from each of the five professions that usually make up a mental health multi-disciplinary team: occupational therapy, clinical psychology, social work, psychiatry and nursing. The participants read fictitious client scenarios and were tested on what they could recall. Some results seemed to support professional stereotypes and archetypes: for example social workers, often associated with family work, scored significantly higher than any other group where details of relatives were concerned, even if information had been minimal such as a passing reference to a long-lost sibling (see Hillary,1988).

Writing about this recently in my reflective journal I outlined what I now believe would have been a more valuable piece of work. The findings disclosed *what* people remembered, but had little to offer about *why* beyond the assumption that this was determined by professional role. Semi-structured interviews as a follow-up might have revealed much more, and this thought prompted speculation on my part. For example, some material might have been remembered because of links to current research interests or plans for a future career direction. Some people might have been content to focus on the part of the narrative most associated with their profession, whilst others might experience such compartmentalisation as limiting and frustrating. Some participants might have related the scenarios to issues in their work with clients or might even have disclosed relevant personal experiences, e.g: "Something similar happened in my family". All of this could have contributed to a study with a title such as

Professional identity and personal interests. But I knew nothing of qualitative approaches and my BSc. training had given me a positivist approach to epistemology which privileged any numerical evidence I could find amongst the mental health professionals and which would undervalue individual narratives as statistically significant knowledge was sought (Snape& Spencer 2003). Thus the study that I handed in over 20 years ago now seems a decidedly 'thin' account of the possible interests and attitudes of the participants.

I use the term 'thin' with reference to Geertz's (1973,p.10) concept of "thick description", which I discuss in the next section.

'Thick description'

Geertz's concept of thickness in description is strongly associated with ethnography and participant observation in research. Bryman's (2004) definition of ethnography includes:

> *...the researcher [immersing] him or herself in a social setting for an extended period of time. (2004,p.539)*

The sometimes daunting nature of the ethnographer's task is well-invoked by Geertz (1973,p.10), who writes that it involves engaging with:

> *...a multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another, which are at once strange, irregular and inexplicit, and which he must contrive somehow first to grasp and then to render.*

Geertz was a social anthropologist and his narrative from Morocco in 1912 provides an example of thick description. There was conflict stemming from sheep-trading and involving three different frames of reference, with the situation viewed differently by local Moroccans, Jewish traders and the colonial French authorities. The ethnographer who heard this story in the 1960s had the task of understanding the relevant "complex conceptual structures" as revealed by people's behaviour and attitudes. Classically the ethnographer approaches this by living alongside people of a particular culture as a participant observer seeking to construct theory from what s/he sees.

For the present study I wanted as thick a description of salient Buddhist identities and lifestyles as the word limit and other constraints would allow. This seemed likely to include a measure of *verstehen* (understanding), as invoked by Inaba (2004) in his study

of aspects of the then FWBO and a Christian group, both of which he classifies as New Religious Movements (NRMs). *Verstehen* is presented as:

> *An attempt to comprehend social action through a kind of empathetic liaison with the actor on the part of the observer. (Inaba 2004,p.11)*

Notwithstanding the influence of any such 'empathetic liaison', Inaba also quotes the dictum of Bryan Wilson, well known for his research on NRMs, that "the sociologist is to remain detached and apart" (Inaba,2004,p.12). There is a need to achieve a balance between finding a substantial level of understanding of a particular group whilst not getting caught up in their attitudes and practices so that all objectivity is lost. Objectivity is of course a disputed entity in research, especially in the qualitative sphere (Snape and Spencer,2003).However, my situation was distinct from that of some ethnographers in two ways. I have participated in Triratna/FWBO for 20 years, and I explore the influence of this on my researcher status as a participant observer in the next section. Also, earlier research on the movement (Bell,1991: Inaba,2004:Bluck,2006) has focused on its values, spiritual practices and associated ways of living, whereas the present study relates Triratna/FWBO culture and identity to the specific social phenomenon of LTC. My task was to give an outline of relevant areas covered by earlier researchers and others and to include this in my application of what is known already to the LTC issues under consideration. Many aspects of Triratna/FWBO are salient to the present study, and Bryman's (2004) criteria regarding case studies helps to highlight this. Citing research by McKee and Bell (1985) on the impact of male unemployment on family life, he acknowledges that all the 45 interviews were undertaken in the same location, Kidderminster, but argues that the location was of only marginal relevance, and that:

> *I would prefer to reserve the term 'case study' for those instances where the 'case' is the focus of interest in its own right. (Bryman,2004,p.50)*

In the present study the case is Tritatna/FWBO, the "community or organisation" (Bryman 2004,p.49) to which the great majority of participants belong. It emerges as a focus of interest in its own right because of the impact of the movement on people's lifestyles and the relevance of this to LTC. Some discussion of Triratna/FWBO culture is essential as it can easily be misunderstood, as when for instance Buddhist lifestyles are assumed to be monastic. In comparison, features of McKee and Bell's study (1985) such as family life, unemployment and, indeed Kidderminster are likely to be more

conceptually familiar to many readers. Further aspects of this are discussed in the ***Survey and Case Study Research*** section below.

The Participant Observer

Overall I believe that knowing many Triratna/FWBO people personally and having some understanding of the movement's culture, terminology and other background has mainly been advantageous. Other aspects of participant observation are considered below.

Holdaway (1983), then a police officer, covertly studied aspects of his force in conjunction with his normal duties. My role and ethical stance required full disclosure of my aims and encouragement of a collaborative process between researcher and participants. However, there are some parallels: Holdaway doubtless became interested in his research questions through his pre-researcher experience in the police and brought elements of this background to his study. My own views about the FWBO, and more recently Triratna, have been forming and changing ever since I arrived at an introductory class in 1990. Thus a full separation of myself as researcher from myself as Order Member is not possible, or, I would argue, desirable.

This brings to mind Goffman's (1959,p.114) "back regions", problematic areas which an outsider may be discouraged or even disbarred from exploring, or, arguably, which a researcher may know something about but feel reticent about raising for discussion.

Triratna/FWBO has been subject to strong public criticism, aspects of which have been outlined in the literature review above. As argued there, the criticism is not of central importance to the present study, although it may have affected Triratna/FWBO people's views of their spiritual life and how the movement is seen by the wider world. Like Baumann (2000,p.391) writing on Triratna/FWBO's TBRLs, I referred to these controversies whilst being clear that I did not expect them to be a primary concern in this study. The word 'expect' is key here, in that of course I did not know what participants would say about this hostile publicity, in terms either of the volume of comment they would make or of the apparent depth of feeling associated with their remarks. As shown below, neither the semi-structured interview schedules nor the questionnaire items directly asked for views on the controversies, although at some junctures there were opportunities for participants to communicate about them and

broader aspects of their lives in relation to the Triratna/FWBO.

Another factor is that Buddhist ordination might be seen as compromising academic judgement. Whilst the movement has scholars such as Tribe (of Williams with Tribe, 2000) and Morrison (1997), there are also well-known non-Buddhist writers who are devoted to the academic study of Buddhism such as Hamilton (2000), who makes her stance explicit in one of her books. Overall there is a complex relationship between being part of a faith tradition and producing academic critiques of that tradition. Nonetheless, while seeing myself as one of the countless heirs to the Buddha's Enlightenment, I am also influenced by the legacy of the 18th century European Enlightenment, valuing my personal autonomy and aspiring to carry out my research "systematically, sceptically and ethically" (Robson,2002,p.18). I might be very pleased to hear of Triratna/FWBO people who have felt well-supported by the movement in their illness or disability and deeply disappointed to hear the opposite: however, my aspiration must be to give the clearest possible picture; in Shakespeare's words (1604/2007,p.2155) my aim is that I "nothing extenuate, nor set down aught in malice".

To achieve this I needed clear research aims and the support of others. Bringing in a characteristically Buddhist approach I also saw the need for a willingness to monitor my own mental state in relation to the research material (Williams with Tribe,2000,pp.2-3). Wilson's admonition to remain "detached and apart" (1982,p.12) has been mentioned, but if I were to become aware of an emotional response to what I was hearing or reading this could offer opportunities for deeper reflection. One interview might leave me in a low mood, another might prompt anger and a third might produce a sense of elation. Certainly some emotional responses are recorded in my reflective journal, and noticing these has proved a valuable part of the research process.

Another aspect relates to what I term basic information. As stated above, I saw my familiarity with Triratna/FWBO as primarily advantageous. As an insider it can be easy to fall into complacent assumption that one knows a particular social world better than people commenting from the outside, although it is equally difficult to produce a genuinely thick and comprehensive description of that world on the basis of a limited period of field work. For example, Bell (1991,p.143) made several references to the what she perceives as the lay nature of the Triratna/FWBO Order, and this being some years after Sangharakshita (1988a) had published his ideas about his 'neither monk/nun nor lay' view of the Order. Of course, whilst Bell was not obliged to accept his views, it

seems an omission that she did not mention them in this context.

In contrast, one aspect of the potential drawbacks of being an insider was highlighted for me when I read Becker's (1998) well-known account of his efforts to get a group of medical students to explain the term 'crock', which they applied to some patients. Specific social worlds are often characterised by the development of their own vocabularies (see "webs of interlocution" in Chapter Three) and researchers take on a valuable task when they ask the users of such terminology to clarify what they mean. For example, in Triratna/FWBO circles the term *kalyana mitra* (spiritual friend) is often invoked, and someone from outside the movement might be more tenacious in asking what constitutes a spiritual friendship and, in the case of the present study, what might be expected of such a friendship in the event of care needs arising on either side. Where interviewer and interviewee are regular users of a term there is a danger of a false consensus where mutuality of usage and understanding is assumed and subtle (or perhaps not-so-subtle) differences remain unclarified. I could only aim to be alert to any such tendency when interviewing or discussing my study.

Many people I know around Triratna/FWBO are aware of my work background. As already mentioned, on occasions I was told that I wanted to open a Buddhist care home. It was true that this academic research contributes to my wider personal aim to look at LTC issues in Triratna/FWBO and that at the very least I wanted to raise the profile of these with the movement. However, a fortunate form of co-existence emerged between my desire to control bias in the research and my pragmatism about practical projects. In both cases I was able to emphasise my quest for more information and forestall assumptions that I was strongly committed to Buddhist-based services as such, or to any particular model of care. Otherwise there was a danger that I would be understood to be seeking or encouraging particular types of answer, with a worst-case scenario being that friends and associates produced inauthentic, favourable response sets to 'humour' me!

Overall the researcher-as-insider needs to be aware of the advantages and pitfalls of the situation. For me, helpful strategies included keeping a reflective journal and free and frank discussions with supervisors about difficult areas in the work.

Survey and Case Study Research

Thus far I have discussed qualitative approaches. Some quantitative dimensions were

also included, making this a mixed methods study (Creswell 2009). Statistics on the demography of Triratna/FWBO are relevant here. Lokabandhu's Order Survey, begun in 2007, provided much valuable information.

The questionnaire awarded numerical scores to relevant attitudes. It was planned that the questionnaires would elicit a wider picture of some relevant attitudes. Whilst I recognised the need to be cautious about claims to representativeness (Silverman,2005) I was prepared to seek broader generalisations about Triratna/FWBO care issues wherever evidence was available. For example I wanted to find out how having care needs oneself might be reflected in questionnaire responses. Overall, it is arguable that the mixed methods utilised included elements of a case study and of a cross-sectional survey.

Bryman (2004,p.49) acknowledges that at times "it can be difficult to determine" the difference between the two approaches just mentioned. A key criterion of his for a case study was quoted above on pages 95-96, and can be re-iterated in a different form by checking if Triratna/FWBO culture was simply "a kind of backdrop to the findings" (Bryman 2004,p.50). If so, he argues this would disqualify it from being classified as a case study. My perspective is that what was undertaken involved the movement as much more than a backdrop and that a relatively detailed awareness of some cultural aspects was essential if the more specific 'case' of Triratna/FWBO people's LTC needs was to be adequately represented. I would propose that the Literature/Background Review content, especially Chapter Two, gave a general picture of this, with interview material and questionnaire additional comments grounding key aspects in personal experience and observation. To give some examples, it was notable that *'TBRLs'* and *'FWBO culture'* emerged as the largest NVivo free nodes, and that the tree node *'Identity and Personhood in Triratna/FWBO Context'* contained much material as to characteristic Triratna/FWBO practices and lifestyles.

The fact that almost all my data came from people involved with Triratna/FWBO (apart from the two interviews in San Francisco) accentuated these case study features. I can informally report that presentations to Buddhists from other schools/movements, mainly through the BHCG chaplaincy group (see pages 8 and 36), indicated many shared concerns as regards LTC. However, any attempt to address the present study's research questions in relation to non-Triratna/FWBO Buddhists would, of course,

require much more research, even if, for example, its scope was limited to UK-resident Buddhists from some of the larger schools of practice.

Nonetheless, the study also had elements of a cross-sectional survey, particularly with its semi-structured interview schedules and its questionnaire's potential for yielding quantitative/quantifiable data (Bryman,2004,p.544). However, as we will see, the evolution of this research included *qualitative* data deriving from the questionnaire proving to be of major interest, and it seems that the study design can be best described as eclectic.

Rights and Identity Politics

Bryman (2004,p.22) cites Becker in a contention that sociologists tend "to be very sympathetic to underdog groups". In electing to study Triratna/FWBO Buddhists in relation to LTC I am representing them as facing some disadvantages in this area, although as discussed above I do not regard them as "underdogs" in all respects (see also page 83 above). Thus they may not fit into the general conceptualisation of identity politics with its emphasis on social exclusion and empowerment as discussed by Dominelli (2008).

Such thoughts can be considered alongside Sangharakshita's (1996b,36) early critique of the concept of rights as firm basis for ethics and social action, originally published in 1951. His argument that these must be balanced with duties is now a familiar one in contemporary discourse. His view that notions of rights arise from perceptions of the self as an atomised individual rather than as someone interconnected with others is more explicitly Buddhist. This links with the previous paragraph; shouting loudly from one's own perspective needs to be tempered with a wider perspective on the needs of others.

I did not know whether my samples' accounts of their experience of care systems would include such ideas. They might, for example, be more influenced by the relatively mainstream perspective outlined by Moore (2009) in relation to the support of older people, where there is a greater emphasis on rights in the contemporary care landscape, with at least some potential advantages ensuing for people using services.

The data collection process is outlined in the next chapter.

CHAPTER SEVEN: DATA COLLECTION AND ANALYSIS

PHASE ONE: INTERVIEWS

Preliminary Comments

A series of in-depth interviews was planned next. Attention was first paid to finding participants with current care needs. A number of the care needs of which I had become aware appeared to be mainly age-related. However, partly because there are still relatively few Order members over 70 years of age, some younger people with disability and/or health problems were included in the six participants who became known as the Current Care group, with the youngest 45 years of age. They were selected on the basis that they had focused on support needs earlier in life than most people and thus had relevant experience to communicate. A second group of interviewees, known as the Anticipating Care group, were to be asked to anticipate possible LTC preferences for the future. Supplementing these were interviews with a number of people believed to have specific expertise in relation to aspects of the study. Named the Expertise group, the focus was on their particular area of knowledge/skills.

Research background for interview schedules

As noted above in the literature review, two studies proved particularly influential in the design. I had previously believed that it would be useful to ask some people to discuss their current care needs, and to ask another group of people, presently free of significant care needs, to anticipate their preferences if such needs arose in the future. A Commission for Social Care Inspection survey (CSCI/MORI,2003) explicitly set out to gain anticipatory data from a wider population of people over 50 years of age on the basis that social policy for LTC must be shaped with a view to both the current population receiving that care and future populations. Some items proved readily adaptable to the Triratna/FWBO context such as preference for domiciliary care, sheltered housing or a care home, and these were included in the schedules for semi-structured interviews (see Appendices A and B).

A second influential study was Kellaher's (2000) report on Methodist Homes (now MHA Care). Some particular questions arose in relation to 'mutuality'. For example, to

what extent did the residents benefit from being in proximity to others from a comparable spiritual background, and were there any disadvantages to this? Another feature of Kellaher's study was a list of seven aspects of the care environment – privacy, dignity, choice, rights, independence, fulfilment and spirituality – these aspects were also incorporated into my schedules.

Groups and interview schedules

The development of items for the interviews and the questionnaire began in 2004 when I piloted some care-related questions with three Triratna/Buddhist friends with care needs who had indicated that they were prepared to help. I made some notes on their responses and discussed them with my supervisors. The focus was primarily on ensuring that the questions were relevant and phrased clearly.

For the Anticipating Care group I planned to focus on people over 50 years of age as did the CSCI/MORI (2003) survey. This was partly on the basis that people younger than this might have given relatively less thought to LTC issues. Also, it was thought that some people in their fifties or beyond might by this stage in their lives have had substantial experience of age-related LTC as delivered to relatives or friends, with their own parents typically being in their seventies or eighties. Their experience might have involved giving informal care themselves and/or some level of witnessing LTC by formal services. As noted above on page 72, Payne suggests a process in relation to end-of-life care whereby "we are hugely influenced by what we witness" (see Moorehead, 2006,p3) and it was felt that this principle might be applicable to LTC also. Thus we might see some links between what we have seen other people experiencing and what we would prefer for ourselves.

Whilst Arthur and Nazroo (2003,p.115) favour the term "topic guide" in relation to the interviewer's provisional agenda, the instruments used for the Current Care and Anticipating Care interviews could be more accurately described as semi-structured schedules. Nonetheless, there was a determination to use these flexibly, to emphasise my interest in what the participants saw as relevant (as in the participant information sheets used; see Appendices C and D), and to encourage the editing and augmentation of draft transcripts. The schedules eventually used were designed to ensure approximately similar amounts of input from the interviewer across the two groups.

Thus the Current Care schedule had 25 questions and the Anticipating Care schedule 23. The main variation was that in the early part of the Anticipating Care schedule participants were invited to comment on; ***"Any situations that have brought you into contact with long-term care services, e.g. illness/disability of a relative or friend, your occupation"*** and so on.

The Current Care interviewees, in contrast, predominantly discussed their own direct experience. Some questions were paired; for example ***"What worked well/What problems were there?"*** in relation to care, and ***"Main hopes/Main fears"*** about the future if needs developed or increased.

Whilst the heterogeneous nature of the Order seemed likely to emerge, some aspects of shared culture were also assumed. Thus both schedules included a question derived from the story of the Buddha's encounter with a sick monk and his neglectful community (Sangharakshita 1991) as discussed in Chapter Two.

As I developed the schedules I reflected further on the interviewer's role and the importance of facilitating active participation as far as possible. I was conscious that substantial power imbalances often exist and can be exacerbated by socio-cultural differences between research participants and the people who study them (e.g. Briggs, 2003). For example, reading about the girl members of urban gangs in Miller and Glassner (2004) one senses people's words and behaviour being represented and analysed in an academic context which seems likely to be largely alien to them. This comment does not necessarily question the ethics of such research but rather underscores the importance of all efforts to maximise the involvement of participants and ensure that they have full opportunity to represent themselves as they would wish and to be clear about the purpose and dissemination of their contribution.

Such principles were in operation during the pre-interview discussion when I read through the participant information sheet with each interviewee. Although this sheet had been sent in advance it was vital to ensure that key points had been understood. The discussion also offered an opportunity to reiterate my priority that interviewees felt able to communicate their views and experiences in relation to LTC issues, and that the specific schedule questions were of secondary importance.

Such measures were necessary in this research, although the power imbalance seemed less evident than in many studies. All the people I interviewed were senior to me as

Order Members and, in my judgment, all were at least my peers in terms of education and general awareness, even if some participants' health status added a potential vulnerability which needed careful monitoring.

One procedural point concerned pseudonyms. The names given to Order members at ordination are typically of two syllables or more. The Triratna/FWBO tradition is to use the name in full, and abbreviations avoided. Inaba (2004), writing on the movement, uses pseudonyms for Order members such as 'Rachel' and 'Jeff', and to people accustomed to the movement's culture this appears anomalous. The alternative adopted was to use two-syllable pseudonyms for Order Members (such as SA and JV), making clear in all associated information that the constituent letters were randomly selected and did not relate in any way to the person's actual Order name.

Sampling and access: Current Care and Anticipating Care groups

(See following pages for tables giving information on participants for Current Care and Anticipating Care interview groups)

Access to participants presented no major difficulties. All Order members are provided with the contact details of all others, so initial approaches were straightforward, usually initiated by an E-mail or letter briefly stating the purpose of the research and asked people to reply if they would like further information. Everyone approached agreed to take part, after which they were sent the relevant participant information sheet and the consent form (Appendix F).

Current Care group - Information on care needs and other life details.

KL- *Age 54, Female* *Ordained 1993, lives alone in council flat, no children.*	Multiple health problems-Osteo-Arthritis, Asthma, Epilepsy, Chronic Fatigue Syndrome.
JV- *Age 55 Female* *Ordained 1977, lives in Buddhist women's community, no children.*	Polio from age of 5 with restricted mobility. Now has 'Post Polio Syndrome'
TN- *Age 68, Female.* *Ordained 2005, lives alone in council flat, 3 sons (all non-local, in UK)*	Osteoporosis Arthritis with restricted mobility. Operations on spine, and on thigh and hip in past.
CH- *Age 45, Female.* *Ordained 1995, lives in Buddhist women's community, no children.*	Spinal injuries in teens and 20s worsening congenital problem. Bowel and bladder paralysis.
SA- *Age 79, Male* *Ordained 1998, lives in care home (privately funded)- 2 daughters (non-local in UK) 1 son (local)*	"Sort of stroke" in 2005, operation for gall-stones at this time. Poor mobility-has urethral catheter.
NR – *Age 60, Male* *Ordained 1978, lives alone in sheltered housing,* *No children*	Multiple sclerosis (Primary Progressive) diagnosed in 2003. Problems with incontinence of bladder (regular) and bowels (occasional)

Information shown above

- Participant pseudonym
- Age and Gender,
- Year of ordination
- Housing situation
- Children or not.

Information shown above

- *care needs*

Table 1 - Current Care Group Participants

Anticipating Care group-Life details and exposure to LTC situations

YP- Age 50, Female, *Ordained 2004, Lives alone in house she owns, no children*	Mother had severe disability and medical problems. YP was full-time resident carer for 6 years till mother's death in 2003. YP is ex-social worker in learning disability.
MB- Age 55, Female, *Ordained 1995, Lives alone in house she owns, no children.*	Mother had Vascular Dementia- father died in October 2003 and MB became main carer. Mother lived with MB, then in unsuitable care home, with MB again, then in private specialist dementia care home for 18 months till her death in March 2006
RT- Age 52, Female *Ordained 1998, Lives with partner (also ordained in FWBO) in house he owns. 3 sons (1 non-local in UK, I has local base but in army, 1 son in Scandinavia)*	Mother (in Finland) in 90s- had 8 months in hospital after broken leg, then home in flat with support, now living in nursing home. RT is Chair of a Triratna/ FWBO Centre and spoke of 3 Sangha people with care needs.
VP- Age 65, Male. *Ordained 1972. Lives in Buddhist men's community. 1 son, 1 daughter (living in Germany)- children from past marriages and VP not in regular contact*	Mother is 88- has medical problems and unable to live alone for long since husband's death. Now lives with VP's sister (non-local in UK) Aunt was in care home, about 15 yrs ago. VP knew Order Member who died in a hospice in past.
DG- Age 47- Male *Ordained 1982, Lives alone in flat (privately rented), no children.*	Mother (in Scotland) had medical problems- needed help at home for 4-5 yrs, latterly had dementia and died in February 2007. DG has been a wheelchair user since spinal injury at age 18.
AK- Age 50, Male *Ordained 1996, Lives with family in house they own, with partner and 2 teenage daughters.*	Father 84, lives alone, recent hernia op-local to AK as are 2 of AK's brothers. Partner's grandmother died in care home 10yrs ago.

Above information arranged   Exposure' to LTC shown above

as for Table 1.

Table 2 - Anticipating care group participants

As noted in Chapter One, the sampling process began with my contact with one eventual participant, SA, and as I spoke more about my research plans a number of people were mentioned to me as possible participants along with others whom I knew or had heard about. This snowballing form of sampling continued, with participants mentioning other potential respondents, typically ones they knew reasonably well. Whilst I knew that representativeness might be a problematic concept here, I kept in mind lifestyles characteristic of the diversity of the movement (e.g. living at a retreat centre, in a community, with a family), and aimed to gather a range of participants conforming to this and other criteria such as gender.

SA is a key example of a Buddhist who lives in a mainstream care service, so notwithstanding input from his family, friends and the local Buddhist Centre the great majority of his time is spent with non-Buddhists in a facility with no specific links to any faith. He agreed to participate, and other people began to be referred to me.

JV is a female Order member who had worked full-time for the movement since the 1970s and whose departure from a women's retreat centre was linked to the exacerbation of the polio she had had from childhood; CH is a female Order member with a spinal injury; KL, an Order member in my local area with multiple health problems including chronic fatigue syndrome (CFS); NR has multiple sclerosis, and TN, recently ordained but with some years of involvement in Triratna/FWBO care-based initiatives and with health problems of her own.

The geographical spread included the Sussex coast, Cambridge, Manchester, Ipswich and London. The same names continued to crop up in interviews as respondents illustrated general points or mentioned people I should meet. Two people were mentioned by more than one interviewee but were not eventually interviewed, these being a woman in her eighties living at a retreat centre of which she was a founder member and a relatively young woman with severe multiple sclerosis. In the former case the retreat centre could not always accommodate male visitors, and I had been told that the younger woman is often unavailable for meetings, although I met the younger woman later and both subsequently completed questionnaires (see below).

Chronic fatigue syndrome (CFS) problems have affected a number of Order members in recent years and are the subject of some debate. KL lives with this and other health problems, and her specific inclusion partly arose from the fact that we know each other

and she lives in the same town as me. However, I would certainly have wanted to include someone with CFS if possible.

To give some examples of lifestyles, SA lives in a care home, has had two careers in the wider world, has three children (one a Triratna/FWBO Mitra), and was ordained in later life. NR is single and childless, lives in sheltered housing, is 20 years younger than SA but has been ordained for 20 years longer and has spent much of his life (as he puts it);

Hovering around Buddhist Centres and being available for activities

. The snowballing process for the Anticipating Care group was less prominent and there was more reliance on people that I have got to know during my years in Triratna/FWBO. The first participant interviewed was a qualified social worker and had been her mother's full-time carer in her final years. She lives in a small northern city and was quite well known to me as she had been very prominent in past attempts to set up care-based TBRLs. Also in her fifties was a female Order member in my local area who had previously asked me for some input in relation to selecting residential care for her mother. Another female Order member in this age group participated and spoke about her mother's care in Finland; she is the Chair of an urban Triratna/FWBO centre and offered further perspectives on patterns of informal care within her Sangha.

At this point it seemed reasonable to include more men. VP is a senior Order Member in his sixties living in the Midlands and has worked and lived full-time in the movement since the early 1970s; in contrast AK, an Order member, combines his Buddhist practice with family life and an international role in a telecommunications software company; and DG, another largely 'full-time' Order Member, is a wheelchair user who does not consider himself as having care needs. Four of the six interviewees are based in the Suffolk/North Essex area where I live.

Reference to these locally-based interviews highlights issues about sampling. Robson (2002,p.265) calls convenience sampling "one of the most widely used and least satisfactory" approaches, and it would have been impossible to form the Current Care group from Order Members in my immediate area. People with LTC needs are in a small minority in the Order and it was essential to be prepared to travel to meet them. The term 'snowballing', which Robson describes as a "particular type of purposive sampling" (ibid,p.266), has been used above for the approach adopted with this group

Purposive sampling is said to derive from "the researcher's judgement about typicality or interest" (ibid,265) and was linked to my experience of the Order as having quite a strong network of communication. There are many contexts in which Order Members meet each other such as retreats, conventions and centres; several means of keeping in touch including online resources and *Shabda*, the monthly journal for people to 'report in' and in which I have discussed my research several times; and people's ill-health is often highlighted (by themselves or friends) in communications around the Order. My experience from the interviews and informal care-related conversations is that if an Order Member develops LTC needs this will typically become known amongst the Order at large, and that people with comparable health problems are often in contact with one another. Thus there were several instances when during Current Care group interviews people illustrated points with reference to other members of the group. My conclusion is that the participants interviewed for the Current Care group had 'typicality' in that they all had higher level care needs within the UK Order, and no-one mentioned regularly in interviews and discussions did not contribute to the study.

It is arguable that the criteria for the Anticipating Care group were less exclusive, and this was a factor in more Order members from my local area being included. Equally, proximity is often linked to frequency of personal contact, and this in turn was often reflected in my knowing about people's personal circumstances (such as MB being closely involved in supporting her mother, who had dementia). Thus it was relatively straightforward to recruit some local Order members who were informally supporting their parents. Some participants in the Anticipating Care group had, in Robson's terms, additional 'interest' such as DG, a long-term wheelchair user, and YP, who had extensive experience of the care sector. RT's role as Chair of a centre and AK's career in the wider world added other variations in lifestyle and responsibilities. RT and AK also reflected the growing trend for Order members to have a more family-orientated life and to be less likely to have ever lived in communities (see Lokabandhu,2009), although the Anticipating Care group balanced this in some measure with the inclusion of VP, who has worked full-time for Triratna/FWBO since the 1970s and now lives in a men's community in a Buddhist village area in Birmingham. Some further aspects of the sampling are explored in Chapter Eight.

Procedure

Participant information sheets were given to and discussed with each person involved, and witnessed consent forms were completed (Appendix F). Active involvement was encouraged with the use of the pre-interview script referred to above.

A digital voice recorder was used in the majority of interviews with participants' consent, although written notes were also taken at every meeting. The recorder was new technology to me at the time, and in two cases I had technical problems and had to rely on my notes. Transcripts were made as soon as possible and sent to the participants for comments, editing and/or additions. I reiterated as required that my focus was on getting the fullest possible picture of their views and experiences rather than on making a perfect record of an interview that had taken place on any particular day, and emphasised that they could add new material if they wished.

Participants typically spoke freely about their views and experiences, and it appeared that in both groups the interview schedules complemented the main points that the participants wished to communicate. One respondent in the Anticipating Care group initially did not seem to have much experience of LTC issues, but when we focussed on his partner's late grandmother and her admission to a care home some useful material emerged. I quite often mentioned examples and issues which I thought might appropriately broaden the discussion, although on listening to the recordings I felt that at times I had spoken too much and modified this in later interviews. Most interviews passed without apparent difficulties for the participant, although one, with whom I am in fairly regular contact, subsequently told me that she had found her first interview *"a deeply depressing experience"*, dwelling as it did on her ill-health and recent loss of a particular benefit. I discuss the ethical and practical dimensions of this situation in Chapter Eight

The follow-up was usually by E-mail if the person lived outside my area or in person if s/he was local, although I visited the participant in Sussex twice (with some content agreed on the telephone) and the participant in London three times. Neither had E-mail at home, response to postal material had been slow and the initial interview with NR in London had taken two sessions because of fatigue on his part.

Expertise group interviews

The Expertise group of interviewees comprised people with particular knowledge and/or experience of long-term care and/or relevant aspects of Buddhism. Here the interview schedules were tailor-made according to the participant's anticipated input to the study, with adapted participant information sheets (see Appendix E) and consent forms as for previous interviews. While visiting California I made contact with one of the senior people at the San Francisco Zen Center. I also interviewed a volunteer organiser for the Zen Hospice Project, mainly to explore links between care work and spiritual practice.

Other Expertise group participants were a long-standing centre Chair with extensive experience of the Triratna/FWBO and detailed knowledge of its central administration and an Order Member who discussed the excellent support he had received from his Sangha when seriously ill. The final interview in this group was with Padmasuri, author of a 2003 book on TBRL, a former nurse and midwife and, as a Public Preceptor, someone with major responsibilities in the movement. With her permission her real name is used so that her interview comments can be read in conjunction with relevant points made in her book.

This category may appear quite miscellaneous, although the aim is consistently to place the research in a broader context by asking, for example, how comparable Buddhist groups are coping with LTC issues. Another factor here is that asking people what they would prefer in relation to their Buddhist identity or other aspects arguably places an ongoing obligation on the researcher to do some work on the background to such preferences. An elaborate wish list would be of minimal value as a practical tool or a contribution to knowledge, and the collective contribution of the Expertise group is intended to ameliorate any such tendency in the study.

Sampling and Access

Access was straightforward, with everyone approached agreeing to participate, including a meeting at the Zen Center arranged via a transatlantic telephone call.

As noted above, the range of potential participants was large, as were the possible topics for consideration. The group eventually consisted of five people, three Triratna/FWBO Order members and two participants interviewed in San Francisco. It is arguable that DS could have been interviewed as part of the Current Care needs group,

although his acute episode of ill-health only commenced in 2005 when the interviews were already under way and he would thus have had a relatively short period of care needs on which to reflect, unlike the rest of the interviewees in the Current Care group. Having known him to some extent before his acute episode, I took note of developments during and after his time in hospital and the narrative of what happened enlarged the picture of informal support of ill-health in the movement. An interview based mainly on this narrative rather than on a schedule was appropriate with this participant.

Procedure

One interview took place on the telephone and was followed up by email, and one Expertise participant was reluctant to be recorded. The written notes for the rest of the participants were converted into summaries, which were then edited according to participant feedback until content was agreed.

PHASE TWO: THE QUESTIONNAIRE

Formulating the questionnaire items

The next phase of the data collection employed a questionnaire. As mentioned in Chapter One, participants' additional comments on the questionnaire items proved rich and unexpectedly abundant and generally of more salience than the questionnaire's numerical scores in their various configurations. However, the scores did yield some useful data. Below I present how the questionnaire items were developed, as this is relevant to all data gleaned from this source.

From an early stage in the research I intended to use more than one method of data gathering and to augment the in-depth interviews with material drawn from a larger population of people in the movement. A questionnaire was a suitable instrument for this, and development of the questions began in late 2006, approximately a year before I decided to refocus the research onto the central theme of supporting Buddhist identity.

Use of a Likert scale was planned with questions that would derive some of their content from issues raised in the interviews and seek views on and experiences of LTC from Triratna/FWBO people in a range of locations and situations. The interviews had been undertaken with people with relevant experience of LTC, and in considering a larger population of potential participants I was aware that some, perhaps many, people might have little or no such experience. A pilot questionnaire item which was not

eventually used required respondents to indicate the extent to which they found the following statement true-*"Buddhists may have good intentions as to providing support and companionship to spiritual friends who are ill or disabled, but in reality they are often too busy to do this effectively".*This statement reflected the substance of remarks by three interviewees. Nonetheless, some major problems quickly emerged.

I had planned to exclude newcomers to Triratna/FWBO on the basis that the questionnaire assumed a level of awareness of the movement's culture that someone with less than a year's experience would typically lack. Even so it was possible that any given participant had met few if any people with the relevant level of needs. Many centres are in contact with some people with such needs whose health/social care issues allow them only intermittent attendance at events, and so only class team members know them.

There is, of course, a difference between being 'ill' with 'flu or recovering from a minor operation and ill in the sense of living with an ongoing and debilitating condition. The statement's wording makes no reference to key factors cited in Chapter Four about how intense support needs might be, or duration (see Pickard,2008 as quoted in Chapter Four), so participants might refer to relatively temporary and transient needs for support. Also, in retrospect the reference to disabled people might be seen as patronising. I had interviewed a man who uses a wheelchair for this study who implicitly acknowledged a level of disability whilst rejecting the idea that he had care needs, and hence became part of the Anticipating Care group. To group disabled people together as needing, and too often being denied, *"support and companionship"* is also questionable. Disabled people may well have access to companionship comparable to any other social group. There may be some need for support (again inadequately defined in the statement) but *all* beings need support to a greater or lesser degree and Buddhist teachings on conditionality insist that no-one is truly and fully independent. Thus this version of the statement was rejected and its revised format reflected the questionnaire's general change of focus.

If Triratna/FWBO Buddhists were experiencing mainstream LTC services as "good, bad and indifferent" it was necessary to find items that brought out some distinctiveness in responses. Everyone participating in the questionnaire would have some level of involvement in Buddhism, and arguably all or most people can imagine what some features of possible Buddhist-based care services (BBCS) might be like. Thus it was

decided that the focus would be these putative services, thereby reflecting the second research question in the initial research proposal.

The fact that commenting on such (currently non-existent) services would involve a measure of speculation for all participants emerged as somewhat advantageous. Whilst some respondents commented on their lack of background knowledge about certain items, my impression was that the speculative element in the questions encouraged a general, even intuitive opinion which they could qualify or amplify as required. Returning to the rejected piloted item statement above, a comparable area of concern is expressed in what eventually became Item 5 of the questionnaire (see Appendix G): ***"Buddhist-based care services might reduce the risk of ill/disabled Buddhists being isolated and neglected".***

This is more appropriately worded than the rejected example. The pilot item was heavily reliant on actual experience, and whilst it is important to include the perspectives of people with such experience I also wanted to seek out a broader range of views including the fantasies and fears that people might harbour.

Development of the questionnaire began with the general care questions piloted with three Triratna/FWBO friends in 2004. Interview data were drawn upon for relevant perspectives, and draft versions of the questionnaire were piloted with two friends in the movement and discussed with my supervisors.

I anticipated that although the questionnaire would include preliminary information about the variety of possible models of care, participants would be able to specify a particular setting if they had one in mind and some items were intended to be open to a measure of interpretation. Thus Item 4 referred to ***"bossy and difficult people in the Buddhist world"*** who ***"might have a negative effect in a Buddhist-based care service".*** Participants might assume that the ***"difficult"*** people might be recipients of care, or staff, or both, although the item raised general questions about interpersonal relations. For example, any sheltered housing provision might emerge as having some of the elements of a Triratna/FWBO residential community. People's responses to this might be guided by their experience or perception of interpersonal relations in such communities, as reflected in comments by KL and others.

A number of items reflected aspects of Buddhist values and practices which require some attention in relation to the diversity of needs in LTC. Item 2 is based on the well-

known trend for Buddhists to be vegetarian or vegan. The value placed on *“quiet reflection and meditation”* is referred to in Item 13; JV commented here on her difficulty finding a place to meditate or a refuge from television when in hospital. The development of mindfulness is reflected in Item 19 (based on a comment by interviewee VP); and another term associated with Buddhism, *“compassion”* is the basis of Item 10. However, in the latter case, partly to deter ‘response sets’, the valence is reversed so that anyone who believes that BBCSs would be more compassionate than mainstream provision has to choose Disagree or Disagree strongly. The numerical scores for the questionnaire were based on a Likert scale from 1 to 5, with 5 representing the most favourable response to BBCSs and 1 the least, so that in Item 10 Disagree strongly scores 5.

Maxim (1999,p.226) comments on the complexity of achieving such a balance; my experience here was of another tendency to imbalance whereby the most plausible items ‘against’ Buddhist-based services were organisational rather than concerned with daily care. For example the interviewee Padmasuri (2003) has stories of a TBRL in its early days only gradually acquiring the necessary work skills (hence Item 12), with another Item (3) on the possibility of people being cut off from the wider world, reflecting comparable debates about faith-based schools (Cairns,2009)-see page 61 above. Issues about the ‘transferability’ of the TBRL model to the care sector are considered in Item 15. Item 16’s focus on staffing is also organisational and had first been mentioned by MB and others.

Comments by KL and NR about how busy friends can be prompted Item 7 and broader worries about people being *“isolated and neglected”* are invoked in Item 5 with Sangharakshita’s (1991) *A Case of Dysentery* a reference point here. Linked to this is Item 8 on LTC provision in the UK, echoing YP’s remarks in her interview about a *“semi-functioning welfare state”*. In his interview, SA’s favourable evaluation of his care home featured the staff’s universal use of his Buddhist name (hence Item 6) and Kellaher’s (2000) work on mutuality was one source of Item 11 about *“like-minded”* people. The presence or absence of creative activities in long-term care formed the basis for Item 17 (Mozley et al.,2007), whilst YP’s argument for responding to the needs of the wider world prompted Item 18. Comments from KL and RT suggested Item 14 about people promoting other religious views. Although it is not explicit in the statement such promotion could conceivably come, for example, from other *residents* in a care home (as implied in RT’s interview comments). Just as Brown Wilson (2009)

argues that interpersonal relations in LTC in general are a neglected area of research, service users' relations with one another (e.g. "What we have in common, and what differentiates us?") appears a much over-looked sub-set of this topic.

Item 9 originated from remarks by CH, KL and TN on personal care. Item 20 explores personal compared to collective responsibility for care and finance, prompted by input from JV, AK, CH and others. Item one, about the money and energy available and suggesting that Buddhist-based services are *"unlikely to actually develop on any significant scale",* arose from material from MB's transcript plus others. Overall, the piloting and discussion process involved the refinement and sometimes abbreviation of questions; Czaja and Blair's (2005,pp.82-83) strictures about "double-barrelled" questions were highly relevant to the feedback received on item 1 (see Chapter Eight).

Czaja and Blair (2005) recommend avoiding the Agree-Disagree format, although Thomas (2004) expresses no concerns about this. It proved difficult to identify an alternative, especially as participants were being asked to give opinions on a phenomenon that does not presently exist – Buddhist LTC services – and thus appeals to direct experience could only be partial. For example, Question 5 might draw on people's actual experience of *"ill/disabled Buddhists being isolated and neglected",* but in exploring the effect of a Buddhist-based care services on this the relevant item could only offer the suggestion that such provision *"might reduce the risk"* and invite general agreement or disagreement.

Czaja and Blair (2005,p.82) quote research highlighting a general "acquiescence response set", whereby participants are more likely to agree than disagree with a statement whatever its content, and that this tendency is linked to education, with less-educated participants showing it relatively more strongly, Converse and Presser (1986) and Schuman and Presser (1981). I was aware that the sample would be relatively well-educated; for example, the people completing the questionnaire at my own centre included three schoolteachers, two information technology workers (one with a degree in biochemistry), an architect and a recently retired consultant surgeon. Inaba (2004,p.92) found that 70% of his Triratna/FWBO sample were university graduates. Whilst some acquiescence might occur the comments boxes gave participants the opportunity to say more about their responses, and piloting suggested that these would be used to a reasonable extent. It was noted that entries in the comments boxes gave some indication of whether a question had been misunderstood (such as ticking for

agreement and then adding remarks which suggested an opposing opinion), and while I remained alert to this I found only a few examples.

Barker (1996,p.245) advises avoiding a Don't Know response category. On deciding that some participants might feel unable to offer an opinion on certain items an Undecided box was included with a request to minimise this response as far as possible in the preliminary guidance notes. While including a comments box after each item might be perceived as making the overall procedure lengthier it was hoped that this would elicit valuable data, particularly regarding items on which participants had strong views and/or specific experiences. Thomas (2004,pp.46-8) discusses the merits and drawbacks of what she terms "open response questions", for instance: ***"What type or types of long-term care do you believe would be most suitable for the Triratna/FWBO Buddhists you know who have such needs?"***

She counsels that these can be off-putting to respondents in terms of the time they take to answer and advises confining their use to focus groups. Overall it was hoped that the closed statements and optional/open response comments boxes would achieve a compromise, securing the engagement of those disinclined to spend more than 10-15 minutes on the questionnaire whilst inviting fuller participation from those who were willing. Thus the version used included an invitation to focus additional comments on self-selected items if wished.

Demographic data were also seen as important, enabling exploration of the influence of features such as having care needs, being an informal carer and working in the care sector, plus some demographic details such as gender, length of time ordained where applicable and other aspects at the end of the questionnaire form (see Appendix G).

Sampling, Access And Procedure

My general aim was to seek opinions from a cross section of people involved in the movement. Friend, Mitra, Postulant and Order Member provide four general categories. Some Friends attend centres for many years, so although "level of commitment" and length of involvement are often related, this is not always the case. Order Members may take on further responsibilities in due course such as Chair of an urban centre or retreat centre, being a Preceptor or having key responsibilities in a TBRL. Non-ordained people (often Mitras and Postulants) may live in residential communities or at retreat

centres, or be on the team in TBRLs, in centre administration and so on. Many in these categories live and/or work in the wider world. Thus a cross-section would include people from the four categories with a variety of lifestyles and Order Members with a varied range of responsibilities.

Tour of Centres and Other Sites

My tour of centres and other sites began in late 2006 after the questionnaire had been approved for use. I visited evening classes in Lancaster, Colchester and Ipswich, and made announcements asking for participation. I made it clear that questionnaire responses would be anonymous and that all information would be treated confidentially. Some people completed the questionnaires that same evening, others took an envelope to post it on, whilst some participants asked me to email it to them. In all three sites there was a generally positive response and high take-up, with only three or four questionnaires not returned. In March 2007 I spent an afternoon in Birmingham inviting people in the small *Buddhist village* (see page 37 above) including centre administration workers, people in the publishing company and an Order Member who lives at the residential community where I was staying, to complete the questionnaire. I attended a public class at the centre that night and although most people attending were beginners, three Mitras who were helping to run the class agreed to take part. An Order Member working at the Centre agreed to me leaving a labelled box with questionnaires and instructions in the reception area so that people attending future events could participate. A comparable process was followed in Cambridge, which also has a Buddhist enclave around it. These two boxes yielded about 10 completed questionnaires over the next two to three weeks.

National Order Weekends

Notwithstanding the wish to have an Triratna/FWBO cross-section, my impression was that Order Members would be the people to whom the questionnaire would be most salient and I intended them to make up the majority of the sample. An ideal opportunity presented itself in February when there was a Men's National Order Weekend at a retreat centre in Norfolk. There are three such weekends a year and all male Order Members resident in the UK are invited to attend. I took hard copies and left them in a

box in the lounge, one of the busiest areas in the centre. Twenty-five questionnaires were completed. It seems that the flexibility of the arrangement enhanced the uptake, the only disadvantage being difficulty locating participants if data were missing or contributions were difficult to read, though this did not prove to be a major difficulty.

It had consistently been my intention to have approximately equal numbers of women and men in the sample. Although male Order members outnumbered women by approximate 2:1 in the UK at the time, the women's wing is growing significantly faster than the men's (Lokabandhu 2009) and if all Triratna/FWBO activities are considered the gender balance appears to be approximately equal. In March 2007 a Women's National Order Weekend took place at the same venue as the men's the previous month and arrangements were made whereby 18 of the Order members attending completed questionnaires. Participants also suggested approaching three other female Order members who are professionally involved in care (a trainee nurse, a GP and a surgeon), and on being contacted by email all three completed questionnaires.

TBRL and other settings

Finally, my three months' residence in Cambridge in the spring of 2007 brought me into contact with a wider range of Triratna/FWBO people, with four people completing questionnaires at the Windhorse:Evolution warehouse, headquarters of the movement's largest TBRL, plus two staff at the city shop, Evolution. Several other TBRL workers living in residential communities near the one I stayed in also completed forms. One of the seven Indian Order Members working at Windhorse:Evolution at the time was in the community where I was a guest. He completed a form, as did a female Indian Order Member who was working at the Birmingham centre. Some aspects of their participation are considered in the next section.

Ethnicity And Cultural Factors

Ethnicity/nationality did not emerge as a major factor in sampling. The questionnaire was completed by people born in India, Mexico, Poland and Holland, though the majority of participants were white Britons, with one UK resident Order member classifying himself as Asian by family heritage. Two Indian Order Members (one male, one female) resident in the UK completed questionnaires; in both cases the respondents

expressed difficulty with the task and I gave additional input to ensure that the statements were understood. The male Order Member commented that he had had little involvement with care systems here, and in both cases cultural differences appeared salient. Thus although it was advantageous to have had some input from Indian Order Members I did note the specific factors influencing their participation as people from a non-European background whose first language was not English.

PHASE THREE: DATA ANALYSIS

The Data Set

  Of the 107 people who completed the questionnaire, 55 were men and 52 women, and 62 – 29 women and 33 men – were Order Members, comprising over 9% of Order members resident in the UK. Proportions of non-ordained people were broadly comparable, with 19 women (7 Postulants, 8 Mitras and 4 Friends) and 22 men (10 Postulants, 5 Mitras and 7 Friends). I had expected that participants would make some use of the boxes headed *“Please add comments below”* after each of the 20 questionnaire items. In fact utilisation of these exceeded my expectations with 89 participants (83% of the total number) adding comments, of which 39 commented on half or more of the items. Some participants added general comments at the foot of the questionnaire form. This gave a corpus of approximately 16,000 words besides the material from the 17 interviews. During the analysis reference was made to the questionnaires completed by individual participants, and also the additional comments were transcribed item by item and grouped on that basis, allowing all comments on a particular item to be viewed together and patterns to be identified. One example at baseline level was noting the number of comments a particular item attracted.

   The scores from the attitude measurement process offered potential areas for investigation, as with the demographic factors outlined above. Overall total scores were of interest, as also scores for such groups on individual items. A further area for attention was how strong a generalised consensus of agreement or disagreement might be found on individual items.

Preliminary analysis using Framework

  Some preliminary analysis of verbal data was undertaken using the Framework approach described by Ritchie and Lewis (2003,pp.219-20) as “a matrix based method

for ordering and synthesising data". The authors describe a process of seeking out each study's main themes and subdividing these "by a succession of related subtopics". A worked example is given with two initial main themes, Personal Details and Life History, which seem likely to be incorporated in many projects as they were in the present study at this stage. I was aware that a standalone CAQDAS package for the framework approach was being developed and planned to train in this and use it once available. In the meantime the priority was familiarising myself with the data, and throughout 2006 and 2007 I supported this with note-making and the use of manually-created A3 matrices. I was aware that the framework approach could be used on computerised spreadsheets, but had only limited experience of these and found the manual matrices useful at this stage.

In view of the aims of the study and the consequent formats for interview schedules and questionnaire items it seemed inevitable that the data clustered around major themes such as mainstream and informal care. It was found useful to note whether any particular aspect of care was seen as Buddhism-related or not. To take some examples, SA's experience of care home staff being willing and able to use his Buddhist ordination name rather than his secular name was certainly Buddhism-related and reflected positively on mainstream services. JV found her encounter with a social care manager "*distressing*" in that some of her difficulties were evaluated in a manner that she perceived as dismissive, with minimisation of costs emerging as an apparent priority. This, however, was not seen as Buddhism-related although, for example her experience of never being able to find a place to meditate when in hospital was classified as related to her Buddhist practice.

Apart from these examples, other categories and ideas about analysis were being developed into 2008. However, I was realising what might be achieved through the use of a computer programme and wished to extend my research skills in this area. In February I heard that the dedicated framework software programme would not be launched until the summer, and sought an alternative, as detailed in the next section.

Learning to use NVivo-7

At this point I received some training and support in the use of the software package NVivo, which was then available in version NVivo-7. I quickly saw the advantages of this for my early attempts at coding the transcribed material. Initial decisions involved

determining what 'free nodes' might be identified there; for instance CH's response to an interview question about choice, included the following;

> *It is important to me...I'd find it difficult if carers or personal assistants were coming in at certain times with a meal I had no control over.*

As one of the early pieces of material coded, this passage generated free nodes about **'Choice', 'Control', 'Time-tabling', 'Meals/Nutrition'** and '**Views of Mainstream Services'.** Bazeley (2007,p.32) comments that these free nodes "do not assume relationships with any other concepts".

Free nodes arise from any category, concept, activity or aspect which the coder sees as potentially relevant or of interest. Thus the free node Meals/Nutrition will include the above piece of text and all other related material from the data, grouped together in a way that facilitates comparisons/contrasts and other reflection on the subject matter for analysis.

The process is flexible. Some large and generalised free nodes emerged such as **'FWBO Culture'**, with pieces of text allocated there whenever they referred to a phenomenon characteristic of ways of living and being associated with the Triratna/FWBO movement. The largest free node was **'TBRLs'.** Text allocated to these large nodes sometimes overlapped with material in nodes with smaller scope. For example, for TBRLs there was overlap with the node **'Just Because a Buddhist'** , a collection of comments in which people argued that relevant job skills need to be given at least as much weight as faith affiliation when TBRLs are recruiting.

As discussed in Chapter Two, Triratna/FWBO lifestyles are a key aspect of this study and initially a large amount of material was categorised in the free node **'FWBO Culture'** with some material re-assigned (or also assigned) to smaller, more focused free nodes as they began to be identified. An example of a more focussed free node that shared some material with FWBO Culture was **'Communities Trying to Cope'**, which brought together narratives about informal input for people with care needs who live in residential communities.

Printouts of the material in the large free nodes offered a broad picture of views and experiences in a particular category. Some nodes were combined or discontinued, though others were maintained even if containing small amounts of data. For example, one comment added to the questionnaire Item 7 stated that the acceptability of a health problem can influence the availability of informal support and contrasted attitudes to

cancer (acceptable) and to Alzheimer's Disease and mental health problems in general (less acceptable). This was made the basis of a free node and was retained as such although no other text was assigned to it. The criteria here were that the node could not be satisfactorily subsumed into any other and it appeared to have salience for concept formation and theory-building in due course.

Further Analysis

In due course 130 free nodes were generated and I began to generate memos. I was influenced by Bazeley's (2007) advice on the use of NVivo; for example:

> *Strive, even from the early stage, to develop the concepts you will be working with to go beyond description, labelling and to think about them independent of the source. Why is this information important? Where will these ideas take me? This will be reflected in the way you name nodes, and in the memos you write.(2007,p.60)*

Some memos emerging at this time helped me to develop concepts related to Buddhist identity. For example, two female Order Members had spoken in their interviews about being a Preceptor. One was a well-established Preceptor whilst the other was preparing to take on this responsibility for a Postulant who had asked her to ordain her. *'Being a Preceptor'* became a free node, and in memos and other writing of this time I noted that both participants appeared to have a strong connection with this aspect of Buddhist life and began to contrast this with less explicitly Buddhist aspects of their ways of living as disclosed in the interviews.

NVivo next involves the development of *Tree nodes* which bring together the existing free nodes in a way that begins to connect ideas and help concepts to evolve. This can involve further rearrangement of data. Thus some material in a particular free node appears appropriate as part of the larger scheme of a tree node, whilst other content seems best renamed as a separate free node and assigned to another tree node. I had assumed that the tree nodes generated for this study might reflect categories such as *'Informal Support and Care'* which had been central to the research questions, although I was vigilant for any other themes emerging from the data. In due course tree node-type formulations were generated which could be displayed in a single diagram (see Appendix I). These encompassed themes emerging from the data and broad categories linked to the research questions.

Bazeley (2007) comments:

> *...the average user of a software programme typically accesses only a small proportion of its capabilities; this is no doubt true for users of NVivo also (2007,p.2)*

As regards the present study this was the case, especially in relation to 'queries' (where data can be regrouped on the basis of specific questions arising), aspects of tree nodes and other features. However, the creation of free nodes, their organisation into lists and the incorporation of memos all proved highly valuable in the analysis of the data from the interviews and the additional questionnaire comments.

The numerical scores from the questionnaire were analysed across several variables, exploring mean scores, numbers of additional comments, age and aspects of experience of LTC care issues. Also an Analysis of Variance (ANOVA) was undertaken on ***gender*** and ***category of involvement*** (based on six categories of involvement in Triratna/FWBO). For the ANOVA tests, an 'R' computer programme was utilised (see Dalgaard,2008). Results are shown in Appendix H and discussed below on pages 172-3.

CHAPTER EIGHT:FURTHER METHOLOGICAL ISSUES

Preliminary Comments

In this final chapter of Part Three I firstly consider ethical aspects of the study. Then I explore validity and reliability, noting the need to reconceptualise these terms when applying them to a study with a mainly qualitative/interpretivist approach. Following this I present a section on the refocusing of the study in late 2007 and the extent to which the research instruments were appropriate for the revised research questions and new title. A final section examines more general strengths and weaknesses of the study as currently perceived.

Ethical Issues

In 2005 the university's Ethics Committee gave approval for the study to be undertaken. Key factors considered were:

- How potential participants were initially approached
- Subsequent further disclosure of the study's purpose and methods
- Consent issues
- Ongoing checking of data and sharing of information with participants
- Confidentiality.

Much of the basis for consideration in all of the above is the perceived power imbalance between researcher and participant. If "knowledge itself is power" (Bacon, 1597/1993,p.45), the researcher is taking from others details of their lives, their personal feelings, their views of other people and so on. All of this has a potential for misuse, so a researcher with a concealed agenda or a careless and unthinking way of working can have a strongly negative effect on participants.

My view was that in this study any power imbalance between interviewer and interviewee was relatively small. In the movement I quite often encountered approval for the study. An E-mail accompanying a returned questionnaire added: "It's great you are doing this*"*, an opinion that appeared to be reflected in the attitudes of many participants. Such a broadly positive starting point helped the emergence of a

collaborative atmosphere, especially in the Current Care group for whom care was already a substantial issue.

Two ethical issues arose at an early stage. Firstly I was aware that it would be necessary to manage expectations. I have consistently said that I want this research to have some practical outcomes, but even if, for example, there was a strong consensus in favour of Buddhist-based care services I remain unable to predict or promise that these will actually be developed. The interim summaries sent out to interviewees mentioned such services being seen by participants as having their place ***"in some circumstances"***, with further updates planned on this. I have had some informal contact with most participants since the interviews, including references to the project, and this providing opportunities for any developments to be put in context. As noted above there were two interviewees whom I had never met before, and I have had no further face-to-face meetings with one of these, although we have spoken on the telephone about her transcript and associated matters. My impression of both is that they are astute, experienced people with realistic expectations, and indeed the once-met participant's interview strongly questioned any notion that the Triratna/FWBO was obliged to *"do anything"* for her. Thus inappropriate expectations have not proved problematic thus far.

Secondly, as mentioned earlier one Current Care participant fed back that her first interview had been a *"deeply depressing experience"*. Much of the rhetoric of qualitative research concerns unheard voices and people who wish to tell their stories (see, for example, Lincoln& Denzin,1994), but in this case an extended narrative of ill-health, disability and obdurate officialdom had left the speaker in a low mood. This participant is a friend of mine, although most of our previous conversation had been on other matters. I had to reflect on whether I was the right person to offer support. I was a lone researcher, and no-one else connected with the study was readily available, although if her situation had worsened I would certainly have sought guidance from my supervisors. Fortunately she lives in my local area, and this helped me to maintain more personal contact for a time and also meant that I knew some of her closest friends. With her permission, I could have considered involving these friends if her low mood had persisted and if she saw their input as helpful. This situation prompted me to reflect further on ethical issues, and I might have hesitated to interview another participant on sensitive issues if I became aware of factors such as a history of depression and lack of

social support. My contact with her included my asking about her mood, and on this self-reporting basis I was able to determine that the low mood had not persisted.

Confidentiality was a broader consideration. Although I believe that the easy access to Order Members' contact details indicates a generally high level of trust within the Order and movement, some specific issues came up. One interviewee spoke of what she perceived as her high level of state support, but sought clarification that confidentiality would be maintained and made some modifications to her transcript accordingly. Sensitivity was also needed when other people were mentioned to illustrate a point, and in some cases these were edited out. Triratna/FWBO is relatively small, and as soon as personal details are given pseudonyms can lose their effectiveness. For example, in Inaba's (2004) study the background material he gives on the participant he calls Jeff is such that this Order Member's true identity could readily be discerned by many people in the movement (see page 69 above). There were some examples of Sanghas in various forms being perceived as giving inadequate support to ill/disabled people. Whilst much goodwill and support was also reported, negative instances can have a particularly strong impact on readers and potentially exacerbate interpersonal difficulties. It was important that such issues were explored while also maintaining confidentiality. To give one instance, an accommodation difficulty between an interviewee and the governing council of his local Centre is explored but minimal details by which this respondent can be identified are given.

My research is part of a general project to raise the profile of LTC in Triratna/ FWBO, and thus I sometimes want to refer to the research in other contexts. This was mentioned to all the interviewees, who all gave their provisional consent, although I can anticipate situations involving sensitive information where further discussion and formal agreement would be needed. There was also a challenge in dealing with the controversies around Triratna/FWBO proportionately. Whatever their primary area of interest, most writers on the movement refer to these issues to a greater or lesser degree. My judgement was that they were neither central to my research concerns nor entirely irrelevant, and this perception is reflected in the research data collected. A valuable reference point emerged late in the process with the publication of a history of Triratna/FWBO by Vajragupta (2010), director of the movement's Development Team. It is a short book that gives proportionate coverage to many achievements whilst also exploring aspects of the Croydon Centre in the 1980s, Sangharakshita's sexual involvement with younger men, perceptions of misogyny and other difficult material.

On such matters I have aimed to apply two key criteria, consistently asking: "Am I being frank enough?", and (more importantly, I believe): "How relevant is this to my study?".

Validity and reliability

Wallace's (2005) discussion of ecological validity encompasses some key aspects of the qualitative approach. He finds the term suggestive of certain priorities, so that:

> *Rather than aiming for reliability or other surrogates of validity, one aims to conduct intensive, extensive and non-reactive observations of the social world of interest which generate understanding and meaning of the social world from the perspective of the insider rather than some objective world view (2005,p.74)*

Similarly Miles and Huberman (1994) link internal validity to:

> *...truth value...do the findings...make sense?...are they credible to the people we study and to our readers? Do we have an authentic portrait of what we were looking at?(1994,pp.278-279)*

The broad question of external validity is whether the conclusions have any wider import, raising issues as to transferability and generalisability. As to the former, the credibility of the interview data has been partially audited through working closely with interviewees editing and agreeing the transcripts and summaries.

When I communicate my findings further I hope to get further feedback from the Order and the movement about the study's wider import and I look forward to seeing how it is perceived by other Buddhist and non-Buddhist faith traditions in the light of their experiences with long-term care. I have also needed to reflect on the construct validity of the questionnaire and ask: 'Does it measure what [I] think it measures?' (Robson,2002,p.102). Participants' entries in the comments boxes are of great value here, both in broadening the dialogue around each item and in occasionally highlighting a gap between what I thought I was seeking and how this was perceived by people completing the questionnaire. For example, QP51,commented below Item 3 on Buddhist-based care services possibly ***"cutting people off from the wider world"****: "Not clear if you mean staff or clients".* It is a truism of literature on institutionalisation that care services can have negative effects both on staff and residents/clients (Barton, 1961), and I had intended the item to encompass both groups whilst having a primary concern for residents/clients. Other items referred to ***"people"*** rather than specifying

them as workers in or clients of a service, and some other participants' comments echoed that of QP51. A revised edition of the questionnaire might find that piloting highlights the benefits of being more specific, e.g. "cutting *clients* off from the wider world", thus improving validity.

Aspects of reliability can also be examined with reference to my audit trail of documentation and the clarity or otherwise with which procedures are discussed. Miles and Huberman (1994) invoke the question "Have things been done with reasonable care?" (1994,p.278) in a discussion that links reliability to auditability and dependability. They give some criteria for the 'domain' of these interconnected concepts, one of which is especially salient here:

> *Were data collected across the full range of appropriate settings, times, respondents, and so on suggested by the research questions? (1994,p.278)*

In response to this I point to the variety of settings in which I collected my data. Inaba (2004) could be criticised for gathering all his Triratna/FWBO material in London, and mainly from the **Buddhist village** Sangha around the London Buddhist Centre in Bethnal Green. In fairness, the transformational dimension of full-time commitment to the 'Three Cs' was a particular concern of his, and such a life-style was more representative of the movement when he did his fieldwork in the late 1990s. His findings might have been different, for example, with a sample of family-based people attending Triratna/FWBO classes in a small outpost, as discussed in Chapter Two. My concern was with a broader range of people, and while I cannot claim absolute representativeness a minimum requirement for my sample was that it included participants from Buddhist **villages, outposts** and other situations. Referring back to Wallace's (2005) concept of ecological validity it could be argued that the interviews were intensive and that the use of the questionnaire in a number of settings gave an extensive dimension to the inquiry. Wallace uses the word "non-reactive" (ibid:74) where others might use the contested term 'objective'. I cannot claim an absence of bias and appeal to readers to evaluate how proportionate or otherwise my treatment of sensitive issues is here.

Strengths and limitations: Some reflections

It has been argued that this study has an eclectic methodology, and I acknowledge that this may reflect a lack of initial clarity as to what was required. Thus, for example, more detailed examination of case study/idiographic approaches (Bryman 2004,p.50) and their possible application here might have been beneficial. As it was, the interview schedules for the Current Care and Anticipating Care groups err on the side of being excessively structured, giving them the appearance of cross-sectional survey instruments. In fact my meetings with the generally forthright and eloquent interviewees tended to include my relaxing somewhat in the application of the schedules, and my attempts to create more space for each interviewee to explore their primary concerns as to LTC and related matters. The questionnaire was comparably designed to yield some readily quantifiable/quantitative data, though again a qualitative tendency proved to be in operation, with abundant additional comments providing rich data which could be added to the interview material for NVivo analysis. Thus the numerical data from the questionnaire was somewhat eclipsed by the verbal material in earlier versions of the thesis, though some recent re-writing has included a greater emphasis on the value of the quantitative data (see page 134 below). Although the study's eclectic approach did appear suitable and flexible in a number of ways, the overall research strategy did have a number of limitations.

Firstly I acknowledge that it would have been helpful to all concerned if I had started the research with my concern with Buddhist identity already in place. Failing this it would have been better if I had seen the limitations in my initial framework at an earlier stage, perhaps before my data-gathering was complete. As it was, the refocusing came later, although it was advantageous that key thematic material for the revised framework on LTC situations and care/support issues was plentiful in the data. Nonetheless I welcome the fact that an iterative process was in operation, involving "a weaving back and forth between data and theory" (Bryman 2004,p.10). The initial absence of a sustainable framework was problematic, although starting with an unduly rigid sense of what I was investigating might also have created difficulties.

A strength in the study is that the Current Care and Anticipating Care interviews were participative, with people prepared to talk about key issues in detail and to put considerable effort into the revision of transcripts so that these adequately represented their views and experiences. This process was augmented by the interviews with the

Expertise group which enriched the narratives of long-term care in the Triratna/FWBO context.

The questionnaire achieved a fairly high level of involvement in the time available, with Order Members predominant but Postulants, Mitras and Friends also included. It would have benefited from larger-scale piloting with wider discussion of potential topic areas and of wording of questions. Item 1 has been criticised by a number of participants as a double-barrelled statement.It might have been preferable to word it simply *"BBCS are unlikely to actually develop on any significant scale"* without making it dependent on the the first statement whereby these *"would take a lot of money and energy to set up"*. Item 20 proved to attract an unusually low score (typically 2), perhaps because *"to take responsibility"* is seen as a generally desirable course of action in Buddhism and the wider world. However, additional comments from a number of participants contributed to the debate about personal and collective responsibility, which this item was intended to explore. As to intentions in general, it was intriguing to see how additional comments often reflected both some measure of consensus and more individual concerns relating to the subject under question or how the questionnaire presented it.

I regret not including an item on end-of-life care in the questionnaire, although again some participants' comments mentioned this and provided valuable material. Some chagrin also arises from not having translated Chapter Four's parallel between Western Buddhist and LGBT identities into any questions/items for data collection particularly as a number of people from LGBT communities (including two transgender people) participated in the research. Both these regrets are explored further in Chapter Ten.

Finally, a number of areas for related research are mentioned in the Conclusions section below. Certainly if care-based TBRLs are seen as a practical proposition more work with potential Buddhist clients will be needed, using more stratified sampling of, for example, residential community-dwellers and people in family situations. Further numerical data about preferences and priorities would also be useful. Overall, however, it is the qualitative material that has given substance to the idea of the Buddhist identity and elaborated both the vulnerabilities of such identities in LTC situations and possibilities for suitable support.

The study's findings follow in Chapter Nine.

PART FOUR – FINDINGS, DISCUSSION AND CONCLUSIONS

Part Four continues and concludes the thesis as follows:

- Chapter Nine presents the findings of the study. These are grouped into key themes and then divided into relevant sub-themes.

- Chapter Ten discusses the findings with reference to the background material/literature review in Chapters Two to Five.

- Chapter Eleven presents conclusions from the study.

Note: Questionnaire Participant is abbreviated as QP, with each participant given an identifying number, e.g. QP35.

CHAPTER NINE: FINDINGS

Preliminary comments

An account has been given of the data-gathering using interview and questionnaire instruments. The study was then refocused on the new core theme of ***Buddhist identity***, and although the instruments had not been designed with direct reference to this theme, much of the data remained applicable. The results of the questionnaire exploring attitudes to Buddhist-based care services (BBCSs) indicated considerable positivity towards such possible projects and remarkable uniformity across the various groupings into which participants' scores could be arranged-see Appendix H. Both phenomena can be noted , with numerical scores showing little deviation from the mean score of 74.96 across all participants when other factors (for example,experience of informal care) are explored. This high consensus in the numerical scores also translated into notable findings on individual items. This was most marked for Item 15, to which all but three participants registered either strong agreement or agreement. Other numerical data was explored in relation to age, experience of LTC issues, gender and category of involvement (based on six categories of involvement in Triratna/FWBO). For the last two an Analysis of Variance test was undertaken with results not found to be statistically significant. Nonetheless numerical data did inform the study throughout, as with the finding that female participants typically had greater experience of LTC issues than men, or at least were more inclined to write about these on their questionnaire. Thus the female to male differential was 5 to 1 on informal care experience, narrowing to 2 to 1 on relevant paid work in the care sector (again see Appendix H for further details). Whilst may reflect trends in wider society, it was noted that the male participants' average age was over 6 years younger than the women's, and, for example the men who did have informal care experience tended to be older.

A major contribution to the study was made by the unexpectedly large volume of additional comments which added a corpus of 16,000 words to the data set. The number of comments attracted by a questionnaire item appeared salient. Comments often signalled some diversity of concerns about item statements. Usually a consensus of opinion could be identified with some participants also highlighting a range of other aspects of the issue in question. For example, Item 2 on vegetarian/vegan diets attracted

comments indicating that this was a key issue in LTC situations. A minority questioned this and others raised questions about potential Buddhist and non-Buddhist service-users who are neither fully or partially vegetarian for health and other reasons, the healthiness of retreat centre menus, aspects of special diets, and other associated matters. Thus the data set included rich and abundant material for the study's academic purposes and yielded some issues which could be salient to the practical development of potential future care services on a TBRL basis. Overall this verbal material was the main contribution emerging from the questionnaire, though as already noted for Item 15 the numerical scores did highlight some areas of high consensus, and when juxtaposing verbal and numerical findings the phenomenon of 'opposite halves' was identified. This signified that participants *either* showed a strong consensus on an Item *or* were likely to offer additional comments in abundance. When average scores for Items and number of additional comments were ranked 1-20 (as shown in Appendix H, Tables 3 and 4) Items tended to appear in the opposite halves of the rankings. Thus we can first note the high consensus reflected in terms of relevant mean scores (considered to be those above 4) on item 15 as just cited plus item 13 (on quiet reflection and opportunities to meditate), item 2 (vegetarian/vegan diets), item 19 (mindfulness), item 11 (like-mindedness), item 6 (Buddhist names) and item 5 (risk of isolation/neglect). Linked in all of these cases is a paucity of additional comments and ranking of this placing all these in the 11-20th half of the scale. Only one item with a relatively high consensus mean score (of exactly 4) also yielded a high ranking number of additional comments (6th in the ranking scale), this being item 3 and participants generally opposing the idea that having Buddhist-based care services would have the effect of "cutting people off from the wider non-Buddhist world". This apparent 'trade-off' between aspects of verbal and numerical evidence is explored further in the Chapter Ten discussion below.

   Four major thematic categories emerged from the data analysis and formed the tree node shown in Appendix I. As outlined below, they related to identity and personhood in the Triratna/FWBO context, informal care and support, mainstream services and TBRLs in the LTC sector. Appendix H shows **Buddhist life** and **Secular life** as discrete nodes or sub-categories contributing to the larger theme of identity and personhood. A subsequent revision of the data led to a decision to combine some material for these sub-categories and to present them with reference to **semi-monasticism** and to being **highly idealistic.**

Identity and personhood in the Triratna/FWBO context

Background to this theme

Relevant aspects of identity and personhood have been explored in Chapter Three. The responses include participants describing situations in terms of a ***nightmare*** or a ***dream*** and descriptions of worst and best scenarios to which dream/nightmare imagery was not applied but a comparable level of emotional response was invoked. It will be argued that the participants' self-reports about such responses were often related to identity issues, with dream situations reflecting a sense of a fulfilled ideals about identity, and nightmare scenarios entailing denial of such ideals.

The identities of Triratna/FWBO people are considered in relation to two other areas of the data. First, demographic details were sought from all participants. The interviewees were asked about key areas of their lifestyles and this was augmented by the interview content and some material from the questionnaire. Someone who has lived for many years in single-sex residential spiritual communities, working full-time for the movement with a modest package of financial support exemplifies the semi-monastic features of Triratna/FWBO lifestyles as conveyed by Nagabodhi (2004,p.3). Second, recalling the other element of Nagabodhi's descriptor, high idealism, we can explore what relevant patterns emerge from the data and their implications for the support of Buddhist identity.

Buddhist/secular life and semi-monasticism

The Triratna/FWBO is not and never has been a monastic movement. However, the Three Cs lifestyle is sometimes described as ***semi-monastic***, being most strongly thus when people are working closely together and living, in many cases in single sex communities. JV comments that *"communities are on the wane",* mentioning that in the city where she lives:

> *There are only two women's communities…there used to be four.*

Her perceptions are echoed by other participants including CH. Changes in communities are mentioned by TN, commenting in 2005 on an invitation to a meal at a men's community which was formerly closed to women and her mention that a local women's community *"Let their boyfriends in once a fortnight".*

The Three Cs tradition has helped to shape many individuals' lifestyles in the movement and has been associated with aspects such as living on a modest income, not

having a live-in partner or children and valuing work in terms of spiritual practice rather than its manifest content or associated status. In such respects these lifestyles are distinct from many features of the secular/non-Buddhist world.

NR comments that he has found that *"in some ways Pension Credit is quite a big rise"*. In the past he has worked in TBRLs and on a retreat centre team as well as working as a hospital porter until about three years ago. Low average income appears to be one reason for only two of the twelve Current Care and Anticipating Care interviewees being owner occupiers. However, all three Order Members in the Expertise group own their own homes, in one case helped by a legacy. Lack of personal finances emerged in the data as a phenomenon linked by many participants to the movement's obligations to its pioneers and stalwart contributors, and this is referenced more fully in the Mutuality and the Sangha Jewel sub-section below.

QP14 adds a comment on the questionnaire:

> *...the FWBO also has some obligations to people who have served it loyally,.often for many years, for very little.*

Only 2 of the 15 Order members interviewed had live-in partners. Whilst some had partners/lovers on an LAT basis, as Padmasuri discusses above, the single life appeared to be well-represented. In the past two interviewees had taken on the *Anagarika* (homeless) lifestyle, which includes abstention from sexual activity, and both had practised this for a number of years. Only five were parents, and one of these was not in regular contact with his two adult children. QP11, a former social worker, made a connection between such trends and LTC issues:

> *...there is a lot of expectation of help from family from the statutory agencies many Buddhists made life choices that involve being single or not having children. When we go forth and encourage others to do so too, we need to plan for the consequences.*

Similar comments were made by QP31, QP17 and others. The above reference to the choice to 'go forth' derives from Siddhartha, the future Buddha, and his departure from the security and opulence of home to take up the spiritual life (Carrithers,1991). The phrase is often applied to life changes in which someone abandons a non-Buddhist/secular refuge and goes in a spiritual direction. There were examples amongst the interviewees, with VP leaving his job as an architect to work full-time for the movement in the 1970s at about the same time that JV was becoming inspired by Buddhism whilst studying economics at university in New Zealand. She has been much involved in the Three Cs ever since, commenting:

I've lived in communities for 30 years…all my life.

This is often linked to livelihood. JV worked in a range of TBRLs and then became part of a team which helps to prepare female postulants for ordination, based at a women's retreat centre in Wales. She comments:

I'm a people person and would like to live communally for as long as possible.

There has been some question of her present community breaking up, and if this happens she would like to share a flat with Buddhist friends. However, she notes that Registered Social Landlords (RSLs) /Housing Associations tend to be geared to single and couple occupancy only.

Considering other Triratna/FWBO lifestyles, for some interviewees a Buddhist Centre has been their main sphere of involvement in the movement. For example MB, who had lived alone and been a college assistant principal, made her Buddhist practice increasingly full-time in conjunction with taking early retirement. AK, with a family and a career in software development, was somewhat unusual as to lifestyle when ordained in 1996 (having no background in TBRLs or residential communities), though demographic trends have since mitigated this.

Disability and illness have played a significant part in some interviewees' lifestyles and income levels with, for example CH's second spinal injury occurring in her early twenties. She expressed appreciation of her residential community, where she lives in an annexe adapted to her disability, and felt that her 15 years of community living brings some *"experience and stability"* to the situation. Like several other interviewees (KL, RT, JV, TN,VP) she was interested in the possibility of adapting traditional Triratna/FWBO forms of communal living in a way that could support more people with care needs and would include the presence of paid staff.

Elements of the semi-monastic lifestyle appeared less prominent in the movement overall, but continue to function in various contexts and are valued by a substantial number of people. They support aspects of the identity of some participants in this study, especially where their involvement has been longstanding and, as explored in the next sub-section, there is a high level of associated ideals.

Buddhist/secular life and being "highly idealistic"

The semi-monastic lifestyle has been associated with a high level of idealism. Padmasuri gives an account of what drew her to retail work:

We could explore what team-based right livelihood was and what being a Buddhist was...we could also make a lot of money to give away to the movement...if that wasn't in place I wouldn't be working in a gift business.

TBRLs have certainly been a focus for idealism in the movement and have been associated with ideas of a 'new society'. There were critiques of this in the data, including the following from QP 31 on the question of compassionate care services:

I would hope that...the staff were emotionally and spiritually mature. It would be a mistake to be too naively idealistic in the way that the FWBO has been in the past in its mission to build a 'new society'.

Comparable criticisms came from QP36, QP 51 and others. SA mentioned the problems at the Croydon centre in the 1980s, and QP45 referred to issues in the Norwich Sangha at approximately the same time:

Ask the women in the movement whose partners went to live in communities, while they raised the kids on benefits what it was like.

It is notable that all the participants quoted on this page are Order Members. Whilst disillusionment with a particular situation led to some people resigning or becoming inactive in the Order/movement, others see past problems as reminders of what can go wrong if idealism is not tempered by what QP 31 calls *"emotional and spiritual maturity"*.

Some traditional idealism is represented in a positive light. CH and RT refer to an Order Member now in her eighties who lives at a women's retreat centre of which she was a founder member, and whose *dana* (generosity) was crucial when the fledgling setup there had minimal resources. CH comments:

And she's put her pension into the kitty and taken out less, which I don't think many people would do these days. So she's an example of an older generation Order Member, where there was more that model of dana...we just live in very different times.

Many participants signalled their ongoing confidence that Buddhist practice has the potential to transform people and situations, as for instance QP23, an Order member for over 20 years, comments on expectations as to compassion in Buddhist-based services:

I do expect Buddhist-based care services to be more compassionate. What is metta about after all?

Several interviewees, including NR, TN, JV and CH, emphasised the importance of their meditation practice. Buddhist approaches to cultivating skilful states of mind and

being were highlighted by QP17, QP35, QP53, QP70 and others. Links between such practices and Buddhist identity were apparent when JV spoke about being unable to find anywhere to meditate on her periodic admissions to hospital and MB commented that her mother had formerly had an interest in meditation and Buddhism but that it was unclear what this meant to her now that she had dementia. MB may have had this in mind when, in response to an interview question about the advantages of a Buddhist LTC service, she says:

> *People could be supported to continue their spiritual practice.*

More specifically she refers to:

> *...keeping a live practice. I think practice is more short-term memory than long-term memory.*

These examples from JV and MB are explored further in Chapter Ten. Such practices form part of the Threefold Way and of Going for Refuge as outlined in Chapter Two. Meditation is one aspect, whilst ethics would be associated with vegetarianism, avoidance of harsh attitudes and speech (see QP35, QP46) and other elements. Wisdom is less tangible, although it is invoked by several participants. QP38 writes about it in a care context as *"not trying to brush out the reality of a situation"* and Padmasuri sees some progress with wisdom being attainable in a care-based TBRL with spiritually-committed people. Where wisdom is associated with dialogue, practice and study, QP87s comment is salient:

> *There will also be many of us who would wish to discuss the Dharma in our twilight years and practise with people who understand. This will never be available in a non-Buddhist centre.*

Shared ideals seem to be important, and notwithstanding changes in relation to the Three Cs there is much idealism to be found in Triratna/FWBO. One focus for this is ordination. There were the following comments in relation to Item 6 about ordination names being respected and understood:

> *As a recently ordained person this all feels very precious at present. (QP11).*

> *Important for this great commitment to be recognised and understood. (QP98).*

> *That's quite important actually. (QP67).*

Some of the interviewees have ordained other people. JV's narrative contained material on her work as a Private Preceptor to 38 women, commenting:

> *That keeps me busy…they have their ups and downs.*

A factor in her decision to move to East Anglia was that up to twelve of the people she has ordained live in the area and living nearby facilitates the recommended regular contact and ongoing spiritual friendship.

At the time of interview, KL was working towards becoming a Private Preceptor, having been asked by a Postulant to ordain her. She commented in response to a question about fulfilment:

> *I don't know what the outcome of that will be, but that feels really important.Is fulfilment the right word? It's more of an honour…that someone sees in me that capacity to witness their Going for Refuge.*

The Private Preceptor's giving of a Buddhist name is another major example of how identity might be viewed in the Triratna/FWBO context. Some Order Members (a minority as I understand it) abandon their birth name entirely, changing to their Buddhist name by deed poll for official purposes and asking non-Buddhist relatives and friends to use it too.

In work and social situations the picture is variable, although I am aware of several examples of people using their Buddhist name in their secular workplace. Certainly within Triratna/FWBO the practice is to use the Buddhist name from the moment of the public ordination (a ceremony held a few days after the name is given to the individual) for the remainder of the person's life. While these names can potentially be a barrier to communication, for example when a newcomer to the centre finds the Sanskrit/Pali syllables difficult to pronounce, they can be a supportive condition in, for example, sustaining Buddhist identity and taking it further. At the very least they are a frequent reminder of Buddhist affiliation, and as the name reflects spiritual qualities it can be seen as a constant invitation to live up to those positive features with which the bestowal of the name has associated the individual.

Order Members whose relatives and work colleagues do not use the Buddhist name will hear it relatively rarely, whilst those who spend most of their time in specifically Buddhist contexts (e.g. working in a TBRL business, living in a community, living/working at a retreat centre, leading classes at an urban centre) will be at the opposite extreme. Several of this study's participants do use their Buddhist name full-time (for example VP, KL and SA) and an estimate would suggest that the majority of

Order members contributing to this study are addressed by their Buddhist names more often than not.

This sub-section has considered aspects of idealism in the movement. Being a Preceptor, being ordained and taking on an ordination name were seen as areas in which people's sense of identity is located but which might appear arcane to the uninitiated wider public.

Dreams: Valued experiences and goods

A number of participants went into some detail about their vision of LTC. RT responds as follows to an interview question about her hopes regarding such provision if she should need it in the future:

> *My dream situation would be to live with other people in a community situation…I'd like to be fairly independent, but have other people around…and I wouldn't want my Mum's situation at all…live by myself with no company*

She made it clear later that this community would be a Buddhist community. However, in a further question about options in LTC and supported living she refers back to this "*dream situation*" and says

> *Yes, except that I don't think it's a real option…because I don't think a community is going to take on care of a disabled person…not really…and in a way this seems kind of unfair to expect that of your family and friends, so that I think that probably my choice would be something like sheltered housing.*

Her comments overall are an example of a vision of what LTC might be at its optimum, with valued experiences and goods in life as embodied in having suitable company, although this is tempered by the perceived realities of what is feasible.

TN has been working on plans for a co-housing project to support older people:

> *You could have writing groups…and I think of BV (*pseudonym for Order Member)*, who does her sculpting. I would like to have a lovely big garden…and have a bed out there in it. And to.have my sons visiting.*

Other participants offer their visions. Here, for example, are two responses to response to Item 17 on the apparently dull lives and lack of creative activity in some LTC situations.

> *There is an appreciation of 'individuals', creativity, community, arts, friendship etc amongst Buddhists which would tend to counteract this (QP 61)*

> *Yes, if our life isn't about material possessions, watching TV then hopefully our values of finding meaning, having time for reflection, study, communication, friendship, the Arts could permeate what we could offer.*
> *(QP 37)*

It is implicit in both these responses that in an ideal LTC situation the clients and staff would have some measure of shared values and the service offered could at least aspire to meeting the needs of all involved, whether receiving or offering care.

QP 33, who disclosed that her late mother was latterly in residential LTC, comments:

> *Most of the long-term residential/nursing homes I have visited are unsuitable for Buddhists because of our need to be together, practice together, and be among like-minded sensitive people. Also, many of us are vegans, so our diet is specialised, and we like a quiet environment, with maybe a good library, and gardens to sit in.*

This response offers a brief manifesto about how an LTC environment might be planned where Buddhists and Buddhist identity might thrive. One feature of this and other dreams is a positive view of the possibilities of communal living, probably reflecting Triratna/FWBO Buddhists' experience of being on retreat together and (in some cases) of living in residential communities. QP33's manifesto links readily to other visions as quoted above and to further material in the sections below on aspects of mainstream services and potential TBRLs.

Nightmares: Worst case scenarios and fears

Two participants explicitly invoked nightmares about LTC. NR, asked the interview question *"Do you consider there would be any advantage in receiving care from a Buddhist long-term care service?"* included the following remarks in his reply:

> *...and a Buddhist wants to die with awareness, wants to live with awareness, wants to do everything with awareness, and if you were struggling in a place where that wasn't particularly valued, well, it would be a bit like a nightmare, wouldn't it?*

QP14 offers these thoughts on dietary provision:

> *I have nightmares about having to go into residential care and being served pie and peas. I know some very good establishments but they are very traditional with their food. It is clear they have little understanding of vegetarian food.*

JV's interview included the remark: *"The assessment by Social Services was a nightmare"*, saying that the social care manager *"verged on being abusive"* and the process:

...was constrained by money issues. My washing and toileting needs were a legal responsibility, but she could get around everything else and she did.

Thus there was no allowance for cleaning, supported activities outside the home or freshly-cooked meals, with the manager saying:

You look to me as though you could put things in a microwave.

JV spoke of all this having *"an undermining effect"*.

QP35, an experienced care worker and an Order Member, offered this scenario in response to Item 11 on like-mindedness:

Personally I dread being thrown together with people who do not share the same values as myself, should I become infirm or senile.

In response to Item 3 on care-based potentially cutting people off from the wider Buddhist world she outlines situations where identity might be at risk and suggests how Sangha-based input might help:

For an individual with dementia or someone who is bedridden but extrovert, there is little support for their move towards emotional positivity and calm, as they are isolated from such supports. If a 'service' takes place within a Sangha, such supports are there and individuals can support each other also, if able.

Emotional positivity and calm are well-known aspirations in the Buddhist life, with the former often associated with the *Metta Bhavana* (loving-kindness) meditation and calmness frequently linked to the Mindfulness of Breathing practice.

Other participants focused on how one might be viewed when vulnerable and needing LTC. This brought issues about personhood to the fore. This is a concept closely associated with identity but arguably has particular application when someone is frail and, in Kitwood's (1997,p.45) terms, is especially vulnerable to the "malignant social psychology" which others may bring to the situation.

Thus in response to questionnaire Item 9 on personal/intimate care QP 37 writes:

I like the idea of being cared for by someone who shares my ideals. Taking more of me into consideration. I wouldn't just be some anonymous old dear.

Somewhat comparable to this is RT's example of an (approximately middle-aged!) Buddhist friend in hospital. RT witnessed health care assistants speaking to her in an apparently infantilising way about Christmas saying:

Something like…'have you been naughty today?'…'Father Christmas won't bring you anything'.

Perhaps the fact that this was in a care context prompted RT to associate this with a general concern:

That when you're very elderly people don't take very much notice of you…and you become a nonentity, become a nobody.

After recounting the Father Christmas story above, RT concludes:

So that would be a fear of mine; that I would be talked to like an idiot, or like a child or, you know like an intellectually impaired person.

Informal care and Buddhist identity

Background to this theme

As discussed above, Triratna/FWBO has consistently emphasised spiritual friendship, which is also seen as the basis of the Sangha, the community of practising Buddhists.

Amongst other characteristics a cohesive Sangha is one in which spiritual friendships are strong, with regular contact between people and support emerging readily when someone is having difficulties. This is not to suggest that the Sangha is the only source of informal support for Triratna/FWBO Buddhists; participants mentioned partners, children and other non-Buddhist relatives and friends, although the Sangha may have an accentuated contribution to make in the support of Buddhist identity. VP has worked full-time within the movement for most of the years since his ordination in 1972 and comments:

The ideal in a Buddhist context is that you are looked after by those who are closest to you spiritually.

But how feasible and available is such support? 'Burden' issues are often cited in relation to informal care and emerged as a theme in this study. A category of this name was developed to encompass not only material in which participants voiced their reluctance to be a burden because of care needs, but also input about the general topic of care burden. Closely linked to this was the perceived busyness of others, explored in a section below.

In Triratna/FWBO each Centre has a Chair, an Order member who coordinates its spiritual direction and oversee its financial and legal operation. When interviewed for the present study, RT a centre Chair, spoke about how we *"take care of each other",* acknowledging variation in this and suggesting:

I think it depends on the sort of development of the centre.

From this and other material the sub-theme of the cohesiveness of local Sanghas emerged. The results include material suggesting that interpersonal factors might influence the availability of informal support. Informal support emerges as a complex and multi-faceted phenomenon in itself which can range from the occasional telephone

call through to the full-time carer responsibility described by interviewee YP with her late mother. These sub-themes are considered below.

Burden issues

As discussed above, 'burden' is a well-established element in research on informal care. In her interview JV referred to a discussion with her community co-residents, who had made it clear that they would be able to offer little practical support before she moved in. And yet JV comments that:

> *If I had more respiratory problems, or was wheelchair bound…it would be.very weird if the person helping wasn't a Buddhist.*

She also speaks of preferring a carer *"who is not too alien from what I hold dear"*.

At the time of interview JV needed help with some shopping, cleaning, ironing, transport, and before and after a bath. Her current arrangement was with a friend and fellow Order member who is a co-resident in the community, whom she has known for 30 years and employs as a part-time carer (she was seeking an increase in her Disability Living Allowance-DLA). However, this friend was planning to stop doing the care in a few months time. JV was starting to look around the local Sangha for a replacement, knowing that no-one at the house would take this on. An additional factor here was that one of the co-residents had in the past lived in another community where an Order Member had been supported in the last stages of terminal cancer. There have been several such situations in the movement, and they reflect spiritual friendship in impressive, practical action. Nonetheless, it had been communicated to JV that *"that situation had been a huge strain"* and she linked this to the caution with which her co-residents viewed the prospect of meeting care needs.

It is arguable that burden-related issues weigh heaviest when people are co-resident.This is reflected in the first of QP 11's telling comments below:

> *My own experience of being ill was that friendships in a residential community cracked under the strain (QP11).*

> *Sangha friends [have] their own elderly parents to care for…this can lead to the heart being pulled in different directions!(QP11)*

Such matters can be stressful. Some participants refer to fairness, for example:
> *It's unfair to expect friends to shoulder the responsibility. (QP103)*

I think people in the FWBO do give a lot of care to those who are ill or disabled-but it can be a strain on their friends. As those in the movement age I don't think it is fair to expect the younger generation to give up much of their lives to care for them. (QP42)

The intensity and duration of care needs, as discussed in Chapter 4, are the focus of the following example:

Being sick one may be cared for if it's a short term thing but, with ageing, people need ongoing care and this is much harder to be available for.

This perception is echoed by interviewees RT and JV, whilst QP 35 reports:

The resources are often there for continuing friendship, but not for such things as intimate personal care-washing, dressing and feeding (sometimes cooking).

Padmasuri, a senior Order member and a former nurse and midwife, mentions a disabled Order member with whom she is in contact, who:

...has carers coming in three times a day, she can't feed herself...now basically that's a full-time live-in job...well, I wouldn't want to be the sole carer in that way.

Padmasuri describes the full personal care she received from Buddhist friends, when over ten years ago *"my back went completely"* and she was incapacitated for about five weeks. This worked well and one Mitra who had studied with her said:

It's so nice to be able to give you something back.

Although the current research found a number of examples like this of Buddhist-to-Buddhist personal care, invariably if this continued over an extended period it was on a paid-for basis-see ***Lived Experience/paid for care*** section below.

QP48, a disabled Order Member, found the Sangha:

... very strong...There's a rota of 11 people cooking my lunches which I then freeze.Three people...make my suppers...one of them grows her own vegetables, and tries to make the meals with organic ingredients.

QP48 has home carers attending each day, and if there are any thoughts or expectations of the Sangha providing such a service these are not voiced. It seems that the meal-making arrangements and ongoing friendship were helping to fulfil her perception of feasible Sangha support.

There is a wide variety of situations and personal experiences. One factor in a person's perceived need for informal care is the level of formal support received. KL spoke at some length in her interview about the reduced quality of her life since her DLA had been withdrawn meaning that she could no longer employ her home help. In relation to shopping trips and such-like:

> *I have to think 'Who shall I ring up this time?' I do find that difficult…I don't find it dignified having to ask for help.*

KL lives alone. CH lives in the annexe/granny flat of a residential community which is home to six women. Having been assessed as having a high-level disability, CH has a care set-up with two employed personal assistants (PAs). She emphasises how much better it has been since she received direct payment funding and can have a "clear contractual relationship" with her carers and contrasts this with past informal situations, where notwithstanding a general attitude of kindness there were times when some co-residents at a previous community were:

> *Really helping me and then getting resentful.*

CH explicitly links this past experience to more typical scenarios:

> *And if you look at people caring for their parents, often there's so much resentment and bitterness and so on.*

CH's perspective on the problems of relying on informal care is echoed by QP12:

> *Established care services benefit all and ill/disabled people do not want to feel they are a burden (I am disabled). Professional help leaves friendship intact.*

CH's interview included reference to an Order member, now in her eighties, who was a founder member of a retreat centre, Her pension is a major source of early income and she has been able to stay on there in retirement. This Order Member completed a questionnaire and commented:

> *People are very good in my community. But if I needed a lot of care long-term that would be very difficult for them. (QP23)*

This comment reinforces the overall impression that friendship, kindness and ongoing contact are usually available to ill/disabled Triratna/FWBO people, but that the perception of it as a burden contributes to informal long-term personal care not being commonly available, nor indeed is it expected by those who might be thought eligible.

Others' 'Busyness'

This study has made a number of references to the neglected monk with dysentery (Sangharakshita,1991) first mentioned in Chapter Two. In his interview NR commented that in contemporary conditions busyness is more the problem, with informal care for some individuals compromised by the full lives that their spiritual friends lead.

In the traditional Triratna/FWBO lifestyle based around centres, communities and TBRLs much of the activity is focused on spreading the Dharma. This is mentioned by a number of participants, including Padmasuri, QP19 and QP90. For those around Triratna/FWBO living more fully in the wider world Dharma work is also often a

priority, and there may be other major preoccupations, with QP80 commenting *"Many people have to earn a living"*.

KL talks about the local Sangha's responses to her multiple health problems, appreciating what is offered by friends but noting the limits of this:

> *Everyone I know is incredibly busy…they've got the needs of their kids,husbands,partners.*

Whilst QP37 admits to being "very busy" QP 46 sees this as a question about:

> *How [Buddhists] prioritise their time and choose to do some things rather than others.*

YP has been professionally involved in social care and was her late mother's full-time carer. Her ongoing commitment to supporting others includes helping with a friend's daughter when her friend's mental health *"is not so good"*. She adds:

> *I've got less commitments than most people and choose to keep my time free. I'm in a position where I can help out, and financially I'm more spacious than many people.*

In the same Sangha another participant, DS, was well-supported during his 14-week hospital admission and beyond. In DS's case one factor that enabled the more or less daily visits from one Buddhist friend was that the latter was not in paid employment at the time.

The use of the word '***should'*** in the statement for Item 7 prompted some remarks around obligation and positive motivation. Several participants criticised those too busy to help spiritual friends, with QP85 responding: *"Shame on them"*.

Whilst some participants explicitly rejected any 'should factor' in the development of care-based TBRLs in lieu of informal support (Padmasuri, QP41, QP46, QP52) QP2 acknowledged conflicting loyalties.

> *If anyone has a friend, Buddhist or not, they should find time to help and visit, however in this busy society it is sometimes not always possible to provide the help required either for financial or other family responsibilities.*

Other participants deny that 'busy-ness' is the key issue, with QP27 and QP 59 referring to a possible lack of skills. The latter also cites *"physical strength"* and the former *"ignorance"* as compromising people's ability to offer adequate informal care.

Both QP95 and QP97 focus on the level of care needed as the crucial factor. Both their perspectives are covered by the latter's remark:

I think it is more that the sort of care required is more than a friend can give – or of a different sort.

Whilst QP 100 suggests:

I feel it is more of a 'money' issue than a 'time' issue.

Presumably with many people who are ill or disabled there is a time factor involved in friends travelling to visit or help. JV mentions that she's lived in communities for 30 years. She comments in relation to her care situation that at the retreat centre where she formerly lived *"everyone is very busy"* and that when moving to her current women's community it had been made clear by the other residents that they could offer minimal informal support. JV adds:

They are at work all day, and they are not often in...we eat communally, but they have full lives.

It seems that where someone with care needs lives in a Buddhist community there can be ongoing issues around informal support.

Cohesiveness of local Sanghas

VP, quoted above, focuses on the *"ideal"* situation of being cared for by *"those who are closest to you spiritually"*. Closeness has many dimensions, and the term can be applied to individual friendships as also to the cohesiveness or otherwise of a particular Sangha. Both dimensions have implications for informal care and the extent to which VP's ideal is a practical possibility.

QP63 emphasises friendship in this context:

Surely we'd rather our friends cared for us if at all possible...

This was in response to Item 9, which asked about the relative merits of receiving personal/intimate care from Buddhist spiritual friends, with the pre-existing relationship sometimes counterbalanced by factors such as embarrassment, as related by QP38. QP53 signalled a preference to receive such care from someone with whom *"one has the deepest connection – a spiritual friend",* and QP 67 gave a comparable opinion. QP33 responded:

I think most Buddhists are happy to be with other Buddhists, especially if they need care or work as a carer.

Many factors determine the relative cohesiveness of any given Sangha. In a large Buddhist centre in a Buddhist village as discussed in Chapter Two people live and work together in an urban enclave. This is reflected in a narrative from QP32, who reports that during an extended period of ill-health she was *"visited and very well-looked*

after". One aspect of this was that a local TBRL restaurant *"sent their leftover food my way"*.

Though she has been ordained since, QP32 was then a Mitra sharing accommodation with an Order Member. The fact that other Triratna/FWBO people were in close proximity and the existence of a Buddhist food outlet nearby appear to have been favourable conditions in the Sangha's informal help with her needs. QP32 was adamant that if seriously ill or dying she would rather receive care from fellow Buddhists than from her mother or siblings due to key *"ways of understanding"*,notwithstanding good relationships with these relatives. QP32 clearly places a high value on the support of her Buddhist identity in care situations, and experience has shown her that the resources for this exist in her local Sangha.

Some other situations in a ***Buddhist village*** context could be seen as problematic. NR describes difficulties with the governing council of one of the movement's largest centres who wanted him to find new accommodation when he became the only tenant at a former community house. Unbeknown to him a family friend wrote to the centre council telling them that *"there wasn't enough care"* for a long-standing Order member living with a degenerative illness (Multiple Sclerosis). At this point a council member visited NR to reassess the options. Subsequently he was pleased with help received from another community where he stayed temporarily and then the input of an Order Member in finding a sheltered flat. NR acknowledged that the situation was *"quite complex"*, and it seems that the relatively large size of the local Sangha may have contributed to aspects being overlooked initially. QP31 comments on her experience some years ago in the same Sangha after breaking her leg and needing cleaning and shopping help, which proved *"very patchy"*, involving just a few friends, both in and out of FWBO". She concluded that informal care is:

> *More likely if the person is well-connected with personal friends – being in the Sangha per se wasn't enough.*

At this time QP31 had been an Order member for 16 years, was working in the wider world and living in a flat. In Chapter Ten I compare the support received by her, by QP48 (living with multiple sclerosis and receiving help with meals from the Sangha) and by QP32, part of whose support was spare food from the TBRL restaurant. Although the three women were different in many respects they all experienced care needs in geographical areas where a substantial number of fellow Buddhists live.

A smaller, *outpost* Sangha may be more cohesive in some respects. The one described by DS (an Order member and interviewee in the Expertise group) is in a small northern city with a rural hinterland. Weekly classes take place in rented premises and study groups are held in people's homes. DS, aged 55 at the time of interview, suffered a pulmonary embolism and was in hospital for 14 weeks in 2005, with some residual problems with mobility and other aspects of his health. He is divorced and lives alone, with his only daughter living abroad. One Sangha member visited him in hospital almost every day and he found he needed

To moderate visitors and their generosity.
His final comment in an interview in 2007 was that:

I have no limit to my continued appreciation of the Sangha.

The Triratna/FWBO centre where RT, of the Anticipating Care group, is Chair arguably falls somewhere between the Sanghas experienced by QP32 and DS. It is in a medium-sized town in southern England where the movement purchased its own centre in 1998. RT commented:

It's quite a task to create a friendship network or something.

She saw this network as ideally available to visit people with care needs (two people living in residential care were mentioned, amongst others). She remarked:

I do feel sort of responsible for this, but I do know that I cannot take on everybody.

One example she gave was of a woman aged 91 (here given the pseudonym Joy) who latterly lived in a private care home. Joy had studied for many years with the Buddhist Society (see Chapter Two, page 24 for more about the Society) and had attended the Centre for a time. RT had the impression that Joy could have benefited from some advocacy-type input in relation to her care; e.g. she was reported to have expressed the desire for assistance to have baths more often. Joy appeared to have some level of cognitive decline. She was visited by two Buddhists from the centre on an intermittent basis. RT mentioned that she had heard that staff at the home:

...provide her with Christian books...whether that's her...choice. Or whether...it's...suggested to her that these might be better books for her to read...it's difficult to know.

Only a partial story was available here, although issues of Buddhist identity are evidently raised. Joy died during the course of the study, with a contribution to her funeral by one of her Buddhist visitors according to her wishes.

Another example was cited whereby a local Postulant recovering from a broken leg was able to come out of hospital early because arrangements were made for her to stay at the homes of RT and a mitra. She added that such input *"falls on very few people, that's the difficulty"*.

She mentioned the Jehovah's Witnesses (with whom a relative had been involved) and referred to a perception that in this group there was more of:

> *...a sense of looking after each other's kind of practical needs and financial affairs and so on.*

RT acknowledged a lingering sadness about the relatively individualistic attitudes implicit in her remarks about the Sangha, adding:

> *Seriously ill (people) turn to their families rather than other Buddhists.*

One conclusion she drew from this was that Sangharakshita:

> *...may have lthought of the Sangha replacing the family for people, but I think that would take generations.*

This is echoed by QP36, an experienced Order member from a larger centre who wrote:

> *[I'm] not sure we have the depth of connection one has in families to look after our Buddhist friends.*

Cohesiveness appears to be a complex phenomenon in this context, and experiences of informal support may vary considerably as do Triratna/FWBO Sanghas in different places and the individuals who make them up. Perhaps other aspects need to be considered before any conclusions are drawn.

Interpersonal factors

Interpersonal issues and popularity can be relevant when looking at how Buddhists perceive others, and such considerations appear relevant to LTC. One example of this was provided by TJ, a senior priest at San Francisco Zen Center and a member of the Expertise group, who mentioned a man who was receiving a lot of voluntary input whilst ill with oesophageal cancer, adding that he is someone *"the community loves"* and that such a response:

> *...would be more difficult when the person is a difficult, stubborn person.*

RT acknowledged attractiveness of personality as a factor in how a Sangha responds, but added:

I don't have confidence that we could look after the most popular person in the Sangha.

We can ask, then, where spiritual friendship comes into the picture. QP38 asserts:

Personal connections are where care is happening at present.

This suggests that strength of friendship is closely linked to levels of informal support. JV explicitly says this, adding that *"friendship…is not everyone's forte",* and QP82 states:

There do seem to be Order members who are not well connected and unwell.

Later in the interview she refers to factors that can limit the availability of informal care, mentioning the familiar issue of duration and situations where *"the recipient is resistant to their needs being met".*

Returning to JV's term *"well-connected"* opens up further questions, apparently based on comparisons with others who have close friends and/or relatives who live close by and are available to assist, and with whom interpersonal factors may or may not play an identifiable part.

In the overall study some participants point to Buddhist practice as helpful in efforts to *"manage aversion"* (QP47), or suggest that people perceived as difficult may be *"working with these tendencies"* as part of their commitment to Buddhism. (QP35). The latter was in response to Item 4 on the possible influence of ***"bossy and difficult"*** people in any possible Buddhist-Based Care Service (BBCS). It was included to gauge attitudes to interpersonal conflict in Triratna/FWBO activities, and in fact this item drew additional comments from 60 participants, being in this respect the most productive item of all. There was a strong consensus that such people exist in all areas of lifeand that if anything there are fewer in the Buddhist world, although only two participants (QP53 and QP67) dismissed the question as irrelevant to their experience of the movement. People in the movement may have experiences and views of one another from retreats, community living, workplaces and so on from many years ago. KL refers (apparently half-jokingly it seems) to an archetypal Buddhist who spends his time *"banging on about the Abhidhamma"*, a collection of famously abstruse Buddhist texts. This person is invoked as someone who might comment adversely on *"my TV viewing".* This is in the conceivable context of living closely in a residential BBCS setting with such a person, with KL concluding *"No thank you!"* .She presents this scenario as an argument for having *"your own space…if you didn't want to see other people some of the time"* e.g. having one's own small kitchen.

Although the above context is informal care, it seems evident that differences in lifestyle (serious Buddhist study versus television viewing) and associated perceptions (bossy and too serious versus frivolous) might also influence friendship patterns and the general assistance people might offer one another.

If bossy people can be seen as representing one type of challenge, a man given the pseudonym Peter in RTs narrative exemplifies another. Generally seen as eccentric, Peter, a man in his fifties, had struggled for many years with poverty and communication difficulties, living alone in conditions of considerable squalor in a housing association flat. Attending the local Buddhist Centre for a number of years he became a Mitra, established friendships and received some help with of everyday living tasks and visits when in hospital (he had diabetes and, latterly, respiratory problems). In 2006 RT commented: *"I really can't see how we can take him on"*.

This was a reference to the interpersonal difficulties people experienced with Peter and his increasing medical needs. Peter's respiratory condition worsened over the following months and he died in 2007. We can note QP31's comments on the acceptability of various conditions, including her suggestion that cancer is generally well-tolerated in the movement as in the wider world, whilst Alzheimer's disease and mental health conditions in general are less accepted. Although Peter received a measure of support and friendship within the movement, his psychosocial and communication problems may have contributed to limiting the available input. Possibly Joy's cognitive deterioration, mentioned above, had a similar effect.

Interpersonal factors are an emotionally-loaded issue in this context and it is difficult to give an adequate account of their influence on informal support in the Triratna/FWBO. One suggestion detected in this study is that interpersonal factors can be influential, although the data gathered on this in this study are limited.

Concluding comment

Some level of informal support and practical help arising from spiritual friendship is often available to people with care needs in Triratna/FWBO. This is modulated by various factors including those outlined above, although no examples were found of unpaid care for spiritual friends featuring high intensity and long duration as specified by Pickard (2008).

The next section considers some comparable care issues and Buddhist identity in the context of mainstream LTC services.

Mainstream LTC and Buddhist identity

Background to this theme

The study participants had a range of experiences of mainstream services including having care needs themselves, having relatives or friends with needs, or working in the care sector. Other people had had limited or no contact with the LTC sector, whilst offering a general impression of what it might be like. Material tended to relate to residential care for the elderly, although some mentioned domiciliary care, sheltered housing, assessments by social workers and hospital/hospice care. There were occasional references to other services such as the benefits system and housing provision, some of which were seen as relevant data for the mainstream. Some participants were strongly critical of LTC, reflecting the legacy of suspicion which characterises some views of this sector amongst the wider public (see Goodman& Redfern,2006). In contrast, a number of people emphasised their experience and/or perception that there are many good people and good services in the mainstream.

A valuable distinction was noted, initially in responses to Questionnaire Item 6. This was that Buddhist names, given at ordination, are more likely to be understood and respected by staff in a Buddhist-based care service than in a comparable non-Buddhist service. A number of participants focused on the terms *"understood"* and *"respected"* in this context and separated out their respective meanings.

Legacy of suspicion in LTC situations

The CSCI/MORI research (2003) previously quoted indicated a strong preference for possible future care needs to be provided at home and to avoid residential care, reflecting suspicion of the latter. This was confirmed by the views of this study's participants, although, as discussed below, this was tempered regarding possible residential care-based TBRLs.

Item 8 sought opinions on mainstream LTC, with relevant material emerging in response to other items and in the interviews. Numerical scores indicated no notable variance according to whether people had care needs themselves, had experience of informal care or worked in the care sector (see Appendix H), although the number of

participants declaring care needs was low, at 7. The majority of comments related either to the system in general or to residential care in particular. Although other participants mentioned domiciliary/home care, all the detailed material on this came from QP48. She was highly critical of the service she was receiving, including the fact that:

> *The agency couldn't find me a carer for breakfast today.*

Besides the intermittent negative media coverage of domiciliary/home care, the main anxiety about LTC was of an institutional, uncaring residential facility.

QP23 (an Order Member in her eighties) commented:

> *One hears tales of people being cruelly treated in some homes.*

QP 101 echoes this and raises issues voiced by other participants:

> *Long-term care services by the state are threatened by funding issues, e.g. home closures etc. Health care in the UK varies dramatically…Private care such as retirement homes are very expensive. Many places treat elderly residents poorly.*

YP spoke with major disappointment about the *"warehousing"* which she felt her late uncle (who had Alzheimer's disease) had experienced, adding that in the care home where he had died:

> *There was no opportunity for individuality or independence to manifest.*

She gave the example of a photobook about his life which was taken in by his family as an aide to reminiscence work but never used by the staff.

MB described the first home in which her late mother, who had had vascular dementia, had been a resident, commenting:

> *People spent a lot of time in their rooms, and there was a lot of different staff. There wasn't much engagement with individual needs…it was a big complicated place, and there seemed to be a lack of care.*

TN recalled visiting an elderly friend, who had taught her modern languages at Cambridge University, in a care home. TN witnessed her receiving assistance:

> *The nurse said: 'Up you come my darling'…my husband commented on how humiliating it must be for her.*

AK gave the example of his partner's grandmother, who had died in a care home about ten years ago. While he felt the basic care was adequate he had noticed her deterioration after her admission:

> *She used to watch the news all the time and, you know, was very up on current affairs and things…but all they had on was soaps and rubbish really…she became quickly institutionalised…they weren't mistreating her, but they didn't…do anything to…engage her mind, keep her mind active.*

Reference to mistreatment (or in fact, its absence) prompts the observation that this study included no detailed accounts of any mistreatment, and caveats about services were mainly concerned with under-engagement with individual needs, and care

standards which were disappointing rather than scandalous. Nonetheless, taking AK's quotation above as an example it is not difficult to generate concerns specific to this study. If a familiar aspect of identity such as someone's interest in current affairs was overlooked and deterioration ensued, this does not bode well for another person whose Buddhist identity might need supporting in a comparable setting.

Care workers themselves tended to be exonerated from blame if provision was poor. Instead responsibility was at times attributed to the *"system/employers"* (QP8), the tendency for the care sector to be *"driven by money"* (QP7), plus *"staff turnover"* (QP38), and other factors. One Order Member (QP80) however commented:

> *Having worked in the NHS a lot of care staff seem to hate their work.*

Several participants (including QP35, QP42 and MB) saw the better end of care being associated with financial status:

> *...the quality of care that a person receives can be very variable, and can also depend on what they can pay. (QP31)*

Mention of financial provision for old age prompted QP44, a former TBRL worker and mature student nurse, to respond:

> *Massive discussion there, as if you have worked in the FWBO for many years as I did you have no means to do that.*

Overall, residential care emerged in a relatively negative light, with some detailed accounts of situations where engagement with individuality, awareness of dignity/respect and similar attributes appeared inadequate. Some of the situations were specific to LTC, and it was interesting to gauge whether specificity was as evident when participants discussed their perceptions of *"very good people/services"* in current operation.

'Very good people/services'

Item 10, referring to compassionate services, produced several emphatic responses which argued that, in the words of QP6:

> *There are some very good people/services out there.*

Participants were quite often at pains to dispel assumptions that Buddhists are necessarily characterised by a compassionate attitude:

> *I don't think we have the corner on compassion. (QP36)*

> *There are some very compassionate nurses out there and some very uncompassionate Buddhists. Compassion isn't a Buddhist prerogative. (QP44)*

There are some fantastic carers out there. We certainly do not have a monopoly on 'compassion', and as many of us fall short as do the rest of the community. (QP45)

As noted in the previous section, where services were poor, individual care workers tended not to be blamed, with fault attributed to *"the system"* and management. There were several cases of high praise for professionals/care workers e.g. CH's social worker, the speech and language, physiotherapy and occupations therapists who had treated YP's mother, the multiple sclerosis team supporting NR and a hospice nurse whom VP recalled caring for a dying Buddhist friend and whom he characterised as:

...an exceptionally sensitive, warm-hearted woman, who was quite exemplary.

Only one very positive and detailed LTC scenario emerged. MB described the second private residential home where her mother lived:

Mum now has physical comfort: she has a nice room, is well-fed, her needs are met and she's treated very well, personally and with physical affection by those around her.

MB linked this to her mother being able to afford private care, as did QP42, an Order Member and GP who referred to the expensive dementia care service where her mother is resident. MB also refers to the *"saintly qualities I have seen with some carers"*, with particular reference to the second home's ways of working with her mother's dementia.

Two aspects are highlighted here. Firstly, YP distinguished between the excellent input her mother received from the therapists mentioned above for specific health problems and the minimal help she received in the *"daily slog"* of informal day-to-day caring for her mother. Perhaps the daily slog, arguably characteristic of much LTC, is more problematic in terms of maintaining a high quality service with skilled, aware staff.

Secondly, experiences of Triratna/FWBO (and possibly other Buddhist groups) have informed participants' perspectives on compassion and other personal qualities inside and outside the Buddhist world. In a series of additional comments QP51 refers to disillusioning experiences in a TBRL retail setting, whilst more generally QP36 remarks:

I think we can be isolationist, and maybe even a bit arrogant sometimes i.e. not receptive to the kindness and strength in the wider world.

Thus responses about mainstream services in the context of a questionnaire on possible Buddhist-based care services elicited some critiques of existing non-care sector TBRLs and aspects ofTriratna/FWBO in general.

Respect for Buddhist identity

A worst case scenario regarding Buddhist identity might be outright disrespect for someone that is clearly based on an evaluation of his/her identity as a Buddhist. A possible example of this came in KL's narrative. Meeting with a panel considering her appeal against her Disability Living Allowance (DLA) being stopped, KL found that the doctor on the panel had an attitude that she found objectionable:

> *The way he referred to my being a minister of religion: it was more like contempt the way he said it.*

KL speculates on the basis for such contempt adding:

> *For all I know I was sitting opposite three devout Christians. I suppose they thought I was getting an income from my Buddhist activities.*

KL spoke elsewhere in her narrative of negative responses to her health problems from some professionals to her, especially her chronic fatigue syndrome (CFS), and concluded that:

> *I felt discriminated against in terms of my religion and my illness.*

The implications of this are explored further in Chapter Ten. A number of respondents reported, in KL's words, *"traumatic"* encounters with services (JV's initial social care assessment, NR's difficulties in obtaining housing benefit) but KL's was the only narrative which raised questions about discrimination.

SA spoke about times before he was admitted to the care home. He mentioned that his situation improved when a friend from his local Buddhist centre took on some home-help work for a time. He had welcomed the fact that she handled his Buddhist artefacts with respect, which had not been the case with one of her predecessors. In the care home he found that his vegetarianism was respected, as was his meditation practice (called *"praying"* by some staff) and his Buddhist name. He commented that his name was respected and used by staff even when talking amongst themselves although *"without [them] knowing what it means"*. Arguably the same was true for his diet; some staff did not understand his refusal to eat things that had been killed or his meditation, which, many Buddhists would argue, is substantially different to praying.

In response to questionnaire item 14, QP82 alludes to progressive developments in diversity as follows:

> *My sense is that the current system in care is much more sensitive around these issues.*

Similar comments were made by QP16, QP24, QP36 and QP87. The same item elicited some problematic narratives, including this from QP8:

> *When in hospital for only a few days with a broken ankle I found the volunteer chaplaincy visitor (Christian) very persistent in trying to 'save' me from 'going to hell'.*

Nonetheless, official policy about respect for minority groups often translated into some level of respect for Buddhist identity and practices. Perhaps, however, understanding is a separate matter. An example is provided by QP 23 in relation to use of her Buddhist name when she was in hospital. Staff tended not to use it, although she believes that this:

> *...doesn't mean that they don't respect it. But don't understand it. And prefer to use my given name.*

Understanding of Buddhist identity

The word 'understanding' occurs frequently in the data. The distinction in Item 6 about Buddhist names between 'respect' and 'understanding' has already been mentioned. This item had 85% of questionnaire respondents indicating strong agreement or agreement with the statement that such names would be better respected and understood in a Buddhist-based care service. However, no examples of disrespectful attitudes or behaviour were reported in the additional comments, whilst 'understanding' was emphasised by QP2, QP8, QP22, QP56,QP98 and QP103.

Understanding was also referenced in additional comments about other items. For example, Item 10 on compassionate services elicited the following responses:

> *Yes, to expect more compassion isn't really the issue. It's more people having an UNDERSTANDING of what's important to us as Buddhists. (QP37)*

> *It is not just a matter of compassion but of understanding the aims and ideals of a Buddhist life. Also, as Buddhists actively cultivate loving kindness as a practice, it is more likely that an atmosphere of warmth, understanding and kindness will prevail in such situations. (QP35)*

The material reviewed below for the sub-theme ***Lived Experience of Buddhist-to-Buddhist paid-for care*** indicates (at least implicitly) that care recipients value the understanding that a fellow Buddhist might bring to a situation: for example, CH mentions that her PAs *"support me in my meditation practice"*.

Of course, understanding may come from someone not necessarily labelling themselves Buddhist: SA was delighted when a young Polish care worker took an interest in the Buddhist art in his room, borrowed a book and came back with questions

about Amitabha, an archetypal Buddhist figure. Overall, however, understanding at a certain level seems to be associated with an explicitly Buddhist orientation linked to views about possible Buddhist-based care services as reviewed below.

Further findings about Buddhist-based care services and the application of TBRL principles in this field follow in the next section.

TBRL principles applied to LTC situations

Background to this theme

As noted above, after the interview phase of the research it was decided in 2006 to focus the questionnaire on views about **Buddhist-based care services** (BBCS), and in retrospect this can be seen as part of a process of giving the study a clearer direction. Subsequently in 2007 the study was refocused on Buddhist identity as noted above, and the BBCS-related material needed to be viewed in a somewhat different light. The development of BBCS was potentially relevant to questions of Buddhist identity, as it was arguable that values and practices might be shared by clients and staff alike and that staff who were Buddhist or sympathetic to Buddhism might thus be better able to support clients in their ongoing spiritual life.

There was also the possibility that Buddhist aspirations to calm, mindful and compassionate states of being might be evident in some measure in a care-based TBRL, with staff and clients working together in a relatively harmonious manner. Indeed, although the study's title is primarily focused on clients receiving care, it could be said that Buddhist *staff* might have their spiritual identity supported in a care-based TBRL more than they would in many comparable workplaces or types of occupation-see the section below on **Altruistic livelihoods**. Two reference points in this respect are people's lived experience of Buddhist to Buddhist paid-for care, and existing non-care sector TBRLs. Some material relating to the latter is included in the section on perceived feasibility and pitfalls.

Whilst organisational aspects of TBRLs, as discussed in the perceived feasibility section, might appear less immediately related to identity issues, it is arguable that they are relevant. Care-based TBRLs are certainly cited as one strategy for supporting Buddhist identity in LTC, but anyone exploring this area surely has a duty to seek evidence that Buddhist-based care services are feasible. Equally some thought needs to

be given to the model(s) of care which might be provided and the overall structure; e.g. whether such services might emerge as a fully realised Triratna/FWBO TBRL or have a broader Buddhist foundation. The study participants include people with a range of experience in the care sector and of TBRL/Buddhist work projects of various kinds, so their ideas seemed likely to be of interest.

Mutuality and the Sangha Jewel

As noted above, shared values of various kinds are regularly cited in the LTC literature. Whilst Triratna/FWBO teachings often emphasise the development of the individual, this does not signify an atomised, self-obsessed individualist and it is commonly said that we need the support and encouragement of other Buddhists if we are to make progress. Hence along with the Buddha and his teaching, the Dharma, there is the third Jewel of Buddhism: the Sangha, or community of fellow Buddhists.

Material cited above has already referred implicitly to what Kellaher (2000) calls 'mutuality' in her study of residential care. This is described as a mix of friendliness, respect and support, and in Kellaher's research is linked to the Christian faith. An example from the present study is TN's response to a question about advantages which might be associated with a Buddhist-based care service:

> *Lots. Shared ideals would be a central advantage.*

In response to the questionnaire item on creative activity, QP6 says of a prospective TBRL:

> *It could provide more spiritual activity.*

On the same Item, QP 14 comments:

> *But I'd personally prefer to give them a try as their ideal of fulfilment and creative activity are more likely to coincide with mine.*

More broadly, there was some expectation that a TBRL would offer more in some respects:

> *I think although the NHS is quite good on the whole it doesn't look after people's spiritual needs, does it?(QP67)*

As mentioned above, the needs being met may not only be those of the clients. Here is an example from a mental health nurse who is a Mitra:

> *As someone who works in care services I have often longed to be able to work alongside other Buddhists in this way: partly because the attitudes/perspectives of many of my colleagues are often at odds with my spiritual values, and also because it would provide a way of developing spiritual friendships and deepening work as practice. (QP47)*

The above is an additional comment to Item 15, which suggests that a Buddhist-based care service could offer new opportunities for Buddhists to work together to make their work more of a spiritual practice. It is notable that all but 3 of the 107 participants either agreed or strongly agreed with this.

A notable theme in the study was concern for Order Members living within a Three Cs (TBRLs, communities and centres) structure and now entering later life:

> *Clearly it would be good if someone who has spent their life in a Right Livelihood, working hard for the Dharma, could be supported in their old age (QP 90)*

> *...there are those who entered the movement in the early days, and threw .themselves in wholeheartedly, those people now have little or no provision for. their old age and are owed a debt by the movement. (QP 8)*

Comparable opinions came from eight participants in response to Item 20. Practical suggestions included the redistribution of wealth within the movement (QP104) and a care fund like an insurance (QP101). QP 38 and QP61 specifically referred to care homes as possible resources, and such provision appeared to be part of some participants' vision about how the movement's elders could be suitably supported if they needed the relevant level of care. QP90 raised the problem of trying to assess what he called someone's *"care value"* based on her/his contribution to the movement ; he saw this as undesirable and advocated people making their own arrangements. San Francisco Zen Center were reported to have a standard package for older priests who had worked there for 20 years and were over retirement age, so that they were guaranteed free board and lodgings. To avoid favouritism this was non-discretionary.

Altruistic livelihoods

As mentioned above, the livelihoods of Buddhists are often considered in terms of their altruistic dimensions. Triratna/FWBO full-timers might be found, for example, cooking at a retreat centre or leading classes and management work at an urban Buddhist centre, or working in a Buddhist-based team in a retail or catering outlet. This can be seen as altruistic in that one way or another such work is helping to spread the

Dharma or supports this. Around the Triratna/FWBO in general, however, a large and increasing number of people are not involved in any such full-time Dharma work, and, if working, are earning their living in the wider world. A proportion of people involved in most centres work in health or social care in some capacity, and participants in this study included two nurses, three social workers and three doctors as well as people with experience as project/support workers in learning disability, mental health and elderly care.

As noted in the previous section, there was a strong consensus in response to Item 15 supporting care-based, with QP53's comment typical:

It's an obvious 'right livelihood'.
QP37's response included the following:

We need more team-based businesses so this would be a new area of something that could be of real value to society.
Whilst unqualified jobs in care work may be fairly easy to obtain, CH, who has employed a number of people as PAs. comments:

I think it's quite an advanced practice being a carer.
Although an opportunity was missed here to ask CH for more details on this, she indicates the potential Buddhist practice involved in such work. Taking some possible examples, features of this might include an expanding awareness of the needs of others, further development of *kshanti* (patience/forbearance), and so on.

Another participant suggests:

Buddhists would be more 'engaged' than most who work in care which is generally seen as low status, low paid. (QP7)
The vocational aspects of care work are thus touched upon, as are elements of personal change, in the following comment from QP36:

If there were such services, I think it would strongly affect those working together.
This takes us back to QP47, the mental health nurse quoted in the previous section who feels that trying to meet the needs of others in a Buddhist-based context might also meet many of her own needs (spiritual, personal and professional). Such altruism and idealism offers a positive foundation for good general care and for the support of Buddhist identity in care situations. It is very difficult to fully evaluate such idealism in terms of everyday reality, but the next section offers some concrete examples of Buddhists employing Buddhists for personal support/care to shed further light on the possibilities.

Lived Experience of Buddhist-to-Buddhist paid-for care

Findings about Buddhist-to-Buddhist paid-for care were of major interest to this study. Firstly, there was evidence of more care of this type than anticipated. Secondly, anyone interested in questions about Buddhist-based care services might well look to these as prototypes for what might emerge on a larger scale. Evidence came primarily from three interviewees. First, TN:

> *For years I have had a lovely Buddhist carer...I see her once a week and I pay her out of my own money. When I have needed more personal care she has slept in, in my spare bedroom.*

The carer is 32 years of age and is also a yoga teacher who TN has got to know through the local Buddhist centre, and TN appears pleased that as well as having her input for general support and domestic tasks *("she's...a good cleaner")* they share other activities; *"We meditate and do yoga together."*

CH was also very positive about the two PAs she employs through her Direct Payments scheme to support her with her spinal disability. Above she is quoted as saying:

> *They support me in my meditation practice...I've always employed Buddhists, and I've always employed friends really.*

She acknowledges that a larger organisation might be seen as being discriminatory about equal opportunities in this respect, but her understanding is that;

> *As an individual employer I can do what I like.*

She highlights some (apparently minor) disadvantages to her set-up, but has concerns about employing people she doesn't know at all:

> *Like my nephew has got care needs, and one of his carers nicked his PIN number and went and took money out of his bank account...and you can get people who come in and just talk at you all day long...so I think on balance I've always chosen to stick with Buddhists.*

CH finds that the only disadvantage of employing Buddhists is drawing boundaries. Some of her PAs have been Mitras and can try to draw upon her experience as an Order Member at inappropriate times:

> *They want to tell you about themselves and you have to say 'I'm sorry, can you just get me my breakfast?'*

However, she does not see this as an issue unique to Buddhists *"It's to do with having people in your home"*. CH feels able to set *"very, very clear boundaries"* and concludes: *"But that's really completely my responsibility"*

CH also refers to a drawback for the PAs themselves:

> *[it's] not a very fulfilling rewarding job long-term…so usually people work for me for one or two years and then they move on.*

JV mentions the care input she receives from a fellow community member whom she has known for 30 years. She makes no specific evaluation of this support but is explicit that she would find other arrangements problematic. As noted above, at the time of interview JV was looking for someone to take over the care input from her friend and hoping to find someone who is:

> *… not too alien from what I hold dear...I would find it very hard to have to employ non-Buddhists.*

Two general points might be made. CH talks about having to replace her PAs regularly and JV is having to find a new person for part-time support. It would be of value to find out more about turnover and how PAs/carers perceive their work. For example, does one-to-one work have particular drawbacks about social contact which working with even a slightly larger number of clients might ameliorate? It is also notable that TN has the longest-standing arrangement with a carer, and as a part-time yoga teacher the carer might share her profile with many others who might work in Buddhist-based care services in the future. In my experience, practitioner-type work in complementary and alternative medicine, physical therapies and similar fields attracts many people, including many who are around Buddhist centres but cannot always provide a consistent income. Care work may be less attractive to many but paid work is often available.

Perceived feasibility and pitfalls

Some questionnaire respondents offered comments which explicitly or implicitly warned against unduly high expectations about what Buddhists can achieve in the complex field of LTC. As noted above, QP 51 referred several times to disillusioning experiences in a TBRL shop, and commented:

> *Typically Buddhists come together and think they can conjure skills sets out of thin air. That just because they want to do something they think they can – NOT because they have the training, skills or experience. This is called naiveté.*

Other participants were concerned that the spiritual emphasis of a Buddhist-based care service might overshadow its core purpose, as in QP31's response to Item 15 on care-based TBRLs:

> *...with the proviso that their primary focus was the cared-for person.*

Some participants placed strong emphasis on the need for *"the right level of professional competence"* (MB). The central importance of appropriate training was mentioned by 6 questionnaire participants in response to Item 12 on organisational and professional skills, and by QP16, QP70 and QP97 regarding Item 9 on personal/intimate care.

QP61 gave a specific example of what he considered to be an inappropriate application of the Buddhist practice of mindfulness in the workplace and (as far as I am aware) in a TBRL situation:

> *...wrong emphasis on aspects of mindfulness can be a problem. I've seen 'mindful' workers do tasks far too slowly or with awareness on one aspect being overemphasised and not taking into account other aspects of the environment.*

Since TBRLs aim both to create a Buddhist context for work and to complete tasks efficiently there can be a trade off about employment of people committed (or at least sympathetic) to the organisation's spiritual ethos compared to others who are less committed but more capable as workers. QP45 indicated the way a major TBRL has proceeded with such dilemmas, suggesting that like the Windhorse:Evolution gift business any future BBCS should prioritise:

> *... Recruiting the best of carers out there and running the care service as a business.*

There were some questions about whether the UK population of Buddhists would be sufficient to justify such projects (QP53 and QP57), and people commenting:

> *...I couldn't see you getting funding. (QP52)*

or

> *I haven't seen evidence of a strong impetus to do this. (QP29)*

However, the majority of comments proceeded on the assumption that care-based TBRLs would be possible in due course, with, for example, QP25 advising:

> *Keep it simple – start small and build.*

Several participants expressed confidence that, in QP70's words:

> *I think there would be enough expertise around.*

QP 59 also saw such projects as feasible:

> *...I think set up costs could be recouped in a relatively short time. The key factor is demand, which I think would be significant.*

As with predictions about the possible quality of care, ideas about feasibility remain relatively speculative and much rests on what might be hoped. This was noted as a general tendency in the questionnaire additional comments, with, for example, responses from ten participants to the item on compassionate services featuring the words *"hope"* or *"hopefully"*.

Thus there is evidence of a body of opinion that hopes for Buddhist-based services in LTC and argues for their feasibility, suggesting that they will have a part to play in supporting Buddhist identity in LTC contexts.

CHAPTER TEN: DISCUSSION

Preliminary comments

The task for this chapter is to relate the above findings to the literature and background material. Some general observation may first be helpful. We can note that some of the 17 interviewees gave what amounted to an abbreviated life story, with for example JV offering an account of her 30 plus years of devotion to the movement and interlacing this with some background as to her close relationships, her disability, her current living situation and aspects of the future. In contrast, the 107 questionnaire participants were typically less 'known', and their experience of LTC issues and relevant involvement in Triratna/FWBO can only be estimated from whatever background information they disclosed on the questionnaire form and any additional comments they wrote. At one extreme someone might complete a questionnaire with no additional comments, no apparent experience of LTC issues and only very limited other information, raising questions as to how valid their contribution really was.

Having registered this caveat we need not let it detract unduly. It is reasonable to be concerned about taciturn questionnaire participants . But we can note that they are a decided minority with only 18 out of 107 people making no comments. Equally the people who elect to be silent can be seen as having a proportionately minor influence on any outcomes or conclusions gleaned from the study. In contrast we can again take the example JV's full and compelling account of her situation (see above), noting that it is cited on five occasions in Chapter Nine-Findings and thus has a suitably high profile throughout this research.

Conducting an interview certainly created opportunities for people's narratives to take such a profile, though one of the section headings below in this chapter is derived from a questionnaire participant, and their additional comments are quoted liberally here and at all stages of Part Four of the study. Often I found questionnaire participants writing from specific experience (e.g. QP39 *"Carer for my mother and organised her care")* , then offering clear and pithy opinions of current provision, and moving on to the future prospect of Buddhist-based care services (BBCSs) with *"hopes"* which blended visionary possibilities with the challenging realities of any such project. I feel that I

could not have asked for a better general response, and the additional comments were readily integrated with the interview material and jointly analysed using NVivo-7.

The richness of this verbal data could bring with it the danger that the numerical data was undervalued. Silverman (2004,p.343) notes qualitative researchers' concern to champion the "actor's perspective" (usually expressed verbally) as against anything associated with "benighted number-crunchers" and their concern for "mere 'facts'". But the quantitative data certainly made its own contribution to the study- see Appendix H. Item 15 showed resounding support for the idea of care work as a form of spiritual practice, and the relevant numbers (59 strongly agreeing, 45 agreeing and just 3 dissenting voices) illustrate this well. Turning to the number of additional comments we can note item 15 ranking 19th of 20, with an apparent trend on some items for participants to feel that choosing a category of response adequately encompassed their relevant attitude(s) and that few if any words needed to be added.

As outlined in the previous chapter (see page 135 above), and Appendix H there was the 'opposite halves' phenomenon, in relation to which we can note the high consensus on seven questionnaire items being linked to relatively low level of verbal data (in terms of additional comments).

If the high quality of the additional comments sometimes drew attention away from the numerical results, I can readily remind myself that the high concensus responses contributed much to my general report. Along with item 15 and TBRLs, there was also evidence of strongly-held attitudes on support for meditation/reflection, vegetarian diets, mindfulness at work, contact with the like-minded, issues of isolated and neglected Buddhists, and respect/understanding of Buddhist names. The mean scores across these topics demonstrated a recognition of key elements of Buddhist identity, awareness of gaps in informal care, concerns about mainstream provision and perceptions as to the advantages of Buddhist-based services in LTC.

In contrast, items revealing diversity of opinion as regards mean scores were sometimes fruitful as to the quantity of additional comments. Broadly, 'straightforward' questionnaire items seemed often to produce a high consensus and few comments, 'straightforwardness' being defined operationally with reference to 3 items. The highest number of comments concerned *"bossy and difficult"* people and their effect in BBCS, with people feeling moved to comment on a range of aspects and arguably some of the response activated by the emotive topic of interpersonal conflict. The issue as to whether there is *"LTC…provided for everyone"* mainly sparked denials that this was

the case, and a wealth of input on aspects which people saw as relevant. Item 9 explored the area whereby the advantages of having a spiritual friend giving *"personal/intimate care"* might be counterbalanced by other factors (such as dignity issues). This produced a full range of responses. This and the other examples seem less 'straightforward' than, for instance asking if BBCS provision would be relatively *"better"* on vegetarian/vegan diets.

The interview schedules had a grounding in previous research, drawing some of their content from the Kellaher (2000) and the CSCI/MORI (2003) studies. The resulting data in turn was often utilised to shape the questionnaire items (see pages 113 et seq. above) but the links to more established research instruments were somewhat attenuated by this stage and could be seen as one reason for a minority of poor quality items such as those featuring 'double-barrelled' statements (Czaja& Blair,2005).

It has been noted above that the study's methodology was eclectic, and the same description could be applied to the theoretical background informing the work. Giving just a few examples, I applied personalisation from social care practice and research, generativity from lifespan and developmental psychology, life goods from a philosopher, and personhood from dementia studies. I hope that utilising these terms helped towards a wide perspective on LTC, and one which was suitably adapted to the 'special case' of Triratna/FWBO life-styles. With a view to further research I would express an intention to remain receptive to the concepts and practices associated with these terms, and to update and refine my understanding of them when drawing upon them in future work.

I will come back to some related issues at the end of this chapter, utilising Wallace's concept of *Ecological Validity* to give further evaluation. The next section will outline how the four research questions will be addressed in the remainder of the chapter.

The research questions and structure for their discussion

The sections below take their main headings from quotations from four participants. Each addresses a research question, and as issues of Buddhist identity and personhood could be seen as the most complex area of the study these are considered last. Thus the first main section gives a focus for a discussion of informal care, and thus of research question two. It is drawn from an 83 year old participant, QP23, whose prospects for

ageing in place at her retreat centre community are explored with reference to the 'Three Cs' life-style and issues of care burden. Examples are drawn from other participants for this and the next sub-section, in which informal Sangha care outside the 'Three Cs' is considered and levels of **Busyness** may be especially salient. A third sub-section examines the above with reference to aspects of Tritatna/FWBO culture and traditions. Overall this informal care section covers a range of aspects of Triratna/FWBO lifestyles, and hence has relatively more space devoted to it.

The second main section takes its title from data given by NR. Having just speculated about a mainstream care environment which could be non-conducive to Buddhist practice, he acknowledged that some non-Buddhist care services might be better than this. An opportunity thus arises to consider aspects of mainstream care in relation to data on both general quality of care and specific support of Buddhist practice and identity. So this section addresses research question three.

In the next section, CH is quoted in relation to her high satisfaction with the care arrangements she has, with Personal Assistants (PAs) who are recruited through the local Sangha. She proposes her set-up as a template for the further development of BBCSs, and this section focuses on research question four.

Comments from SA about his care home provide the title for the final section. His assertion that "*I get a lot of recognition here*" raises issues as to being 'seen' in LTC, as a person and, in SA's case as a Buddhist. This section explores the first research question in relation to identity and personhood.

A **Dreams and Nightmares** perspective is a recurring theme, whereby actual experience or anticipatory visions invoke what in Taylor's (1989,p.63) terms are "strong evaluations" such as what one person *"dreads"* about LTC and what another has found to appreciate. Interacting with this is a Buddhist/Non-Buddhist dimension, whereby basic quality of care might be hoped for without any reference to someone's spiritual identity, whilst in some specific instances Buddhist identity may be highly relevant.

"But if I needed a lot of care long term that would be very difficult for them"-(Research question two).

Informal care and burden in a 'Three Cs' context

   As noted above, the quotation which gives this section its overall title came from an 83 year old Order Member, QP23. Immediately prior to the quoted phrase she avers that *"People are very good in my community",* followed by the *"But…"* as to a future scenario. Two aspects are as to the level of care need, this being *"a lot"*, and the duration, visualised as *"long term"*. This readily links to some of the literature reviewed above, especially Pickard (2008) and her emphasis on whether the level of care need is intense, over 20 hours a week according to Hirsch (2006) and of extended duration (thus measured in years rather than weeks/ months of input).

   Firstly we can note some features of QP23's situation. Her Buddhist identity might seem relatively unassailable, as she lives with fellow practitioners at a Buddhist retreat centre of which she is a founder member, is called by her Buddhist name at all times around the retreat centre, has ready access to a vegetarian diet and so on. Also, she has described her co-residents as *"very good"* in relation to helpfulness, and is referred to in other people's narratives as an exemplar of generosity, as with putting her pension into the communal kitty in the retreat centre's early days. Her home was founded in 1985 as the first women's retreat centre in the movement (Bluck,2006), and she is probably known to every woman Order Member in the UK, and to many Triratna/FWBO people, female and male, in this country and beyond. We can re-iterate that 'home' and familiar aspects of the environment (including other people) appear to be of particular importance for older people see Peace et al (2006), Frank (2005) and Carstensen's (2000) work as reviewed by Mather (2006). Such importance may include emotional, cognitive, conative/action-related and spiritual aspects, which the term ***Identity*** may encompass if we accept Atchley's (2009,p.50) view of identity as a "metaconception of self".

   'Ageing in place', as discussed by Peace et al (2006) appears a good option for QP23 as for many older people. And yet QP23's own comments indicate a measure of doubt as to its long-range viability.QP23's data does not include detailed information on the particular retreat centre community, and to get a fuller picture it seems necessary to look more broadly at features of the 'Three Cs' lifestyle.

On the one hand, the Triratna/FWBO movement in general has grown steadily since the 1970s. Over the same period, the ethos of living, working and practising together did *not* enlarge in a commensurate way. Lokabandhu (2009) indicates that far fewer newly ordained people have extended experience of this way of life than Order Members of an earlier generation, which would include QP23 and interviewee JV (a former member of the women's ordination team). The "highly idealistic" (Nagabodhi 2004,p.3) orientation of those who saw the 'Three Cs' as the "nucleus of a New Society" (Sangharakshita 1996,p.44) has been associated with a large measure of commitment to Buddhist practice. JV's narrative might bring to mind Batchelor (1994,p.333) contrasting a "spiritual pastime" attitude to Buddhism with a "fully committed engagement with the Dharma". In JV's case it has equated with a semi-monastic lifestyle (Nagabodhi 2004,p.3), living and working mainly with other Buddhist women. Having decided that her increasing disability precluded continuing at a retreat centre (which, comparably to QP23, she helped to establish), she was able to negotiate the move to her new place in an urban area.

Historically, Triratna/FWBO set-ups of all kinds run on a modest budget (Bloyce, 2010), and this is reflected in the size of the resident community which a retreat centre can support. Returning to QP23's situation of being a retired founder member where she lives, this is presently unique in a number of ways. She, along with Sangharakshita, is one of the very few Order Members who are already over eighty. As in some comparable schools of practice , there is certainly a Triratna/FWBO tradition of celebrating the work done by the movement's pioneers (Kulananda,2000). Thus alongside QP23's personal qualities and friendships at her community she might be seen as a 'living link' with the retreat centre's foundation and early development. From the information available, it seems that a possible future increase in care needs is the main (and perhaps the only) real threat to her ageing in place there.

A number of factors seem relevant in a 'Three Cs' context when decisions are being made in relation to someone with LTC needs, including someone's perceived contribution to a spiritual situation. Additionally the data suggests that other aspects will parallel those relevant in the general population, including the level of care need, the availability of informal and statutory care, any personal resources (including finance) to which the person might have access, and so on (McDonald,2010).

All Triratna/FWBO urban Centres and retreat centres are set up as separate charities (Vajragupta,2010). Thus decisions as to whether people can remain at retreat centres are

made on a local case by case basis. It seems likely that others will find themselves in a similar position to JV but, in view of a lack of other options will have a strong preference to stay where they are. San Francisco Zen Center's arrangements for retired priests are mentioned above. However, cultural/contextual differences include Zen Center being more long-standing and high profile (Downing 2001) than any Triratna/FWBO set-up, and thus probably more affluent, and statutory provision for those on low incomes in the USA being more limited than is presently the case in the UK (Alesina& Glaeser,p.2004).

Perceptions of burden emerged as a key issue. The review above showed the term to be well-established in the literature, and often associated with family relationships and a sense of obligation, as with the title of Pitkeathley's (1989) book *It's my duty, isn't it?*. There is doubtless a risk of informal care being too readily associated with negative experiences, and Fear and Boddy (2009) note evidence where the care process is seen as having enriched relationships. However, their examples are consistently within a family context, and Triratna/FWBO's residential communities provide a different test case. As noted above, some participants did make a direct comparison here. Kinship ties were seen as more likely to prompt personal care than was spiritual friendship, echoing Lowenstein's (2005) finding in the general population that the proportion of informal care by anyone other than family members was minimal. QP11's comments from her own experience highlight two salient aspects of 'Three Cs situations'. Thus the conflict she reports between the needs of spiritual friends and those of ageing parents is somewhat reminiscent of 'sandwich generation' dilemmas where filial and *parental* responsibilities become difficult to reconcile (see Grundy& Henrettap.2006). Gender factors were relevant here, with approximately half of female questionnaire participants reporting informal care experience, as against less than 10% of men, and this reflecting in some measure differentials in the general population (Pickard,2008). Her second point, of finding that when ill (apparently longer-term) in a residential community *"friendships...cracked under the strain"* links readily to narratives from other participants. Thus in the past CH had experienced co-residents *"really helping me and then getting resentful"*, and QP12 saw paid support as giving protection to on-going friendship . Overall, burden issues emerged as mainly linked to co-residence.

JV's example of the *"intense discussion"* which took place before she moved into her current community could be seen as an issue of people managing expectations. The past involvement of one of the co-residents in informal palliative care gives an example of

friendship being strongly expressed in practical assistance (see also Nagabodhi,1998) and someone's Buddhist identity being supported through to death (see Watson et al, 2009). At the same time, JV voiced her impression of this being *"a huge strain"* for the community involved, and thus relevant background to her current co-residents' initial caution as to agreeing to her moving in. Some might be disappointed that the Buddhist aspiration to assist all beings (Geshe Gelsang Gyatso,1995) is often tempered by pragmatic considerations. It does seem arguable that JV's prospective community had the challenge of not falling into a weak-minded 'niceness' (Robinson 2000) whereby more help is promised or implied than can really be sustained. Thus they ruled out regular informal care input. Admittedly JV was asking to move in as a new community member, but we can compare QP23's doubts as to care availability, and recall her very strong credentials as an established member of her retreat centre community and the Triratna Order and movement in general.

We might speculate how such doubts would compare with expectations of informal care on the part of the growing proportion of Order Members who live with their partners/spouses, with a hypothesis that levels of informal care from live-in partners (now or in the future) would be comparable to those available in the wider population. Such research remains to be done, and the present study could only claim some preliminary findings as to 'Three Cs' settings. However, it was notable that although this study involved over 9% of the UK Order, no evidence was found of a single case in which long duration, high intensity Buddhist-to-Buddhist *informal* **c**are had been available. JV's interest in living communally in a sheltered housing context is notable. Although there is some evidence that such services are becoming more available to people outside the usual 'single people and couples' population (ERoSH 2010) it remains unclear how many Triratna/FWBO people will take on this way of living.

Overall, it seems that 'support' for one another can cover a continuum of activities and forms of contact. QP35, experienced as an Order Member and as a care worker, encapsulates the situation well and her conclusions are re-iterated as follows;

> *The resources are often there for continuing friendship, but not for such things as intimate personal care- washing dressing and feeding (sometimes cooking)*

Her general point appears accurate in the light of this study's data, with only the additional need to emphasise the dimension of time. The data does in fact include accounts of 'unpaid' intimate personal care emerging in a context of spiritual friendship,

such as Padmasuri during an acute problem with her back. However, evidence from this study would support the view of another participant, QP37, that such help is usually *"a short term thing"*, and that with some older people there is a need for *"ongoing care and this is much harder to be available for"*.

In summary, evidence from the study indicated relatively limited availability of informal LTC in 'Three Cs' situations, and refuted ideas that such support was likely to be readily available and non-problematic. This seemed especially so for urban communities, which in any case were described as *"on the wane"* by JV and others. The same interviewee's narrative gave an example of how rural retreat centres can have difficulty in accommodating people with care needs, whilst even the well-loved and well-placed QP23 saw her ongoing 'ageing in place' as subject to change if her care needs increased in intensity and duration. Such factors were generally discussed in a dispassionate manner, with no perceptions of unkindness or dereliction of duty voiced or implied.

Informal care and the wider Sangha: 'Busyness' and other factors.

Amongst Sangha members who were not co-resident, **Busyness** appeared a particularly influential phenomenon. For example an 'Anticipating Care' group interviewee, YP could be seen as exemplifying the trend highlighted by Lokabandhu (2009). She comments that *"I have never chosen to live in a Buddhist community"*. YP is a notably eligible participant for the present study, with her background as a social worker, then being her mother's full-time carer for 6 years, and her taking a leading part in efforts to establish Buddhist-based TBRLs (in the field of learning disability).

The 'semi-monastic' element of the Order and movement has not been prominent for YP but a 'highly idealistic' orientation does show through, with her data indicating spiritual and altruistic principles being applied in everyday situations.

Of all the participants it was YP who was the most explicit about her intentions *not* to join what Griffin (2010) has termed the 'Cult of Busyness' in contemporary life. She indicated that she was presently able not to have to seek paid work, and spoke of being more *"financially spacious"* than most people. There was another example in YP's Sangha **(**classified here as an **outpost**) where absence of paid work was a likely factor in the availability of informal support, with this involving DS's very regular visitor during his prolonged hospitalisation. A second aspect might be the person's orientation to support and care-related activities. YP spoke of having to learn a lot in order to be her

mother's carer, and sometimes being able to pass this on to others. Helping with her friend's daughter and her two late uncles were other spheres of informal support.

It is arguable that YP is an exceptional person, both in her refusal to be *"busy"* and the level of her commitment to informal support of others. Participants commonly saw the latter (informal support) compromised by the former and, as NR commented, the problem often being *"A Case of Busyness"* rather than *"A Case of Dysentery.*(Sangharakshita 1991). Turning to other narratives, we can note the contrasting experiences of QP31 and QP32, with both women living near the same large urban Centre. It was QP32 who benefited from the leftover food from the TBRL vegetarian restaurant and who found herself well-supported by people (who were not co-resident) in the local Buddhist village over a period of illness which often confined her to bed and which lasted for over a year. QP31 reported a different experience following breaking her leg, with reflection on the significance of being *"well-connected with personal friends",* as it had turned out that *"being in the Sangha per se wasn't enough".*

This, with other additional comments would have been well worth further exploration in an interview. It seems evident that the Findings' NVivo categories of 'Cohesiveness of local Sanghas' and 'Interpersonal Factors' are relevant here. Presumably people can find themselves insufficiently *"well-connected"* for a number of reasons. Located at an individual level this might be seen in terms of varying levels of popularity, or it could be viewed as a matter of Sanghas which are more or less successful at fostering spiritual friendship and its expression in terms of practical help. When interpersonal factors in a care context include outright dislike it becomes an awkward area for professionals to explore, with Stockwell's classic nursing study *The Unpopular Patient* (1972) a rare example. Doubtless such feelings are comparably difficult for many Buddhists with their aspirations to emotional positivity, though it was notable that questionnaire item 4 on interpersonal issues attracted the most additional comments. The consensus was that there were fewer such people in the Buddhist world as against wider society, and there was also reference to meditation practices intended to help the overcoming of aversion (Paramananda,1996).

Some foundation of friendliness and co-operation seems essential in 'Three Cs' situations where people find themselves in close proximity, though outside this, especially at large Centres there may much scope to avoid those we find 'unattractive", with some unfortunate people left with few contacts. Thus, the senior priest in San

Francisco was in no doubt that a *"difficult, stubborn"* Zen practitioner would receive less support than a currently ill man who was someone *"the community loves"*. Whilst the questionnaire item coupled 'difficulty' with a more specific trait of 'bossiness', the examples above of Peter and Joan (pseudonyms) had other features which might reduce Sangha contact and informal support. In this and other respects more research would be welcome, though it seems safe to conclude that participants saw **Interpersonal factors** as a relevant variable in informal input from Sanghas.

A comparable verdict might be made on the 'Cohesiveness of Sangha' theme, with its influence evident at times but more data clearly needed. The three-way typology of Sanghas as **Buddhist village, medium-sized** and **outpost** had some utility, whilst theoretically underdeveloped. Buddhism in Britain has enlarged in the years between Oliver (1979) and Bluck's (2006) research but may still be too small as yet for scholars to do detailed work on specific movements at particular localities. Also whilst acknowledging the limited evidence available from the study, we can recall the Buddhist teaching of the Samgravastus (Thurman,1978) and the way in which the Sangha is said to be likely to be more unified when four spheres of activity are prominent. These are generosity, kindly speech, beneficial activity and exemplification.

Exemplification might be expected most from the more committed/experienced people in the Sangha, who would often be Order Members. This can take us back to YP, whose emphases on not over-filling her time and assisting others might well have a positive influence in her Sangha. Although busyness is not irrelevant in a 'Three Cs' setting, with JV commenting on people in her former and current communities having respectively *"very busy"* and *"full"* lives, it seems most salient in relation to Buddhists who are not co-resident. Interacting with this factor may be aspects such as proximity, so that QP32's receipt of spare food and many visits may have been partly linked to being nearby enough to have abundant contact with Buddhist friends, some of whom doubtless had *"full"* schedules. QP 31 was probably right to emphasise the importance of being *"well-connected with personal friends"* in explaining the limited help she received in the same Sangha. More background information would have been welcome in this case, whilst QP48 gave a fuller account of why *"I find the Sangha very strong"*. Disabled with Multiple Sclerosis and living alone, she has a domiciliary care service supporting her (of which she is highly critical) whilst being well-connected to a large local Buddhist Centre. She reports that a team of people from the Centre are involved in preparing meals for her to freeze, with features such as organic vegetables. Perhaps

unsurprisingly there is no sign of anyone in the Sangha being willing or able to take on full-time care of QP48. Equally there is no evidence of QP48 'expecting' or even wishing for anything of the kind. It does appear that on-going spiritual friendship, and the practical help exemplified by the meal preparation fulfil QP48's expectations of the Sangha, to the point where she finds it *"very strong" i*n its support.

In summary, informal support from the non co-resident Sangha appeared to be modulated by by a number of factors as outlined above. As in the 'Three Cs' context, it appeared that 'good will' and relatively extensive networks of people were available to many involved with Triratna/FWBO. Also comparable to 'Three Cs' situations the study's data confirmed the limitations on intensity and duration of informal LTC. Whilst more research would be welcome here, the available evidence suggested that the level of informal support from the wider Sangha would be less than might be expected from a willing and able live-in partner or other family member. Noting that an increasing number of Order Members are now living in family-type situations, we must also acknowledge that many are not, including a number who pioneered the movement's key projects. This raises questions as to the development of traditions in how elders might be supported (discussed in the next sub-section), and as to the utilisation of mainstream services. The latter might be predicted to emerge as higher than for the wider population in coming decades, and is discussed below in the relevant sections from page 184 onwards.

Triratna/FWBO traditions and care: past, present and future

The Triratna/FWBO movement has a limited tradition of informal care. This has certainly been true in relation to LTC and issues arising in later life, and the evident demographic reasons for this have been commented upon several times.

However, if we go back to the core emphasis placed on spiritual friendship we can understand why in the early 1980s Sangharakshita (1991) chose to talk to his mainly youthful audience about the plight of a sick monk ignored by his supposed brethren. 'Care' and 'support' are relatively broad term, and in the *Case of Dysentery* talk (and subsequent book chapter) Sangharakshita focuses on the need for the Buddhist community to 'support its own'. The encouragement and assistance of others are clearly areas in which altruism can manifest, so such activities become spiritual practices in themselves. Also, he argues that if Triratna/FWBO people fail to offer support to one

another some will seek emotional sustenance elsewhere and may eventually abandon the spiritual life altogether.

We might speculate that the unfortunate monk in *A Case of Dysentery* might have received better care if he had lived in later eras of settled monasticism (Ray,1996). As the years went on the *bhikkhus* ('monks') became accustomed to receiving support in various forms from the laity. It seems from Kariyakarawana's (2010) input that frail older monks in contemporary Sri Lanka are relatively well cared-for. This may reflect Buddhism's established status in Sri Lankan society, and a centuries-long tradition giving monks many precedents for meeting care needs as they arise, for example, in the Preceptors who taught and ordained them. In a Triratna/FWBO context it might be seen predominantly as an expression of spiritual friendship, with caution as to judgements such as *"Shame on them"* (see page 149) but concern as to what support might be possible.

It seems unsurprising that LTC is only becoming an area of wider interest in Triratna/FWBO as a growing number of people involved start to enter later life. This demographic trend in turn seems likely to make informal support and some measure of care more of a "natural part" of the life of the Order (and, by extension, the movement), and the foundation of the Abhayaratna Trust welfare fund (2008) exemplifies this. As noted above, the concept of a "natural part" of spiritual life was invoked by Sangharakshita (2009b) in relation to palliative care situations, and more recently he has suggested visiting isolated older people as a good focus for altruistic activity (Sangharakshita 2010).

The key point for this sub-section is that although Buddhism dates back many centuries, the Triratna/FWBO movement is in historical terms very new. Sangharakshita refused to take on any particular Eastern tradition in a 'wholesale' manner, and prioritised commitment over lifestyle (see Bluck,2006:Subhuti,1994). It is arguable that a consequence of the latter is an increasingly dispersed and diverse range of lifestyles, so that there is no evident Eastern template for how our frail elders might expect to be supported, and traditions as to informal care are only beginning to emerge in the face of necessity and actual experience. Looking ahead to the next section, we can be sure that whatever responses emerge in relation to LTC, they will involve some informal care and support, and some contact with mainstream LTC services, with some Order Members using these and others visiting/supporting people within them.

"We might be surprised…that there was actually quite a lot of awareness there" (Research question three).

Mainstream LTC- Nightmare or Dream?

The *"We might be surprised"* quotation is from NR. After referring to the *"nightmare"* of being in a care situation where Buddhist-type awareness was not valued, he then said that we might be pleasantly surprised by some non-Buddhist settings. NR was 60 years of age at the time of interview, has Multiple Sclerosis and lives in sheltered housing in an inner city area.

Concerns about LTC were commonplace amongst this study's participants, and this seemed to be comparable to relevant anxieties amongst the wider public (CSCI/MORI, 2003). Any positive visions or *"dreams"* as to what shape an LTC situation ideally might take tended to be linked to ideas as to Buddhist-based care. At the other extreme, there seems abundant evidence that NR's worries as to potential carers possible lack of interest in *"awareness"* might in some 'care' environments prove fully justified, along with poor staff engagement with many other aspects of valued identity. Examples could include Lee-Treweek's (2000) bleak picture of a care home's inhumane culture, and through this type of lens what Goodman and Redfern (2006,p.82) call a "Legacy of Suspicion" can seem entirely understandable.

And yet NR is open to the possibility that there might be *"quite a lot of awareness"* present in a mainstream LTC situation. His comments could be seen as reflecting a trend for some participants to be cautious about pre-judging mainstream care services. This caution may have a number of 'roots'. Vishvapani's (2001) reference to the perception of arrogance that some have had in relation to the movement (see Bunting,1997) might equate with a misguided tendency to over-value anything 'Buddhist', particularly Triratna/FWBO, and to under-rate all phenomena which are not. Many factors may have helped to modify this tendency. Vajragupta (2010) calmly describes the manifestations of Triratna/FWBO approaches which have not stood the test of time, with many TBRLs and residential communities proving short-lived. People witness this, and perhaps they mature as the years go on (Subhuti,1990). Also they can notice that to run an effective, consistent organisation in any sphere is no easy matter, and that, of course, many non-Buddhists have high ethical standards and admirable personal attributes, so that MB, for example, commented on the *"saintly qualities"* of

some of the staff who cared for her mother. Thus a greater measure of humility may emerge, and the questionnaire item 10 on compassionate care provided an example of this, so that it was one thing to value spiritual practices which are intended to promote positive emotional states (Paramananda,1996), and quite another to imagine that they are indispensable to such ways of being.

However, it was noted above that the praise of mainstream workers and services was often non-specific to LTC, for example the hospice nurse encountered by VP. Also, the participants who were most positive about LTC (in both cases they were daughters discussing care of their mothers who had dementia) put some emphasis on the economic dimension (see Pollock,2005). This was especially so with QP42, an Order Member whose work as a GP included much contact with the LTC sector, and who was clear that the specialist private home caring for her mother would be far beyond the means of many Triratna/FWBO people. The general trend was for participants not to place responsibility for failings in the service on the workers themselves, but on inadequate management, an emphasis on *"money"* and comparable factors.

Nonetheless, the failings of mainstream LTC were highlighted by many participants, and these could be seen in terms of Taylor's (1989,p.93) concept of "life goods", and the previously mentioned Nightmares-Dreams dichotomy. Thus 'basic' life goods could include a sense of being treated with respect (see Kellaher,2000), and the availability of acceptable food. These were both areas in which people reported *"nightmare"* situations. Thus JV referred to a social worker assessing her needs who *"verged on being abusive"*. QP 14 feared the prospect of being *"served pie and peas"* in a care setting which had little understanding of vegetarian food, and Olivant (2007) comments that mainstream LTC vegetarian provision is "generally poor". More specific to Buddhist spirituality was NR's characterisation of Buddhists as wanting to *"die with awareness…live with awareness…do everything with awareness"* followed by the comments outlined at the beginning of this section. In this context, Buddhist visions of awareness might be seen as what Taylor (1989,p.63) calls "hypergoods", features which are crucial to identity and without which life may seem intolerable. Another example was QP35's reference to having shared values with people and the *"dread"* she feels at the prospect of *"being thrown together"* with others in an LTC situation where this was not the case. There were other, less dramatic stories where it sounded as though aspects of valued identity might be slowly, quietly eroded through lack of choice, an uninspiring environment and other demerits. For example, Joy's desire for more baths

was exactly echoed by a lady in Cooney and Murphy's (2009) research, and it was notable that RT linked this to a lack of advocacy. Joy also had no immediate family, and as acknowledged by the Relatives and Residents Association (2009) people in this situation might be particularly vulnerable to inadequate care. They might also, by extension, be especially dependent on care staff for support of any valued aspects of identity, making this a salient point for the many single people amongst older Order Members. It also accentuates the responsibility of such Order Members' spiritual friends, with advocacy-like input a probable growth area as levels of LTC use increase.

Participants quite often emphasised their lack of experience in relation to LTC, but whether experienced or not it was commonly an area of concern. Admittedly it might be difficult to separate worries about LTC as such from anxious perceptions of later life derived from a stereotypical emphasis on decline, as discussed by Mulley (2007). Also, the predominant "legacy of suspicion" (Goodman& Redfern 2006,p.82) could be seen as excessively focussed on residential care, though as noted above QP48's account of her domiciliary care was highly critical. In summary, mainstream LTC was seen as a problematic category in which lack of financial resources could compound someone's difficulties in a sector where poor general standards too often applied and there also was commonly a lack of focus on what Timonen (2008,p.139) called people's "higher level needs". In saying this participants were cautious not to dismiss the positive efforts of many people and services in the wider society, or to assume that Buddhist carers would necessarily be better. Specific issues as to respect and understanding are explored in the next sub-section.

Respect and Understanding

The above two words were used in questionnaire Item 4 on Buddhist names, and it was notable how the comments of some participants highlighted the distinctive connotations of these terms and of expectations associated with them. Broadly it seemed that basic respect for someone being a Buddhist was available in mainstream LTC, or at least it was generally expected that this would be the case. The only example of perceived disrespect *specifically in relation to Buddhism* was KL's experience at a Benefits Tribunal, and one aspect of this was the 'adversarial' context (see Powell,2000) which is absent in typical care-related encounters. There were some other narratives indicating a lack of tolerance and/or awareness, for example the volunteer chaplain invoking *"hell"* in discussions with QP8, but no suggestion from anyone that they were

typical. In fact participants tended to assume in a diverse, multicultural society that care services will aim for some awareness of people's spiritual backgrounds, as reflected in staff handbooks such as Mootoo's (2005) and the HOPE approach to spirituality (Harrington,2010).

However, participants quite often focussed on the word *"understanding"* and this was typically located with fellow Buddhists. Taking two examples from SA, it may be unsurprising that his Buddhist home help had a better awareness of how to handle his shrine room artefacts during cleaning duties than her non-Buddhist predecessor. The former's attendance at the local Buddhist Centre would have provided an induction into such matters which many workers would lack, however much good will and receptivity to guidance was present. Later in the care home, we can only speculate about the Polish carer who borrowed a Buddhist book from SA and came back with questions. We cannot know if on the one hand she was going against Timonen's (2008) reported trend of overlooking higher level needs, and instead taking an interest in something which was clearly important to SA, or on the other if this was arising from her being in some measure 'sympathetic to Buddhism'. Tweed's (1999) work would suggest that we might have difficulty establishing this, considering the fluidity of contemporary spiritual identity and some people's ambivalence about labelling themselves (see Heelas& Woodhead,2005). Notwithstanding such factors, and dissenting voices citing "uncompassionate Buddhists" and the like, the general trend here was to be at least 'doubtful' about mainstream provision and to place a some value on interventions arising from a Buddhist background. Thus for example in relation to activity programmes in care homes (see Mozley et al,2007), questionnaire Item 17 suggested that positive approaches to these might be relatively more available in a Buddhist context, with QP 14 giving a typical comment that "their idea of fulfilment and creative activity are more likely to coincide with mine".

"Everything supporting me, expressing my values" Research Question Four

Personalisation and Mutuality

This section considers Buddhist-based care services, beginning with the personalised arrangements which one Order Member (CH) has created for herself. It broadens out to include aspects of **mutuality** (see Kellaher,2000) and the Order and movement's relationship to its elders and others in the Sangha who require care. A second sub-section discusses implications for applying Triratna's TBRL principles to the LTC sector.

Her care arrangements, including employment of Personal Assistants(PAs) are an example of the **personalisation a**genda which has been intended to transform social care and to maximise the service-users' control of what they receive . CH was 45 years of age at the time of interview, and her comments concur with research indicating that it is younger disabled people who register the highest level of satisfaction with such an approach (Social Care Institute for Excellence/SCIE,2009)**.** Key dimensions of her situation are indicated in three examples from her interview. In saying *"I'd find it difficult if carers/PAs were coming in at certain times with a meal that I had no control over"* she was echoing both the 'Putting People First' principles (Department of Health, 2007) and Langer and Rodin's (1976) core emphasis on the maintenance of 'control' as an aspect of wellbeing. She also speaks of having *"always employed friends"* and as to security and trust issues cites her nephew having money stolen by a 'carer'. In contrast Heng (2007,p.21) is a service-user who describes his unease when he has to employ total strangers. Whilst of course previous acquaintance is no guarantee of problem-free arrangements, the relatively large personal networks of many Order Members appear to be one of their advantages in this type of LTC situation.

To have reasonable levels of control over meals and trust in paid staff seem like 'basic' aspirations for support. More specifically Buddhist is the fact that her PAs *"support me in my meditation practice"*, with this apparently representing what Taylor (1989) calls a 'life good' or 'hypergood'. The same seemed true for TN who reports having *"a lovely Buddhist carer"* for years, adding that *"We meditate and do yoga together"*. Having "shared values" with those offering care/support emerged as a key factor, mentioned in one form or another by many participants (see page 164). The three detailed accounts of Buddhist-to-Buddhist paid-for care from interviewees did report it as working acceptably, and CH and TN were notably positive. All three people

receiving this paid-for support said more about the possibilities for larger scale projects, and they and other participants were well-disposed to some form of residential care provision on the proviso that it was run according to Buddhist principles. Two of these three were very experienced 'Three Cs' community-dwellers, and this might be contrasted with the general population of people considering LTC, the majority of whom will never have lived communally (McDonald,2010).

"Shared values" could be equated in some measure with the term **mutuality** as used by Kellaher (2000)-see page 58 above, and raises questions as to personal responsibility. We may find that we take this in relation to family members, close friends and others with whom we have links. What Dalley (2002) calls 'affinity groups' could come together on a variety of grounds, with spiritual affiliation a prominent example. Notwithstanding the mainstreaming tendency in LTC (Valins 2002) there was evidence that the spiritual/cultural elements of the Jewish and Methodist provision discussed above was appreciated by residents, and that they had some regrets at the limitations on sharing these with staff. These were seen as 'Traditional' manifestations of identity, whilst Western Buddhists and LGBT (Lesbian, Gay, Bisexual and Transgender people) were viewed as Emerging identities which would have their own needs in relation to LTC. As the public profile of these groups continues to rise, it seems likely that some services will increasingly become known as (at least) friendly to relevant minorities. Heaphy and Yip's (2006) finding amongst their sample of people from LGBT communities that the prospect of using hypothetical care/support services was seen as much more positive if they were said to be run by people from those same communities again suggests that a gap exists between basic respect and substantial understanding. Thus the latter might be appreciably more linked to lived experience and aspects of identity. Also, Brown Wilson et al (2009) wisely explore the interaction between care home residents and the ambience which this can create. Certainly some participants had positive visions of Buddhist-based care communities, seeing them as places where Buddhist practice, friendship and creative activity might flourish.

It did seem that the idea of BBCSs to some degree met participants concerns that the movement would respond appropriately to the needs of frail older Order Members, especially 'pioneers' who had lived out the 'Three Cs' lifestyle and now had little in the way of finance and family support (especially from live-in partners). This raises many questions, particularly the extent to which any given model of support would meet such needs. Participants tended to assume that residential care was the most likely option.

Notwithstanding all the criticism surrounding it, it remains an important resource particularly for frail older people (Froggatt et al,2009), and might serve as such for some Triratna/FWBO elders. Some aspects of the feasibility/practicalities of care-based TBRLs are discussed in the following sub-section.

In trying to encapsulate the above sub-section, I would add the fresh point that the two words providing its title might be seen as in some tension, with ***personalisation*** a very individual term and ***mutuality*** as necessarily collective.CH, however, gives an account of her own needs being met through personalisation of funding, but sees access to like-minded employees through her Sangha as a key factor, and is happy to contemplate living collectively in the future with people who also require long-term support. Perhaps two key phrases are *"shared values"* and *The Whole of Me,* the title of Knocker's report on the LGBT community in LTC situations. These suggest a view that the interplay between self and others in this context is such that both personal autonomy and a supportive community are made more viable when people find affinities with one another. Traditional cultures of Methodism and Judaism are reported to support some level of mutual understanding to which some people with these backgrounds gravitate when LTC is needed. There is some evidence for people with the emerging identities of LGBT and Western Buddhist (in this study) favouring comparable choices, with an ideal being voiced whereby "the whole of me" is best expressed in the context of what Dalley (2002) terms an "affinity group".

TBRLs in the LTC sector

The general idea of care-based TBRLs was strongly supported, as with questionnaire Item 15 on teams of people taking on care work as a form of spiritual practice. People's 'visions' of this were mainly positive, but generally did not appear utopian in outlook. The paid-for support received from fellow Buddhists by interviewees CH,TN and JV provided one reference point for the realities of such a service, whilst existing TBRLs away from the care sector provided another. As to the former, the fact that interviewees had been able to recruit effective PAs/carers from the Sangha suggested that workers might be available for a larger scale service, notwithstanding general concerns about the quantity and quality of the LTC workforce (Pollock,2005). The existing TBRL legacy seemed to underpin comments that staff should be suitable and well-trained and not taken on simply because they are Buddhists, and references to naïve, arrogant and idiosyncratic/ineffective approaches to work tasks. In mitigation we can note the trend

towards greater professionalism and a preparedness to employ sympathetic non-Buddhists (Tejasvini,2007). Also we can speculate that QP51's criticisms of a TBRL shop arose from an unusually bad experience, whilst noting these and other comments (such as that on the *"wrong emphasis on aspects of mindfulness")* as sobering feedback as to what can go wrong.

On the positive side, there were references to specific Buddhist practices intended to enhance kindness, compassion, mindfulness and other qualities, and to the perceived links between caring vocations and spirituality. The former were seen as helpful in an LTC context, and this recalled Kitwood's (1998) interest in some forms of meditation as a form of personal development for staff. To Buddhists involved in LTC the description of this interest as "rather unrealistic in practice" (Baldwin and Capstick 2007,p.269), might seem unduly dismissive. Though implementation might arouse the suspicions of forthright secularists such as Paley (2009) it would readily find its place in any service influenced by Buddhist principles, arguably to the benefit of clients and staff. As to 'caring vocations' it was notable that some care workers saw TBRLs as a good focus for this, as with a mental health nurse QP47 speaking of it as *"a way of developing spiritual friendships and deepening work as practice"*. Comparably QP7 suggested that Buddhists working in LTC would be *"more ' engaged' than most who work in care"* .One the one hand such a vocational orientation,along with Buddhism's relatively positive public profile in the West (see Wuthnow& Cadge 2004) might make the 'Legacy of Suspicion' less marked in the wider population towards a care-based TBRL. At the same time Buddhism is culturally unfamiliar to many, and Triratna/FWBO's controversial history may make its projects unattractive to some people. There were a number of comments as to the population which such a TBRL might serve, with a possible formulation making it open to all who wished to receive its services, but it having a particular sensitivity to the needs of Buddhists in general and Triratna/FWBO, and Buddhists in particular.

Participants raised many other practical and general issues, in relation to Triratna/FWBO and other Buddhist movements. These are likely to be valuable when more focused work on possible TBRLs in LTC can be done. At this speculative stage it might be acknowledged that, for example, Joy's (modest) *"dream"* of having more baths could not necessarily be guaranteed by a TBRL anymore than it could for Cooney and Murphy's (2009) participant in mainstream care. However QP14's nightmare of

"pie and peas" and the "generally poor" vegetarian provision reported by Olivant (2007) might be less likely in a Buddhist set-up where a diet without meat or fish is simply part of the culture. Such factors might explain why the words *"hope"* and *"hopefully"* featured frequently in discussions of such services, and it was this, rather than any overconfidence as to feasibility and successful outcomes which appeared most prominent.

This and the previous sub-section (on ***Personalisation and Mutuality***) do appear to offer especially fertile territory for further research. More detailed mapping of people's preferences (current or anticipatory) could be matched in some measure to resources (existing or potential), with factors such as staffing (from within or outside local Sanghas), available finance, preferred living situations and issues as to *"understanding"* it does seem feasible that personalisation principles might be well operationalised here and developed further over time. Qualitative approaches will be predominant, though some quantitative work seems likely to be relevant, with 'early' anomalies with this project (such as the gap between female and male questionnaire participants' average ages-see page 134) being minimised as to any impact as larger samples are included.

"I get a lot of recognition here"-Research question one.

The term *"recognition"* as used her by SA has an immediate resonance in the present context where identity in LTC situations is the central focus, because of the way it was applied by Kitwood (1997). As such the quotation provides a focus for discussion of the first research question as to how identity and personhood might be conceptualised in a Triratna/FWBO context. Recognition is one of three words which Kitwood places at the core of his definition of personhood, along with trust and respect. A worst case might be someone with dementia who is no longer seen as a person with a past, present and future. Such a mind-set is characteristic of what Kitwood (1997,p.45) called malignant social psychology, with its nihilistic assumptions augmenting whatever organic deterioration is already in process. It seems to spread all too readily beyond the category of dementia, since although Lee-Treweek (2000) found demeaning and dismissive staff attitudes towards the elderly none of the residents in her study are identified as having cognitive impairment.

If recognition as a person is vital at a foundation level in LTC, we can note the importance of 'being seen' as an aspect of Buddhist tradition. Thus in Chapter Nine above KL speaks of being asked to be someone's Preceptor and the *"honour…that someone sees in me that capacity to witness their Going for Refuge"*. We can recall the centrality of Going for Refuge in Triratna/FWBO and other Buddhist traditions. This core commitment to the Buddha, the Dharma and the Sangha can also be formulated in terms of the Threefold Way of practice and its focus on ethics, meditation and wisdom. Such a commitment arguably constitutes ***Buddhist identity,*** informing for example what Atchley (2009,p.47) calls the person's "ideal self" and general "self-system", with Buddhist practice a means of self-verification of spiritual identity (Burke& Stets 2009) and with a beneficial sense of meaning and purpose flowing from this identification, as discussed in general terms by Poll and Smith (2003) and others. KL's above use of the term "witness" underlines the vital importance of this commitment being recognised by others, specifically the Preceptor at the time of ordination. Spiritual friends and the wider Sangha also support this, and at a minimal level this might consist simply in offering a context in which one is seen as a practising Buddhist.

The concept of generativity is mentioned above, and being seen is relevant here also. The man in De Medeiros's (2008,p.100) narrative has a subjective sense of "fading away", which his creative activities do something to mitigate. It is commonplace to talk

about the invisibility associated with later life, or the marginalisation of older people (Bytheway,1995), with generativity signalling an opposite process whereby someone of senior years is instead a focus of due attention. Contextual factors are likely to be highly relevant here, with younger people 'looking to' their elders and receiving something from them on which they place value (Erikson et al,1987). SA's narrative contained two apparent examples, the first of which was his being asked about his work as a pioneering music therapist by his son's musician girlfriend. Thus the subject matter was not specifically Buddhist, though there was a shared context in relation to music. The second example, already mentioned in relation to the Polish care worker *did* have spiritual content, though as noted she was not explicitly a Buddhist. However, it and other examples did suggest a context for generativity in which spiritual experience could be a focus of attention, and in which the older person could feel recognised and supported in her/his Buddhist identity.

Potentially there can be many debates as to what constitutes ***Buddhist identity***, and many aspects are beyond the scope of this study, not least because it focussed almost exclusively on one movement. Tweed (1999,p.72**)** is quoted above referring to the difficulty in defining it in terms of "beliefs…practices" or the joining of organisations, and it would be equally problematic to view in terms of a particular life-style, be it "semi-monastic" (Nagabodhi 2004,p.3) or otherwise. Sangharakshita's emphasis on Going for Refuge, and the commitment to practice which this entails can often involve observable phenomena, as can the Threefold Way of practice (see page 19 above). Thus SA wanted to be addressed by his Buddhist name, to have a vegetarian diet, and to have his meditation practice respected. The care home staff made an effort with these, though it seemed implicit in SA comment about his name (that they use it *"Without knowing what it means"*) that such understanding would be desirable. Comparable understanding would seem vital, for example, when MB, with reference to her mother's dementia and former interest in meditation, speaks of people being *"supported to continue their spiritual practice".* Taking a developmental approach we can argue that there might be opportunities to go beyond 'continuation' of current levels of practice and that later life has some advantages in taking the spiritual life further. This could be seen as implicit in the way in which 'busy-ness' is seen as a hindrance in many areas of life (and presumably is often linked to the features such as paid employment), whilst all too often the perceived deterioration of older people's lives is equated with boredom and stagnation. We can recall QP 37's reference to *"having time for reflection, study,*

communication, friendship, the Arts…" and other positive visions of LTC based on Buddhist values (see Chapter Nine above), and these remarks implicitly suggest spiritually favourable conditions applying for some older people. As it stands most of the relevant participants' comments are linked to hypothetical living situations which combine an LTC function with Buddhist-based communal living. Further research might elicit more on a wider set of conditions in which older Buddhists might be living and how this might be seen as influencing their practice.

Many people can offer some foundation of support to Buddhists, and often there will be a respectful attitude to spiritual diversity. A measure of understanding may be present, and further information sought, though participants in this study often located *"understanding"* with fellow Buddhists. There seem to be many ways in which that understanding might be translated into actual support in LTC situations, and the situations will range across informal support, domiciliary care, sheltered and Extracare housing, care homes, and other options. Principles of Sangha and spiritual friendship suggest that contact with fellow practitioners is beneficial to most individual's Buddhist practice, and hence to their Buddhist identity. When that identity becomes vulnerable, as it can when LTC needs develop, it can only be asked of their spiritual friends to consider how they might best give support, and to hope that effective and creative responses will emerge.

'Ecological validity'

This heading is one of the terms explored above (see page 129) and the section in which it previously appears prompts a number of questions as to the study. Before the next chapter identifies some conclusions, it seems appropriate to briefly review Wallace's (2005,p.74) concept of "ecological validity" and associated terms and, having presented and discussed the study's findings to again comment on its strengths and weaknesses.

Wallace (2005,p.74) asks for "intensive, extensive and non-reactive observations". I believe some claims could be made for the "intensive,extensive" nature of the data gathering, so that for example the questionnaire was used a range of UK locations, included people from different levels of involvement in Triratna/FWBO and involved over 9% of the Order in Britain. Although the term "non-reactive" is ambiguous, I have been aware of some possible biases in how relevant material is discussed. Thus if earlier writings from within the movement avoided any real engagement with its difficulties

and associated 'scandals' (so that Subhuti,1995 just ignores them), I believe I have adopted a more recent trend to seek frankness on these, with Vajragupta (2010) another example.

  Wallace (ibid) asks that these observations are made "of the social world of interest" and "generate understanding and meaning", with such insights coming from "the perspective of the insider rather than some objective world view". Such principles echo material from the Methodology chapters (in Part Three above) and one thinks of Geertz's quest (see page 94 above) for "thick description" , Weber's focus on *verstehen* (see Inaba 2004 and page 95 above) and Silverman's (2004,p.343) on the "actor's perspective". Applying such criteria to the present study, we can immediately ask if the "social world" promised by the title is what the content actually represents. As noted above, the development of the title *Supporting Buddhist Identity in Long-Term Care Situations* approximately coincided with abortive plans to look beyond the Triratna/FWBO so that, for example, representations of **Buddhist identity** would not have the manifest inadequacies associated with including participants from just one spiritual movement (see page 9 above). Nonetheless I think I was rightly counselled against enlarging the study, as a reasonable amount of data had been collected and I was probably emulating many previous anxious researchers in my belief that all difficulties will disperse if I did some more interviews. Two points come to mind. Smith's (2008) study of Triratna/FWBO in conjunction with people from another Buddhist movement, SGI International was published too late for the planning stage of my study, but does give a realistic way of achieving some balance between depth and breadth of coverage when Buddhists are being represented. Certainly I have had much informal contact with non-Triratna/FWBO Buddhists on LTC matters . These have doubtless influenced by thinking in general terms, and assuredly I will be building on this in the future as I try to put my findings into practical effect, and also consider more research. A second point is that the study's title does merit some criticism for its overinclusiveness, but a parallel case might ameliorate this. Kellaher (2000) found something of a 'continuum' of religious affiliation in her sample of residents of Methodist Homes (now MHA) facilities with the majority Methodist, others were active members of other Christian denominations and a few said "they supposed they were Christians". Personally it seems acceptable to me that one of Kellaher's (2000) chapters is called *The Christian basis of care and the maintenance of sense of self* , since this title gives a general idea of what is

being covered and the nuances of what 'Christian' signifies can be explored in the relevant text.

As it happens, the work of late Sharon Smith (also known by her Triratna/FWBO name as Vijayatara) also appears relevant to another aspect of the study, since the book chapter in which she supported another researcher (Yip with Smith, 2010) considers the dual identity issues of those who are Western Buddhists *and* are from LGBT communities. This is a neglected area, and the chapter does reveal some complexities, with Buddhism in its many forms sometimes perceived as supportive and at other times as problematic for aspects of identity associated with LGBT backgrounds. It became available very late in the life of the present study, but otherwise could have been valuable, especially as 'Western Buddhist' and 'LGBT' were taken as examples of emerging communities in the LTC context.

Regret in relation to this area has been expressed above (see page 130) and in tandem with there was disappointment as to the missed opportunity to include a questionnaire item on end-of-life care. Again, a 'missing' piece of research could have made a positive difference, and although I was aware of Froggatt's (2007) study of deaths in care homes I underestimated its importance, and did not link it back to the faith-appropriate respect which many services aspire to provide in relation to death and dying (see Neuberger 2004 and page 84 *et seq* above). If as reported up to 25% of deaths of people over 85 occur in care homes in England then this is a major and gradually growing issue for Buddhists, with what Watson et al (2009) cite as their particular needs in palliative/end-of life care(see above).

The exploration of end-of-life care and LGBT identity do seem to have the potential to further "generate understanding and meaning" of aspects of the Triratna/FWBO "social world" (Wallace 2005,74). Like all data collection and analysis in this study there would have been an aspiration to portray the experience of "the insider" rather than imposing a strong theoretical model on the emerging evidence. I can only hope that sufficient opportunities were created for such perspectives to show through, and can point to QP32 and NR who did comment on death and dying issues notwithstanding the study's neglect of the topic. In this as so much else, I feel much gratitude to the participants.

Along with the concept of ecological validity I quoted above Miles and Huberman's (1994,p.278) question "Have things been done with reasonable care?". Posing it more globally to the whole study, I would give an equivocal answer. For a proportion of what

was discussed in this chapter, the phrase "could do better" comes to mind. Even so, I think there are grounds to claim some contribution to knowledge, which I will develop in Chapter Eleven-Conclusions to follow. It did seem possible to operationally define Buddhist identity for the purposes of this study, and often to focus on observable phenomena (for example vegetarianism and meditation). If anyone believed there was a highly developed network for informal support in relation to LTC needs, the study refuted this, notwithstanding much active kindness and good will. People were often anxious about mainstream LTC services, and enthusiastic about Buddhist-based TBRLs developing in this field. As well as confident on these points, I feel conscious of addressing a new area in relation to a group of Western Buddhists, with their movement being sufficiently established that their 'faith' is not now the main focus for research attention and the cohort is large enough for social care issues to become of interest. Considering the novelty of the venture, I feel some confidence that I have learned much from doing it, and, like the participants in relation to TBRLs in LTC, I allow myself some hope for improvements in future research.

CHAPTER ELEVEN: CONCLUSIONS

Preliminary comments

In this final chapter I will identify key conclusions, make recommendations and comment on my own learning in the course of the study. The research is intended to make an original contribution to knowledge and has been undertaken in an academic context. In parallel with this I will seek to identify practical implications from what has been explored.

Starting out I knew that there was much I did not know about Triratna/FWBO and that dispelling some of this ignorance was essential to an effective research study. One example of this was my limited picture of the women's wing of the Order. I was aware also that little was known about the long-term care (LTC) needs of Triratna/FWBO people, either in the present or as to how they might emerge in the future. This was heartening when I considered claims as to the study's originality and the possibility of making a contribution to knowledge. However, deciding to address this and to give some account of the general Buddhist background and of Triratna/FWBO I found *no* research studies specifically concerned with *long-term* care issues for *Western* Buddhists. This prompted a realisation that there was an exciting opportunity here. Accompanying this was apprehension as to the size of the gap in academic knowledge which was there to be filled, and as to the methodological difficulties whilst cohorts of frail elderly Western Buddhists remain small.

Equally I had no idea that I would come to focus on 'Buddhist identity', with this and other changes in perspective emerging during the life of the study. At times such changes were linked to concepts encountered along the way, which then came to illuminate central aspects. For example, my basic awareness of Erikson's model of lifespan development was enhanced by further reading, and then by the insight that generativity was particularly relevant in the present context. An instance of a different type of learning occurred in relation to the personalisation agenda in social care, and I value the fact that the first detailed account I had of Direct Payments arrangements and personalisation came from someone experienced in utilising the service herself .Turning to my outline of conclusions, I will start with reference to the second of the four research questions, with the complex issue of identity and personhood in Triratna/FWBO (as represented in the first research question) here reviewed last.

Informal care

I regard my most robust conclusion as being that *informal* care of frail elderly people within Triratna/FWBO is an area for concern, and that it is possible that some frail Order Members will be disadvantaged as to the quality and quantity of care-related input they receive. This is highly relevant to Buddhist identity, as often frail people in later life are best able to express their values and pursue their interests by 'ageing in place' rather by moving from their homes on the basis of an increase in care needs. A key factor here is a possibly reduced availability of informal support and care from live-in partners and adult children in comparison with the general population. This interacts in a complex manner with the ethnographic and demographic details of the movement.

Characterisation of the movement as 'semi-monastic' has never fully encompassed all the lifestyles within it. Today this descriptor fails to match the lifestyles of the majority of Order Members, and the great majority of Postulants, Mitras and Friends. However, as some of the care needs explored in this study are age-related it is unsurprising that some people with long-standing involvement in the movement feature amongst the participants, and that such individuals' Buddhist practice and Buddhist identity are closely linked to the 'Three Cs' model. Of the four themes explored in relation to informal support and care, it emerged that Burden Issues were of particular salience for those living in residential communities. This was often associated with ***Others' Busyness*** though the theme of Busyness applied more generally to people in the Sangha whatever their living arrangements. Similarly there was perceived to be a broad influence from the relative ***Cohesiveness of the Sangha***. At a more individual level, Interpersonal factors were mentioned and explored by a number of participants.

An 'ideal' picture of residential community life doubtless would include co-residents caring for each other in all circumstances, though the reality is more complicated and perceptions of ***Burden*** play their part. Kindness and friendliness were commonly present, and there was reference in the data to instances of end-of-life care being given in a residential community context. However, difficulties were discussed in relation to care needs of relatively long duration. Examples of *informal* care over months and years and of an intense nature (requiring 20 hours a week or more of input) were not found in residential communities and were confined to some family situations. Difficulties in residential communities included people with care needs having concerns about being a

burden, and reference to friendships eroding, whilst solutions included paid care arrangements within the Sangha and potential co-residents making it clear what they could and could not offer.

There were participants who described limitations on informal support and care in terms of shame and regret, whilst others (including some people with care needs) ruled out any undue emphasis on obligation. It is true that the Buddha saw the need to admonish the monks who had neglected their brother with dysentery, and that Sangharakshita applied this story to contemporary conditions in the 1980s. In the Triratna/FWBO of 2010, such a teaching is ever-more relevant, because of the growing number of people with care needs. And yet talk of *"shame"* may be inappropriate and counterproductive. Reminders can be helpful, but probably the key process is making the support of people who are frail or who have other care needs more of "a natural part" of the Order and movement's life, with some examples outlined at the end of this section.

Apart from residential communities, there was a range of data on informal support and care, with loneliness and help in emergency situations both being discussed. It was notable that examples of support/care existed on a continuum from general 'keeping in touch' at one end to full-scale personal care within a specific time-frame at the other.

The manifestation of a good level of informal support for people with care needs is surely a sign of a cohesive, successful Sangha, and progress seems possible whatever the local variables as to size, geography and other factors apply. There were many examples of ongoing support and practical help arising from friendship within the Sangha. Facilitative 'conditions' with this seemed to include people being reasonably well-known at the local Centre and maintaining connections to personal/spiritual friends; identification of specific tasks with which people could help (such as preparation of meals); and potential helpers' level of busyness. This last factor seemed influential across a wide range of situations, involving spreading the Dharma, family commitments (including Triratna/FWBO people's own elderly parents), earning a living and many other possible activities. Where circumstance and/or lifestyle decisions meant that people were relatively less busy there was some evidence of this creating situations where the Samgravastu teachings, including beneficial activity and exemplification, were more fully expressed in the form of practical help.

This leads us on to recommendations. The Samgravastus often feature in Centre teaching programmes, Order gatherings and other events. There is scope for these to be

applied more fully to the changing demographics of the movement. Sangharakshita's recent reference to visiting frail and isolated people is another relevant example, with its focus on including people in the 'natural life' of a Sangha who might otherwise move to its margins if attending events becomes more difficult. The data included examples of people being given lifts and general support to facilitate them getting to classes, and development of this is to be encouraged, as are improvements in accessibility of Centres wherever possible. The Abhayaratna Trust's (Order Welfare Fund) is to be welcomed in itself and its efforts to give some funding to financially disadvantaged Order Members to enable them to attend retreats and other Triratna/FWBO events, also noting that finance, mobility and health are often interconnected factors in this context. There is also a need to be mindful of interpersonal factors here, so that the sharing of resources and help is encouraged. Otherwise assistance can flow disproportionately to 'popular' people and quieter, perhaps sometimes more 'difficult' people can be overlooked and thus their Buddhist identity might be less well supported.

All the matters cited in the previous paragraph are recommended for greater attention and encouragement. They apply to people in the Sangha whatever their lifestyle. The data also included material on the 'Three Cs' lifestyle, with changes in (and sometimes decline of) this way of life exacerbating uncertainties as to the future. A recommendation here is that liaison work with registered social landlords/housing associations would be beneficial in some circumstance so that spiritual friends can live together outside the single person/couple frameworks that are the norm in this field.

Mainstream LTC

Mainstream health and social care services have been expected to respond to diversity and encompass a full range of needs in an increasingly multicultural society. There seems to be evidence of some progress in this regard, with instances of gross disrespect for someone's spirituality or cultural background occurring relatively rarely. Where disrespect was perceived, additional factors appeared to be in operation which are likely to be absent in many, and probably most, care contexts. However, understanding of an individual's spiritual life was commonly associated with fellow Buddhists or people of 'Buddhist sympathy', and was welcomed when available. Participants were well aware of the absurdity of assuming altruism, compassion or anything else on the basis of 'faith' affiliation in itself, and critical material on some Triratna/FWBO projects and perceived attitudes were elicited in this discourse. However, there were no examples of

participants with an entirely sanguine perspective on mainstream LTC provision, with most demerits attributed to 'the system' rather than individuals. There was reference to cruel or poor treatment of elderly residents though no detailed narratives emerged and one participant's reference to 'mythical' bad care homes was accompanied by comments as to fears arising from media sources and general impression. Even where such perceptions have an anecdotal basis it seemed that they can have a substantial effect on our images of later life.

Concerns encompassed both quality of care in general and attention to specific aspects of Buddhist identity in particular. The latter included vegetarian diets, understanding of Buddhist names and opportunities for meditation and quiet reflection. One suggestion is that decent basic care provides a foundation for a general level of well-being which is commonly a prerequisite for Buddhist practice. More specifically spiritual aspects of care and the care environment might build upon this foundation, facilitating access to Buddhist 'life goods' and to opportunities to regularly self-verify as a Buddhist with on-going practice . In some of the worst of care scenarios as depicted in Chapter Four, Personhood and any valued sense of identity would seem to be in peril, with hostile staff, depressing surroundings and a dull daily routine contributing to a general sense of decline and futility. Inadequate nursing and medical care could be another area, again a problem for devalued older people and likely to reduce personal well-being. By extension, it would also undermine the ongoing commitment to spiritual practice which many Buddhists wish to maintain and augment whatever their age or circumstances. It was notable that, in terms of the reports of service users, the most critical evaluation of provision was a single detailed narrative on domiciliary care, indicating that concerns about LTC need to move well beyond the walls of the uninspiring care home.

There were some very appreciative comments about some mainstream services and paid carers/professionals working in them. These tended to be non-specific to LTC of older people as such, with this sector emerging as one in which the maintenance of high standards was seen as comparatively difficult to achieve. However the predominantly positive comments included two Order Members on the subject of residential care for their mothers, both of who had dementia.

Both made salutary points, with one drawing on her professional background to say that the specialist, privately funded unit in question would be far beyond the means of many Triratna/FWBO people. The second Order Member had high praise for the small-scale private care home where her mother had received kindly and skilled care, though

her interview included an account of concerns about the quality of care from a district nurse and from the local GP surgery. Thus the first highlighted the part which income can play in relation to the securing of good care, and the latter indicated an ongoing need for advocacy. We have noted Triratna/FWBO's caution about using a rights-based framework in such situations, and it might be preferable to consider it as another, and relatively unfamiliar, context in which spiritual friendship can be expressed. If a dear friend moves somewhere we will be interested in how she/he is settling, and if there are difficulties we will surely want to help, perhaps especially if choice was limited. The friend may be able to assist the person receiving care in getting across practical aspects of Buddhist life and practice, and 'networking' with others offering friendship and support in similar contexts. Printed material and DVDs may also be helpful, and as noted in Chapter Ten Triratna/FWBO has people with relevant skills for the production of such material. Information could be tailored to particular models of care, drawing on people's experience as to what is relevant in sheltered housing (favoured by a number of participants), domiciliary care and other contexts.

Overall, mainstream LTC emerged as an area of concern in relation to people's friends and relatives and for people contemplating their own future. Lack of finance and family input may disadvantage some Triratna/FWBO people, and although there have been promising policy initiatives (such as personalisation) and general development (such as Extracare schemes) funding and access are likely to be problematic. In a time of budgetary stringency it is arguably unrealistic to expect widespread quality improvements, especially as demand increases with an ageing population. Recommendations here include spiritual friendship taking on a form of advocacy where needed, supported by networking and education materials. The next section will consider some aspects of Buddhist-based LTC services. These seem to have some prospect of emerging, though even so they are likely to do so gradually and on a small-scale. Assuredly there will be many Buddhists receiving care in the mainstream. At times they might well need support with their spiritual identity in such contexts, to help retain contact with the 'Sangha Jewel' and with the sense of meaning of purpose to which their practice contributes.

Buddhist-based care services and TBRLs

The study's data gives a strong mandate for further work to be done on the possibility of Buddhist-based care services. In some respects any such provision would be going against trends in wider society, where mainstreaming of LTC and other facilities is the norm, as with the debates as to whether Jewish people or Methodists have benefited from having dedicated care services available . In this study it is assumed that any such service would be open to all who wished to receive input from it, with a particular sensitivity to the needs of Buddhists and an equal sensitivity to those who did not wish to be involved in discussions or activities of a Buddhist nature. Also it was assumed that the actual model of any service which emerged would depend on many factors, including finance, assessed needs of eligible people and the areas of experience and, indeed, enthusiasm which potential service users and staff might have.

Some of the 'conditions' for the emergence of Buddhist-based care services appear to be already in place. There is evidence of a growing number of Buddhists needing LTC services. Some of them have expressed a preference for care from Buddhists, or people sympathetic to Buddhism if possible, and support of spiritual identity is a factor here. There is frequent mention in the data of 'shared values' and environments which facilitate ongoing practice, such as having a dedicated area or shrine room for meditation and devotional practice. There was an example of generativity occurring between a care-giver and a Buddhist client/resident on spiritual themes, and it seemed likely that this would occur more readily in a Buddhist-based care service.

There are also a substantial number of people involved with the movement who are qualified and/or experienced in care-related work. There was a very strong consensus that LTC would be a suitably altruistic focus for TBRL-type projects, and a widespread perception that more TBRLs were needed, permitting an extension of current opportunities to make one's work a form of spiritual practice. It was argued that Buddhist practices to promote mindfulness and positive emotion were highly applicable in LTC contexts. Kitwood's ideas as to meditation as a form of development for staff have been neglected. This neglect may mirror wider cultural trends, but his vision in this respect might be readily applicable in a Buddhist-based context.

There is evidence of Buddhism enjoying a positive public image in some Western societies, and perceptions of a vocational motive existing in a Buddhist care

organisation was seen by some participants as likely to be more attractive to the public than that, for example, of some corporate providers.

Although fewer young people are being ordained today, there are many younger people involved with Triratna/FWBO events and Centres. In current economic conditions, more than usual numbers might be interested in joining the workforce of any emerging Buddhist-based care service. More broadly, Buddhist affiliation/sympathy is one way in which people with Direct Payments arrangements for purchasing care located their Personal Assistants (PAs). The advent of Individual Budgets and the personalisation agenda may mean that eligible Buddhists can create a care/support situation which is relatively 'tailor-made' to their particular needs, as with one participant whose PAs *"support my meditation practice"*. Her PAs were usually drawn from the local Sangha. Detailed data on three such paid-for Buddhist-to-Buddhist care were included in the study, giving some small-scale information as to the feasibility of a larger TBRL service, with all three care recipients making positive evaluations. A notable perspective from all three was a positive vision of communal living where based on Buddhist principles. There was a hope that this could be inclusive of people with substantial care needs, with suggestions that ***Mutuality*** may be especially supportive for those who are frail and have restricted mobility.

A second area of 'reality check' came from comments as to existing non-care based TBRLs, with participants often underlining the centrality of appropriate skills and training and often placing these ahead of spiritual affiliation.

It was notable that participants tended to focus on residential care, though material was included as to domiciliary care, sheltered housing and Extracare. General atmosphere and friendliness were mentioned by some participants, and for 'emerging' groups in LTC, such as LBGT (Lesbian, Gay, Bisexual and Transgender) people and Western Buddhists these terms might have a specific dimension to them. Minority groups have made some progress in the wider society over the years of 'identity politics', but in an area such as LTC there is no doubt that some LBGT people experience suspicion or even hostility. Active disrespect has been noted as relatively rarely experienced by Western Buddhists, but a general sense of being understood may be conducive to feeling 'at home' and free to be oneself. No doubt for all services for emerging groups there will be ways of communicating how LGBT-friendly, Buddhist-friendly and so on a particular organisation is being perceived.

The idea of Buddhist-friendly care services received a generally warm welcome from the study's participants. Notwithstanding debates about obligations and expectations, many people indicated a wish to ensure the best possible support for Order Members if they become frail. No single service will meet all needs, and though I may applaud a domiciliary care service developing around one Centre, and a residential 'care community' emerging somewhere else they will not benefit me personally if they are in other regions and I prefer to age in place in my usual locality. But it appears that people do see the development of services as in some measure honouring our elders. Also care-based TBRLs are seen as doing something to offer care which we may not be able to offer consistently on an informal basis, and which we may hesitate to seek for ourselves or our friends in the LTC mainstream.

Thus the key recommendation is that the general idea of having Buddhist-based care services in the LTC sector be taken forward as a practical proposition. Models of care, funding issues, workforce planning, and the extent of applicability of TBRL principles are amongst the issues which will require further exploration.

Identity and Personhood in a Triratna/FWBO context

It has been implicit in the conclusions outlined above that Buddhist identity can be most readily associated with Buddhist practice and values, as with the Threefold Way and Going for Refuge. Whilst is misleading and unhelpful to equate being a committed Buddhist practitioner with any specific lifestyle, many Triratna/FWBO people have found the 'Three Cs' way of life as supportive of their Buddhist aspirations, including the development of spiritual friendship. Thus it was vital to take into account the variety of lifestyles existing within Triratna/FWBO, where some people are keen to maintain their practice of communal living whilst for others it holds minimal appeal. All the findings and conclusions of this study would benefit from further exploration, but this is especially true for this research question, as Buddhist identity as such was not discussed with participants, though relevant material often emerged in the data and was notably present with some of the Current Care needs interviews. Aspects of Personhood emerged in fears of being disregarded as an ordinary human level and some perceptions and/or hopes that this might be less likely in a context of shared spiritual values.

Another key area for further inquiry centres on spiritual identity in the various forms in which it might exist in people requiring support and the people offering it. Such work

will need to acknowledge the complexity of how people define their spirituality and, for example, the ways in which this can express itself in people feeling included or excluded.

In the interests of both academic inquiry and practical planning of support, more data is needed on people's perceptions of their own Buddhist identity (and spiritual identity) and personhood in relation to LTC. Thus the recommendation here is for more research, especially on how people perceive 'life goods' and the best way of supporting them in relation to these if significant care needs emerge, and taking account of personalisation principles and resource issues as touched upon on pages 189-191 above.

Concluding comments

To briefly recap, key conclusions included the centrality of Buddhist practice to the identity of many participants; factors as to informal care which might make 'ageing in place' less feasible than for people in the general public; some apprehension in relation to mainstream LTC as to general quality of care and support of Buddhist identity; evidence that many participants would value being cared for by Buddhist friendly people, and see Buddhist-based care services as a desirable future development; and the key part which spiritual friends can play in supporting Buddhist identity in the full range of care contexts.

If I had to encapsulate this whole study in a few words, I would invoke the concept of a 'natural part' of life. I would relate this to Buddhist identity, the Triratna/FWBO movement, emerging needs for LTC support, and issues of respect and understanding in the wider world. Ideally we will see LTC support becoming a more natural part of the life of the Triratna/FWBO Order and movement, and Buddhist identity becoming a more familiar aspect of life in wider society, including LTC contexts.

I will end this study with reference to SA, the man who in 2001 prompted me to start reflecting on this area. Now 84 years of age, he lives in a different care home from the one where he was interviewed, in a pleasant West Country environment where his elder daughter lives across the road and is able to visit regularly. I visited him there this summer, and came away thinking how well he embodies his Buddhist name, with its meaning of Gentle Wisdom. He had brought this quality to his experience as an 'accidental pioneer', exploring how a committed spiritual practitioner fares in a care environment where understanding of his values and way of life were limited. In the first

care home he had to be firm about his diet, and educate the staff on what he could and could not eat. As time went on he was able to engage well with the carers, learning a language from one and inspiring another with the Buddhist art on his walls. It seemed to me that one aspect of his wisdom is to 'work with' life as it is, whilst holding on to his ideals. My sense is that in this specific care environment he was able to establish his Buddhist identity as a natural part of daily life, and that some friendly exchange around 'life goods' and common humanity thus emerged. In the interviews we spoke about spiritual friends visiting, about him getting lifts to the local Centre so he could attend a daytime class, about the possibilities for Buddhist-based care services (which he says he would have preferred if available), and about Triratna/FWBO people 'looking out' for each other's welfare. In response to the last point, he made a key statement which could be extended to much of the debate covered in this study. He never spoke in terms of obligation, or rights, and eschewed any criticism of those, Buddhist or otherwise, for whom LTC is a marginal concerns. Instead he offered the following epigraph for the study, and thus its final words:

But you see, like everything (in the movement), it's based on good will.

APPENDICES

APPENDICES FOREWORD.

 The following pages contain Appendices as referenced in the text.

Appendices A and B are the Semi-structured interview schedules for the Current Care Needs and Anticipating Care Needs groups respectively. As discussed in Chapter 7, page 112, there is no schedule as such for the third group of interviewees, the Expertise group because the interviews were more individually 'tailored' to the experience of the particular participants.

Appendices C, D and E are the Participant Information Sheets for the 3 groups of interviewees. The basic structure of these is uniform but there are some variations in relation to the nature of the interviews.

Appendix F is the consent form as completed by all participants (with the signature witnessed in all cases).

Appendix G gives the 20 Items of the questionnaire. To save space it is shown in 'compressed' form with Item 1 having boxes for selecting levels of Agreement/Disagreement and for Additional Comments. These are not shown for the other 19 Items but such boxes were used for the version given to participants.

Appendix H gives a summary of key results for the questionnaire.

Appendix I shows a Tree Node generated through use of the NVivo programme on the study's qualitative data

Changes during the lifetime of the study

Some of the documents shown below have existed since 2004. It can be noted here that a number of changes have occurred during the life of the study as follows-

The study was re-named 'Supporting Buddhist Identity in Long-Term Care Situations' in 2007

The 3 interview groups were re-named as indicated on the 3 Participant Information Sheets-Appendices C, D and E.

The University was re-named Anglia Ruskin University in 2005- it is shown under its former name of Anglia Polytechnic University on the Consent Form (Appendix F).

The Buddhist movement which is the study's main focus was re-named the Triratna Buddhist Community in May 2010, with ordained people now belonging to the Triratna Buddhist Order. The main text uses the term 'Triratna/FWBO', though in the documents below the 'old name', FWBO is used.

Additional points

  In the Participant Information Sheets for interviews there are references to an "independent assessor", who it was initially planned would sample some of the data (see pages 218-9, 222-3,227-8 below). For a number of reasons this plan was not followed through, and no independent assessor was involved in the data analysis.

Appendix A- Semi-Structured Interview schedule for *Current Care Needs* group (formerly known as Group C)

(*Prior to the main interview, brief details will be sought as to the informant's age, people in close contact e.g. partner, children, and the informant's employment history and current housing situation*)………………………………………………………………………..

1. Please would you tell me about your current care needs? ……….

2. What type of care are you receiving now?……………………..

3. What other types of care have you received in the past?…………………..

4. What is your overall view of the care received, now and in the past?

5. What have been the main problems with the care received (if any)?

6. What has 'worked well' as regards the care received (if applicable)?

Listed below are some principles considered to be important in long-term care. Where applicable, please comment on these in relation to your own experience and/or those of people you know (relatives, friends etc). Please feel free to discuss examples…………………………………..

7.Privacy

8.Dignity

9.Choice

10.Rights

11.Independence

12.Fulfilment

13.Spirituality

14. Overall, what could make your life better in the future?

15. If your care needs increased significantly in the future, what would be your main hopes as to the care service you might receive?

16. If your care needs increased significantly in the future, what would be your main fears as to the care service you might receive?

17. Taking a situation as follows, which may have happened for you in the past or may occur in the future; because of illness and/or disability you are unable to manage everyday living tasks without assistance.

What would be your preferred life-style?

(please add comments as wished)

a) To remain in your present home with support from home care staff and others

(e.g.friends and relatives)

a) To live in sheltered housing

b) To live in a residential or nursing home

c) Another option (please specify

18. There has been some discussion of the idea of developing Buddhist-based long-term care services. What are your views of this idea?

19. Do you consider there would be any disadvantages in receiving care from a Buddhist-based long-term care service?

20. Do you consider there would be any advantages in receiving care from a Buddhist-based long-term care service?

21. Do you think that Buddhist-based long-term care services will actually develop in the future?

22. What practical issues do you consider would make Buddhist-based care services relatively?

  a) less likely to develop in the future

  b) more likely to develop in the future

23.Many Buddhists will know the story told in 'A Case of Dysentery', in which the Buddha discovers an ill monk being neglected, attends to his needs, and then brings together the community of monks to remind them of their responsibility for each other's welfare. Is this story applicable or not to Buddhists in the UK today?

24. In your experience, do people in the FWBO take responsibility for each other's welfare? (please feel free to discuss examples)

25. Within the general field covered above, are there any further points you would like to make?

(As for Group C, prior to the main interview, brief details will be sought as to the informant's age, people in close contact e.g. partner, children, and the informant's employment history and current housing situation).

1. Please would you tell me about any situations that have brought you into contact with long-term care services (e.g. illness/ disability of relative or friend, your occupation etc) ?……………………….. ………………………………………….

Taking the situation which has brought you into most contact with long-term care services and/or which comes most readily to mind:

2. Please say what was your overall view of the care received……………………….

3. Overall, what 'worked well' as regards the care received (if applicable)……………

4. Overall, what were the main problems with the care received (if applicable)?

Listed below are some principles considered to be important in long-term care. Where applicable, please comment on these in relation to the situation which we have been discussing?……………………………..

5.Fulfilment…………………………………………………………………..

6.Choice……………………………………………………………………

7.Dignity…………………………………………………………………

8.Spirituality…………………………………………………………….

9.Rights…………………………………………………………………….

10.Privacy…………………………………………………………………….

11.Independence…………………………………………………………….

12. Apart from the situation mentioned above, please specify other comparable situations (if any) and any relevant views you have about these…………………..

13. If you develop long-term care needs in the future, what would be your main fears as to the care service you might receive?..

14. If you develop long-term care needs in the future, what would be your main hopes as to the care service you might receive?..

15. Taking a situation as follows; at some time in the future you develop disability and/or illness to the point where you are unable to manage routine tasks of living at home without assistance. What would be your preferred life-style:

 a) To live in a residential or nursing home ?..

b) To live in sheltered housing?…………………………………………………….

c) To remain in your present home with support from

home care staff and others (e.g. relatives, friends)?...........................……………

d) Another option? (please specify)………….…………………………………….

16.   There has been some discussion of the idea of developing Buddhist based long-term care services. What are your views of this idea?

17. Do you consider there would be any advantage in receiving care from a Buddhist-based long-term care service?...……………………………

18. Do you consider there would be any disadvantage in receiving care from a Buddhist-based long-term care service?......................................…………………...

19. Do you think Buddhist-based care services will actually develop in the future?……………………………………………………………

20. What practical issues do you consider would make Buddhist-based care services relatively more likely to develop in the future?

less likely to develop in the future?……………………………….

21.Many Buddhists will know the story told in 'A Case of Dysentery', in which the Buddha discovers an ill monk being neglected, attends to his needs, and then brings together the community of monks to remind them of their responsibility for each other's welfare. Is this story applicable

or not to Buddhists in the UK?

22. In your experience, do people in the FWBO take responsibility for each other's welfare? (please feel free to discuss examples)……………………………………..

23. Within the general field covered above, are there any further points you would like to make?

ADDITIONAL NOTES – These will be as for the Group C schedule.

SECTION A : THE RESEARCH PROJECT   Group C information

Project Title: Long-term care issues in a British-founded Buddhist movement.

An overview of the project:

The purpose of this study is to explore long-term care issues in the Friends of the Western Buddhist Order (FWBO), and I am planning to meet primarily with FWBO Buddhists to find out more about;

1. Their views of 'mainstream' long-term services in health and social care.

2. Their views as to possible Buddhist-based care services that might emerge in the future.

   I am an Order Member in the FWBO, with a work background in nursing, professional education and research. I am planning to seek information from 4 groups of people, and I am requesting that you participate as a member of what I have called Group C. Group C will comprise FWBO Buddhists with current care needs (the group name being derived from the letter C in the word 'care'). I will be pleased to give further information on the other groups involved, so please let me know if you would like this. In this document, however, I will focus on details which seem likely to be relevant to Group C people.

   My main objective in the interviews will be to find out about people's concerns and interests in relation to long-term care. Thus although I will have an initial schedule of basic questions for use in the interviews I will aim for a flexible approach so that participants can make their views and experiences known as fully as possible.

 The initial schedule for Group C has 25 questions. Participants in this group will be asked to focus mainly on their personal experiences of care, though they are welcome to refer to the experiences of friends, relatives etc where these are relevant to overall views about long-term care.

   This interview material will be analysed and further contact made with participants to follow up on key themes arising. The research will be written up as an academic dissertation, discussing the findings with reference to ideas about diversity e.g. do FWBO Buddhists have particular needs, and if so how could these be best met? Other central themes will be 'community' and 'values', in relation to the FWBO and the long-term care needs of some people involved with it.

I believe the study will potentially have 2 main benefits. Firstly, there is increasing discussion within the FWBO of long-term care issues, but there has been no formal research to explore FWBO Buddhists' hopes, fears preferences etc in this area. Secondly, the UK's 152,000 Buddhists (2001 census) appear not to have been studied as to their experiences and views of mainstream care services, and this study may make some contribution to better understanding. It is my intention that the research will be used to influence developments in the future, especially in the FWBO where various responses to long-term care issues are under consideration.

SECTION B: YOUR PARTICIPATION IN THE PROJECT

The invitation:

I have invited you to contribute to the study because:

I believe you have experience and/or ideas relating to the study's subject area, and I would welcome the opportunity to discuss these with you, thus also taking forward the overall research project.

If you decide that you would like to take part, I will contact you to make a mutually convenient time to meet with you during (*relevant month to be inserted)*. The research will take a mainly 'qualitative' approach, so that I am interested hearing about people's experiences and ideas in some depth, rather than in trying to draw lots of statistical conclusions. Nonetheless, through a range of methods I hope to derive a reasonably full picture of long-term care issues in the FWBO.

For participants in Group C , I am expecting the initial interview to take 60-90 minutes. I am happy to travel (where applicable) to your workplace, private home or other convenient location, though if you would like to make other arrangements please let me know. When all the initial interviews for these groups have been completed, I will analyse the data, combining thorough readings with the use of a computer software package (NVivo). I am also planning to check a sample of my analysis with an independent assessor, who is an experienced researcher with no other connection with this study or any of the participants. This procedure has been included so as to reduce any 'personal biases' on my part in how I interpret the data. I will then make contact with all participants in these groups to further explore themes arising from the initial interviews. These second round interviews will be 'face-to-face' as far as possible, though telephone or E-mail contact may be used if distances are large or people are otherwise unavailable. These are expected to be no more than 60 minutes in duration.

If you are willing, the interviews will be recorded, using a digital that is compatible for use with my computer. I will supply you either with a full transcript of the content and/or with a summary that you can check for accuracy and discuss with me as required. On reading the transcripts and/or summaries you will also be able to let me know of anything you would like to add, and of any material which on reflection you would prefer to have deleted. When all work on the research project has been completed, all recordings, computer files and 'hard copies' will be deleted/destroyed, and a witness will sign a declaration that he/she has seen this being done.

I anticipate having gathered all interview material and other information by the end of 2005. I am planning to have an interim report ready for all participants by the end of April 2006, with a full summary of my findings being sent out to everyone involved by December 2006. Should circumstances require changes to this time-scale I will inform you and give revised deadlines etc.

I can assure you that all information given to me will be treated in the strictest confidence. In any ensuing presentation of the research material I will use pseudonyms instead of participants' real names, and will discuss with you if other identifying details should be obscured to protect your anonymity *UNLESS* you request otherwise. These principles will also apply to any people or organisations you mention in your interviews. The data from the project will be kept in a secure location at my home to which only I will have access. The data will not be used for any other project without re-gaining your consent. The independent assessor, who will see some of the data, is, as noted above, an experienced researcher and I will review all confidentiality issues with him and ask him to sign a confidentiality agreement with respect to this study.

As you will see from the attached form, you have the right to withdraw from the project at any point during the course of the study by simply informing me that you wish to do so. I can also confirm that I will not seek to discuss the reason(s) for any such decision unless you indicate that you wish to have a discussion with me.

The study has been given ethical approval by the university ethics committee, and meets the requirements of the Data Protection Act (1998). The consent form is attached to this letter.

I look forward to hearing from you

Yours sincerely

Martin Hillary

(also known by my Buddhist name as Dayasara)

Appendix D-Participant Information Sheet for *Anticipating Care Needs* group (formerly known as Group A)

SECTION A: THE RESEARCH PROJECT   (Group A information)

Project Title: Long-term care issues in a British-founded Buddhist movement.

An overview of the project:

The purpose of this study is to explore long-term care issues in the Friends of the Western Buddhist Order (FWBO), and I am planning to meet primarily with FWBO Buddhists to find out more about;

1. Their views of 'mainstream' long-term care services in health and social care.

2. Their views as to possible Buddhist-based care services that might emerge in the future.

I am an Order Member in the FWBO, with a work background in nursing, professional education and research. I am planning to seek information from 4 groups of people, and I am requesting that you participate as a member of what I have called Group A. Group A will comprise FWBO Buddhists who will be asked to anticipate their preferences in relation to care needs should these arise in the future (the group name being derived from the letter A in the word 'anticipate'). I will be pleased to give further information on the other groups involved, so please let me know if you would like this. In this document, however, I will focus on details that seem likely to be relevant to Group A people.

My main objective in the interviews will be to find out about people's concerns and interests in relation to long-term care. Thus although I will have an initial schedule of basic questions for use in the interviews I will aim for a flexible approach so that participants can make their views and experiences known as fully as possible.

The initial schedule for Group A has 23 questions. Participants in this group will be asked to express preferences should they have significant care needs in the future. It is expected that these preferences will be linked to overall views about long-term care, and usually to some level of experience of relevant services e.g. observing a friend or relative receiving such services, liaison with relevant services as an 'informal' carer, working in the care field etc.

This interview material will be analysed and further contact made with participants to follow up on key themes arising. The research will be written up as an academic dissertation, discussing the findings with reference to ideas about diversity e.g. do

FWBO Buddhists have particular needs, and if so how could these be best met? Other central themes will be 'community' and 'values', in relation to the FWBO and the long-term care needs of some people involved with it.

I believe the study will potentially have 2 main benefits. Firstly, there is increasing discussion within the FWBO of long-term care issues, but there has been no formal research to explore FWBO Buddhists' hopes, fears preferences etc in this area. Secondly, the UK's 152,000 Buddhists (2001 census) appear not to have been studied as to their experiences and views of mainstream care services, and this study may make some contribution to better understanding. It is my intention that the research will be used to influence developments in the future, especially in the FWBO where various responses to long-term care issues are under consideration.

SECTION B: YOUR PARTICIPATION IN THE PROJECT
The invitation:

I have invited you to contribute to the study because:

I believe you have experience and/or ideas relating to the study's subject area, and I would welcome the opportunity to discuss these with you, thus also taking forward the overall research project.

If you decide that you would like to take part, I will contact you to make a mutually convenient time to meet with you during (*relevant month to be inserted).* The research will take a mainly 'qualitative' approach, so that I am interested hearing about people's experiences and ideas in some depth, rather than in trying to draw lots of statistical conclusions. Nonetheless, through a range of methods I hope to derive a reasonably full picture of long-term care issues in the FWBO.

For participants in Group A , I am expecting the initial interview to take 60-90 minutes. I am happy to travel (where applicable) to your workplace, private home or other convenient location, though if you would like to make other arrangements please let me know. When all the initial interviews for these groups have been completed, I will analyse the data, combining thorough readings with the use of a computer software package (NVivo). I am also planning to check a sample of my analysis with an independent assessor, who is an experienced researcher with no other connection with this study or any of the participants. This procedure has been included so as to reduce any personal biases on my part in how I interpret the data. I will then make contact with all participants in these groups to further explore themes arising from the initial

interviews. These second round interviews will be 'face-to-face' as far as possible, though telephone or E-mail contact may be used if distances are large or people are otherwise unavailable. These are expected to be no more than 60 minutes in duration.

If you are willing, the interviews will be recorded, using a digital voice recorder that is compatible for use with my computer. I will supply you either with a full transcript of the content and/or with a summary that you can check for accuracy and discuss with me as required. On reading the transcripts and/or summaries you will also be able to let me know of anything you would like to add, and of any material which on reflection you would prefer to have deleted. When all work on the research project has been completed, all recordings, computer files and 'hard copies' will be deleted/destroyed, and a witness will sign a declaration that he/she has

seen this being done.

I anticipate having gathered all interview material and other information by the end of February 2006. I am planning to have an interim report ready for all participants by the end of April 2006, with a full summary of my findings being sent out to everyone involved by December 2006. Should circumstances require changes to this time-scale I will inform you and give revised dead-lines etc.

I can assure you that all information given to me will be treated in the strictest confidence. In any ensuing presentation of the research material I will use pseudonyms instead of participants' real names, and will discuss with you if other identifying details should be obscured to protect your anonymity *UNLESS* you request otherwise. These principles will also apply to any people or organisations you mention in your interviews. The data from the project will be kept in a secure location at my home to which only I will have access. The data will not be used for any other project without re-gaining your consent. The independent assessor, who will see some of the data, is, as noted above, an experienced researcher and I will review all confidentiality issues with him and ask him to sign a confidentiality agreement with respect to this study.

As you will see from the attached form, you have the right to withdraw from the project at any point during the course of the study by simply

informing me that you wish to do so. I can also confirm that I will not seek to discuss the reason(s) for any such decision unless you indicate that you wish to have a discussion with me.

The study has been given ethical approval by the university's ethics committee, and meets the requirements of the Data Protection Act (1998). The consent form is attached to this letter.

I look forward to hearing from you

Yours sincerely

Martin Hillary (also known by my Buddhist name as Dayasara)

Appendix E-Participant Information Sheet for *Expertise* group (formerly known as Group E)

SECTION A: THE RESEARCH PROJECT

Project Title: Long-term care issues in a British-founded Buddhist movement.

An overview of the project:

The purpose of this study is to explore long-term care issues in the Friends of the Western Buddhist Order (FWBO). This was founded in London in 1967 by Sangharakshita, a UK-born spiritual teacher. Somewhat associated with the hippie culture of the time, the FWBO attracted mainly young disciples, many of whom worked full-time in establishing urban Buddhist Centres, rural retreat centres, Buddhist work projects etc. In 2005 the average age of the UK's 600 Order Members (i.e. those who have taken a non-monastic spiritual ordination) is 47. There are Order Members in their seventies, and there appear to be an increasing number of people around FWBO Centres who have health and social care needs. Especially amongst those who have worked full-time for the movement there may be concerns about financial and social support in later life. This in turn raises questions as to any 'special needs' which Buddhists requiring long-term care might have, and as to Buddhist-based care projects which have sometimes been discussed.

Most of the data I collect in this study will come from interviews and other material obtained from FWBO Buddhists, whereby I hope to find out more about;

1. Their views of 'mainstream' long-term services in health and social care.
2. Their views as to possible Buddhist-based care services that might emerge in the future.

In addition, I am inviting participation from a small group of people with specific knowledge and/or skills in relation to long-term care issues. I am requesting that you participate as a member of this group which I have called Group E (the group name being derived from the letter E in the word 'Expert').

I anticipate that the data obtained from the FWBO Buddhist participants and from Group E will give a reasonably detailed picture of key aspects. Group E input is likely to be of particular value in ensuring that the major contemporary issues in long-term care are duly reflected in the study, and that there is an interaction between questions as to what people are saying they would like, and what might actually be available/possible.

The research will be written up as an academic dissertation, discussing the findings with reference to 3 cultural themes, these being 'diversity', 'community' and 'values'.

I believe the study will potentially have 2 main benefits. Firstly, there is increasing discussion within the FWBO of long-term care issues, but there has been no formal research to explore FWBO Buddhists' hopes, fears preferences etc in this area. Secondly, the UK's 152,000 Buddhists (2001 census) appear not to have been studied as to their experiences and views of mainstream care services, and this study may make some contribution to better understanding. It is my intention that the research will be used to influence developments in the future, especially in the FWBO where various responses to long-term care issues are under consideration.

SECTION B: YOUR PARTICIPATION IN THE PROJECT

The invitation

I have invited you to contribute to the study because:

I believe you have experience and/or ideas relating to the study's subject area, and I would welcome the opportunity to discuss these with you, thus also taking forward the overall research project.

If you decide that you would like to take part, I will contact you to make a mutually convenient time to meet with you during (*relevant month to be inserted)*. The research will take a mainly 'qualitative' approach, so that I am interested hearing about people's experiences and ideas in some depth, rather than in trying to draw lots of statistical conclusions. Nonetheless, through a range of methods I hope to derive a reasonably full picture of long-term care issues in the FWBO.

In Group E, each participant will have different knowledge/ experience to draw upon, so it is not possible to have a standardized structure for the interviews. However, if you decide you would like to take part, I will send you a Consent Form for signature , and I will be pleased to discuss any other aspects of the research which you might like to know about. I will also be in contact to discuss the first interview so that an outline 'agenda' can be agreed, and I can post or E-mail confirmation of this to you. Thus, for example we might agree to focus mainly on sheltered housing, home care issues, financial questions etc. Some issues may arise from the interviews with FWBO Buddhists, and I believe it will be possible to discuss general themes from these interviews whilst respecting the confidentiality of individual participants.

For participants in Group E, I am expecting the initial interview to take 60-90 minutes. I am happy to travel (where applicable) to your workplace, private home or other convenient location, though if you would like to make other arrangements please let me know. I anticipate that in many cases one interview will be sufficient, though if additional issues arise perhaps further contact may be helpful e.g. by telephone, E-mail or in person , and I will always check as to whether this is convenient to you or not. For the interviews with FWBO Buddhists I have planned to use an NVivo software package as part of the data analysis. Also I have planned to sample some of the material with an independent assessor who is an experienced researcher with no other connection with this study or any of the participants (with a view to reducing any 'personal biases' on my part in how the data is interpreted). Whilst I believe that the independent assessor and NVivo software are unlikely to be utilised for the Group E data, it is possible that this may be appropriate depending on the themes and issues discussed in particular interviews.

If you are willing, the interviews will be recorded, using a digital voice recorder that is compatible with my computer. I will supply you either with a full transcript of the content and/or with a summary that you can check for accuracy and discuss with me as required. On reading the transcripts and/or summaries you will also be able to let me know of anything you would like to add, and of any material which on reflection you would prefer to have deleted. When all work on the research project has been completed, all recordings, computer files and 'hard copies' will be deleted/destroyed, and a witness will sign a declaration that he/she has seen this being done.

I anticipate having gathered all interview material and other information by the end of 2005. I am planning to have an interim report ready for all participants by the end of April 2006, with a full summary of my findings being sent out to everyone involved by December 2006. Should circumstances require changes to this time-scale I will inform you and give revised dead-lines etc.

I can assure you that all information given to me will be treated in the strictest confidence. In any ensuing presentation of the research material I will use pseudonyms instead of participants' real names, and will discuss with you if other identifying details should be obscured to protect your anonymity *UNLESS* you request otherwise. These principles will also apply to any people or organisations you mention in your interviews. The data from the project will be kept in a secure location at my home to which only I will have access. The data will not be used for any other project without

re-gaining your consent. The independent assessor, who will see some of the data, is, as noted above, an experienced researcher and I will review all confidentiality issues with him and ask him to sign a confidentiality agreement with respect to this study.

As you will see from the attached form, you have the right to withdraw from the project at any point during the course of the study by simply informing me that you wish to do so. I can also confirm that I will not seek to discuss the reason(s) for any such decision unless you indicate that you wish to have a discussion with me.

The study has been given ethical approval by the University's Ethics Committee, and meets the requirements of the Data Protection Act (1998). The consent form is attached to this letter.

I look forward to hearing from you

Yours sincerely

Martin Hillary

(also known by my Buddhist name as Dayasara)

Appendix F- Consent Form (for interviews)

Valley View
Hadleigh Rd
Ipswich IP2 0BT

NAME OF PARTICIPANT:

Title of the project: Long term care issues in a British-founded Buddhist movement

Main investigator and contact details: Martin Hillary (Buddhist name Dayasara), Valley View, Hadleigh Rd, Ipswich IP2 0BT. Telephone 01473-252821, 07748-375923 (mobile), E-mail Dayasara2001@yahoo.co.uk

1. I agree to take part in the above research. I have read the Participant Information Sheet which is attached to this form. I understand what my role will be in this research, and all my questions have been answered to my satisfaction.

2. I understand that I am free to withdraw from the research at any time, for any reason and without prejudice.

3. I have been informed that the confidentiality of the information I provide will be safeguarded.

4. I am free to ask any questions at any time before and during the study.

5. I have been provided with a copy of this form and the Participant Information Sheet.

Data Protection: I agree to the University' processing personal data which I have supplied. I agree to the processing of such data for any purposes connected with the Research Project as outlined to me*

"The University" includes APU and its partner colleges[4] ~~"The University" includes APU and its partner colleges~~

_____

Name of participant (print)......................................Signed ....Date....................

Name of witness (print)..Signed............................Date ....
YOU WILL BE GIVEN A COPY OF THIS FORM TO KEEP

-
If you wish to withdraw from the research, please complete the form below and return to the main investigator named above.

Title of Project: Long Term Care Issues in a British-founded Buddhist movement
I WISH TO WITHDRAW FROM THIS STUDY
Signed_____   Date:

General information

This questionnaire is part of the work I am doing on long-term care issues in the FWBO. For this I am doing a research degree (MPhil) with Anglia Ruskin University (Cambridge and Chelmsford).People completing the questionnaire will be treated as 'anonymous' when I write up the results. All information you give here will be treated as confidential, and you can withdraw from the study at any time by contacting me and asking for your responses to be taken out, with no need to give any explanation. Please make a note of your Questionnaire Number, in case you wish to withdraw or wish to discuss other points..

There has been discussion over the years about the possible development of Buddhist-based care services. This means services which are founded on Buddhist principles, and which are staffed by people sympathetic to such principles. It is expected that many non-Buddhists would receive care from such services, though a significant number of ill/disabled Buddhists might also receive the services. Similarly it is anticipated that such services would employ 'sympathetic' non-Buddhists, whilst probably employing a significant proportion of Buddhists.

'Care service(s)' could mean offering people care in their homes, offering day care services, offering sheltered/ very sheltered housing, setting up residential/nursing care homes, or giving some other form of 'paid' care. If when responding to an item you wish to make it clear which type of care you have in mind, please use the 'Please add comments' box-see next paragraph. For care services which are not Buddhist-based I have used the general term 'mainstream services'.

You will notice that there is a space after each question inviting additional comments. These comments are very useful to me, and you are welcome to add comments on as many questions as you wish; if the 'box' is too small, please continue your comments at the end of the questionnaire. However, if you are short of time, I would suggest reading through the questionnaire and deciding which questions you would like to prioritise in terms of adding comments. I am anticipating that most people will complete the questionnaire within 15-30 minutes.

At the end of the questionnaire I have asked for some brief additional information. This will be useful to me, for example to see any patterns of response which may be influenced by people's age, gender, being ordained, being a mitra etc. Again, all this information will be anonymous and treated as confidential.

Please respond to the following statements by choosing one of the following categories; "Disagree strongly", "Disagree" "Undecided","Agree", "Agree strongly". Please just place a tick in the box for the category which comes closest to your opinion on the statement. Don't spend too long thinking about them-trust your initial response as far as possible. If you really feel unable to give an opinion please choose "Undecided"- however, it is helpful to me if answers in this category are kept to a minimum.

1. Buddhist-based care services would take a lot of money and energy to set up, and are unlikely to actually develop on any significant scale .

Disagree strongly	Disagree	Undecided	Agree	Agree strongly

Please add any comments

2. Buddhist-based care services are likely to offer better diets for vegetarians and vegans than most mainstream services.

3. Buddhist-based care services might have the effect of 'cutting people off' from the wider, non-Buddhist world, and this would be unhelpful

4.There are 'bossy' and 'difficult' people in the Buddhist world and they might have a negative effect in a Buddhist-based care service.

5. Buddhist-based care services might reduce the risk of ill/disabled Buddhists being isolated and neglected.

6. Buddhist names (given at people's ordinations) are more likely to be understood and respected by staff in a Buddhist-based care service than staff in a comparable non-Buddhist service

7. The FWBO should develop care services because Buddhists often find themselves too busy to offer ill/disabled spiritual friends the help they need.

8. In Britain there are long-term care services provided for everyone who requires them, so our worries about ill/disabled Buddhists may be exaggerated, and usually they will get the input they need.

9. When most people need personal/intimate care they are likely to prefer this being given by some-one who attends only for that purpose, rather than by a person who is also a Buddhist spiritual friend.

10. It is a mistake to expect Buddhist-based care services to be more 'compassionate' than mainstream services.
.

11. Buddhist-based care services may help Buddhists to be in contact with 'like-minded' people.

12. An effective care service needs a high level of organisational and professional skills, and these may not be available to a Buddhist-based care service.

13. Buddhists often place a high value on quiet reflection and opportunities to meditate, and a Buddhist-based care service might respect this relatively well.

14. Buddhists can find that illness/disability brings them into contact with people who want to press different religious views upon them; Buddhist-based care services may make this less likely to happen.

15. A Buddhist-based care service could offer new opportunities for Buddhists to work together and to make their work more of a 'spiritual practice'

16. Recruiting and supporting suitable staff is a real problem in long-term care, and this means that good quality Buddhist-based care services are unlikely to be feasible.

17. Many people receiving long-term care may appear to have relatively dull lives with little fulfilment or creative activity; Buddhist-based services might address this problem "better than most"

18. Buddhists working in care would do better to focus on improving services in the wider world rather than putting their energy into Buddhist-based care services

19. Buddhists are interested in developing their 'mindfulness', and this might be an advantage in Buddhist-based care services.

20. Individual Buddhists should be encouraged to take responsibility for themselves when considering care needs and financial support, as movements such as the FWBO may not have the resources to offer much help.

It would be helpful to have the following additional information, which will be treated as confidential. Please place a tick next to the applicable category, or enter the information (for example your age) as requested.

Age
Male/Female

Length of involvement with FWBO-
  Less than one year
 1-2 years
 2-5 years
5 years plus
10 years plus
20 years plus

Do you have personal experience of long-term care issues? If so, it would be helpful if you would specify what this experience is- for example,. having care needs yourself, being a carer for a relative or friend, working in the care sector,or other .

Are you:

A friend of the Centre

A mitra

Some-one who has asked for Ordination

An Order Member- for less than 5 years

> - *for 5-10 years*
> - *for 10 years plus*
> - *for 20 years plus*

With thanks and Metta- Dayasara

Appendix H- Results from Questionnaire

This Appendix presents a selection of results from the Questionnaire (see Appendix G for full details of questionnaire items and other aspects). Firstly Table 3 shows each of the 20 items with the mean scores and the number of additional comments made by participants, plus rankings. Then Table 4 focuses on 'agreement', showing scores of 5 (Agree strongly) and 4 (Agree), again with rankings. Pages 237-8 shows an Analysis of Variance of scores based on Gender and Categories of Involvement in Triratna/FWBO.Finally additional information gathered from participants is explored.

Items 1-20	Average score/ranking 1-20	Number of additional comments/ranking 1-20
1.BBCS-money&energy	3.17 (19th)	55 (3rd)
2.Vegetarian/vegan diets	4.41 (3rd)	31 (joint 13th-see items 14 & 17)
3.BBCS-cutting people off	4 (8th)	46 (6th)
4.Bossy/difficult people	3.63 (12th)	60 (1st)
5.Risk of isolation/neglect	4.05 (6th)	36 (12th)
6.Buddhist names	4.02 (7th)	26 (16th)
7.Too busy to help	3.17 (18th)	53 (4th)
8.LTC for everyone	3.77 (11th)	57 (2nd)
9.Personal/intimate care	3.43 (joint 15th-see item 16)	51 (5th)
10.More compassionate?	3.42 (17th)	45 (joint 7th- see items 16& 20)
11.Like-minded	4.17 (5th)	16 (20th)
12. Organisational skills	3.6 (13th)	44 (10th)
13.Reflection/meditation	4.43 (2nd)	23 (17th)
14.Others' religious views	3.56 (14th)	31 (joint 13th-see items 2&17th)
15. TBRL as practice	4.48 (1st)	18 (19th)
16.Staff problem	3.43 (joint 15th-see item 9)	45 (joint 7th-see items 10& 20)
17. Dull lives/activities	3.82 (10th)	31 (joint 13th-see items 2&14th)
18.Wider world	3.84 (9th)	40 (11th)
19.Mindfulness	4.2 (4th)	20 (18th)
20.Responsibility for selves	2.34 (20th)	45 (joint 7th-see items 10&16)

Table 3 - Questionnaire scores and comments

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Presenting these findings in the above format highlights the phenomenon of what I have termed 'opposite halves', so that items which attracted a relatively high numerical score which places them in the upper (1-10) half of that ranking scale were typically found in the *lower* half of the ranking scale for the number of additional comments. The picture is somewhat complicated by the number of joint rankings, but these apart there are 12 instances where items appear in the opposite half of the ranking scale for the two relevant values. Taking two examples, item 15 ranks first in the average numerical score but 19th as to the number of additional comments, whilst item 4 attracts the highest number of additional comments but has the 12th in the ranking of average scores. Interpretation of this trend is offered in Chapter Ten-see page 170.

Items 1-20	Number of 5s scored	Number of 4s scored	Aggregated 4s+5s total and ranking 1-20
1.BBCS-money& energy	8 (16th)	41 (joint 16th)	49 (18th)
2.Vegetarian/vegan diets	59 (joint 1st)	41 (joint 16th)	100 (joint 3rd)
3.BBCS-cutting people off	23 (9th)	69 (2nd)	92 (6th)
4.Bossy/difficult people	17 (joint 10th)	53 (9th)	70 (12th)
5.Risk of isolation/neglect	39 (4th)	48 (12th)	87 (8th)
6.Buddhist names	34 (5th)	55 (7th)	89 (7th)
7.Too busy to help	7 (joint 17th)	41 (joint 16th)	48 (19th)
8.LTC for everyone	25 (8th)	49 (11th)	74 (11th)
9.Personal/intimate care	12 (joint 13th)	41 (joint 16th)	53 (17th)
10.More compassionate?	12 (joint 13th)	54 (8th)	66 (14th)
11.Like-minded	33 (6th)	66 (5th)	99 (5th)
12.Organisational skills	17 (joint 10th)	52 (10th)	69 (13th)
13.Reflection/meditation	56 (3rd)	45 (joint 14th)	101 (2nd)
14.Others' religious views	6 (19th)	60 (6th)	66 (14th)
15. TBRL as practice	59 (joint 1st)	45 (joint 14th)	104 (1st)
16.Staff problem	7 (joint 17th)	47 (13th)	54 (16th)
17.Dull lives/activities	12 (joint 13th)	70 (1st)	82 (joint 9th)
18.Wider world	15 (12th)	67 (4rd)	82 (joint 9th)
19.Mindfulness	32 (7th)	68 (3rd)	100 (joint 3rd)
20.Responsibility for selves	3 (20th)	13 (20th)	16 (20th)

Table 4 - Questionnaire '5' and '4' scores

This alternative presentation of key questionnaire scores is based on the numbers of 5s and 4s scored for each item with ranking scales, and an aggregated total for those scores

with a further ranking scale. Scores of 5 and 4 collectively are taken to represent levels of concordance with the general idea of developing Buddhist-based care services (BBCS). With item 15 and others a score of 5 signals that participants 'Agree strongly' and 4 that they 'Agree'. For some items (such as item 10 on BBCS's being potentially more compassionate or not) the statement's valence is reversed so that the participant would *disagree* with the statement to register concordance with the general idea of BBCSs.. It is notable that 4 is the modal score for generalised questionnaire response and accounts for 47.9% of all scores generated by participants.

Analysis of Variance

This was undertaken for two variables, Gender and Category of Involvement in Triratna/FWBO, and to check for any interaction between the variables. The latter refers to 6 categories into which participants can be divided, and which are taken as indicating ascending levels of involvement in the movement. Three categories comprise non-ordained people, these being **Friend** (someone attending classes but not necessarily seeing her/himself as a Buddhist), **Mitra** (someone who has had a ceremony 'declaring' her/himself as a Buddhist) and **Postulant** (someone who requested ordination, also referred to as a Man/Woman who has asked for ordination).

For Order Members there were three categories, these being **New** (ordained for less than 10 years), people ordained for **10-20 years**, and people ordained for **more than 20 years.** It was taken that longer duration of ordination could be equated in some measure with relatively greater 'involvement' with the movement. Thus it was also noted that amongst the 9 participants who had been ordained for **more than 20 years** 'full-time' involvement was higher in this than any other group (5 lived at retreat centres, one worked at a TBRL and was formerly a member of the women's ordination team, and 2 were Public Preceptors taking on major responsibilities for ordinations and key aspects of the movement's development). Thus at least in terms of lifestyle there was some relationship between length of ordination and Involvement in Triratna/FWBO. Results from the analysis are shown below in Table 5

Term	Degrees of Freedom	Sum square	Mean square	F value	Probability (< F)
Category (of Involvement)	5	471.7	94.344	1.8631	0.1081
Gender	1	0.1	0.078	0.0015	0.9688
Category AND Gender	5	345.5	69.093	1.3644	0.2446
Residuals	5	4810.7	50.639		

Table 5 - Questionnaire - Analysis of Variance

None of the 3 'terms' (as shown in the far left column) were found to be significant at the less than 0.05 level, although Category was found to have a weak effect in this sample.

Age was initially included in the above analysis, but was found problematic as a variable with multiple levels. However, with ages available for all but 4 participants it was possible to make some observations about 'age' and these are included on page 239 below.

Additional information requested from participants

Age

This as requested at the end of questionnaire yielded some valuable material on the 52 women and 55 men who participated. There was some 'missing data', with for example one man and three women not disclosing their. These non-disclosers apart, participants' average ages were 52.69 for women and 45.89 for men. It should be noted that participants were drawn from the whole Triratna *movement* , and thus included Friends, Mitras and Postulants as well as Order Members. Nonetheless for both sexes Order Members were the largest group in the samples, with 29 women and 33 men. Taking Lokabandhu's (2007) figures this appears close to the average age for women Order Members of 51.7. Potentially this has become closer still with his 2009 assertion that average age continues to rise and that it is over 50 for Order Members of both sexes. The male sample was relatively higher in its proportion of Order Members and had a notable deviation from Lokabandhu's (2007) figure of a 49.3 male average age in the Order. Also it can be noted that the women's sample included only 2 people under 40, whilst the men's had 19 participants under this age- see page 134 above on this.

Relating this to Category of Involvement as discussed on page 237 above, one group that appeared worthy of exploration as to age factors were Order Members ordained for **more than 20 years.** This category included the questionnaire participant of 83 years, QP23, plus three people who were 60 years of age and four in their fifties. It can be noted that this group's average score of 78.55 was higher than the average score across all categories. This was 74.96 for all participants, and was 74.63 if the **more than 20 years** ordained group's scores were excluded. However, the group itself was small and effects of 'category' were non-significant overall, but further investigation of relevant attitudes in longer ordained people may prove of interest.

Informal care

Enquiry on this indicated much higher levels of involvement of women than men. It must be noted that information was minimal and gleaned from responses to the question on the final page as to *"Do you have personal experience of long-term care issues?"* and if so if this included *"being a carer to a relative or friend?"*. Typical responses included *"Mother-her carer and organised her carer"* (QP39) or *"Parents in sheltered accommodation"* (QP17). The latter was not unusual in not giving specific information on the research participant's level of involvement, and there was a strong element of

self-definition in classing oneself as a carer. Clearly there was much potential scope in seeking further background on this, which was done in the present study. Nonetheless it was notable that 26 of the 52 female participants referred to some experience of this type, giving a score of exactly *50% for women.* Male responses included *"Have had three relatives in residential care"* (QP87), but there were only 5 men out of 55 participants disclosing anything of this kind so a score of *9.09% for men* was found.

When the scores of all those declaring informal care experience are taken together as a group, an average score of 74.27 emerged, which was very close to the average total score for all participants of 74.96.

Paid work in care sector

33 participants disclosed paid work, current or in past, in the care sector. This included work as social workers, nurses, doctors, psychologists, project workers in
learning disability, support workers with the elderly and in mental health, and other non-specific involvement as for example QP15 who wrote she had been a *"professional in the care sector for 21 years"*. Much of the work cited by people appeared to be non-specific to elderly LTC, but the policy was include participants as having paid care experience if they had cited such work on their questionnaire. The reasoning here was that by virtue of referring to such work they were (at least implicitly) claiming this as relevant in their completion of the questionnaire.

In terms of gender there was a remarkable distribution, with *22 women (42.3%)* citing such experience and *11 men (20%)* , which would have been an exact 2:1 ratio
if not for the slightly larger male sample in the study.

Grouping together the data for all people with paid work experience revealed an average score of 74.43, which again was notably close to the average score for all participants of 74.96.

'Having care needs oneself'

This was included as a variable which might well influence attitudes to LTC. It proved to be a small group (7 in total) within the questionnaire participants, with wide-ranging needs and situations being mentioned. To give some examples, QP48 was severely disabled with Multiple Sclerosis, QP31 had had a broken leg recently, QP23 was in her eighties and had had hospital admissions and QP99 (though generally fit and well) had

some level of Rheumatoid Arthritis which was likely to get worse. Overall 'having care needs oneself' appeared to be a factor worth investigating

within questionnaire participants and potentially augmenting related material from the Current Care needs interviews. At the same time the smallness and heterogeneity of the group appeared likely to limit its salience of its data. Again the score derived from this group's data showed minimal deviation from the mean for all participants, with a group average of 73.57.
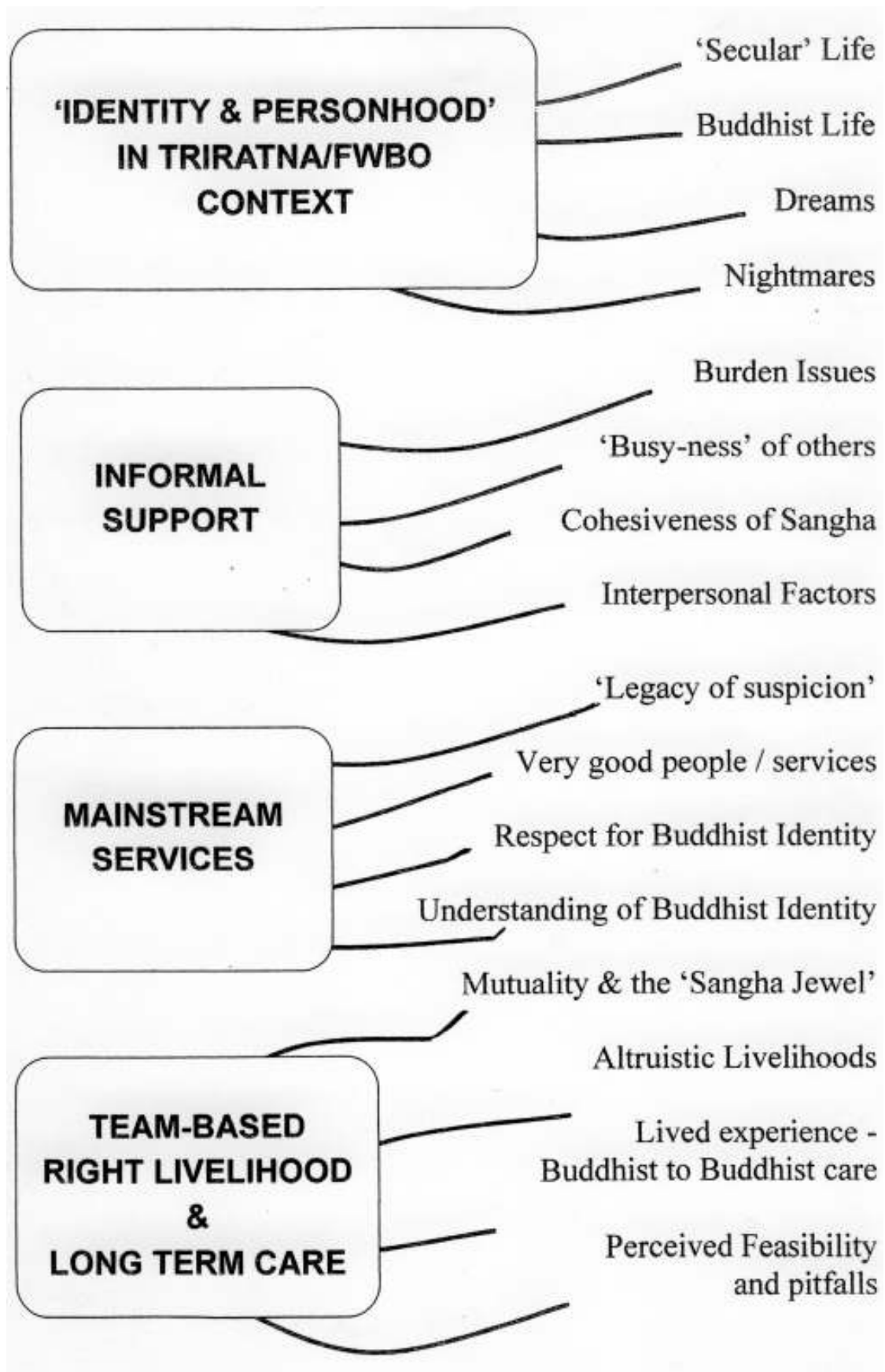
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