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# **Caring and Coping: The Family Perspective on Living with Limb Loss**

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## Foreword

This research commenced with the title 'Blesma Families Study'. We always knew families played a key part in recovery and rehabilitation, albeit quietly, but this was based on experience rather than documented investigation. We sought harder evidence. What we found is family members as primary carers, some officially recognised as such. This fostered the title 'Caring and Coping: The Family Perspective on Living with Limb Loss'. Seeing a partner or close family member as such is a step change in parameters.

This report is based upon Grounded Theory. That is to say the interviewees talk freely and the conversations are all theirs. There are other conversations that could be added; local authority social care agencies, NHS GPs and Limb Centres, to name but three. However, it is the subject and those closest to them that have to endure and, if their independence and fulfilment are to be improved, it is their story we must listen to first. The other point to note is that we deliberately focussed upon a cohort other than Iraq and Afghanistan Veterans. This cohort has not had the benefit of modern and more comprehensive recovery and rehabilitation pathways now in train as a result of these recent conflicts.

What we have found is that the journey for the subjects and their carers has largely been episodic rather than holistic and while supporting agencies have usually delivered their required services satisfactorily there are gaps between. These gaps are very personal, detailed and very much tied to everyday living and the challenges therein. They are most often matters that the majority of us do not ever have to deliberately think of.

This report sets down some very good frameworks, largely tactical rather than operational or strategic. They can apply in very individual circumstances and acknowledge that subjects and their carers can be in 'different places' physically and emotionally at the same time. The tactical impact of supporting agencies can be more complete if these frameworks are adopted on a more formal basis than they are now, by practitioners in the field. The operational impact will come from supporting agencies filling in the gaps noted above for their clients and beneficiaries on a more widespread basis. The strategic message is that all who operate in this realm need to keep doing what they do now but better, in a deeper and more coordinated fashion; making absolutely sure the basics are being addressed and woven together.

There is still scope for agencies to be closer in their communications with one another and the subjects and their carers. This report should certainly be a prompt at the local level. As far as Blesma is concerned, we have identified information and training on coping with limb loss as areas to refresh; this will also help counter the feeling of isolation. Fortuitously a LIBOR grant is going to enable us to invest more in supporting Members in their own communities, for which we are grateful, and we thank the Forces in Mind Trust and The National Lottery for funding this timely Report; it seems the identified need and matching resources are aligned.



**Barry Le Grys MBE**  
Chief Executive, Blesma

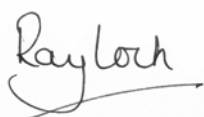
## Foreword

This helpful and interesting report highlights the work that can, and should, be undertaken to improve the lives of those living with the limb loss of a family member. Much of the report is positive, and this reflects the fine leadership of Blesma in this area, although, as the report honestly acknowledges, inevitably there is some effect of the subjects' self-selection. So we warmly welcome the list of Recommendations, and would urge those stakeholders with responsibility to look closely through them, and apply them with vigour and determination.

It is worth highlighting two areas of common ground that this report's Recommendations enjoy with much of our work across the whole range issues affecting the ex-Service community. Key amongst the Recommendations, and perhaps unsurprisingly given the title of the study, is the need to support the whole family unit and not just the Service leaver/person with limb loss. We know that transition out of service is more successful for those from a strong family, and that any support should therefore be both targeted at, and mindful of, the family unit. These needs, as the report highlights, will vary over time, and often be subject to complex co-morbidity. A tailored approach will deliver greatest success.

The second area is that of communications. As with so many aspects of supporting the Armed Forces Community, solutions are less about providing greater resources, and more about ensuring that those which are already available are better understood by potential service users, and better coordinated. No one mechanism alone will be successful; but a layered, constant and consistent messaging from service providers tuned to the needs of users should ensure the best chance of matching those needs with provision.

The hard work of the research team is, for now, nearing an end. The harder work for those supporting families coping with, and caring for, those living with limb loss continues.



**Air Vice-Marshal Ray Lock CBE**  
**Chief Executive, Forces in Mind Trust**

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## Executive Summary

This report presents findings of research into how veterans with limb loss, and their families, live with limb loss. Using Grounded Theory, data has been collected from 72 veterans and family members using unstructured interviews, structured questionnaires and closed question telephone interviews. Findings indicate, firstly, that the central concern of veterans with limb loss, and families, is coping during living with limb loss, and that the veteran with limb loss and their carer/s may experience differing levels of coping (low, mid, high) during any specific time period.

Each coping level is characterised by behaviours/characteristics to which appropriate support can be aligned; secondly, there are distinct time periods where certain types of Blesma/organisational support are more likely to effectively support coping ability. This report presents these findings, which are developed into a practical Living with Limb Loss Support Model (LLSM). The LLSM identifies specific periods where timely support is more likely to be relevant and effective in supporting individual needs and coping levels, as further explained in the 'Practical Application of Findings' (see pages 16-23).

Conclusions suggest recommendations for support and practices Blesma and other support organisations could develop, suggestions for future research, and development of an evidence base, that will underpin policy making and service delivery, to enable sustained and positive change for veterans and their families. Furthermore, although this research was carried out with veterans and their family members, the recommendations are intended to be transferable to other persons with limb loss (PWLL) and their families. This is a collaborative study between Blesma and The Veterans & Families Institute for Military Social Research (VFI), at Anglia Ruskin University, and is funded by the Forces in Mind Trust (FiMT).

## Key Recommendations

From the research findings, the following key recommendations are reported as being of central importance. These key recommendations are situated within wider recommendations, which follow afterwards.

### **Recommendation A2**

It is recommended that the work involved in caring within a family unit be recognised as essential in maintaining the PWLL's independence. Routines that persons have in place to facilitate independent living need better recognition, and it is recommended that the work that goes into establishing these routines be acknowledged. Recognition of this aspect of caring may be specifically relevant in the 'being home' and 'adapting to being with limb loss' stages (as demonstrated in the Living with Limb Loss Support Model, see page 22).

### **Recommendation B1**

PWLL and their main family carer/s can experience different levels of coping to each other at the same time. Examples of coping, and recognition of coping levels, are detailed in this report, and it is recommended that these are used as a basis for assessing coping levels of the PWLL and their main family carer/s separately. It is also recommended that application of the LLSM be evaluated to assess its effectiveness in identifying individual levels of coping and support.

### **Recommendation C1**

There are key stages in the limb loss life course that have specific requirements, as presented in the Living with Limb Loss Support Model (page 22). It is recommended that support relevant to each stage be identified in accordance with the needs and circumstances of the PWLL/family carer/s. It is recommended that application of this model be evaluated to assess its effectiveness in supporting independence and wellbeing for longer in PWLL and their family carer/s.

### **Recommendation D3**

It is recommended that the status of the veteran and the obligations set out in The Armed Forces Covenant be disseminated within and across health professionals' training and continued professional development, in order for awareness of the veteran to be increased.

### **Recommendation F1**

Specific to veterans with limb loss, experiences of pain may not always be admitted to. This may be due to a military legacy of admitting to pain being seen as demonstrating weakness, but this may also be because individuals do not know how to describe, or explain, phantom pain. Equally, health professionals may not be versed in understanding the effects or consequences of being in the military, and how this might continue to shape the life course, and behaviours and attitudes, of the PWLL, after leaving active service. It is recommended that a crib sheet with questions to ask health professionals be developed, for veterans/PWLL, carers and health professionals to use, in order to describe pain and/or ask relevant questions to explain/assess pain, to assist in appropriate management of pain associated with limb loss. It is recommended that health professionals have additional education about the management of pain associated with limb loss.

## Wider Recommendations

### Group A

#### Supporting the family unit

##### Recommendation A1

It is recommended that opportunities to talk about living with limb loss be offered to individuals. A resounding feature in this research is that no one talks about the limb loss, and no one asks how individuals feel/have managed/have accepted limb loss, leading to feelings of low emotional coping. Individuals with limb loss, main family carer/s, and their wider family and friends, need opportunity to explain possible feelings of sadness/resentment, and how they have/could overcome such feelings. It is important that such support be offered at the individual level within the family caring unit, in order for each person to feel able to express their anxieties safely and without worry, guilt or recrimination.

##### Recommendation A2

It is recommended that the work involved in caring within a family unit be recognised as essential in maintaining the PWLL's independence. Routines that persons have in place to facilitate independent living need better recognition, and it is recommended that the work that goes into establishing these routines be acknowledged. Recognition of this aspect of caring may be specifically relevant in the 'being home' and 'adapting to being with limb loss' stages (as demonstrated in the Living with Limb Loss Support Model, see page 22).

##### Recommendation A3

It is recommended that family carer/s may need support to be assertive in enabling the PWLL to engage with self-care/independent activity. Being assertive is difficult within the family caring unit, even when in the best interests of enabling maximum independence for the PWLL. Being assertive in the caring relationship is not identified in the wider professional and academic literature, and in itself warrants further insight and understanding in order to better support the carers/families of Members.

##### Recommendation A4

It is recommended that generational differences between PWLL are recognised as signalling differing support needs. Younger families look internally into themselves and do not request help from their wider family/friends, and may be more socially isolated because of this. Mature PWLL and their main family carer/s may not admit to/accept needing additional support, with increasing age leading to frustration within the family unit and possible social isolation. Generational differences and accompanying coping and support needs therefore warrant further enquiry.

##### Recommendation A5

It is recommended that organisations consider ways in which information about help and support can be disseminated across the wider family unit. Families generally want to help and support the PWLL and their main carer/s, however, families do not always understand the hidden nature of caring or find it difficult to provide support/care if the PWLL does not admit to needing/refuses family support and care. This needs further exposure.

## **Group B**

### **Recognising and supporting coping in PWLL and their family carer/s**

#### **Recommendation B1**

PWLL and their main family carer/s can experience different levels of coping to each other at the same time. Examples of coping, and recognition of coping levels, are detailed in this report, and it is recommended that these are used as a basis for assessing coping levels of the PWLL and their main family carer/s separately. These key recommendations are situated within wider recommendations which immediately follow this section.

## **Group C**

### **Application of the Living with Limb Loss Support Model (LLSM) across the life course**

#### **Recommendation C1**

There are key stages in the limb loss life course that have specific requirements, as presented in the Living with Limb Loss Support Model (page 22). It is recommended that support relevant to each stage be identified in accordance with the needs and circumstances of the PWLL/family carer/s. It is recommended that application of this Model be evaluated to assess its effectiveness in supporting independence and wellbeing for longer in PWLL and their family carer/s.

#### **Recommendation C2**

It is recommended that the hidden work that occurs, in order for the PWLL to learn to regain independence in living with limb loss, be recognised. In particular, it should be recognised that pre-planning, required in order to leave the home, needs to be explored and possibly further supported, as this can be a source of low coping for both the PWLL and their family carer/s.

#### **Recommendation C3**

It is recommended that particular attention be given to the coping needs of family carer/s, as the PWLL becomes increasingly more confident in their ability to return to independent living. The increasing independence of the PWLL can be excessively worrying for family carers due to worry for wellbeing and safety when they are not there to care for the PWLL. This aspect needs further understanding and exploration.

#### **Recommendation C4**

It is recommended that individual and family goal setting is made significant and realistically achievable to the PWLL, their main family carer/s, and where relevant the wider family. In particular, raising the visibility of small, everyday achievements, and resuming pre-limb loss activity and interests, is important in helping individuals and families cope with limb loss. It is also recommended that the achievement of small goals be recognised and represented in public spaces, such as in relevant literature.

## **Caring and Coping:**

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## **Group D**

### **Recognising the veteran identity**

#### **Recommendation D1**

When limb loss is in relation to veterans, it is recommended that the term veteran be used wisely. Awareness is needed that not all individuals may associate with being a veteran, or consider themselves worthy of veteran status. It needs to be noted that a military legacy may shape behaviours and attitudes differently for each veteran PWLL. For some, a military legacy will provide skills in coping with limb loss and, for others, admitting to needing support may be viewed as weakness. Being a veteran, and having a military legacy in some sense, is deeply personal, and it should not be assumed that all veterans are the same. It is additionally recommended that organisations consider how the term is used in relation to the age of the individual and the circumstance of limb loss, as not all veterans consider themselves as worthy of veteran-specific care and support.

#### **Recommendation D2**

It is recommended that obligations set out in the Armed Forces Covenant are emphasised to veterans and their family carer/s, so veterans are aware that, where their injury may be directly attributable to their time in service, they may be eligible for prioritised treatment and care.

#### **Recommendation D3**

It is recommended that the status of the veteran and the obligations set out in The Armed Forces Covenant be disseminated within and across health professionals' training and continued professional development, in order for awareness of the veteran to be increased.

## **Group E**

### **Care of co/multi-morbidities in PWLL and their main family carer/s**

#### **Recommendation E1**

It is recommended that a forward-looking approach is needed to support PWLL and their main family carer/s in relation to managing co/multi-morbidities, and a wider gaze is necessary to support PWLL and family carers in maintaining each other's wellness and independence. In particular, family carers need to be considered as to how their morbidities are being cared for and managed, and this in particular needs further exploration.

#### **Recommendation E2**

It is recommended that how the PWLL and main family carer worry about each other's co/multi-morbidities be assessed, with relevant inter-professional health and social care support structures put in place to maximise wellness for both. It is recommended that barriers to looking after the individual's morbidities be considered. For example, difficulties in accessing and navigating health services need to be further explored.

## **Group F**

### **Managing phantom limb pain and pain**

#### **Recommendation F1**

Specific to veterans with limb loss, experiences of pain may not always be admitted to. This may be due to a military legacy of admitting to pain being seen as demonstrating weakness, but this may also be because individuals do not know how to describe, or explain, phantom pain. Equally, health professionals may not be versed in understanding the effects or consequences of being in the military, and how this might continue to shape the life course, and behaviours and attitudes, of the PWLL, after leaving active service. It is recommended that a crib sheet with questions to ask health professionals be developed, for veterans/PWLL, carers and health professionals to use, in order to describe pain and/or ask relevant questions to explain/assess pain, to assist in appropriate management of pain associated with limb loss. It is recommended that health professionals have additional education about the management of pain associated with limb loss.

#### **Recommendation F2**

It is recommended that family carers learn about pain related to amputation, as a means of being able to support the PWLL who may experience pain, and to enhance coping levels, of both the PWLL and the family carer/s, in managing pain effectively. Where relevant, this should include younger children who witness their parent in pain, and who want to try to help their parent to minimise their pain. Similarly, mature siblings need information on how to support their older parents in managing pain.

## **Group G**

### **Managing prosthetics and prosthetic services**

#### **Recommendation G1**

It is recommended that information is supplied to PWLL and their family carers on how to manage changes in the stump and use of prosthetics with increasing age. In particular, managing changes in the stump shape, lack of confidence in the prosthetic, and fear of falling, can be a source of anxiety to persons and can lead to social isolation.

#### **Recommendation G2**

It is recommended that health professionals/service providers are aware of possible variations in prosthetic provision and provide support in communicating with and gaining access to services. Variance across provision of prosthetic services needs to be standardised. Limited access to quality prosthetics services is a cause of family anxiety as it debilitates the PWLL.

## **Group H**

### **Organisational support for coping and maintaining independence of the PWLL/carer/family**

#### **Recommendation H1**

Support and information giving needs to be honest and realistic as to what PWLL and family carer/s can expect to experience, and what care will need to be given re living with limb loss. It needs to be noted that peer support/groups for carers/the family do not need to be veteran and limb loss specific, rather they should focus on the caring role itself. Support groups for the veteran with limb loss do not always need to

## **Caring and Coping:**

### The Family Perspective on Living with Limb Loss

be limb loss specific either, rather it is the 'being in the military' that creates commonality in understanding, acceptance and support.

#### **Recommendation H2**

It needs to be understood that gain from planned focussed social activity may be short term; after the activity is complete, or a goal reached, the PWLL may feel a sense of loss and uncertainty as to what to plan next, which may in turn lead to feelings of depression. Support after focussed activity needs to be in place to support individuals, should feelings of isolation be experienced.

#### **Recommendation H3**

It is recommended that the main family carer/s and wider family need more direct information to understand how they can support the PWLL. This should start at the rehabilitation process onwards. Specifically, family carers need access to learning about safe mobilisation of the PWLL, pain management, and how to manage the PWLL's improved independence as living with limb loss becomes more accepted. This could include younger children learning from others who have grown up with limb loss.

## **Group I**

### **Further research needed into loss of use of limb, coping and caring**

#### **Recommendation I1**

It is recommended that further research be undertaken to explore the use of the Living with Limb Loss Support Model, considering variables such as demography and morbidity, and the role of coping as mediator in the individual's and family's adjustment to living with limb loss. This is an area for further enquiry and understanding.

#### **Recommendation I2**

It is recommended that further work is needed to understand how PWLL adapt to their limb loss across the limb loss life course. In particular, the process of 'becoming' with limb loss, and 'being' with limb loss, needs further insight. Related to this, further insight is needed into how PWLL cope with use of mobility aids, such as prosthesis, across the life course, and adopt coping strategies across demographic and disability-related variables, and what adjustment factors there are that relate to an individual's ability to adjust to and cope with limb loss across the life course.

#### **Recommendation I3**

It is recommended that the relationship between coping, amputation and pain be explored. In particular, further work be conducted in understanding pain and limb loss, and the role of the military legacy in living with and managing pain. A PhD studentship has been funded by the VFI to explore the narratives of pain in veterans, as a direct result of this research study, to be completed within the next 4 years. Further work is needed to explore how pain may be catastrophised within a care unit, and how people witness the pain of others.

#### **Recommendation I4**

It is recommended that research be undertaken to explore barriers to communicating with, and accessing, health and care services, and the role of the family. For example, mature children are not always fully aware of their parents' needs, as they are detached from their parents and often living separately, and therefore can only offer limited support in the communication aspects of care. More work is needed to understand

how families manage this process, and what support can be provided to maximise service use to promote future independence.

**Recommendation I5**

It is recommended that further work explore the nature of living with no function of limb/s. This research focussed on loss of limb, however, for some participants, loss of function, due to a prior experience, was sufficiently disabling for them to seek elective amputation. How this is experienced needs further understanding in order for organisations, such as Blesma, to provide focussed and relevant support that maximises independence and coping within the family unit.

**Recommendation I6**

It is recommended that further work is needed to explore the remit of the family. This research sought to explore variance between and across families in relation to limb loss, however, understandings about how caring really occurs need deeper insight, especially in relation to the hidden nature of the emotional aspects of care. It is therefore recommended that future work explores hidden caring in and across the family unit.

**Recommendation I7**

There are limited support opportunities offered to the wider family. For example, children living with a parent with limb loss do not have access to resources that might help them understand and support their parents in the future, which in turn, might be helpful in supporting parents as they age. Further work is needed to explore this in detail in order to inform future service provision.

**Recommendation I8**

Future work is needed to understand the role of coping from the family carer's perspective, especially in relation to feelings of anxiety, worry, anger and fear. These need to be heard in order to develop better support for future persons who may experience suddenly becoming a carer.

**Recommendation I9**

It is recommended that further research is needed to explore how the family cares for one another, especially when the PWLL refuses to admit to/accept needing extra support and care.

## Glossary

<b>ADVANCE Study</b>	Armed Services Trauma Rehabilitation Outcome Study  A 20-year study of the long-term medical and psychosocial outcomes of battlefield casualties from the UK's military operations in Afghanistan and Iraq, which took place from 2001-2014. These casualties include combat-related injuries such as amputations, head injury, fragmentation wounds and vision loss.
<b>Blesma</b>	'The Limbless Veterans'  The UK Armed Forces charity established, following World War I, to support ex-Service men and women who have lost a limb(s), use of limb(s), an eye or their sight. Blesma provides rehabilitative activities, support, financial aid and assistance in navigating the NHS.
<b>Blesma Support Officer (BSO)</b>	Provides advice and support to veterans and their families. Each BSO supports Blesma Members, within a specific area of responsibility in the UK, by providing a welfare visiting service. BSOs form a key point of contact between Blesma and its Members.
<b>Comorbidity</b>	More than one disease or illness occurring in an individual at the same time.
<b>Coping</b>	The process of experiencing, adapting to and managing life difficulties. In relation to this study, the term is used specifically with regards to living with limb loss; coping is defined as either high, middle or low and each individual's experience will be reflected in a different level of coping.
<b>Family</b>	Individuals who are centrally involved in supporting and caring for the Member, and who may or may not be biologically or conjugally affiliated to the Member.
<b>Forces in Mind Trust (FiMT)</b>	A charity supporting veterans and families with a specific remit to fund research and evaluation.
<b>Limb loss</b>	The traumatic loss or surgical amputation of a part of the body, such as an arm or leg.
<b>LLSM</b>	Living with Limb Loss Support Model  A model, developed from the findings of this research study, which details the five stages following the initial limb loss/amputation and shows both the support needs of the PWLL and family carer/s, as well as detailing how organisations can provide for these needs at each stage of the limb loss journey.

<b>Member</b>	An individual with limb loss who meets the criteria for either Ordinary or Associate Membership of charity Blesma and has been accepted on this basis.
<b>Members' Weekend</b>	A residential activity weekend organised by charity Blesma. The weekend is an opportunity for Members, along with their partner/carer, to socialise together, participate in activities and learn more about Blesma and how the charity is developing.
<b>Military legacy</b>	The resulting effects or consequences of being in the military that continue to impact on or shape the life course, behaviours and attitudes of an individual, after leaving active service.
<b>Morbidity</b>	A disease or illness.
<b>Multi-morbidity</b>	More than two diseases or illnesses occurring in an individual at the same time.
<b>National Health Service (NHS)</b>	The NHS is the publicly-funded healthcare system of the United Kingdom. It is primarily funded through the taxation system, is overseen by the Department of Health and Social Care, and most services are free to individuals at the point of use.
<b>Operation Herrick</b>	All UK military operations conducted in Afghanistan from 2001-2014.
<b>Operation Telic</b>	All UK military operations conducted in Iraq from 2003-2011.
<b>Partner</b>	The person identified as being part of an established couple, or 'partnership', with the Member. Partners in this study include those who are in married and unmarried couples.
<b>Phantom limb sensation</b>	The sense or feeling that a lost or amputated limb still exists and is attached to the body.
<b>Phantom Limb Pain (PLP)</b>	Painful sensations that feel as if they are associated with a limb that has been lost or amputated.
<b>Prosthetic limb</b>	An artificial substitute or replacement for a part of the body, such as a leg or arm.
<b>PWLL</b>	The acronym used to abbreviate 'person/s with limb loss'.
<b>Stump pain</b>	The feeling of pain located in the part of the limb remaining after limb loss or amputation.
<b>Veteran family</b>	A family unit that includes at least one person who has served in the Armed Forces.

## Caring and Coping:

### The Family Perspective on Living with Limb Loss

## Practical Application of Research Findings:

### Living with Limb Loss Support Model

This research explores living with limb loss from the veterans' and their families' perspectives. From the findings, a Living with Limb Loss Support Model (LLSM) has been developed (see diagram 4). Whilst formed on data from veterans and their families, the model is intended to be transferable to all persons with limb loss (PWLL), the families that care for and support PWLL, and the service provider organisations that provide care and support for PWLL and their families. The Living with Limb Loss Support Model is explained as follows:

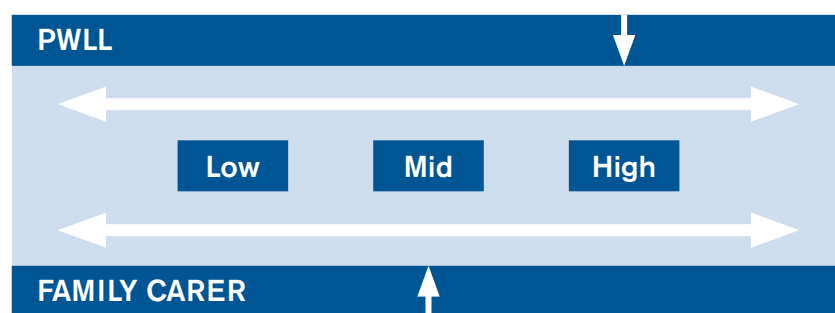
#### Coping and limb loss

Individuals and families care for and adapt to living with limb loss through a process of coping. There are three levels of coping: low, middle and high. These are set out below, alongside examples of behaviours/attitudes of PWLL and family carer/s that service providers/or health professionals could observe that might indicate how well the PWLL and their family carers are coping:

Coping Level	Characteristics	PWLL Examples	Family Carer/s of PWLL Examples
Low	<b>PWLL:</b> being passive e.g. constant reliance on other <b>Carer/s:</b> high emotional burden e.g. constant worry	Reliance on another to maintain Activities Daily Living (ADLs) Reluctance to mobilise Not managing own health conditions Reluctance to socialise/isolation Not admitting to needing help and support	Constant monitoring of PWLL's physical needs Constant monitoring of the physical environment Constant worry about what could happen Reluctance to socialise Feelings of isolation Not admitting to needing help/support in caring role Not managing own health conditions
Mid	<b>PWLL and Carer/s:</b> active e.g. establishing safe routines	Managing own ADLs Mobilising independently inside and outside the home Taking medications Managing own health conditions Liaising with health/support services Socialising Allowing carer to have their own time	Intervening in ADLs only when needed Acceptance that accidents can happen Recognition when they are struggling to cope Perseverance when coordinating/liaising with health support/services Managing their own health conditions Enabling/encouraging PWLL to go out independently Socialising independently
High	<b>PWLL and Carer/s:</b> increased capacity of self-awareness, self-care and self-efficacy	Managing own ADLs Actively seeking help and support Forward planning ahead re current and future health and living needs Self-determining with potential to thrive	Actively seeking help and support Independently socialising Thinking ahead Being realistic re future needs Potential to thrive and gain self-fulfilment through caring role

**Diagram 1** Assessing coping levels of PWLL and their carer/s

Using examples as prompts, for assessing the coping state of the PWLL and family carer/s, is likely to alert the service providers as to how individuals are coping, and from here, to identify the most appropriate sources of support. It is important to note that coping is a lived activity that is negotiated in the social space within which it occurs, for example, within the social space of the home, the family and the community. This social space may be limited to comprising of the PWLL and partner; or wider, for example, PWLL, partner and wider family; or more diverse, PWLL, partner, family and community space. Within these structures, relevant individuals may be coping to greater or lesser degrees. For example, a PWLL independently socialising may be experiencing mid to high coping, whereas the partner may experience low coping through feelings of over vigilance and worry as to their partner's safety and wellbeing at such times. Coping, therefore, is a changing and bi-directional process, in which individuals in the care relationship can display differing levels of coping at any one time. See diagram 2 as an example.



**Diagram 2:** Example of differing individual coping levels for the PWLL and carer/s

The model is currently limited to the PWLL and their main carer/s, but could be expanded to recognise the wider family.

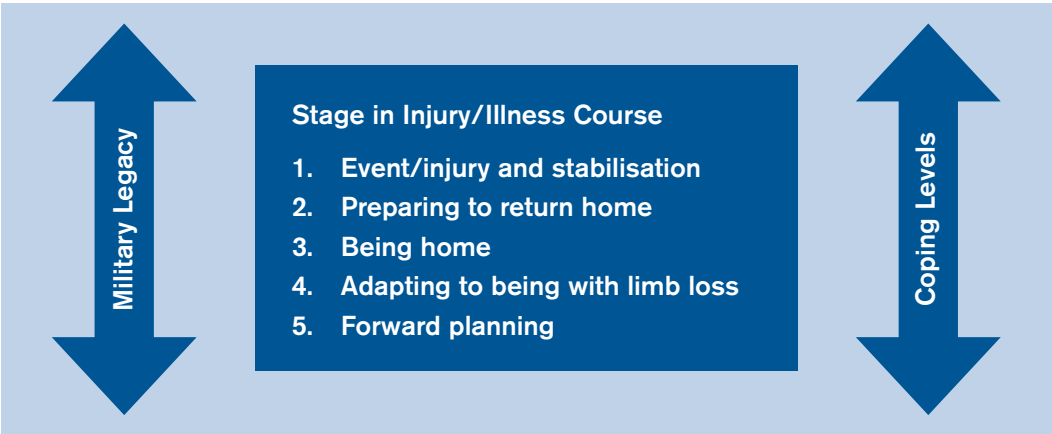
### Living with Limb Loss Support Model (LLSM)

There are distinct times in the limb loss life course where interventions are most likely to support coping in the PWLL and their partner. These are:

- **The event and stabilisation**
- **Preparing to return home and discharge**
- **Being home**
- **Adapting to being with limb loss**
- **Forward planning**

Each stage has distinct characteristic needs, against which levels of coping (for the PWLL and their family carer/s) can fluctuate. Support/information giving therefore needs to be timely in relation to the limb loss life course and where information/support may be more or less useful in relation to that stage. Specific to

the veteran population of this research is the military legacy, which refers to learnt behaviours/perceptions from the military. For some, this will provide coping skills to manage and adapt to being with limb loss, whereas for some, it may mean they identify injury as weakness, and this may mask perceptions of levels of coping. What is important is that, although certain similarities of being in the military, how these relate to living as a veteran in civilian communities will be unique in their presentation in individuals and families. Note, the military legacy could be replaced by an individual legacy, which represents the individual's/family's unique socio-cultural legacy. Timely interventions therefore need to recognise, and enquire into, the lasting effect of individual legacies, to determine actual levels of coping of the PWLL and family carer/s in order to provide timely and relevant support. The relationship between individual legacies, stages in injury recovery, and coping, are shown in diagram 3:



**Diagram 3:** Attributes of living with limb loss, the military and coping

These stages are presented as the Living with Limb Loss Support Model (see diagram 4), with the addition of support that organisations could provide at timely points during the limb loss life course. Each stage is discussed in the LLSM, and further explanation can be found in appendix 1. It is important to note that there are no fixed time lines to each stage, and individuals may experience them for shorter/ longer durations, and some may remain fixed in one stage and not move into the subsequent stages. PWLL and family carer/s may reach a certain stage, then experience a specific life event or difficulty and as a result move back into a previous stage of coping.

It is also possible for an individual to experience several levels of coping simultaneously. For example, high levels of emotional coping may be shown, but middle levels of coping may be shown for physical or practical aspects during the limb loss recovery process. The following are case studies, which offer exemplification of how coping levels at different stages of the limb loss life course can be observed in a PWLL and their family carer/s, based on data collected in this study. Case Study One is of a traumatic amputation, which is the removal of a limb due to trauma, medical illness, or surgery, and can often be a sudden life-event. Case Study Two is of an elective amputation, where an individual chooses to undergo a surgical amputation, usually following a prolonged period of time in which the limb causes debilitation and pain.

## Case Study One

**Pseudonyms of Alan and Jane are used.**

Alan is in his early 60s and four years ago underwent a traumatic trans-femoral amputation of his left leg, due to an infection in his finger. In the preparing to return home stage, Alan set himself the goal of being able to walk his daughter down the aisle at her wedding. He was supported in the achieving of his goal by an NHS physiotherapist and his partner, who self identifies as his main carer. During the time he was working towards his goal, Alan exhibited high physical and emotional coping levels, for example, by actively seeking help from physiotherapists so he could learn to walk using a prosthetic leg. However, once being home, and after he had achieved his goal, Jane recognised that he showed signs of depression and *'he did slide backwards and it was like he lost focus'*. Alan therefore seemed to regress to a lower level of coping, in particular showing a lower level of emotional coping, although he retained the high level physical coping skills learnt during physiotherapy.

Jane experienced shock at the traumatic amputation, where she simultaneously felt relief that Alan survived, and during the event and stabilisation stage, angry that this unexpected life-changing event should occur. Jane felt she could not admit her feelings of anger and upset to others as she felt this would be uncaring and others would *'judge her'* for feeling this way. During this time, Jane was experiencing low coping. Whilst Alan was learning to walk using a prosthetic, Jane took photographs to document Alan's recovery, and this helped her to cope (mid) with the situation. Once Alan achieved his goal, and Jane recognised that Alan was showing signs of depression, she organised events for Alan to achieve, demonstrating mid to high coping whilst Alan was in low coping. As time progressed, Jane and Alan began to adapt to being with limb loss, and daily life returned to incorporate pre limb loss living activity, such as returning to employment, demonstrating mid to higher levels of coping. However, Jane continues to feel angry that the traumatic amputation occurred and feels there are no persons she can admit these feeling to, a sign of low coping.

## Case Study Two

**Pseudonyms of John and Sarah are used.**

John is in his early 40s and underwent an elective below-knee amputation of his right leg. John and his family made the decision to amputate following a decade of John living with pain in his right ankle, which was caused by an injury he sustained during basic military training. Over a period of time, John's injury worsened and he found it painful to walk. This in turn impacted negatively on his ability to work, as John had limited mobility, and family life, as John was unable to play with his two young children.

Following the amputation, John and his partner initially felt relief that John had been freed from chronic pain and, during the being home stage, John showed high levels of physical and emotional coping, as he felt he could mobilise independently for the first time in years and was able to *'just get on with stuff'*. Similarly, John's partner Sarah initially showed high levels of coping, during the being home stage, as she could envisage a more positive future for them as a family with their children and felt *'like the light at the end of the tunnel had been switched on, you know, at least some part of our lives where we could look forward to, having more of a normal life, doing more things again'*. Furthermore, Sarah found fulfilment through her role as main carer to John, as she felt useful and able to carry out tasks to support John's recovery.

During the adapting to being with limb loss stage, John continued to show high levels of physical coping, showing determination to attend rehabilitation, and enthusiasm towards using his prosthetic and wheelchair to aid his mobility; as the nature of John's amputation was elective, John felt confident he could improve upon the level of mobility he experienced pre limb loss and so he remained positive in outlook regarding his physical ability.

However, as the realities of life as a young family became apparent, the emotional coping levels of both John and Sarah decreased; John's rehabilitation included periods of time spent at a residential centre, which put a strain on the couple's relationship and family-time, as there were inadequate facilities for family and children visiting the centre, and no opportunity for the couple to spend time alone together. John also experienced an increase in phantom limb pain when his family situation was stressful. When John was away, Sarah looked after their two children and felt guilty for finding it easier to manage when she experienced time alone whilst John was away, because she did not have to constantly worry about and monitor him. At the latter end of adapting to living with limb loss, Sarah continued to show lower signs of physical coping, due to hyper-vigilance of John and worry for his wellbeing. Sarah also experienced reluctance to socialise, feeling that she needed to be constantly *'at home'* and also did not admit to needing support for her own health concerns, because she felt she had *'already got one person with joint problems, I'm not allowed to have pain'*.

## **Living with Limb Loss Support Model (LLSM)**

The LLSM presents a schema from which differing stages of living with limb loss can be used to identify how PWLL and their family carer/s are adapting and coping, and apply timely and relevant support. It is important that the needs of both are recognised to be co-committal but also independent. Focus, therefore, needs a shift to consider how to support individuals and families living with limb loss, depending on where in the limb loss life course they may be and how they may be coping. Within this, support needs to be alert to differing levels of coping in the family unit, and secondly, delivery of timely interventions/support to PWLL to help develop and facilitate effective coping strategies. The LLSM, as shown in diagram 4, has been developed directly from the findings of this research.

## **Conclusion**

The LLSM suggests a shift in focus to consider how to support PWLL and family carer/s living with limb loss, depending on where in the limb loss life course they may be and how each may be independently coping. A key theme in the data is that PWLL and families do not talk about the effects of limb loss, some for many years, because they have not been asked. A significant feature of this model, therefore, is opportunity for the PWLL, family carer/s and wider family coping to be considered individually and within the co dependant caring partnership, to provide relevant and timely support that may enhance coping and independent living. Findings from this research recommend that the coping of PWLL and their family carer/s be considered as both separate and co committal. Also, that the LLSM be used to identify practical opportunities for service providers to deliver support at timely points in order to maximise coping and independence for both the PWLL and their family carer/s.

**Diagram 4: Living with Limb Loss Support Model**

Military Legacy	Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support	Coping Levels of PWLL and Family Carers
	<b>1 - Event and stabilisation</b> Acute stage of injury/illness Short term, usually within acute professional health services	<b>Information:</b> Diagnosis, prognosis and treatment/s Honest about what to expect physically and emotionally <b>Physical:</b> Initial learning how to do/assist with ADLs*** <b>Emotional:</b> Initial relief the PWLL is alive and recovering from incident Worry about how to cope and manage future changes to lifestyle <b>Learning:</b> <b>Family/Carer</b> - Inclusion within rehabilitation therapies to learn how to assist in PWLL recovery	<ul style="list-style-type: none"> <li>Organisational visibility</li> <li>Realistic and honest information giving about physical/emotional aspects of immediate effects of limb loss for the PWLL/Family/Carer</li> <li>Encouraging Family members to engage in care and rehabilitation services, especially moving and handling and managing ADLs</li> <li>Sign posting re support services/charities, support groups for PWLL and Family/Carer</li> <li>Ensuring initial contact and access to prosthetic services</li> </ul>	
	<b>2 - Preparing to return home and discharge</b> Rehabilitation stage usually within professional/rehabilitation health services Moderate term	<b>Preparing to return home:</b> <b>Physical:</b> Focus on physical needs such as safe mobilisation of PWLL, care of the stump, understanding medications <b>Emotional:</b> <b>PWLL</b> - May feel able to cope and confident with skills to mobilise/self-care whilst in professional care <b>Family/Carer</b> - May experience low coping and uncertainty about return home and how they might cope <b>Discharge:</b> <b>Both</b> - Initial low coping and feelings of isolation on discharge/being alone in the home environment <b>Learning:</b> Practicing new ADL skills, being involved in rehabilitation therapies Medication management Managing multi-morbidities (of PWLL and Carer) <b>Information:</b> What support is available and how to access support/community resources <b>Feedback:</b> On how each are doing in learning new caring skills Feedback on emotional coping	<b>Preparing to return home:</b> <ul style="list-style-type: none"> <li>Checking home environment is safe and suitable to enable independent living from PWLL/Family/Carer</li> <li>Adaptation of living environment: wheelchairs/bathing aids/chair lifts</li> <li>Independent assessment of coping levels of PWLL and Family/Carer</li> <li>Sign posting immediate care service support, e.g. GP, community nurse, prosthetic services, and other networks/support groups</li> <li>Checking understandings of medication regimes of PWLL and Carer (if required)</li> <li>Checking other health conditions of PWLL and Carer are being managed</li> <li>Being visible on immediate discharge</li> </ul> <b>Discharge:</b> <ul style="list-style-type: none"> <li>Re – enforcement of moving and handling techniques to PWLL and Carer</li> <li>Independent assessment of coping levels of PWLL and Family/Carer</li> <li>Realistic and honest information giving about physical/emotional aspects of intermediate effects of limb loss for the PWLL/Family/Carer</li> <li>Signposting who to contact if feelings of inability to cope are experienced</li> <li>Checking wider Family information needs and understandings of types of support available</li> </ul>	
	<b>3 - Being home</b> First few months after PWLL returns home Moderate term	<b>Physical:</b> Focus on physical needs, safe mobilisation of PWLL, trying to second guess needs, fear that harm might occur <b>Emotional:</b> <b>PWLL</b> - Anxiety and frustration re difficulties self-caring in the home environment Frustration/anxiety in needing to accept help/care from Family/Carer Frustration they may be dependent upon others May lose confidence as unable to compare their progression with others with limb loss <b>Family/Carer</b> - High anxiety and uncertainty about whether they are good enough to support PWLL and manage the home Possible frustration at new role as Carer <b>Both</b> - Feelings of isolation on discharge Difficulty in adapting to providing care in the home Uncertainties re changing role of care in the couple's partnership <b>Information:</b> Realistic impact of providing care in everyday life <b>Training:</b> Additional support to manage care in the home, e.g. safe moving and handling <b>Feedback:</b> On how both are coping in the home with physical care and emotional care	<ul style="list-style-type: none"> <li>Independent assessment of coping levels of PWLL and Family/Carer</li> <li>Independent discussion about changing nature of caring roles in the of PWLL and Family/Carer</li> <li>Assisting in setting relevant and achievable goals for PWLL/Family/Carer, including literature that describes everyday adaptation to limb loss for both PWLL/Family/Carer</li> <li>Where relevant, enabling contact with others at a similar limb loss stage</li> <li>Moving and handling support/ learning for PWLL and Family/Carer</li> <li>Pain management information giving/support, e.g. pain Q &amp; A crib sheet, ways to describe pain and types of questions to ask health professionals to help manage pain</li> <li>Sign posting long term care service support, e.g. GP, community nurse, prosthetic, and other networks/support groups</li> <li>Checking co/morbidities (if any) are being managed in both PWLL/Carer</li> </ul>	

Continued overleaf

**Diagram 4: Living with Limb Loss Support Model Cont.**

	Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support	
Military Legacy	<b>4 - Adapting to being with limb loss</b> After a period of adjustment in the home Long term	<b>Physical:</b> Focus on safe and independent self-care established routines <b>Emotional:</b> <b>PWLL</b> - Focus on what next and future opportunities Where possible, resuming pre limb loss living activities Where not possible, refocus on new activity Possible frustration/anxiety if cannot return to previous activity (e.g. employment) <b>Family/Carer</b> - Wish to resume aspects of living pre-limb loss, such as employment, hobbies <b>Both</b> - Opportunities to talk about limb loss and seek support from others in similar situations, e.g. support groups (not necessarily veteran specific), socialising with other veterans (not necessarily only with limb loss) <b>Information:</b> How to access/maintain work/socialising opportunities. Recognition of and planning for the future, including future health crises/events that may change care giving demands, for example, what if Carer becomes ill? <b>Feedback:</b> Continued feedback on how both are coping in the home and possible future support requirements	<ul style="list-style-type: none"> <li>Independent assessment of coping levels of PWLL and Family/Carer</li> <li>Checking prosthetic service access/support</li> <li>Checking health/social care support is accessed/appropriate to needs</li> <li>Sign posting other support networks, e.g. support groups</li> <li>Reassessment home living support needs, e.g. suitability of home adaptations</li> <li>Checking co/morbidities (if any) are being managed in both PWLL and Family/Carer</li> <li>Assistance in setting achievable goals to reinstate life pre-limb loss, such as social activity, resuming hobbies/interests</li> <li>Starting to discuss/information giving about future proofing re housing/finances/pensions</li> </ul>	Coping Levels of PWLL and Family Carers
	<b>5 - Planning forward</b> Long term	<b>Physical:</b> Focus on maintaining self-care routines and maximising independence Managing co morbidities Managing changes in stump/prosthetic care Maintaining maximum independence <b>Emotional:</b> Thinking ahead about how to cope with aging Not admitting to changes in physical states to manage self-care/care for other Worry and anxiety re health of each other in the future Worry about housing appropriateness Worry about finances/pensions Feelings of lower coping and anxiety about what might happen Feelings of isolation Not wanting to burden their Family re concerns about future <b>Information:</b> Focus on future possibilities for care for PWLL/Carer Opportunity to talk about concerns with others in similar situations Opportunity to talk with wider Family re potential future care needs <b>Feedback:</b> Honest separate appraisal of how well PWLL and Family/Carers are coping	<ul style="list-style-type: none"> <li>Independent assessment of coping levels of PWLL and Family/Carer</li> <li>Planning for the long term: pensions/finance etc</li> <li>Information about alternative safe housing/living/financial support directed to PWLL, Carer, Family unit as relevant</li> <li>Where necessary, helping in Family conversations re long term future care and support needs of the PWLL/ Family/Carer</li> </ul>	

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\*PWLL refers to Person with Limb Loss

\*\*Family/Carer refers to those central in the care of the PWLL. This may be a partner, or sibling/s, or friend/s, or child/ren

\*\*\*Activities of Daily Living

NB. A double page fold-out version of this model occurs at the close of this report, to which you can refer throughout your reading.

## Caring and Coping: The Family Perspective on Living with Limb Loss

### Introduction and Context

The purpose of this research is to explore living with limb loss in veterans and their families. Since 2001, 353 personnel have lost limbs during their service (Ministry of Defence, 2015) and most of Blesma's current 3,093 Membership are veterans living with limb loss (Blesma, 2017). Since WW1 Blesma has supported 62,000 limbless veterans (Blesma, 2017). Despite veterans with limb loss not being a new event, there is limited literature that considers the needs of veterans and their families living with limb loss, and what there is tends to focus on the aetiology of limb loss, and conditions associated with limb loss, rather than the lived experience. A holistic view of the veteran, limb loss and the family is therefore needed.

To better understand how individuals live with limb loss, consideration must be given to the wider social structures within which the individual lives, such as the family. Family members are recognised as centrally important in health and wellbeing because the family is a primary resource of care and support (Fehr and Pearlman, 1985; Furstenberg and Kaplan, 2004; Widmer, 2004). There is however limited empirical focus on the family, both military and veteran, and where there is, most studies focus on help from the nuclear family and do not consider the wider social and family contexts and their structural properties (Faber and Wasserman, 2002; Emerson, et al., 2010). As family contexts have become more heterogeneous (Kohli, 2007; Shanahan, 2000), focus on what it means to be a veteran family needs considering. Fossey and Hacker Hughes (2014) also conclude that there is limited research that considers the nature of living with limb loss in the family in the UK. From an international perspective, literature indicates that the active participation of families in the rehabilitation and recovery process of people with a range of injuries or health conditions, potentially leads to improved clinical and social outcomes. Preliminary (unpublished) findings from an evaluation of Blesma's Activities Programme, conducted by St Mary's University Twickenham, suggest that activity should be more family focused, adding support to the importance of understanding not just Members' needs but also those of their families. The active engagement of families in the rehabilitation process is, however, not usual practice in the UK, and Fossey and Hacker Hughes (2014) conclude that policy makers and service providers need to consider the importance of the family in improving and supporting the outcomes for serving personnel and veterans who have lost limbs.

Where literature is specific to veterans, it tends to be US based with a focus on limb loss from the Vietnam era. For example, Foote, et al. (2015) present a mixed method cross sectional survey of 247 US Vietnam veterans with combat related limb loss, and identify a negative impact of limb loss on quality of life, in association with co morbidities, such as arthritis, cardiovascular disease, diabetes, depression and phantom limb pain. This suggests a better understanding is needed about how individuals live with limb loss and manage multiple morbidities. Ciechanowski, et al. (2003) also identify that limb loss is associated with secondary conditions such as depressive symptomatology, which adversely affect the rehabilitation process, and Kashini, et al. (1983) report that persons with a trauma-related amputation reported the highest levels of depressive symptoms, with younger age associated with higher rates of depressive symptoms. Greater understanding of secondary conditions, such as pain and depression, therefore, may lead to better treatment, improved outcomes and quality of life for PWLL. However, Sterling, et al. (2005) report that

when compared with factors such as level of education, marital status, and the individual experience of pain, neither age nor aetiology were found to be significant predictors of depressive symptoms. Foote, et al. (2015) interviewed 20 veterans of the Vietnam War and identified those who, 40 years after being injured, experienced significant pain and mental health complications from their combat injuries, with morbidities such as arthritis, cardiovascular disease, and diabetes potentially being associated with their limb loss. As such, literature indicates there are long term effects of limb loss, but how the individual lives with, and manages, limb loss and possible long term physical effects, is limited, and with a lack of information about background variables, such as education, employment, economic, civil status and co morbidity, meaningful analysis is limited (Sinha, van den Heuvel and Arokiasamy, 2011).

To conclude, literature provides only the parameters of amputees' experience, with a focus on physical aetiology, little on the holistic lived experience, and the role of the family and their needs has little attention. This research addresses this gap in understanding by providing insight into the lived experiences of veterans with limb loss and their families. The focus on the family and the veteran is important because it will provide insight into and understanding of their needs and how they experience, manage and adapt to living with limb loss, which is absent within current literature and research.

## **Research Objectives**

To provide an evidence-base to inform policy makers and service providers, research is needed into the experience of families of veterans living with limb loss. The aims are to:

- Provide understanding about how different members of the family experience the impact of limb loss, including the psychological and social effects
- Enquire into how veterans and families overcome difficulties experienced with living with limb loss
- Articulate recommendations based on the findings of this study
- Inform and collaborate with relevant research, such as the ADVANCE Study

## **Methodology**

To explore the lived experiences of veterans and families living with limb loss, a grounded theory approach was used. Grounded theory is relevant because it enables the lived experience to emerge through simultaneous data collection and analysis, which seeks to identify emergent patterns and similarities in and across experiences. The aim of grounded theory is to identify a working theory that explains the lived experiences of its participants, identifying key themes and explaining the relationships between those elements. Grounded theory is therefore practical, with a focus that seeks to explain the main concerns of people in their lived context and how they go about addressing and or resolving their concerns. It is the practical nature of the grounded theory approach that best suits the purpose of the proposed research – to enquire into the lived experiences of veterans and families living with limb loss.

To explore this research purpose, the research was conducted in distinct phases; however, each phase informs the next. The process of this is detailed as follows:

## **Caring and Coping:**

### The Family Perspective on Living with Limb Loss

## **Ethical Approval**

Ethical approval to undertake the Blesma Families Study was gained by the Anglia Ruskin University Faculty of Health, Social Care and Education ethics panel, study reference number: 15\_16 020, available to view at <http://bit.ly/BlesmaFamiliesStudy>. Please also visit this website link to view the participant information and consent forms that were given to individuals prior to interview.

## **Sampling and Recruitment**

Grounded theory research starts from the participants' perspectives: it enables them to tell us what they think is most important to them, and questions are developed from thereon. Sampling in grounded theory therefore is sequential, beginning with initial purposive sampling to gain a general understanding of the lived experience, and moving towards focussed theoretical sampling to explore common themes that are emergent in the data.

To ensure the most appropriate persons were invited to participate, the following inclusion and exclusion criteria were used:

### **Inclusion criteria:**

- Those with amputations attributable to their military service, but not gained in Operation Herrick (Afghanistan 2001-2014) or Operation Telic (Iraq 2003-2011)
- Those who underwent amputations during service but that were not acquired on operations
- Those whose amputations occurred after their service and are not linked to their military service
- Over the age of 18 years
- Ability to give informed consent

### **Exclusion criteria:**

- Those with amputations attributable to their military service gained in Operation Herrick (Afghanistan 2001-2014) or Operation Telic (Iraq 2003-2011)
- Individuals under the age of 18
- Participants in the ADVANCE Study

An important strand of this research is to explore the family perspective of living with limb loss. The term 'veteran family' is used to refer to a family unit that includes at least one person who has served in the Armed Forces, although the term itself is multi-faceted and recognises differences between individuals and family units, and as such there is no 'one' type of veteran family. For the purpose of this research, we are defining the family as individuals who are centrally involved in supporting the Member without financial compensation. This encompasses all persons who are involved in care of the Member, who may or may not be biologically or conjugally affiliated to the Member. To explore this further, participating Members were invited to define who they considered their family to be, and these persons were invited to participate in the

research. The sampling therefore, was both purposive and self-selecting.

### **Recruitment to participate in the research is detailed in the following three phases.**

#### **Phase 1:**

To gain first-hand accounts of the lived experience of living with limb loss, from veterans and their families, in-depth unstructured interviews were used. A total of 37 individuals consented to participate in this phase: 16 Members (1 female), 14 partners (1 male), 6 children and 1 extended family member. In total, 23 interviews were conducted, with some Members wishing to be interviewed alone, and some wishing to be interviewed together with the identified family members. The interviews were conducted by the lead researcher visiting the homes of participants. Regional locations of participants interviewed included South West (50% families), South East, West Midlands, North West, North East, Yorkshire and the Humber. The interviews were deliberately broad in scope, with inviting questions such as:

- Tell me about your limb loss: how did it happen?
- What was it like when you first left hospital/MOD?
- What do you think it was like for your partner?
- What was most difficult? And how did you overcome these difficulties?

From such broad questions, conversations would flow that enabled the individual to tell what was important or meaningful for them. From this, similarities and differences across the data were emergent, which instigated the questions to be asked. For example, phantom limb pain and managing pain were introduced by the interviewees, and pain was physically experienced during interviews, therefore questions about pain became the broad question 'do you/the Member get pain from the amputation?' and depending on the answer, the following questions 'what does the pain feel like' 'what is it like for you when he/she is experiencing pain?' and for those who did not report any current pain, 'have you ever experienced pain from the amputation?' or 'when was the last time you had pain from the amputation'. In this way, the interviews progressed, and questions were asked that were emergent from information shared within previous interviews. These interviews were transcribed and coded, from which distinct and grounded patterns in the interview data were used to inform two structured questionnaires, one for Members, and one for main carer/s, as implemented in phase 2.

#### **Phase 2:**

Phase 2 implemented the two closed questionnaires, one for the Member, the other for their carer/s (available to view at <http://bit.ly/BlesmaFamiliesStudy>), as informed by the emergent patterns in the phase 1 analysis. The questionnaires were distributed at the Members' Weekend in the welcome packs, and an overall presentation of the study was given to the delegation, explaining the study, and inviting people to participate by completing the questionnaires. In total, 35 respondents returned their questionnaires anonymously, consisting of 22 Members and 13 carers. This data was analysed, and compared with phase 1 analysis, to check if the findings in phase 1 were relevant/not relevant to a wider number of Members/families. Analysis of the structured questionnaires was compared and contrasted to phase 1, so building a rich set of patterns that explains most participants' concerns in their living with limb loss. From this, a final

## **Caring and Coping:**

### The Family Perspective on Living with Limb Loss

set of 16 closed statements (available to view at <http://bit.ly/BlesmaFamiliesStudy>) was developed that explain the emergent findings.

#### **Phase 3:**

Phase 3 checked the emergent statements using telephone interviews with Members that had participated in phases 1 and 2, and who had given their permission for the research team to contact them.

Ten Members and five family members were interviewed to see if the closed statements were viewed as relevant/appropriate to themselves in their context. The telephone interviews were annotated by the lead researcher, and the findings can be viewed online at <http://bit.ly/BlesmaFamiliesStudy>.

*See appendix 2 for further information regarding the biographical sample overview.*

#### **Analysis**

Analysis in grounded theory occurs throughout the data collecting phases, and uses coding and constant comparison of codes as the data collection continues. Analysis starts initially by broadly describing patterns in the data, and as analysis continues, descriptions become explanatory in order to conceptually explain patterns, and their meanings and relevance to each other. As grounded theory is practical in its nature, it presents findings in terms of actions, or what people do, to make sense of their lived experiences. In analysis terms, these are presented as Gerunds (verbs that end in 'ing') as a means of demonstrating their action properties. To present the analysis, a conceptual explanation of patterns in the data is presented that details the central experiences and concerns of the participants in the study, followed by the main themes that seek to explain, and describe their relevance, in relation to the research aims and purpose.

As grounded theory is practical in its purpose, its findings and conclusions should be able to be applied directly to the context of the research and, importantly, readers who have knowledge about the research context should recognise familiarity within the explanations. It should therefore be expected that readers will be able to see the findings as directly relevant and applicable to the context, that is, there should be a sense of intelligibility in the findings, and this acts as the main tenet of credibility to a grounded theory research study.

# Research Findings

## Note on Findings

This report details findings from an enquiry into how Members and their families live with limb loss, and from the outset of the data collection, Blesma as an organisation and the work of the Blesma Support Officers (BSOs) are highly valued and appreciated:

***'I can't fault them. They have been brilliant. When we need them, they are there'*** (Partner)

The focus of this report is on how Members and family carers themselves perceive their situations, how they manage their everyday living with limb loss, what is helpful and what could be helpful. Focus, therefore, is not on the support that Blesma provides, but rather on identifying aspects of living with limb loss that are important to PWLL, which may not be overtly observable or discussed, in order for Blesma as an organisation to have deeper insight into everyday living with limb loss. This report, as a result, does not seek to evaluate what is being offered by Blesma, but rather to illuminate patterns in living with limb loss, to which support could be targeted in accordance with its community.

The term 'Member' is used in the findings to refer to the veteran with limb loss (who is a Member of Blesma), and 'partner' is used to refer to another person who lives in a partnership with the Blesma Member, and whom provides direct everyday care. Terms such as son/daughter are used throughout the data to signify their relationship with the PWLL.

## Conceptual Explanation of Findings

The overarching explanatory concept that explains living with limb loss is coping. From the research findings, three differing levels of coping are experienced - high, middle and low – and each relates to how individual being with, and living with, limb loss is experienced/adapted/managed at any one time. For example: low levels of coping signify difficulties in adapting to limb loss, limited requests for support, and lower levels of community integration. High levels relate to acceptance of limb loss, requesting support, and high levels of community integration. Within the family unit, the differing levels of coping can be experienced at different times: for example, the individual with limb loss can experience high levels of coping, whilst the partner/main carer can simultaneously experience low levels of coping. This is because each person will experience the limb loss recovery timeline differently.

The limb loss recovery timeline explains distinct but interlinked stages in the recovery process from limb loss, during which the Member and their family may experience specific difficulties/have specific needs. These stages ('event and stabilisation', 'preparing to return home and discharge', 'being home', 'adapting to being with limb loss', and 'forward planning') present as key strategic times where resources and support can be provided to the individual and their family carer/s to support levels of coping. From this, a model of timely interventions is developed: the Living with Limb Loss Support Model (see page 22), which identifies relevant support specific to each stage in the limb loss recovery timeline. Across this timeline is a military legacy.

A military legacy informs and influences how individuals and families might cope with limb loss. The military legacy is important because it presents as 'not talking about', 'getting on with', 'not admitting to' and 'not

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asking for help', which are important in relation to coping. In connection with the military legacy, caring is hidden because support is not always admitted to, as it is not the 'military way', or because civilian support networks do not understand 'the military way'. Caring, and how individuals cope, is therefore hidden and often unseen by the wider family, community and health service providers. Within this explanation, about how Members and their families live with limb loss, are patterns in and across the differing data sets. These patterns, or themes, bring to the fore core aspects over time as to daily living with limb loss, difficulties experienced, and how they can be overcome, which are presented as follows. Here, examples and direct quotations anonymised from the data are used to present how the participants live with limb loss:

## Findings

The purpose of this section is to explain the concept of coping, which addresses how people manage living with limb loss. Within the core concept are themes, and sub themes, that describe and tell us what coping means in the sample. As such, the findings are presented as themes to tell the stories of coping, using direct quotations and data to demonstrate the twists and turns, and holism, of living with limb loss. The findings are presented in three main themes:

- Hidden caring and coping: the family perspective
- Caring, coping and limb loss: the individual and family perspective
- Support for coping in individuals, carers and families

## Hidden Caring and Coping: The Family Perspective

### Who is caring?

This research seeks to understand how families care; it is a useful starting point to explore who is caring. From the interview participants, 5 partners self-identified with the term carer when describing their role in supporting the Member, and 1 person specifically mentioned being a registered carer. All 13 responses to the carer questionnaire identified themselves as the Member's partner and as their main carer, of which 4 are registered carers. If the main carer is not available, data indicates that it is adult siblings that will step in to provide support and that otherwise there is minimal support. The data in this sample therefore suggests that generally, it is the partner who acts as the main carer to the Member, with additional support from adult siblings.

The data suggests a general geographical dispersion of families: *'my family's scattered all over the country and there's a few in different countries and we don't really see each other much'* (Partner). Generally, mature participants have at least one adult child close by who can help, *'my daughter comes along and hoovers around, and helps me clean up type things'* (Partner). Younger participants, however, could not identify other persons that would help if the main carer (partner) was unable to care for the Member: *'it's just us really. No one else'* (Partner) and *'since 2003, it's been me and him and then obviously the kids came along. We don't rely on anybody, we don't ask anybody to do anything for us, and we don't ask anybody to have our kids'* (Partner). Younger participants did refer to their brothers, sisters and parents, but with a reluctance to ask for help from them if needed. For example, in relation to the above quote, the corresponding Member was asked who he would call on if his partner was unwell/unable to be the main carer for him and/or

children and he responded, *'pretty much no-one'*. This is an important finding in the data as it indicates that younger Members and their families are less likely to ask for help/support from their wider family. Younger participants, in particular, presented a sense of isolation in that they looked internally to themselves to help each other. This sense of isolation is linked to living in a civilian society where family and friends do not understand either limb loss or being in the military. This is addressed in further detail in the 'Coping and the Military Legacy' sub-theme of this report (see page 49).

Isolation was also evident for those with adult children living outside the family home. Alongside this, is a sense of detachment: *'because they weren't living at home with us they didn't see the day to day challenges'* (Partner), as characterised below:

**Partner** *Because your own family don't truly understand. When we were trying to move here, [daughter] was always emailing and saying there's this property that property, we said it's no good my love, because it's not suitable for a wheelchair, we can't access, because we have to park too far away, because they weren't living at home with us they didn't see the day to day challenges*

**Member** *Their heart was in the right place, just the practicalities*

**Partner** *But no-one truly understood it, because they weren't going through it every day... And that was, so even the lack of understanding in close family members has been a challenge hasn't it*

This sense of detachment is recognised by the adult children: *'because we're detached. We don't get that same feeling of the pressure that mum's, we know that it's pressure'* (Son). One aspect of detachment is a general reluctance of their parents to ask for help: *'he always, you got the impression that he was, the man of the family and when there was an issue, he constantly tried to hide it. He could never, there was never anybody that he could turn to, and he'd never ask. Still won't'* (Son) and *'he's very much the man of the family, he won't tell, he won't ask'* (Daughter). As such, much of the daily caring work that is provided by the main carer is unseen because it is not overtly evident to those who are not engaged in that care on a daily basis. An important finding therefore is that adult children try to provide care and support regardless of geographical dispersion, however, there is a detachment because they are not living the caring role daily and because their parents may not ask for help and support – the extent of care is hidden from those who do not live it daily.

#### **Recommendation A4**

It is recommended that generational differences between PWLL are recognised as signalling differing support needs. Younger families look internally into themselves and do not request help from their wider family/friends, and may be more socially isolated because of this. Mature PWLL and their main family carer/s may not admit to/accept needing additional support, with increasing age leading to frustration within the family unit and possible social isolation. Generational differences and accompanying coping and support needs therefore warrant further enquiry.

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#### Recommendation A5

It is recommended that organisations consider ways in which information about help and support can be disseminated across the wider family unit. Families generally want to help and support the PWLL and their main carer/s, however, families do not always understand the hidden nature of caring or find it difficult to provide support/care if the PWLL does not admit to needing/refuses family support and care. This needs further exposure.

#### Recommendation I4

It is recommended that research be undertaken to explore barriers to communicating with, and accessing, health and care services, and the role of the family. For example, mature children are not always fully aware of their parents' needs, as they are detached from their parents and often living separately, and therefore can only offer limited support in the communication aspects of care. More work is needed to understand how families manage this process, and what support can be provided to maximise service use to promote future independence.

## Doing caring

Members and carers described the types of care they provide for their partner and this ranged across all activities of daily living (ADL). Carers in the interviews described their daily routines:

*'You know, some people go to work in the morning and they just got out of bed, gone to work, and I get out of bed and shower, check and I go, I've got to get [Member]'s everything ready for him' and 'I start at 8 'o' clock. So we get up at half six every morning....Shower, breakfast and everything's there, [Member] has a shower, I'm around here when he has a shower and then I go upstairs, make the beds, cos we sleep separately now, can't sleep together, then I Hoover through, and that's before I go to work'*

An evening routine was also described:

*'So I'll sit on the chair, [partner] will take my right leg and put it over there and then I'll, [partner] will go upstairs and meet me at the top, I'll come up and then we'll have, we've got a commode upstairs in the bed from as our toilet's out the back there, I'll sit on the commode with one leg. We'll get to the bed, I roll on to the bed, [partner] takes my leg off. And she wedges the commode up, I take a pee bottle. And some tissues and that and that's me tucked up for the night and in the morning, then [partner] helps me get back down' (Member). After which, his partner will, 'So what I'll do then, the night before I get everything here on here. The socks go on the radiator to air out and everything's here. But it's got to be here and if, if I forget one thing....It's frustration, if he can't get it' (Partner)*

Questionnaire respondents were asked to identify the activities of daily living for which they considered the Member to need support, with the following findings showing how many Members and carers identified each particular activity:

Activity Daily Living	Examples of	Member	Carer
Personal hygiene	Bathing, grooming	7	7
Dressing	Ability to physically dress oneself	3	0
Eating	Ability to eat independently	1	2
Maintaining continence	Physical ability to use a bathroom	2	5
Mobility	Moving oneself from seated to standing, getting in and out of bed, being able to get from bed to bathroom	6	2
Communication skills	Assistance in communicating with others, using the phone, mobile phone, email or the Internet	2	2
Transportation	Either by driving oneself, arranging transport or the ability to use public transport	4	5
Meal preparation	Meal preparation and the ability to safely use kitchen equipment	6	3
Shopping	The ability to make appropriate food and clothing purchase decisions	4	5
Housework	Doing laundry, cleaning dishes and maintaining a hygienic home	9	5
Managing medications	Taking accurate dosages at the appropriate times, managing prescribed medications	4	1
Managing personal finances	Operating within a budget, writing cheques, paying bills	2	2
Planning for the future	Planning ahead for a future safe living environment, care help and support for Member and carer	4	1

**Diagram 5** Table of care needs and activities

From this table, some differences between Members and carers can be seen, which is interesting as there may be variance between what each considers care-wise is being done, and there may be differing value attached to various caring activities. For example, the greatest differences in responses are evident in mobility, meal preparation and housework, as activities that a higher number of Members recognised need carer support. This may indicate that carers are not recognising all of the ways in which they actively support the Member and therefore the extent of their caring role. To note, on the other hand, there was equal recognition by Members and carers of personal hygiene as an activity for which the Member needs support, which may be indicative of how this activity is recognised as a typical caring activity, where other activities are not. Further work is needed in this area to ascertain if differences in value attached to care activities is problematic within the caring relationship.

### **‘It’s the little things’**

A reoccurring narrative in the interview data was explaining the regular and ‘little’ aspects of living and caring: *‘you know and it’s a little, we had to find out these things, it’s like the first day I was home in my wheelchair and I was in the lounge and I thought to myself I wanted a cup of tea. So I thought I’ll wheel myself into the kitchen, kettle, made a cup of tea.....I was sat there thinking. How do I get this back into the lounge’* (Member). Realisation that previous small, regular, activities have suddenly

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become difficult, is needed. These little things are often aspects that would not otherwise be noticed or are thought of as otherwise insignificant. For example, one Member described not being able reach a dish towel to help with washing up: *'my biggest thing was frustration, it's, like I said to [partner] you know, I know, you know, you're brilliant, but I'm sat sometimes when I haven't got me legs on and I'm sat down here and [Partner]'s chucked the dish towel in for a wash and I can't reach it and I want to dry up for her and I said try and get used to [Partner] putting the wash bin, putting a new down for me like, I know it's simple, you may not think, but for me it's a big thing cos I can't reach it. I'm sat there thinking o, where's the towel and, I know, in the wash bin and it's frustration, I don't mean to be'* (Member). Bringing about a better awareness of the little things is one aspect that was said to be needed: *'you know, its little things like that and you know, so yeah, if there was a connection, some sort of process where Blesma could be informed at the start'* (Member).

Aspects of moving and handling were said to be a particular problem, and interviewees felt they were not sufficiently equipped or informed of how best to help the Member mobilise around the home environment. The following are descriptions of how carers assist in the mobility of the Member in the early days post-amputation, on their return to the home environment.

*'Things like, the things that takes a toll on the families is like, for me its piggy-backing him, I piggy-backed him for years from car to house, or from upstairs if he wanted to do something and you're out and there's no lifts, its oh well I'll piggy-back him upstairs and then come back down for his chair. It's things like that'* (Partner)

*'I used to carry him up and down the steps.....The stairs .....On me shoulders. Went on me paws, yeah..... But I'm suffering for it now .....I can't stand for long, me walking is getting less and less every week'* (Partner)

The term 'piggy backing' was used across the age ranges of the interviewees, suggesting this is a practice that has been undertaken for many generations, and that Members and carers are still not being adequately prepared to assist in both the safe moving of the Member, and for the safety and wellbeing of the carer. Indeed, a younger carer referred to her *'knees already being knackered'* as a direct result of her piggy backing activities. It is important to note, therefore, that how moving and handling occurs in the privacy of the home environment may not be reflective of safe moving and handling for the Member nor the carer.

No interviewees could recall having any specific moving and handling learning and practice prior to the Member returning to the home environment post rehabilitation, and as such, they *'just managed'*. This was supported in the Member questionnaire, where only one person responded that they had received professional advice as to how to move the Member, with nine responding they had not. There was limited presence of the family in the rehabilitation process as a whole, in which no family members interviewed were felt to be included in the rehabilitation process, although the questionnaire data indicates that 5 persons were included in the rehabilitation process. What is included within the rehabilitation process therefore needs further exploration.

Leaving the home and managing the external environment was problematic: *'I'm always thinking ahead.....of where we can go.....I've got to get [Member]'s everything ready for him'* (Partner). Thinking ahead and often doing a 'recce' of the environment to ensure safety were described:

*'When we went anywhere, I would almost want to do a recce first to see where is the drop curb, that's the trouble, you know, you've got him out in the wheelchair, where's the drop curb, oh there's one there, but the other one is right up there and you'll take them along in the road, I mean the best thing that happened at [town name removed] was [organisation name] cos they built drop curbs, but we didn't have them before' (Partner)*

*'I went round with a piece of string to see if I could get through different places and there was a few stones, in the way, these great big stones.....from [name removed] I got them to move them slightly' (Partner)*

Constant forward thinking and planning can become overwhelming:

*'We don't go out very often because there's too much planning, too much, but the, it's me, he'll just think oh shall we go out or shall we go for tea or shall we do this, and he'll just think of we'll just pick somewhere and we'll go. Where are we gonna go? What we gonna do? Has it got a lift? Has it got stairs? Has it got this? You know, that is literally especially years ago where a lot of places didn't have' (Partner)*

*'If [partner] says she wants to go out, first thing I'm thinking is, how are we gonna get there, where we gonna park, what we gonna do, because I know she wants to interact with the kids, but if the kids'll run off different ways, there's very little she can do about that. So, I do know a lot of it'll come down to me and like I say, when we go out I always want to know I can park close by so she's not having to struggle from the car to where and if that carpark close by I'll drop her off at the door, then I'll go park up and I'll walk in' (Partner)*

This can result in a reluctance to go out, because forward planning becomes overly onerous: *'just to go anywhere I was always thinking about, park there, we'd get there, oh God it would be a nightmare. So we stopped' (Partner).*

Other concerns about falling, from the carer's perspective, relate to the carer's daily routines/having to pre-plan in everyday life/carer feeling worried or helpless/carer being vigilant and cautious. These concerns are generally not discussed, but are important in enabling the Member and carer to engage in community and social activity. It is recommended therefore that organisations consider the worry carers may experience when engaging in social activity, and that such worry could be prohibitive in organising social activity.

### **Recommendation A2**

It is recommended that the work involved in caring within a family unit be recognised as essential in maintaining the PWLL's independence. Routines that persons have in place to facilitate independent living need better recognition, and it is recommended that the work that goes into establishing these routines be acknowledged. Recognition of this aspect of caring may be specifically relevant in the 'being home' and 'adapting to being with limb loss' stages (as demonstrated in the Living with Limb Loss Support Model, see page 22).

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#### **Recommendation C2**

It is recommended that the hidden work that occurs, in order for the PWLL to learn to regain independence in living with limb loss, be recognised. In particular, it should be recognised that pre-planning, required in order to leave the home, needs to be explored and possibly further supported, as this can be a source of low coping for both the PWLL and their family carer/s.

#### **Recommendation C3**

It is recommended that particular attention be given to the coping needs of family carer/s, as the PWLL becomes increasingly more confident in their ability to return to independent living. The increasing independence of the PWLL can be excessively worrying for family carers due to worry for wellbeing and safety when they are not there to care for the PWLL. This aspect needs further understanding and exploration.

#### **Recommendation H3**

It is recommended that the main family carer/s and wider family need more direct information to understand how they can support the PWLL. This should start at the rehabilitation process onwards. Specifically, family carers need access to learning about safe mobilisation of the PWLL, pain management, and how to manage the PWLL's improved independence as living with limb loss becomes more accepted. This could include younger children learning from others who have grown up with limb loss.

#### **Recommendation I6**

It is recommended that further work is needed to explore the remit of the family. This research sought to explore variance between and across families in relation to limb loss, however, understandings about how caring really occurs need deeper insight, especially in relation to the hidden nature of the emotional aspects of care. It is therefore recommended that future work explores hidden caring in and across the family unit.

Carers were asked to identify if they felt sufficiently supported, with responses as follows showing how many carers ticked yes/no for each statement:

The Carer	Yes	No
Emotional needs are considered by the Member	5	4
Family/friends understand what it's like to care for a person with limb loss	4	6
Finds it difficult to contact/get help from health professionals	6	4
Feels their life is on hold because of caring	4	6
Feels physically tired because of caring	7	4
Feels mentally tired because of caring	6	5
Feels stressed about caring	4	6
Worries about long-term health, wellbeing and financial security	10	1
Feels socially isolated in the caring role	3	8
Feels guilty for wanting time alone	4	7
Has become a more tolerant person through caring	4	6
Has experienced many positive things from being a carer	3	6
Feels valued by the person they are looking after	6	4
Feels that they are doing the best possible caring job	9	1
Can manage most situations with the person they care for	11	0
Feels frustrated with the person they care for	4	6
Worries about the Member's wellbeing when they are separate from each other	9	1

**Diagram 6** *Do the carers feel sufficiently supported?*

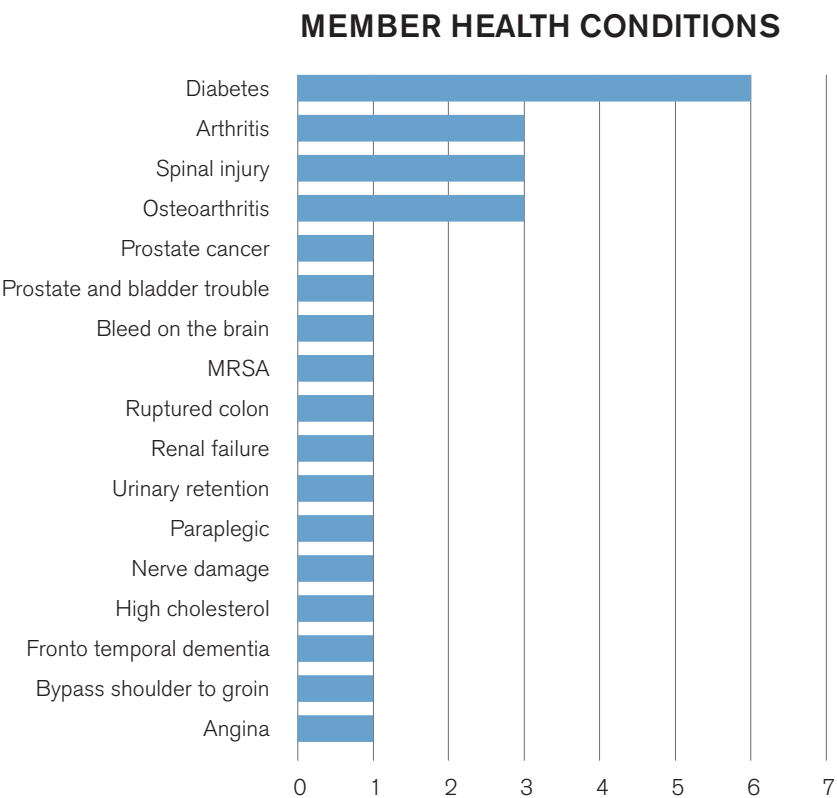
From this, there is a rough spread of responses indicating that caring is not a negative experience. For example, most carers feel they *'can manage most situations with the person they care for'* and feel *'that they are doing the best possible caring job'*. However, responses also tell us that carers are likely to feel tired, worry about long-term wellbeing, and worry about the Member's wellbeing when they are apart. Worrying about each other is inherent within the caring relationship, but also mutual: *'my wife and I have no children or relatives in the south of UK. We support each other and live day by day. We both worry about the other, especially if one of us were to pass unexpectedly'* (Member). It is important to note, therefore, that there is a sense of worry for one another inherent in the caring relationship, and this may bring about an additional source of concern. Worry as a concept is not widely addressed, but could be central in how the caring relationship operates, and as such, needs further investigation.

**Care, caring and wellbeing**

Morbidities	Number of Members with multiple morbidities
1	11
2	9
3	3
4	1
5	1

*Diagram 7 Members and co/multi-morbidities*

64% of Members identified themselves as living with multiple health conditions in addition to their limb loss. Following is a list of co/multi-morbidities across the whole sample:



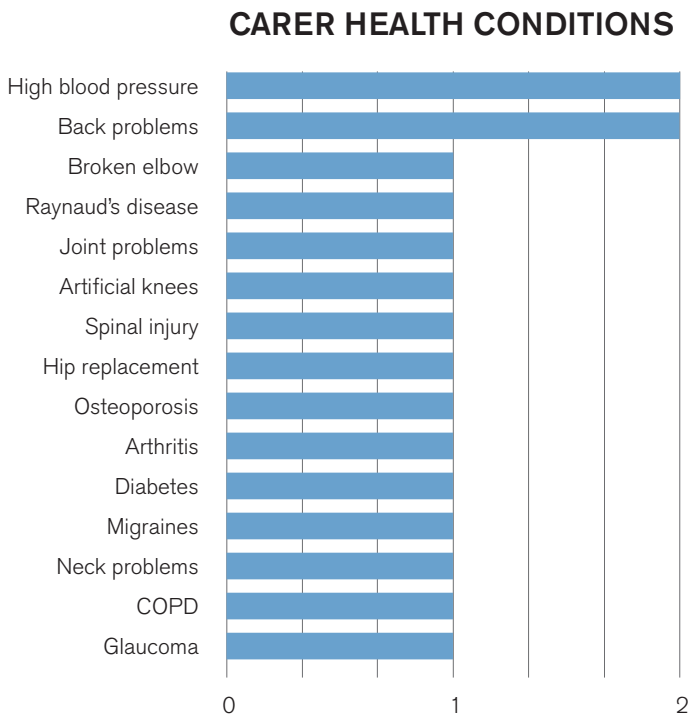
*Diagram 8 Member co/multi-morbidity conditions*

Carers sampled also indicated that they have one or more morbidities:

Number of co/multi-morbidities	Number of Carers with multi-morbidities
1	5
2	2
3	1
4	0
5	1

**Diagram 9** Carer co/multi-morbidities

Following is a list of co/multi-morbidities across the sample:



**Diagram 10** Carer co/multi-morbidity conditions

The carer's morbidities are not always recognised: *'whenever I had problems with my knee, I've already got one person with joint problems, I'm not allowed to have pain if that makes sense'* (Partner). *'Getting on with it'* and *'not complaining'* were evident across families, for example, a son recounted how his mother would often say *'I'm not very well this morning, but I've got two lots of washing on the line, I'm Hoovering the hallway'*. This was supported by the Member *'This goes with being an old-fashioned family girl'* (Member). *'Getting on with it'* was related to being in the military, especially when parenting a young family, which was most evident in the mature participants:

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*'As naval wives, we've been used to getting on with it and dealing it' (Partner)*

*'I was on my own all the time bringing up three children. So you know to me it was nothing, the kids got sick, one got measles. You just used to deal with it' (Partner)*

*'Cos I said to you, you must have had a time when you really want to let go and cry and it's really difficult to get it out of him, I think it's cos he's ex-Army, he was in for 22 years and he's got this attitude, that you have to get on with things and it's sort of rubbed off on me quite a bit' (Partner)*

However, it is interesting to note that even if the partner was not with the Member as a military partner, the attributes of being in the military were subsumed within the partner's coping. The younger families also talked about coping and managing, however, it was in a sense that they have to *'always be on the go'* or they won't cope:

*'I do find it hard, but then I do get frustrated him saying that because I think well okay, if I don't do it, it just mounts up. Who's gonna do the ironing, who's gonna do the cleaning' (Partner)*

*'It's all gonna be a case of everything revolves around him, just making sure everyone's got what they need' (Partner)*

*'The only person I probably have relied on to deal with it is [respondent's partner] and that's probably not down to self-consciously doing it, it's just been naturally doing that, she's always been there and I probably put a lot on her that I don't even know' (Member)*

*'Getting on with it'* and caring with co/multi-morbidities for others with co/multi-morbidities is evident in data, but as to how the carer's health conditions are managed is not evident in the data. Caring with morbidities has only recently started to feature in the medical and health care literatures, and as such, this research supports the need to better identify and understand how it is that carers with morbidities care for others with morbidities. This is therefore an important finding, that further research in this field is needed, as is addressed both in the literature review and conclusions. Being in the military is also important in explaining how persons adapt to and live with limb loss, and this is developed in the *'Coping and the Military Legacy'* sub-theme (see page 49).

#### Recommendation E1

It is recommended that a forward-looking approach is needed to support PWLL and their main family carer/s in relation to managing co/multi-morbidities, and a wider gaze is necessary to support PWLL and family carers in maintaining each other's wellness and independence. In particular, family carers need to be considered as to how their morbidities are being cared for and managed, and this in particular needs further exploration.

#### Recommendation E2

It is recommended that how the PWLL and main family carer worry about each other's co/multi-morbidities be assessed, with relevant inter-professional health and social care support structures put in place to maximise wellness for both. It is recommended that barriers to looking after the individual's morbidities be considered. For example, difficulties in accessing and navigating health services need

to be further explored.

**Recommendation I8**

Future work is needed to understand the role of coping from the carer's perspective, especially in relation to feelings of anxiety, worry, anger and fear. These need to be heard in order to develop better support for future persons who may experience suddenly becoming a carer.

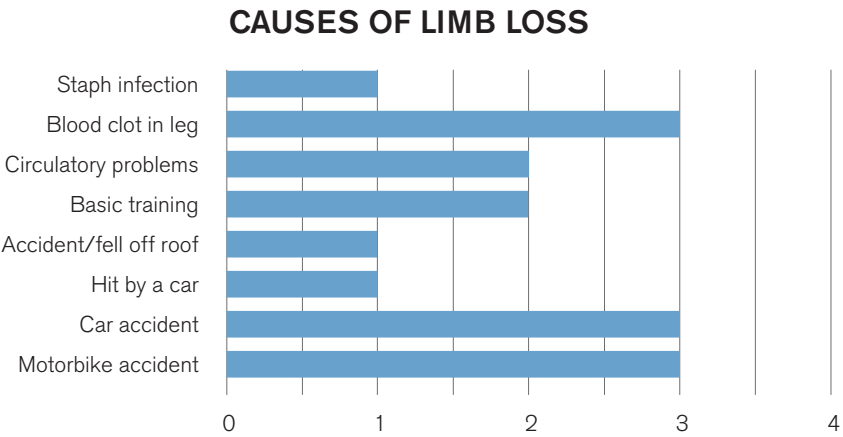
So far, findings illustrate the caring structure in a family, what care occurs, and what is problematic. To explore this further, the unique context of limb loss is explored through the next theme.

**Caring, Coping and Limb Loss: The Individual and Family Perspective**

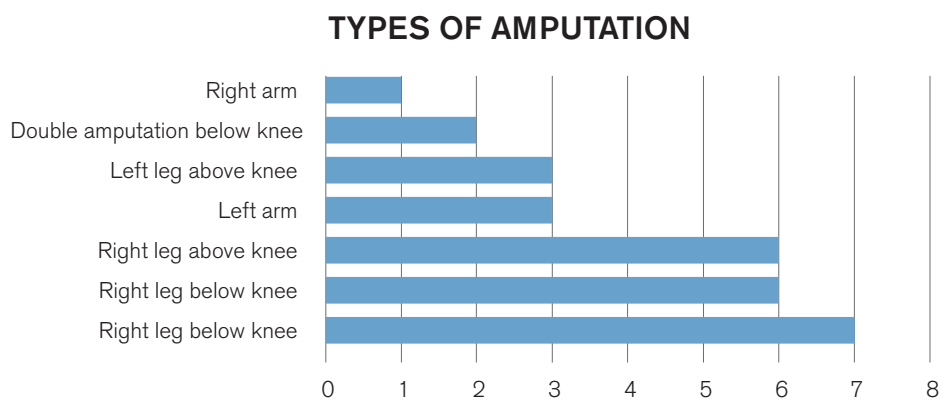
How the limb loss occurs is important, and the reason/s as to why a person has an amputation has a direct relationship to how a person might accept and adapt to their limb loss. Three differing reasons for amputation are evident in the data:

- Sudden/acute trauma e.g. car accident/haemorrhage
- Chronic due to systemic morbidities e.g. diabetes
- Chronic due to injury sustained in military e.g. as a result of a routine drill or training

The causes of amputation, and types of amputations, are presented here:



**Diagram 11** Causes of limb loss



**Diagram 12** *Types of amputation in sample*

Most persons in the sample had accepted their limb loss: *‘but on the whole I think I’ve had it 60 odd years now so, I’ve accepted it’* (Member). Acceptance was often related to the life stage of the individual, for example, *‘you realised you’re lucky ‘cos you’re an old man losing a limb and not a young man’* (Member), and often framed within the life biographical historical context of when the loss occurred. For example, a mature Member, with a below knee amputation when in his twenties, reported that it changed his and his family’s life for the better because it made him retrain, from which a career of fulfilling employment and living internationally occurred. Another participant, with a single above elbow limb loss, reported that he had retrained, which he would not otherwise have done, and maintained work irrespective of the limb loss. Two other participants with arm loss, as well as leg loss, also reported that the limb loss itself was not restrictive of their life, as they had adapted their life to manage that limb loss.

Two circumstances of limb loss are evident in the data – sudden/unexpected limb loss, and expected limb loss. Each has implications as to how the limb loss is initially managed:

Sudden/unexpected limb loss:

*‘Well I think the big thing to remember here, I’m sure it happens in most limb cases, is that it was so sudden’* (Member)

*‘I was in a coma for four days and when I eventually woke up my leg was already gone’* (Member)

*‘One was a plastic surgeon to see you know what’s going on, they said it can’t be saved, so they’d got to take it off two days later. The next day they said we can’t wait any longer and they just took it off’* (Member)

In the circumstance of sudden trauma, the initial reaction is that of relief:

*‘Because he was almost dead, his kidneys had given up and everything, he wasn’t expected to survive’* (Partner)

*‘It could have been worse and he’s like there with his cage on him, saying, how worse could it be and I said, I could have been doing your funeral’* (Partner)

*'I was grateful, very grateful for being alive, because I knew I should have been dead really'* (Member)

In this circumstance, there was no time to prepare for life post limb loss: *'we cut to sort of waking up in the operating theatre with the leg missing and didn't know how to handle that'* (Member), *'cos I couldn't believe how what life we had and it completely changed overnight'* (Member) and *'just that freak accident, everything's different'* (Member). A sense of 'what if' is evident: *'it could have been worse if I was paralysed, if I broke my back and was paralysed, that would be worse'* and *'luckily I wasn't the sole survivor and that makes a difference, if I'd been the sole survivor I'd have felt guilty, luckily there was two others who survived'* (Member), and as such, a sense of relief to be alive is presented.

However, the suddenness of the event, combined with relief, and a reality that life has changed irrecoverably, can be difficult: *'it was the suddenness because of course, because of that, nothing had been prepared at home'* (Partner) and *'seeing [Member] to hospital and going to work and in between crying, that was it, I was just really upset, how we gonna get through this'* (Partner). Here, a sense of isolation is experienced, *'we just didn't know what we were going to do, how we were going to manage. Everyone says it's going to be OK, and I just had to be, but there's no real help out there at this time. People come and go. They mean well, but in the end, it's just us'* (Partner).

Professionally led care was said to be good across the sample, although this was recognised as being mostly focussed on the physical and medical aspects of care: *'the support all through the process from the NHS, was absolutely wonderful, wonderful, you couldn't expect for anything better'* (Member). However, this support tended to be medical in orientation: *'but I think, I mean one of things we did find, there was a lot of support, sometimes too much, but it was all sort of medical advice more than anything, we didn't have what, we felt was practical advice, you know, this is the reality etc. and what, you know, you're sat in a hospital and it's going on and you're thinking, you, he's never gonna work again, how we gonna manage with that and your mind is just going over so many things and ...'* (Partner) and: *'you go to a consultation meeting with the consultant and whilst it, in reality you might be able to walk a couple of hundred yards but it's going to be so tiring for you because it's, you're going to use 100% more energy than you know, the normal person and I started getting angry and it wasn't the consultant's fault'* (Partner). It is at this point, therefore, that support is needed for persons whose limb loss is sudden. This support needs to present both the medical and physical reality of learning to live with limb loss, and also the everyday practicalities of what to expect and how to go about coping; *'the reality of it all really'* (Member) and *'it was very medical, it wasn't personal enough'* (Member). Although the medical support may be classed as excellent, there is a role for Blesma/organisations to offer insight into the future of coping to live with limb loss from a practical and holistic perspective.

For those who had amputation due to long term injury or chronic systemic morbidity, the removal of the limb was prepared for. In this circumstance, the injured limb was restricting living, and was described in the data as *'a dead bit of bone'* and *'a dead weight'*, that often had *'to be carried'*, painful, and *'I couldn't let anyone physically touch, I couldn't touch it, I couldn't look at it'* (Member). In this sense, participants described existing, but not living: *'it wasn't living it was just existing, day to day'* and *'while I had my leg they, they noticed the change completely cos normally I'm loud, bubbly, try anything, but when I had it, I kind of like closed in an myself cos everything was hassle to do'* (Member).

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A difficult aspect of living with a limb that has limited use is pain: *'they say pain don't kill you, but it's the actions of how bad the pain is that you react to' and 'all that pressure builds up and you pop and I popped several times'* (Member). For these Members, removal of the limb made sense: *'it was just like it was an alien part of my body and my brain didn't associate with it being me, so quite early on, it was like right, to get better, as a medic, the leg is the problem, get rid of the leg and that's the solution'* (Member) and *'what do you do if you've got a bearing surface on a mechanical item that's that screwed. Well, you replace the bearing surface. If you can't replace the bearing surface you replace the bearing and if you can't replace the bearing you write the blasted thing off'* (Member).

#### Recommendation I5

It is recommended that further work explore the nature of living with no function of limb/s. This research focussed on loss of limb, however, for some participants, loss of function, due to a prior experience, was sufficiently disabling for them to seek elective amputation. How this is experienced needs further understanding in order for organisations, such as Blesma, to provide focussed and relevant support that maximises independence and coping within the family unit.

Removal of the limb for those in this circumstance was therefore more positive and seen as life restarting:

*'One of the best things was when I brought her back from hospital, so she just had a stump, she hadn't even received the leg or anything like that, the day we got back from the hospital, she sat here, the boys were all in bed, I went and woke them up, brought them all down, put them out in the hall, once they were all ready, walked in, soon as they saw her they just ran and jumped on her, and for that to happen was brilliant because for two years previous they wouldn't go near her'* (Partner).

The amputation for these people was therefore wanted, and the elective nature of the procedure provided opportunity to plan to prepare to live post amputation: *'I'd got everything ready, whilst I still could, and we had time, I was mentally ready for it as well' but even with foreseen preparation, amputation still 'changed life completely', and 'we hadn't really thought everything through'* (Member). This is because the focus was on the physical removal of the limb, where the removal signified a return to the same living as pre-injury, and potential problems associated with amputation were not wholly thought through, for both the Member and the main carer. This was particularly relevant at the point of rehabilitation:

*'I'd been living in the dark for a long time and it was all nothing to look forward to, what's the point really, and then after he's had his operation I was like I just, for me, having something to do every day, being with him at the hospital and just doing little things to help him, just felt brilliant. Because it was just really nice to be able to do something useful and it was a bit like the light at the end of the tunnel had been switched on, you know, at least some part of our lives where we could look forward to, having more of normal life, doing more things again and then he went, after a week in hospital, he went into [name removed]. And he stayed there for four weeks and at that point it was really really weird for me. he'd been doing really well with everything and with, the initial stage of his recovery, it'd be a bit like, he had a family room there at [name removed] and me and the kids would go and see him on a Friday night and we'd stay there Saturday and Sunday. And then, it was kind of weird*

*because, it's one of those things you really look forward to going to see them and spending time with them, but, the whole time you know what children are like. They're just stress balls on legs and it, yeah, and you know it's a whole I want I want, I'm gonna have a fight now, rrrrrah, and the more that they do any kind of shouting or not doing as they're told it gets stressful and for [Member] that had quite a big effect on his phantom pain. When the kids were being stressful, the, it would just ramp up and ramp up and ramp up and, rrrrr, so it'd get to a point where the end of the weekend I think he couldn't wait for us all to go, basically. So it was a bit weird for me cos then I'd come back home and it'd be quite anticlimactic cos I'd feel a bit like I was not wanted if you know what I mean. Like he just wanted to get rid of me although I knew it wasn't so much me, so much as the kids and then, you'd be coming back here and it would be a bit bleak and depressing' (Partner).*

This quotation demonstrates complexity in the emotional aspect of coping with limb loss, where there is a sense of relief that the Member is progressing well. However, for the carer, there is a conflicting sense of relief the Member is doing well, whilst enjoying aspects of independence free from being the Member's main carer: *'then it would come towards the weekend and it'd be at the point where I didn't want to go to see him because I just got into that rhythm where I was happy and in some ways it felt like I was just a single mum. And although I wouldn't wanna be a single mum, it did feel quite nice actually at times' and 'and then it got to the point where I was actually dreading him coming home cos it was a bit like, I'm not gonna get as much stuff done anymore, I'm gonna lose all my me time. So, yeah, that side of things was quite weird'* (Partner).

Coping with limb loss in the early stages is therefore complex and multi-faceted, and dependent on the circumstance of the limb loss. However, it is at this stage that the Member is likely to feel they are coping well because of the planned professional care and attention they are receiving. However, the carers are likely to be in a state of emotional flux, because for them their lives are changing, possibly, in ways they may not have predicted, if the amputation was elective. The data therefore indicates that the reason for limb loss is important, and that there is a critical juncture in the recovery timeline, where support is required that is more than medical and physical in focus, and where an honest overview of *'being with'* is presented for both the carer and the Member, and that needs to be made relevant to the circumstance, and life stage, of the individuals concerned. Within this, it needs to be recognised that coping may be different for each person: the Member may feel they are coping well because they are in a supported care environment, however, the carer may feel they are not coping, because they lack understanding and insight into the changes that limb loss may mean for their everyday living. It is recommended therefore, that coping levels for each person are considered at the pre-discharge from professional acute/rehabilitation services for each person, and for the carer, that a more honest and open appraisal of what they can expect be made available. Within this, another additional theme that tells more about how individuals come to cope with limb loss is if the individuals self-identify as a veteran, which is discussed as follows in the next sub-theme.

### **Recommendation B1**

PWLL and their main family carer/s can experience different levels of coping to each other at the same time. Examples of coping, and recognition of coping levels, are detailed in this report, and it is recommended that these are used as a basis for assessing coping levels of the PWLL and their main family carer/s separately. It is also recommended that application of the LLSM be evaluated

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to assess its effectiveness in identifying individual levels of coping and support.

#### Recommendation C1

There are key stages in the limb loss life course that have specific requirements, as presented in the Living with Limb Loss Support Model (page 22). It is recommended that support relevant to each stage be identified in accordance with the needs and circumstances of the PWLL/family carer/s. It is recommended that application of this model be evaluated to assess its effectiveness in supporting independence and wellbeing for longer in PWLL and their family carer/s.

#### Recommendation I1

It is recommended that further research be undertaken to explore the use of the Living with Limb Loss Support Model, considering variables such as demography and morbidity, and the role of coping as mediator in the individual's and family's adjustment to living with limb loss. This is an area for further enquiry and understanding.

## Identifying as a veteran

Across the data, there was a trend that mature participants viewed themselves as veterans, whereas younger Members did not. For example, mature Members related being a veteran to remembering past experiences when in the military: *'I see meself as an ex-squaddie, veteran, well, I mean, a veteran's, oh, yeah, I am'*. To these Members, being a veteran meant *'thinking about things we did, when we were in the forces, we saw some traumatic things and traumatic accidents'* and attending local remembrance services and wearing their medals. This was partly seen to be age related, rather than experience dependent: *'over fifty years and you're a vet'*, and for another, he self-identified as a veteran in more recent times due to society's focus on veterans: *'I do actually, yeah, more so, since I've left, because there's been more concentration on ex-service personnel, I left the forces in '87, it's different now. In those days, when you left, you never considered yourself a veteran, but there's been more emphasis on it since Afghanistan and that of people serving in the forces, leaving the forces and then being called a veteran'*. This is important to note because there are likely to be veterans with limb loss in the community that do not self-identify as veterans. Not identifying as a veteran was particularly relevant for younger Members.

Younger participants were not so certain that they identified as veterans. This was partly due to a view that a veteran is an older person: *'I think I'm too young for that. I think it's my dad who's a veteran not me. I, I've got my badge in the garage in a little box, a little veteran badge, I see people wearing them who are younger than me and I'm like, but why, I understand why, but for me, no, I'd not class myself as a veteran, not yet anyway'* (Member) and *'no. I consider, I think veterans are more, more like an old, old people. Like that's, that's how I see a veteran, but to be, well I'm, I don't see that as old, or veterany-type thing. I see old people as veterans'* (Member).

Other ideas about who constitutes a veteran relate to perceptions about rank:

*'Veterans, I always think of someone who's more senior. And higher ranking as well, cos they're older they've obviously done their time, a lot more time and if it weren't for the senior guys, especially World War II, like the World Wars, I see them as veterans, heroes and that kind of stuff. I'm just*

*someone that got broken in the Army, who's now out, or gonna be out. So I don't, I'm not in the same category' (Member).*

Words such as in the quote above, *'that got broken'*, were evident across the data for young Members who were injured early in their military career outside of conflict. For these participants, being a veteran denotes a sense of entitlement, or worthiness, and being injured outside of conflict was expressed as their not *'really deserving'*, *'there are other people who are more worthy'* and *'I feel kinda like a fraud'*. For example:

*'You don't like really deserve to be here because you didn't get blown up in Afghan'*

*'Because it didn't happen over there. Like the cliché, but, so when people say, they kind of assume that it was done in, in combat but, no it hasn't'*

*'So yeah, what would you rather do? Have it blown off doing something real, or a stupid little accident and a bit incompetence and it culminate in this in the end'*

Whilst being in the military, the circumstance of limb loss therefore informs a sense of worth, and what the individual ought to receive treatment and support wise: *'when I had me accident I pulled myself away from the military completely. Part of that is I never done the tour' (Member).*

However, one Member described how he did begin to realise he was entitled to support:

**Member** *I picked up the phone, I rang [name removed] and I basically turned round and said that I know you're not interested in me and that's fine. What, I said, I weren't blown up in Afghan. I was Royal Navy, not Army. Cos common consensus was that they'd only dealt with Army and if you were blown up in Iraq and Afghan, which is actually bollocks. So yeah suddenly gone from this person who hurt their foot whilst serving, but not really doing anything, to suddenly becoming this thing called a veteran, almost overnight.*

**Interviewer** *But you didn't think you were a veteran before?*

**Member** *No. No, suddenly dragged into this world where, I still fit*

A sense of being able to *'fit'* was at first described as confusing: *'so there's me being dragged into this world of suddenly being a veteran, but trying not to be at the same time. It's a bit bizarre' (Member).* This becoming a veteran was *'strange'* and not necessarily easy:

**Interviewer** *What did it feel like becoming a veteran?*

**Member** *Very strange, very self-conscious as well because, I'm very conscious of being who I am and not anyone else. And the reason is there's so many accused of pretending to be someone they're not and all the rest of it, I don't want to be accused of anything. If you see what I mean. I feel very self-conscious about the short time that I was in and that I wasn't, I didn't go anywhere and do anything exciting so to speak.*

**Interviewer** *And is that what you wanted to do when you joined up?*

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**Member** *I wouldn't have joined up otherwise. I'd have much rather my foot was blown off in action than a stupid fricking accident that happened on base, that wasn't diagnosed by a bunch of idiots.*

**Interviewer** *So do you feel angry because of how the injury happened?*

**Member** *No, I'm angry at what happened afterwards. Can you tell? But, to me, it's a waste. This isn't for anything, there's no, justification in this. It's just shit luck.*

Therefore, although a sense of identifying as a veteran was gained, it is with a feeling of not deserving. From two other younger veterans: *'I couldn't associate myself with people that had, to me I felt like you weren't on the same terms if you know what I mean. I hadn't experienced things I expected to experience'* and *'you feel guilty for going away [to rehabilitation], so there's half of me that's like well surely there's other people who deserve it more, cos I didn't do anything spectacular'*. A sense of *'being a fraud'*, because of how the injury occurred, remains:

*'Of having an amputation normally relates to operations in Afghan or Iraq, but mine never was. So I feel kinda like a fraud'* (Member)

*'Feeling a fraud, and even going to [name removed], I felt like I was not, unworthy of being there, because there were people who have actually been in, injured in action, and that's how I felt, who needed these spaces more'* (Member)

This is important because simply giving the title veteran does not necessarily align with the individual's perception of what being a veteran is. As such, Blesma/organisations need to consider how the term is used in relation to the age of the individual and the circumstance of limb loss, in order to provide relevant and timely support.

This in turn relates to ideas of how Members access help and support from military, veteran and civilian services: *'I think because he got in his head, because he wasn't blown up, or because he wasn't shot, he wasn't entitled to any help.... you know, that he couldn't access any of this, he couldn't do this, he couldn't do that because he wasn't blown up and I think that's what stopped him a lot of lot of years doing anything'* (Partner). This is important to note as Members may not feel worthy of accessing health and support services, and may need to be encouraged to recognise their value as a person who was once prepared to defend the country: *'I've realised that it makes no difference, they just appreciate the fact that you did choose to serve and the fact that it doesn't make no difference how you were injured or whatever and that makes a massive difference'* (Member).

Within this narrative of worthiness, therefore, are ideas formed whilst in the military, or of a military legacy.

#### Recommendation D1

When limb loss is in relation to veterans, it is recommended that the term veteran be used wisely. Awareness is needed that not all individuals may associate with being a veteran, or consider themselves worthy of veteran status. It needs to be noted that a military legacy may shape behaviours and attitudes differently for each veteran PWLL. For some, a military legacy will

provide skills in coping with limb loss and, for others, admitting to needing support may be viewed as weakness. Being a veteran, and having a military legacy in some sense, is deeply personal, and it should not be assumed that all veterans are the same. It is additionally recommended that organisations consider how the term is used in relation to the age of the individual and the circumstance of limb loss, as not all veterans consider themselves as worthy of veteran-specific care and support.

#### **Recommendation D2**

It is recommended that obligations set out in the Armed Forces Covenant are emphasised to veterans and their family carer/s, so veterans are aware that, where their injury may be directly attributable to their time in service, they may be eligible for prioritised treatment and care.

#### **Recommendation D3**

It is recommended that the status of the veteran and the obligations set out in The Armed Forces Covenant be disseminated within and across health professionals' training and continued professional development, in order for awareness of the veteran to be increased.

## **Coping and the military legacy**

The role of being in the military in informing individuals' experience living with limb loss is evident across all generations in the data *'the Army head is not the civvy street'* (Member). Interviewed Members considered their military colleagues as friends, irrespective of how long they were in the Army, *'when you've got a friend, you've got them for life in the service'* and this is lasting, irrespective how long a person has been left the military, *'the military family, you could not speak to them for quite a while, then you could just pick up the phone it's like you spoke to them yesterday'* (Member), or the length of time they were originally in the military: *'but it's then you realise that even for someone that's only done basic, cos I did basic and I carried on a bit more but, even for someone whose only done basic, you've gone through a process. And that is a very deliberate process of bending the mind away from civvy street. And into a military mind set. It only takes eight to ten weeks to do'* (Member). This legacy has an enduring effect: *'there is that bond and you can't help it'* (Member), but importantly, it is a bond of understanding that other civilians can never have: *'know as well within that military family, if I had a problem I could ring any single one of them, but I wouldn't be able to ring any civilian friend'* (Partner).

The characteristics of being determined and stubborn were repeated in the data: *'determination. But I mean that is born, of being a serviceman'* (Member) and belief that few things are impossible: *'the answer is, you know, there's nothing impossible, I learnt that in the Army, they said you cannot strike a match on wet turf, that's the only thing I've ever found in life that you cannot do'*.

The character traits of being stubborn and determined were a driving force in how the individuals learnt to live with limb loss: *'you wouldn't let anyone walk over you, so that's probably one of the reasons, as well as my military training, that I was stubborn enough'* (Member). Having a positive attitude was said to be essential: *'positive. Positive thinking. If you go in the garage you will find row upon row upon row of positive thinking books and I quite regularly take one out and read it again'* and *'I am one of those sort of people that accept what's happened'* (Member). Humour was another characteristic described by Members:

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*'I just managed everything. I've always been someone who doesn't, not hold back, but someone who likes to have a joke, a laugh, not as, not to be really nasty or anything but just to play up and what have you'*

*'That's the Army way, you just, you always make light of a bad situation'*

These characteristics were shared in the family unit. The following is an exchange between a Member and partner:

**Partner** Or ex-military, really, are not gonna give up

**Member** With the military background, you haven't got that choice. You don't give up or carry on, you just carry on, there's no giving up. There's no giving up if you're a serviceman, you know. That doesn't enter your thoughts at all

The not giving in or giving up characteristic was inherent from being a military family: *'the other thing they've got to take into thought as well, is the fact that we're both [from] naval families and we're used to getting on with stuff on our own, without much support'* (Partner). The traits of being determined and stubborn could, however, mask what the individual may be experiencing. For example, there is a view that illness or injury is a weakness: *'the way the Army breaks you down, they put you back together the way they want you and it's [pause] having, going sick or having an injury or anything like that, it is like weakness, just, just man up and crack on with it and get on'* (Member), which means that *'you crack on and do it and struggle me arse off than ask for help'* (Member). For one Member, it is the stoic attitude of getting on with it that is an *'attitude that injures more people'*.

Similarly, the use of humour was seen as masking emotional responses to limb loss: *'he's such a laugh, he laughs and jokes and you do wonder and I think you have you must have had, cos I said to you, you must have had a time when you really want to let go and cry and it's really difficult to get it out of him, I think it's cos he's ex-Army, he was in for 22 years and he's got this attitude, that you have to get on with things and it's sort of rubbed off on me quite a bit'* (Partner).

Recognising the military way is important because individuals may be presenting as coping because this is how they think they ought to present, as admitting to not managing is felt to be a weakness. For Blesma/organisations, this is important to note throughout the living with limb loss life course as the appearance of coping may be just that, appearance, and two particular factors were demonstrated, the trait of not asking for help, or admitting to when additional help may be required; living with pain, and living with prosthetics, which are discussed in the next sub-theme.

## Coping, pain and military legacy

Across the data, pain is a dominant feature. In the interview data, there were 263 references to the word pain, and it was the 35th most frequently used word of a minimum 4 letters, and discounting words that are most likely part of normal conversation (e.g. when, what), it is the 9th/10th most frequently used word, featuring above words such as, work, home, family, limb, hospital, wife, different. In addition, a search of the narrative data using synonyms and stems (e.g. discomfort; soreness; agony; suffering; distress;

torture) returned 57 additional references across 17 sources. There were, in total, 360 references to pain/synonyms for pain across the narrative data sets. The levels of pain experienced ranged across the sample; however, no particular type of pain was unique to any age group. For example, there were more mentions of pain/synonyms in the age group 50s/60s, but there were almost exactly the same number of mentions from people in their 30s/40s and from people in their 70s. This indicates that the youngest and oldest participants are mentioning, or talking about, pain at a similar rate. Pain is therefore a dominant theme across the data, and how pain is lived with, and managed, gives important information about how individuals cope.

The following quotations describe pain experienced by Members:

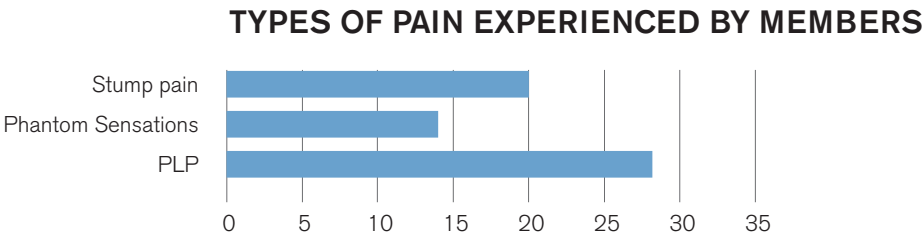
*'Like someone's got a knife in a fire, heated it til it's red hot, then just stuck it in your stump, then pulled it out and then stuck it in again and it goes on like, it just jumps and then stops and jumps and stops'*

*'It's quite like a sick feeling pain, like you really just have to get it taken off and it literally feels like you've just took your own leg off, by removing it'*

*'It feels just like somebody's hit me with an iron bar, it's just stops me, if I'm doing something, I just stop, cos I just can't break through it'*

*'It is a physical reaction to that, to that excruciating pain, which is, I suppose it's difficult to describe it, I suppose, it's more like somebody shoving and holding your hand in an electrical socket'*

Overall across the sample, stump pain, phantom sensations and phantom limb pain (PLP) were evident, and the sample reflects Blesma's projections that 50%-80% of amputees will experience PLP (Blesma, 2015), which in turn reflects wider literature.



**Diagram 13** *Types of pain experienced*

In this interview sample, participants were able to differentiate clearly between stump pain, phantom sensations and phantom limb pain. For example:

*'I don't get phantom pain, I get nerve pain in, actually in the stump itself.....And that is horrendous ..... Like someone's got a knife in a fire, heated it til it's red hot, then just stuck it in your stump, then pulled it out and then stuck it in again and it goes on like, it just jumps and then stops and jumps and stops' (Member)*

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*'I can feel the foot still there, all the time .....Psychologically it's still there ..... I can feel it, but no pain from it at all'* (Member)

*'It is random, highly random, having said that, there are things that do trigger it. Bending over. For some bizarre reason, does that, things like sugar, alcohol, spices, will set it off, static electricity on clothing, that can set it off and it is, it is, very much phantom limb'* (Member)

The participants reported phantom sensations in feet, toes, arms, legs, and some people reported phantom sensations after significant periods of time post amputation: straight after the amputation, over three years, 10 years, even 40 years later. For phantom limb pain (PLP), occurrences reported were one-off, fortnightly, two or three times a year, every three or four months. When PLP does occur, the pain reported ranged between 20 seconds every now and then, half a minute or a minute, a few minutes, five minutes, and various – sometimes three minutes/sometimes 10 minutes, every day, half an hour, for a one-off fortnight it was there almost all the time, for two or three days. Reasons as to why pain started were varied across change in the weather, dampness, family stress/illness, diet, weight bearing, being hurt on other parts of the body (e.g. hitting thumb with a hammer).

A significant cause of discomfort for Members is use of prosthetics:

*'I'd cause myself a lot less pain by not wearing a prosthetic'* (Member)

*'I probably weight bear far too much on the point of it, which causes it to get sore and things.'* (Member)

Use of prosthetics, and discomfort from, is a major theme in the data, and is further addressed in the 'Coping and Living with Prosthetics' theme (see page 57).

Analgesia was discussed across the data. In particular, morphine/opiates, paracetamol, Zomorph, Methadone, Amitriptyline, Gabapentin, Warfarin, Ketamine, Tramadol, Fentanyl and codeine phosphate, were mentioned. Participants also describe being prescribed different regimes of analgesia over time. For example:

*'I used to be on Zomorph. But because I was on it for a long time, they were worried about, being on it for too long. So now I take Methadone. Which replaced it and I take [medication] and Amitriptyline at night'* (Member)

*'I was away with the fairies, then I was on Zomorph, used to take one before I went to bed and that was even worse, then that [medication], cos I had a couple of falls and split my stumps open and I just used to drink the [medication] like it was a cup of tea'* (Member)

Other forms of pain relief were described, including ice packs, hot water bottles, creams, mirror therapy, having electrodes inserted into the head with portable control box, and a block put into the back. Participants indicated that they did not always want to use analgesia. Reasons for not using pain relief included:

- Not strong enough/doesn't work

- Memory loss
- Makes you feel zonked/like a zombie, with no energy
- Horrible side effects
- Makes you feel drowsy/not good for your body
- Withdrawal symptoms come very quickly
- Wanting to feel the pain so it can be treated rather than masked/relieved temporarily

One Member's reason for not using analgesia was to be alert for the family:

*'It's easier to sleep it off than try and like than try and like take a load of medicines, especially the fact that like with the kids and that, some of the lads and that I've talked to, some of the meds they're on literally knock them out. If I go for a nap I'm still alert, such that with having the kids and things I'm still there and around and with [Partner] and we can still do things together and still be a family'*

However, generally, there were no generational differences between analgesia uses evident, although the above quote indicates that being alert for the family is an important aspect of managing pain in Members with a young family. There is indication that older Members are on long-term paracetamol use, however this could be associated with other comorbidities and not phantom pain. There is also indication that paracetamol is the recommended form of analgesia by health professionals for phantom pain, but again it is not clear if the types of pain relief/combinations of medications used in the older generations are partly dependent on coping with multi-morbidities. Only one younger Member reported problems with specific medications and side effects of forgetfulness and memory loss, and who also reported taking medication in conjunction with a comorbidity.

## **Coping and not admitting to pain**

Members indicate that they are often in more pain than they admit: *'I'm probably in more pain than she actually realises at times'*. Family members however did state that they are often aware of more pain than is being admitted to by the Member: *'he never shows pain does he mum? Do you dad?'* (Daughter) and *'he will grin and bear it to walk'* (Partner).

There is evidence that the Member may more honestly admit how they feel to non-family members, for example:

*'Say if it was like a work colleague, you just, yeah, yeah, how you doing, oh it's effing shite this, it's really hurting, I can't do anything about it, I just want to go home, ahhh, you have an offload. If it's like a close friend they're like how you doing, yeah, still hurting but I just, I have some shit days and that's it, but if it's a loved one you're like, yeah it's fine'* (Member)

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*'If it's a loved one you're like, yeah it's fine..... yeah .....it depends on what you say to them, cos you don't want them worrying about you, they worry about you anyway' (Member)*

This is an important finding as it implies that Members may be more honest about their pain to persons other than their family. Therefore, it is recommended that BSOs seek opportunity to ask Members about their pain where the family may not be present.

## **'Not admitting to', being in the military and pain**

Interview participants described how being in the military influenced how they responded to pain:

*'Because there's that stigma of, you going sick, yeah, you biff and it's all a negative thing, so with people who haven't, didn't get treatment sooner than what they should of, they've ended up with worse injuries. Cos they didn't want to get labelled a biff. So, that's one thing the Army has done and that's, probably not a good thing, is that, asking for help or going sick is a sign of weakness' (Member)*

*'And that was weird, because I've been out for so long, but it's then you realise that even for someone that's only done basic, cos I did basic and I carried on a bit more but, even for someone who's only done basic, you've gone through a process. And that is a very deliberate process of bending the mind away from civvy street. And into a military mind set' (Member)*

*'With the military background, you haven't got that choice. You don't give up or carry on, you just carry on, there's no giving up. There's no giving up if you're a serviceman, you know. That doesn't enter your thoughts at all' (Member)*

*'I, I, don't think, I don't think they noticed that I had any pain, because I rarely complained you know' (Member)*

*'It's beneficial pain because it needs to be, get used to it and start desensitisation stuff, so it will get worse before it gets better' (Member)*

However, even though the Member may not be being wholly honest relating to pain experienced, seeing the Member in pain is a significant factor that families find hard to manage/support, which can lead to feelings of distress and helplessness:

*'Cos he's suffering from phantom pain and I mean I know I shouldn't but just one day it would be really nice if I could have a day when he didn't have any pain in his arm' (Partner)*

*'She gets worried when the stump starts jumping cos she can't do anything, she really does worry, there's nothing she can do, she tries everything, hot water bottles and you know, holding it with her hand trying to heal it, but nothing works' (Member)*

*'You just feel, even now, you just feel so helpless, that you can see that he's in pain and you just feel so helpless that there is nothing physically or mentally that you can do for him' (Daughter)*

Supporting the family in being able to admit to, and talk about, pain, is a significant factor that Blesma/organisations needs to be alert to. Not admitting to/talking about, indicates a lower level of coping, which could be supported, should the Members/families feel able to talk about pain without there being an assumption of weakness.

**Recommendation F2**

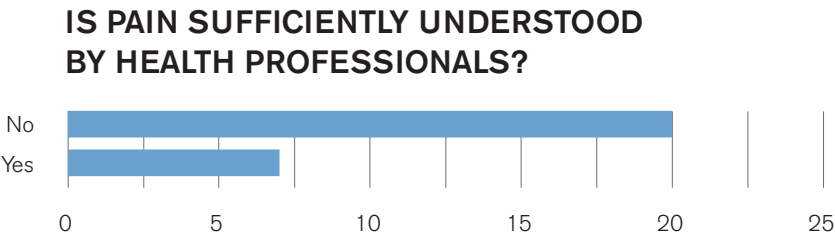
It is recommended that family carers learn about pain related to amputation, as a means of being able to support the PWLL who may experience pain, and to enhance coping levels, of both the PWLL and the family carer/s, in managing pain effectively. Where relevant, this should include younger children who witness their parent in pain, and who want to try to help their parent to minimise their pain. Similarly, mature siblings need information on how to support their older parents in managing pain.

**Recommendation I3**

It is recommended that the relationship between coping, amputation and pain be explored. In particular, further work be conducted in understanding pain and limb loss, and the role of the military legacy in living with and managing pain. A PhD studentship has been funded by the VFI to explore the narratives of pain in veterans, as a direct result of this research study, to be completed within the next 4 years. Further work is needed to explore how pain may be catastrophised within a care unit, and how people witness the pain of others.

**Coping and communicating pain**

Being able to talk about pain is not easy, and when this was tried, it was felt that health professionals do not understand pain relating to amputation, with a majority of the sample feeling that pain is insufficiently understood by health professionals: *'yeah, but they just don't know what, how to sort of stop it I don't think'* (Daughter) and *'tweaks in medication, that's what it's all been about really'* (Member). This is reflected in responses to the Member questionnaire:



**Diagram 14** *Is pain understood by health professionals?*

Interviewed Members and families said they were not sure how to make their pain understood: *'well you could tell them about the pain and they, the things they prescribed were not for that type of pain, they weren't ..... They didn't understand amputation, I don't think'* (Partner). Prescribed regimes for pain relief were

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reported as being trial and error in nature, as opposed to specific and targeted to the actual pain the Member was reporting: *'he'd try something, and it seemed to get better and then it would go bad again and but I think it was because he became immune to the actual tablets he was taking. Then they'd tried something else'* (Partner) and *'they said I've got to get on top of this pain .....he said because something to do with pain if you gain control of it, but unfortunately it didn't'* (Member).

Interviewed participants also reported being discharged from hospital post amputation with little knowledge and understanding about pain and its management: *'so I was on Ketamine and drips and there, Ketamine and Morphine in there and I'd come out, I'll never forget, coming out of hospital with this big bag on my lap'* (Member), further indicating that, when recovering from limb loss, discharge from acute care to the home is a crucial point at which support is required.

Interview participants were asked if an information/questions to ask crib sheet would be useful to assist communications about pain with health professionals, with a positive response that it would be helpful, and from the questionnaire, 21 out of the 35 Members and carers sampled would value having a pain information and questions to ask sheet to use when discussing pain with health professionals. The data therefore suggests that Members and their families need additional help in being able to firstly recognise that pain is not a weakness, and secondly, support in how they can make their pain, and the limitations of the pain, understood by health professionals.

#### **Recommendation F1**

Specific to veterans with limb loss, experiences of pain may not always be admitted to. This may be due to a military legacy of admitting to pain being seen as demonstrating weakness, but this may also be because individuals do not know how to describe, or explain, phantom pain. Equally, health professionals may not be versed in understanding the effects or consequences of being in the military, and how this might continue to shape the life course, and behaviours and attitudes, of the PWLL, after leaving active service. It is recommended that a crib sheet with questions to ask health professionals be developed, for veterans/PWLL, carers and health professionals to use, in order to describe pain and/or ask relevant questions to explain/assess pain, to assist in appropriate management of pain associated with limb loss. It is recommended that health professionals have additional education about the management of pain associated with limb loss.

#### **Recommendation G1**

It is recommended that information is supplied to PWLL and their family carers on how to manage changes in the stump and use of prosthetics with increasing age. In particular, managing changes in the stump shape, lack of confidence in the prosthetic, and fear of falling, can be a source of anxiety to persons and can lead to social isolation.

#### **Recommendation G2**

It is recommended that health professionals/service providers are aware of possible variations in prosthetic provision and provide support in communicating with and gaining access to services. Variance across provision of prosthetic services needs to be standardised. Limited access to quality prosthetics services is a cause of family anxiety as it debilitates the PWLL.

### Coping and living with prosthetics

A dominant theme in the data was difficulties in living with prosthetics. Most interviewed participants were regular prosthetic users: one Member interviewed had an above arm amputation, did not use a prosthetic and had no other mobility concerns, and two other Members had above arm amputations for which they did not use a prosthetic, but did use lower limb prosthetics. For those with lower limb amputation, all interviewed participants and questionnaire respondents stated they used their prosthetics on a regular basis to differing degrees:

How often do you use your prosthetic?	Member response
Never	2
Sometimes	1
Most of the time	11
Always	13

**Diagram 15** *Average use of lower limb prosthetics*

A variety of different types of prosthetics were described, including one Member reporting using 26 different prosthetic legs over time. Examples of past legs described include:

- Wooden legs
- Less flexible legs e.g. rigid leg/knee
- Metal socket, frame + piece of rubber underneath to walk with
- Metal socket with a foot
- Hand-carved wooden socket with straps
- Leather with steel braces and a corset, or harness and a strap over the shoulder
- Legs that could be manually moved/flexed: button to bend the knee e.g. to sit down, lever at the side that you push to walk with

More recent prosthetics described include:

- Legs that suction onto the body
- Carbon fibre, fibreglass/plastic
- Mechanical - KX leg/C-Leg
- New Genium model: it has a microprocessor computer chip, can be synced to an app, which can be programmed with three different speeds, with a knee joint that acts like a 'normal knee' and flexes/stiffens according to speed/movement, and with different activity modes, e.g. cycling,

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skiing, running, allowing movement in any direction

- Cosmetic limbs – with hair
- Swim/wet leg

Discussion about prosthetics was mostly about the socket and managing the socket. Types of socket care referred to in the data include: pin method, sponge material, thicker socket to absorb shock, fibreglass outer, stump stockings inside the socket, polyurethane sockets. Looking after the prosthetic is an important part of maintaining independence, and often seems to affect overall experience and satisfaction of living with the prosthetic. There was little differentiation across the generations sampled relating to how satisfied they were with their prosthetic, and the same daily living with prosthetic issues are reported across the generations, e.g. problems if the socket is the wrong size, chafing and prosthetic pain. One partner expressed concern about potential stump breakdown and the Member's diabetes: *'he is wearing it too much, it rubs away at the skin and he can't take the risk again, cos he's a diabetic he's slow to heal, of reinfection there, so that's a constant'*, suggesting that living with an amputation and multi-morbidities is a constant worry. This is also identified in the 'Hidden Caring and Coping: The Family Perspective' theme of the findings (see page 30).

There are key statements from younger Members that indicate high levels of satisfaction with their prosthetic: *'without a care in the world wearing a prosthetic', 'first time that I sort of felt like my old self, the fact that I could just get up and do something', 'I've got my leg now, I'm sorted'*. Younger Members were generally satisfied with the prosthetics available to them, having access to current prosthetics technology. At least one of the younger Members has the latest Genium model. Adapting to new prosthetic models is said to take time, with adjustment causing pain/soreness/cuts, muscles being sore/confused by what leg is being worn, if several different legs are being used, and if ill fitting, causing hip misalignment and pain.

The data also suggests that older Members adapt and cope well with their prosthetic and possible prosthetic difficulties. They show determination to stay active and persevere with their prosthetic, and where problems are experienced, overcoming such hurdles satisfies them, and when they have the correct prosthetic they gain satisfaction. For example, the character trait of being stubborn and determined assisted in rehabilitation and learning to walk with a prosthetic: *'the main physio, was, she said most people who have a limb removed at [Member's] age, they just give up and it was because he was determined that they wanted to work with him. Cos it was a sort of, how can I, it was different for them to find someone in that age bracket who wanted and appreciated the help'* (Partner).

However, some of the older Members discussed issues surrounding their prosthetic, such as stump soreness/blistering, but are reluctant to remove their prosthetic for fear that they will become fully dependent on others or a wheelchair. Use of wheelchairs varied across the data. Use of wheelchairs was ascertained in the Member questionnaire and from some interviewees:

If you are a wheelchair user, how often do you use it?	Member Response
Never	3
Sometimes	11
Most of the time	3
Always	5

**Diagram 16** Average use of wheelchair

The interview data presents that there are generational differences evident. Generally, younger Members are more willing to use their wheelchair as needed, and view it as an extension to their mobility, and as such, as part of their independence: *'if my leg's sore, I'll take it off and use the chair'*.

The cause of limb loss was relevant here also. For those interviewed who had amputation due to injury during training/routine manoeuvres, and had a significant period of time with a damaged limb prior to limb loss, the effects of the prosthetic were particularly positive. This may be because the younger Members in the sample interviewed generally lost a limb due to injury either during training/routine exercises or as a result of motor vehicle accident whilst on leave. Focus here is on the relief at losing a limb that was causing pain and of no use, where the prosthetic enables 'normal' living to start. In these cases, living with a limb with no functionality, and one causing pain, was the cause of distress. The removal of the limb itself brought liberation and normal life restarting. Up to amputation, the Members were living in a hiatus, where the limb was burdensome, painful, and stopping the individual from participating in their normal family life. Generally, therefore, younger Members indicate that they are more willing to remove the prosthetic when uncomfortable and use a wheelchair instead as it maintains their independence.

Older Members, however, see the wheelchair as signifying a loss of independence and signalling reliance on others to maintain their mobility and independence: *'once I got clear of the wheelchair, I became slightly more independent in that, that I was able to move around on sticks and stump and I sent the wheelchair back and I haven't had it since'* (Member, 83 years old) and this was because *'my aim from the word go was that I was gonna be as independent as I possibly could..... and I think I've achieved that at the present'*, so demonstrating the determinedness that characterised the sample interviewed.

However, this determinedness can be difficult for the family. For example, one Member described having *'strict rules'* when being in a wheelchair relating to how he was pushed, which part of the pavement to use, but mostly because he felt it was too much for his 80-year-old partner. His son, on the other hand, felt there was great value in his father being able to consider the wheelchair as an aid to maintaining his independence. The following is a lengthy excerpt from an interview with a Member, his partner and their son:

**Son**      *You don't necessarily need it to go into town, you drive to the carpark and you walk slowly to your coffee or wherever you're going, Debenhams or whatever it might be, absolutely fine, but when you're going out and about, whether it be to a function or an event be prepared to.....Be prepared for somebody to push your around in a wheelchair, but*

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*he doesn't want to put on anybody....so I'd much rather have it in the boot, we walk around for two hours, dad says cor I'm feeling a bit, or bit of pain in the hip, no problem, let's whip the wheelchair out and we'll still go around all the stalls. It's bridging that gap*

The sense of stubbornness in this discussion continued between father and son:

**Son** *But say for example we went to, I don't know, let's go to [name removed] for the day, they've got some jousting on, we haven't been there for years, let's take the wheelchair, now it wouldn't be you two going, it would be me and [partner] or [brother] would come with us, or [name] my son, he would come with us, whatever it might be, there's the support, there's the family support there, it wouldn't just be.....That's what I say, if you have a wheelchair, you don't have to use it all the time and the chances are when you go out with mum, you're doing things where you're not gonna need it.....For years, because you take your time, you bumble about, that's absolutely fine, but where you're going somewhere bigger, with the family if you like, then, the world can still be your oyster*

**Father** *I wouldn't think [name place] a good idea. No, I'm being practical because trying to push somebody round in a wheelchair at [name], on grass and gravel.....And that sort of thing*

**Son** *Gravel paths and things aren't an issue, cos we've done that before, with [Partner's] dad and that sort of thing. But there are ways to do it*

**Father** *You've gotta have a truck going behind you, with all the boards to put down*

**Son** *They do it, nowadays, everywhere is disabled friendly, they have to be*

**Father** *Is it?*

**Son** *There are ramps and things everywhere, honestly, you'd be surprised*

**Father** *It's not even that, I don't think it's fair to expect other people*

**Son** *That's the key word*

**Father** *What*

**Son** *You don't expect anything, that's what you've got to change, it's not you expecting people to push you round in a wheelchair, it's people offering to push you round in a wheelchair and that really is the important change. We don't care, we want to do it, because we want to be, with you, to do things. But we would do it, because something's cropped, oh, yeah, mum and dad might like that, but then you'll say oh yeah but I'm not gonna go in a wheelchair cos I don't want you to push me around and it dies a death, you know, whereas, if you were to try to just change a little bit and be a bit more open to those ideas, the, I think, the, another key thing apart from the expectation part, is, that the wheelchair wouldn't be permanent, it's not a case of we're gonna get a wheelchair*

This is useful as it seems reasonable to infer many similar conversations occurring within families. Here, it is opportunity to talk openly within the family that is needed, whereas without this, having conversations where the family need the Member to change aspects of their behaviours may not occur. From a stage 3 telephone interview, the son identified that the Member had since used a wheelchair on a day out, and by using it, gained more independence from the day because he had experienced the whole day without discomfort. It is important to recognise, therefore, that use of mobility aids, such as a wheelchair, may be perceived as losing independence by older Members and this may need to be openly discussed in supporting the family to live independently with limb loss for as long a period as possible. A stubbornness to admit to changes in mobility and health due to age may be the display of signs of changes in coping, where a perseverance to continue as 'is' is perceived as coping, but it may rather be representing lower levels of coping.

#### **Recommendation 19**

It is recommended that further research is needed to explore how the family cares for one another, especially when the PWLL refuses to admit to/accept needing extra support and care.

### **Prosthetics as limiting**

Where there was dissatisfaction expressed by Members, it was related to the prosthetics being unreliable, leading to a lack of confidence and trust in their limb. For example:

*'Just making sure I've got a limb that is safe and I've had a state where they had just kept collapsing, not collapsing, but the knee wasn't locking and it just kept giving way'*

*'But it was so heavy, I mean, it looked so much like a real limb, but it was difficult'*

*'They should lock and they don't, so you just get it at that sort of angle then it gives way and down you go'*

*'Because if the socket's a bit loose, you don't know it's gonna happen'*

This in turn leads to falling:

*'Falls, oh dear, the last fall was five months ago, I broke two ribs'*

*'I'd hate to count how many falls I've had'*

*'The mechanism is giving way as he's walking'*

*'I can't stop myself and over the years I've learnt to relax and just crunch to the floor'*

*'I fell over. At one time if I fell, it didn't worry me because I used to roll over like I was trained in the RAF, for parachute jumping, but now, that's gone. I fell over and I was straight to my face, but again luckily I healed very quickly, but it makes you more careful, I have to be more careful when*

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*I walk to make sure I lift my feet up, rather than push them'*

*'The strap holding my prosthetic leg had slipped over my knee and I fell to the ground. I didn't hurt myself but I did feel a fool'*

*'I fell over and hit the window sill and I just laid there for about, then you get up and just carry on'*

*'I had a couple of falls and split my stumps open'*

This in turn leads to worrying about falling, particularly from family members: *'his stumbling, yeah, he sort of stumbles'* (Partner), *'same as mum's, it's his stumbling'* (Daughter), *'inside he's very conscious of something else happening again, where he's gonna fall down and have a serious accident. ....He's afraid of falling in it, that's the truth of it'* (Partner). This can lead to Members feeling reserved about going out: *'yeah, I would say he did. There were times when he, he sort of didn't want to go out. ....Because he was aware of something like that happening'* (Partner). Falls, or falling, were mentioned across the data. The most common place for falls in the sample interviewed was in the bathroom/toilet, most often during the night, *'he fell over the other night, in the bathroom in the middle of the night'* (Partner), *'straight into the toilet, pushed the toilet cistern back, broke two of his ribs'* (Partner). Other places in the home mentioned included the kitchen, followed by outside the home. Falling outside home was felt to be particularly problematic, either due to the public not helping: *'he fell and that day he didn't, he just had normal jeans on, and so you know, people just walked past him, it took a man in a mobility scooter who helped him up'* (Partner) and *'people just thought I was drunk'* (Member), or the public helping: *'if I need help I'll ask that's what I say'* (Member). Falling outside the home was a considerable worry to all the main carers interviewed, and part of their caring was *'checking out see if it's ok to go there'* (Partner). This is discussed in further detail in the 'Hidden Caring and Coping: The Family Perspective' theme (see page 30), but it is important to note here that risk of falling due to poor fitting prosthetics is a constant worry to carers, and can be characteristic of low coping with a hyper vigilance over trying to reduce potential risk when the Member is independent of the family carer.

The need for the prosthetic to be fitted correctly was evident across the data, and access to and quality of local prosthetic services were discussed as sources of satisfaction or dissatisfaction, the latter being of particular importance in relation to coping with limb loss.

## **Accessing prosthetic services**

Mixed responses to satisfaction of local prosthetic services is evident. Generally both younger Members and mature Members were satisfied, and the Member questionnaire indicates that 11 were satisfied, however six stated that they were not satisfied. Geographical differences were present, for example services in the Midlands area were praised, whereas services in the West Country were seen to be lacking. Those Members who were not generally satisfied had other morbidities, such as obesity, which could affect how able they might be to gain full independence from a prosthetic, and one Member showed a limb that was heavy and cumbersome to use, with the feeling that if the prosthetic was better, they would be able to mobilise independently, and then lose weight.

Most issues related to length of time waiting for replacement sockets and difficulties contacting the service:

*'And if you lose weight, you lose weight around your stump.....So the socket is too big and I say it takes three months now to get a new socket made' (Member)*

*'But, my take on it is, it's been five and a half years, it's about time, you had legs that fitted and to be honest he sent a leg away for refurbishment about three months ago and it took forever to get the measurements right..... And that shouldn't be the case. Especially when you're obviously dependent upon it' (Member)*

For some, these problems were long standing: *'I think the biggest recollection is the problems he had with the leg itself, trying to get the leg and there were issues with it, trying to get the support that was there....Even now, he still has a problem, all these years on, with all the technology and everything they've got, he had, it was a very very heavy leg, only there was so much he wanted to do and he couldn't do it, but there'd never seemed to be anybody there for him to turn to. It was long and arduous and painful to try and get anything sorted out and it just seemed to go on and on and on. Hard for him, which is very much as it is today' (Son).*

Having a second limb was seen as essential to the Member's independence: *'when you've only got the one limb, always had two, but I've only got the one limb so if this one goes I've had it, I'm completely snookered' (Member)* and *'got to be nearly two years now I've been waiting for a second limb' (Member)*. Contacting prosthetic services was found to be difficult by some. For example:

*'You have to phone them three or four times and when you phone them, you're number one in the queue, you're number two in the queue and you sit there and the one time I was on the phone 12 minutes and I was still number one in the queue' (Member)*

*'They keep putting it down to money but I don't think it is just money, when you phone up for something and they don't get back to you, you leave a message all over the place, they don't get back to you' (Member)*

Frustration at communicating with a prosthetic service were felt across the family:

*'He just gets, like you said, they just get so fed up of constantly banging their heads against a brick wall and getting nowhere' and 'it was long and arduous and painful to try and get anything sorted out and it just seemed to go on and on and on. Hard for him, which is very much as it is today' (Son).*

In this family, communicating with the service was delegated to the son:

*'My sister [name] phones me up and said dad's having problems with his leg again and I'll just phone up the limb centre in [name removed] and say look I want somebody to see him. Well, excuse after excuse, right I want to speak to so and so, eventually I speak to somebody and they say well we didn't know anything about that, you think well, you're a department, what's wrong with communicating, it doesn't take much to communicate and it seems all along that the communication problem and the support' (Son)*

However, when communication with the service works, satisfaction seems high:

*'They're supportive, they're positive, and they've just made things happen' (Member)*

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*'I now come under the rehabilitation centre in [name removed] and they've been fantastic. You know, I got this leg, I've had a couple of legs, this is my latest one, which I've had, where I had this fitted and saw a physio.....But I go back there once a quarter, just to get the knee tightened up, as it's shrinking.....And they're absolutely fantastic. Nothing is too much bother and it's just great' (Member)*

*'They're gonna make me this socket, which will help me tremendously for, getting the legs on and off cos I've got a problem with my hands as well' (Member)*

Those who have been treated in military hospitals may have experienced more satisfactory prosthetic services than in comparison to civilian prosthetic services. For example, *'when I was at [name removed] it was, I mean, they'd do it there and then virtually, but not here, it's, over the years it's just got worse down there hasn't it, the limb centre'* (Member). One Member *'shopped around'* to find a service they felt was satisfactory, but doing so was hard work: *'but on the inside it's like a hell of a lot of hard work. Same with the prosthetic care. I finally found a centre that's doing the prosthetic castings properly, so I've got a socket that fits really well now'* (Member). Negotiating health and social care services was mentioned across the data, for example, finding and accessing services in relation to managing other health conditions was difficult, and one factor that is either ignored, or left for other family members to deal with. For example, parents' frustrations in contacting/accessing services is usually displaced to mature children, who take up the cause of contacting services in order for relevant support to be provided. This presents as another example of hidden caring within a family unit. However, if there is not another person who can take on this role, there is a sense of giving up because of frustration and demotivation, and this can have a lasting effect on the Member's overall wellbeing, especially where comorbidities may be prevalent. The findings therefore indicate that where Members are satisfied with their prosthetic service, a good quality of care is perceived, however, for those who do not experience this, it is a source of frustration for the family and debilitation for the Member. Lack of reliability on the prosthetic therefore leads to low levels of coping for the Member and family. As such, intervention to support Members in liaising with, and accessing prosthetic services, could support coping.

This needs further investigation by Blesma, and it is recommended that when BSOs or other health professionals/service providers check with Members that they are satisfied with local services, and offer support in times where frustrations may be occurring, they place more emphasis on levels of satisfaction and consider how well Members are coping with their prosthetic. The need for effective communication and access to prosthetic services is not visible in the literature, and further enquiry is needed to gain an overview of how prosthetic services are accessed and used.

#### Recommendation I2

It is recommended that further work is needed to understand how PWLL adapt to their limb loss across the limb loss life course. In particular, the process of 'becoming' with limb loss, and 'being' with limb loss, needs further insight. Related to this, further insight is needed into how PWLL cope with use of mobility aids, such as prosthesis, across the life course, and adopt coping strategies across demographic and disability-related variables, and what adjustment factors there are that relate to an individual's ability to adjust to and cope with limb loss across the life course.

So far, the data demonstrates that the cause of limb loss and the military legacy are important in coping with limb loss. The data presents the 'work' that goes into managing events that occur because of the limb loss – it is not the limb loss per se that causes problems, but rather it is factors essential to coping with limb loss that are important, such as managing pain and accessing prosthetic services. As such, a lot of time and effort is put into managing factors such as pain and the prosthetic, which is largely unrecognised (hidden) by people outside the family unit. The data also demonstrates key junctures in the recovery from limb loss process where key support would be beneficial. The nature of this support is addressed, as follows, in the next theme.

## Support for Coping in Individuals, Carers and Families

### Becoming involved

Data demonstrates that overall, professionally led care in relation to the physical loss of a limb is good or excellent:

*'The support from the NHS was constant, you know, we had the district nurse turning up every so often, the physio coming to the house, phone calls and GPs were fantastic, it was hard to describe you know. You hear these stories on TV about how bad the NHS is, I've never ever agreed with that, it was wonderful. To the extent that at some stages, there was too much support, do you know what I mean, in a nice sort of way' (Member)*

*'We really can't fault them. They were excellent. We felt really looked after' (Partner)*

Overall, participants said they had coped mostly well in adapting to their limb loss, *'but I think he coped, coped and still copes with it extremely well, physically that is, but I don't think there was anywhere near enough support for him otherwise'* (Daughter). Limited professional focus on the affective aspects of limb loss was evident through the data: *'we were just left to it all of a sudden'* (Partner) and *'that's it, I was home in a wheelchair with a box of meds and left to it, we didn't know what to do'* (Member). It is at this point where the role of family is particularly evident:

*'I mean there's professionals around you and you kind of hope they do the holistic thing, we all know that that holistic thing isn't always there and you do need family looking out for you and advocating when you're that vulnerable and unfortunately that is the reality, even now, you know, I think you have to have, you know, somebody to voice things on your behalf' (Partner)*

To overcome this, some families were creative in how they made sense of their sometimes-new life change and adapting to living with limb loss. One partner, for example, described how she used photography as a means to make sense of their situation: *'I've had a camera since I was 10, I was taking pictures of him on my phone and all the rest of it and I started doing it as he was having all this physio, I thought he's gonna come through this, he is gonna get down, I wanna show him how bad it was and how far he's come and that's how that album came to be'*. This brought a sense of purpose and comfort because it visually documented how far the Member had come during his recovery time: *'when you're sat in the hospital you haven't got a clue what is ahead of you and I'd put it together as an album... we made another copy up and we took it up and we gave it them and to cut a long story short they've used it in the hospital....we still use that as therapy because every so often we'll sit in here with the albums and a bottle of wine and just go through it'*. Examples from the photo journal are presented in appendices 3-7, as shown with the permission of the participants, who would also be willing to share the making of their book with other Members and families.

Another aspect that helped couples and families cope was goal setting: *'I suppose in one sense it was probably quite lucky for me that [daughter] was getting married in March, because I had something to aim for, otherwise I probably would have sunk into a pit of depression and not done anything'* (Member). Another Member used sport as a means to develop a sense of independence: *'so I got invited to go along and try*

wheelchair basketball, which took a lot of persuading for me to do. Went along, enjoyed it, then I got involved with hand cycling and did a cycle ride from Edinburgh to London. Hand cycle yeah. In five days with less than two months of training'. Becoming involved in social activity changes how the Member re-finds their confidence in themselves:

*'When I got involved in sport and it was as if I started to come out myself and things and doing more myself and that's when she [partner] started to realise the change in me and things as well'* (Member)

*'That was the first time that I sort of felt like my old self, the fact that I could just get up and do something and it's weird because I could only ever use crutches to walk on my prosthetic and I think it was cos the paths out there were completely flat and I'd not been to a place like it where it's just flat to walk on, it was easier, I was able to walk on my prosthetic no problems, it was comfortable and like, when two days of being there I was walking without my crutches and that was the first time I'd ever walked without crutches. It just like sort of magically happened'* (Member)

In this case, becoming involved in activity outside the home had wider implications as to how the Member re-engaged with negotiating their use of health and social care services. For example: *'by getting involved with the sport was what changed the care with my prosthetic care'* (Member) and *'he started to go out training on his own and he, he'd go, kind of built up to go to the shop on his own and things like that and it just started, he just started getting better'* (Partner).

It should, however, be noted that Members require ongoing support to continue goal setting/participating in activity. One Partner remarked that after the Member had *'reached his first goal, he did slide backwards and it was like he lost focus'*, reflecting the need for encouragement of the Member, once they have reached a goal, to plan for the next goal or activity in which they wish to partake, in order to ensure the Member continues being involved and moving forward.

## **Recommendation H2**

It needs to be understood that gain from planned focussed social activity may be short term; after the activity is complete, or a goal reached, the PWLL may feel a sense of loss and uncertainty as to what to plan next, which may in turn lead to feelings of depression. Support after focussed activity needs to be in place to support individuals, should feelings of isolation be experienced.

Another source of activity was identified in the data: these were the *'small things'*, for example, *'it's just little things like being able to walk hand in hand, we've never been able to do before, but we will be able to do in the future'* (Member). The setting of *'small things'* to be achieved is key: *'make things for yourself to do, that's why [Member] has, go out and, and say I'm gonna do that, don't give up, I'm going to go up on the moors, I'm going to walk on a beach, which is seeming a bit even a bit impossible for [Member] at the moment, but he will'*. The important aspect here is activity that can be independently achieved without additional physical support from others. The achievement of the small thing is significant: *'it's not that far, it's not that far at all, but for me that was like a little mini marathon, and I was dead pleased'* (Member). Participants also

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described hobbies, such as painting, DIY and stamp collecting, as being important to resume as a means of *'focusing on something else'* (Member).

Becoming involved therefore is not (always) about 'big' achievements, but rather achievements that point to life as it was pre-limb loss, and aspects that can be achieved together either as a couple or as a family. However, it was also seen that 'small' achievements were not as well recognised by wider society, where only the 'big achievements' are seen to be reported, and whilst interviewees recognised their importance, they do not necessarily reflect everyday living circumstances: *'you only read about the boys doing exciting things, like climbing mountains. You never hear of the everyday stuff that is a major thing for the likes of me'* (Member).

Becoming involved again in small things was dominant across the data, however participants also described that these seemingly small challenges are rarely publicly recognised or celebrated. Raising the visibility of small everyday achievements, and the resuming of pre-limb loss activity and interests, may therefore be important in helping individuals and families cope with limb loss, and needs further exploration.

Achieving small things may also assist in developing confidence as to how well Members are doing in adapting to living with limb loss, because they offer realistic comparisons. This is indicated through participants asking the interviewer, 'how they are doing in relation to others' who had been interviewed. On probing, this is because once in the home environment, Members/carers lose sight of what is overtly visible in other public spaces, such as a hospital ward, or a rehabilitation unit, where they can self-identify how well they are doing.

Being able to determine how well they are doing in adapting to limb loss is therefore important, but mostly unseen as focus on smaller, achievable activities is seldom presented in public spaces, and thus they remain unseen, even though they are likely to be important in raising levels of coping in Members and their carers. Participants were keen to identify that literature relating to Members/families should represent the average, everyday living experience of limb loss of the majority, as well as other events that may appeal to certain groups of the Blesma community. For example, reading about exciting achievements was welcomed by participants as important for fitter/younger Members, but also the suggestion that experiences more aligned to their current physical wellbeing be represented as well:

*'The Blesma magazine that comes out, that's fantastic, it shows guys going sailing, playing golf and all this, I mentioned it to [name removed], cos I think one of [removed] does a lot of sailing and I've done a lot of sailing as well, and I've always thought I'll get involved in that and every time I read the magazine I think it looks fantastic you know, it's not that I don't want to, it's just not having the opportunity and sometimes you look at this magazine and you think it's fantastic, you know, they're going on a Greek sailing holiday for four weeks, you know, but in reality getting four weeks off work is a challenge'* (Member)

This is a practical action that Blesma/organisations can promote across their communications with Members and their families, especially as participants often referred to Blesma Magazine content as a means of keeping in touch with Blesma and finding out about how others live with limb loss.

An additional important aspect in becoming and feeling involved is recognising the importance of the family to spur the Member on to become involved, and for the carer, the Member becoming involved again

is a central aspect of coping. At this point, it was often a family member that encouraged, sometimes persuasively, the Member to be involved again, and engage with activity inside and outside the home. Examples included the partner filling in application forms on the Member's behalf, or arranging transport for the Member to attend an activity, or *'making him go'* (Partner). In relation to activity outside the home, partners described actions they would take to spur the Member into re-engaging with life outside the home, and the sometimes forcible nature that is required of themselves to do this: *'sometimes I think he thinks I'm being mean, and his folks do too, but if I don't, he won't, and then it's worse for all of us, so I have to really'* (Partner). Being forceful in enabling the Member to re-engage with activity inside and/or outside the home was also difficult for the carer, where it meant they also needed to step back from being a carer. This is hard to do initially: *'thought I can't send him there on his own, oh God he'd panic, he wouldn't know what to do, so we went, we met them and then it kind of went from there, cos they kind of like, they could see that he wouldn't do anything'* (Partner), and is an aspect that is often not discussed, but is recognised:

*'But it's the carer that takes the brunt of it. When I'm angry and depressed, I'm shouting at [Partner], everything's her fault, you know, when it's not, it's all my fault and, but she's managed me through that process, so I think it's very important, particularly at my age, when something like this happens, that support from the carer is recognised. Because she does take the brunt of it all'* (Member)

The need to at times forcefully enable another person to engage with activity is not necessarily talked about, and is not identified in the wider professional and academic literature. This in itself warrants further insight and understanding in order to better support carers/families of Members.

### **Recommendation A3**

It is recommended that family carer/s may need support to be assertive in enabling the PWLL to engage with self-care/independent activity. Being assertive is difficult within the family caring unit, even when in the best interests of enabling maximum independence for the PWLL. Being assertive in the caring relationship is not identified in the wider professional and academic literature, and in itself warrants further insight and understanding in order to better support the carers/families of Members.

### **Recommendation C4**

It is recommended that individual and family goal setting is made significant and realistically achievable to the PWLL, their main family carer/s, and where relevant the wider family. In particular, raising the visibility of small, everyday achievements, and resuming pre-limb loss activity and interests, is important in helping individuals and families cope with limb loss. It is also recommended that the achievement of small goals be recognised and represented in public spaces, such as in relevant literature.

The role of the wider community in enabling a Member to return to their pre-limb loss activities was also recognised. For example, *'we had an allotment up the road. I go up there now, cos a lot of our friends are returned and when [wife]'s at work, I go up on me scooter and have a chat'* (Member). In this case, the local community is important in enabling the Member to re-engage with pre-limb loss life, and in some cases, the presence of an active local community was essential to their wellbeing. Examples of the local community involvement included ex colleagues moving boulders out of the way of a favourite cliff top walking route

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to enable access on a scooter, and another cited the local community holding parties in a centrally located grass space outside the home, for the Member to be able to attend, and for his wife to enjoy the party without worrying about the Member, and being able to get to the local pub independently to be involved with, and chat to, their friends, as would have occurred pre limb loss.

The role of the local community is important in supporting individuals to reengage with life pre limb loss. However, where a local community is not available, interviewees reported feelings of isolation: *'here on me own sort of thing and didn't see anybody one week to the next'* (Member), *'he just didn't want to go out and he just didn't want to do anything and I remember saying, no, you've been invited, I don't know, yeah, but maybe I want to go. And you looked at me as if to say, what, but my life was going to pot. Because we'd always done things together'* (Member) and *'I kind of like closed in on myself cos everything was hassle to do'* (Member). This in turn effects how others respond to the Member, for example, losing contact with friends: *'a lot of friends then stopped bothering because it was like, oh it's too much hassle'* (Partner) and *'his friends stopped taking him out when he was first injured, and we were first together, because it was too much hassle'* (Partner). This in turn leads to the Member and carer isolating themselves: *'it was the fact I wasn't socialising, I wasn't talking to anyone'* (Member).

The implications of limited contact with friends and the local community are as substantial for the main carer/s and a factor that is often not discussed within the family unit, *'but I can't talk to him about it'* (Partner) and *'I couldn't tell certain friends or family members I was feeling that way'* (Partner). Reasons as to why a Member/carers may not be open about feelings of isolation were related to guilt: *'it sounds so awful. He's the one that is injured, not me, and if I say how angry I feel, others think I'm means and selfish'* (Partner) and *'if you don't live it, you don't know it, so others can't see it, so I don't say it. Not event to him really'* (Partner). Not talking about isolation is lasting: *'I still don't tell people so much about it'* (Partner). These expressions signify low levels of coping in both the Member and their main carer/s, and is something that Blesma BSOs and health professionals need to listen out for in order to identify if there are local community support groups that could help to reduce feelings of isolation.

*'Becoming involved'* is interlinked with the sub-theme, *'It's the little things'* (see page 33), and brings to the fore that it is regular everyday living that presents barriers and challenges to Members and their families. When these barriers are overcome, this leads to a sense of better coping for both the Member and their family carer/s. Importantly, becoming engaged in small tasks can be difficult, but these are major achievements when achieved, which can be instrumental in developing coping. Similarly, becoming engaged in social activities is instrumental in developing higher levels of coping for the Member. Those who are not able to engage may experience lower levels of coping, for both the Member and their main carer. It is recommended that Blesma is aware of what kinds of activity Members may be engaging in, but also identify why Members may not be engaging in social activity, and be aware of the potential effects it has in the caring relationship. It should also be noted that engaging in activity may be small things, and it may be these that have the overall benefits on the caring and coping relationship.

## Participant recommendations for support

The final group of findings relate to suggestions as to what support participants would find particularly useful, and in many ways the quotations presented speak for themselves. From the data, the most important source of support was talking to others who have been through living with limb loss: *'go and try and talk to somebody who's lost a limb, have a word with them, they will tell you all about it, they will discuss it with you and tell you the pros and cons and the things to look forward to'* (Member). This information giving needs to be realistic and, most importantly, honest: *'tell them the truth from start to finish'* (Member) and *'I think the thing that's got to happen, is that somebody's got to talk to the people, the younger ones now that just lost limbs, talk to them and don't just go over the, oh you're gonna have an artificial leg and you'll be able to walk and do this that and the other, tell the truth about how hard it is'* (Partner). However, a word of caution was attached to this: *'but be careful 'cos some people are so negative, when they lose a limb'* (Member).

The need for information giving and support for the whole family was dominant across the data:

*'Talk to the family. Ask the family if there's anything, not the person who has lost the limb, talk to the family themselves'* (Daughter)

*'Talk to partners and things like that maybe, sort of, see how they feel. Because there's a lot of, for the person that it's happened to, but the person that's got, that's with their partner, like the partner, they need somebody to talk to them as well'* (Partner)

*'I think it would be nice if somebody came and talked to the children, if there was somebody who could come and talk to the children about how they feel, yeah cos you don't think about, well you do think about the children, but because you're sort of concentrating on the person that's had the injuries, you don't sort of take into consideration the kids I don't think and how, that would be nice, yeah, somebody, just get somebody to come in and play with them and sort of just gently ease it out of them how they feel about, cos it is hard, you know, when you see your dad with two arms and two legs and then all of a sudden he hasn't got two arms and two legs'* (Partner)

Participants suggested that families with lived experience of caring for limb loss could provide information and support to others going through it. This includes Members willing to share their experience with others:

*'To meet other amputees socially and just hear their challenges and experiences and learn from their experiences'* (Partner)

*'If there had been some sort of system or process in process, okay there's an ex-forces person in hospital who's lost a leg, Blesma could be made aware and from my perspective if somebody who was ex-forces and had lost a leg came along to the hospital and talked to me, I'd probably relate to that'* (Member)

This should also involve wider family members, including the older children of Members, who can provide valuable insight, information and support to others, including partners and younger children:

*'It's like when dad's stump played up when we were younger and you'd see him thumping it and mum says there's not a lot we can do, but, okay, you, I can't do anything but there's a number, if you want to somebody just to calm yourself down, or even the parents and that and dad can talk to*

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*somebody and say look, I'm having this trouble, each individual person, dad's got this pain and that, or we've tried that, how about trying, yeah okay, or vice versa, and it's the same with the children, just being there for them so they could just talk and sort of get feedback off one another, it's not just children, it's the adults, have like say, eight nine upwards and as dad said, that they, they've had, they've seen their parent, whether it's mother brother, anybody that's been in the forces, they've seen them running round and that, all of a sudden, woof, you've been smacked in the teeth, hang on, I used to do that, a couple of weeks ago, why can't I do it now. They don't understand that, where we've grown up with it, so we understand it, but the youngsters nowadays, there's no groups or any feedback for them' (Daughter)*

**Daughter** *If they've got somebody to talk to, like you can talk to your mum and dad and that, but where they can sit and think I can relate to that, okay, my dad, it's like that, or my mum's like that, yeah, I can do that and it gives them a better idea of what's going to, cos it is a, alright we were lucky, not lucky I suppose, but we were, we grew up with it, but now the guys that are in the forces now, they're probably got children that, I wouldn't say grown up but they're*

**Member** *It's suddenly sprung on them*

*'Get some more, as a daughter, get some more groups where the children can actually, as mum said, see videos of other people, how they're coping and that' (Daughter)*

**Member** *A video or something like that, yeah, would be absolutely fantastic*

**Daughter** *I think as well, if somebody has got the guts, somebody, whether it be male or female, that has got the guts that they can, for somebody recently that's lost a limb, have let them see how, like you've lost the limb, this is how it starts and this is how it goes and somebody like dad, if they've got the guts of it, this is how sort of roughly how it went, but this is how it's affecting me now, it's not a short term problem, it's a long term problem and as you keep saying mum is that, it's not what's happening now, you've got to look at the future. What you're going to have to go through, nobody told you what you would go through, where if they can help them now*

**Partner** *It would help them tremendously*

*'Not all the time, just, that there is somebody at the end of the phone you could ring up and say look you know I'm finding this really hard can I talk to somebody please' (Partner)*

*'It would have been beneficial if somebody who had been through that process had said let me just explain to you what's gonna happen now, your husband's not gonna be able to do this, you know, if he's in bed and he's got one leg on, how's he gonna get to the toilet' (Partner)*

*'Just to have somebody to come and, especially if it's, been quite recent is somebody just maybe to talk to the partner of the person it's happened to, see how they feel, just so you know you've got somebody at the end of the phone to talk to' (Partner)*

It is recommended that information to the wider family is developed to incorporate younger family members where relevant. However, this research did not include persons under the age of 18 and therefore further work to explore the needs of younger generations would be beneficial in order to inform how best to provide appropriate information and support to younger family members.

#### **Recommendation A1**

It is recommended that opportunities to talk about living with limb loss be offered to individuals. A resounding feature in this research is that no one talks about the limb loss, and no one asks how individuals feel/have managed/have accepted limb loss, leading to feelings of low emotional coping. Individuals with limb loss, main family carer/s, and their wider family and friends, need opportunity to explain possible feelings of sadness/resentment, and how they have/could overcome such feelings. It is important that such support be offered at the individual level within the family caring unit, in order for each person to feel able to express their anxieties safely and without worry, guilt or recrimination.

#### **Recommendation H1**

Support and information giving needs to be honest and realistic as to what PWLL and family carer/s can expect to experience, and what care will need to be given re living with limb loss. It needs to be noted that peer support/groups for carers/the family do not need to be veteran and limb loss specific, rather they should focus on the caring role itself. Support groups for the veteran with limb loss do not always need to be limb loss specific either, rather it is the 'being in the military' that creates commonality in understanding, acceptance and support.

#### **Recommendation I7**

There are limited support opportunities offered to the wider family, for example, children living with a parent with limb loss do not have access to resources that might help them understand and support their parents in the future, which in turn, might be helpful in supporting parents as they age. Further work is needed to explore this in detail in order to inform future service provision.

## **Awareness of Blesma**

Support and provision offered by Blesma and its BSOs is highly valued and recognised:

*'Blesma seem to be doing a lot for him and he seems to be more confident with Blesma. If he's got a problem he will phone them up and in the fact that he seems to, you get the impression he knows that if he phones Blesma he's going to get a result'* (Partner)

*'Knowing Blesma is there, you know, it is quite a relief you know, to know that there is somebody that can help if you have problems, with your prosthesis, they can contact the limb fitting centre and all the rest of it. I think, I think just the thought of Blesma being there, somebody you can talk to as well'* (Member)

*'I think Blesma's played quite a big part in his life'* (Partner)

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*'They're a charity and they have used their money wisely and kindly. They've been very good indeed and that's why I was quite happy for [the interviewer] to come, because it's the least I can do for Blesma'* (Member)

*'They were brilliant and in many ways they couldn't have done more for me'* (Member)

*'Blesma are very good, they're very generous to me, I've got nothing but admiration for Blesma'* (Member)

*'That's another thing I love about Blesma and [name removed], more Blesma really, they don't differentiate, they don't say, well you didn't lose your leg in the forces so we can't help you. They recognise, well you've been in the forces so you're still one of us'* (Member)

**Partner**            *Oh [BSO's] like a part of the family*

**Member**           *He comes and sees us, he's been brilliant, right do you need anything?*

**Partner**           *Yes, yeah, he he's been absolutely amazing just in terms of saying, you know, if there's anything you want, anything you need for your mobility. Whatever else and you know, let me know*

Participants were keen to pass on their thanks to Blesma:

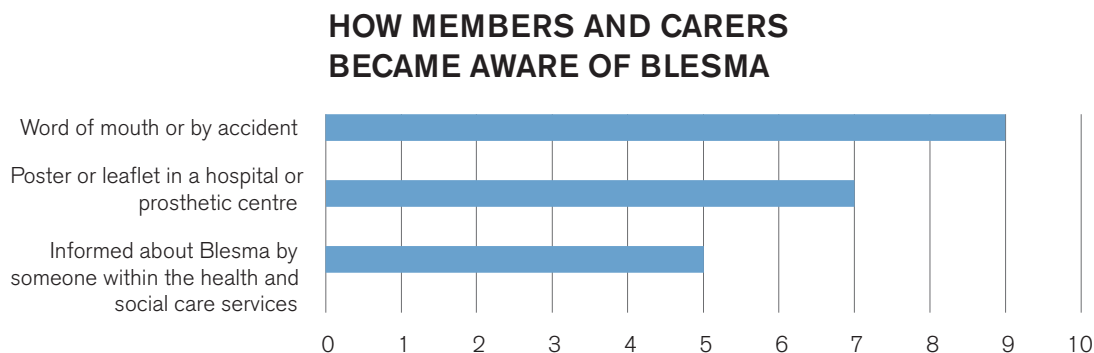
*'To thank them for the support, which is like the everyday, the you know, just talking to somebody, or whatnot, you can't, you're forever in their debt, just little things of making your life easier, making things, making his life easier'* (Partner)

*'If you can feedback to Blesma for me the gratitude'* (Member)

One aspect that could be developed is to increase Blesma's visibility as an organisation, within the public sphere:

*'I wish they advertised more in every hospital, or doctor's surgery, so that, cos, you know, if dad hasn't just by chance that one time he saw it, before that stage, you never, till dad said about Blesma to be honest we'd never heard of it'* (Daughter)

Overall, participants stated that Blesma as an organisation needs more visibility: 8 out of 16 families interviewed mentioned that pre-limb loss there is a lack of awareness of Blesma and described only finding out about Blesma by accident. Similarly, only six out of 35 questionnaire respondents were aware of Blesma pre-limb loss. The following shows how Members and carers became aware of Blesma:



**Diagram 17** Awareness of Blesma

Other means of finding out about Blesma included through Soldier Magazine, a physiotherapist at the local hospital, direct contact from Blesma, an Army pension brochure, the local hospital after losing the leg, Black Watch Assistance, a friend who is a Blesma Member, a surgeon and from a ward Sister at a local hospital.

However, the quiet and assured nature of Blesma was seen as positive:

*'And the thing I like about Blesma, and I like about the [name removed], is they don't shout about support, they don't shout this is what we do, they keep it to themselves, but if you know where to go, the support is fantastic' (Member)*

As part of the Member and Carer Questionnaires, participants were invited to give free-text responses to the question, 'so Blesma can better understand family and Members' individual circumstances, what do you think Blesma should know about?'. Responses reflect practical suggestions of the factors that a charity in Blesma's position should be considering:

*'Age of family members, housing work situations, lack of interest in NHS and local services'*

*'Treat everyone the same. We all served in the British Forces'*

*'To urge councils and other authorities to recognise disabilities and not financial situations'*

*'I think it would be helpful to those Members with spinal cord injury (who may also be an amputee) for Blesma to have more specific questions aimed at this group. Home education regarding SCI'*

*'Speak more to the family rather than just the Member, so Blesma can be more fully aware of home life'*

*'My wife and I have no children or relatives in the south of the UK. We support each other and live day by day. We both worry about the other, especially if one of us were to pass unexpectedly'*

*'Access to medical specialists and lawyers for guidance and support'*

*'The difficulties limb loss presents and the importance of how rehabilitation makes a huge difference. It's my view that some limb loss is a serious disability but not necessarily a serious handicap, except with two or more limbs lost'*

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*'Mainly the fact that [Member's name] has cognitive issues and difficulty processing situations as a result of his injury. I believe Blesma is fully aware of this and is very supportive'*

*'Age of all parties, housing situation, work situation, money situation of both parties, travel to hospitals and access to local events, support by NHS services'*

Participants also took the opportunity presented by this question to praise Blesma for the service they provide, which is indicative of the strong and positive relationship that Blesma and its BSOs have with their Members: *'nothing, Blesma is a fantastic association.'*

## Literature Review of Themes

The purpose of this section is to review literature in relation to the central themes that are emergent in the data. There is limited literature that explores living with limb loss; however, there has been research in other fields, such as caring for stroke survival and caring for other life limiting illnesses. As amputation is a lifelong condition, but not necessarily limiting of life, aspects of empirical literature relating to living with long term conditions can be inferred only with caution. As such, the literature review draws from inter-professional literature to present a current overview of knowledge in relation to the central concerns of the participants in this research, and is used to develop insight into how we can better understand, and support, individuals and families living with limb loss. Similarly, the transferable nature of the findings to other persons with limb loss means that, from hereon, the term persons with limb loss (PWLL) will be used.

### Coping

Coping is the core theme in this research, for which participants describe high, mid and low coping and where coping levels can vary at differing stages of recovery from limb loss, and at different times across the family unit. Participants describe coping as both a practical and emotional concept, and one that is not recognised or supported. See diagrams 1-4, and accompanying explanations (pages 16-23), for further detail of the coping process, as generated from the data.

In the literature, coping as a concept has been extensively discussed, but mainly within the field of health psychology (Folkman, et al., 1986; Hagger and Orbell, 2003; Leventhal, Diefenbach and Leventhal, 1992; Yi-Frazier, et al., 2015). Much of this research has focused on the categorisation of various 'coping strategies' (Dunkelschetter, et al., 1992; Silver, et al., 2002; Moskowitz, 2005; Dempster, Howell and McCorry, 2015; Moskowitz, et al., 2015), or alternatively on coping as a distinct process (Pennebaker, Colder and Sharp, 1990) that overlaps with the concept of adaptation to illness (Charmaz, 1995; Persson, et al., 2013). Psychological studies on coping are supported by health-related quality of life research that has led to the development of metrics such as the COPE inventory (Carver, Scheier and Weintraub, 1989) and the Ways of Coping Questionnaire (Folkman and Lazarus, 1988); these and other measures are used to assess aspects of coping (Kato, 2015) and their relationships to health outcomes (Penley, 2002). However, these dominant approaches for understanding coping focus almost exclusively on the individual affected by illness, for example their personal attributes (Taylor and Armor, 1996) or their abilities to make behavioural/cognitive changes towards coping (Moskowitz, et al., 2015).

Sociologically informed work on chronic illness (e.g. Charmaz, 1995) tends to emphasise 'identity work' (e.g. reconciling one's notion of self to a changing body), with discussion of social influences limited to interpersonal relationships (Revenson, et al., 1991) rather than overarching social structure. This focus on the individual points to an individualistic approach to illness, which is also the dominant discourse in policy language, which centres coping in terms of 'self-management' (Lorig, et al., 2010). In this sense, self-management presupposes an 'activated' patient-consumer who 'co-produces' their health care through informed choice (Hibbard, 2003). This research, however, does not find PWLLs and their carers/family as active consumers who are actively engaged in the self-management of their care. Rather, they are passive recipients, because liaising with health services is difficult and tiring, and it is an aspect of care and support that adult children take on as a means of supporting their parents, who also find it frustrating and difficult. As the adult children in this research often live apart from their parents, and are maturing with their own

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health concerns, it seems increasingly likely that the family unit themselves will need support in helping their parents to manage access to, and use of, health care services.

Indeed, as Atkin, Stapley and Easton, (2010) and Moore, Frost and Britten (2015) have noted, there are potential disconnects between self-management as an instrumentalist policy goal and the meaningful practices that people might make in order to live well. Atkin and colleagues forward that 'coping is socially negotiated, defined by the social space in which it takes place' (2010, p. 392). This research clearly identifies that coping is negotiated within the social space of the home, then the family, and then the community. For example, participants in this research identify that those with limited, or those that limit, social engagement and support, or those that extend community engagement, are defined within that unit, or social space, itself. What this research identifies, and adds to, is that this social space may be limited, for example, to comprising of the PWLL and carer, or wider, for example, PWLL, carer and wider family, or more diverse, PWLL, carer, family and community space. What is important here is that within these structures, individuals may be coping to greater or lesser degrees. For example, for a PWLL to independently socialise in the community (mid to high coping), the carer may experience low coping through over vigilance of the PWLL and worry as to their safety and wellbeing when the PWLL is out independently. Coping, therefore, is a changing process, in which individuals can display differing levels of coping at any one time. It also needs to be identified that the support role Blesma/organisations have is experienced and part of the participant's emotional support network, and as such, Blesma/organisational based support and interventions need to be relevant to the individual PWLL's care giving units, and timely in relation to current and potential future needs.

## **Coping and co/multi-morbidities**

PWLL and carers report living with multiple chronic health care conditions (e.g. diabetes, heart disease, arthritis). Living with, and caring for others with multiple long-term conditions, is a theme in this research.

Living with two or more chronic conditions is referred to as multi-morbidity, and it is estimated that 95% of the primary care population aged 65 years and older are living with multi-morbidities (Violan, et al., 2014). Living with multiple long-term conditions (LTCs) is therefore a pressing and difficult challenge facing healthcare systems, and the monitoring and management of chronic illness is a top priority in policy terms (WHO, 2016). In England, people with long-term conditions use a disproportionately high level of health and social care services, and the National Health Service (NHS) emphasises the prevention of LTCs and their risk factors as a key focus for action (NHS England, 2014).

Although the prevalence of multi-morbidity increases with age, it is not exclusively a condition affecting the elderly, with many studies reporting high rates of multi-morbidity amongst working-age populations (Violan, et al., 2014). Risk factors for multi-morbidity have not been well studied, and although ageing is the most consistent risk factor, it has recently been proposed that multi-morbidity may be the result of a multisystem loss of reserve and function that leads to a low-grade pro-inflammatory state, multiple hormonal dysregulation, and an increased susceptibility to chronic diseases (Fabbri, et. al, 2015a; Fabbri, et al., 2015). Women and those with a lower socioeconomic status appear especially prone to developing multi-morbidity (Violan, et al., 2014), although the reasons for this are not clear. A 10-year follow-up

project conducted in Finland reported that predisposing factors for multi-morbidity amongst a disease-free population were smoking, physical inactivity and high body mass index, with hypertension and low level of education as additional risk factors reported in men (Wilkström, et al., 2015). Other studies have found a clear association between obesity and multi-morbidity (Nagel, et al., 2008; Booth, Prevost and Gulliford, 2014; Ruel, et al., 2014), with one project demonstrating that accumulating unhealthy lifestyle factors progressively increases the risk of multi-morbidity (Nagel, et al., 2008). The consequences of multi-morbidity are wide-ranging and severe. People with multi-morbidity die prematurely (Menotti, et al., 2001); they have more frequent hospital admissions and longer hospital stays (Vogeli, et al., 2007); and they see many different medical specialists during a typical year (Vogeli, et al., 2007). A recent analysis of the direct costs of multi-morbidity in the United States Veterans Affairs Health Care System reported that, of the 5% of the highest-cost patients in the system (who accounted for 47% of total healthcare costs), approximately two-thirds had multiple chronic conditions (Zulman, et al., 2015). Zulman, et al. (2015) also point to the heterogeneity of patients with high costs suggesting that a one-size-fits-all intervention may not be the optimal approach.

The evidence base for how to manage multi-morbidities is limited, and questions remain about how best to identify patients and match services to their needs. There may be, for example, individuals with stable chronic conditions and strong social support who are unlikely to benefit substantially from intensive health intervention programmes. Other patients may have highly specialised needs, for example, those with cancer and schizophrenia may have lower levels of multi-morbidity, but high acute morbidity. Primary care programmes that focus on coordinating care for multiple chronic conditions may not be the best fit for patients whose care needs are dominated by both acute and chronic conditions. Here, those who have cancer or a serious mental illness, but few multi-morbidities, may be better suited to receive care within multidisciplinary programmes that are focused on these specific diseases. The urgency surrounding living with multi-morbidities is that the needs of people living with multiple long term chronic conditions are not being fully met by health systems that have historically focused on single, acute conditions. This research identified that caring for others with multi-morbidities is unrecognised. Often, the carer's chronic health conditions are not recognised as being potentially problematic in the caring relationship. As focus is on caring for another person, the care of the carer is not being supported, even though the family may be aware of the chronic health conditions of the carer. One barrier to supporting carers with multi-morbidities is difficulty in liaising with health services for the PWLL, which reduces motivation to access services for themselves. Another barrier is that the carer may not admit to needing support for their own health conditions, partly stemming from the stoic personality of being a carer and partly due to the military legacy that they cope regardless. Work needs to be instigated in this area to specifically explore how carers with multi-morbidities manage, whilst caring for others and themselves, with these morbidities.

## **Coping and the military legacy**

The sample in this research are all veterans and their family members, and as such, it is once being in the military that is the unique distinction. Self-identifying as a veteran is important, because in the UK, The Armed Forces Covenant (Ministry of Defence, 2011) states that veterans should receive priority treatment where it relates to a condition, subject to clinical need, which results from their service in the Armed Forces. This means that Armed Forces personnel injured in service, whether physically or mentally, should be cared for in a way that reflects the nation's moral obligation to them, whilst respecting those individuals' wishes. This states a reciprocal relationship, including the mutual exchange of privileges from one party to another, with the aim of establishing and maintaining equality between parties. In relation to veterans, the concept of reciprocity refers to society's recognition of prior service in the Armed Forces, which will in turn be rewarded with prioritised health service access and treatment for conditions directly associated from that service.

The ethics of this reciprocity are discussed elsewhere (see Engward, 2018), however it is worth considering if a veteran sees themselves as a veteran, as this can be key in enabling individuals to access prioritised health and social care services: this research however identifies that the veteran does not always identify themselves as having veteran status, and reasons for this can be diverse, generationally led (for example, younger participants were less likely to identify as veterans) and context informed (for example, veteran status was less ascribed to if they had been injured in routine life, and not in military combat). This is relevant because it is the assessing health professional's responsibility to enquire as to whether an individual may have veteran status, to determine if the current cause of concern is linked to military service, and if so, if this justifies prioritised treatment of that concern. However, from a survey (Ipsos-MORI, cited in Parliament, House of Commons, 2011) of 500 GPs, 81% responded that they knew little about priority treatment for veterans, and 85% had not informed secondary care providers of a veteran's entitlement to priority treatment within the prior year, so suggesting that health care professionals need to be aware of the covenantal duty to ascertain whether the patient has veteran status, and from this, to determine if the nature of the clinical need is linked to that active service.

One reason as to why a veteran may not self-identify as a veteran links to the difference between the military and civilian communities; transition from the military to civilian community may be difficult for some, because of the unique nature of being in the military. This includes processes of basic training in which military personnel are socialised to adhere to military cultural norms, including acceptance of regimentation, hierarchy and depersonalisation in favour of the collective, and it is this reproduction of a very specific view of the social world that radically differs from the civilian social world (for further reading on this, refer to Cooper, et al., 2017). For some veterans, the move from active military service to civilian life is a major change in culture, leading to problems in independently gaining housing and employment, and adjusting to civilian cultural norms. Cohn defines this as a 'cultural gap' in which differences in the norms, values and culture between the military and civilian spheres exist, leading to a 'connectivity gap' and diminishing contact between the Armed Forces and society (Cohn, 1999). In relation to the UK, Cohn concludes that these lead to a 'respect-value' gap, characterised by citizens respecting but placing little value on the sacrifice of those placed in harm's way to serve the country. The extent to how this is played out in contemporary healthcare provision for veterans needs further enquiry and understanding (Forster, 2012), and it cannot therefore be assumed that veterans will have health needs that differ from the civilian population, but it must be recognised that unique needs may stem from military service. It may indeed be

that the potential vulnerability that results from being or having been active service personnel is unique and distinct from the civilian population. That potential vulnerability creates a distinct duty which should not be overlooked by health professionals and organisations that provide care and support for veterans with limb loss. This research provides two key examples of how the military legacy may be influential in how veterans and families cope with limb loss: amputation and phantom limb pain, and managing prosthetics, reviewed as follows.

### **Coping, amputation and PLP**

In this research, phantom limb pain was a reoccurring theme. Phantom limb pain is a common distressing phenomenon that can occur after the amputation. Although there are no conclusive etiological models or theories about PLP (Subedi and Grossberg, 2011), it is thought that post-amputation changes in the cortical representation of body parts adjacent to the amputated limb contribute to the development of phantom pain and non-painful phantom sensations (Ramachandran and Hirstein, 1998). Studies report the prevalence of PLP to be more common among upper limb amputees than lower limb amputees. It was also reported to be more common among females than males (Davidson, Khor and Jones, 2010). The phantom pain and sensation may have its onset immediately or years after the amputation, although two peak periods of onset are reported: the first within a month, the second a year post-amputation (Schley, et al., 2008). The prevalence is reported to decrease over time of amputation (Schley, et al., 2008) and the most commonly described pain is tingling, throbbing, piercing, and pins and needles sensations (Wilkins, et al., 2004). The presence of pre-amputation pain is also reported to increase risk of PLP (Ephraim, et al., 2005), and amputees with depressive symptoms were more likely to characterize their pain as more severe than those without depressive symptoms (Ephraim and Wegener, et al., 2005).

However, Pucher, Kicking and Frischenschlager (1999) also found that patients with better coping strategies suffer less from painful sensations than patients with poorer coping strategies, and that the experience of pain is influenced by the coping strategies. They also indicate that the ability to cope with limb loss and to adjust to his or her body image proved to be independent of the following factors: the time elapsed since the amputation; patient age; the initial disease; the point of amputation (i.e. whether thigh or calf, the side on which the amputation was performed); and patient gender (Pucher and Kicking, 1999). Although these factors were not specifically explored in this research, there is initial evidence in the data that those who appeared to be coping well reported limited pain, however, this needs further exploration, and is suggested as future research Blesma may wish to consider. What is also evident in the data, and is not evident in the literature, is difficulty in making associated pain from limb loss understood, and receiving consistent analgesic support. Difficulties in describing pain, and health professionals not necessarily asking the right questions to understand pain, is problematic, and needs further investigation.

### **Coping and managing prosthetics**

Managing prosthetics, and care of, was problematic across the data. In the literature, people with physical disabilities as a group have been found to be at risk for psychological and social adjustment problems (Wallender, et al., 1998). However, relatively little attention has been paid to amputees as a specific

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subgroup of persons in terms of describing their adjustment risk (Williamson, et al., 1994). What literature that is available is dated, however it suggests that as the individual begins to regain strength and develop some security in coping on a physical level, their focus shifts to learning how to survive emotionally with limb loss (Whyllie, 1981). Reactions of anxiety and grief among people with amputations have been reported (Shukla, et al., 1982; Frierson and Lippmann, 1987; Grossman, 1990; Marshall, Helmes and Deathe, 1992; Schubert, 1992) and rates of clinical depression detected in outpatient settings have been found to range from 21% to 35% in four studies employing standardized self-report measures (Frank, et al., 1983; Rybarczyk, et al., 1992). Physical factors involved in adjustment include the prosthesis itself and accompanying medical issues. Ham and Cotton (1991) found that the less trouble the patient experiences with the prosthesis, the fewer emotional problems will be exhibited and the better social integration will be.

Prolonged pain can also impair general functioning, ability to work, social relationships, and emotional adjustments. Lindsay (1985) compared a group of amputees experiencing long-standing PLP with a group in no pain and found that those with PLP had more complaints of other painful conditions, both related and unrelated to the amputation; with symptoms of depression. Parkes (1984) found that individuals suffering from PLP tended to develop greater degrees of despair and withdrawal than those who did not. Carabelli and Kellerman (1985) found that the experience of PLP interfered with prosthetic training. PLP therefore is an unwanted response to amputation that can present as a major obstacle to successful rehabilitation and impedes adjustment to prosthesis. Pain in the amputated stump also contributes to the distress of the amputee because the discomfort it induces can prevent the use of prosthesis. Sriwatanakul, Kelvie and Lasagne (1982) demonstrated that the experience of stump pain is related to the amount of depression or anxiety that the person is experiencing. McCrae (1982) emphasised the importance of considering the other effects of illness or injury that gave rise to the amputation, because concomitant disease processes may exacerbate the maladaptive psychological impact of amputation and limit functional restoration and the return to an active lifestyle (Buttenshaw, 1993; Barsby, 1995).

The adjustment to wearing a prosthesis can also vary depending on demographic variables - age and gender - and disability-related variables, length of time with the prosthesis and site and cause of amputation. For example, among young adults, the response to limb loss depends on its cause and the degree of disability and disfigurement resulting from it. For them, the greatest challenges may be in terms of identity and social acceptance (Racy, 1989). For the older patient, ill health, less psychological resilience, social isolation, and financial limitations can complicate the adjustment to the artificial limb (Aldwin, 1990). As a working instrument, the functional efficiency of an artificial leg is greater than that of an artificial arm and is therefore more readily accepted as a substitute limb. Furthermore, an upper limb prosthesis is more noticeable and socially less acceptable (Ham and Cotton, 1991). In addition to the site of amputation, the ways in which limbs are lost may affect adjustment. Individuals who undergo an elective amputation fare better in the postsurgical period than those who suddenly lose a limb because of an accident (Ham and Cotton, 1991). Finally, increased time since amputation has been found to be associated with improved quality of life and less anxiety and depression (Rybarczyk, et al., 1995). The process of adjustment to prosthesis is therefore important. Those who abandon their prostheses report that they do not fit, and will so continue to abandon them; consequently, there is no point in prescribing prosthesis for these individuals (Ham and Cotton, 1991).

A potential mediator of the adjustment to amputation and acquiring of an artificial limb is possibly the coping strategy employed. As Cohen and Lazarus have noted, "adjustment to an illness or injury which

is life-threatening and potentially disabling may require considerable coping effort" (1979, p. 218). The reason for considering coping strategies is therefore to understand why people differ in their responses to the same significant life events and how differing responses relate to overall wellbeing (Aldwin, 1991). The outcome or effects of coping can lead to changes in psychological wellbeing, somatic health, and social functioning (Suls and Fletcher, 1985; Knussen and Cunningham, 1988; Aldwin, 1991; Folkman, 1993). Research on physical disability indicates that coping strategies may play a significant role in predicting adjustment (Anson, et al., 1993; Blalock, De-Vellis and Giorgino, 1995; McCracken, Semenchuk and Goetsch, 1995; Aikens, et al., 1997; Young and McNicholl, 1998).

Coping therefore may play an important role in the process of adjustment to limb loss. Further work is needed to explore the relation between adjustment to a prosthetic limb (emotional wellbeing, the acceptance and physical comfort of a prosthesis, and the pain experienced that is subdivided into phantom limb pain, stump pain and other pain), demographics (age and gender), disability-related variables (length of time with a prosthesis, cause of amputation, and site of limb loss), and coping. Based on the above review of the relevant literature it could be postulated that the use of coping strategies will vary across the demographic and disability-related variables; adjustment factors would vary across the demographic and disability-related variables; and coping may act as mediator in the individual's adjustment to a prosthesis. This is an area for further enquiry and understanding.

## **Coping and organisational support**

The sample in this research were highly appreciative of Blesma, the BSOs and the support provided. The findings highlight the roles that Blesma Support Officers fill by providing several kinds of support to PWLL and caregivers. These findings add to existing research that has documented the nature of different types of support provided by friends and family, and has identified how Blesma and BSOs become part of the PWLL and caregiver's social network of support in the care-giving process (Gage-Bouchard, et al., 2015; Hill, Huff and Chumbler, 2017).

These findings identify that the transition between acute and rehabilitation services into the community is not always positive. Here, PWLL and their families experience a sense of loneliness and isolation, which is managed by looking inwards for support, and not externally verbalizing the range of physical and emotional needs they may have. What is evident however, is that when support is provided, this is experienced as a type of emotional support which supports existing, and the learning of new care giving skills, which in turn contributes to an enhanced sense of coping and wellbeing, and confidence in their ability to provide care and support. It is also reasonable for all health professionals to note that the provision of routine care, logistical and informational support, can provide emotionally supportive benefits to the PWLL and their families, and as such, forms part of their social support networks.

These findings also underscore the importance of Blesma providing timely and situationally specific information, echoing previous research on the necessity of caregivers receiving tailored information (Washington, et al., 2011; Mastel-Smith and Stanley-Hermanns, 2012). When caregivers received useful informational support from health professionals related to disease processes, patient care techniques, and home equipment management, caregivers reported integrating this information into their own care routines.

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For some caregivers, this integration of new information into their care giving routine increases their and the PWLL's comfort (e.g. wound care, moving and handling, pain management), and for others this new information alleviates the physical strain of care giving (e.g. specialized equipment, such as wheelchairs and stair lifts). This type of support highlights that, in order for caregivers to receive helpful informational support, their information needs must be assessed in light of current care giving circumstances (Byrne, Orange and Ward-Griffin, 2011). This suggests Blesma and other support organisations should not merely disseminate information, but be aware of caregivers' situational information needs, and subsequently provide pragmatic and understandable information that caregivers can incorporate into their routines. This includes non-health care information, for example, financial information related to current and long-term care needs (Hurley, et al., 2014). Blesma as an organization, and BSOs as key providers of support, need to note the integral position they have in identifying, and connecting caregivers to other types of professionals with specialised knowledge at appropriate points in the care giving experience. This in turn can broaden caregivers' social networks, and consequently increase the pool of supportive resources available to them.

## Conclusions

Within the sample studied, which was a representative spread of Blesma Members, this research identifies the following key distinctions as important to living with limb loss in individuals and families:

### Families

Key families findings:

- Care work is hidden: the full extent of caring for a PWLL is often unseen and/or not admitted to. This may reflect low coping.
- Opportunity to talk about the limb loss and what it means to individuals is rarely discussed, which can indicate low emotional coping.

### Families and caring:

- Generally, the family care relationship is the parent/child/ren unit. Most often, it is the partner of the PWLL who provides most informal care.
- Carers are likely to feel tired, worry about long term wellbeing, and worry about the PWLL's wellbeing when they are apart, which are examples of low coping.
- Carers can become over protective and reduce going to environments where safety cannot be guaranteed, leading to isolation, and this is reflective of low coping.
- Carers can become increasingly over-protective, because it is perceived as their responsibility to ensure the safety of the PWLL, and can find it hard to 'let go' of caring activities when the individual becomes more independent, which can signify low coping in the carer.
- Older PWLL see using a wheelchair as signifying a loss of independence, and reliance on others to maintain their mobility and independence.

### Families and support:

- Families look internally for support and do not always ask for support and help as needed.
- More mature families are likely to have children who are geographically dispersed, and who do not fully understand their aging parents' current and future needs.
- Mature PWLL/carers may not necessarily admit to the level of support needed due to a coping and managing attitude. Not feeling they can ask for help may indicate low coping.
- There are limited support opportunities offered to the wider family, for example, children living with a parent with limb loss do not have access to resources that might help them understand and support their parents in the future, which in turn, might be helpful in helping parents as they age.
- Younger families would value support that enables young children to become actively engaged in

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supporting the parent with limb loss, and to have the opportunity to talk to other children who have a parent with limb loss.

#### **Families and health:**

- Living with co and/or multi-morbidities for both the PWLL, and the main carer, and how the carer copes with caring whilst managing their own morbidities, is not recognised in the support the PWLL/family might receive.
- Barriers to communicating with and accessing health and care services can be a source of frustration and anxiety, and is an example of hidden caring. Communicating with services is often handed to mature children as a means of coping. Mature children are not always fully aware of their parents' needs as they are detached from their parents, therefore can only offer limited support. More work is needed to understand how families manage this process, and what support can be provided to maximise service use to promote longer independence.
- There is limited future proofing; PWLL and families manage and cope with the immediate here and now, but do not forward think or plan ahead. This includes potential health and care needs, but also housing and pensions.

#### **Coping and living with limb loss**

- Coping is a major aspect of living with limb loss. This research identifies three coping levels - low, mid, high (see page 16 for explanation). PWLL and their carers may experience differing levels of coping at different times, and from each other, and each individual's coping level should be assessed independently.
- There are stages in adapting to living with limb loss (event and stabilisation, preparing to return home and discharge, being home, adapting to being with limb loss, planning forward). Each stage has differing support requirements. Provision of relevant support distinct to each stage may enable better progression through stages and support coping in PWLL and their carer/s.
- The nature of the limb loss is important (sudden/sustained/chronic) to how the individual and family copes and adapts to living with limb loss.
- The nature of discharge from MOD/NHS acute services to the community is a critical point where individuals can feel abandoned, leading to a sense of isolation and forcing the individual and carers to cope and manage living with limb loss.
- Goal setting is important and needs to be realistic and achievable, and may differ according to which limb loss phase PWLL are in. Early goals need to relate to physical care and everyday living achievements. Achievement of small goals can lead to confidence and enhanced levels of coping. Goal setting moves to reintegration with the community and reengaging with pre-limb loss normal living activities/employment/hobbies/interests. Support may be required to assist in setting realistically achievable goals at each phase, to develop achievement of enhanced levels

of coping.

- It is important for PWLL/carers/families to be able to see/read about others who have adapted to living with limb loss. This includes 'non-sensationalist' achievements, such as hobbies, interests and everyday activities.
- Managing and coordinating health care services and support is 'hard work' across the life course, leading to families looking inwards for help and support, and who in turn find it hard to manage and coordinate healthcare and support services.
- Access to, and quality of, prosthetic services can be a source of stress to the family unit.
- Pain associated with limb loss is not recognised by health professionals, not effectively managed, and is a source of stress to the family.

## **Military legacy**

- There is an enduring military legacy that gives a 'veil' of coping that remains over the life course, which means individuals may not always be honest about how they are coping, especially if they feel they are not coping well enough.
- Not all PWLL consider themselves to be veterans because they feel 'there are other people who are more worthy' of the title and of support that is specifically for veterans, especially if injury was sustained in routine operations and not as a result of frontline military combat. This can prevent requests for support services because they do not feel eligible to access services for veterans. This is especially important for younger PWLL.
- There is a 'military family' where accepted types of communication are understood between veterans, which is different to civilian communications. Having contact with other veterans is important to maintain a sense of military identity, through engaging with colloquial military language, but this does not need to be specific with limb loss. It is the sense of understanding accepted discourses of the military that is important.
- The military family is seen as a support for the main care giver, irrespective of whether the partner was in the military themselves.
- Support services for carers do not need to be veteran or limb loss specific. Rather, it is the concept of being a carer and how the carer manages their role that is important.

## Key Recommendations

This study has been undertaken with Members of Blesma, their families and carers. During this research it became apparent that the role of the Blesma Support Officer (BSO) is integral to Blesma's work and there is evidence that the important relationship Members form with their BSO can have a significant impact on how well the Member, carer and wider family adjust to and cope with living with limb loss, in particular the practical aspects (see pages 29, 73-76 and 83). As the role of the BSO forms a key point of contact between Blesma and its Members and families, it seems BSOs are well-placed to respond to suggestions participants have made and support a holistic approach, which may not be evident in related professional services but is likely to be integral in facilitating higher coping with limb loss. It should be noted that the purpose of this research is not to evaluate the work of the BSOs. Rather, with regards to participants' overall experience of limb loss, it is recommended that Blesma could implement practical recommendations through the key role of the BSO and importantly ensure that the BSO Toolkit and future training of new and existing BSOs recognise the extent and potential of this role; the BSO role is key to Blesma continuing to further develop and position itself as being a central limb loss charity for their targeted Membership.

The findings, conclusions and recommendations of this study are therefore relevant to Blesma, as well as applying to health and social care services and all organisations that work with individuals who have suffered limb loss. As such, the following recommendations are written to be relevant to all organisations that provide support and care for individuals and families that live with limb loss.

## Group A: Supporting the family unit

### Recommendation A1

It is recommended that opportunities to talk about living with limb loss be offered to individuals. A resounding feature in this research is that no one talks about the limb loss, and no one asks how individuals feel/have managed/have accepted limb loss, leading to feelings of low emotional coping. Individuals with limb loss, main family carer/s, and their wider family and friends, need opportunity to explain possible feelings of sadness/resentment, and how they have/could overcome such feelings. It is important that such support be offered at the individual level within the family caring unit, in order for each person to feel able to express their anxieties safely and without worry, guilt or recrimination.

### Recommendation A2

It is recommended that the work involved in caring within a family unit be recognised as essential in maintaining the PWLL's independence. Routines that persons have in place to facilitate independent living need better recognition, and it is recommended that the work that goes into establishing these routines be acknowledged. Recognition of this aspect of caring may be specifically relevant in the 'being home' and 'adapting to being with limb loss' stages (as demonstrated in the Living with Limb Loss Support Model, see page 22).

#### **Recommendation A3**

It is recommended that family carer/s may need support to be assertive in enabling the PWLL to engage with self-care/independent activity. Being assertive is difficult within the family caring unit, even when in the best interests of enabling maximum independence for the PWLL. Being assertive in the caring relationship is not identified in the wider professional and academic literature, and in itself warrants further insight and understanding in order to better support the carers/families of Members.

#### **Recommendation A4**

It is recommended that generational differences between PWLL are recognised as signalling differing support needs. Younger families look internally into themselves and do not request help from their wider family/friends, and may be more socially isolated because of this. Mature PWLL and their main family carer/s may not admit to/accept needing additional support, with increasing age leading to frustration within the family unit and possible social isolation. Generational differences and accompanying coping and support needs therefore warrant further enquiry.

#### **Recommendation A5**

It is recommended that organisations consider ways in which information about help and support can be disseminated across the wider family unit. Families generally want to help and support the PWLL and their main carer/s, however, families do not always understand the hidden nature of caring or find it difficult to provide support/care if the PWLL does not admit to needing/refuses family support and care. This needs further exposure.

### **Group B: Recognising and supporting coping in PWLL and their family carer/s**

#### **Recommendation B1**

PWLL and their main family carer/s can experience different levels of coping to each other at the same time. Examples of coping, and recognition of coping levels, are detailed in this report, and it is recommended that these are used as a basis for assessing coping levels of the PWLL and their main family carer/s separately. It is also recommended that application of the LLSM be evaluated to assess its effectiveness in identifying individual levels of coping and support.

### **Group C: Application of the Living with Limb Loss Support Model (LLSM) across the life course**

#### **Recommendation C1**

There are key stages in the limb loss life course that have specific requirements, as presented in the Living with Limb Loss Support Model (page 22). It is recommended that support relevant to each stage be identified in accordance with the needs and circumstances of the PWLL/family carer/s. It is recommended that application of this model be evaluated to assess its effectiveness in supporting

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independence and wellbeing for longer in PWLL and their family carer/s.

#### **Recommendation C2**

It is recommended that the hidden work that occurs, in order for the PWLL to learn to regain independence in living with limb loss, be recognised. In particular, it should be recognised that pre-planning, required in order to leave the home, needs to be explored and possibly further supported, as this can be a source of low coping for both the PWLL and their family carer/s.

#### **Recommendation C3**

It is recommended that particular attention be given to the coping needs of family carer/s, as the PWLL becomes increasingly more confident in their ability to return to independent living. The increasing independence of the PWLL can be excessively worrying for family carers due to worry for wellbeing and safety when they are not there to care for the PWLL. This aspect needs further understanding and exploration.

#### **Recommendation C4**

It is recommended that individual and family goal setting is made significant and realistically achievable to the PWLL, their main family carer/s, and where relevant the wider family. In particular, raising the visibility of small, everyday achievements, and resuming pre-limb loss activity and interests, is important in helping individuals and families cope with limb loss. It is also recommended that the achievement of small goals be recognised and represented in public spaces, such as in relevant literature.

## **Group D: Recognising the veteran identity**

#### **Recommendation D1**

When limb loss is in relation to veterans, it is recommended that the term veteran be used wisely. Awareness is needed that not all individuals may associate with being a veteran, or consider themselves worthy of veteran status. It needs to be noted that a military legacy may shape behaviours and attitudes differently for each veteran PWLL. For some, a military legacy will provide skills in coping with limb loss and, for others, admitting to needing support may be viewed as weakness. Being a veteran, and having a military legacy in some sense, is deeply personal, and it should not be assumed that all veterans are the same. It is additionally recommended that organisations consider how the term is used in relation to the age of the individual and the circumstance of limb loss, as not all veterans consider themselves as worthy of veteran-specific care and support.

#### **Recommendation D2**

It is recommended that obligations set out in the Armed Forces Covenant are emphasised to veterans and their family carer/s, so veterans are aware that, where their injury may be directly attributable to their time in service, they may be eligible for prioritised treatment and care.

**Recommendation D3**

It is recommended that the status of the veteran and the obligations set out in The Armed Forces Covenant be disseminated within and across health professionals' training and continued professional development, in order for awareness of the veteran to be increased.

**Group E: Care of co/multi-morbidities in PWLL and their main carer/s****Recommendation E1**

It is recommended that a forward-looking approach is needed to support PWLL and their main family carer/s in relation to managing co/multi-morbidities, and a wider gaze is necessary to support PWLL and family carers in maintaining each other's wellness and independence. In particular, family carers need to be considered as to how their morbidities are being cared for and managed, and this in particular needs further exploration.

**Recommendation E2**

It is recommended that how the PWLL and main family carer worry about each other's co/multi-morbidities be assessed, with relevant inter-professional health and social care support structures put in place to maximise wellness for both. It is recommended that barriers to looking after the individual's morbidities be considered. For example, difficulties in accessing and navigating health services need to be further explored.

**Group F: Managing phantom limb pain and pain****Recommendation F1**

Specific to veterans with limb loss, experiences of pain may not always be admitted to. This may be due to a military legacy of admitting to pain being seen as demonstrating weakness, but this may also be because individuals do not know how to describe, or explain, phantom pain. Equally, health professionals may not be versed in understanding the effects or consequences of being in the military, and how this might continue to shape the life course, and behaviours and attitudes, of the PWLL, after leaving active service. It is recommended that a crib sheet with questions to ask health professionals be developed, for veterans/PWLL, carers and health professionals to use, in order to describe pain and/or ask relevant questions to explain/assess pain, to assist in appropriate management of pain associated with limb loss. It is recommended that health professionals have additional education about the management of pain associated with limb loss.

**Recommendation F2**

It is recommended that family carers learn about pain related to amputation as a means of being able to support the PWLL who may experience pain, and to enhance coping levels, of both the PWLL and the family carer/s, in managing pain effectively. Where relevant, this should include younger children

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who witness their parent in pain, and who want to try to help their parent to minimise their pain. Similarly, mature siblings need information on how to support their older parents in managing pain

## **Group G: Managing prosthetics and prosthetic services**

### **Recommendation G1**

It is recommended that information is supplied to PWLL and their family carers on how to manage changes in the stump and use of prosthetics with increasing age. In particular, managing changes in the stump shape, lack of confidence in the prosthetic, and fear of falling, can be a source of anxiety to persons and can lead to social isolation.

### **Recommendation G2**

It is recommended that health professionals/service providers are aware of possible variations in prosthetic provision and provide support in communicating with and gaining access to services. Variance across provision of prosthetic services needs to be standardised. Limited access to quality prosthetics services is a cause of family anxiety as it debilitates the PWLL.

## **Group H: Organisational support for coping and maintaining independence of the PWLL/carer/family**

### **Recommendation H1**

Support and information giving needs to be honest and realistic as to what PWLL and family carer/s can expect to experience, and what care will need to be given re living with limb loss. It needs to be noted that peer support/groups for carers/the family do not need to be veteran and limb loss specific, rather they should focus on the caring role itself. Support groups for the veteran with limb loss do not always need to be limb loss specific either, rather it is the 'being in the military' that creates commonality in understanding, acceptance and support.

### **Recommendation H2**

It needs to be understood that gain from planned focussed social activity may be short term; after the activity is complete, or a goal reached, the PWLL may feel a sense of loss and uncertainty as to what to plan next, which may in turn lead to feelings of depression. Support after focussed activity needs to be in place to support individuals, should feelings of isolation be experienced.

### **Recommendation H3**

It is recommended that the main family carer/s and wider family need more direct information to understand how they can support the PWLL. This should start at the rehabilitation process onwards. Specifically, family carers need access to learning about safe mobilisation of the PWLL, pain management, and how to manage the PWLL's improved independence as living with limb loss

becomes more accepted. This could include younger children learning from others who have grown up with limb loss.

## **Group I: Further research needed into loss of use of limb, coping and caring**

### **Recommendation I1**

It is recommended that further research be undertaken to explore the use of the Living with Limb Loss Support Model, considering variables such as demography and morbidity, and the role of coping as mediator in the individual's and family's adjustment to living with limb loss. This is an area for further enquiry and understanding.

### **Recommendation I2**

It is recommended that further work is needed to understand how PWLL adapt to their limb loss across the limb loss life course. In particular, the process of 'becoming' with limb loss, and 'being' with limb loss, needs further insight. Related to this, further insight is needed into how PWLL cope with use of mobility aids, such as prosthesis, across the life course, and adopt coping strategies across demographic and disability-related variables, and what adjustment factors there are that relate to an individual's ability to adjust to and cope with limb loss across the life course.

### **Recommendation I3**

It is recommended that the relationship between coping, amputation and pain be explored. In particular, further work be conducted in understanding pain and limb loss, and the role of the military legacy in living with and managing pain. A PhD studentship has been funded by the VFI to explore the narratives of pain in veterans, as a direct result of this research study, to be completed within the next 4 years. Further work is needed to explore how pain may be catastrophised within a care unit, and how people witness the pain of others.

### **Recommendation I4**

It is recommended that research be undertaken to explore barriers to communicating with, and accessing, health and care services, and the role of the family. For example, mature children are not always fully aware of their parents' needs, as they are detached from their parents and often living separately, and therefore can only offer limited support in the communication aspects of care. More work is needed to understand how families manage this process, and what support can be provided to maximise service use to promote future independence.

### **Recommendation I5**

It is recommended that further work explore the nature of living with no function of limb/s. This research focussed on loss of limb, however, for some participants, loss of function, due to a prior experience, was sufficiently disabling for them to seek elective amputation. How this is experienced needs further understanding in order for organisations, such as Blesma, to provide focussed and relevant support that maximises independence and coping within the family unit.

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#### **Recommendation I6**

It is recommended that further work is needed to explore the remit of the family. This research sought to explore variance between and across families in relation to limb loss, however, understandings about how caring really occurs need deeper insight, especially in relation to the hidden nature of the emotional aspects of care. It is therefore recommended that future work explores hidden caring in and across the family unit.

#### **Recommendation I7**

There are limited support opportunities offered to the wider family. For example, children living with a parent with limb loss do not have access to resources that might help them understand and support their parents in the future, which in turn, might be helpful in supporting parents as they age. Further work is needed to explore this in detail in order to inform future service provision.

#### **Recommendation I8**

Future work is needed to understand the role of coping from the family carer's perspective, especially in relation to feelings of anxiety, worry, anger and fear. These need to be heard in order to develop better support for future persons who may experience suddenly becoming a carer.

#### **Recommendation I9**

It is recommended that further research is needed to explore how the family cares for one another, especially when the PWLL refuses to admit to/accept needing extra support and care.

## **Limitations of Research**

This research reports original and unique findings that add to understanding of living with limb loss in the veteran community, and has transference to the civilian community. However, some limitations should be noted. This sample is self-selected and within this, articulate and likely to be positive about the support they received from Blesma. Not all findings are therefore transferable to the wider Member population; future research is needed to firstly identify 'hidden' Members within Blesma, and to identify their experiences, and the types of support they may require. Secondly, further research is needed into how Blesma can help Members and their caregivers manage living with limb loss in the community. It must also be noted that not all caregivers will have social network ties to Blesma and BSOs, therefore future research needs to consider those who do not directly use Blesma as a resource for gaining support and information.

## **Report Conclusion**

This report has explored how veterans and families live with limb loss. The findings identify that coping is central to how veterans and families adapt to living with limb loss. Using the data in this research an assessment of coping levels and the Living with Limb Loss Support Model (LLSM) have been developed, against which there is a backdrop of the military legacy. These tools can be used to better understand the needs of the veteran with limb loss and their family carer/s, and to provide focussed support to the individual with limb loss and their family carer/s. Importantly, this report contributes to understandings of

transition between the military and civilian contexts, where transition is the period of reintegration into civilian life from the military, and encapsulates the process of change that a service person necessarily undertakes when her or his military career comes to an end (Forces in Mind Trust, 2013). This report identifies the nature of transition as ongoing over an individual's life course, and using the example of coping with pain and prosthetics, clear examples are provided as to how transition contributes to individuals and families' adaption to, and living with, limb loss over the life course, and with considered assessment of the veterans and their carer, appropriate resources can be provided that will better enable independent living. This report therefore suggests that to understand transition is to understand the uniqueness of the individual and family, their health and support needs, and in the case of veterans, with a backdrop of being in the military.

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## About the Veterans and Families Institute for Military Social Research (VFI)

The Institute is one of only two UK academic centres solely dedicated to research in the area of military veterans and families. The VFI now hosts the Veterans and Families Research Hub and the Forces in Mind Trust Research Centre. The VFI staff are currently researching diverse areas relating to the impact of transition on UK veterans and their families. This work includes studies on traumatic amputation, employment, criminal justice interventions and early service separation.

## About the Authors

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**Kristina Fleuty** is a Research Assistant in the Veterans and Families Institute for Military Social Research. As well as assisting on this study, Kristina is involved with the Veterans and Families Research Hub and is also part of a group exploring the use of arts interventions to improve the health and wellbeing of trauma populations. More broadly, Kristina combines qualitative and literary research into the key theme of communicating traumatic experiences. She is interested in how individuals and families talk about and use creative language to understand and come to terms with their own, and collective, life experiences and traumas.

**Matt Fossey FRSA** is the Director of the Anglia Ruskin University Veterans and Families Institute for Military Social Research. Matt originally trained as a mental health social worker and spent a number of years working in front line services. He worked in both local government and for the UK National Health Service. In 2002, he moved from practice to strategic delivery and policy and spent 5 years at the Department of Health as the Deputy Director of a £0.5 billion programme to improve access to psychological therapies. After leaving the DoH, Matt worked for a number of NGOs and Think Tanks developing work on diverse topics including: mental health stigma, liaison and consultation psychiatry, borderline personality disorder and female offenders and veterans' health and wellbeing. Matt is a member of the NATO research groups considering military to civilian transition and is co-chair of the NATO group researching sexual harassment in the military. He is a member of a number of national and government level boards focusing on the challenges faced by service personnel, veterans and their families. In 2014 Matt was elected a Fellow of the Royal Society of Arts. He is a member of the Society of Evidence Based Policing and is a Fellow of the Institute for Mental Health. He has previously held honorary teaching appointments at the Universities of Sussex and Nottingham.

## About Blesma (The Limbless Veterans)

This research study was commissioned by Blesma and conducted independently by the VFI. The key point of contact at Blesma for the research was Heather Betts, Director Independence and Wellbeing.

Since 1932, Blesma has been the only national Armed Forces Charity supporting limbless veterans for the duration of their lives. Blesma continues to help all serving and ex-Serving men and women who have lost limbs, or lost the use of limbs or eyes, to rebuild their lives by providing rehabilitation activities and welfare support.

As a charity, Blesma has supported numerous research projects over the years, with Blesma Members participating in projects commissioned by clinicians and academics which have focused on health issues, such as phantom limb pain. Members have often spoken about the key role that their families play in supporting them through rehabilitation and recovery, and how their voices are not being heard. An academic review of the literature (Fossey and Hacker Hughes, 2014) showed that there has been very little recognition of the role of the family in regards to limb loss and to caring for family members who have lost limbs; this led to Blesma commissioning this study, its first that focussed on the families of Members. The findings from this report will have an impact not only on Blesma's future service delivery, but also on support provided by the wider charity sector and statutory health and social care services.

**Heather Betts** is Director Independence and Wellbeing at Blesma, and as such has responsibility for research. Heather has worked in the military charity sector since 2005, following an 18 year career as an officer in the Royal Navy. She joined Blesma in 2008 in the (then) role of National Welfare Officer and leads a team responsible for delivering support to Blesma Members, with a view to enabling them to lead independent and fulfilling lives. Over the last 10 years, Heather's role has changed considerably, driven by the requirement for Blesma to remain relevant to Members of all ages, from those injured in recent conflicts who have survived with complex and serious injuries, the disabling nature of which leads to the expectation of a requirement for life-time support, to older veterans whose needs are increasing in complexity.

## Appendices

### Appendix 1

#### Limb Loss Life Course Stages

The following is a further explanation of each stage, and where relevant literature is used to support findings in this research in each stage, although, as noted in the Introduction and Context section (see page 24), this is inferred. As a reminder, the uniqueness of the veteran population is the lasting military legacy, due to which help may not be admitted to/asked for, and this needs to be remembered as a backdrop to communications with PWLL and their family carer/s.

Individuals and family carers however, rarely receive preparation to support the person with limb loss.

##### **Stage 1: The event/diagnosis and stabilisation**

Initial focus is on the immediate health event, which can be either chronic (e.g. amputation from a long-term condition, such as diabetes) or acute (trauma). The context is in hospital and focus of treatment is on survival/stabilisation of the patient. It is often of short duration, lasting from a few days to a few weeks. Focus is on the current health event and treatment. This stage may be characterised by a high degree of uncertainty (O'Connell, Baker and Prosser, 2003). There is an immediate need to understand "what's it all about" (Brereton and Nolan, 2000).

Once the condition is stabilised, focus is on specific markers for patient improvement, such as mobility. Carers are likely to express relief that the individual has survived, but generally do not realise the impact that limb loss will have on their lives. During this stage, carers need information about the particular effects of the amputation and will want to receive reasonable estimates of the extent of the recovery (Wiles, et al., 1998). Anxiety and worry may begin to increase if information on the impact of the limb loss is not immediately available and the waiting period ensues while healing appears.

##### **Stage 2: Preparing to return home and discharge**

This stage occurs before the patient returns home, and can be short if the PWLL is returning home from the acute care environment, or extended if they are attending rehabilitation. At this time, the individual's medical condition has stabilised, and emphasis is on preparing the patient to return home. This stage is of particular importance as the data and wider literature (Bakas, et al., 2002) indicates that carers who felt poorly prepared during acute care and/or inpatient rehabilitation report feeling additional stress and poor confidence when the patient returned home (Brereton and Nolan, 2002). As such, it is essential for the main carer and the family to be involved in the rehabilitation process, to learn how to safely assist the PWLL in moving and handling, support activities of daily living, and start to introduce aspects of secondary prevention including medication and lifestyle change. This research identifies that the family are not included in the rehabilitation process and adds to stress on return to the home environment, therefore it is recommended that the family are invited to participate in the rehabilitation process.

As discharge approaches, PWLL may feel more confident about their return home, and feel they can cope, whereas carers may become increasingly concerned about their abilities to provide care in the home and

if they will be able to manage (Brereton and Nolan, 2000) and their coping levels may be low. Specifically, information and training to assist with the provision of physical care in the home (Brereton and Nolan, 2000) and learning about signs of potential problems that could signal other adverse health events are essential. Feedback about caring activities is required to enhance skills and build confidence in performing these activities (Brereton and Nolan, 2000). Caregivers also require information about community services and assistance, so they can submit applications to appropriate organisations or plan ahead (Wiles, et al., 1998). By this time, many caregivers will have spent considerable time in the acute care setting, having temporarily forgone many other external demands and responsibilities. In addition to preparing for their relative's return home, many caregivers may experience additional strain as they re-establish existing family and work routines.

### **Stage 3: Being home**

This is when the patient returns to the home environment. Here, both the PWLL and family carer/s learn how to adapt to living in their home environment. This time is critical that targeted support be available to enable the PWLL and family carer to learn to transition into the home environment. During this stage, coping levels of the PWLL and family carer may fluctuate, and independent assessment of coping levels of the PWLL and carer is recommended to determine relevant support for both parties. At this time, primary responsibility for providing care shifts from health care professionals to family and professional care becomes intermittent, and can vary across patients/communities and depend on resources available. The PWLL and family carers are learning through experience as they attempt to apply the skills they have learned in the acute/rehabilitation environments. At this time, everyday living activities may appear as unachievable to the PWLL and main carer, and support may be required until a routine of managing these tasks is established. Focus initially is on the provision of physical care as routines (Brereton and Nolan, 2000), which may be trial and error until a working routine is established, the PWLL and main carer can feel isolated, and coping may be low until routines are established. Aspects that PWLL and their carer/s are likely to find most difficult at this point are mobility in the home environment, daily living activities (dressing/hygiene/toileting), coordinating community service care (e.g. GP appointments), organising mobility and transportation to enable the PWLL to access health resources, and prevention of secondary conditions through coordinating medications, diet and lifestyle changes (Smith, et al., 2004). The PWLL may begin to lose confidence in their rehabilitation as they have no other persons to compare their progression with. Emotionally, carers may be anxious or uncertain about their care giving abilities and may have feelings of inadequacy (Brereton and Nolan, 2000), and start to experience the personal consequences of providing care, such as emotional, physical, social, and role changes (Bakas, et al., 2002). Goal setting at this stage needs to be realistic, with small achievable goals planned, almost on a daily and weekly bases. Additional support may be required to ascertain that goals set are achievable, as non-achievement of goals may result in feelings of helplessness and low coping.

### **Stage 4: Adapting to being with limb loss**

This occurs when the physical needs of living at home have stabilised and routines are set. At this point, coping levels relating to physical care may be mid/high as the PWLL and carer/s may feel more confident in managing the physical aspects of daily living. Focus may then shift to emphasise the emotional consequences of limb loss, which may be acknowledged within the individual, but not necessarily talked about as a couple or in the family, which may be symptomatic of low emotional coping, and there may be

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a need for support to discuss emotional reactions to the limb loss. Goal setting for both the PWLL and family carer may change to incorporate re engagement in social activities, such as driving, employment, socialisation and travel (Wiles, et al., 1998), and focus needs to be on resuming pre-limb loss normal activity and be realistically geared towards their hobbies, interests and social engagement. During this stage, the PWLL and carer/s may become increasingly aware of the personal consequences of providing care and may take greater notice of the restrictions that care giving has imposed on their own abilities to socialise with family and friends (Pierce, Steiner and Govoni, 2002). Opportunities to socialise may be tried, and if found difficult, not tried again, leading to further isolation and internalising of care. Carers may feel that maintaining the PWLL's safety is their responsibility, where forward planning to socialise can become all encompassing, resulting in socialisation not occurring. Main carers may report needing a break from their care giving activities and begin to report difficulties dealing with competing demands and roles in their lives (Kerr and Smith, 2001). Support therefore may be required to enable pre-limb loss life activity to resume for both the PWLL and the main carer. High coping at this stage would be represented by reintegration into the community setting, resuming of pre-limb loss activities, and forward planning for what they would like to achieve in their mid and long-term future. Family members are likely to want to help and give support, but may be unsure of what support they can provide at a distance, and communications between Blesma/care organisations and the wider family may be appreciated in helping to understand what help and support the PWLL and main carer may require, and to prompt the PWLL /carer in recognising/admitting to/asking for/receiving support.

#### **Stage 5: Forward planning**

Focus here is on looking ahead to future care support needs. PWLL/carers/families need to think about the future with changes in health or circumstances. The PWLL and carers may not actively consider this, and be more passive, due to living on a day to day coping basis, although this may be worrying. Support is needed to provide information early for long term planning for financial, pension, benefits, and appropriate living conditions. Mature children are important as a means of encouraging their parents to actively plan ahead for their future, but are likely to feel unable to fully assist as they do not understand the everyday living aspects of their parents, and may also experience the stubbornness of their parents not wishing to admit to changes in their independent living or to accept additional support from health and community services. A whole family approach (where appropriate) is therefore required, and additional support from Blesma/organisations may be required to enable families to have difficult conversations regarding the PWLL and carer's long-term future living in their mature years.

Appendix 2

Biographical Sample Overview

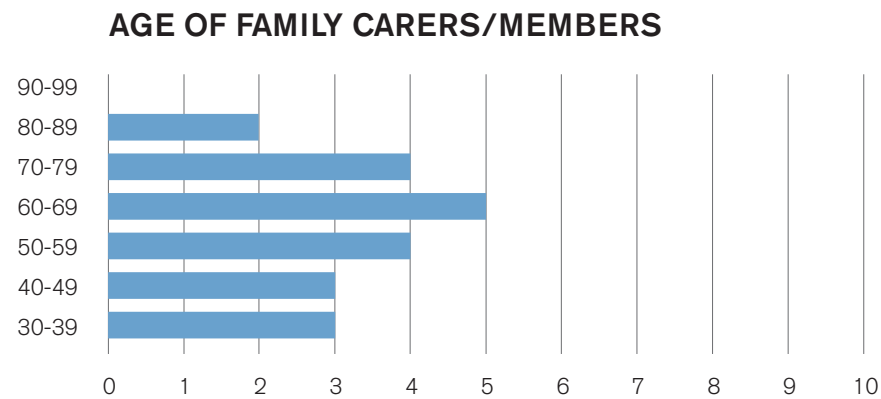
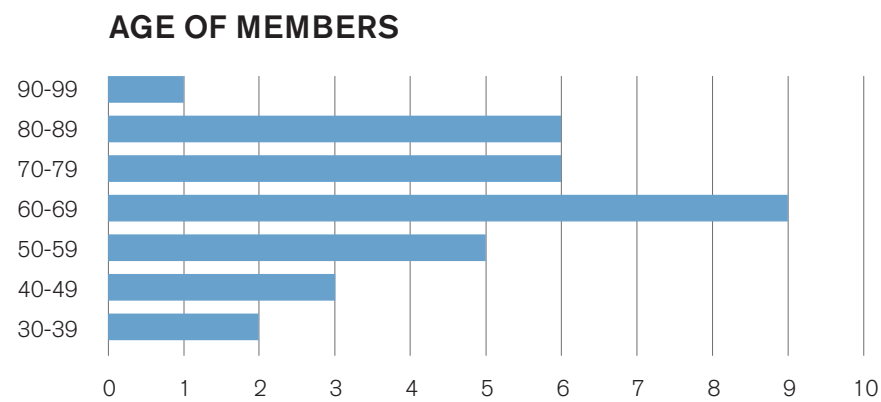
The following is an overview of the sample recruited for each phase of the study:

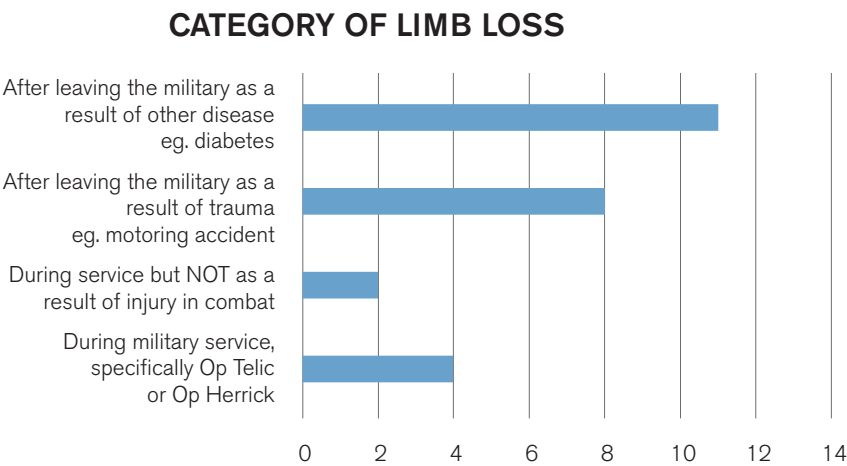
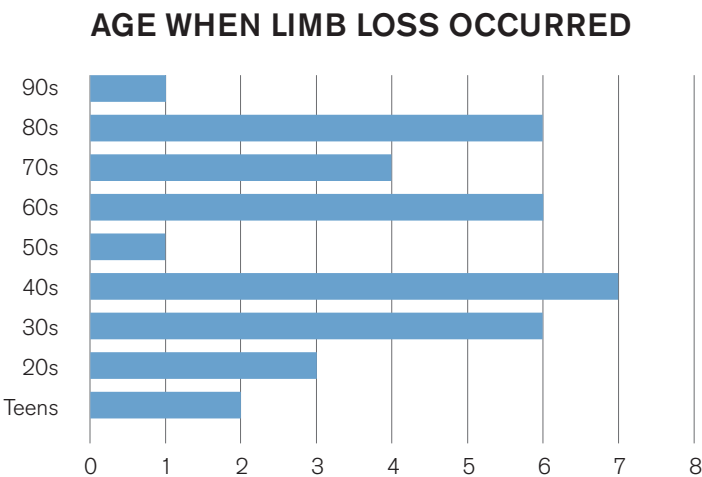
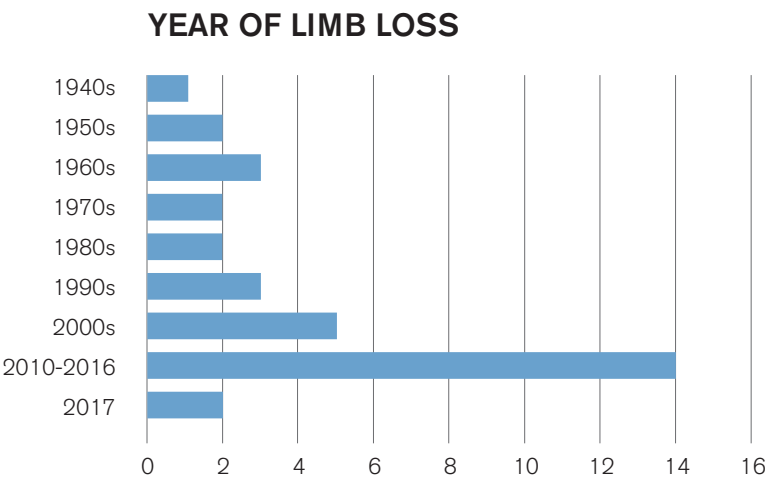
**Phase 1:** 37 individuals consented to participate in the study. This included 16 Members (1 female), 14 partners (1 male), 6 adult children and 1 extended family member. In total, 23 interviews were conducted, with some Members wishing to be interviewed alone, and some wishing to be interviewed together.

**Phase 2:** 35 respondents returned their questionnaires, consisting of 22 Members and 13 carers.

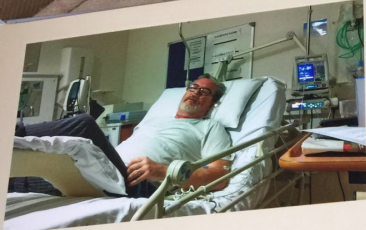
**Phase 3:** 15 telephone interviews of participants who had participated in phases 1 or 2: 10 Members, 3 wives, and 2 daughters.

Across the sample, 13 Members lost their limb whilst in the military, and 22 lost their limb post-military. The following are the circumstances of limb loss across the sample:





Appendix 3      Page of Member's Photo Journal

A photograph of Pete lying in a hospital bed, looking towards the camera. He is wearing a light blue hospital gown and has medical equipment visible in the background.

**January 11th (Friday)**

When Pete made no improvement he went to surgery again on the Friday for a second clean out.

**January 13th (Sunday)**


Pete went to theater for a third time as it was thought the infection had got to his heart. He was given additional antibiotics for a secondary chest infection but his condition continued to worsen.

**January 15th (Tuesday)**

Late in the evening it was decided that Pete should go to theater for the fourth time to explore further up the left leg. It was still painful to touch and Pete was no better and in extreme pain. Surgeons discovered that a bacteria, *Streptococcus 'A'*, had destroyed two large muscles in his leg and it couldn't be saved.

**January 16th (Wednesday)**

Pete's left leg was removed above the knee to prevent the infection spreading to other organs and he spent several days in ICU recovering. The decision was not taken lightly and was shared by three surgeons. When the biopsy came back another large muscle which seemed to be unaffected, had the bacteria present.

A photograph of Pete lying in a hospital bed, looking towards the camera. He is wearing a light blue hospital gown and has medical equipment visible in the background.

Appendix 4      Page of Member's Photo Journal

Pete set his first goal, to walk his daughter Harriet down the aisle, in just seven weeks. The physiotherapists all shared his goal with him, and intensive physiotherapy began by taking his first steps with use of the PPAM aid.

This was a great moment for Pete as he was able to walk again and get out of his wheelchair.

**February 13th**

Pete was measured up for his first prosthesis at the mobility clinic at NDDH.

A photograph of Pete standing in a wheelchair, being assisted by a physiotherapist who is kneeling and holding a yellow bar. Pete is wearing a red t-shirt and black shorts.

A photograph of Pete standing in a wheelchair, being assisted by a physiotherapist who is kneeling and holding a yellow bar. Pete is wearing a red t-shirt and black shorts.

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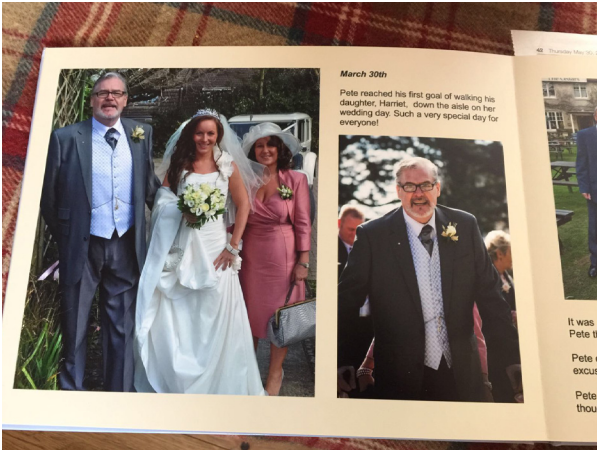
**Appendix 5**      Page of Member's Photo Journal



**Appendix 6**      Page of Member's Photo Journal



**Appendix 7**      Page of Member's Photo Journal



# Blesma

THE LIMBLESS VETERANS

For more information on what we do  
go to [www.blesma.org](http://www.blesma.org), or call 020 8590 1124