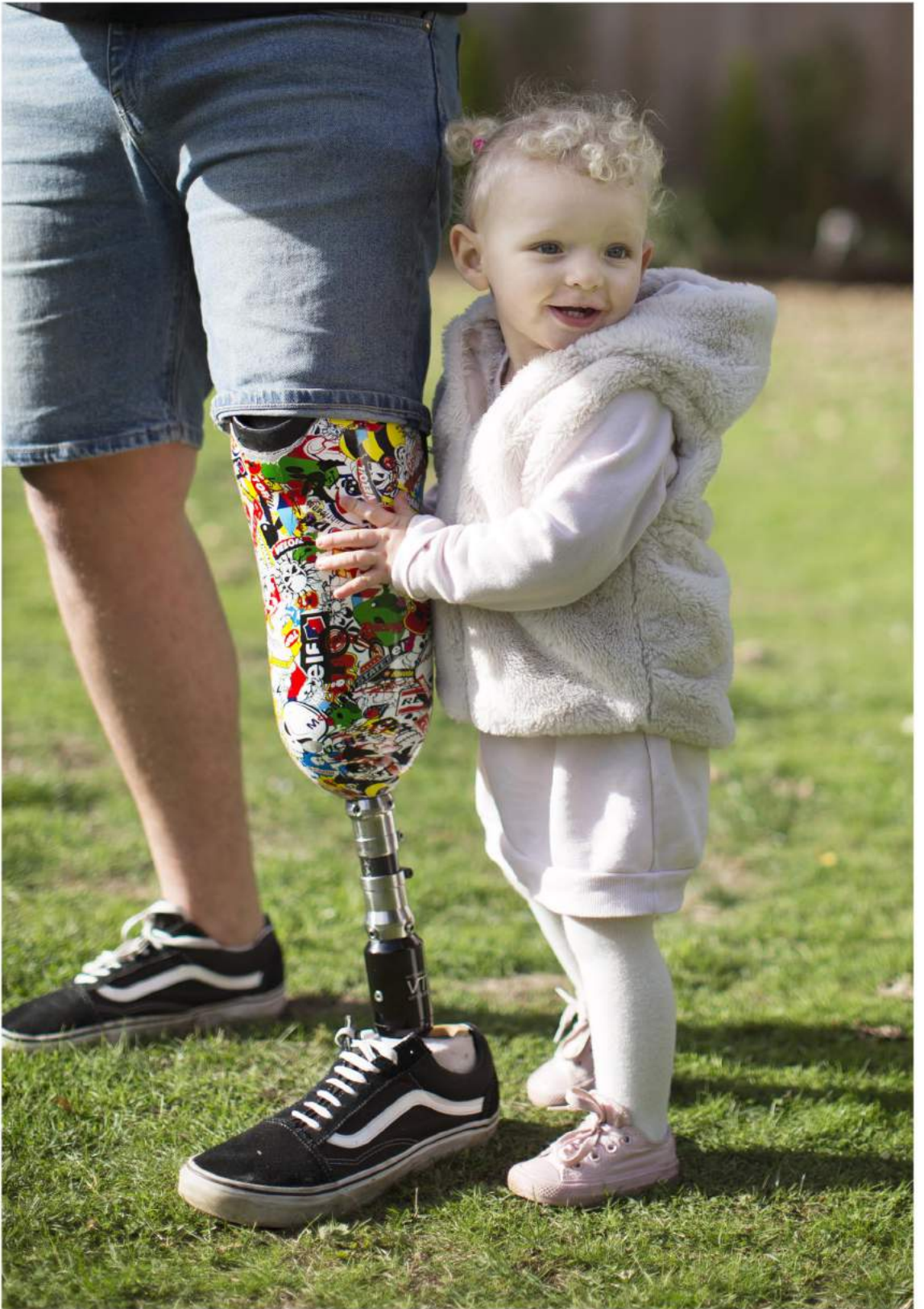


## Caring and Coping





## Background

After almost 100 years of supporting limbless veterans, Blesma has developed an unrivalled insight into living with limb loss. What is less clear and understood is the impact on the families of those living with limb loss. To understand more about this, Blesma commissioned the Veterans and Families Institute for Military Social Research at Anglia Ruskin University to carry out a research project. *Caring and Coping: The Family Perspective on Living with Limb Loss* explores how veterans with limb loss and their families live with, and support each other, every day. This research was funded through the Forces in Mind Trust, and the outcomes are applicable to every person with limb loss (PWLL) and those who care for them.

This leaflet provides a summary of the main findings of the report, as well as practical information on what support is available and how to access it.

## Caring is often hidden

Caring is often not talked about. Rather, it is a practical activity that is done but not discussed between people, even though people know it is occurring. This might be because people 'get on with it' and it is difficult to admit to needing extra support, even if it is available in the family unit.

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## What do we mean when we talk about caring?

In the context of the study, we use the term caring in its widest sense to mean the emotional and practical care given to the PWLL. We do not mean professional care given by medical practitioners or registered care givers who may be employed from time to time. In essence, we are talking about the unpaid family carer/s.

### What some of those interviewed said:

**"She's always been there, and I probably put a lot on her that I don't even know."**  
(PWLL)

**"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."**  
(Partner)

**"We don't get the same feeling of pressure that mum's got, we know that it's pressure."**  
(Son)

## What do we mean when we talk about coping?

Individuals and families care for those / adapt to living with limb loss through a process of coping.

Coping is the process of experiencing, adapting to, and managing life difficulties. In relation to the 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. These coping levels are set out opposite alongside examples of behaviours/attitudes of the PWLL and family carer/s. These examples may be observed by health professionals or service providers but they may also be recognised by the individuals themselves.

A person's ability to cope may be affected by other factors of everyday life and may change accordingly. There is a correlation between a person's coping level and the care they either need or are able to give.

Coping Level	Characteristics	PWLL* Examples	Family Carer/s** of PWLL Examples
<b>Low</b>	<p><b>PWLL:</b> being passive e.g. constant reliance on other</p> <p><b>Carer/s:</b> high emotional burden e.g. constant worry</p>	<ul style="list-style-type: none"> <li>• Reliance on another to maintain Activities of Daily Living (ADLs***)</li> <li>• Reluctance to mobilise</li> <li>• Not managing own health conditions</li> <li>• Reluctance to socialise/isolation</li> <li>• Not admitting to needing help and support</li> </ul>	<ul style="list-style-type: none"> <li>• Constant monitoring of PWLL's physical needs</li> <li>• Constant monitoring of the physical environment</li> <li>• Constant worry about what could happen</li> <li>• Reluctance to socialise</li> <li>• Feelings of isolation</li> <li>• Not admitting to needing help/support in caring role</li> <li>• Not managing own health conditions</li> </ul>
<b>Middle</b>	<p><b>PWLL and Carer/s:</b> active e.g. establishing safe routines</p>	<ul style="list-style-type: none"> <li>• Managing own ADLs</li> <li>• Mobilising independently inside and outside the home</li> <li>• Taking medication</li> <li>• Managing own health conditions</li> <li>• Liaising with health/support services</li> <li>• Socialising</li> <li>• Allowing carer to have their own time</li> </ul>	<ul style="list-style-type: none"> <li>• Intervening in ADLs only when needed</li> <li>• Acceptance that accidents can happen</li> <li>• Recognition when they are struggling to cope</li> <li>• Perseverance when coordinating/liasing with health support/services</li> <li>• Managing their own health conditions</li> <li>• Enabling/encouraging PWLL to go out independently</li> <li>• Socialising independently</li> </ul>
<b>High</b>	<p><b>PWLL and Carer/s:</b> increased capacity of self-awareness, self-care, and self-efficacy</p>	<ul style="list-style-type: none"> <li>• Managing own ADLs</li> <li>• Actively seeking help and support</li> <li>• Forward planning of current and future health and living needs</li> <li>• Self-determining with potential to thrive</li> </ul>	<ul style="list-style-type: none"> <li>• Actively seeking help and support</li> <li>• Independently socialising</li> <li>• Thinking ahead</li> <li>• Being realistic of future needs</li> <li>• Potential to thrive and gain self-fulfilment through caring role</li> </ul>

\*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

# The Living with Limb Loss Support Model (LLSM)

- 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 can fluctuate. Each individual is likely to cope differently at any given time. The level of support needed at each stage may well be different for the PWLL and their partner or other family member in a caring role. It is important to understand and acknowledge this. Health or other service providers need to recognise this too, as the support they provide may be more or less effective at given times.

There are distinct times in the limb loss life course when specific interactions are most likely to support the coping of the PWLL and their partner. These are:

The Living with Limb Loss Support Model (LLSM) has been produced as a guide to the support needs of the PWLL and their family.

## RECOVERY STAGE 1

### Event and stabilisation

Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
<p><b>Event and stabilisation</b></p> <p>Acute stage of injury/illness</p> <p>Short term, usually within acute professional health services</p>	<p><b>Information:</b> Diagnosis, prognosis and treatment/s</p> <p>Honest about what to expect physically and emotionally</p> <p><b>Physical:</b> Initial learning how to do/assist with ADLs***</p> <p><b>Emotional:</b> Initial relief that the PWLL is alive and recovering from incident</p> <p>Worry about how to cope and manage future changes to lifestyle</p> <p><b>Learning:</b></p> <p><b>Family/Carer</b> - Inclusion within rehabilitation therapies to learn how to assist in the PWLL's recovery</p>	<ul style="list-style-type: none"> <li>• Organisational visibility</li> <li>• Giving realistic and honest information 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>• Signposting support services/charities, support groups for the PWLL and Family/Carer</li> <li>• Ensuring initial contact and access to prosthetic services</li> </ul>

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\*\*\*Activities of Daily Living



## RECOVERY STAGE 2

# Preparing to return home & discharge

Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
<p><b>Preparing to return home and discharge</b></p> <p>Rehabilitation stage that is usually within professional/rehabilitation health services</p> <p>Moderate term</p>	<p><b>Preparing to return home:</b></p> <p><b>Physical:</b> Focus on physical needs such as safe mobilisation of the PWLL, care of the stump, understanding medications</p> <p><b>Emotional:</b></p> <p><b>PWLL</b> - May feel able to cope and confident with skills to mobilise/self-care whilst in professional care</p> <p><b>Family/Carer</b> - May experience low coping and uncertainty about return home and how they might cope</p> <p><b>Discharge:</b></p> <p><b>Both</b> - Initial low coping and feelings of isolation on discharge/being alone in the home environment</p> <p><b>Learning:</b> Practising new ADL skills, being involved in rehabilitation therapies</p> <p>Medication management</p> <p>Managing multi-morbidities (of the PWLL and Carer)</p> <p><b>Information:</b> What support is available and how to access support/community resources</p> <p><b>Feedback:</b> On how each is doing in learning new caring skills</p> <p>Feedback on emotional coping</p>	<p><b>Preparing to return home:</b></p> <ul style="list-style-type: none"> <li>• Checking home environment is safe and suitable to enable independent living from the PWLL/Family/Carer</li> <li>• Adaptation of living environment: wheelchairs/bathing aids/chair lifts</li> <li>• Independent assessment of coping levels of the PWLL and Family/Carer</li> <li>• Signposting immediate care service support, e.g. GP, community nurse, prosthetic services, and other networks/support groups</li> <li>• Checking understandings of medication regimes of the PWLL and Carer (if required)</li> <li>• Checking other health conditions of the PWLL and Carer are being managed</li> <li>• Being visible on immediate discharge</li> </ul> <p><b>Discharge:</b></p> <ul style="list-style-type: none"> <li>• Enforcement of moving and handling techniques to the PWLL and Carer</li> <li>• Independent assessment of coping levels of the 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>



## RECOVERY STAGE 3

# Being home

Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
<p><b>Being home</b></p> <p>First few months after the PWLL returns to the home</p> <p>Moderate term</p>	<p><b>Physical:</b> Focus on physical needs, safe mobilisation of the PWLL, trying to second guess needs, fear that harm might occur</p> <p><b>Emotional:</b></p> <p><b>PWLL</b> - Anxiety and frustration at the difficulties of self-caring in the home environment</p> <p>Frustration/anxiety in needing to accept help/care from Family/Carer</p> <p>Frustration that they may be dependent upon others</p> <p>May lose confidence as unable to compare their progress with others with limb loss</p> <p><b>Family/Carer</b> - High anxiety and uncertainty about whether they are good enough to support the PWLL and manage the home</p> <p>Possible frustration at new role as Carer</p> <p><b>Both</b> - Feelings of isolation on discharge</p> <p>Difficulty in adapting to providing care in the home</p> <p>Uncertainties about changing role of care in the couple's partnership</p> <p><b>Information:</b> Realistic impact of providing care in everyday life</p> <p><b>Training:</b> Additional support to manage care in the home, e.g. safe moving and handling</p> <p><b>Feedback:</b> On how both cope in the home with physical and emotional care</p>	<ul style="list-style-type: none"> <li>• Independent assessment of coping levels of the PWLL and Family/Carer</li> <li>• Independent discussion about changing nature of caring roles in the life course of the PWLL and Family/Carer</li> <li>• Assisting in setting relevant and achievable goals for the PWLL/ Family/Carer, including literature that describes everyday adaptation to limb loss for the 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 the PWLL and Family/Carer</li> <li>• Pain management information giving/ support, e.g. pain Q &amp; A leaflet that highlights ways to describe pain and types of questions to ask health professionals to help manage pain</li> <li>• Signposting 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 the PWLL/Carer</li> </ul>

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\*\*\*Activities of Daily Living

Caring is often not talked about. Rather, it is a practical activity that is done but not discussed



## RECOVERY STAGE 4

# Adapting to being with limb loss

Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
<p><b>Adapting to being with limb loss</b></p> <p>After a period of adjustment in the home</p> <p>Long term</p>	<p><b>Physical:</b> Focus on safe and independent self-care established routines</p> <p><b>Emotional:</b></p> <p><b>PWLL</b> - Focus on what next and future opportunities</p> <p>Where possible, resuming pre-limb loss living activities</p> <p>Where not possible, refocus on new activity</p> <p>Possible frustration/anxiety if cannot return to previous activity (e.g. employment)</p> <p><b>Family/Carer</b> - Wish to resume aspects of living pre-limb loss such as employment, hobbies</p> <p><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)</p> <p><b>Information:</b> How to access/maintain work/socialising opportunities</p> <p>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?</p> <p><b>Feedback:</b> Continued feedback on how both are coping in the home and possible future support requirements</p>	<ul style="list-style-type: none"> <li>• Independent assessment of coping levels of the 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>• Signposting other support networks, e.g. support groups</li> <li>• Reassess home living support needs, e.g. suitability of home adaptations</li> <li>• Checking co/morbidities (if any) are being managed in both the 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 areas such as housing/finances/pensions</li> </ul>

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\*\*\*Activities of Daily Living

## RECOVERY STAGE 5

# Forward planning

Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
<p><b>Planning forward</b></p> <p>Long term</p>	<p><b>Physical:</b> Focus on maintaining self-care routines and maximising independence</p> <p>Managing co/morbidities</p> <p>Managing changes in stump/prosthetic care</p> <p>Maintaining maximum independence</p> <p><b>Emotional:</b> Thinking ahead about how to cope with aging</p> <p>Not admitting to changes in physical states to manage self-care/care for others</p> <p>Worry and anxiety over health of each other in the future</p> <p>Worry about housing appropriateness</p> <p>Worry about finances/pensions</p> <p>Feelings of lower coping and anxiety about what might happen</p> <p>Feelings of isolation</p> <p>Not wanting to burden their family with concerns about the future</p> <p><b>Information:</b> Focus on future possibilities for care for the PWLL/Carer</p> <p>Opportunity to talk about concerns with others in similar situations</p> <p>Opportunity to talk with wider family about potential future care needs</p> <p><b>Feedback:</b> Honest separate appraisal of how well the PWLL and Family/Carers are coping</p>	<ul style="list-style-type: none"> <li>• Independent assessment of coping levels of the 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 the PWLL and Family/Carer as relevant</li> <li>• Where necessary, helping in family conversations about long-term future care and support needs of the PWLL/Family/Carer</li> </ul>

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\*\*\*Activities of Daily Living



A Person with Limb Loss is not alone. Family members are also impacted by the situation



## Summary

It should be acknowledged that a PWLL is not alone in the limb loss life course. Family members are also impacted by the situation and each will experience varying coping levels, which are often different from those of others at any given time. This is normal and natural. By understanding this, and knowing what support is available and when that support is most likely to be needed, those living with limb loss may be better able to cope with all aspects of daily living.

The Living with Limb Loss Support Model identifies times and situations that have an impact on coping, and support organisations are given guidance on how to appropriately support the PWLL and the family carer or carers.

# Where do I get support?

Support for the PWLL and their families comes from a number of sources, either statutory or the voluntary or charitable sectors. Additionally, support may be found within the family unit itself. Below is a list of support organisations

or services. Blesma Support Officers (BSO) are available to give advice on access to support and assist as required depending on individual needs. The list below is not exhaustive and your BSO can provide specific advice as required.

## Useful information

Statutory	Voluntary/Charitable Sector
<p><b>General Practice Doctor (GP)</b> Primary Care – general health concerns, medication, pain relief, referral to other medical services</p> <p><b>Local Authority/Social Care</b> Housing adaptations, care services, benefits and allowances advice</p> <p><b>NHS Secondary Care (Hospitals/Limb Services)</b> Consultant-led services, pain management, prosthetic provision, physiotherapy</p>	<p><b>Blesma</b> <a href="http://www.blesma.org">www.blesma.org</a> 020 8590 1124</p> <p><b>Veterans' Gateway</b> <a href="http://www.veteransgateway.org.uk">www.veteransgateway.org.uk</a> 0808 802 1212</p>

# Blesma

THE LIMBLESS VETERANS

## Caring and Coping

A further series of six information leaflets from Blesma, The Limbless Veterans is available. All these leaflets can be downloaded from

[www.blesma.org/leaflets](http://www.blesma.org/leaflets)

If you prefer, you can receive hard copies by calling **020 8590 1124**  
or by emailing [chadwellheath@blesma.org](mailto:chadwellheath@blesma.org)

- 1 Introduction and General Information
- 2 Amputation Explained
- 3 NHS Limb Service and Prosthetic Information
- 4 Phantom Limb Pain
- 5 Stump Care
- 6 Wellbeing

[www.blesma.org](http://www.blesma.org)