

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

Living with Limb Loss Support Model (LLSM)

The *Caring and Coping: The Family Perspective on Living with Limb Loss*¹ research explores how persons with limb loss (PWLL) and their family carers live with limb loss. The people asked in this research were veterans, however, what they told us is important to all persons with limb loss. The following summarises what PWLL and their family carer/s told us:

- PWLL and their main family carer/s cope differently, which means the needs of both the PWLL and carer/s should be considered separately
- There are distinct time periods when differing types of support would help the PWLL and their family carer/s

From this, increased awareness of the following steps would help support both the PWLL and their family carer/s.

- 1 People will cope with living with limb loss differently. Coping levels can be seen by looking for behaviours that suggest how they might be coping. For example:

Coping Level	PWLL Examples	Carer of PWLL Examples
Low	<ul style="list-style-type: none"> • Not wanting to do own bathing/dressing (Activities of Daily Living (ADLs)) • Not wanting to mobilise on their own • Not managing health conditions/taking medications independently • Not wanting to socialise • Not admitting to needing help and support 	<ul style="list-style-type: none"> • Constant assistance with PWLL's physical needs • Constant worry about what could happen • Not wanting to socialise • Not managing own health conditions/taking medications • Not admitting to needing help/support
Middle	<ul style="list-style-type: none"> • Doing own ADLs • Mobilising independently • Managing own health conditions/taking medications • Liaising with health/support services • Socialising with carer and independently 	<ul style="list-style-type: none"> • Intervening in ADLs only when needed/asked for • Enabling/encouraging PWLL to go out independently • Acceptance that accidents can happen when the PWLL is outside independently • Recognising if they feel they are struggling to cope/asking for support • Managing their own health conditions/taking medications

- 2 Talk to family carer/s and the PWLL separately. It is often assumed that both the PWLL and their family carer/s are coping at the same levels, but this is not always true. For example, when the PWLL is starting to go outside independently, the carer may overly worry about that person's safety when they are apart. However, because the carer is rarely asked, their worries are often hidden and unrecognised.

- 3 Everyone has their own life stories. Specific to veteran families is a military legacy. The military legacy is the resulting positive and negative effects that being in the military continues to have on a person's life after they have left the military. The military legacy is important because it might mean that families are 'not talking about', 'not admitting to' and 'not asking for help' and look as if they are 'getting on with it', because this is the 'military way'. How veterans with limb loss and their main family carer/s are really coping may, therefore, be hidden from their wider family, community and health service providers. How individual life stories and circumstances affect all PWLL/families/carers need to be better considered.

4 There are differing stages to living with limb loss over the life course.

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

Professional support and care, therefore, needs to be timely in relation to where in the limb loss life course persons are, related to the individual's level of coping, and recognise a possible military legacy/ individual life stories. For example, the below table shows suggested support and care for PWLLs and family/carer across two stages of the limb loss life course:

Recovery Stage	PWLL and Family/Carer Support Needs	Organisational Support
<p>2 Preparing to return home and discharge</p> <p>Rehabilitation stage usually within professional/ rehabilitation health services</p> <p>Moderate term</p>	<p>Preparing to return home:</p> <p>Physical: Focus on physical needs such as safe mobilisation of PWLL, care of the stump, understanding medications</p> <p>Emotional: PWLL – May feel able to cope and confident on skills to mobilise/self-care whilst in professional care Family/Carer – May experience low coping and uncertainty about return home and how they might cope</p> <p>Discharge: Both – Initial low coping and feelings of isolation on discharge/being alone in the home environment</p> <ul style="list-style-type: none"> • Learning: Practicing new ADL skills, being involved in rehabilitation therapies. Medication management. Managing multi-morbidities (PWLL and Carer) • Feedback: On how each is doing in learning new caring skills. Feedback on emotional coping 	<p>Preparing to return home:</p> <ul style="list-style-type: none"> • Checking home environment is safe and suitable to enable independent living of PWLL and family/carer • Independent assessment of coping levels of PWLL and family/carer • Signposting immediate care service support • Checking management of co/morbidities and medication • Being visible on immediate discharge <p>Discharge:</p> <ul style="list-style-type: none"> • Re – enforcement of moving and handling techniques to PWLL and family/carer • Independent assessment of coping levels of PWLL and family/carer • Realistic and honest information giving about physical/emotional aspects of intermediate effects of limb loss for the PWLL/family/carer • Checking with wider family information needs and understandings of types of support available
<p>3 Being home</p> <p>First few months after PWLL returns home</p> <p>Moderate term</p>	<p>Physical: focus on physical needs, safe mobilisation, fear that harm might occur</p> <p>Emotional: PWLL - Anxiety and frustration re. difficulties self-caring in the home environment May lose confidence as unable to compare their progression with others with limb loss Family/Carer - High anxiety about whether they are good enough to support PWLL. Possible frustration re. new role as carer Both - Feelings of isolation on discharge. Difficulty in adapting to providing care in the home</p> <p>Training: Additional support to manage care in the home e.g. safe moving and handling</p> <p>Feedback: On how both are coping in the home with physical care and emotional care</p>	<ul style="list-style-type: none"> • Independent assessment of coping levels of PWLL and family/carer • Assisting in setting relevant and achievable goals for PWLL/family/carer • Where relevant, enabling contact with others with limb loss at a similar limb loss stage • Moving and handling support/learning for PWLL and family/carer • Pain management information giving/support • Signposting long-term care service support • Checking co/morbidities (if any) are being managed in both PWLL and family/carer

C. Engward, H. (2018)

To find out more about this research, to read the full research report and to see its recommendations, please go to www.blesma.org/familiesproject

¹Engward, Fleuty & Fossey. 2018. Caring and Coping: The Family Perspective on Living with Limb Loss. Blesma, available at www.blesma.org/familiesproject