

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

Living with Limb Loss Support Model (LLSM)



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 family of those living with limb loss. To understand more about this, Blesma and the Veterans and Families Institute for Military Social Research at Anglia Ruskin University carried out the *Caring and Coping: The Family Perspective on Living with Limb Loss*¹ study to explore 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 all persons with limb loss (PWLL) and those who care for them.

This provides a brief summary of the main findings:

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:

“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 that same feeling of pressure that mum’s got, we know that it’s pressure.” (Son)

This might be because people ‘get on with it’ and because it is difficult to admit to needing extra support, even if it is available in the family unit.

People are told what to expect, but not how to cope

Learning to cope with limb loss is central to adapting independently to limb loss.

- There are different levels of coping: **Low, Mid or High**.
- PWLL and their main family carer(s) often cope differently at the same time. For example:

PWLL	Family carer(s)
<ul style="list-style-type: none"> • Not managing their own health conditions or not wanting to mobilise independently. • Coping Level therefore might be Low 	<ul style="list-style-type: none"> • Managing to assist in everyday living and caring, and feels supported in their caring role. • Coping Level therefore might be Mid
<ul style="list-style-type: none"> • May be managing everyday living, and socialising independently both with and without their carer. • Coping Level may be Mid 	<ul style="list-style-type: none"> • Constant worry about the PWLL's wellbeing and what might happen when the PWLL is socialising independently. • Coping Level might be Low
<ul style="list-style-type: none"> • Actively plans forward for future health and living needs, and actively seeks help and support where needed. • Coping Level may be High 	<ul style="list-style-type: none"> • Is realistic about future needs and thinks ahead. • Coping Level may be High

- This means that the needs of the PWLL and carer(s) should be considered separately.

Living with limb loss changes over life

There are distinct time periods when differing types of support would help the PWLL and their family carer(s) – and this support can be more or less effective depending on when, and by whom, it is provided. These stages are:

- The limb loss event and stabilisation (perhaps from injury to medical interventions and early rehabilitation)
- Preparing to return home and discharge (arranging for home adaptations, for example)
- Being home (may be some time after limb loss event)
- Adapting to living with limb loss (learning new ways to carry out activities of daily living (ADL))
- Forward Planning (limb loss is for life and looking forward is beneficial as needs may change over time)

How will this benefit the PWLL and their family carer(s)

- Knowing that individuals cope differently means each person should be considered both individually and as a family caring unit, with ongoing support tailored to those needs.
- Knowing that there are key stages in living with limb loss, and that certain types of support are more relevant to each stage, is important to maximise long-term independence and wellbeing in the family caring unit.
- By increasing awareness of the above key findings, the PWLL and those around them may become empowered to exercise some control over their situation.

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