

## Living with Limb Loss Support Model\*

The Living with Limb Loss Support Model (LLSM) is developed directly from research (*Caring and Coping: The Family Perspective on Living with Limb Loss*<sup>1</sup>) exploring how persons with limb loss (PWLL) and their families live with limb loss. Findings demonstrated, firstly, that the coping levels of the PWLL and their family carers could differ at any one time and that coping levels of those in the caring relationship ought to be assessed separately. Secondly, distinct stages across the life course were identified, to which differing support and care needs can be aligned. This Model is intended for support organisations to use as a tool to better understand, and support, PWLL and their families.

### Coping and Limb Loss

Individuals can experience three levels of coping: low, middle and high. These are set out below, alongside examples of behaviours/attitudes of PWLL that service providers/or health professionals could observe that might indicate how well the PWLL and their caregivers are coping:

Coping Level	Characteristics	PWLL Examples	Family Carer/s of PWLL Examples
<b>Low</b>	<b>PWLL:</b> being passive e.g. constant reliance on another <b>Carer:</b> high emotional burden e.g. constant worry	<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 worry about what could happen</li> <li>Reluctance to socialise</li> <li>Not admitting to needing help/support</li> <li>Not managing own health conditions</li> </ul>
<b>Middle</b>	<b>PWLL and Carer:</b> active e.g. establishing safe routines	<ul style="list-style-type: none"> <li>Managing own ADLs</li> <li>Mobilising independently</li> <li>Managing own health conditions</li> <li>Liaising with health/support services</li> <li>Socialising</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 struggling to cope</li> <li>Managing own health conditions</li> <li>Enabling/encouraging PWLL to go out independently</li> </ul>
<b>High</b>	<b>PWLL and Carer:</b> increased capacity of self-awareness, self-care and self-efficacy	<ul style="list-style-type: none"> <li>Managing own ADLs</li> <li>Actively seeking help and support</li> <li>Forward planning ahead re. current and future health and living needs</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 re. future needs</li> </ul>

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

It must be noted that coping is a changing process in which individuals in the care relationship can display differing levels of coping at any one time. Therefore, it is recommended that each person be assessed separately.

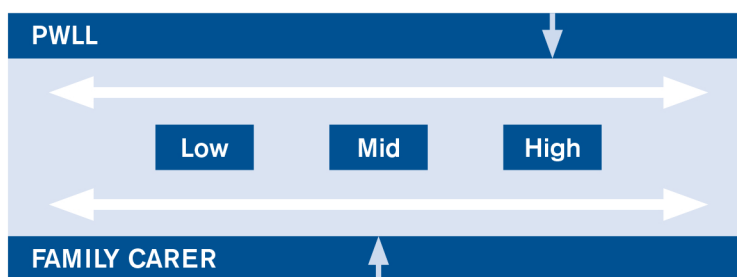


Diagram 2: Example of differing individual coping levels for the PWLL and family carer/s

### Living with Limb Loss Life Course

In the living with limb loss life course there are distinct stages, each characteristic of needs, during which levels of coping can fluctuate. Support/information giving needs to be timely in relation to the limb loss life stage and in relation to the individual's level of coping. Running alongside this is the individual's socio-cultural position, and timely interventions need to recognise the lasting effect of individual legacies.

The relationship between individual legacies, stages in injury recovery and coping are shown overleaf in a summarised version of the LLSM:

<sup>1</sup>Engward, Fleuty & Fossey. 2018. *Caring and Coping: The Family Perspective on Living with Limb Loss*. Blesma, available at [www.blesma.org/familiesproject](http://www.blesma.org/familiesproject)

\* 'Caring and Coping: The Family Perspective on Living with Limb Loss', in partnership with Blesma and funded by the Forces in Mind Trust

	Recovery Stage	PWLL* and Family/Carer Support Needs**	Organisational Support
Individual Socio-Cultural Circumstance	<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 <b>Physical:</b> Initial learning how to do/assist with ADLs*** <b>Emotional:</b> Honest about what to expect physically and emotionally. Worry about how to cope and manage future changes to lifestyle <b>Learning:</b> Family/Carer - Inclusion within rehabilitation therapies to learn how to assist in PWLL recovery	<b>Organisational visibility</b> <ul style="list-style-type: none"> <li>Realistic and honest information giving about physical/emotional aspects of immediate effects of limb loss for the PWLL/family/carers</li> <li>Encouraging family members to engage in care and rehabilitation services, especially moving and handling, and managing ADLs</li> <li>Signposting re. support services/charities, support groups for PWLL and family/carers</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 on 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 (PWLL and Partner) <b>Feedback:</b> On how each is 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 of PWLL and family/carers</li> <li>Independent assessment of coping levels of PWLL and family/carers</li> <li>Signposting immediate care service support</li> <li>Checking management of co/morbidities and medication</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 family/carers</li> <li>Independent assessment of coping levels of PWLL and family/carers</li> <li>Realistic and honest information giving about physical/emotional aspects of intermediate effects of limb loss for the PWLL/family/carers</li> <li>Checking with 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, fear that harm might occur <b>Emotional:</b> <b>PWLL</b> - 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 <b>Family/Carer</b> - High anxiety about whether they are good enough to support PWLL Possible frustration re. new role as carer <b>Both</b> - Feelings of isolation on discharge. Difficulty in adapting to providing care in the home <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/carers</li> <li>Assisting in setting relevant and achievable goals for PWLL/family/carers</li> <li>Where relevant, enabling contact with others with limb loss at a similar limb loss stage</li> <li>Moving and handling support and learning for PWLL and family/carers</li> <li>Pain management information giving/support</li> <li>Signposting long-term care service support</li> <li>Checking co/morbidities (if any) are being managed in both PWLL and family/carers</li> </ul>
	<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> PWLL - focus on 'what next' and future opportunities. Resuming pre-limb loss living activities. Where not possible, refocus on new activity <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 seeking support from others in similar situations <b>Feedback:</b> Continued on how they 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/carers</li> <li>Checking prosthetic service access/support</li> <li>Reassessment of 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/carers</li> <li>Assistance in setting achievable goals to reinstate life pre-limb loss, such as social activity, resuming hobbies/interests</li> </ul>
	<b>5 Planning forward</b>  Long term	<b>Physical:</b> Maintaining independence Managing co/morbidities and changes in stump/prosthetic care <b>Emotional:</b> Both - Not admitting to changes in physical states to manage self-care/care for other Feelings of lower coping and anxiety about what might happen to each other <b>Information:</b> Opportunity to talk about concerns with others in similar situations <b>Feedback:</b> Honest separate appraisal of how well PWLL and family/main carers are coping	<ul style="list-style-type: none"> <li>Independent assessment of coping levels of PWLL and family/carers</li> <li>Planning for the long term: pensions/finance etc.</li> <li>Information about alternative safe housing/living/financial support directed to PWLL, family unit/carers as relevant</li> <li>Where necessary, helping in family conversations re long term future care and support needs of the PWLL/family/carers</li> </ul>

\*PWLL refers to Person with Limb Loss

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

\*\*\*Activities of Daily Living