

# Caring for someone with Lymphoma or CLL



## OVERVIEW

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A diagnosis of lymphoma or chronic lymphocytic leukaemia (CLL) can be devastating and life-changing for the individual. It can also have a profound impact on that person's loved ones and carers. Although the needs of someone with lymphoma or CLL vary from person to person, it is often the case that the needs of the carer go unnoticed and unmanaged.

This fact sheet will identify some of the unique challenges associated with caring for someone with lymphoma, as well as discuss some practical options for carer support.

## WHO IS A CARER?

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A carer is defined as someone who provides physical, emotional and practical support to a person with a disability or disease (in this case, cancer). Carers come in all different shapes and sizes. They are often direct family members such as spouses, siblings, parents and children, but can also be relatives, close friends or neighbours. The needs of the individual with lymphoma or CLL may range from occasional transport assistance through to 24-hour care.

You may not identify yourself as a carer, but as someone who simply 'helps out' from time to time. It may feel like a natural extension of your relationship with the person with lymphoma, or it may feel like you "had no choice" but to take on these caring responsibilities.

It is important to note that being a carer for someone with cancer can be a very rewarding experience and, in some ways, can strengthen your relationship in ways you may not have imagined. While there are challenges in the carer's experience, many carers report high levels of life satisfaction, happiness and a feeling of profound connectedness.

## WHAT DOES BEING A CARER FEEL LIKE?

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When someone you love has been diagnosed with lymphoma or CLL, it is common to experience intense emotions including shock, sadness, fear and even anger. It is important to know that there is no normal timeline for your emotional response to the news; some people process the information immediately, while others take much longer.

It is also very common to feel afraid or fearful about the future, and what this diagnosis means for your loved one and yourself. It can be very tempting to use the internet to find out more information, or ask others what they may know about lymphoma, its treatment and prognosis. While the internet can be a wonderful source of information, it can also contain inaccurate information which may not be helpful for you to read. It is advised that you speak directly with the treating team of the person diagnosed about what websites and resources will be most helpful and relevant to you both at this time. Many people report reduced stress and anxiety about the future once they have more information about lymphoma and CLL, the subtype that has been diagnosed and what treatments are recommended.

Many carers describe intense pressure to be "the cheerleader" for the person who they are caring for, encouraging positivity and happy thoughts at all times. Often, carers will feel they need to "be strong" for the person they are caring for, and not reveal that they themselves may be struggling with powerful emotions such as sadness, fear and anger. While a positive mindset can be helpful, it is essential that carers communicate openly and honestly about their own concerns or struggles.

## WHAT IF I MISS THE LIFE WE HAD BEFORE CANCER?

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Many carers experience a 'grieving period' once the reality of their situation sets in. It is very normal to miss the activities that you used to enjoy before the lymphoma diagnosis including socialising, work, exercise or intimacy. The person you are caring for may also be feeling this sense of loss and grief, where they may even direct anger and resentment towards you because of this.

It can be helpful to have open and honest discussions about what each of you 'misses' about life before the diagnosis. Although these conversations can be uncomfortable at first, they may also allow you to feel closer to the person you are caring for and understand their point of view, and vice versa.

## WHAT CAN I DO TO COPE WITH BEING A CARER?

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While each carer's experience is different, there are some practical strategies you can use to help manage the stress and

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emotional toll of being a carer:

- Be open and honest about your emotions and what your experience has been like
- Find a safe person to talk to if you do not feel like you can share your feelings with the person you're caring for - close friends or family members
- Talk to a counsellor, psychologist or spiritual care worker
- Ask for practical help from those around you. This is not always easy, but asking others to help with transport, cleaning, cooking etc can alleviate stress.
- Discuss respite options with your GP or the treatment team
- Taking time out for yourself to engage in your hobbies, or just for relaxation
- Setting boundaries around the type of care you provide
- Connect with carer support services such as Carer's Australia, or Carer Gateway (see list at the end of the factsheet)
- Practice regular 'self-care' (see below)

## WHAT IS SELF CARE?

The expression 'you cannot pour from an empty cup' is resonant when we talk about managing the emotional and practical needs of the carer. It is very difficult to look after another person if you are or have been unable to adequately look after yourself. Some options for self-care include:

- Exercising
- Making healthy food choices
- Socialising with friends
- Taking time out to access massage, acupuncture and reflexology
- Limiting alcohol consumption
- Practising meditation and mindfulness
- Connecting with others regularly
- Creating a regular sleep schedule for yourself

## WHAT IF I NEED A BREAK?

As a carer, it is essential that you regularly take time for yourself to recharge and relax. **Respite or respite care** is when others are allocated to take care of the person you care for, allowing you to take time to look after yourself, rest or attend to other life matters. Respite can be provided by friends or family, but there are also services available in Australia which can provide other respite options depending on the needs of the person with lymphoma or CLL.

Depending on where you live, respite facilities should be easy to find and access. Cost can be a significant challenge, which is why the Government can subsidise respite options in some cases. Services like My Aged Care or NDIS can arrange respite care in some circumstances, although there are strict criteria you

must fulfil. If you feel that you are considering respite options for yourself and the person you are caring for, make an appointment with your GP to discuss options available in your area. (More information can be found on the Carer's Gateway website - see resource list at the end of the fact sheet).

It is important to note that what supports one person may not be helpful to another. As a carer, it is essential that you find a balance between taking care of someone who needs you and taking care of your own needs. With the right amount of information, support and connection, caring for someone with lymphoma or CLL can be a very rewarding experience.

## RESOURCES AND SUPPORT

Organisation	How can they help?
Lymphoma Australia	<ul style="list-style-type: none"><li>• Lymphoma Australia offers a wide variety of resources and support for people with lymphoma or CLL and their carers. Please visit our website <a href="http://www.lymphoma.org.au">www.lymphoma.org.au</a> for further information</li><li>• Lymphoma Nurse Support Line: 1800 953 081 or email: <a href="mailto:nurse@lymphoma.org.au">nurse@lymphoma.org.au</a></li><li>• Online private Facebook group: Lymphoma Down Under <a href="http://bit.ly/2mrPA1k">http://bit.ly/2mrPA1k</a></li></ul>
Cancer Council Australia	<ul style="list-style-type: none"><li>• Resources and information via the website visit: <a href="http://www.cancer.org.au">www.cancer.org.au</a> or call 13 11 20 to talk to specially trained staff who can answer your questions and offer emotional and practical support options</li></ul>
CanTeen	<ul style="list-style-type: none"><li>• CanTeen is an organisation working with young people affected by cancer 12-25 years, including those whose parents have cancer. They have resources, online support chat rooms, phone and face to face counselling as well as fun events and camps. There is also online support available for parents. <a href="http://canteen.org.au">canteen.org.au</a> or email <a href="mailto:support@canteen.org.au">support@canteen.org.au</a> or call 1800 835 932</li></ul>

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Carer Directed Respite Care (CDRC)	<ul style="list-style-type: none"> <li>Australian Government program which allows carer's to have more input in the respite options based on the needs of the carer and the individual needing care. Call 1800 052 22</li> </ul>
Carer Gateway	<ul style="list-style-type: none"> <li>Information on carer's payments, carer support options, list of helpful resources and short courses for practical skills. Call 1800 422 737</li> </ul>
National Carer Counselling Program (NCCP)	<ul style="list-style-type: none"> <li>Short term counselling, emotional and psychological support services for carers in need of support. Call 1800 242 636</li> </ul>
WeCan	<ul style="list-style-type: none"> <li>WeCan is an Australian supportive care website to help find the information, resources and support services they may need following a diagnosis of cancer. Visit <a href="http://wecan.org.au">wecan.org.au</a></li> </ul>
Medicare Australia	<ul style="list-style-type: none"> <li>Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan can give you up to 10 sessions with a registered psychologist either significantly or completely subsidised by Medicare. For more information visit: <a href="http://bit.ly/31ahL36">http://bit.ly/31ahL36</a></li> </ul>
Redkite	<ul style="list-style-type: none"> <li>RedKite provides essential support to children, young people and their family/ friends from cancer diagnosis, treatment and after treatment aged 0-25 years. <a href="http://www.redkite.org.au">www.redkite.org.au</a> or email <a href="mailto:support@redkite.org.au">support@redkite.org.au</a> or call 1800 REDKITE (1800 733 548)</li> </ul>