

Emotional Impact of Living with Lymphoma



A diagnosis of lymphoma or chronic lymphocytic leukaemia (CLL) can be a very stressful and emotional experience. It can be difficult to manage the range of emotions that can occur before, during and after treatment. It will take some time to come to terms with everything you have been through and manage any side effects of treatment you may be experiencing.

Many people living with lymphoma or CLL say that life after diagnosis is permanently changed. The physical and emotional impacts of the disease and its treatment may come and go during the different phases in the cancer experience, but do not necessarily disappear after someone completes treatment or receives news they are in remission.

While most people with lymphoma or CLL will require treatment at some point, there are situations where treatment may not be required for a period of time, or treatment may not cause obvious side effects (i.e. hair loss). In these situations, friends and family members may comment on how "well" you look despite feeling unwell on the inside. While these comments generally come from a good place, it can be frustrating to hear this. Practicing open and honest communication about how you're coping can be very helpful. People also find that seeking some emotional support and advice from a psychologist or counsellor can be especially helpful.

MANAGING YOUR EMOTIONS

Commonly, people describe their emotional wellbeing as an undulating path where feelings of stress and anxiety may increase and decrease intermittently. While certain chapters of the cancer journey may generate excessive stress, many people with lymphoma benefit from creating life-long strategies to support their emotional well being.

Creating a network of supportive people around you can greatly assist with stress management and emotional well being. Support networks often look different for each person, but commonly involve people who support you in emotional or practical ways.

Your support network may consist of:

- Family members, spouses or, parents
- Friends

- Support groups, online or community-based
- Other patients who you may meet during treatment
- External support services such as psychologists, counsellors, social workers or spiritual care workers
- Lymphoma Australia online private Facebook group: Lymphoma Down Under

Reaching out to the members of your support network when you're experiencing high levels of stress and anxiety can be helpful. A chat over coffee, a walk around the garden or a drive to shops can all be helpful when you're in a state of distress. Often, people want to offer support to you, but aren't quite sure how. Asking others to help with transport to appointments, some light household cleaning or even asking a friend to cook a hot meal can be helpful options while you're not feeling well. (See "Gather My Crew" website: gathermycrew.org.au)

SELF-CARE

When we consider the additional stress which a diagnosis of lymphoma or CLL can place on our lives, it is realistic to consider that we may need extra time for self-care activities in order to cope (see 'Self-care and lymphoma' fact sheet). It is also important that carers of people with lymphoma regularly take time for self care. For more information on this, see the 'Caring for someone with lymphoma' fact sheet via the Lymphoma Australia website.

Some examples of self care include:

- Giving yourself permission to experience your emotions as they arise, including taking time to cry if you feel you need to
- Continuing enjoyable hobbies, or taking up new, relaxing hobbies for example swimming, craft groups or meditation classes
- Joining the private Facebook support group for people with lymphoma or CLL '**Lymphoma Down Under**' and connecting with others in similar situations
- Learning to meditate and practice mindfulness. There are many free smartphone apps for this, or you can look into whether there are some meditation groups in your local area
- Making time for exercise as often as possible. Even 5-10 minutes a day can significantly reduce stress levels during treatment (see Lymphoma Australia Fact sheet: 'Exercise and Lymphoma')

FACT SHEET

- Making healthy food choices and including more fresh fruits and vegetables. Ask for a referral to a dietitian if you aren't sure about what your dietary requirements are (see 'Nutrition and lymphoma' fact sheet)
- Listening to your body and understanding when it needs rest and when it needs activity. Keeping a journal or diary can greatly assist with this strategy
- Regularly setting aside time for safe complementary therapies such as massage, acupuncture or reflexology (for more information see the 'Complementary and Alternative Therapies and Lymphoma' fact sheet)
- Creating a sleep schedule and allowing time for rest and relaxation (for more information (see 'Sleep Management and lymphoma' fact sheet).

WHEN YOUR LYMPHOMA DOESN'T REQUIRE TREATMENT STRAIGHT AWAY

There are some forms of lymphoma that are slow growing (indolent) and doctors may suggest a plan of 'watch and wait' or active monitoring rather than giving treatment for lymphoma straight away. It refers to a period of time when you have no treatment but attend for regular check-ups. This type of treatment approach is most often used in people who are diagnosed with indolent lymphoma and have no symptoms or other risk factors that require immediate treatment. For more information see the 'Understanding Watch and Wait' fact sheet on the Lymphoma Australia website.

'Watch and Wait' may initially cause distress to some people as it may seem a risky or passive approach to a serious disease. Discussing your concerns with your treating team may help. But if you are finding it very hard to cope with being on 'watch and wait', make sure you let your doctor know and ask what options there are for support.

If you are struggling with significant levels of stress and anxiety at any stage in your experience, please don't hesitate to reach out. Lymphoma Nurse Support Line – 1800 953 081, or email: nurse@lymphoma.org.au

RESOURCES AND SUPPORT

| Organisation | How can they help? |
|--------------------|---|
| Lymphoma Australia | <ul style="list-style-type: none"> • Lymphoma Australia offers a wide variety of resources and support for people with lymphoma or CLL and their carers. Please visit our website www.lymphoma.org.au for further information |

| Organisation | How can they help? |
|--------------------------|---|
| | <ul style="list-style-type: none"> • Lymphoma Australia Fact sheets & booklets (lymphoma.org.au/page/1218/fact-sheets) Including: <ul style="list-style-type: none"> • Lymphoma subtypes • Understanding 'Watch & Wait' • Sleep Management & lymphoma • Nutrition and lymphoma • Exercise and lymphoma • Emotional impact of lymphoma diagnosis and treatment • Complementary & Alternative therapies • Self-care and lymphoma • Caring for someone with lymphoma • Lymphoma Australia YouTube Channel: Presentations on a variety of topics about lymphoma subtypes and management: youtube.com/user/LymphomaAustralia • Lymphoma Nurse Support Line: 1800 953 081 or email: nurse@lymphoma.org.au • Online private Facebook group: "Lymphoma Down Under": http://bit.ly/33tuwro |
| Beyond Blue | <ul style="list-style-type: none"> • Beyond Blue provide phone, online and email support for those experiencing high levels of depression, anxiety, stress or suicidal thoughts. Call 1300 22 4636 or visit: www.beyondblue.org.au |
| Calm | <ul style="list-style-type: none"> • Calm is a free smartphone app which contains over 100 guided meditations for anxiety, stress and sleep management. From beginners to advanced listeners. Visit: www.calm.com |
| Cancer Council Australia | <ul style="list-style-type: none"> • Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live. Visit: www.cancer.org.au or call 13 11 20 |

FACT SHEET

| Organisation | How can they help? |
|--|---|
| CanTeen | <ul style="list-style-type: none"> 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. canteen.org.au or email support@canteen.org.au or call 1800 835 932 |
| Gather My Crew | <ul style="list-style-type: none"> Gather My Crew connects people going through tough times with friends and family who want to provide practical help: www.gathermycrew.org.au |
| Headspace | <ul style="list-style-type: none"> Phone, face-to-face counselling and programs for those affected by mental health issues aged between 12-24 years. Call: 1800 650 890 |
| Leukaemia Foundation | <ul style="list-style-type: none"> The Leukaemia Foundation provide support groups, accommodation and transport assistance for people living with blood cancers and their carers: www.leukaemia.org.au |
| Lifeline | <ul style="list-style-type: none"> Australia-wide 24-hour telephone crisis support and counselling for those in crisis or need of support. Call 13 11 14 (24/7) |
| Australian Cancer Survivorship Centre (ACSC) | <ul style="list-style-type: none"> The ACSC is a unique service based at the Peter MacCallum Cancer Centre in Victoria. It provides a comprehensive collection of resources and information for cancer survivors and their carers: petermac.org/services/support-services/australian-cancer-survivorship-centre |
| Medicare Australia | <ul style="list-style-type: none"> 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: http://bit.ly/31ahl36 |

| Organisation | How can they help? |
|--------------------|---|
| MensLine Australia | <ul style="list-style-type: none"> Telephone counselling service for men specialising in relationships, domestic violence, mental health, wellbeing and discussion forums. Call: 1300 78 99 78 |
| Redkite | <ul style="list-style-type: none"> RedKite provides essential support to children, young people and their family/ friends from cancer diagnosis, treatment and after treatment aged 0-25 years. www.redkite.org.au or email support@redkite.org.au or call 1800 REDKITE (1800 733 548) |
| WeCan | <ul style="list-style-type: none"> 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 wecan.org.au |

This resource was last reviewed and updated January 2020