

Emotional Impact of Relapsed or Refractory Lymphoma



OVERVIEW

Unfortunately, sometimes cancer can come back after successful treatment (relapse). This can occur days, weeks, months or years after successful treatment. Sometimes lymphoma or chronic lymphocytic leukaemia (CLL) doesn't respond to treatment (refractory). Coping with a relapse or refractory lymphoma can be just as hard as coping with your original diagnosis, and sometimes even harder.

For more information on what is relapsed or refractory lymphoma and how these are treated, please see the fact sheet "Relapsed or Refractory Lymphoma" on Lymphoma Australia website: lymphoma.org.au/page/1218/fact-sheets

EMOTIONAL IMPACT WHEN LYMPHOMA RELAPSES

When you are told that your lymphoma or CLL has relapsed or refractory, it is normal to feel angry, upset or overwhelmed. Even if your treating team had prepared you for the possibility of relapse, it is still very disappointing news to take in.

Many people say that being told they have relapsed triggers an intense emotional response, similar to how they felt when they were initially diagnosed. Feelings of anger, fear, sadness and anxiety are common, many people even saying that it is more intense the second time around. It can be frightening to think about the possibility of having more treatment, especially if you struggled with significant side effects previously.

You may initially doubt whether you have the motivation and mental strength to go through it all again. But you could find that your previous experience with cancer has given you some skills, knowledge and resources which may help you to cope with the next chapter. For example:

- You know more about your diagnosis, the treatment and prognosis
- You have strategies for dealing with side effects
- You have relationships with your treating team; nurses, allied health & doctors
- You understand the healthcare system, and who can help you with what
- You have an established support network and strategies for stress reduction

WHAT DO I DO NOW?

It can be helpful during this time to acknowledge the need for increased support and assurance from your network. Activities, habits and support services that helped you during your first round of treatment may need to be restarted or increased in order to help you cope again. For example, if you found it helpful to talk to a counsellor or psychologist during your previous treatment, it may be beneficial to reconnect with that therapist now.

Some other strategies that may be helpful 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 Lymphoma Australia 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' <https://bit.ly/2QorAbw>).
- 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
- 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
- Creating a sleep schedule and allowing time for rest and relaxation (for more information, see the 'Sleep Management and Lymphoma' fact sheet on the Lymphoma Australia website: <https://bit.ly/2rZbPi6>)

It is important to understand that every person who receives a Lymphoma diagnosis has a unique physical and emotional experience. What may ease the stress and anxiety for one person following relapse may not work for the next. 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 lymphoma.org.au for further information Lymphoma Australia fact sheets that can assist include: <ul style="list-style-type: none"> Relapsed or Refractory Lymphoma Lymphoma subtypes Exercise and Lymphoma Sleep Management and Lymphoma Understanding Watch and Wait Fear of Cancer Recurrence & Scan Anxiety Caring for Someone with Lymphoma lymphoma.org.au/page/1218/fact-sheets Lymphoma Australia YouTube Channel to watch presentations about a variety of topics including lymphoma subtypes, management and supportive care: youtube.com/user/LymphomaAustralia Lymphoma Nurse Support Line: 1800 953 081 or email: nurse@lymphoma.org.au Online private Facebook support group: "Lymphoma Down Under" for support from other patients and carers. facebook.com/groups/471933462984263
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: beyondblue.org.au
Calm	<ul style="list-style-type: none"> Calm is a free smart phone app which contains over 100 guided meditations for anxiety, stress and sleep management. From beginners to advanced listeners. Visit: calm.com
Cancer Council	<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: cancer.org.au or call 13 11 20

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. They have resources, online support chat rooms, phone and face to face counselling as well as fun events and camps: 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: gathermycrew.org.au
Headspace	<ul style="list-style-type: none"> Phone and face-to-face counselling 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: 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)
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: https://bit.ly/2QPcBGz
Redkite	<ul style="list-style-type: none"> Redkite provides essential support to children, young people and their family or friends from cancer diagnosis, treatment and after treatment aged 0-25 years. 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 people affected by cancer 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 December 2019