

Emotional Impact of a Lymphoma Diagnosis & Treatment



A diagnosis of lymphoma or chronic lymphocytic leukaemia (CLL) can be a very stressful and emotional experience. There is no right or wrong way to feel after you have been diagnosed, but it can be helpful to know that you are not alone.

HOW WILL I FEEL AFTER MY DIAGNOSIS?

A diagnosis of lymphoma or CLL is often devastating for both the patient and their families or carers. Many people experience a state of shock and disbelief after they are initially diagnosed. It can be normal to feel angry or upset with those around you, or even yourself. Many people describe initially feeling very angry with their doctors, specialists or nurses for not picking up on their illness earlier. As well as shock and anger, many people report high levels of anxiety, sadness and fear about how their diagnosis will impact their lives.

After an initial lymphoma or CLL diagnosis, you will likely come up with a series of important questions.

- What does my diagnosis mean?
- What will my treatment be?
- What is my prognosis?
- How will I support my family?
- Who will support me?

It is easy to become overwhelmed and anxious while thinking about these questions and what the answers may be. Many people use the internet to get more information and answers. While the internet is a wonderful source of information, it is easy to find articles and resources which are (A) not relevant to you, (B) not written by reliable sources or (C) not helpful to read during this period. You can ask your nurse and treatment team about which websites have relevant and appropriate information for you and your lymphoma subtype. The Lymphoma Australia website is a good place to start - www.lymphoma.org.au.

High levels of anxiety and stress are commonly reported just after receiving a diagnosis. You may find it helpful to know that during this time period, your stress levels may be at their absolute highest, especially as you may also be waiting for test results, treatment plans or more in-depth consultation appointments. Stress and anxiety can also be exacerbated by the physical symptoms that often accompany a diagnosis of lymphoma or CLL, including fatigue, low energy and insomnia.

Some practical tips for managing stress and anxiety during this time can be:

- Talking to your family, friends or loved ones about how you are feeling
- Writing down or journaling your thoughts and feelings
- Gentle exercise which has a focus on regulating breathing
- Healthy food choices and drinking plenty of water
- Limiting excessive alcohol consumption
- Meditation and mindfulness practice
- Talking with a counsellor or psychologist

It is important to note that there is no specific timeline that your emotional experience should follow. Some people may begin to process their diagnosis immediately, for others it can take much longer. With enough time, enough information and plenty of support you can begin to start planning and preparing for the next chapter of your life.

WHAT WILL STARTING TREATMENT FEEL LIKE?

If you have never had treatment for cancer before, walking into a treatment centre or hospital can feel foreign and uncomfortable. You are strongly encouraged to bring a support person with you on your first day, regardless of how well you feel. You are also encouraged to bring items that may distract and relax you. Some people enjoy bringing in magazines, books, knitting needles and wool, card games, iPads or headphones to listen to relaxing music. Televisions are often set up on treatment floors as well. If you feel that your anxiety is not relieved by these distractions and you are in a sustained high level of distress, it may be helpful for you to discuss this with your nurses or treatment doctor.

Some people find their experience of stress and anxiety begins to subside slightly once they begin treatment and understand their new routine. Knowing the names and faces of the hospital staff can also make the treatment experience less stressful.

It is important to note that not all people with lymphoma or CLL will need treatment right away. Many people with indolent (slow growing) lymphoma or CLL may often wait months or even years before requiring treatment. More information on this can be found in the Lymphoma Australia's "Understanding Watch and Wait" factsheet.

HOW CAN I MANAGE MY EMOTIONS DURING TREATMENT?

Commonly, people describe their emotional wellbeing during treatment as an undulating path where feelings of stress and anxiety may increase and decrease intermittently. Medications commonly prescribed with chemotherapy such as steroids can have significant impact on your mood, sleeping habits and emotional fragility. Many men and women on these medications report high levels of anger, anxiety, fear and sadness during treatment. Some people may find they are more tearful.

During treatment, it can be helpful to have or create a personal support network of people. 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"**: <http://bit.ly/33tuwro>

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: www.gathermycrew.org.au)

Other helpful tips for managing emotional distress during treatment are:

- Giving yourself permission to experience your emotions as they arise, including crying if you feel you need to
- Talking openly and honestly with others about your experience with people you trust
- Discussing your emotional concerns with your nurse, GP, treating team – remembering that they are just as important as your physical concerns
- Keeping a diary or journal during treatment documenting your emotions, thoughts and feelings each day
- Practising meditation and mindfulness
- Listening to your body and exercising 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')

Every person who receives a Lymphoma or CLL diagnosis has a unique physical and emotional experience. What may ease the stress and anxiety for one person 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 www.lymphoma.org.au for further information • 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)
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
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

Organisation	How can they help?
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 October 2019