

Emotional Impact After Completing Lymphoma Treatment



The end of treatment for lymphoma or chronic lymphocytic leukaemia (CLL) is generally perceived by many as the end point or “goal” of treatment, something that should be celebrated. Because of this great anticipation, there is often a sense of shock or disappointment when feelings of anxiety or stress are not alleviated when treatment ends.

Some people may even find that finishing treatment is when they are finally able to emotionally “process” their diagnosis, as things start to slow down. This may bring up new thoughts, worries or fears that lay dormant during treatment. Worrying about the cancer recurring is also very common following treatment completion. The Lymphoma Australia factsheet on **‘Fear of Recurrence and Scan Anxiety’** may be helpful to read if you are struggling with this. This can be found on the Lymphoma Australia website.

The following fact sheet will discuss some of the common thoughts and emotions experienced after treatment for lymphoma or CLL. Some practical coping strategies will also be offered.

WHAT IS THE RECOVERY PHASE?

The recovery phase post treatment is unique and often much more protracted than predicted. Many people find they are still experiencing residual physical side effects from treatment for many weeks, sometimes months after treatment ends. It can be reassuring to know that this is very common and is helpful to remember that the recovery process takes as long as it takes.

Some common feelings or experiences that may arise during this time include:

- Reduced tolerance to stress
- Significant changes to memory or concentration
- Lower levels of energy
- Reduced capacity to feel happiness
- Changes in sex drive or desire for intimacy
- Low self-esteem
- Emotional fragility or mood swings

For more information on late onset physical side effects after lymphoma treatment please see the Lymphoma Australia fact sheet **‘Late onset side effects of lymphoma treatment’** which

can be found on the Lymphoma Australia website.

It can be helpful, during this time to acknowledge the need for continued support and assurance from your network. Activities, habits and support services that helped you during treatment may need to continue for some time following treatment. For example, if you were seeing a counsellor or psychologist during treatment, it may be advised to continue seeing them for a few months post treatment, or as long as you need.

WHAT CAN I DO TO START FEELING MYSELF AGAIN?

It can also be helpful to engage in ‘self-care’ activities which can boost your self-esteem, restore your confidence and improve your overall well-being following treatment. Examples of self-care activities which can be helpful during the recovery period can include:

- Regular gentle exercise such as walking, yoga, pilates or swimming
- Making healthy food choices and including more fresh fruits and vegetables
- Listening to your body and understanding when it needs rest and when it needs activity
- Massage, acupuncture and reflexology
- Creating a sleep schedule and allowing time for rest and relaxation
- Meditation and mindfulness practice
- Keeping a journal of your thoughts, feelings and experiences after treatment

It is important to note that each person who completes treatment for lymphoma or CLL will have a different experience of recovery; mentally and physically. It can be helpful to connect with others who may be experiencing similar situations, but you should be cautious not to compare your experience to others. There is no right or wrong way to feel after treatment ends, there is also no normal timeline your recovery should follow.

HOW CAN I HELP THOSE AROUND ME UNDERSTAND HOW I AM FEELING?

Many people feel immense pressure from others around them to “move on” and “be normal again” immediately after treatment

FACT SHEET

is finished. This pressure typically arises from comments made by families, friends, work mates or even members of the treatment team. While generally these comments are said with good intentions, it is often not helpful for the person with lymphoma to hear, and may even bring up feelings of failure or inadequacy.

While physically, you may start to look yourself again after treatment finishes (eg. hair growing back, regained lost weight, less fatigue, healthy skin colour), it is often the case that on the inside, you are feeling far from normal. Many people suffer silently with emotional, spiritual, financial and psychological effects long after treatment ends.

It may be helpful to know that for many people, the emotional processing of a lymphoma diagnosis and treatment may not begin until after treatment ends, and this may take weeks, months or even years. While those around you may never truly understand what you are experiencing, explaining that you need time and support to heal after treatment can help during the recovery period.

Some conversation starters/ statements suggestions:

- My doctor has told me I am in remission, but I am still struggling with (fear, worry, anxiety or stress) and I would really appreciate your support with this.
- I may look physically well, but I don't feel well on the inside and I'm not sure how long it will take for me to feel better
- I hope you can understand that the time between my diagnosis and treatment starting was not long enough for me to process what has happened. I will need some time for this over the next few weeks or months.
- I know you want the best for me, but comments such as "but you're cured, you should be happy", and "why aren't you back to normal yet" are not helpful for me to hear right now.

WHAT IF MY TREATMENT DOESN'T HAVE AN END DATE?

For some people with Lymphoma or CLL, treatment does not have a set end date. Many people are advised to remain on treatment for years, sometimes for the rest of their life.

This can be hard for family and friends to comprehend and is often exhausting for the patient to explain repeatedly. For those with no treatment end date, having a firm understanding of your subtype and treatment plan can be helpful when explaining to others why your treatment is ongoing.

It may also be helpful to follow some of the practical tips for self care listed above. Connecting with others who are in similar situations can also be reassuring. Lymphoma Australia's private

Facebook group "Lymphoma Down Under" is a safe space for those affected to share thoughts and feelings.

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 treatment 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 nurses@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
The 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: http://bit.ly/2nfy5kc
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

FACT SHEET

Organisation	How can they help?
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
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: 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)
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)

Organisation	How can they help?
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