

Psychological Support for People Living with CLL

What is the psychological impact of a CLL diagnosis?

Defining cancer-related psychological distress

Typically, cancer-related psychological distress is characterised by feelings of **sadness, fearfulness and helplessness**. Although it is expected that every person diagnosed with cancer will experience some degree of distress, **if unmanaged it can add to the patient's burden of cancer and impact QoL**.¹



“A multi-determined, unpleasant, emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.”¹

Causes of cancer-related psychological distress

Cancer-related psychological distress is a **significant psychosocial issue** for at least 25% of people with CLL.^{2,3} There is **no one single cause** to which it can be attributed.¹

Cancer-related psychological distress can originate from a **multitude of causes** which are likely to **vary between individuals**.¹

Common causes include:¹

- Health-related factors, namely uncontrolled symptoms (either from the cancer, treatment, or both)
- Having limited access to healthcare
- The financial burden associated with healthcare costs
- Having a poor support network

Common reactions from people after a CLL diagnosis

A CLL diagnosis can be both confusing and overwhelming, as most people are either asymptomatic or may be concerned with other potential illness at that time.⁴

As the direct causes of CLL still remain an area of uncertainty, those receiving a CLL diagnosis are often unsure about its cause, which may result in them experiencing a state of shock and denial.⁵

A recent survey conducted by Leukaemia Care showed:

At the time of diagnosis, only **66%** of participants fully understood that CLL was a cancer and only **42%** understood the impact of their diagnosis.⁵

The distress associated with receiving a CLL diagnosis can negatively impact the everyday functioning of those affected by:



Interfering with their sleep cycles, which then hinders their ability to focus⁶



Influencing their ability to make decisions related to their health, often resulting in health deterioration and therefore increased visits to the emergency room¹



Having a more direct impact on their health by reducing length of life¹

How cancer-related psychological distress can be triggered⁷

There are certain instances which are more likely to trigger a state of distress. Distress is frequently piqued when:



Those undergoing testing⁷

either due to the anxiety associated with waiting for results, or from the diagnosis received from testing¹



Awaiting treatment⁷

due to their fear of developing complications and side effects following the onset of treatment¹

Your role as a HCP

- You can support people living with CLL by displaying compassion and an understanding of the adjustments needed
- In helping people to try and understand their emotions, it may be useful to ask questions to elicit what is specifically triggering their distress
- Actively listening to problems without trying to fix them and ensuring you are responding without judgement can help normalise feelings and emotions

Summary

- Psychological distress is a common response to a CLL diagnosis
- Although psychological distress can occur at any time, it is frequently triggered during testing or when awaiting diagnosis
- Experiencing psychological distress can have a major impact on the physical health and mental wellbeing of those living with CLL and their QoL

Useful resources

CLL Support is a patient-led UK charity that aims to empower people affected by CLL and other related conditions through education and access to reliable information. It supports people living with CLL as well as their carers by informing them of advancements in treatments and research.

The Leukemia & Lymphoma Society is the world's largest non-profit health organisation dedicated to funding blood cancer research.

Lymphoma Action is the UK's only charity dedicated to lymphoma, ensuring that no one faces lymphoma alone by providing a support network and information endorsed by medical experts.

Cancer Research UK provides high-quality information to help inform those living with cancer and their families, as well as access to support organisations.

Blood Cancer UK is a charity that aims to ensure that everyone affected with blood cancer has access to the right support at the right time.

Macmillan Cancer Support is the UK's leading cancer care charity and focuses on raising money to provide a range of support services and networks to those living with cancer.

CLL, chronic lymphocytic leukaemia; HCP, healthcare professional; QoL, quality of life
1. National Comprehensive Cancer Network®. Distress during cancer care. 2020. <https://www.nccn.org/patients/guidelines/content/PDF/distress-patient.pdf>. Accessed 13 July 2022; 2. Halilova KI, et al. J Clin Oncol 2016;34:201; 3. Shanafelt TD, et al. Leuk Res 2009;33:263–70; 4. Holland JC, et al. Psychosom Med 2002;64:206–21; 5. Pemberton-Whiteley Z, et al. Leuk Lymphoma 2019;3:690–1; 6. Agostinelli G, et al. Front Psychol 13:872329; 7. Albrecht TA, et al. J Hosp Palliat Nurs 2012;14:462–8