

Live well
with CLL

CLLSA

CLL Support Association



Have you recently been diagnosed with CLL
(chronic lymphocytic leukaemia)?

Are you looking for advice from someone
who knows all about CLL?

We are the CLL Support Association (CLLSA)
and we can help you

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Please call us on **0800 977 4396**
or go to our website – www.cllsupport.org.uk

We look forward to hearing from you

What is CLL?

CLL is a cancer of a particular type of white blood cell called a B lymphocyte.

It causes these lymphocytes to grow which puts pressure on the other key elements of your blood system.

CLL is a complex and individual condition and can take a while to get your head around when first diagnosed.

It often takes quite some time to understand how CLL may affect you. A good place to start is to have a look at our website. Take your time, be a discerning reader and move forward at your own pace.

The next important point to make is that this is a “chronic” condition so that’s why in most cases your doctor will advise that you should “watch and wait”. Not an easy thing to take on board but that’s what we can talk to you about.

What treatments are there?

Up to the mid-1990s we only had one proven effective treatment for CLL – the chemotherapy agent Chlorambucil which had been used since the late 1950s.

But the good news is that in recent years over 12 licensed drugs have been developed including several containing no chemotherapy agents at all. These have significantly improved the effectiveness of treatment and have extended options and quality of life for CLL patients. So there continues to be real progress.





How can we help YOU?

We are a patient-led UK charity run by unpaid volunteers who are all CLL patients or carers. So we do know what you are dealing with.

This is what we set out to do for all CLL patients

- We provide up-to-date and accessible information about CLL and the range of treatments currently available plus the latest research into the care and treatment of CLL
- We do this through our website, newsletters and telephone help line.
- We bring you together with other CLL patients to give you **opportunities to share understanding and personal experience** by arranging member conferences across the UK.
- We also act as a voice for CLL patients, representing their interests with the pharmaceutical industry, clinicians, NHS, cancer care policy and drugs regulation authorities, funding and commissioning groups, and politicians.
- Finally, we seek to **promote awareness of CLL, and the role of the CLLSA, amongst health care providers and decision makers**, providers of non-healthcare products and services, **other blood cancer patient groups and the wider public**. So please join CCLSA for free, help us help each other and support our fight against CLL.



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Facts and figures

- Around 3,000 patients are diagnosed every year in the UK
- 75% of people who are diagnosed with CLL are over 50
- The median age for treatment is 72
- There are approximately 30,000 patients with CLL in the UK
- CLL is the most common form of blood cancer amongst UK adults

CLLSA

- We rely on donations from members and some funding from pharmaceutical companies to allow us to develop our support work
- We provide member conferences around the UK where around 100 members attend each meeting
- We issue regular newsletters and keep our website up to date
- We offer a personalised telephone helpline
- We have excellent links with all CLL clinicians in the UK and each conference is addressed by a leading clinician on latest developments with treatments
- We work hard to ensure that the CLL patient voice continues to be heard

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CLLSA is a registered charity number 1113588