Newly diagnosed with chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)

A guide for patients

Leukaemia Care
YOUR Blood Cancer Charity

Lymphoma action

Acknowledgements

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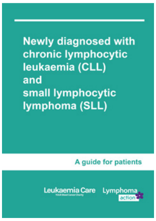
Leukaemia Care and Lymphoma Action have worked together to produce this book. Both versions contain the same information. All illustrations are copyright of Lymphoma Action.



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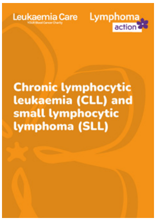
Leukaemia Care Lymphoma action



Leukaemia Care Lymphoma action

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)

We hope you find this page useful to help you keep track of your care, who is looking after you and how to contact them if you need to.

My diagnosis (type, stage, date):

....

My treatment or monitoring plan:

....

....

....

Key contact

Name: ....

Role: ....

Contact number: ....

Contact	Name and number
GP	
Consultant	
Nurse	
Hospital	

About this book

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are slow-growing types of blood cancer.

They are two forms of the same illness.

- In CLL, the cancer cells mainly build up in the blood and bone marrow.
- In SLL, the cancer cells mainly build up in lymph nodes.

Being diagnosed with CLL/SLL can be a shock, particularly if you have never heard of it before. Leukaemia Care and Lymphoma Action have worked together on this book to help you understand what CLL/SLL is, how it is diagnosed and monitored, and the available treatments.

There is a lot to take in. Some people find it helpful to dip in and out of this book, rather than reading it all at once.

If you would like a list of the references we used to compile this book, please contact us (pages 76 and 77).

We welcome feedback to help us improve our information and make sure it meets your needs. Get in touch with us by email, phone or post (see back cover), or use the following links and QR codes to complete our surveys.

Leukaemia Care
short survey

Lymphoma Action
short survey

If you would like a copy of this book in large print, please contact us (pages 76 and 77).

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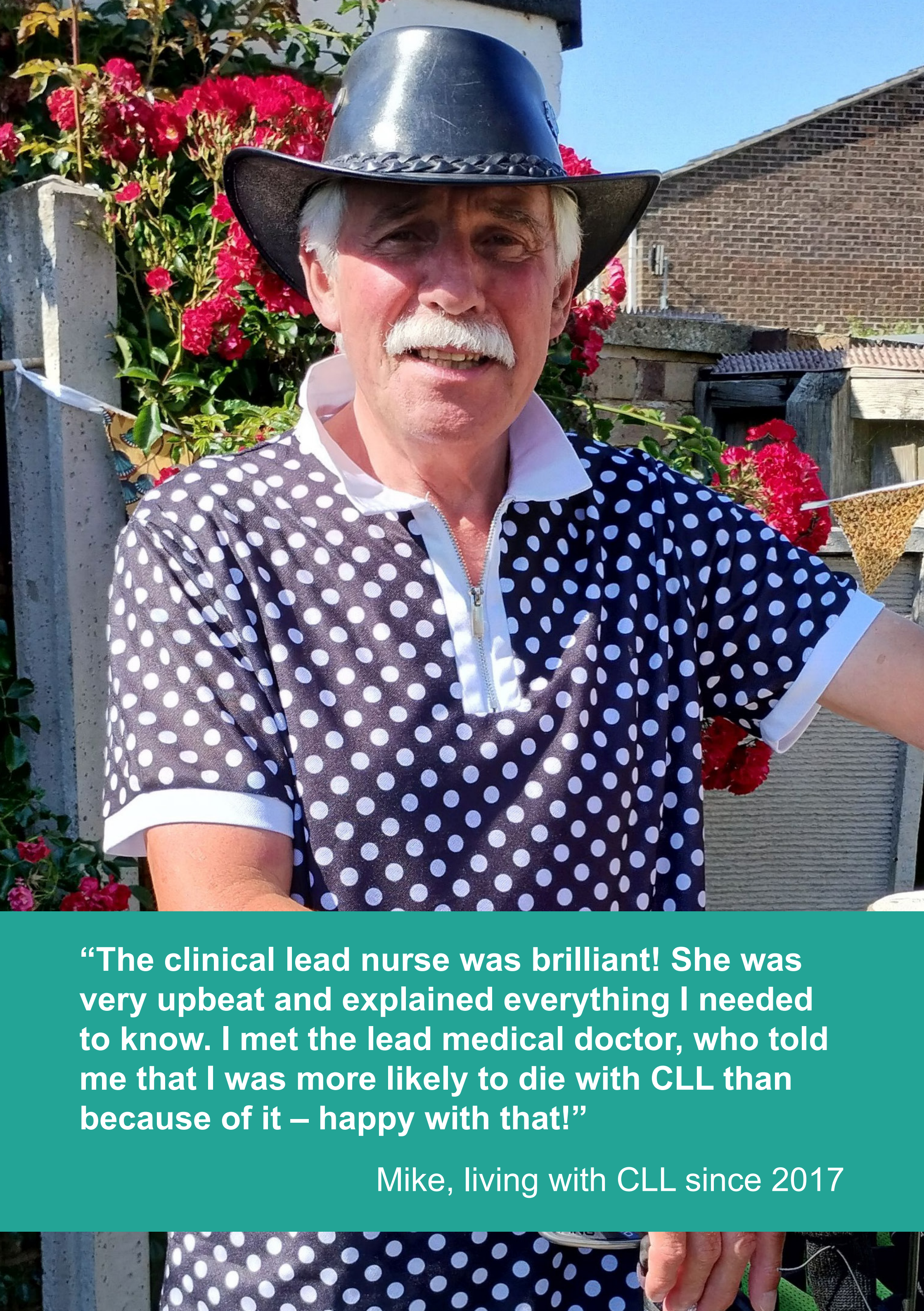


"The clinical lead nurse was brilliant! She was very upbeat and explained everything I needed to know. I met the lead medical doctor, who told me that I was more likely to die with CLL than because of it – happy with that!"

Mike, living with CLL since 2017

What is CLL/SLL?

What is CLL/SLL?

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are two different forms of the same illness.

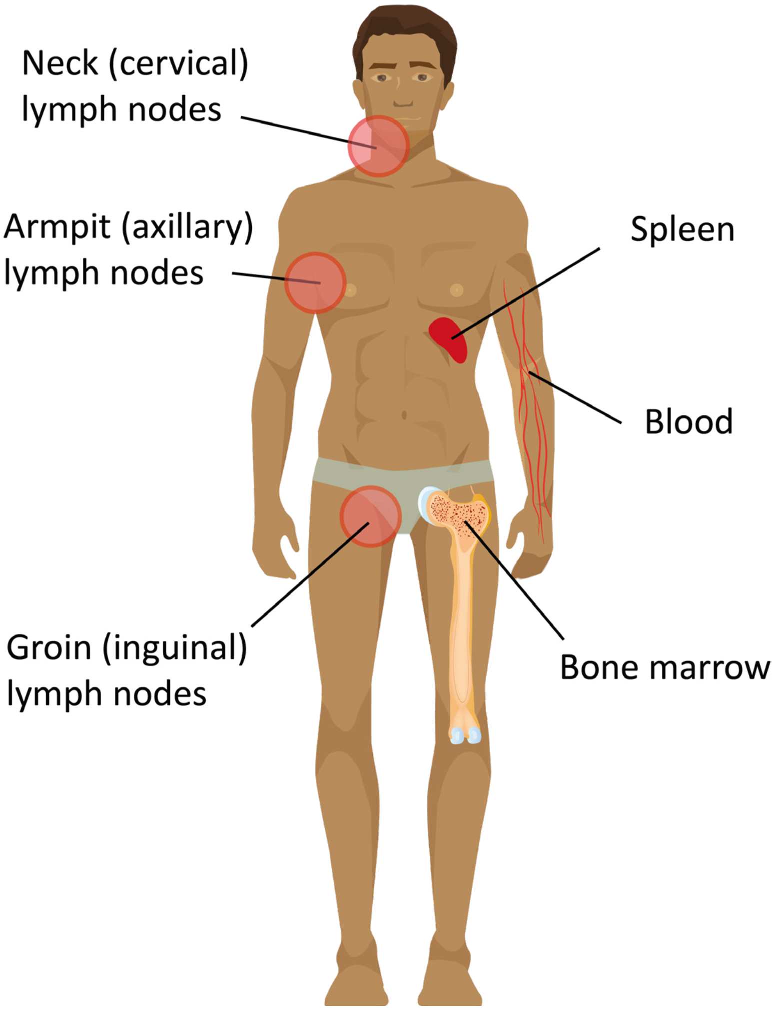
In this book, we use the term ‘CLL/SLL’ to refer to both conditions, except where there are important differences.

CLL and SLL are slow-growing types of blood cancer. They develop when white blood cells called lymphocytes stop working properly and grow out of control.

These abnormal lymphocytes build up in different parts of your body.

- If you have CLL, the abnormal lymphocytes mainly build up in your blood and bone marrow.
- If you have SLL, the abnormal lymphocytes mainly build up in your lymph nodes and other parts of your lymphatic system.

In this book we refer to these abnormal lymphocytes as CLL/SLL cells.



Parts of the body where CLL and SLL cells often build up

What are lymphocytes and what do they do?

Lymphocytes are a type of white blood cell. They help your body fight infections by recognising and killing germs. They also remember infections you've had before so you can fight them off quickly if you get them again.

Lymphocytes are made in your bone marrow. They travel around your body in your blood and lymphatic system.

There are two main types of lymphocyte:

- B lymphocytes (B cells) make antibodies. Antibodies stick to germs or infected cells. This can either kill them or tell other parts of your immune system to come and kill them.
- T lymphocytes (T cells) kill germs or cells infected by germs. They can also kill cells that have become abnormal, such as cancer cells.

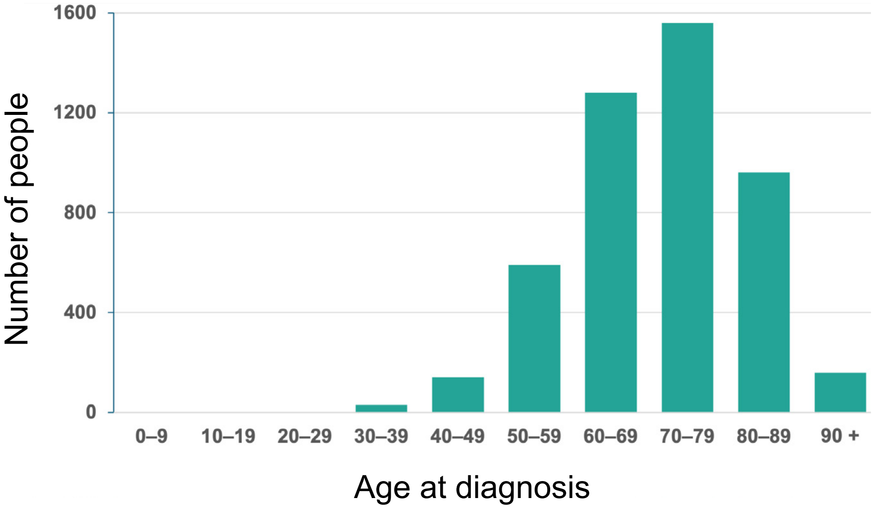
There are B cell and T cell blood cancers. CLL and SLL both develop from B cells.

Who gets CLL/SLL?

Around 4,500 people are diagnosed with CLL/SLL every year in the UK making it one of the most common blood cancers in adults.

You're not alone – more than 12 people are diagnosed with CLL/SLL every day in the UK.

CLL/SLL is more common in people over 60, with an average age at diagnosis of 72 years. It is rare in young people.



Number of people diagnosed in the UK each year by age

Source: Haematological Malignancy Research Network

CLL/SLL affects nearly twice as many men as women. It is also more common in white people than in people from Asian, African or Hispanic backgrounds.

> **“My GP surgery said they needed to see me for a consultation. I will never forget hearing the words, ‘Karl we have a high suspicion that you have chronic lymphocytic leukaemia.’ A week later I met with the consultant who officially confirmed my CLL diagnosis.”**
>
> Karl, living with CLL since 2023

What causes CLL/SLL?

If you have CLL/SLL, it’s not because of anything you did or did not do. You can’t catch CLL/SLL or give it to somebody else.

CLL/SLL develops when the genetic code (DNA) inside B cells changes. This stops them from responding to signals that usually keep them under control. They divide when they shouldn’t, or don’t die when they should. These abnormal B cells don’t work properly and they can build up in your body.

One DNA change on its own is not enough to cause CLL/SLL. It usually takes many different changes before a cancer starts to grow. Most of the time, these DNA changes happen by chance.

In most cases, there is no known cause of CLL/SLL.

In some cases, there are factors that might make you more likely to develop the DNA changes that could result in CLL/SLL. These are called ‘risk factors’. They include:

- **Age.** The risk of developing CLL/SLL increases as you get older. This is because genetic changes in your cells tend to build up throughout your life.
- **Sex.** Men are more likely to develop CLL/SLL than women.
- **Family history.** CLL/SLL is not passed on from parent to child. However, if you have a close relative (parent, brother, sister or child) with CLL/SLL you have a higher chance of developing it too. The risk is still very low. Most people who have a close family member with CLL/SLL do **not** develop CLL/SLL.
- **Monoclonal B-cell lymphocytosis.** Some people have a low level of abnormal B cells in their blood with no other signs of CLL/SLL. This is called monoclonal B-cell lymphocytosis (MBL). It is fairly common in people over 60. There are no symptoms for MBL so most people with this condition never know they have it. However, each year around 2 out of every 100 people with MBL go on to develop CLL/SLL.
- **Chemicals.** Working in a job where you’re exposed to high levels of industrial chemicals might slightly increase your risk of developing CLL/SLL. However, there is no strong evidence for this. Most people who work in these occupations do **not** develop CLL/SLL.

What is the outlook for people with CLL/SLL?

CLL/SLL usually grows very slowly. This means you might not need treatment straight away and you'll be offered active monitoring (page 42). You might also hear this referred to as 'watch and wait'. Around 1 in 3 people never need treatment, while 2 in 3 people do.

Treatment generally aims to keep CLL/SLL under control so you can have a good quality of life. There are lots of effective treatment options for this. Current treatments cannot cure CLL/SLL.

Most people live with CLL/SLL for many years, with some periods when they need treatment, and other periods when they do not. It is hard to predict how long it might be before you start treatment.

Some people have particular genetic changes in their CLL/SLL cells that mean it grows faster and is likely to need more frequent treatment.

Your consultant is best placed to advise you on your outlook based on your individual circumstances and test results.

> **"Most people go a long time without needing treatment. Even those high-risk patients. CLL does not move quickly in most people."**
>
> Dr Scott Marshall, Haematology Consultant

Rarely, CLL/SLL transforms (changes) into a faster-growing type of lymphoma. This is known as ‘Richter transformation’. It happens to about 1 in every 100 people with CLL/SLL each year.

Most of these cases transform to a type of diffuse large B-cell lymphoma (DLBCL) but they can occasionally transform to other non-Hodgkin lymphomas or Hodgkin lymphoma. Transformed CLL/SLL is more difficult to treat.

We have more information on this. Visit lymphoma-action.org.uk/Types-lymphoma or search ‘CLL’ at leukaemiacare.org.uk

What is CLL/SLL?

Summary

- CLL and SLL are slow-growing blood cancers, which develop when white blood cells called B cells grow abnormally.
- Abnormal B cells build up in the blood and bone marrow in CLL, and the lymph nodes and lymphatic system in SLL.
- CLL/SLL is one of the most common blood cancers in the UK, particularly in people over 60.
- You can't catch CLL/SLL – in most cases there is no known cause.
- If your CLL/SLL is not causing problems, you might not be offered treatment straight away. Instead, you'll be monitored until you need treatment.
- Most people live with CLL/SLL for many years, and some people never need treatment.

Medical terms used in this chapter

B cell or B lymphocyte
The type of white blood cell that becomes abnormal if you have CLL/SLL.

Bone marrow
The spongy centre of your bones where blood cells are made.

DNA
The genetic code that tells your cells how to grow and behave.

Lymphatic system
The network of tubes, tissues and organs running throughout your body, which helps protect you from infection.

Lymph nodes
The small bean-shaped glands in your neck, groin and many other parts of your body, which are part of your immune system.

> “I’d been feeling tired and washed out, occasionally a bit light-headed and dizzy. I’d go to work, but by mid-afternoon, I would feel as if someone had pulled out my power cord.”

Paul, living with CLL since 2016

Signs and symptoms of CLL/SLL

How common are symptoms of CLL/SLL?

Most people have no symptoms when they are diagnosed with CLL/SLL.

It’s usually found by chance when doctors notice high levels of lymphocytes on a blood test done for another reason.

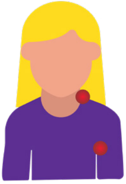
More than 3 in 4 people have no symptoms when they are diagnosed

As abnormal B cells build up, you might develop symptoms, although some people never do. Any symptoms tend to be mild at first and gradually get worse over months or years.

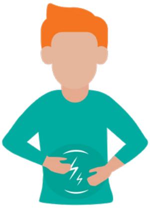
> **“I didn’t have any of the common signs and symptoms of leukaemia. I went to my GP for a routine blood test, where they picked up that something wasn’t quite right. I saw a local consultant within a couple of weeks.”**
>
> Eileen, living with CLL since 2015

Signs and symptoms of CLL/SLL

Symptoms of CLL/SLL vary a lot from person to person and depend on where in your body the abnormal cells build up. You might feel generally unwell or notice some of the following symptoms.



Swollen glands. They can swell up anywhere in your body but most often in your neck, armpit or groin.



Abdominal (tummy) swelling. If the cells build up in your spleen or liver, they might become enlarged. You might feel full quickly or lose your appetite. You might feel bloated or feel pain at the top-left of your tummy.

Fatigue. You might feel exhausted for no obvious reason.

Frequent infections. You might develop infections more often than usual or have difficulty getting rid of them.

Fever. You might have a high temperature (above 38°C or 100.4°F) that comes and goes.

Night sweats. You might sweat so much in the night that your nightclothes and bedding become soaked.

Weight loss. You might lose weight over a short amount of time without trying to.

Low blood counts. If abnormal B cells build up in your bone marrow they can take up space needed for healthy blood cells to grow.

> **“Our symptoms vary greatly, so what my problems are you may never see, or their effect may not be the same for you. On top of CLL, I have several other medical problems which complicated my case.”**
>
> Mick, living with CLL since 2007

What are low blood counts?

Although you might have a high number of lymphocytes, other types of blood cell might be low.

- A low red blood cell count (anaemia) can make you feel tired, breathless or dizzy.
- A low platelet count (thrombocytopenia) can make you bruise or bleed more easily than usual.
- A low count of a type of white blood cell called neutrophils (neutropenia) can make you more likely to pick up infections and make it harder to recover from them.

About 1 in 10 people with CLL/SLL develop low blood counts caused by an autoimmune reaction. This happens when their immune system attacks and destroys healthy blood cells by mistake. This can cause:

- Low red blood cells (autoimmune haemolytic anaemia or AIHA)
- Low platelets (immune thrombocytopenic purpura or ITP)

For more information about AIHA and ITP, search 'CLL' at leukaemiacare.org.uk

Signs and symptoms of CLL/SLL

Summary

- Most people don’t have any symptoms when first diagnosed with CLL/SLL.
- CLL/SLL symptoms vary from person to person. Some people never get any symptoms.
- You may get mild symptoms that worsen over time as abnormal B cells build up in your body.
- Common symptoms include swollen glands, a change in appetite, night sweats, weight loss, fatigue, frequent infections and low blood cell counts.

Medical terms used in this chapter

Bone marrow
The spongy centre of your bones where blood cells are made.

Lymphatic system
The network of tubes, tissues and organs running throughout your body, which helps protect you from infection.

Lymphocyte
A type of white blood cell that helps fight infections.

Neutrophils
White blood cells that help you fight inflammation and infection.

Spleen
The fist-sized organ under the left side of your rib cage that filters blood and helps fight infection.

> “When I first got diagnosed it was a bit of a shock, but as time goes on you start to realise that life can go on for many years.”

Doreen, living with SLL since 2007

Tests, diagnosis and staging

Diagnosis of CLL/SLL

You might be diagnosed with CLL/SLL by chance when you are having tests for something else. Or, if your GP suspects you have CLL/SLL based on your symptoms, they will arrange for you to have further tests.

A range of tests can be used to confirm the diagnosis, understand the stage of your CLL/SLL and help decide the best treatment for you, if you need it. Many people don't need treatment straight away.

CLL and SLL can be hard to tell apart, and your diagnosis may change depending on your symptoms and test results. Luckily, monitoring and treatment are the same for CLL and SLL, so don't worry if this happens to you.

You usually have your tests done at the hospital, as an outpatient, and go home the same day. Then your medical team will gather all the information needed to decide how best to look after you. This can take a few weeks.

It can be a worrying time while you're waiting. Your medical team should tell you how soon you'll hear and how you'll be told about your results.

You usually have a face-to-face appointment to discuss your diagnosis with a specialist doctor. You may want to take someone with you to this appointment, as there can be a lot to take in.

Many people feel anxious whilst waiting for test results. If you would like to talk to someone, our Helpline services can offer support.

Leukaemia Care freephone helpline: 08088 010 444
Lymphoma Action freephone helpline: 0808 808 5555

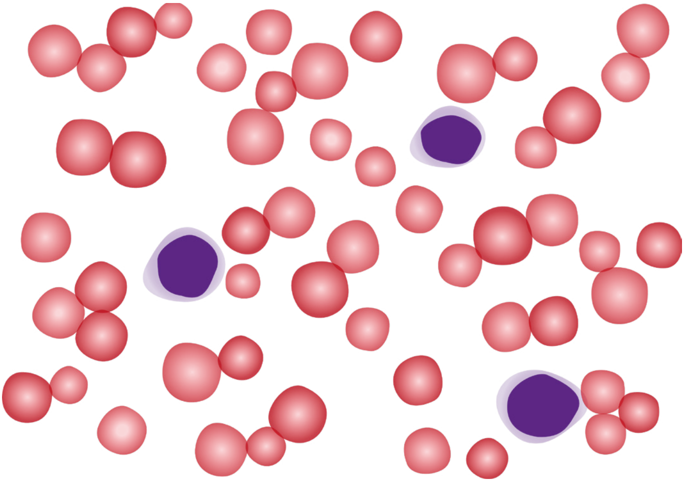
For tips on how to cope whilst waiting for test results visit lymphoma-action.org.uk/Waiting

Blood tests

CLL can be diagnosed from a blood test where a specialist examines a sample of your blood under a microscope. SLL cannot be diagnosed using a blood test alone so you'll need to have other tests. This usually includes a lymph node biopsy.

You also have blood tests to look at your general health. These measure your antibody levels and check whether your kidneys and liver are working well. If you are starting treatment, you might have blood tests to check for viral infections that could flare up during treatment.

For most blood tests, you don't need to do anything to prepare. Check with your clinical team if you are unsure. A doctor, nurse or phlebotomist (someone trained to take blood) takes the sample. The whole process only takes a few minutes.



How CLL/SLL cells (purple) and red blood cells look under a microscope

Visit labtestsonline.org.uk for more information on any blood tests you are having.

Biopsies

A biopsy is a minor procedure to take a sample of cells from your body. It is usually done under local anaesthetic. Most people have it done in hospital as an outpatient and go home the same day.

The type of biopsy you have depends on which cells need to be tested.

Lymph node biopsy

You are likely to have a lymph node biopsy if your doctor thinks you might have SLL.

A lymph node biopsy involves taking a sample of cells from a swollen lymph node, or sometimes removing the whole lymph node, for testing. Your doctor will diagnose SLL if your lymph node biopsy shows a large number of abnormal B cells that all look the same.

Bone marrow biopsy

You might have a bone marrow biopsy if you have low blood counts. This will check if you have CLL/SLL cells in your bone marrow. You might also have one after you finish treatment to assess how well you have responded.

A bone marrow biopsy involves removing a sample of liquid or spongy tissue from the centre of a bone, usually your hip bone. This is usually done under a local anaesthetic using a syringe or a special hollow needle.

Visit lymphoma-action.org.uk/Bone-marrow-biopsy or search 'bone marrow biopsy' at leukaemiacare.org.uk for more information.

Specialist tests

Your blood or biopsy samples go to the lab for specialist tests. These look for particular proteins or genetic changes in the CLL/SLL cells that can affect how they respond to treatment. The most important variations include:

- **del17p and TP53** – changes to genes that usually stop tumours from growing
- **IGHV** – variations in genes called immunoglobulin genes

Your medical team will use the results of these genetic tests to work out the best treatment options for you.

For more detailed information about the tests and scans you might have, visit lymphoma-action.org.uk/Tests

Scans

CT (computed tomography) scans can help your medical team find out which parts of your body are affected by CLL/SLL. They are used to check how big your lymph nodes, liver and spleen are. You might have repeat scans as part of active monitoring (watch and wait), or at the end of treatment to check how well it has worked.

“After my diagnosis, it was a case of watch and wait. I had a full head-to-toe examination from my GP, and CT scans and endoscopies to check my spleen and my lymph nodes. Then I had a series of fortnightly blood tests to monitor my white blood cell count. After that, the plan was to monitor me every six months, which was good news.”

Karl, living with CLL since 2023

Staging

Your medical team uses the results of your tests and scans to work out how widespread your CLL/SLL is and how it is affecting you. This is called staging.

Staging is important because it helps your medical team plan the best treatment for you and when to start it.

Staging of CLL

Staging of CLL is based on your blood counts and whether your lymph nodes, spleen or liver are swollen:

Stage A	You have fewer than three areas of ‘lymphoid swelling’ (swollen liver or spleen, or swollen lymph nodes in your neck, armpits or groin)
Stage B	You have three or more areas of lymphoid swelling
Stage C	You have a low red blood cell count (anaemia), a low platelet count (thrombocytopenia) or both, with any number of lymphoid swellings

Staging of SLL

Staging of SLL is based on where the SLL is in relation to your diaphragm (the sheet of muscle separating your chest from your tummy):

Stage 1	You have only one group of lymph nodes affected anywhere in the body
Stage 2	You have two or more groups of lymph nodes affected, all on the same side of the diaphragm (either above or below)
Stage 3	You have lymph nodes affected on both sides of the diaphragm
Stage 4	You have SLL either in organs outside the lymphatic system or in the bone marrow

The stages are sometimes written as Roman numerals: I, II, III and IV.

For more detailed information about the staging system for SLL visit lymphoma-action.org.uk/Staging

Tests, diagnosis and staging

Summary

- If you have CLL, your diagnosis will be from a blood test. It’s often found by chance when you have a blood test for something else.

- If you have SLL, your diagnosis will be from a biopsy, usually from a lymph node.

- You might have further tests on your blood or biopsy samples to find out more about your CLL/SLL.

- You might have other tests or scans to see how widespread your CLL/SLL is and how it’s affecting you.

- Your doctor will use your test and scan results along with your symptoms, to decide if you need to start treatment and which would be best for you.

Medical terms used in this chapter

Antibody
An immune system protein that can help fight infections by sticking to proteins on the surface of cells that don’t belong in your body.

CT (computed tomography)
A detailed scan that uses X-rays to take cross-sectional images of your body.

Endoscopy
A test to look inside your body using a long, thin tube with a camera inside.

Gene
A section of DNA that tells cells how to make a protein.

Immunoglobulin
Another name for an antibody.

Lymphatic system
The network of tubes, tissues and organs running throughout your body, which helps protect you from infection.

“I had a gradual return to work after treatment and carried on playing league table tennis through most of my treatment.”

Michael, living with CLL/SLL since 2015

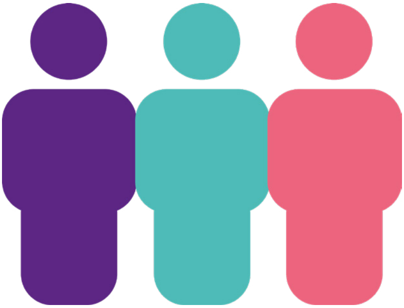
Treatment

Planning treatment

CLL and SLL are treatable. Treatment usually aims to keep CLL/SLL under control rather than curing it.

CLL/SLL is slow-growing and there is rarely an urgent need for treatment. Some people might never need treatment, or not for many years.

Your medical team will consider carefully whether you need treatment straight away and what treatment is best for you. You may have times when you are having treatment and other times when you are not.



Around 1 in 3 people need treatment soon after their diagnosis.
Around 1 in 3 people need treatment at some point in the future.
Around 1 in 3 people never need treatment.

A multidisciplinary team (MDT) made up of different professionals plans your treatment. They each have knowledge and expertise in a different specialist area.

The team meets to discuss and plan your treatment to help offer you the best care. They will take into account your individual needs, general health and preferences. Your family or carers can also be involved to help you make an informed decision.

Your medical team

The multidisciplinary team looking after you will often include:

- A clinical nurse specialist (CNS)
- A consultant oncologist or consultant haematologist
- A pathologist
- A pharmacist
- A radiologist

For more on these roles, visit lymphoma-action.org.uk/MedicalTeam

The person with overall responsibility for your care is likely to be a consultant haematologist or a consultant oncologist.

You should have a key worker you can contact with any questions or concerns you might have. This could be about your CLL/SLL or treatment, including how it affects your day-to-day life. Usually, your key worker is your clinical nurse specialist (CNS).

Leukaemia Care and Lymphoma Action can offer you support and information. Pages 76 and 77 list some of the services we offer.

Active monitoring

If your CLL/SLL is not causing you problems, you do not need treatment straight away. Instead, your medical team monitors you regularly. This is called active monitoring or ‘watch and wait’.

It can be difficult to hear that you have cancer but are not starting treatment. However, research shows there is no benefit to starting treatment before you need it. While you are well, you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it.

If you are worried about your health at any time, contact your medical team or GP. You don't have to wait for your next appointment.

> **"Treating well patients with early-stage CLL/SLL can actually do more harm than good. It's best practice to save targeted therapies for when they're needed. When CLL/SLL becomes more active and starts to make you less well, treatment usually makes you feel much better quite quickly and improves overall survival rates."**
>
> Dr George Follows, Consultant Haematologist

Order a separate book about active monitoring (watch and wait) for free at lymphoma-action.org.uk/Books or shop.leukaemiacare.org.uk

You are likely to start treatment if:

- Your symptoms get worse or become difficult to cope with.
- Your lymph nodes, spleen or liver become swollen enough to cause symptoms.
- You develop low blood counts that suggest your CLL/SLL is progressing.
- The number of CLL/SLL cells in your blood rises very quickly. In CLL, your lymphocyte doubling time is a measure of this.

"In May 2023, my white blood cells shot up, so my consultant decided to monitor my blood more closely with more frequent tests. Throughout the year, my white blood cell count continued to rise, reaching a peak in December. My doctor decided my treatment plan needed to change and in January 2024 I started targeted therapy."

Karl, living with CLL since 2023

Treatment options

If you need to start treatment, your medical team will recommend the most suitable option for you. This will depend on:

- Your preferences
- The stage of your CLL/SLL
- How it is affecting you
- The particular genetic changes in your CLL/SLL cells
- The potential side effects or late effects (health problems that develop months or years after treatment) of the treatment
- Your age and general health, including any other conditions you have and medicines you are taking

Depending on your individual circumstances, you might need several different types of treatment during your illness.

Treatment aims to reduce your symptoms and keep the CLL/SLL under control for as long as possible with as few side effects as possible. Most people have long periods of feeling well between courses of treatment.

Targeted medicines

Most people with CLL/SLL are treated with targeted medicines.

Targeted medicines are specially designed to attack CLL/SLL cells. They target particular proteins that are overactive in CLL/SLL cells compared with healthy cells. These proteins are often important in helping the cancer cells grow and survive. Blocking them with targeted medicines helps kill the CLL/SLL cells specifically, with fewer effects on your healthy cells.

Targeted medicines used to treat CLL/SLL include:

- Ibrutinib
- Acalabrutinib
- Zanubrutinib
- Venetoclax

These targeted medicines are usually tablets or capsules that you take by mouth.

> **“After initial treatment, I had several years of active monitoring before the CLL and symptoms came back. I started continuous therapy with ibrutinib in 2020. Four years on, I live well and continue taking my treatment tablets every day. My symptoms and CLL remain under control.”**
>
> Nick, living with CLL since 2010

Targeted medicines can be used in two ways:

- **Fixed duration therapy** is when you take medicine for a set period of time, often 1 to 2 years. In this case, you usually have a targeted medicine alongside another targeted medicine or antibody therapy. When you finish fixed duration therapy, you usually go back to active monitoring (watch and wait).
- **Continuous therapy** is when you keep taking the medicine unless you get troublesome side effects or your CLL/SLL stops responding. In this case, you usually take one targeted medicine on its own. If you need to stop continuous therapy, your consultant will discuss your options with you, which might include trying a different treatment.

Visit lymphoma-action.org.uk/Targetedtreatments or search ‘CLL’ at leukaemiacare.org.uk for more information.

Antibody therapies

Antibody therapies are antibodies made in the lab. They are designed to recognise and stick to specific proteins on the surface of CLL/SLL cells. This triggers the body's immune system to destroy the CLL/SLL cells.

Antibody therapies used to treat CLL/SLL include:

- Rituximab
- Obinutuzumab

You usually have antibody therapy in the hospital as an outpatient. You'll have it through a drip into a vein. You often have it alongside another targeted therapy, such as venetoclax, taken as a tablet.

"After 13 years of watch and wait, I'm nearing the end of one year's treatment with obinutuzumab and venetoclax. Generally, I've been delighted my watch and wait period lasted as long as it did. Most of the time I felt reasonably well and had a full and fulfilling life. The only times anxiety kicked in were the days leading up to my consultant appointments."

Ann, living with CLL since 2008

Other treatment options

You may be offered treatments other than targeted therapies depending on your symptoms, stage of CLL and medical history.

Radiotherapy

Radiotherapy uses high-energy rays, usually X-rays, to destroy cancer cells. Radiotherapy is rarely used for CLL but is sometimes used to treat SLL that is only affecting one part of your body.

High dose chemotherapy and stem cell transplant

High dose chemotherapy can be used to kill as many CLL/SLL cells as possible. However, this also destroys your stem cells – the cells in your bone marrow that make new blood cells. You'll be given a stem cell transplant to replace these cells with healthy stem cells, usually from a matched donor.

A stem cell transplant is an intensive form of treatment. Stem cell transplants are rarely used to treat CLL/SLL because there are now very effective targeted treatments. You might be offered one if you have a very aggressive form of CLL/SLL, and you are fit enough to cope with the treatment.

Visit lymphoma-action.org.uk/Treatments or search 'CLL' at leukaemiacare.org.uk for more information.

Clinical trials

Your medical team may ask if you’d like to take part in a clinical trial. These are research studies to find out what treatments work best for people with CLL/SLL before they are offered more widely. They might test:

- New medicines
- New ways to use existing medicines, such as different combinations or doses

If your medical team suggests a clinical trial, they should explain the risks and benefits of taking part. It is completely up to you whether you’d like to do it and you can withdraw from a trial at any time.

For more information visit
lymphoma-action.org.uk/About-clinical-trials

Side effects

Treatment aims to destroy the CLL/SLL cells in your body but it can also damage healthy cells. This leads to side effects.

Most people get side effects as part of their treatment, but they can often be controlled and are usually temporary.

Different treatments have different side effects. They can also vary from person to person. People might experience different side effects even if they are having the same treatment.

Most side effects go away soon after you finish treatment. Others get better gradually over time. Some side effects might last longer.

Tips for coping with side effects

- Ask your medical team what side effects to expect and how to manage them.
- Make sure you know who to contact if you have any concerns.
- Tell your medical team if you have any side effects, even if they seem minor. There are often effective treatments available.

Supportive treatments

As well as treatments to control your CLL/SLL, you might have treatments to help relieve your symptoms or prevent or treat infections. These might include:

- Antibiotics, antifungal and antiviral drugs to prevent or treat infections
- Vaccinations against flu, pneumonia, respiratory syncytial virus (RSV), shingles, and COVID
- Growth factor (G-CSF) injections to boost your white blood cell count
- Immunoglobulin replacement therapy to strengthen your immune system if your level of natural antibodies is low and you have problems with repeated infections
- Red blood cell transfusions or platelet transfusions to treat low blood cell counts
- Steroids, antibody therapy or treatments to dampen your immune system, if your low blood counts are caused by CLL/SLL antibodies attacking your blood cells

Follow-up

If your treatment is for a fixed duration, you are likely to go back onto active monitoring (watch and wait) if your CLL/SLL is under control.

If you are taking a continuous targeted treatment, you might stay on it for a number of years. You have regular clinic appointments and blood tests to make sure your CLL/SLL is under control. You might be asked to monitor your own blood pressure.

As part of your follow-up, your medical team will check your general health and look for signs of your CLL/SLL becoming more active again. This usually happens quite slowly. They will check for changes in your blood test results, and check you for new symptoms or new swollen lymph nodes.

If you are worried about your health at any time, contact your medical team or GP. You don't have to wait for your next appointment.

Relapsed or refractory CLL/SLL

Treatment for CLL/SLL is often effective. However, it is common for CLL/SLL to come back (relapsed CLL/SLL) and need more treatment. Occasionally, CLL/SLL doesn’t respond well to the first treatment you’re offered (refractory CLL/SLL). Some people with CLL/SLL need several courses of different types of treatment during their illness.

After successful treatment, how long your CLL/SLL stays under control (remission) can vary a lot. It can be difficult to predict how long it might be before you need more treatment.

Some people stay in remission for several years but others need more treatment sooner. As new and more effective treatments for CLL/SLL become available, remissions are generally getting longer.

It can be hard living with uncertainty. We are here to help.

- **Leukaemia Care freephone helpline: 08088 010 444**
- **Lymphoma Action freephone helpline: 0808 808 5555**

When you need more treatment, your doctor considers the same factors as for your first treatment. But they also take into account:

- Your preferences for treatment
- What treatment you had before
- How well you responded to your previous treatment
- How your previous treatment affected you

“My treatment of rituximab and venetoclax was complicated to begin with and it felt like I could never get away from hospital, but it got easier. I learnt that it is okay to admit when you need help and it’s empowering to be able to do that.”

Bethan, living with CLL since 2015

Treatment

Summary

- Treatments aim to control rather than cure CLL/SLL.
- If you have no symptoms or mild symptoms, you may not need treatment straight away. Instead, you'll be offered active monitoring, sometimes called 'watch and wait'.
- If you develop worsening symptoms, have low blood counts, or have problems with enlarged lymph nodes or an enlarged spleen, you'll be offered treatment.
- There are many effective treatments available when you need them.
- Most people are offered targeted medicines to take by mouth at home as a first treatment. Sometimes this is alongside an antibody treatment you have through a drip as a hospital outpatient.
- Your medical team will suggest the most suitable treatment for you based on your individual case.

Medical terms used in this chapter

Antibody
An immune system protein that helps fight infections by sticking to targets on the surface of cells that don’t belong in your body.

Haematologist
A doctor who specialises in diseases of the blood.

Lymphocyte doubling time
The time it takes for the number of lymphocytes in your blood to double.

Oncologist
A doctor who specialises in cancer.

Refractory CLL/SLL
When your CLL/SLL does not respond well to your first treatment.

Relapsed CLL/SLL
When your CLL/SLL comes back after successful treatment.

Remission
When tests or scans after treatment can find little or no cancer left in your body.

Targeted therapy
Medicines designed to attack CLL/SLL cells with fewer effects on healthy cells.

> “Active monitoring was really positive for me. I had no symptoms at the time so it was good for me to put my diagnosis to one side and get on with life as usual.”

Helen, living with atypical B cell CLL since 2015

Living with CLL/SLL

Feelings and emotions

CLL/SLL can have a significant impact on your emotional wellbeing. Although it can take time, many people adapt well to a diagnosis, and live well with CLL/SLL.

There is no right or wrong way to feel, and there is support available, however you are feeling.

You're likely to experience a range of thoughts and emotions, some of which may feel strange or unfamiliar. These may include uncertainty, isolation, anxiety, anger, sadness and depression. It can help to tell other people how you feel, even if you simply say that you are confused about your feelings.

> **"CLL/SLL is a slower-growing cancer that you can live in harmony with and get on with your life. For most people, CLL/SLL does not need to ruin your life. We can't get rid of it, we can't just take it away. But it's often the anxiety around being told the diagnosis that can ruin your life far more than the actual disease."**
>
> Dr Scott Marshall, Haematology Consultant

You are not alone with CLL/SLL. Talking to other people can help you learn how to manage it.

Some people find our Support Groups and online meetings help them connect with others going through a similar experience.

Our Buddy schemes also offer one-to-one support and the chance to talk to someone in a similar situation to you.

Our Helpline services can help you find support that's right for you.

Leukaemia Care freephone helpline: 08088 010 444
Lymphoma Action freephone helpline: 0808 808 5555

It’s a good idea to tell your healthcare team how you’re feeling, as it will help them look after you. Be open and honest with them about your symptoms and how you’re coping. They can give you treatment and support that helps you live well with CLL/SLL.

Tips for communicating with your medical team

For your first appointment, bring a list of:

- Your symptoms
- Your current medicines and doses, including any complementary therapies
- Your medical history
- Any allergies you have

Take someone with you to your appointments to provide support and take notes.

Make a list of questions to take to your appointments, such as:

- What tests will I have and why?
- What sort of treatment might I need, how long will it last, and how successful do you expect it to be?
- What side effects might I experience?
- Will I be able to continue working?

Telling people

It is up to you who you tell about your CLL/SLL and how much you tell them. Letting some family and friends know how you are and how you feel about it may help. If they know your situation, they can support you better and help you live your life well.

Tips for talking to other people

- Try to communicate openly with people and let them know what you find helpful and unhelpful.
- Offer to share any printed information you have (such as this book) with family and friends. You could also tell them about websites you've found helpful.
- Consider joining a support group, attending an online support meeting or seeking counselling.

Find out more at
leukaemiacare.org.uk/support-and-information or
lymphoma-action.org.uk/Support-You

Fatigue

Fatigue is exhaustion that doesn’t get better with rest or sleep. It is not the same as ordinary tiredness. You can feel physically, emotionally, or mentally exhausted or a combination of all three.

If you are affected, you might not be able to do things you normally take for granted because of sheer exhaustion or brain fog. Or you may feel worn out after doing very little.

> **“The fatigue was really tough – eventually I had to give up work and I would limit what I did.”**
>
> Doreen, living with SLL since 2007

Fatigue is very common in people with CLL/SLL – this can be due to the condition itself, side effects of treatment, low mood, heightened stress and anxiety. It can be one of the most troublesome symptoms of CLL/SLL.

Although there is no medical treatment for fatigue, there are lots of things that can help you cope. Having a healthy lifestyle (page 69) is also important.

Tips to help with fatigue

- Take regular, gentle exercise, such as walking.
- Have a consistent sleep routine.
- Before bed, avoid screens and stimulants, such as alcohol, coffee, tea or chocolate.
- Keep your bedroom quiet and at a comfortable temperature.
- Prioritise tasks and pace yourself. Save your energy for things that are most important to you, and build in rest periods.
- Ask family and friends for help where you can.
- Try mindfulness or relaxation exercises.

Reducing your risk of infection

If you have CLL/SLL, you have a higher risk of developing infections than other people. If you get an infection, it might last longer than you'd usually expect, or be more severe. This is because your immune cells don't work as well as they should.

You might also have low antibody levels and low levels of some types of white blood cell (which usually fight infections). Many treatments for CLL/SLL can reduce your immunity too.

> **"Each day, I wake up and am grateful. My life isn't as I expected it to be but sometimes I am even grateful that CLL slowed me down and made me appreciate the good things in life; the blue skies, the noise of the waves on the beach, the little hands of my granddaughters in my hand, the good friends I have, my family, the laughter and the tears too."**
>
> Bethan, living with CLL since 2015

Tips to reduce your risk of infection

There is always a balance between taking care and living a fulfilling life. Different people are comfortable with different risks. These tips are a guide to things you can do, if you want to:

- Try to stay away from people who have infections. Avoid crowded places where infections might spread easily.
- Your medical team might prescribe medicines to help prevent infections.
- Have any vaccinations your medical team recommend. Encourage the people you live with to have their vaccinations, too – this will help protect you.
- Wash your hands often and maintain good personal hygiene.
- Brush your teeth well and go to the dentist regularly.
- Make sure you store and prepare food correctly. Don’t eat undercooked food or products that have passed their ‘use-by’ date.
- Take care to avoid cuts and grazes. Always wear shoes outdoors and wear gloves for gardening. If you shave, consider using an electric shaver instead of a razor.
- Online resources can help you think about your personal risk and what steps you might choose to take. Visit the International COVID-19 Blood Cancer Coalition at **www.icbcc.info/campaign-materials** for more information.

Signs of infection

Possible symptoms and signs of infection include, but are not limited to:

- Fever (temperature above 38°C or 100.4°F)
- Hypothermia (temperature below 35°C or 95°F)
- Shivering
- Chills and sweating
- Feeling generally unwell, confused or disorientated
- Blocked nose, earache, sore throat or sore mouth
- Cough or difficulty breathing
- Redness and swelling around skin sores, injuries or intravenous lines
- Diarrhoea or vomiting
- A feeling of burning or stinging when you pee, or needing to pee more often than usual
- Genital discharge or itching
- Unusual and new stiffness of the neck with discomfort around bright lights
- New or worsening pain

Contact your medical team straight away if you have any signs or symptoms of infection. It is important to get prompt treatment.

Healthy living

Many people find that a diagnosis of CLL/SLL makes them think about their lifestyle. Keeping healthy can help you deal with symptoms and cope better with treatment.

Tips for looking after yourself

- Eat a healthy diet with a wide variety of foods, including fruits, vegetables, seeds and pulses.
- Keep your body at a healthy weight. Ask your medical team for advice if you are struggling to eat well or if you have any problems with weight loss or gain.
- Drink plenty of fluids.
- If you smoke, try to stop. You have a higher risk of lung infections and long-term side effects from treatment if you continue to smoke.
- Keep active. This can improve your physical health and your emotional wellbeing. Build up slowly if you need to. Exercise can be particularly helpful for fatigue.
- Protect your skin from the sun. Some treatments can make your skin more vulnerable to skin changes. Wear suitable clothing, seek shade when the sun is hot, and use a sunscreen of at least SPF 30 with UVA protection.

Day-to-day living

A diagnosis of CLL/SLL and its symptoms can impact your everyday life including your home life, education, work and finances.

At home, you may need to arrange help or support to manage things you previously did for yourself. You may need help temporarily while adjusting to a new treatment, or in the longer term.

If you are working or studying, it may help to tell your employer or education provider about your CLL/SLL diagnosis. Then they can put the support you need in place. You may need to explain CLL/SLL, as most people won't have heard of it before.

Some people pause their studies or take temporary leave from work depending on how they're coping with their CLL/SLL.

> **"We get asked a lot: 'Is there anything I can do to slow it down?' The answer is: 'Not really'. If we knew there was something you could do, we would share that information. It's best to live a good healthy lifestyle, including exercise. Do what you enjoy!"**
>
> Helen Knight, Clinical Nurse Specialist

As CLL/SLL is a type of blood cancer, you are covered legally by the Equality Act. This means that your employer cannot discriminate against you and must, by law, make reasonable adjustments to allow you to continue working.

This could include:

- Temporary sick leave or a reduction in working hours
- Time off for appointments
- Adjustments to help you avoid infections, especially if your job brings you into close contact with people more likely to carry infections

Your GP can provide you with letters to confirm your diagnosis and the effects it may have on your work life.

A diagnosis of cancer automatically meets the government's definition of disability. This means that there's a wide range of financial support you might qualify for from the government. Some of this depends on your savings and earnings.

"When you are diagnosed with cancer, you assume that's it, you're done. But that isn't always the case. Since my diagnosis, I've moved house, been promoted and got on with my life. It hasn't meant the end for me. I feel a degree of anxiety whenever I go for my check-ups, but most of the time, I don't even think about it."

Paul, living with CLL since 2016

NHS prescriptions are free for everyone in Wales, Scotland and Northern Ireland. If you live in England and have CLL/SLL, you are eligible for a medical exemption certificate that entitles you to free NHS prescriptions. Your GP or clinical nurse specialist will complete the application form for you to apply for this.

If you need financial help, contact Leukaemia Care's advocacy team. We can help you access support you are entitled to. Call 08088 010 444 or email us at advocacy@leukaemiacare.org.uk

Macmillan Cancer Support offer financial information and support. Call 0808 808 0000 or search 'financial support' at macmillan.org.uk

Lymphoma Action and Leukaemia Care have more information on managing the physical, practical and emotional aspects of living with CLL/SLL on our websites.

Visit lymphoma-action.org.uk/LWL or search 'living well with leukaemia' at leukaemiacare.org.uk

Order a free book about living with and beyond lymphoma at lymphoma-action.org.uk/Books

Living with CLL/SLL

Summary

- You may experience a range of emotions when you are diagnosed with CLL/SLL.

- Be open with your medical team about your symptoms and how you are coping so they can best support you.

- Talk to family and friends about your CLL/SLL and how you feel about it. Let them know what you find helpful and unhelpful.

- People with CLL/SLL often have fatigue. If you are affected by fatigue, try to work out what helps and what doesn't so you can still do things you enjoy.

- People with CLL/SLL have a higher risk of infection, so you may want to take extra care to reduce your chance of getting ill.

- If you need to, tell your employer or education provider about your diagnosis so they can support you with time off or reasonable adjustments.

- You might be eligible for financial help. Contact Leukaemia Care's advocacy team to find out what is available and for help to apply.

Medical terms used in this chapter

Antibody
An immune system protein that helps fight infections by sticking to targets on the surface of cells that don’t belong in your body.

Atypical B cell CLL
A type of CLL which differs from classic CLL due to the shape, size and structure of the cells.

Complementary therapies
Non-medical treatments ranging from acupuncture, aromatherapy, herbal medicine, meditation and yoga used alongside your CLL/SLL treatment.

Fatigue
Extreme tiredness or lack of energy that can interfere with your usual activities.

Medical Exemption Certificate
This entitles you to free NHS prescriptions in England. It does not include free dental care or help with other NHS costs.

Mindfulness
A way of being fully present and aware of where you are and what you are doing in the present moment.

Disclaimer

Although we make reasonable efforts to ensure the content of our publications is accurate and up-to-date at the time of going to press, we make no representations, warranties or guarantees, whether express or implied, that the content is accurate, complete or up-to-date, particularly in relation to medical research which is constantly changing.

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Information and support

Lymphoma
action

If you or someone you love is affected by lymphoma, we're here for you. We have a range of support services that are free to access.

Find out more at **lymphoma-action.org.uk/support-you**

Helpline: a free helpline available Monday to Friday, 10am to 3pm, on **0808 808 555**, or use Live Chat on our website

Peer support: including online support meetings, our Buddy Service and our closed Facebook Group

Preparing for Treatment Service: online support and information to help you prepare for treatment

TrialsLink: our clinical trials information service

@lymphomaaction lymphoma_action

Leukaemia Care
YOUR Blood Cancer Charity

Leukaemia Care is a UK charity dedicated to ensuring that people affected by blood cancer can access the right information, advice and support.

Our services include:

- **Freephone Helpline:** Call **08088 010 444** (Monday to Friday, 9am to 4.30pm) or **WhatsApp 07500 068065** (Monday to Friday, 9am to 5pm)
- **Support Groups:** Meet or talk to other people going through a similar experience
- **Buddy Support:** Register for one-to-one phone support with a trained volunteer who has been affected by leukaemia themselves
- **Counselling Service:** Access up to six sessions of counselling
- **Advocacy and Welfare:** Find out about financial support, welfare advice and more
- **Cost of Living Fund:** Apply for a grant to help with essential living costs
- **Information:** Subscribe to our free magazine and access up-to-date information at **leukaemiacare.org.uk**

For more information on any of our support services, go to leukaemiacare.org.uk/support-and-information/support-for-you or email support@leukaemiacare.org.uk

/LeukaemiaCare /leukaemiacareuk /LeukaemiaCareUK

Other organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites and helplines.

Blood Cancer UK funds research, campaigns for change, and supports people affected by blood cancer.

British Association for Counselling and Psychology provides a list of accredited counsellors in your area.

Cancer Research UK offers information on all types of cancer, a searchable database of clinical trials and support for people affected by cancer.

Carers UK offers advice, information and support for carers.

Citizens Advice offers advice on benefits and financial assistance.

CLL Support provides information and support for those affected by CLL. Their Support ACT resource offers a toolbox of emotional wellbeing exercises to help you live well with CLL.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's Centres offer free practical, emotional and social support to people with cancer and their loved ones.

Plenty of ways to give

There are so many ways you and your loved ones can support the work of Leukaemia Care, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer your donation straight from your account to ours. Our bank details are:

Sort code: **20-98-61**
Account number: **80823805**
Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at **www.leukaemiacare.org.uk/donate** or scan the QR code to donate.

By phone

You can call us to pay by debit or credit card over the phone. Simply call **01905 755977**.

This booklet has been produced by Leukaemia Care in collaboration with Lymphoma Action. It outlines what chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are, and how they are diagnosed and treated. It also includes practical tips to help you live well with CLL/SLL, and details of where to go for further information and support.

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)
WhatsApp: **07500 068065**
Office Line: **01905 755977**
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

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Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum

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