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

A guide for those diagnosed and their loved ones

Leukaemia Care
YOUR Blood Cancer Charity

Lymphoma action

About this book

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are slow-growing types of blood cancer. They are two different 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 the 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, and how it is diagnosed and treated.

Each chapter is in a different colour. Practical tips on how to live well with CLL/SLL are printed in the chapter colour. We also include signposts to other useful sources of information.

If you would like a list of the references that we have used to prepare this book, please email or call:

- communications@leukaemiacare.org.uk or 01905 755977
- publications@lymphoma-action.org.uk or 01296 619400

If you would like the information in this book in large print, please contact us.

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"The doctor and the clinical nurse took time to explain what CLL is and they gave me a booklet. They said I should concentrate on the chronic bit rather than the cancer bit, and that helped me."
Antje, diagnosed with CLL in 2017 at 53.

What is CLL/SLL?

Summary:

- CLL and SLL are both slow-growing types of blood cancer. Most people live with CLL/SLL for many years.
- CLL/SLL develops when white blood cells called lymphocytes become abnormal. If you have CLL/SLL, your body makes too many of these abnormal cells. They can build up in your blood, bone marrow or lymphatic system.
- Anyone can get CLL/SLL, but your risk of getting it increases as you get older. It's rare in young people and more common in people over 60. It affects nearly twice as many men as women.
- Around 4,700 people in the UK are diagnosed with CLL/SLL every year.
- Scientists don't know what causes CLL/SLL. It is **not** because of anything you did or did not do.

Medical words in this chapter:

- **Lymphocyte:** The type of white blood cell that is abnormal if you have CLL or SLL.
- **Bone marrow:** The spongy centre of your bones where blood cells are made. It contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.
- **Lymphatic system:** A network of tubes, tissues and organs that runs throughout your body and helps protect you from infection.
- **Lymph nodes** (sometimes called 'lymph glands'): Small, bean-shaped structures in your lymphatic system that trap germs and abnormal cells.

What is CLL/SLL?

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

CLL and SLL are slow-growing types of blood cancer. They develop from white blood cells called lymphocytes.

In people who have CLL/SLL, 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.

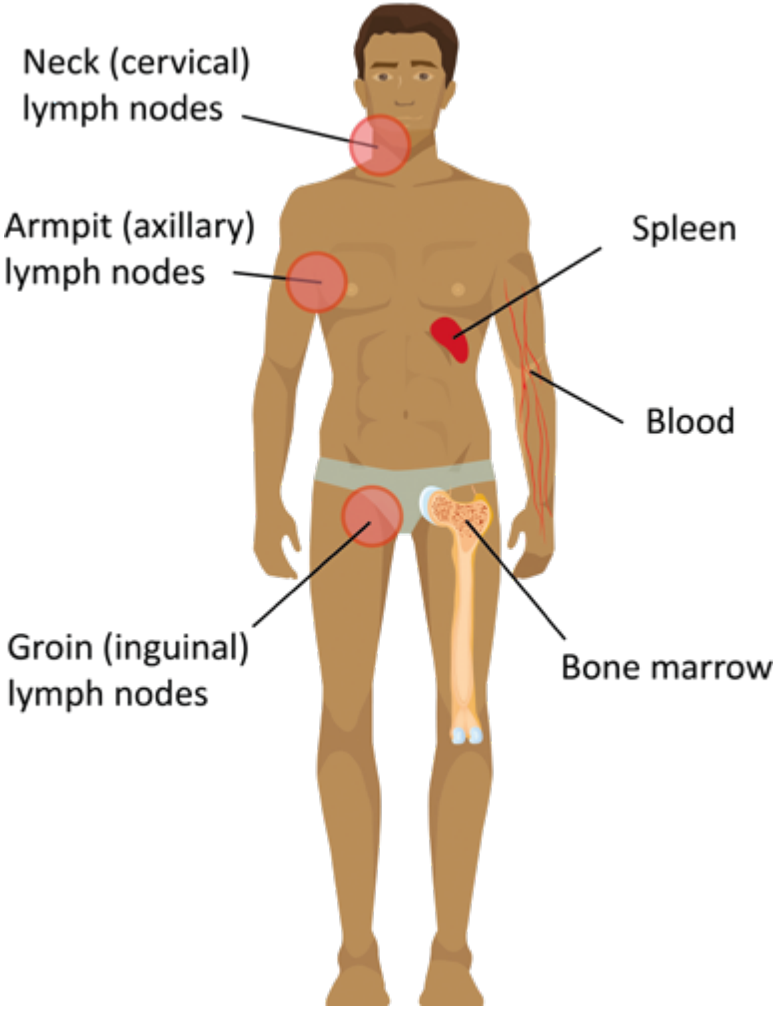


Figure: Parts of the body where CLL and SLL cells often build up.

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.

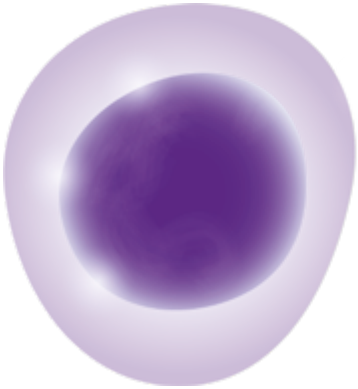


Figure: A lymphocyte.

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 (also called B cells) and T lymphocytes (also called T cells).

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

CLL and SLL both develop from B cells.

Who gets CLL/SLL?

CLL/SLL usually affects older people. The average age at diagnosis is 72. It is rare in young people.

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. Scientists don't know why this is.

Figure: Two out of every three people with CLL/SLL are male.

How common is CLL/SLL?

Throughout the world, over 100,000 people are diagnosed with CLL/SLL every year. In the UK, around 4,700 people are diagnosed each year – an average of around 12 people every day.

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

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 and you can't give it to anybody else.

CLL or SLL develop when the genetic code (the DNA) inside B cells changes. The changed B cells stop responding to the signals that usually keep them under control. They divide when they shouldn't, or do not die when they should. These abnormal B cells don't work properly and they can build up until they outnumber your healthy B cells.

One DNA change on its own is not enough to cause CLL/SLL. It usually takes a number of different changes before a cancer starts to grow. Most of the time, the DNA changes happen by chance. In some cases, there are factors that might make you more likely to develop the DNA changes. 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, people who have a close relative (parent, brother, sister or child) with CLL/SLL have a higher chance of developing it themselves. The risk is still very low and 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. Most people never know they have it and it does not usually cause any problems. However, each year around 1 to 2 out of every 100 people with MBL go on to develop CLL/SLL.
- **Weight:** People with a body mass index over 30 have a higher risk of developing CLL/SLL.
- **Chemicals:** Working in a job where you're exposed to high levels of industrial chemicals (for example, crop farming or hairdressing) might slightly increase your risk of developing CLL/SLL, although scientists are not sure if there is a link. Most people who work in these occupations do **not** develop CLL/SLL.

Most people who develop CLL or SLL have none of these risk factors and the cause is unknown.

Signs and symptoms of CLL/SLL

"I didn't have any symptoms but when I went for a routine mammogram they detected something in my right breast. I had two biopsies and it was confirmed as lymph nodes. I was then referred to haematology where I was told I had CLL/SLL."

Sylvia, diagnosed with CLL/SLL in 2017 at 70.

Signs and symptoms of CLL/SLL

Summary:

- Most people have no symptoms when they are first diagnosed with CLL/SLL.
- Symptoms usually develop slowly. Some people never develop symptoms.
- Common symptoms include fatigue, weight loss, night sweats, fever and swollen lymph nodes.
- Some people get lots of infections, or have infections that last longer than usual.
- Some people feel bloated or lose their appetite.
- CLL/SLL is different for everyone.

Medical words in this chapter:

- **Spleen:** A fist-sized organ under your rib cage on the left side of your body. It filters blood and helps fight infections.
- **Bone marrow:** The spongy centre of your bones where blood cells are made. It contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

Signs and 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.

Figure: More than three in four people have no symptoms when they are diagnosed.

Over time, you might start to develop symptoms. Any symptoms tend to be mild at first and get worse slowly over a period of months or years. Some people never have symptoms.

You might feel generally unwell, or notice some of the following symptoms.

Signs and symptoms of CLL/SLL

Fatigue: you might feel so exhausted that it's hard to carry on with your normal activities.

Frequent infections: you might develop infections more often than usual, or they might be more severe or last longer.

Lumps: you might notice lumps (swollen lymph nodes) in your neck, armpits, groin or other places.

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 without trying to.

If CLL/SLL cells build up in your bone marrow, they take up space that is normally used to make new blood cells. This means your body might not be able to make enough healthy blood cells, causing low blood counts.

- Red blood cells carry oxygen around your body. A low red blood cell count (anaemia) can make you feel tired, breathless or dizzy.
- Platelets help your blood clot. A low platelet count makes you bruise or bleed more easily than usual.
- White blood cells, such as lymphocytes and neutrophils, help fight infection. If you have CLL/SLL, you might have a high level of lymphocytes, but they might not work properly. You could still have low levels of neutrophils. A low functioning white blood cell count makes you more likely to pick up infections, and can make it harder to get rid of them.

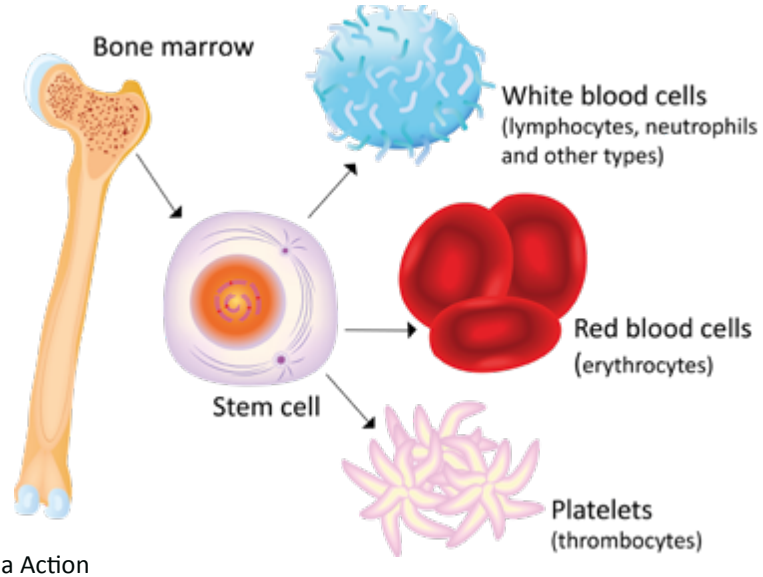


Figure: Bone marrow and the blood cells it produces.

Signs and symptoms of CLL/SLL

If CLL/SLL cells build up in your spleen, you might feel full quickly when you eat, or lose your appetite. You might feel bloated or notice that your tummy is swollen. Some people notice a lump in the top-left side of their tummy.

You might experience completely different symptoms. CLL and SLL vary a lot from person-to-person.

"In 2011, I had a lump on the left-hand side of my neck. I didn't think anything about it, but after a month or two decided I should see my GP, just in case. My doctor wasn't very worried, but he arranged for blood tests. I had further tests with the ear, nose and throat department, and they arranged a surgery for the next day." **Carl, diagnosed with CLL in 2011 at 40.**

Diagnosis of CLL/SLL

"There is life after a CLL diagnosis. I had a gradual return to work after treatment and carried on playing league table tennis through most of my treatment."

Michael, diagnosed with CLL/SLL in 2015 at 62.

Diagnosis of CLL/SLL

Summary:

- CLL can be diagnosed following a blood test and by examining your blood under a microscope.
- SLL is diagnosed through a minor procedure called a biopsy. This involves taking a sample of cells, usually from a swollen lymph node, to look at under a microscope.
- Doctors perform specialised tests on your blood or biopsy samples to find out more about your CLL/SLL and help them decide on the most appropriate treatment for you.
- You might have other tests or scans to find out how widespread the CLL/SLL is and how it is affecting you.

Medical words in this chapter:

- **Antibody:** A protein made by white blood cells that recognises and sticks to things that don't belong in your body, such as viruses, bacteria or some cancer cells.
- **Chromosomes:** Thread-like structures in your cells that contain DNA.
- **Computed tomography (CT):** A scan that uses X-rays and a computer to take cross-sectional images of your body.
- **Gene:** A section of DNA that tells your cells how to make a protein.
- **Ultrasound:** A scan that uses sound waves to take pictures of the inside of your body.

Diagnosis of CLL/SLL

You might be diagnosed with CLL/SLL by chance when you are having tests for something else, or your doctor may suspect you have CLL/SLL based on your symptoms. If this is the case, they will arrange for you to have tests to confirm the diagnosis.

"When I was first diagnosed my GP told me that I simply knew something today that I didn't know yesterday. He was so right and I am very lucky that, nearly ten years later, that hasn't changed." **Person diagnosed with CLL.**

Blood tests

CLL can be diagnosed from a full blood count (a blood test that measures the number of different blood cells you have) and by examining a sample of your blood under a microscope (a blood film or blood smear). Your doctor will diagnose CLL if these tests show a large number of abnormal B cells which all look the same (known as CLL/SLL cells). CLL/SLL cells appear as small, dark purple/blue cells under a microscope. SLL can't be diagnosed on a blood test alone.

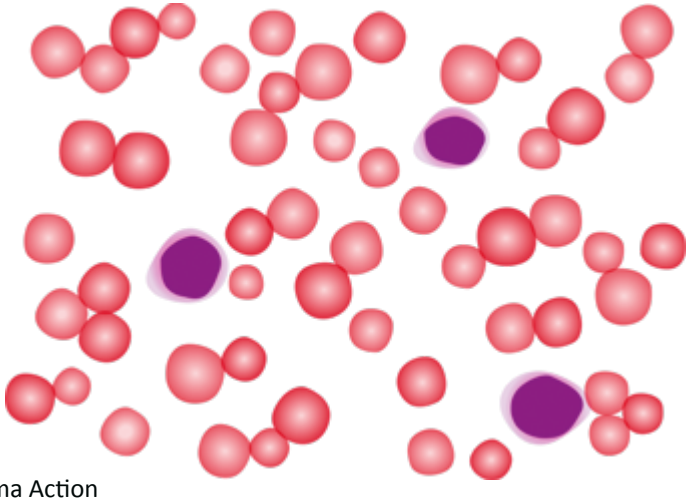


Figure: How CLL/SLL cells (purple) and red blood cells look under a microscope.

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

"At first I was told I had mantle cell lymphoma. After 3 months of chemo, my bone marrow was still full of malignant cells. A second opinion led to my SLL diagnosis." **Kate, diagnosed with SLL more than 20 years ago at 58.**

Biopsies

A biopsy is a minor procedure to remove 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.

- You are likely to have a lymph node biopsy if your doctor thinks you might have SLL.
- You might have a bone marrow biopsy, or a similar procedure called a bone marrow aspiration, if you have low blood counts, such as anaemia or low platelet levels. 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.

Lymph node biopsy

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 which all look the same (known as CLL/SLL cells).

Bone marrow aspiration or biopsy

A bone marrow aspiration or 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 that removes a small cylinder of tissue.

Visit lymphoma-action.org.uk/Bone-marrow-biopsy or search Google for "Leukaemia Care bone marrow biopsy" for more information.

Specialist tests

In the lab, specialist tests are carried out on your blood or biopsy samples to look for particular proteins or genetic changes (mutations) in the CLL/SLL cells. These can help your medical team choose the treatment that's most likely to benefit you.

There are three important mutations in CLL/SLL cells that can alter the way the condition behaves and how people respond to treatment.

These are:

- Deletion of part of a chromosome called 17p (del17p), which can make some treatments for CLL/SLL less effective.
- A mutation in a gene called TP53, which usually helps stop the growth of tumours. A TP53 mutation can make CLL/SLL less responsive to some treatments.
- Mutations in genes called immunoglobulin genes (IGHV). Random IGHV mutations happen naturally in healthy B cells as a normal part of their development. CLL/SLL can develop from B cells either with or without IGHV mutations. People with CLL/SLL that developed from cells with IGHV mutations tend to respond better to chemotherapy than people with CLL/SLL that developed from B cells without IGHV mutations ('unmutated IGHV patients'). However, newer targeted therapies (page 34) seem to work just as well whether your CLL/SLL cells are IGHV mutated or not.

Because of their impact on the treatment for people CLL/SLL, del17p and TP53 are known as high-risk mutations.

Your consultant will assess any genetic changes in your CLL/SLL cells before deciding on the most appropriate treatment options for you.

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

Other tests

You might have other tests to confirm the stage of your CLL/SLL and help your consultant to determine the treatment you are most likely to benefit from.

Imaging tests

Ultrasound or CT (computed tomography) scans help your medical team find out which parts of your body are affected by CLL/SLL and how enlarged your lymph nodes, liver and spleen are. These scans are used as a reference or 'baseline'. You might have repeat scans at the end of treatment to see if your lymph nodes, liver or spleen have shrunk.

Immunoglobulin (antibody) levels

Blood tests to measure your levels of antibodies help your medical team check how well you are able to fight infections. For example, depending on your individual circumstances, you might have your pneumococcal and tetanus antibody levels tested. If they are low, you might be offered a booster vaccination to improve your protection against these infections.

Antibody levels can also check how your body may respond to treatment.

Staging

Your consultant uses the results of your tests and scans to 'stage' your CLL/SLL. Staging is a scoring system that indicates where in your body the CLL/SLL is and how it is affecting you.

The staging system commonly used in the UK is called the Binet system (page 27). This is a three-step staging system based on the number of swollen lymph nodes you have and your blood test results.

A system called the Rai staging system is often used in the United States. It goes from Stage 0 to Stage IV. You might see reference to this in information that is not from the UK.

To find more about this system, search Google for "Leukaemia Care CLL", search 'Rai staging' at cllsociety.org, visit lymphoma-action.org.uk/CLL

Staging your CLL/SLL helps your doctor predict how quickly your CLL/SLL might progress, and plan the best treatment for you.

Binet staging system	
Stage A	Fewer than three areas of swollen lymph nodes*
Stage B	Three or more areas of swollen lymph nodes*
Stage C	Anaemia: Haemoglobin less than 10g/dL** **and/or** Low platelet count of less than $100x10^9$/L*** Any number of areas of swollen lymph nodes*

*The areas where lymph nodes are seen are the neck, the armpits, the groin, the spleen and the liver. The involvement of both groins or both armpits each count as one area.

** Haemoglobin is a protein inside red blood cells that carries oxygen around your body. The normal range is around 13 to 16.5g/dL for men and 11 to 16g/dL for women.

*** Platelets are a type of blood cell that help to stop bleeding. The normal range is 100 to 450 thousand million cells per litre of blood. This is written as 100 to 450 x 10^9/L.

"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, diagnosed with SLL in 2007 at 50.**

Having treatment for CLL/SLL

"I was on watch and wait for about 4 years before it was agreed that it was time to consider treatment options. My consultant said I could have FCR treatment (chemotherapy with antibody therapy) or go onto a clinical trial testing whether newer targeted drugs work better than FCR. I chose to go onto the trial and my treatment has been very effective."
Carl, diagnosed with CLL in 2011 at 40.

Having treatment for CLL/SLL

Summary:

- There are lots of effective treatments for CLL/SLL. They usually aim to keep CLL/SLL under control rather than curing it. Many people with CLL/SLL have a normal lifespan with a good quality of life.
- If you have no symptoms or only minor symptoms, you will not need treatment straightaway. Instead you have regular blood tests and check-ups to monitor your condition. This is called 'active monitoring' or 'watch and wait'.
- If you develop symptoms, low blood counts, or your lymph nodes become swollen enough to cause symptoms, your consultant will recommend that you start treatment.
- Your first treatment for CLL/SLL is likely to be a targeted therapy, sometimes combined with antibody therapy. Some people might have chemoimmunotherapy.
- If your CLL/SLL doesn't respond or comes back some time after treatment, other effective treatment options are available.

Medical words in this chapter:

- **Allogeneic:** Cells or tissues that come from another person, usually a healthy donor.
- **Chemoimmunotherapy:** A combination of chemotherapy and antibody therapy (treatment that sticks to proteins on the surface of CLL/SLL cells and stimulates the body's immune system to destroy them).
- **Spleen:** A fist-sized organ under your rib cage on the left side of your body. It filters blood and helps fight infections.
- **Targeted therapy:** Treatment that is designed to target cancer cells more precisely than chemotherapy.

Having treatment for CLL/SLL

CLL and SLL are generally very treatable. It is usually possible to keep them under control, often for many years. They are not usually cured, but many people with CLL/SLL have a normal lifespan with a good quality of life. You might have several different treatments over the course of your illness.

Active monitoring or watch and wait

CLL/SLL is a slow-growing condition and there is rarely an urgent need to start treatment.

If your CLL/SLL is not causing you any problems, you will not need treatment straightaway. Instead, you have regular blood tests and check-ups with your medical team to make sure you remain well. This is often called 'active monitoring' or 'watch and wait'.

It can be difficult to understand why you don't need treatment yet, but research has found that there is no benefit to treating CLL/SLL if it is not causing problems.

Download a book on active monitoring from Leukaemia Care at http://bit.ly/LCBooklets or Lymphoma Action at lymphoma-action.org.uk/Books or find out more at lymphoma-action.org.uk/ActiveMonitoring

It is important to attend all your check-ups while you are on active monitoring so your medical team can decide if, or when, you need treatment.

If you have any problems or concerns in between check-ups, contact your medical team.

When will I start treatment?

Some people need treatment soon after diagnosis. Some people never need treatment. 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
- The number of CLL/SLL cells in your blood rises very quickly

Treatment

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

- The stage of your CLL/SLL
- Any genetic changes in your CLL/SLL cells (page 23)
- Your age and general fitness
- Your personal preferences

Your first treatment for CLL/SLL might be a treatment that you take for a fixed length of time and then stop, or a treatment that you carry on taking unless it stops working or you develop side effects that are difficult to cope with.

Examples of fixed-length treatments include:

- A targeted therapy such as venetoclax (page 38), plus an antibody therapy such as obinutuzumab (page 35).
- A combination of chemotherapy and antibody therapy (chemoimmunotherapy) such as combinations of fludarabine, cyclophosphamide and rituximab (FCR) or bendamustine and rituximab (BR) (page 39).

Examples of treatments that you carry on taking include ibrutinib or acalabrutinib (page 36). These are sometimes combined with antibody therapy for the first part of your treatment (page 35).

Different treatments have different benefits, and some are only available on the NHS in specific circumstances. Your medical team will discuss the different options with you to choose the best treatment for your individual circumstances.

If your CLL/SLL does not respond to your first course of treatment, it is called ‘refractory’. If your CLL/SLL responds at first but then comes back, you are said to have ‘relapsed’.

Effective targeted therapies for people with relapsed or refractory CLL/SLL include ibrutinib, acalabrutinib, idelalisib, or venetoclax. Venetoclax might be given on its own or combined with antibody therapy. Idelalisib is combined with antibody therapy.

Your medical team will recommend the most appropriate treatment for you depending on:

- Treatment you’ve already had
- How well you responded and how long your response lasted
- How you coped with treatment
- Your symptoms
- Any other medical conditions you have (for example, heart conditions or kidney problems)

Treatment details

There are lots of different treatments for people with CLL/SLL, whether it is your first course of treatment or you've been treated before. This section describes all these treatments available for people with CLL/SLL, irrespective of your particular symptoms or genetic changes.

Targeted therapy

Targeted therapies have been developed to target CLL/SLL cells more precisely than older treatments such as chemotherapy. This means they have less of an effect on other cells in your body, and therefore cause fewer side effects. Targeted therapies are transforming the outlook for people with CLL/SLL and new ones are being developed all the time.

Download Leukaemia Care's CLL - Starting Active Treatment booklet at http://bit.ly/LCBooklets or for the latest information, visit lymphoma-action.org.uk/TargetedDrugs

Targeted therapies have complicated names based on the proteins they affect.

At the time of writing, the main types of targeted therapies used in CLL/SLL are:

- Antibody therapies
- Bruton's tyrosine kinase (BTK) inhibitors
- Phosphoinositide 3-kinase (PI3K) inhibitors
- B-cell lymphoma-2 (BCL-2) inhibitors

Antibody therapies

Antibody therapies are antibodies made in the laboratory that 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.

The most common target for antibody therapies is a protein called CD20, which is found on the surface of nearly all CLL/SLL cells.

A number of antibody therapies that target CD20 are available, including:

- Rituximab
- Obinutuzumab

You have them through a drip into a vein. They are usually given in combination with chemotherapy or another targeted therapy.

Bruton's tyrosine kinase (BTK) inhibitors

BTK is a protein that binds to B cells and causes the cell to divide. CLL/SLL cells are particularly sensitive to these signals, so they keep dividing when they shouldn't. This produces too many CLL/SLL cells.

BTK inhibitors are drugs that block these signals to reduce the number of CLL/SLL cells. BTK inhibitors include:

- Ibrutinib
- Acalabrutinib

They are most often used as a first treatment for people with CLL/SLL who have high-risk genetic changes or who are not fit enough to have chemoimmunotherapy, or for people with relapsed or refractory CLL/SLL.

You have them as tablets or capsules that you take by mouth once or twice a day. You usually carry on taking them unless you develop troublesome side effects or your CLL/SLL stops responding.

"I had chemotherapy in 2010 that kept my CLL under control for nearly 5 years, I have had three bone marrow biopsies and have to infuse antibodies every week. However I feel incredibly well on ibrutinib and am so grateful to doctors and my lovely nurse." **Person diagnosed with CLL.**

Phosphoinositide 3-kinase (PI3K) inhibitors

PI3K is a protein involved in controlling cell growth. In CLL/SLL cells, this protein can be faulty and results in the production of too many CLL/SLL cells. PI3K inhibitors block PI3K, which disrupts the signals that help the CLL/SLL cells stay alive.

Idelalisib is a PI3K inhibitor. It is not often used in the UK. It might occasionally be used for people with CLL/SLL that has relapsed quickly after other treatments, or rarely as a first treatment for people with CLL/SLL with high-risk genetic changes who can't have other treatments. You have it combined with rituximab.

Idelalisib is a tablet that you take by mouth twice a day. You usually carry on taking it unless you develop troublesome side effects or your CLL/SLL stops responding.

Duvelisib is a newer PI3K inhibitor that is approved in the UK for adults with relapsed or refractory CLL/SLL who have had at least two previous courses of treatment. It is a capsule that you take by mouth twice a day. At the time of writing, it is not available on the NHS, although this could change.

B-cell lymphoma-2 (BCL-2) inhibitors

BCL-2 is an important protein that helps control the natural process that makes cells die when they are damaged or worn out. Cancer cells often make too much BCL-2, which helps the cells survive when they shouldn't. BCL-2 inhibitors block the protein, which triggers cells to self-destruct.

Venetoclax is a BCL-2 inhibitor. It is used in combination with obinutuzumab as a first treatment for CLL/SLL, or in combination with rituximab for people with relapsed or refractory CLL/SLL. It can also be used on its own for people who can't have, or have relapsed after, chemoimmunotherapy or other targeted therapies.

Venetoclax is a tablet that you take by mouth once a day. You start on a low dose and gradually increase under the close supervision of your medical team. If you have it on its own, you carry on taking it unless you develop troublesome side effects or your CLL/SLL stops responding. If you have it combined with rituximab or obinutuzumab, you usually stop taking it after 1 to 2 years.

"The current treatments for me now are great – just pop a few pills each day, every three months a blood test and a consultation. I just hope my body holds on a while longer. I have been on my latest drug for 4 years so fingers crossed. This doesn't disturb my life at all. I feel lucky to be able to have oral treatment."
Jenny, diagnosed with CLL in 2008 at 63.

Chemoimmunotherapy

Chemoimmunotherapy is the combination of chemotherapy and antibody therapy. It used to be a standard treatment for CLL/SLL, but targeted treatments are used more often nowadays. Chemoimmunotherapy can still be very effective for people without high-risk genetic mutations, particularly younger people who are more able to tolerate side effects.

Chemoimmunotherapy combinations sometimes used to treat CLL/SLL include:

- **Fludarabine + cyclophosphamide + rituximab (FCR):** FCR is very effective in people with CLL/SLL. It is more suitable for fit, younger people (65 and under) because it is an intensive treatment that can be hard for the body to tolerate.
- **Bendamustine + rituximab (BR):** BR is more suitable for older people (65 or above) or people with kidney disease who cannot tolerate the side effects of FCR.
- **Chlorambucil + obinutuzimab:** Chlorambucil is a gentler type of chemotherapy that is given as a tablet. It is suitable for people who are not fit enough to have intensive treatment.

Other chemoimmunotherapy options are available. Your medical team might suggest a different one based on your circumstances.

You have most of these chemoimmunotherapy treatments through a drip into a vein. You have treatment in regular cycles with treatment on some days and rest periods in between for your body to recover.

Figure: Intravenous drugs are given through a drip (infusion).

Allogeneic (donor) stem cell transplant

A stem cell transplant involves having high dose chemotherapy 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. When you have an allogeneic stem cell transplant, you are given healthy stem cells from a donor to replace these.

A stem cell transplant is an intensive form of treatment. It can take many months to recover.

Stem cell transplants aren't often used to treat CLL/SLL nowadays because there are many, less intensive treatments available. You might be offered one if you have a very aggressive form of CLL/SLL, and you are fit enough to tolerate the treatment. If this might be an option for you, your haematologist will discuss it with you and give you a chance to ask questions.

For more information about stem cell tranplants, download one of Leukaemia Care's booklets from http://bit.ly/LCBooklets, visit lymphoma-action.org.uk/SCT

Radiotherapy

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

Surgery to remove your spleen

On very rare occasions, people with CLL/SLL have an operation to remove their spleen. This is known as a 'splenectomy'.

Your medical team might recommend it if your spleen is very enlarged despite other treatments, or if your CLL/SLL cells are making antibodies that are destroying red blood cells in your spleen (page 52).

A splenectomy is quite a straightforward operation and people usually recover well. People tend to live a full life without a spleen, although you have a higher risk of getting infections.

Visit lymphoma-action.org.uk/Splenectomy to find out more.

Clinical trials

Treatments for CLL/SLL are developing rapidly. As more become available, it is important to discuss your options with your CLL/SLL team. They might also ask you if you'd like to take part in a clinical trial to help find out more about effective treatments for CLL/SLL.

To find out more about clinical trials or to search for a trial that might be suitable for you, visit lymphoma-action.org.uk/TrialsLink

Outlook for people with CLL/SLL

CLL and SLL can manifest themselves very differently in different people. In most cases, it is a long-term condition that grows very slowly (if at all).

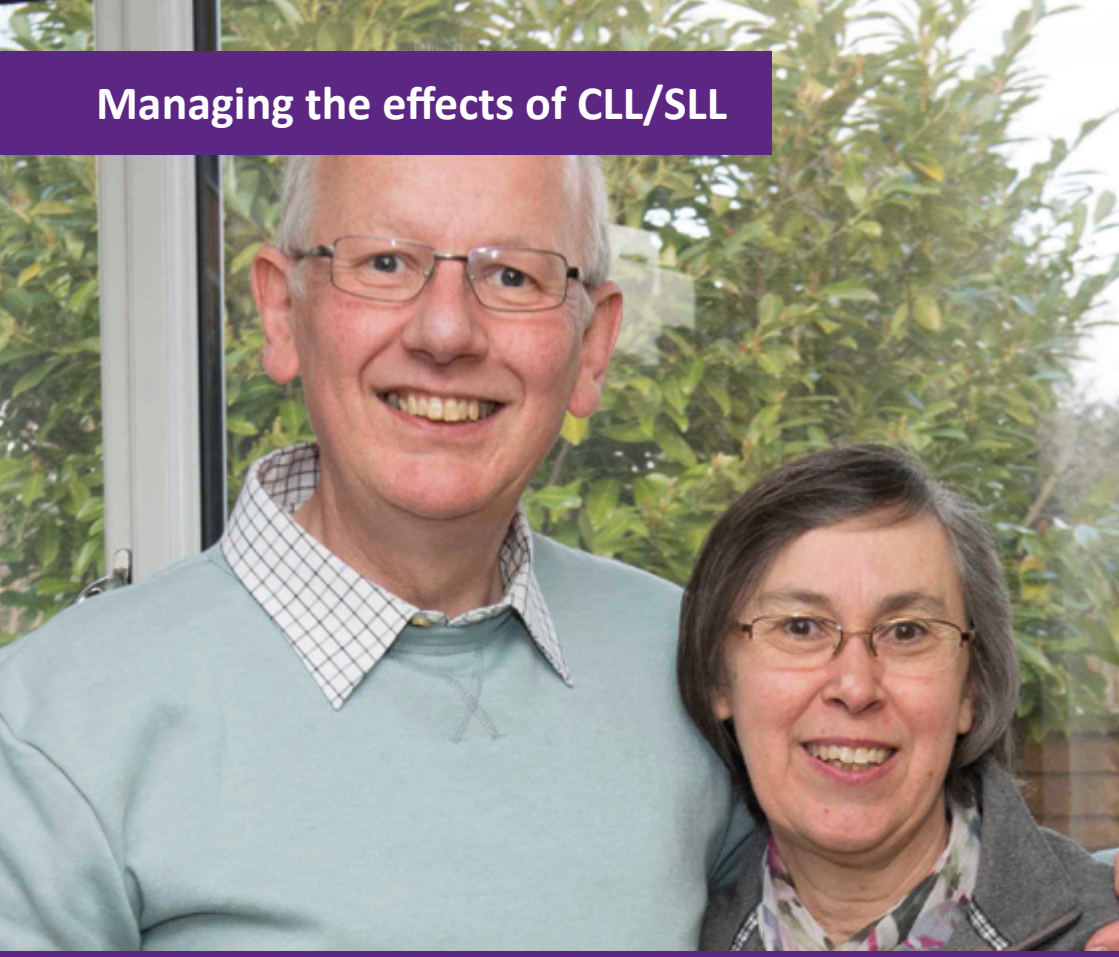
Treatments generally work well and keep CLL/SLL under control, often for many years. Most people need treatment from time-to-time, with long periods between treatment when they feel well.

Treatment might reduce the number of CLL/SLL cells in your body, or it might clear them completely (called 'minimal residual disease negative' or 'MRD negative'). If you are MRD negative after treatment, you are likely to have a longer lasting remission than if you still have some CLL/SLL cells left. As new and more effective treatments for CLL/SLL become available, remissions are generally getting longer.

However, sometimes, CLL/SLL can be faster-growing and might need treatment more often. Your medical team can give you the best advice about what to expect.

"CLL might not be curable but it is treatable and for myself I will enjoy my life as much as I can." **Antje, diagnosed with CLL in 2017 at 53.**

Managing the effects of CLL/SLL



"The fatigue was really tough – eventually I had to give up work and I would limit what I did. Another symptom was feeling uncomfortable when I ate. A third symptom were the big nodes. I was very aware of the node on my neck, so I'd often wear a little scarf."
Doreen, diagnosed with SLL in 2007 aged 50.

Managing the effects of CLL/SLL

Summary:

- Most people live with CLL/SLL for many years. There are things you can do to help manage any effects you have.
- Many people with CLL/SLL experience fatigue. Gentle exercise, a healthy sleep routine and relaxation techniques can help. It is important to pace yourself.
- You are likely to have a higher risk of infection than other people. Make sure you know the signs to look out for and take steps to reduce your risks.
- You might have low blood counts. These can be treated effectively.
- If you are having treatment, you are likely to experience some side effects. Tell your medical team. They can support you, offer advice or prescribe medicines to help.
- Rarely, CLL/SLL can change into a faster-growing type of blood cancer. Your medical team will check for this, and if if it happens, they will discuss different treatment options.

Medical words in this chapter:

- **Blood transfusion:** Having blood or blood products from a donor through a drip into one of your veins.
- **Haemophilus influenzae type B (Hib):** A germ that can cause serious infections, such as pneumonia, meningitis or blood poisoning.
- **Immunoglobulin replacement therapy:** Treatment with donor antibodies to boost low antibody levels.
- **Mindfulness:** Being fully in the ‘present’ and aware of your body, where you are and what you are doing.
- **Palliative care:** Treatment to relieve symptoms.
- **Steroids:** Medicines that affect lots of processes in your body, including your immune response.

Managing the effects of CLL/SLL

Most people live with CLL/SLL for many years. Although you might experience symptoms or complications, these can often be managed effectively. In the following pages, we cover some of the more common effects of CLL/SLL, and ways to help control them.

Fatigue

Fatigue is extreme tiredness or exhaustion that doesn't usually improve after rest or sleep. If you are affected, you might not be able to do all the activities you usually would, or feel exhausted after doing quite little. It can be one of the most troublesome symptoms of CLL/SLL.

Regular gentle exercise, such as walking, can improve fatigue and maintain your fitness. It's a great way of releasing your anxiety and frustration.

The idea of getting out and being active may be the last thing you want to do when you are experiencing fatigue. However, exercise is one of the best ways of managing fatigue.

Tips to help with fatigue

- Have a regular sleep routine – try going to bed and waking up at around the same time every day and avoid lying in.
- At bedtime, avoid stimulants such as alcohol, coffee, tea or chocolate. Stay off laptops, tablets or mobile phones for an hour or so before bed.
- 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. Build in rest periods.
- Ask family and friends for help where you can.
- Try mindfulness or relaxation exercises to help you calm your mind, release tension and ease any pain.

"I don't think that anyone that has not had fatigue can imagine what it is like. I have learnt to manage my fatigue over the years. Mine comes on either immediately or up to 48 hours after I have overdone it emotionally, physically or practically and it can also come on if I overdo it with what personally stresses me."
Erica, age 71, diagnosed with CLL in 2003.

Infections

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). As well as the CLL/SLL itself, many treatments for CLL/SLL also reduce your immunity.

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

Tips to reduce your risk of infection

- Wash your hands often and maintain good personal hygiene. Brush your teeth well.
- Keep your home clean.
- Stay away from people who have infections. Avoid crowded places where infections might spread easily.
- 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.
- Have any vaccinations your medical team recommends. Encourage the people you live with to have their vaccinations, too – this will help protect you.

Signs or symptoms of infection

Signs or symptoms of infection that you might experience include:

- Fever (temperature above 38°C)
- Hypothermia (temperature below 35°C)
- Shivering
- Chills and sweating
- Feeling generally unwell, confused or disorientated
- Blocked nose, earache, sore throat or sore mouth
- Cough or shortness of breath
- Redness and swelling around skin sores, or injuries to intravenous lines
- Diarrhoea or vomiting
- Burning or stinging sensation when you wee, or weeing more often than usual
- Unusual genital discharge or itching
- Unusual stiffness of the neck and discomfort around bright lights
- New or worsening pain

Most infections can be treated by your GP with medicines that you take at home. If your infection becomes severe or your medical team has any concerns, you might be treated in hospital.

Visit lymphoma-action.org.uk/Infection to find out more.

Treatment to prevent infections

If your medical team thinks you have a particularly high risk of developing an infection, they might recommend treatment to try to prevent this.

Vaccinations

You might be offered the pneumococcal vaccine, COVID-19 vaccine and the annual flu vaccine. Your medical team might recommend other vaccines depending on your circumstances. Not all vaccines are suitable for you, and you might not respond as well to vaccination as other people.

- 'Non-replicating' vaccines (vaccines that can't cause infections) are **safe** for people with CLL/SLL. This includes the vaccines for pneumonia, meningitis, Haemophilus influenzae type B (Hib) and COVID-19. The injected flu vaccine and a brand of shingles vaccine called Shingrix® are also non-replicating.
- 'Live' vaccines (vaccines made using weakened versions of live germs) are **not recommended** for people with CLL/SLL because they might cause infections. This includes the vaccines for measles, mumps and rubella (MMR), tuberculosis (TB) and the nasal flu vaccine. A brand of shingles vaccine called Zostavax® is also live.

Antibiotic or antiviral drugs

If you have a very high risk of infection, or you've had certain viral infections in the past that could flare up if your immune system is low, you might be given antibiotics or antiviral drugs to take regularly at home.

Immunoglobulin replacement therapy

If you have low antibody levels and you keep getting severe or frequent infections, your doctor might recommend treatment with donor antibodies. This is called immunoglobulin replacement therapy. You have it in one of two ways:

- Through a drip into a vein every 3 to 4 weeks. This is done as a hospital outpatient.
- As an injection just underneath the skin of your thigh, tummy or upper arm. You have this once a week. You might be taught how to do it yourself at home.

Visit lymphoma-action.org.uk/Immunoglobulin for more information.

Low blood counts

People who have CLL/SLL might have low blood counts for a number of reasons:

- If you have CLL/SLL cells in your bone marrow, they take up space that is normally used to make healthy blood cells.
- Treatment for CLL/SLL aims to kill CLL/SLL cells but some healthy blood cells can also be destroyed.
- Sometimes, CLL/SLL can cause your immune system to make antibodies that stick to your own blood cells and destroy them. This is called 'autoimmune cytopenia'. It usually affects red blood cells or platelets.

Symptoms of low blood counts

If you have a low red blood cell count:

- You might feel tired, dizzy or short of breath.
- You might look paler than is normal for you. This is often more noticeable on the inside of your eyelids.

If you have a low platelet count:

- You might bruise more easily than usual or bleed for longer than you'd expect if you cut yourself.
- You might have bleeding gums, nosebleeds or heavier periods than normal.

If you have a low white blood cell count:

- You have a higher risk of developing infections than usual.

Treatment for low blood counts

If your blood counts are very low or are causing troublesome symptoms, your medical team might offer you a red blood cell transfusion or a platelet transfusion. This involves having donor blood cells through a drip into a vein, usually in your arm.

If your low blood counts are caused by antibodies destroying your red cells or platelets, you are most likely to be treated with steroid tablets. If your blood counts don't improve, your medical team will suggest other treatments.

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 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.

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.

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

For more information on side effects of CLL/SLL treatment and tips on how to manage them, search Google for "Leukaemia Care CLL" or visit lymphoma-action.org.uk/SideEffects

Transformation

Rarely, CLL/SLL can change (transform) into a faster-growing type of blood cancer, usually a type of lymphoma called diffuse large B-cell lymphoma. This is known as 'Richter's transformation'. It happens to about 1 in every 100 people with CLL/SLL each year.

Your medical team look for signs of transformation at your check-ups. They monitor your blood tests and check your symptoms.

Contact your medical team if your symptoms get worse or you develop new ones. They can check for signs your CLL/SLL might have transformed. CLL/SLL does not transform in most people.

Transformed CLL can be difficult to treat. The most likely treatment is chemotherapy, possibly followed by a stem cell transplant (page 40) if you are fit enough to have one. You might be able to enter a clinical trial or you might consider palliative care, where you have treatment to control your symptoms.

Living well with CLL/SLL

"I wanted to live – to live with SLL/CLL, not die – and that meant ignoring it as much as possible and really appreciating life. We each find our way of coming to terms with whatever happens and that was my way."

Kate, diagnosed with SLL more than 20 years ago at 58.

Living well with CLL/SLL

Summary:

- You may experience a range of emotions when you are diagnosed with CLL/SLL. Speak to your doctor or clinical nurse specialist if you are finding it hard to cope.
- Be open with your healthcare team. Tell them about your symptoms and how you are coping.
- Talk to family and friends about how you feel. Let them know what you find helpful and unhelpful.
- You may wish to tell your employer about your diagnosis, so they can support you with any adjustments or time off you might need. You might be eligible for financial help.
- Your medical team might offer you support to relieve your symptoms and maintain your quality of life. This is known as palliative care.
- If you are in the last few months or years of your life, your medical team will talk to you about your wishes and the type of care you would like.

Medical words in this chapter:

- **Complementary therapy:** Therapy used alongside standard treatment for CLL/SLL to help you feel better and improve your quality of life. It does not treat the CLL/SLL itself.

Living well with CLL/SLL

It can take time to adjust to a diagnosis of CLL/SLL.

Allow yourself time to do the things you enjoy when you feel well enough. Make plans for the future and live your life. This can help you feel more ‘normal’.

Emotional impact

Being diagnosed with CLL/SLL can be very upsetting. It can affect you emotionally at any point.

It is likely that you will experience a range of complex thoughts and emotions, some of which may feel strange or unfamiliar to you. 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.

Sometimes, you may experience an increased heart rate, rapid breathing, and muscle tension. This is part of the natural ‘fight or flight’ response that helps us to face danger or run away. It is completely natural. If you are experiencing this, tell your doctor or clinical nurse specialist. They can suggest ways to help you cope.

You may also find yourself feeling low, which is natural given your situation with the illness, treatment and recovery process. However, if this low mood persists for more than several weeks, and you feel hopeless, lose interest and pleasure with things in life, then you may have depression.

If you, or someone close to you, thinks you might have depression, talk to someone.

Your GP is a good first contact. They can help you get the support you need.

Talking about CLL/SLL

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

Talking to your haematologist and healthcare team

Talking effectively with your haematologist and healthcare team is important to develop a good relationship.

Be open when you discuss your symptoms and how you are coping. Good communication tends to improve outcomes for people with CLL/SLL.

Tips for communicating with your medical team

- At your first appointment, take a list of:
  - Your current medications and doses, including any complementary therapies.
  - Your medical history, including any other illnesses you have and your previous treatments, procedures or complications.
  - Any allergies you have.
- Take someone with you to your appointments. They can provide support and take notes.
- Make a list of questions to take to your appointments, such as:
  - What tests will I have and what might they show?
  - What sort of treatment might I need? How long will it last? How successful do you expect it to be?
  - What might the side effects of my treatment be?
  - Will I be able to carry on working?

Talking to family and friends

Let your family and friends know about your CLL/SLL and how you feel about it. It can be difficult for you to explain to your family and friends how it affects you.

Be open about how you feel. This can help create a positive, supportive and caring environment to help you move forward with your life.

People often make assumptions and do what they think helps. For example, they might say you look well, tell stories of others with a similar diagnosis, or encourage you to stay positive. However this isn't always what you might really want to hear. In many ways, the more you talk to them the better.

"It was suggested I try out a support group where I would meet others in a similar situation to myself. The people there were so informative, friendly and positive. It was also reassuring to speak with others who had been diagnosed with non-Hodgkin lymphoma over 20 years beforehand; what a hopeful thing that was."
Carl, diagnosed with CLL in 2011 at 40.

Tips for talking to other people

- Try to communicate openly with people and let them know what you find helpful and unhelpful.
- Try to stay relaxed when talking to people about your diagnosis. This will help keep both you, and the people you're talking to, calm.
- Offer to share any printed information you have (such as this book) with family and friends. You could also tell them about any helpful websites you have used.
- Consider joining a support group. Find out more at **leukaemiacare.org.uk/support-and-information/support-for-you** or **lymphoma-action.org.uk/Support-You**

Looking after yourself

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.

For more information on living well with CLL/SLL download Leukaemia Care's booklet on living well with CLL at http://bit.ly/LCBooklets or to order a free book on living with and beyond lymphoma, visit lymphoma-action.org.uk/LWL

Tips for looking after yourself

- Eat a healthy diet with plenty of fruits and vegetables, and keep your body at a healthy weight. Ask your medical team for advice if you are struggling to eat 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 sensitive.

"I was able to start some part time work for my employers at home about 3 months after [my treatment] started and I returned to work full time in my office 3 months later. 2 years later I chose to retire, having satisfied myself that the impact of having CLL and being on a clinical trial had not affected my ability to carry out a stressful job which also involved a 27-mile daily commute using the M1 at peak times."
Michael, diagnosed with CLL/SLL in 2015 at 62.

Work arrangements

Being diagnosed with CLL/SLL can sometimes lead to difficulties relating to your work life. It is often useful to let your employer know about your CLL/SLL diagnosis so they can put in place any support you need.

It is often worth taking time to explain CLL/SLL to your employers, as it is likely they will never have heard of it before.

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, or, if you need it, stopping work altogether
- Time off for appointments
- Adjustments to help you to 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.

Find out more about working if you have CLL/SLL at lymphoma-action.org.uk/Day-to-day or download Leukaemia Care's booklet on living well with CLL at http://bit.ly/LCBooklets

Financial help

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.

- **If you need financial help, Leukaemia Care have a dedicated welfare officer who can help you with finding out what benefits you are entitled to, letting you know what other types of support you can access and helping you apply (e.g. completing forms, writing letters). Email them at advocacy@leukaemiacare.org.uk or call 08088 010 444.**
- **You can also speak to a member of the Information and Support team at Lymphoma Action or an Advocacy team member at Leukaemia Care. They can provide you with general advice about benefits.**
- **Macmillan Cancer Support offer financial information, support and assistance. Search 'financial support' at macmillan.org.uk or call 0808 808 0000.**

If you have CLL/SLL, you are eligible for a medical exemption certificate that entitles you to free NHS prescriptions. Your GP or clinical nurse specialist can tell you how to apply for this.

Palliative care

Palliative care aims to improve your quality of life. It is also known as 'supportive care'. Palliative care takes a 'whole person' approach to your illness. It includes managing your symptoms as well as psychological and social support for you and your family. It should be available to you throughout your illness, from diagnosis to treatment and follow-up.

Palliative care is provided by health and social care professionals trained in palliative medicine. These will include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists and occupational therapists.

Palliative care aims to relieve your symptoms, control the CLL/SLL, extend survival, and give you the best quality of life possible.

If you are considering palliative care, your doctor will discuss the options with you in detail. Palliative care services may be provided by the NHS, the local council or a charity. You may receive day-to-day care at your home or nursing home.

End-of-life care

Most people with CLL/SLL have a normal lifespan with a good quality of life. However, occasionally CLL/SLL stops responding to treatment and there might not be

a suitable alternative available, or you might not be fit enough to have it. Some people might choose not to have further treatment.

End-of-life care is support for people who are in the last few months or years of their life. The aim is to help people with CLL/SLL enjoy a good quality of life until they die, and die with dignity.

If you are nearing the end of your life, your healthcare team will ask you about your wishes and preferences on how you want to be cared for. They will support you to implement these wishes. They will also support your family.

You will be able to decide where you want to receive end-of-life care, be it at home, in a care home or a hospice. The same will be true of where you would like to die. Wherever this is, you will receive high quality end-of-life care.

Call Leukaemia Care's Helpline on 08088 010 444 or Lymphoma Action's Helpline on 0808 808 5555 or download Leukaemia Care's booklet on end of life at http://bit.ly/LCBooklets or visit lymphoma-action.org.uk/End-of-life for more information.

Information and support

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure that nobody faces lymphoma alone. Our services include:

- Accurate and up-to-date **information** online and in print: **lymphoma-action.org.uk/Books**
- Emotional support through our **Helpline** (10am to 3pm, Monday to Friday): Freephone **0808 808 5555** or live chat on our website
- **Peer support** including Support Groups, buddies and our Facebook community: **lymphoma-action.org.uk/support-you**
- **Personal stories** shared online and through our podcast **Lymphoma Voices**: **lymphoma-action.org.uk/stories**
- **Lymphoma TrialsLink** clinical trials information service: **lymphoma-action.org.uk/TrialsLink**

Visit lymphoma-action.org.uk for full details.

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Leukaemia Care
YOUR Blood Cancer Charity

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

- Regularly updated, disease-specific and general support **booklets** online and in print: **http://bit.ly/LCBooklets**
- Emotional support through our **Helpline** Monday to Friday 9am to 5pm, and Thursdays and Fridays 7pm to 10pm on **0808 801 0444** (freephone). We have two nurses on hand to answer your questions and offer advice and support. Call our Helpline, email **support@leukaemiacare.org.uk** or speak to them via **Whatsapp** on **07500068065**
- Our nationwide **support Groups** and **buddy support** are a chance to meet and talk to people going through a similar experience.
- **Financial support** and advice through our advocacy team and grants for hardship and counselling.
- For more information on any of our **support services**, go to **leukaemiacare.org.uk/support-and-information/support-for-you**

You can access up-to-date information on our website at leukaemiacare.org.uk

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Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel and other expert advisers as well as our Reader Panel. In particular we would like to thank the following people for their assistance with this book:

- Dr George Follows, Consultant Haematologist and Clinical Lead for CLL/Lymphoma, Cambridge University Hospitals; Visiting Professor of Haematology, Anglia Ruskin Medical School; Associate Lecturer, University of Cambridge. Dr Follows has received honoraria from Astra Zeneca, Abbvie, Roche, Janssen and Bayer.
- Helen Knight, CLL Clinical Nurse Specialist, Nottingham University Hospitals.

Lymphoma Action would like to thank AbbVie, Bristol Myers Squibb, Incyte, Janssen, Kyowa Kirin and Takeda UK Ltd for part-funding this book. As per Lymphoma Action policy, they have no influence over the content.

Special thanks to Antje, Carl, Doreen, Erica, Jenny, Kate, Michael, Sylvia and other people diagnosed with CLL for sharing their experiences. Quotations from their stories are featured throughout the book.

This book outlines what chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are, and how they are diagnosed and treated. It includes practical tips to help you live well with CLL/SLL, and details of where to go for further information and support.

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Helpline freephone: 08088 010 444
support@leukaemiacare.org.uk
www.leukaemiacare.org.uk

Lymphoma Action has been providing information and support to people affected by lymphoma for over 30 years. We're here for you.

Helpline freephone 0808 808 5555
information@lymphoma-action.org.uk
www.lymphoma-action.org.uk

Date published: October 2021
Revision date: October 2024
ISBN 978-1-914948-01-5