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

What are CLL and SLL?
Tests, scans and staging
Monitoring and treatment
Living with CLL and SLL
This booklet has been researched and written by Lymphoma Action, the only UK charity dedicated to those affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer all our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued. From everyone at Lymphoma Action and on behalf of those affected by lymphoma, thank you.

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### Key contact

Name: __________________________

Role: __________________________

Contact details: __________________________

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<tr>
<th>Job title/role</th>
<th>Name and contact details</th>
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<tbody>
<tr>
<td>GP</td>
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<tr>
<td>Consultant haematologist/oncologist</td>
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<tr>
<td>Clinical nurse specialist</td>
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About this book

Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are different forms of the same disease. They are treated in the same way, so ‘CLL’ is used to refer to both forms of disease in this booklet, except where there are important differences and SLL is discussed separately.

CLL is a slow-growing type of cancer. This booklet explains what CLL is, and how it is diagnosed and treated. It offers tips on living with CLL and there is space for notes.

Important and summary points are written in the chapter colour.

- Lists practical tips.
- Space for questions and notes.
- Lists other resources you might find useful.

The information in this booklet can be made available in large print.
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My diagnosis focused my mind on life time-management. Places to visit and things to do were placed on my bucket list and prioritised into things that can wait a while and things that need to be achieved whilst energy and health allow. So I encourage you – make it happen.

Doreen, diagnosed with SLL in 2007 at 50
What is chronic lymphocytic leukaemia?

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Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are different forms of the same disease. They are treated in the same way, so 'CLL' is used to refer to both forms of disease in this booklet, except where there are important differences and SLL is discussed separately.

What is CLL?

CLL is a slow-growing type of cancer. It behaves like a chronic (long-term) condition, and needs treatment from time-to-time to keep it under control.

In CLL, changes happen in cells called 'lymphocytes'. These changes prevent them working properly. The abnormal cells are not useful to your body. Most of the time, your immune system gets rid of cells that have gone wrong. If your immune system doesn’t recognise the abnormal cells, cancer can develop.

Both CLL and SLL are often grouped as low-grade (slow-growing) non-Hodgkin lymphomas, as they are cancers of lymphocytes. CLL is also called a ‘leukaemia’ because it mostly affects the blood.

What are lymphocytes and what do they do?

Lymphocytes are a type of white blood cell that fight infection. They mainly collect in your lymph nodes (glands), but they can be found almost anywhere in your body.
There are two main groups of lymphocytes, T lymphocytes (T cells) and B lymphocytes (B cells).

**In CLL, B cells that don’t work properly build up in your body.**

In CLL, the abnormal B cells are found mainly in your blood and bone marrow (the spongy tissue in the centre of your large bones where blood cells are made). In SLL, they are mainly in your lymph nodes (glands) or other lymphatic tissue, such as your spleen (an organ of your immune system).

![Diagram showing parts of the body where CLL and SLL are often found](image-url)

**Figure: Parts of the body where CLL and SLL are often found**
Who gets CLL?

Anyone can get CLL, but your risk of developing it increases as you get older. It is uncommon in young people and more common over the age of 60. It affects twice as many men as women.

![Figure: Two out of every three people with CLL are men](image)

You’re not alone – around 10 people are diagnosed with CLL every day in the UK.

What causes CLL?

There isn’t usually any known cause of CLL. You are more likely to develop it if one of your close relatives (parent, brother, sister, child) has it but the risk is still small.
Symptoms

You might have symptoms before you are diagnosed or not until long after your diagnosis. Some people never have any symptoms.

Symptoms often develop gradually as the abnormal lymphocytes build up.

Common symptoms of CLL include:

- lumps (swollen lymph nodes), often in several places
- feeling generally unwell
- fatigue (extreme tiredness)
- fevers, night sweats, weight loss (these are known as ‘B symptoms’)
- frequent infections or difficulty shaking off infections.
You might get low blood counts. Your body is continually making new blood cells from blood stem cells in your bone marrow. You have lots of different types of blood cells. The blood count is a blood test that measures how many of each type of blood cell is in your blood.

Figure: Bone marrow and the blood cells it produces

If the abnormal CLL cells build up in your bone marrow, they take up space and you might not have enough normal cells, resulting in low blood counts. See page 22 for more on low blood counts.
Some people get low blood counts for another reason. CLL can cause an autoimmune reaction, where your body destroys your own blood cells.

- Low red blood cells can be due to **autoimmune anaemia**.
- Low platelets can be due to **immune thrombocytopenic purpura (ITP)**.

Your medical team do tests to find out what is causing your low blood counts.

Low blood counts due to autoimmune conditions need different treatment from low blood counts caused by too many abnormal cells in your bone marrow.

**Outlook**

CLL usually grows very slowly. It behaves more like a chronic (long-term) condition than a cancer – you are likely to need treatment from time-to-time with long periods without treatment in between.

*Treatments generally work well and keep CLL under control, often for many years, but do not usually cure it.*
Although the outlook for CLL is generally good, it can vary considerably between each person.

- Some people have a faster-growing form and might need treatment more often.
- CLL at a low stage can usually be kept under control for longer than CLL that is causing more problems when it is diagnosed.

Your medical team can give you the best advice about what to expect.

“I was 40 when I was diagnosed and had so many questions. ‘How long do I have to live?’ ‘How will things develop?’ I wanted to run out of the hospital room as fast as possible and for things to go away.”

Carl, diagnosed with CLL in 2011 at 40
I was only diagnosed with SLL because I had a CT scan for something else. The CT scan revealed large lymph nodes all over my body.

Michael, diagnosed with SLL/CLL in 2015 at 62
Tests, scans and staging

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Diagnosis

CLL is often discovered by chance. You might be having blood tests for another reason, but the laboratory notice that you have more lymphocytes in your blood than normal.

You might be having symptoms, for example you have found one or more lumps, or you have lost weight without trying to. If you are having symptoms, you are likely to have blood tests to help your doctors find out what is wrong.

If you have too many lymphocytes in your blood, the laboratory look at them in more detail and do tests on them to find out if you have CLL, SLL or another condition.

The SLL form is usually diagnosed by finding abnormal lymphocytes in a biopsy (sample) of a swollen lymph node.

- **CLL** is diagnosed when the abnormal lymphocytes are found only in the blood and bone marrow, or are found in the blood and in other parts of the body, such as the lymph nodes.
- **SLL** is diagnosed when the abnormal lymphocytes are found only in the lymph nodes or lymphatic tissue. If there are abnormal cells in the blood as well, the condition is usually called CLL.
Tests on the abnormal cells can detect certain genetic mutations (changes) in the cells that tell your medical team more about how the CLL is likely to behave.

Common genetic mutations or cell changes include:

- A change in immunoglobulin heavy chain (IgVH) genes. This change usually means the CLL will grow slowly and respond well to chemotherapy.
- Changes called ‘17p deletion’, or ‘TP53 mutation’. These changes mean a targeted treatment is likely to work better for you than standard chemotherapy.

It can be very difficult waiting for your test results, but it is important that your medical team have as much information about your CLL as possible so they can recommend the best treatment plan for you.

I was originally diagnosed with mantle cell lymphoma following a blood test that showed a raised white blood cell level. It was only after treatment and a second opinion that my diagnosis was changed to SLL. Kate, diagnosed with SLL more than 20 years ago at 58
Monoclonal B-lymphocytosis

If you have a low level of abnormal CLL-like cells in your blood, but your blood counts are normal and you don’t have other symptoms, you might not have CLL. Instead, you might be told you have ‘clinical monoclonal B lymphocytosis’ (MBL). Many healthy older people (more than 1 in 10 people) have MBL and often they are not aware of it. It does not usually cause any problems.

Research suggests that MBL develops first in all people who go on to develop CLL, but only around 1 to 2 of every 100 people diagnosed with MBL develop CLL each year.

Most people with MBL never develop a high enough level of abnormal cells to cause any problems. People with MBL who are at greater risk of developing CLL are those with higher numbers of abnormal cells. These people might have blood tests every so often to check if the level of abnormal cells is rising.
Blood tests

You have regular blood tests if you have CLL.

Blood tests are used to:

- monitor the level of CLL cells in your blood
- find out more about your general health.

Blood can be tested for lots of different things, but one of the main tests your medical team is interested in is the full blood count.

Full blood count
The full blood count (FBC) is a test that measures how many blood cells there are in your blood. The number of each type of blood cell is often called the ‘count’.

There are lots of different types of blood cells that do different jobs in your body.

The FBC is an important measure of how your CLL is affecting you. If you start to develop low blood counts, you might need to start treatment. Treatment can cause low blood counts but they should start to rise when the CLL has been reduced.
The table shows low blood counts that are common in people with CLL.

<table>
<thead>
<tr>
<th>Medical name</th>
<th>White cells</th>
<th>Red cells</th>
<th>Platelets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutrophils and lymphocytes</td>
<td>Neutrophils and lymphocytes</td>
<td>Erythrocytes</td>
<td>Platelets</td>
</tr>
<tr>
<td>What do they do?</td>
<td>Fight infection</td>
<td>Carry oxygen</td>
<td>Stop bleeding</td>
</tr>
<tr>
<td>Neutropenia and lymphopenia</td>
<td>Neutropenia and lymphopenia</td>
<td>Anaemia</td>
<td>Thrombocytopenia</td>
</tr>
<tr>
<td>What's the shortage called?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are the symptoms?</td>
<td>Infections</td>
<td>Pale skin, feeling tired, breathless, cold, dizzy</td>
<td>Bruising easily, bleeding longer or without warning (for example nosebleeds)</td>
</tr>
</tbody>
</table>
Other blood tests
There are lots of other blood tests you are likely to have regularly – see the examples on page 24.

You might not need all of these tests and you might have other tests that are not listed here. Your doctor orders tests based on your individual circumstances, including any other health conditions you have.

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

Some people like to keep a record of their blood tests so they can track what happens over time.
<table>
<thead>
<tr>
<th>What is the test?</th>
<th>What does it mean?</th>
<th>Why is the test done?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunoglobulins (Igs)</td>
<td>Another word for antibodies</td>
<td>To see if your immune system is working well</td>
</tr>
<tr>
<td>Urea and Electrolytes (‘U and Es’), and sometimes creatinine</td>
<td>Electrolytes keep your body balanced; urea and creatinine are waste products</td>
<td>To measure the health of your kidneys</td>
</tr>
<tr>
<td>Liver function tests</td>
<td>Measure substances that are made in the liver</td>
<td>To assess the health of your liver</td>
</tr>
<tr>
<td>Inflammatory markers, for example LDH, CRP, ESR*</td>
<td>Measure substances in your blood that increase if you have inflammation</td>
<td>To see if you have any signs of inflammation (your body’s response to injury or infection)</td>
</tr>
<tr>
<td>Infection markers and blood cultures</td>
<td>Infection markers are substances that raise if you have an infection; blood cultures grow bacteria found in your blood to find out what the infection is</td>
<td>To see if you have signs of an infection and to find out what the infection is so it can be treated</td>
</tr>
</tbody>
</table>

*LDH: lactate dehydrogenase, CRP: C-reactive protein, ESR: erythrocyte sedimentation rate.
Other tests and scans

When you are diagnosed, you have a physical examination to check for other signs of CLL, such as enlarged lymph nodes or an enlarged spleen.

You might have other tests to find out if CLL is causing problems in other parts of your body. For example:

- X-rays
- a scan, usually a CT scan
- bone marrow tests.

Find out more about the tests and scans you are having at www.lymphoma-action.org.uk/Tests
Staging

The tests you have are part of ‘staging’ – working out how widespread your CLL is and how it is affecting you.

Staging is important because it helps your doctor plan the best treatment for you.

CLL is staged differently from other types of non-Hodgkin lymphoma and other types of cancer because it is mostly found in the blood. The abnormal cells are therefore carried around the body in a different way to types of lymphoma that are mostly found in the lymph nodes.

There are two main ways to stage CLL. In the UK and Europe, the Binet staging system is most commonly used.

<table>
<thead>
<tr>
<th>The Binet staging system</th>
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<tbody>
<tr>
<td>Stage A</td>
</tr>
<tr>
<td>Fewer than three groups of swollen lymph nodes</td>
</tr>
<tr>
<td>Stage B</td>
</tr>
<tr>
<td>Three or more groups of swollen lymph nodes</td>
</tr>
<tr>
<td>Stage C</td>
</tr>
<tr>
<td>Anaemia, thrombocytopenia or both</td>
</tr>
</tbody>
</table>
The Rai staging system is used more widely in the US. You might see this in information that is not from the UK.

<table>
<thead>
<tr>
<th>The Rai staging system</th>
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<tbody>
<tr>
<td>Stage 0</td>
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<tr>
<td>Stage 1</td>
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<td>Stage 2</td>
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<tr>
<td>Stage 3</td>
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<tr>
<td>Stage 4</td>
</tr>
</tbody>
</table>

As SLL usually affects lymph nodes rather than blood, it is often staged in the same way as non-Hodgkin lymphoma. This is also on a scale of 1 to 4, where 1 is the lowest and 4 is the most advanced stage. However, the staging system for SLL is not very useful because most people have SLL in their bone marrow as well as in the lymph nodes, which makes it stage 4, even if they have only low levels of abnormal cells. Unlike for some other cancers, most people with stage 4 SLL have a very good outlook.
Questions to ask about tests and scans

• What tests do I need?
• What do the tests involve?
• When will I get the results of my tests?
• What do the results of my tests mean?
Questions to ask about staging

• What stage is my CLL/SLL?
• How does the stage affect my treatment?
• How does the stage affect my outlook?

My CLL/SLL stage: ________________________________
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 standard 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
Monitoring and treatment

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Treatment overview

If you feel well, you probably won’t have treatment for CLL straightaway. Instead, you have regular check-ups to make sure you remain well. This is called ‘active monitoring’ or ‘watch and wait’. You might be on active monitoring for many years.

Most people with CLL don’t need treatment straightaway and some people never need treatment.

If CLL is causing problems for you, your medical team are likely to suggest that you start treatment. The aim of treatment is to reduce the number of CLL cells in your body as much as possible.

Treatment might give you a:

- **complete remission**, where no CLL cells can be detected on standard tests
- **partial remission**, where the number of CLL cells has been reduced.

Your medical team might also talk about ‘minimal residual disease’ (MRD).

If your CLL is MRD negative, it means no CLL cells can be detected at all, even with very sensitive blood tests.
If your CLL is MRD positive, you still have very low levels of CLL cells. This doesn’t mean you need more treatment straightaway. Reducing the number of CLL cells reduces your symptoms and allows you to have a good quality of life.

You are likely to stay in remission for longer if the CLL cells can be cleared completely, but you can still have long periods without symptoms even if there is CLL left behind after treatment.

After treatment, you go on active monitoring again. Many people with CLL have long periods of feeling well, in between courses of treatment that keep the CLL under control.

If treatment doesn’t control your CLL, it is known as ‘refractory’ and you will need a different treatment.

There is more about the usual treatments for CLL in the following sections.

Visit our personal stories section to find videos and stories of people with CLL and other types of lymphoma at www.lymphoma-action.org.uk/Stories
Active monitoring (watch and wait)

You might have active monitoring before treatment and between courses of treatment. Not having treatment doesn’t mean nothing is being done. You are monitored by having regular check-ups with your medical team so they can make sure you are still well and the CLL is not causing you significant problems.

**There is no benefit in treating CLL before it is causing troublesome problems.**

It can be difficult to understand why you don’t need treatment yet, so ask your medical team to explain why they think this is the best approach for you.

Prepare for your appointments by noting down any questions you have. Take someone with you to appointments if you can – they might be able to take notes for you so you can focus on what the doctor is saying.

*It’s good to have an advocate when things are tough, to be your voice and push for you when you’re not strong enough to do it.*

Doreen, diagnosed with SLL in 2007 at 50
During active monitoring, you have regular blood tests to keep an eye on the number of lymphocytes in your blood and to check for low blood counts (see page 21).

You might have some symptoms, but they should be manageable. You can have treatments to keep symptoms under control during active monitoring (see page 47), but these treatments don’t directly treat your CLL.

**CLL grows slowly and there is rarely an urgent need to start treatment.**

If you remain well, you might have less frequent appointments over time. If your consultant thinks your CLL is unlikely to cause problems for a long time, you might be able to go onto a self-management scheme. You are given information on what to look out for and how to look after yourself. You might have blood tests occasionally at your GP surgery. There are often workshops you can attend to help you manage your CLL.

**You know your body best and you are the most likely person to notice any changes.**

Keep an eye on your health while you are on active monitoring. Get in touch with your medical team if you have any problems or concerns in between appointments. They can reassure you or see you earlier if necessary.
Many people worry when they first go onto active monitoring, but it is common to find you worry less over time and get on with your life.

Find out more about active monitoring on our website, and download or order our booklet. Visit www.lymphoma-action.org.uk/ActiveMonitoring

For 9 years I was on watch and wait. This was an opportunity for me to ‘watch and learn’ and I found out all I could about treatments, and researched a healthy lifestyle and ways to cope with fatigue.
Doreen, diagnosed with SLL at 50
When does treatment start?

If your tests show your CLL is getting worse or you are finding it difficult to control any symptoms, your medical team consider whether you need to start treatment.

You are likely to start treatment if:

- your symptoms (for example fevers, night sweats, fatigue or weight loss) become severe
- the numbers of lymphocytes in your blood rise rapidly
- your lymph nodes, spleen or liver become very enlarged
- you develop low blood counts due to the abnormal lymphocytes collecting in your bone marrow
- you have autoimmune anaemia or thrombocytopenia that is not responding to treatment.

Your doctor might suggest several different treatments. You can discuss the options together to decide on the best treatment for you.

Learn more about different treatments at www.lymphoma-action.org.uk/Treatment
First-line treatment

The first treatment for CLL is usually a combination of:

- chemotherapy (drugs that kill cancer cells)
- the antibody treatment rituximab, which is a laboratory-made antibody that targets a protein called ‘CD20’ on B cells.

Your body makes antibodies naturally to fight infection. Laboratory-made antibodies work in the same way and attach to a specific target to tell your body to destroy it.

Your doctor chooses the chemotherapy that is best for you, taking into account your general health, any other conditions you have and any information they have about your CLL and how it is affecting you. They also take your wishes into account – some people prefer to have less intensive treatments even if their CLL is likely to come back quicker than if they had a stronger treatment.

A common first treatment for people who are fit enough is FCR, which includes:

- fludarabine (F) and cyclophosphamide (C) chemotherapy drugs
- rituximab (R).
FCR is an intensive (strong) treatment, so some people are not fit enough to have it or prefer to have less intensive treatment. Other effective treatments include:

- bendamustine chemotherapy, with or without rituximab
- chlorambucil chemotherapy tablets, which might be given with one of the newer antibody treatments, obinutuzumab or ofatumumab.

Ask your medical team to explain the risks and benefits of the treatment they recommend.

CLL with 17p or TP53 changes
CLL with certain genetic changes (17p or TP53 changes) doesn’t usually respond well to chemotherapy, but there are targeted drugs that work well in these cases (see page 42).

How is chemotherapy given?
Most people have at least some of their treatment intravenously (into a vein).
A bolus or ‘push’ dose is where a drug is given by injection into your vein. This can take a few minutes.

Some intravenous drugs are given through a drip (infusion), which can take several hours.

You usually take some treatments as tablets or capsules as well. Some people take all of their treatment as tablets or capsules.

Chemotherapy is usually given in cycles. Each cycle is a few weeks long. In each cycle, you have treatment on some days and rest periods to allow your body to recover. A treatment course is usually several cycles of treatment over a few months.
Targeted drugs

Targeted drugs are transforming the outlook for people with CLL, and there are already several options available to treat certain people with CLL in the UK.

Targeted drugs are most often given to people whose CLL has come back after previous treatment. Some people have targeted drugs first-line, often those who have CLL with mutations that mean it doesn’t respond well to chemotherapy, or sometimes as part of a clinical trial.

<table>
<thead>
<tr>
<th>Name of treatment</th>
<th>What does it do?</th>
</tr>
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<tbody>
<tr>
<td>Ibrutinib</td>
<td>Blocks signals that B cells send to help them stay alive and divide</td>
</tr>
<tr>
<td>Idelalisib</td>
<td>Blocks signals that B cells send to help them stay alive and divide</td>
</tr>
<tr>
<td>Obinutuzumab</td>
<td>Antibody that attaches to the same target that rituximab does, a protein called ‘CD20’ on B cells, and tells your body to destroy the cells</td>
</tr>
<tr>
<td>Ofatumumab</td>
<td>Another antibody to CD20</td>
</tr>
<tr>
<td>Venetoclax</td>
<td>Blocks proteins that help CLL cells survive; this can make the cells die</td>
</tr>
</tbody>
</table>
Approval and funding is constantly changing for these drugs as researchers learn more about how best to use them. Other drugs could be available through clinical trials.

Targeted drugs might be given in cycles, like chemotherapy, or you might take the treatment as a tablet or capsule every day. You continue to take some of these treatments every day for years or for as long as they are helping you.

Visit our targeted drugs webpage to find the latest information on which treatments might be available to you, www.lymphoma-action.org.uk/TargetedDrugs
Other treatment options

Other treatments that are occasionally used for CLL include:

- **Radiotherapy**, which can sometimes cure early stage SLL. Radiotherapy is not often used for CLL but might rarely be used to reduce large lymph nodes if other treatments are not suitable or did not work.

- A **splenectomy** (surgery to remove the spleen) or splenic radiotherapy (radiotherapy to the spleen). This doesn’t usually treat the CLL itself, but might help if you have severe autoimmune complications of CLL.

- **Steroids** are often used to treat side effects of treatment but can also help to control the CLL.

- A **donor (allogeneic) stem cell transplant** is occasionally offered to people who are young and fit, and who have a suitable donor. This intensive treatment might help keep CLL under control for a long time.
Clinical trials and CLL research

Clinical trials are medical research studies involving human participants. All new treatments have to undergo extensive testing in clinical trials before they can be approved for use and funded on the NHS.

Clinical trials are vital in driving forward improvements in treatment for CLL and there are currently many clinical trials testing new treatments for CLL.

Search our clinical trials information service, Lymphoma TrialsLink, to find clinical trials currently open in the UK for people with CLL at www.lymphoma-action.org.uk/TrialsLink

Side effects of treatment

Treatment for CLL aims to destroy the abnormal cells but it can have other, unwanted effects on your body. These are known as ‘side effects’.

Each drug has its own set of side effects and everyone responds differently to drugs. People can experience different side effects even if they are having the same drug.
Your doctor considers whether you are fit enough to tolerate the expected side effects when planning your treatment. People who are elderly or who have other serious medical conditions are more likely to need less intensive treatments, like chlorambucil chemotherapy tablets.

Treatments like radiotherapy also have side effects but these depend on what part of your body is treated.

Most side effects go away soon after treatment has finished. Others can take longer to gradually get better, or can occasionally be permanent. Sometimes, treatments can cause side effects that only start long after treatment has finished (for example heart problems or second cancers). These are called ‘late effects’.

**Ask your medical team what side effects your treatment is likely to cause and how to manage them.**

There are often treatments and measures you can take to reduce side effects. You should be told what to look out for and who to contact if you have any concerns.

For more information on side effects of lymphoma treatment and tips on how to manage them, visit [www.lymphoma-action.org.uk/SideEffects](http://www.lymphoma-action.org.uk/SideEffects)
Treatments for symptoms and side effects

During active monitoring and treatment, you have therapies that don’t treat the CLL but help to control symptoms or side effects. These might include:

- drugs that prevent or treat infections, such as antibiotics, and antifungal and antiviral drugs
- growth factor (G-CSF) injections to boost blood counts and help fight infection
- immunoglobulin replacement therapy, where you have donor antibody infusions to help fight infection if your own antibody levels are low
- red blood cell transfusions and/or platelet transfusions to boost your blood counts
- drug treatments for autoimmune low blood counts – steroids are usually given initially, but there are other treatment options.

There is interest in whether levels of vitamin D in the blood affect how well people respond to treatment for cancer, or affect how quickly cancers grow. Many people in the UK have a mild vitamin D deficiency, as this vitamin is mostly made by sunshine acting on our skin. It is hard to be sure whether taking vitamin D supplements will benefit you, but you should discuss this with your medical team.
Questions to ask about treatment

• What is the name of my treatment?
• How often do I have treatment and what does the treatment involve?
• How will you know if it is working?
• What side effects am I likely to get and when are they likely to start?
• How long will it take to recover from my treatment?
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 with CLL

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Relapse

Your CLL might stay under control (‘in remission’) for years after treatment but it usually comes back at some point (‘relapses’).

It is natural to be worried about relapse. Many people become more aware of any aches and pains as they worry that these are signs of the CLL coming back.

You will get aches and pains and illnesses like anybody else. Any changes in your CLL are usually gradual.

Tips for monitoring your health

• Be aware of how you feel but don’t let it take over your life.
• Make notes if it helps you keep track of changes in your health.
• Contact your medical team if you have concerns about your health – they would rather see you and reassure you than leave you to worry.
Why does CLL come back?
Treatments for cancer usually work best on cells that are dividing quickly. As CLL cells grow slowly, some cells can be left behind after treatment. Only very low levels of CLL cells might be present but they could gradually build up and cause a relapse, which means the CLL has returned to noticeable levels.

Treatments for CLL are improving, and the length of time between treatments (remissions) is generally increasing.

How is relapse treated?
You might have the same treatment that you had previously if you coped well with it and had a good response to it. Your consultant might suggest a different treatment, particularly if your CLL relapsed quickly after your last treatment. You might have:

- different chemotherapy
- a targeted treatment.

There might be a range of options for you to consider again. Talk to your medical team about the risks and benefits of all the available options so that you can make a decision together.

Many people have several courses of treatment over the years.
I had various different chemotherapies over the years, at first only getting 2 years’ remission after each one and then 5 years, and another 5 years. I never got complete remission, only partial, but my general health stayed good and I was able to put the disease to the back of my mind in between treatments.

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

**Transformation**

CLL can transform (change) into a faster-growing type of lymphoma, usually diffuse large B-cell lymphoma (DLBCL). This is known as ‘Richter syndrome’.

**Your CLL is unlikely to transform – transformation happens in up to 1 in 100 people with CLL (1%) each year.**

As part of your check-ups, your medical team check for signs of transformation. Your blood tests might show a rapid increase in the number of lymphocytes in your blood or an increase in certain chemicals, for example lactate dehydrogenase (LDH) or calcium.
You might have symptoms, for example:

- fast growing lymph nodes or masses in your body
- a change in your symptoms, for example B symptoms (weight loss, night sweats, fevers).

These changes can also happen if you relapse or even if you have another illness; they do not mean your CLL has definitely transformed. Your doctor requests further tests like a biopsy and a scan to check for transformation if they have any concerns.

**How is Richter’s syndrome treated?**

If your CLL transforms into Richter’s syndrome, it can be difficult to treat. It does not usually respond well to treatment.

The most likely treatment is chemotherapy, possibly followed by a stem cell transplant if you are fit enough. A stem cell transplant is an intensive form of treatment that allows you to have high doses of chemotherapy. You have your own blood stem cells collected before the chemotherapy and given back to you afterwards to restore your immune system.
Many people with transformed CLL are older and have had several previous courses of treatment so might not be fit enough for intensive treatment. If you are not fit enough for chemotherapy, you might be able to enter a clinical trial or you might consider palliative care, where you are given treatment to control your symptoms.

Quality of life

Most people live with CLL for many years and it can cause symptoms that affect your quality of life even when it is under control.

You might:

- feel very tired a lot of the time (chronic fatigue)
- get infections that come back or last a long time.
Tips for communicating with your medical team

• Discuss any problems you are having with your medical team. They can give you strategies to help you manage problems like fatigue.
• Seek medical advice promptly if you feel unwell or if you have a fever (temperature above 38°C) as it is important that you get early treatment for infections with antibiotics and antiviral drugs.
• Tell your medical team if their advice or treatments are not working for you – there are often alternatives.

Risk of infection

Be aware that you are more likely to get infections than someone without CLL. This is because both CLL and treatment for CLL affect your immune system. Infections like shingles are more likely to develop if your immune system is not working properly.

Contact your medical team immediately if you think you might have an infection or if you have been in contact with someone with an infection like shingles or chickenpox.

Infections that are treated quickly are less likely to become serious.
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.

**Tips to reduce the risk of infection**

- Keep good hygiene – hand washing is very important in keeping germs at bay.
- Protect your skin from cuts and grazes that could allow germs to get into your body. Use an electric razor when shaving, and wear gloves if you are gardening.
- Be aware of food-borne infections – wash your hands and preparation surfaces and utensils. Take note of ‘use-by’ dates and storage instructions. Avoid raw or undercooked products and those where you are unsure how they have been handled, such as takeaways and loose bakery products.

**Immunoglobulin replacement therapy**

If you have low antibody levels, your doctor might suggest you have immunoglobulin replacement therapy. You have regular infusions (drips) of donor antibodies, which help you to fight infection.
**Vaccinations**

Vaccines can help reduce your risk of some infections. It is usually recommended that people with CLL and MBL should have vaccinations against influenza (flu) and pneumonia. You might not be able to have live vaccines, though, as these can cause problems for people with a weakened immune system. Live vaccines include the shingles/zoster vaccine. Check with your medical team which vaccinations they recommend for you.

**Living with a chronic condition**

Most people live for many years with CLL and might have treatment from time-to-time with periods of active monitoring in between.

You might struggle with the idea of living with a cancer and not having treatment at times. It can help to think of CLL as a chronic (long-term) condition that you have to manage, rather than a cancer. Over time, many people find that they adjust to a ‘new normal’ way of life with CLL.

**Talk to others**

You are not alone with this condition. There are many other people living with CLL and other types of low-grade non-Hodgkin lymphoma. Talking to other people in a similar situation might help you understand more about the condition. This might give you reassurance and even tips on how to manage it.
Talk to your friends and family – the people who care about you will want to know what they can do to help you, even if the only thing you need is a listening ear.

Your medical team can also offer reassurance and advice and can let you know what support services are available in your local area. There are often workshops that can help you learn more about how to manage your condition.

“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 really reassuring to speak with others who had been diagnosed with lymphoma over 20 years beforehand; what a hopeful thing that was.”

Carl, diagnosed with CLL in 2011 at 40

Find out about our Information and Support team, support groups, buddy scheme and more at www.lymphoma-action.org.uk/Support-You
Look after yourself
Many people find that a cancer diagnosis makes them think about their lifestyle. Keeping healthy can help you deal with symptoms and put you in the best shape for recovering from any treatment.

Tips for looking after yourself

• Ask your medical team for advice and support to keep yourself healthy.
• Drink plenty of liquids, especially if you are having treatment.
• Eat a healthy diet with plenty of fruit 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.
• Stop smoking – you have a higher risk of lung infections and long-term side effects from treatment if you continue to smoke.
• Protect your skin from the sun – some treatments can make your skin more sensitive or cause skin problems. Use a high factor sunscreen suitable for sensitive skin.
• Keep active – build up slowly if you need to, but it is important to keep moving. Exercise can be particularly helpful for fatigue. There might be a local exercise programme for people in a similar situation.
People with CLL have a slightly increased risk of getting skin cancers such as basal cell carcinomas. If you notice anything unusual in your skin, show your family GP or CLL specialist. They can refer you to a specialist skin clinic for further investigations if they have any concerns.

NHS Choices has more information about skin cancer and what to look out for at www.nhs.uk/conditions/non-melanoma-skin-cancer

Work and study
Symptoms or treatment might mean you need to make adjustments to your day-to-day life if you are working or studying. Your employer must, by law, make any ‘reasonable adjustments’ to allow you to continue working. You might want to reduce your hours, change the type of work you do or even retire. Think about what is best for you and your family.

Find out more about the help available at www.lymphoma-action.org.uk/Day-to-day

Hobbies, socialising and travel
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’.
Remember that CLL grows slowly so there is rarely an urgent need for treatment.

Holidays can help you relax and enjoy the world as long as you think carefully about your plans and know how to look after yourself.

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 SLL/CLL in 2015 at 62

Tips for hobbies and holidays

• Discuss your hobbies and travel plans with your medical team so they can advise you of any precautions you need to take.
• At times when your blood counts are low, you might need to avoid crowds and travel, as you are more susceptible to infection.
• Find out what travel vaccinations you need and if it is safe to have them.
• Look for advice on travel insurance and make sure you are covered for your CLL.
Living your life

Try not to let CLL take over your life. It can take time to adjust to a ‘new normal’. Many people with CLL continue to have a full and active life.

- Our webpages and booklet *Living with lymphoma* offer information tips to help you live with CLL. Visit www.lymphoma-action.org.uk/LWL
- The CLL Support Association also produce a range of useful information. Visit www.cllsupport.org.uk
- On our website at www.lymphoma-action.org.uk/Useful-Organisations you will find a list of other organisations you may find helpful.
Even while on watch and wait for CLL, we’ve travelled all over. I like to keep busy and just do it – don’t hold back.

Peter, diagnosed with CLL at 55 in 2009
Information and support

If you’d like to talk to someone about anything to do with lymphoma (including how you feel) get in touch.

Call our Helpline freephone Monday to Friday on 0808 808 5555. You can also use Live Chat on our website.

Come to one of our support groups. Find one near you at www.lymphoma-action.org.uk/SupportGroups.

Join our online forum to chat with others who are affected by lymphoma.

Get in touch with a buddy, someone affected by lymphoma.

Visit www.lymphoma-action.org.uk/TrialsLink to find clinical trials that might be suitable for you.

Like us on Facebook.

Follow us on Twitter.

Check out our YouTube channel.

Follow us on Instagram.
How you can help us

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this booklet. Please visit our website at www.lymphoma-action.org.uk/Book-Feedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support team on 0808 808 5555.

We produce other publications that give information about lymphoma, including CLL, and what to expect from treatment. Visit our website at www.lymphoma-action.org.uk or call 0808 808 5555 for more information.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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Check our website for the most up-to-date details of our services, including opening times.
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This booklet explains what chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL) are. It covers how they are diagnosed and treated, and how to live well.

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 (Mon to Fri, 10am to 3pm)
Email information@lymphoma-action.org.uk
Visit www.lymphoma-action.org.uk
Live Chat via our website (Mon to Fri, 10am to 3pm)