Newly diagnosed with large granular lymphocytic leukaemia (LGLL)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. We are here for you and your loved ones every step of the way. Here are some of the ways we can help.

Helpline

Contact us for advice, support or someone to talk to.

- Call our freephone helpline on **08088 010 444** (weekdays 9am to 4.30pm)
- Send a WhatsApp message to **07500 068065** (weekdays 9am to 5pm)
- Email support@leukaemiacare.org.uk

Support groups

Connect, share experiences and find comfort from other people who've been affected by LGLL.

Buddy support

Chat to someone who's had a similar experience to you and understands what you're going through.

Facebook groups

Connect online with other people with leukaemia or their carers in our closed Facebook groups.

Leukaemia counselling service

Access up to six sessions of counselling to help you cope with the emotional impact of LGLL.

Advocacy and welfare team

Get advice on financial support, housing, employment issues and more.

Cost of living service

Apply for a one-off grant to help with essential living costs.

Will service

Write a free, simple Will so you know what happens to your money, property and belongings when you die.

Information

Find trustworthy, easy-to-understand information online and in print.

Leukaemia Care magazine

Subscribe to our free magazine for inspirational stories, articles and updates.

To access our services or find out more:

- Scan the QR code
- Call **08088 010 444**
- Search 'support' at www.leukaemiacare.org.uk

In this booklet

There is a lot of information about cancer on the internet. Some of it may not be reliable or up to date. A lot of it may not apply to you. Your haematology team are your best source of information because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Check for a quality mark, such as the Patient Information Forum (PIF) tick.

Introduction

Large granular lymphocytic leukaemia (LGLL) is a slow-growing blood cancer. It affects white blood cells known as lymphocytes. In this booklet we cover what LGLL is, how it is diagnosed and what treatments you may have. We also include practical information about living with LGLL.

There is a lot of information in this booklet. Each chapter has a summary at the beginning if you'd prefer a short overview.

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice or guidance from your health professional.

We'd like to thank the expert reviewers and patient contributors who helped us with this information:

- Dr Dima El-Sharkawi, consultant haematologist, Royal Marsden NHS Foundation Trust
- Dr Samir Agrawal, senior lecturer and honorary consultant, Barts Health NHS Trust and Blizard Institute, Queen Mary University of London
- Patient reviewers, Brenda, Katherine, Lesley, Nick and Wiclif

This booklet includes addresses and QR codes that link to webpages for further support. If you cannot access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

About large granular lymphocytic leukaemia (LGLL)

Summary

- Large granular lymphocytic leukaemia (LGLL) is a slow-growing blood cancer. It starts in white blood cells called lymphocytes.
- LGLL can affect people of any age, but it is more common in people over 60. It affects men and women equally.
- We do not know the exact cause of LGLL. It is not because of anything you did or did not do.
- Most people live with LGLL for many years.

About LGLL

Large granular lymphocytic leukaemia (LGLL) is a slow-growing blood cancer. It starts in white blood cells called lymphocytes. These become abnormal and don't die when they should. They also produce substances that kill healthy blood cells. This leads to a high level of abnormal lymphocytes and a low level of healthy red and white blood cells.

There are two main types of LGLL, depending on the exact type of cell it starts in:

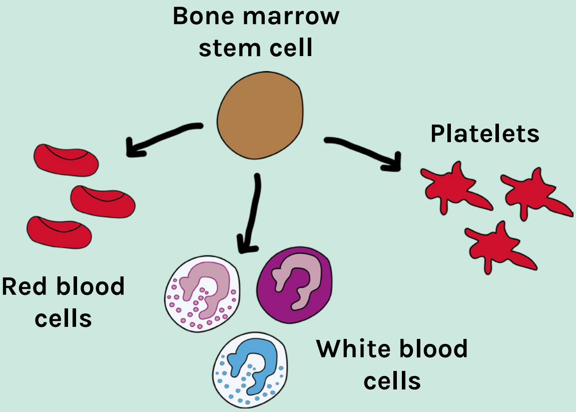
- T-cell LGLL starts in lymphocytes called T cells. Most people with LGLL have this type.
- NK-cell LGLL starts in lymphocytes called NK cells. This type of LGLL is less common.

Diagnosis and treatment options are the same whichever type you have.

More about blood cells

Blood cells grow and develop in the spongy centre of some of your larger bones. This is called bone marrow.

There are three main types of blood cell:



- Red blood cells carry oxygen around your body.
- White blood cells fight infections. There are different types, including lymphocytes such as T cells and NK cells.
- Platelets help clot your blood.

Who gets LGLL?

LGLL is a very rare leukaemia. Fewer than 300 people are diagnosed with it each year in the UK. This is why you might not have heard of LGLL or met anyone with it before.

LGLL can affect people of any age, but it is more common in people over 60. It affects men and women equally.

Most people with LGLL live for many years.

Causes of LGLL

We do not know the exact cause of LGLL. Some scientists think it might start after a reaction to an infection or another trigger, but they are still researching this. LGLL itself is not infectious. You cannot catch it and you cannot pass it on to someone else.

People with LGLL have genetic changes in their leukaemia cells that stop the cells from working properly. However, in most cases we do not know why these genetic changes occur. These changes are not because of anything you have or have not done.

But there are some factors that can increase your chance of getting LGLL. These include:

- Your age – LGLL is more common in people over 60
- Having an autoimmune condition such as rheumatoid arthritis
- If you have or have had a different type of cancer, including blood cancer

Symptoms and diagnosis of LGLL

Summary

- LGLL can cause symptoms such as:
    - Extreme tiredness
    - Infections that last a long time or keep coming back
    - Feeling tired, breathless or dizzy
    - Bruising or bleeding easily
    - Tummy pain, bloating or discomfort
    - Fever
    - Night sweats
    - Losing weight without trying to
- Sometimes you might not have symptoms when you are first diagnosed. You may be diagnosed after a blood test for something else.
- Your haematology team will diagnose LGLL based on blood tests. Sometimes you might also need bone marrow tests.
- Depending on your symptoms, you might have other tests or scans.

It can be difficult waiting for test results. We are here for you if you need support. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Signs and symptoms of LGLL

You might not have symptoms when you are first diagnosed. Many people are diagnosed after a blood test for something else. But you might get some signs or symptoms over time. The signs and symptoms you might get vary from person to person.

LGLL can cause the following signs and symptoms:

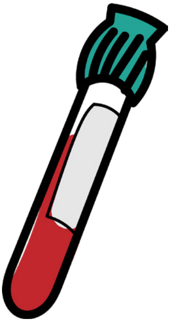
- Fatigue (feeling tired for no obvious reason)
- Infections that last a long time or keep coming back, especially skin, throat or sinus infections
- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia)
- Bruising or bleeding easily (for example, nose bleeds or bleeding gums when you brush your teeth)
- Tummy pain, bloating or discomfort due to a swollen spleen or liver (you may particularly notice this feeling under your ribs on the left-hand side)
- Fever
- Night sweats
- Losing weight without trying to

Diagnosis of LGLL

You'll have blood tests and sometimes bone marrow tests to diagnose LGLL. The samples go to the lab for specialist testing.

Blood tests

You will have blood tests to:

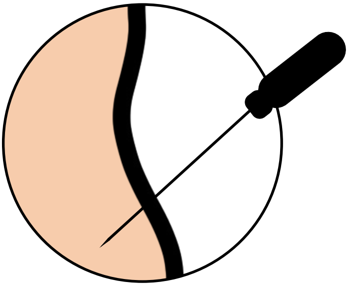


- Measure your numbers of red blood cells, white blood cells and platelets. If you have LGLL, you may have high levels of abnormal lymphocytes. You may have low levels of healthy blood cells.
- See how your blood cells look under a microscope. LGLL cells are larger than healthy lymphocytes and contain lots of granules.

You might also have blood tests to:

- Check how well your liver and kidneys are working
- Look for any signs of autoimmune conditions like rheumatoid arthritis
- Check if you have any infections that could flare up during treatment

Bone marrow tests



You might have a bone marrow test to confirm the diagnosis, but this may not be needed. This involves taking a sample of your bone marrow, usually from the back of your pelvis, with a local anaesthetic.

Cancer Research UK have more information on having a bone marrow test. Follow the link, scan the QR, or search 'bone marrow test' at cancerresearchuk.org

Lab tests

Your doctor will send your blood and bone marrow samples to the lab for specialist tests. They may check what proteins are on the surface of your leukaemia cells, or what genetic changes they have. The results can help your doctor work out the most suitable treatment for you.

Other tests you might have

You might have an ultrasound to check for a swollen liver or spleen. Depending on your symptoms, you might have other tests or scans.

Your test results may take a little while, which can be a worrying time for you. It is important for your haematology team to have all the results so they can make an accurate diagnosis. It can also help them work out the most suitable treatment options for you.

We are here for you if you need support whilst you are waiting for your results. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

Treatment of LGLL

Summary

- If your LGLL is not causing symptoms, you may not need treatment straight away. Instead, you will have regular tests and check-ups, known as active monitoring.
- Between 3 and 5 in every 10 people with LGLL never need treatment.
- You will usually start treatment if you have low levels of healthy blood cells or if you start to develop symptoms.
- Most people with LGLL who need treatment have medicines to lower the immune system. These are called immunosuppressants. They help improve your blood counts and relieve your symptoms.
- Your haematology team might suggest different treatment, depending on your situation.
- You will also have treatment to prevent or treat symptoms or side effects.
- You will have regular tests during your treatment to check how well your LGLL is responding.
- If LGLL does not respond to your first treatment, your team will explain what other treatment options they recommend.

Treatment options

Many people with LGLL do not need treatment straight away. If you do need treatment, your haematology team will explain what treatment they recommend and what you can expect from it.

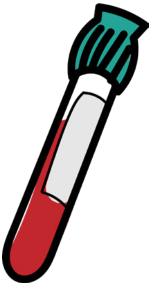
- Between 3 and 5 in every 10 people with LGLL never need treatment.
- Between 5 and 7 in every 10 people with LGLL have treatment at some point.

If you need treatment, your team will base this on many factors, including:

- Whether or not you have any symptoms
- Your age and overall fitness
- Whether or not you have any other medical conditions
- The genetic changes in your leukaemia cells
- The proteins on the surface of your leukaemia cells
- Your preference on how you wish to be treated

Treatment for LGLL aims to control it rather than cure it. It usually involves medicines to lower your immune system. If you have an autoimmune condition, you'll have treatment for that too.

Active monitoring



If your LGLL is not causing symptoms, you may not need treatment straight away. Instead, you might have regular check-ups and blood tests to monitor how LGLL is affecting you. This is called active monitoring. Some people call it watch and wait. If you have stable symptoms and blood results, your check-ups might be by phone or video call.

Your medical team will tell you who to contact if you have any concerns between appointments.

Some people feel relieved or reassured that they do not need treatment straight away. But some people might find it difficult to hear they have cancer but are not starting treatment. However, active monitoring is a safe approach for slow-growing blood cancers. If you're feeling well, there is no benefit to starting treatment before you need it. This means you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it.

You are likely to start treatment if:

- Your blood tests show low levels of healthy blood cells
- You start to develop symptoms or your symptoms become worse

We have separate information on active monitoring. Follow the link, scan the QR code or visit leukaemiacare.org.uk and search 'active monitoring'.

Immunosuppressants

Most people with LGLL who need treatment have medicines to lower the immune system. These are called immunosuppressants. You usually take them as tablets at home. They help improve your blood counts and reduce your symptoms. They may also reduce the number of abnormal lymphocytes in your body.

The main immunosuppressant medicines used to treat LGLL are:

- Methotrexate
- Cyclophosphamide
- Ciclosporin

Your haematology team will tell you which one they recommend for you. They will tell you how to have it and what side effects you might get.

Your medical team will let you know how much you need to have and how often.

It can take at least 4 months to know if your treatment is working well.

If your treatment is working well, you usually carry on taking methotrexate or ciclosporin unless you get side effects that are difficult to cope with.

You usually take cyclophosphamide for up to 12 months.

"I was shocked to be prescribed methotrexate and was nervous about taking it. However, I found I tolerated it really well, as do a lot of people."

Brenda, diagnosed with LGLL in 2018

Other treatments

Sometimes your haematology team might suggest different treatment. This could include:

- A clinical trial, if there is one suitable for you
- Surgery to remove your spleen, if it is swollen and causing symptoms

Macmillan have more information about clinical trials. Follow the link, scan the QR code or search for 'clinical trials' at www.macmillan.org.uk

Supportive treatment

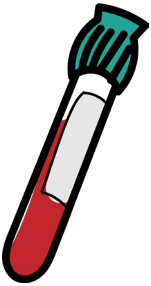
You might also need medicine to prevent or treat symptoms or side effects. This is called supportive treatment. It does not treat your LGLL itself, but it helps you feel better.

Supportive treatment might include:

- Blood transfusions or medicines called growth factors, if your blood counts are low
- Medicine to prevent or treat infections
- Medicine to prevent or treat side effects
- Steroids, which can help with many different symptoms

Monitoring during treatment

You will have regular tests during your treatment to check how well your LGLL is responding. And how well your body is coping with the treatment.



These tests might include:

- Blood tests to check your levels of white blood cells, red blood cells and platelets
- Blood tests to check your liver and kidney function
- Blood tests to check the amount of medicine in your bloodstream
- Bone marrow tests

Treatment if LGLL does not respond

Sometimes LGLL doesn’t respond well to treatment or comes back after treatment.

- Relapsed LGLL is when LGLL comes back after successful treatment.
- Refractory LGLL is when LGLL does not respond to your first treatment.

If this happens, your haematology team will talk to you about your treatment options. They might suggest:

- An antibody therapy such as rituximab or alemtuzumab. These are lab-made antibodies that stick to proteins on the surface of cancer cells. This helps your immune system recognise and destroy the cells. You usually have antibody therapy as an injection or through a drip.
- Chemotherapy medicines. These kill cells that are dividing rapidly, such as blood cells. If your doctor recommends chemotherapy, they will tell you what medicines they suggest and how you have them.

Side effects of LGLL treatment

Summary

- Side effects of some LGLL treatments include:
  - A higher chance of getting infections. Any infections you do get may be more serious.
  - Extreme tiredness (fatigue).
  - Low blood cell counts.
  - Changes in your liver or kidney function.
- Your haematology team will monitor you closely so they can treat side effects promptly.
- Treatment for LGLL can harm unborn babies. Some treatments can damage sperm and eggs. You should not become pregnant, or make someone pregnant, while you are having treatment for LGLL.
- **Tell your team straight away if you have any symptoms or side effects.**

Important side effects of LGLL treatment

Like all medicines, treatment for LGLL can cause side effects. Some of these can be serious. Side effects are different for everyone, and we cannot predict what side effects you may get.

Your haematology team will monitor you for serious side effects. You'll have regular checks and blood tests. This means they can treat side effects promptly if they happen.

Tell your medical team straight away if you have any symptoms or side effects.

Your haematology team will explain the side effects you might get with your treatment. Here, we cover some of the important side effects of LGLL treatment in general. It is not a complete list.

Infection risk

LGLL treatment can lower your white blood cell count. This is called neutropenia. It means your body can't fight infections as well as usual. So, you have a higher chance of getting infections, and any infections you do get may be more serious.

Contact your medical team straight away if you think you have an infection. Signs include:

- A high temperature (38°C or higher)
- Aching muscles, shivering or chills
- Sore throat, blocked or runny nose or cough
- Burning or stinging when you pee, or peeing more often than usual
- Diarrhoea, being sick or tummy pain
- Headache or stiff neck
- Pain or redness around any cuts or wounds
- Feeling very tired or generally unwell

Infections can get worse quickly if you have a weakened immune system, so it is important to get treatment as soon as possible. Your haematology team should tell you who to contact if you think you have an infection.

If your white blood cell count is low, there are things you can do to lower your risk of getting an infection. These include:

- Washing your hands frequently
- Avoiding crowded spaces
- Avoiding people who are unwell
- Storing and preparing food correctly to reduce the risk of food poisoning
- Making sure your kitchen is clean
- Regularly cleaning surfaces that you touch a lot, like light switches and door handles
- Having any vaccinations that you are eligible for

Your haematology team might also prescribe medicines to help prevent infections.

Fatigue

LGLL and its treatment can cause fatigue. This is a feeling of physical or mental exhaustion that doesn't get better with sleep or rest.

Fatigue can be frustrating as it cannot be treated with medicines. But there are things you can do to help you manage it.

> **"Whilst I still suffer from fatigue, I now feel confident that there is a way forward. This has very much been helped by not only the support of my haematology team but also Leukaemia Care."**
>
> Nick, diagnosed with LGLL in 2022

Tips for coping with fatigue

Make plans and pace yourself.

- Prioritise things that are important to you and reserve energy for these.
- Build time to rest around planned busy periods.
- Allow yourself to rest as and when you need.

Keep to a regular sleep schedule.

- Try to go to bed and wake up at around the same time each day.
- Keep your bedroom quiet and a comfortable temperature.
- Avoid eating or drinking alcohol, coffee, tea or chocolate before bedtime.
- Avoid using laptops, tablets or mobile phones before going to bed.

Do regular, gentle exercise to maintain your fitness levels.

Accept help with household tasks.

Make sure to tell your haematology team if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

Problems found on blood tests

You have regular blood tests during treatment to check your blood counts and your liver and kidney function.

- LGLL and its treatment can cause low blood counts. If this happens you might have blood transfusions or medicines called growth factors.
- LGLL can affect your liver and kidneys. If your blood tests find any problems, your team might reduce your dose or stop treatment for a while.
- LGLL can affect the level of fats in your blood.

Hair loss

Some treatments for LGLL can cause hair loss or thinning. Hair loss is usually temporary. It happens gradually. Some people prefer to shave their hair or cut it short. This can give you a feeling of control and reduce the emotional impact of it falling out. You could also cover your hair loss, if you choose to. There are lots of options like hats, headscarves, wraps, turbans or wigs.

Cancer Hair Care have more information on hair loss, including how to care for Afro-textured hair during chemotherapy. Follow the link, scan the QR code or search for 'hair loss overview' on cancerhaircare.co.uk

Other side effects you might get

Side effects vary from person to person. Other side effects you might get include:

- Feeling anxious, depressed, confused or finding it hard to sleep.
- Headache or dizziness.
- Sore mouth.
- Feeling or being sick.
- Diarrhoea, constipation or tummy pain.
- Bone, joint or muscle pain or tremors.
- Fever, chills, feeling generally unwell or weak.
- Pain when you pee or blood in your pee.
- Skin rash, itching, spots.
- High blood pressure.
- Secondary cancers. If you have any concerning symptoms, tell your doctor straight away. Make sure to go to any screening tests you're offered.
- Chest pain, difficulty breathing.
- A fast, slow or irregular heart rate, fluttering fast heart rate.

Pregnancy, fertility and breastfeeding

Some treatments for LGLL may affect your fertility. If you think you may want to have children in the future, tell your haematology team. They can give you advice on sperm or egg storage before starting treatment.

Treatment for LGLL may harm unborn babies. Some treatments can damage sperm and eggs. You should not get pregnant or make someone pregnant while you are having LGLL treatment.

- **If you could get pregnant:**
  - **You must use effective contraception during treatment and for several months after.**
  - You will have a pregnancy test before treatment to make sure you are not pregnant.
  - You might also have regular pregnancy tests during treatment.
  - How long you must continue to use effective contraception after finishing treatment varies for different treatments. Your haematology team will tell you.
- If you think you might be pregnant, tell your haematology team as soon as possible. They will talk to you about your options.
- If you could make someone pregnant, you may need to use effective contraception during treatment and for several months after. It depends what treatment you are having. Your team will tell you.

Treatments for LGLL pass into breastmilk. You must not breastfeed during treatment.

Outcomes of LGLL

Summary

- LGLL is a slow-growing blood cancer. Treatment aims to control it rather than cure it, but it is often effective.
- Most people live with LGLL for many years.
- The outcome of LGLL depends on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person.
- Your haematology team are best placed to discuss what they expect for you because they know your individual case.

Outcomes of LGLL

LGLL is a slow-growing blood cancer. Treatment aims to control it rather than cure it, but it is often effective. You can live with LGLL for many years with or without treatment. Most people with LGLL do **not** die from it.

> **"When I first got my results, my consultant was quite positive. Being told that you have cancer is a bit scary, but I was encouraged by the survival quoted and the fact that a significant percentage of people only need active monitoring."**
>
> Wiclif, diagnosed with LGLL in 2025

Your outcome can vary depending on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person. They depend on lots of different factors, including:

- Your age and overall fitness
- Whether or not you have any symptoms and how severe they are
- Whether or not you have any other medical conditions
- The genetic changes in your leukaemia cells
- The proteins on the surface of your leukaemia cells

Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

If you are interested in general survival numbers for LGLL, we include some figures on the next page. You may prefer not to look at these.

It’s important to remember that survival numbers cannot tell you what will happen in individual situations. They look at what happened to groups of people with a similar diagnosis in the past. They are based on data collected over many years, when people may not have received treatments that are available now.

Often, 5-year survival rates are quoted. This is the proportion of people with a particular condition who are still alive 5 years after diagnosis.

Survival rates do not tell us anything about what people who are not alive 5 years after diagnosis died from. It may have been the condition, or it may have been from another cause.

On average, around 89 in 100 people with LGLL are still alive 5 years after their diagnosis. This means around 11 in 100 are not. But we do not know whether they died because of LGLL or because of something else. Most people with LGLL are over 70 and may have several health conditions.

Living with LGLL

Summary

- Being diagnosed with LGLL can be overwhelming. Give yourself time to adjust before you decide when and how to tell other people.
- You may experience a variety of emotions. There is no right or wrong way to feel. But if you think you may be depressed, contact your GP.
- You probably have a lot of questions. Make a list of them so you don't forget to ask them when you see your haematology team.
- Don't be afraid to ask for help from family, friends, your haematology team or Leukaemia Care support services.
- Having LGLL can affect your work or finances. You may be eligible for financial support. If you're well enough to work or study, you are entitled to reasonable adjustments to help you cope.
- Try to keep active and eat a healthy, balanced diet if you can, to help you feel better physically and emotionally.

Living with LGLL

Being diagnosed with LGLL can be overwhelming. It is something that can affect you both physically and emotionally. Symptoms, the effects of treatment, and hospital appointments, may all impact your day-to-day life. Here, we cover some practical information about living with LGLL and where to get support if you need it.

You might find our newly-diagnosed webpage helpful. Follow the link, scan the QR code or search 'just diagnosed' at leukaemiacare.org.uk.

Managing your emotions

Finding out you have LGLL is difficult. You may need emotional and practical support. It is likely you will experience a range of complex thoughts and emotions, like:

- Shock or disbelief
- Uncertainty, anxiety or fear about the future
- Sadness or depression
- A sense of loss of the person you used to be, and how safe you felt
- Worry about other people's reactions
- Isolation, or a feeling that other people don't understand what you're going through
- Guilt, anger, frustration or irritability
- A loss of self-confidence

Everybody reacts differently. You may experience some of these emotions but not others. You might have different feelings at different times. There is no right or wrong way to feel.

Tell your haematology team how you're feeling, even if you say you are confused about your feelings. They can help you access support. They may be able to refer you for counselling if you need it.

Sadness and depression

You might be feeling low, which is a natural effect of your diagnosis and treatment. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, it is important to contact your GP. They can help you access the support and treatment that you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Scan the QR code for details or go to the 'mental health' section at www.nhs.uk

Where to seek support and how to cope

There are several places where you can seek emotional support, such as:

- Loved ones and caregivers
- Your clinical nurse specialist, if you have one
- Your consultant
- Charities and other organisations

Talking to other people can help. It can be difficult to talk to loved ones, so you might prefer to speak to someone independent. It can also help to talk to other people who have gone through a similar experience.

We're here for you if you need support. Scan the QR code, follow the link or search 'support for you' at leukaemiacare.org.uk to find out how we can help you. Our support services include:

- Helpline and advocacy services to provide information and support
- Support Groups and Buddy Service, where you can connect with people who understand your experience
- A counselling service where we can help you access up to six sessions of counselling, free of charge

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

Some people find relaxation techniques help them cope with difficult emotions, or use complementary therapies like acupuncture, massage or yoga. Some people find faith or spirituality helpful.

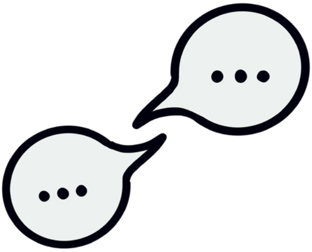
Macmillan have information on complementary therapies, including mindfulness. Scan the QR code, follow the link or search 'complementary therapies' at macmillan.org.uk

> **"Following diagnosis with LGLL both my wife and I felt very alone and apprehensive about the future. Once I realised I could speak to both my consultant and haematology team I felt supported."**
>
> Nick, diagnosed with LGLL in 2022

Telling people

When you are first diagnosed with LGLL, there is a lot to take in. You may need to give yourself time to adjust before you decide when and how you tell others about it. People may be anxious to know what's happening, which can make you feel under pressure to tell them. Let them know you need time to process the information before you are ready to talk about it.

There will be some people you want to tell and others you prefer not to. It is up to you who you tell and how much you tell them. It can help to make a list and plan what you want to say beforehand. In the conversation with your loved ones, you might want to:



- Explain that have a type of blood cancer.
- Explain what symptoms you get (maybe you feel tired or get infections a lot).
- Explain your needs. Your family and friends may be happy to know they can help support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. People who care about you will help you as best as they can.
- Have a print-out or factsheet with you. This means you don't have to remember everything that your friends and family might want to know. Or you could give them a copy of this booklet.

If you can, choose somewhere where you can hear each other clearly and where you're not likely to be interrupted. Try to speak slowly and calmly to give the other person time to take in the information.

Repeating yourself to different people can be draining. You could ask your family or friends to let other people know, so you don't have to tell everybody yourself.

If you are struggling to come to terms with your diagnosis, you can speak to us on our helpline on **08088 010 444**.

Looking after yourself

It's important to look after yourself as well as you can. This can help you feel better physically and emotionally. If you're able to, try to eat a well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with your treatment

The NHS website has information and guidance on eating a healthy, balanced diet. Follow the link, scan the QR code or search 'eat well' at nhs.uk.

Staying active is also helpful. Exercise can improve your wellbeing, quality of life and physical health. It can also help you cope with your emotions. It doesn't have to be strenuous – even a gentle walk or getting some fresh air can help. Choose a level of exercise that works for you and how you are feeling.

If your blood counts are very low, ask your haematology team if you need to take any precautions.

Going to appointments

You may need to attend regular appointments with your haematologist, clinical nurse specialist (if you have one) or sometimes your GP.

Appointments often involve a lot of waiting around. You could download a podcast or TV programme to keep you occupied while you wait. Or take something physical like a book or travel game.

Once you're in your appointment, it can be hard to take in everything your doctor or nurse tells you. Below are some tips to help you get the most from your appointment:

- It can help to take a family member or friend with you for support.
- Ask any questions that you may have. If you don't understand something, ask your medical team to explain. They will be used to this.
- You could take notes on your phone or paper to help you remember. Or you could ask your doctor or nurse to write things down or ask if they're happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping.

> **"I found it was best to monitor my blood counts and take a list of questions whenever I met with my consultant."**
>
> Nick, diagnosed with LGLL in 2022

Questions for appointments

Sometimes it can be overwhelming to know what to ask in your appointments. Some questions you might want to ask include:

- What tests will I need?
- What might the tests show?
- How long will it take to get the results back?
- What treatment will I need?
- How long will my treatment last?
- How will I know if my treatment has worked?
- What might the side effects be?
- Are there any food or medicines that I need to avoid?
- Will I be able to go back to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

Work, education and money

Being diagnosed with LGLL and having to juggle work or education with hospital or GP appointments can be challenging. You may need to take time off work or education when you're feeling unwell and to attend appointments.

You'll probably need to keep your employer or education provider informed. Your consultant or GP can write letters to confirm your diagnosis and explain how this may affect your work or education. Depending on your employment contract, you may be entitled to sick pay. If you are at university, you may want to consider deferring your attendance for a while.

If you are well enough to work or study, you are entitled to reasonable adjustments to help you cope. You may wish to have an open conversation with your employer or education provider about how they can support you.

Having LGLL can affect your finances, whether or not you are working. Being diagnosed with leukaemia can come with extra costs such as extra heating costs, travel to and from hospital and childcare costs. You may be eligible for financial support.

If you have LGLL, you are entitled to free prescriptions. Your haematology team or GP can tell you how to apply for this.

Charities and financial support

We have a range of services that can help you when living with LGLL, including a welfare service and cost of living hub. Follow the link, scan the QR code or search 'support for you' at leukaemiacare.org.uk

Macmillan have information on benefits and financial support you might be able to access. Follow the link, scan the QR code or search for 'benefits and financial support' on www.macmillan.org.uk for more information.

Words you might see or hear

Active monitoring: a way of monitoring your health when you have a blood cancer that doesn't need immediate treatment. You have regular check-ups and you also monitor your symptoms at home.

Anaemia: a low red blood cell count.

Antibody therapy: a lab-made antibody that sticks to targets on cancer cells, so your immune system can kill the cells.

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

Autoimmune condition: a condition that happens when your immune system mistakenly attacks your own body.

Blood transfusion: a procedure to give you donated blood through a drip into a vein.

Bone marrow: the spongy centre of some of your larger bones where blood cells are made.

Cancer: an illness that happens when abnormal cells grow and divide uncontrollably.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Fatigue: extreme tiredness or lack of energy that can interfere with your usual activities and doesn't get better when you rest.

Genetic changes: changes to genes that can affect the proteins a cell makes. This may change how a cell behaves and grows. They are also known as genetic variants.

Growth factor: a type of medicine that boosts your blood cell counts.

Haematology: the branch of medicine that deals with diseases of the blood.

Immune system: the cells and systems in your body that protect you from infection.

Immunosuppressants: medicines that lower your immune system.

Large granular lymphocytic leukaemia (LGLL): a rare slow-growing type of blood cancer that affects white blood cells called lymphocytes. When you look at them under a microscope, the cells are larger than usual and contain granules.

Leukaemia: a group of cancers that usually start in the bone marrow and lead to high numbers of abnormal blood cells.

Liver: a large organ in your body that sits under your ribs on the right. It helps fight infection and disease, balances your hormones, cleans your blood and processes food.

Local anaesthetic: a medicine to numb part of your body so you don’t feel any pain during medical procedures.

Lymphocyte: a type of white blood cell that helps fight infections.

Neutropenia: a low level of white blood cells called neutrophils.

Platelet: a type of blood cell that helps your blood clot and stops bleeding.

Proteins: the building blocks of every cell, tissue and organ in your body. Your body needs proteins for growth, repair, and to fight infections.

Red blood cell: a type of cell in your blood that carries oxygen around your body.

Refractory: cancer that does not respond well to your first treatment.

Relapse: when cancer comes back after successful treatment.

Rheumatoid arthritis: an autoimmune condition that causes your immune system to attack your joints. You may have pain, stiffness and swelling in your joints.

Spleen: a fist-sized organ that sits under your ribs on the left side. It filters and stores blood and makes some blood cells.

Supportive treatment: medicine to prevent or treat symptoms or side effects.

Ultrasound: a scan that uses sound waves to look at the inside of your body.

White blood cells: cells in your blood that help your body fight infections.

Useful contacts and further support

Coping with LGLL can be difficult. You may need support from:

- Your healthcare team
- Family and friends
- Leukaemia Care
- Other charities

Here are some organisations you might find helpful.

Leukaemia Care
Helpline: **08088 010 444** (Monday to Friday, 9am to 4:30pm)
WhatsApp: **07500 068065** (Monday to Friday, 9am to 5pm)
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Blood Cancer UK
Leading charity into the research of blood cancers.
0808 2080 888
bloodcancer.org.uk

Cancer Research UK
Leading charity dedicated to cancer research.
0808 800 4040
www.cancerresearchuk.org

Macmillan

Provide free practical, medical and financial support for people facing cancer.

0808 808 00 00

www.macmillan.org.uk

Maggie's

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggies.org

Carers UK

Offer advice, information and support for carers.

0808 808 7777

www.carersuk.org

Citizens Advice

Offer advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

The Citizens Advice service does not cover Northern Ireland but their website lists contact details for local community advice agencies, depending on where you live.

How you can help us

Share your story

If you've been affected by LGLL, sharing your story can help others in a similar situation. It can also help people understand LGLL better.

To share your story:

- Go to www.leukaemiacare.org.uk/share-your-story
- Scan the QR code
- Email communications@leukaemiacare.org.uk

Volunteer with us

Volunteering with us can help you develop life skills, find a sense of purpose, and make a difference to other people affected by LGLL. There are lots of ways to get involved, depending on how much time you have to give – and we'll be there to provide support. You could:

- Become a Buddy to help someone going through a similar experience
- Join our patient panel to help us shape what we offer

To find out more, email volunteering@leukaemiacare.org.uk

Tell us what you think of this booklet

Please follow the link or scan the QR code to complete a short survey to let us know how we can improve our information. Or get in touch by email, phone or post.

- Email information@leukaemiacare.org.uk
- Call our Head Office on **08088 010 444**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG

You can also contact us if you'd like a list of the sources we used for this booklet.

If we’ve helped you - here’s how you can give back

We are here for people with leukaemia and their families, purely because of public support and generosity – kind people like you.

You can help

- Fancy the chance to win £25,000? Join our weekly lottery from as little as £1 a week.
- Organise your own event. You could host a quiz night or bake sale with friends, at work or school.
- Does your employer make charitable grants or donations to good causes?
- Ask your society, group or sports club about their charity of the year partner.
- Prefer to get outdoors? Take on one of our challenges of varying levels. Walk, run or for the more adventurous, a skydive?

No fuss options

- Make a one-off donation.
- Sign up for monthly donations.
- Or simply spread the word. Raising awareness of Leukaemia Care with your family and contacts is invaluable.

Contact our fundraising team

- Scan the QR code
- Email fundraising@leukaemiacare.org.uk
- Call **08088 010 444**

Plenty of ways to give

There are so many ways you can give to help support people affected by leukaemia. Find one that fits you!

By bank transfer

You can transfer your donation straight from your account to ours:

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

By cheque

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

Online

Simply visit www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us on **08088 010 444** to donate by debit or credit card over the phone.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

- Call our freephone Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Send us a WhatsApp message: **07500 068065** (weekdays 9am to 5pm)
- **www.leukaemiacare.org.uk**
- **support@leukaemiacare.org.uk**

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

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Leukaemia Care
YOUR Blood Cancer Charity

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