Acute lymphoblastic leukaemia (ALL)

What you need to know

leukaemiacare.org.uk

Leukaemia Care

About Leukaemia Care

Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.

Helpline: Contact us for advice, support or a listening ear.

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

Support groups: Connect, share experiences and find comfort from other people who've been affected by ALL.

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 ALL or their carers.

Advocacy and welfare team: Get support with the practical things in life like money, work and your rights.

Leukaemia counselling service: Access up to six sessions of counselling to help you cope with the emotional impact of ALL.

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 reliable information online and in print.

To access our services or find out more:

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

Contents

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 from your health professional.

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 doctor or nurse is your best source of information because they know you and your situation. If you want to search for information yourself, look for trustworthy organisations like the NHS or national charities. Check for a quality mark, such as the PIF tick.

Introduction

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 booklet is about acute lymphoblastic leukaemia (ALL) in adults.

ALL is a fast-growing type of blood cancer. We cover what it is, how it is diagnosed and what treatment you may have. We also include practical information about living with ALL.

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

- Professor Rachael Hough, consultant haematologist
- Lindsay George, haematology consultant
- Caroline Kerr, haematology clinical nurse specialist
- Patient reviewers, Curtis, Heather and Tara

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

About acute lymphoblastic leukaemia (ALL)

Summary

- Acute lymphoblastic leukaemia (ALL) is a fast-growing blood cancer. It affects immature white blood cells called lymphoblasts.
- There are two main types of ALL: B-cell ALL and T-cell ALL.
- ALL can affect people of any age. It is most common in children and young adults (25 and under), but it can affect older adults too. It is slightly more common in men than in women.
- We do not know the exact cause of ALL. **It is not because of anything you did or did not do.**

What is ALL?

Acute lymphoblastic leukaemia (ALL) is a fast-growing blood cancer. It starts in the bone marrow in immature white blood cells called lymphoblasts. These immature cells divide uncontrollably. They fill up your bone marrow and stop it making enough healthy blood cells. The abnormal blood cells can also build up in other parts of your body.

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 cells:

Red blood cells carry oxygen around your body

White blood cells fight infections

Platelets help clot your blood

Types of ALL

Lymphoblasts are immature blood cells. They usually develop into white blood cells called lymphocytes.

There are two main types of lymphocyte:

- B lymphocytes (or B cells) make antibodies
- T lymphocytes (or T cells) recognise and destroy damaged or infected cells

ALL can affect either B cells or T cells. So there are two main types of ALL, depending on which blood cells are affected:

- B-cell ALL. About 8 in 10 people with ALL have this type.
- T-cell ALL. About 2 in 10 people with ALL have this type.

B-cell ALL can be grouped further into subtypes. These are based on the gene changes in the leukaemia cells. They have complicated names so they're usually shortened to their initials. If you have a particular subtype, your doctor will explain what it means.

Your haematology team will tell you what type of ALL you have and what you can expect. You may have different treatment depending on the type of ALL you have.

Who gets ALL?

ALL can affect people of any age. It is most common in children and young adults (25 and under), but it can affect older adults too. It is slightly more common in men than in women.

This booklet focuses on ALL in adults.

Each year in the UK:

- Around 240 adults are diagnosed with B-cell ALL
- Around 50 adults are diagnosed with T-cell ALL

Information on ALL in children

The following charities have more information on cancer in children or teenagers.

- **Children and Young People's Cancer Association**
- **Children with Cancer UK**
- **Teenage Cancer Trust**

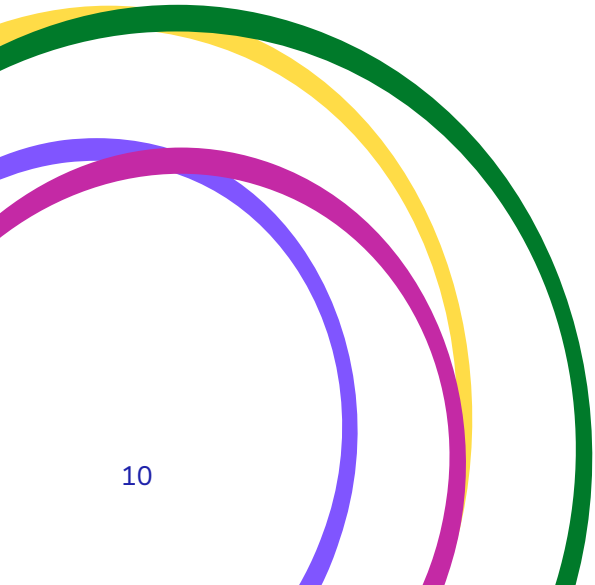
Follow the links, scan the QR code or search 'childhood acute lymphoblastic leukaemia' at **leukaemiacare.org.uk** for more information.

What causes ALL?

We do not know the exact cause of ALL. It is not because of anything you have or have not done.

People with ALL have genetic changes in their leukaemia cells that stop the cells from working properly. In most cases, we do not know why these genetic changes happen.

Most of these gene changes happen by chance during your lifetime. **You do not get them from your parents and you cannot pass them on to any children you have.**



There are some factors that can increase your chance of getting ALL. These include:

- If you have had another type of cancer in the past, including blood cancer
- If you have had some types of chemotherapy in the past
- If you have been exposed to high doses of radiation
- Some genetic conditions

Genetic conditions and ALL

Some genetic conditions can increase your risk of getting ALL. These include conditions called:

- Down's syndrome
- Fanconi anaemia
- Ataxia telangiectasia
- Bloom syndrome
- Nijmegen breakage syndrome

Having one of these conditions does not mean you will definitely get ALL. The risk is still low. But it is higher than in people who do not have these conditions.

Genetic changes in ALL

In ALL changes in your genes, chromosomes or both mean your lymphocytes divide and mature uncontrollably. Your team will consider what genetic changes you have when deciding on the best treatment option for you.

About genes and chromosomes

- Genes are made up of DNA. They contain instructions for your cells on how to make the proteins your body needs.
- Chromosomes are long, coiled strands of DNA that sit in the nucleus of each of your cells. Each chromosome contains lots of different genes.

There are many different gene changes linked to ALL. Gene changes have complicated names so they are usually shortened to their initials.

Some gene changes in ALL help your team work out your subtype of ALL. There are many gene changes that can happen in ALL. Some common ones include gene changes called:

- *KMT2A*
- *ETV6-RUNX1*
- *TCF3-PBX1*
- *IGH-IL3*
- *TCF3-HLF*

Other common gene changes in ALL include:

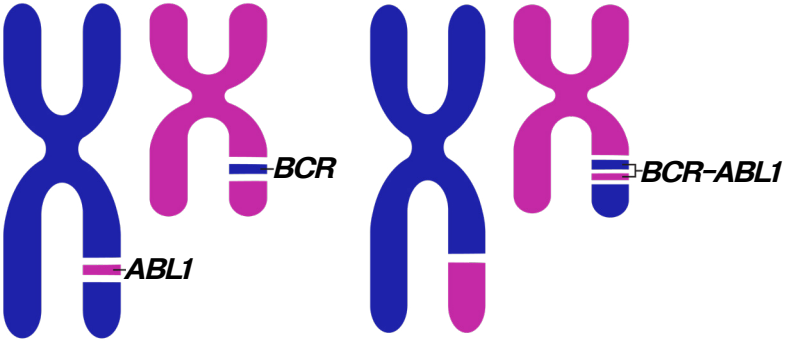
- *BCR-ABL1*, usually known as the Philadelphia chromosome
- *CRLF2*
- *NOTCH1*
- *TAL1*

Your haematology team will tell you what gene changes you have and explain what this means.

Philadelphia chromosome

About 3 in every 10 people with B-cell ALL have a genetic change called a Philadelphia chromosome. Around 7 in every 10 do not have this change.

This chromosome forms when genetic material swaps between chromosome 9 and 22. The swap makes two genes fuse together to make an abnormal fusion gene called *BCR-ABL1*. You might also see this written as *BCR::ABL1* or t(9;22).



A genetic change called *T315I* can happen in the Philadelphia chromosome. This change can make ALL harder to treat with some types of targeted treatments.

Symptoms and diagnosis of ALL

Summary

- ALL can cause different symptoms in different people. Some of the more common symptoms include:
  - Frequent or long-lasting infections
  - Bruising or bleeding easily
  - A rash of tiny dots under your skin
  - Feeling breathless or dizzy and looking pale
  - Fatigue
  - Bone pain
  - Losing weight without trying to
  - Sweating a lot at night
  - Fever, for no obvious reason
- Your doctor will diagnose ALL based on blood tests and bone marrow tests.
- Depending on your symptoms, you might also have other tests and scans.
- **It can be difficult waiting for test results. We are here for you if you need support.**

Signs and symptoms of ALL

The signs and symptoms you might get vary from person to person. You might get some symptoms but not others. They include:

Infections that last a long time or keep coming back.

Bruising easily, or for no reason at all.

Unusual bleeding, like nosebleeds, bleeding gums after brushing your teeth or heavier periods than usual.

A rash of tiny red, purple or darker dots under your skin, or other skin problems. This may be harder to see on black or brown skin.

Feeling breathless or dizzy.

Looking pale. If you have black or brown skin, this may be easier to see on your palms, gums or the insides of your eyelids.

Feeling exhausted or worn out, even after resting.

Fever for no obvious reason.

Sweating a lot at night.

Losing weight without trying to.

Swollen lymph nodes (glands) that don't go down within a few weeks.

Tummy pain, bloating or feeling full quickly after eating.

Losing your appetite.

Bone pain.

Diagnosis of ALL

You'll have blood tests and bone marrow tests to diagnose ALL. 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.
- See how your blood cells look under a microscope. The abnormal cells look different from healthy white blood cells.
- Check your liver and kidney function.
- Check if you have HIV, hepatitis or other infections that could flare up during treatment.

Bone marrow tests

If your haematology team think you have ALL, they will also do a bone marrow test. 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 code, or search 'bone marrow test' at **cancerresearchuk.org**

Lumbar puncture

You team will also do a lumbar puncture to check if you have leukaemia cells in your central nervous system (your brain and spinal cord). A lumbar puncture is a test to collect a sample of the fluid that surrounds your brain and spinal cord.

You have an injection to numb a small area of your lower back first. Then your doctor puts a needle between the bones in your spine to collect a sample of fluid. It may be uncomfortable during and afterwards, and you might get a headache. Ask your doctor or nurse what painkillers you can use if you need them.

Lab tests

Your doctor will send your samples to the lab for specialist tests. They will check:

- The proteins on the surface of your leukaemia cells. These have names such as CD19 and CD20.
- The genetic changes in your leukaemia cells (see **page 11**).

The results help your doctor work out what type of ALL you have and the most suitable treatment for you.

Other tests you might have

Depending on your symptoms, you might have other tests or scans. These might include:

- A heart scan to help work out which treatment options are best for you
- An ultrasound, CT or PET scan to check if the leukaemia cells have spread to other parts of your body
- A biopsy of your lymph nodes

Your test results may take a little while, which can be worrying. 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 while you're waiting for your results.

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

Treatment of ALL

Summary

- Before starting treatment, your team may place a central line to make having treatment and blood tests easier.
- You usually have steroids first, sometimes with chemotherapy.
- Then you start your main treatment. This happens in phases. They are often called induction, intensification and consolidation, and maintenance. The number of phases you have in total will depend on your leukaemia.
- You usually stay in hospital for the first phase.
- ALL treatment involves chemotherapy medicines and steroids.
- You might also have targeted medicines or antibody therapy, depending on the proteins and genetic changes in your leukaemia cells.
- You will also have treatment to prevent or manage symptoms or side effects.
- You will have blood tests and bone marrow tests to check how well treatment is working for you.

Treatment options

Treatment for ALL starts straight away. It happens in phases, with different treatments at different times. These phases have different names. Often, people call them:

- Pre-induction or pre-phase (**page 26**).
- Induction. This usually includes two phases or cycles (**page 27**).
- Intensification and consolidation (**page 28**).
- Maintenance (**page 31**).

Your medical team will work out the most suitable treatment for you based on many factors. These include:

- Your age and overall fitness
- Your subtype of ALL
- The genetic changes and proteins in your leukaemia cells
- Any other medical conditions you have
- Your preference on how you wish to be treated

They will tell you what treatment they recommend for you and what you can expect.

Your treatment will include:

- Chemotherapy medicines which kill cells that divide rapidly. Chemotherapy kills cancer cells but can also affect other fast-growing cells like hair cells or the cells lining your gut.
- Steroids, which have anti-cancer effects. They can also help reduce some treatment complications and side effects.

Depending on the proteins and genetic changes in your leukaemia cells, you might also have:

- Targeted medicines, which block specific pathways in leukaemia cells.
- Antibody therapies, which stick to proteins on leukaemia cells so your immune system can kill the cells.

Medicine to prevent or treat ALL in your central nervous system

Sometimes ALL can spread to your brain or spinal cord. This is called your central nervous system.

Your haematology team will give you chemotherapy medicines to prevent or treat this. You have them as an injection into the fluid surrounding your brain and spinal cord. It is called **intrathecal chemotherapy**. You have it through a lumbar puncture (**page 19**).

Before treatment

There are a few things that will happen before you start treatment.

Having a central line fitted

Your treatment will involve a lot of medicines that have to be given as an injection or drip. It will also involve having regular blood tests. Your haematology team may place a central line to make this easier.

You have a local anaesthetic to numb your skin first so it does not hurt when the line goes in. You might have a sedative too, if you need one.

You might have an ultrasound before your nurse or doctor puts the tube in, and a chest X-ray afterwards. This is to make sure the tube is in the right place.

You'll need to keep your central line clean and dry to reduce the chance of it getting infected. It needs to be flushed with sterile fluid once a week to stop it getting blocked. While you are in hospital, a nurse will do this. Once you are at home, your team will arrange for someone to do it for you. This may be during your outpatient appointments at hospital.

Fertility options

Treatments for ALL may affect your fertility. If you might want children in the future, tell your doctor or nurse. They can talk to you about your options. Your haematology team may refer you to a fertility specialist. This may not be possible for everyone.

More about central lines

A central line is a long, thin plastic tube that enters the skin in your arm or chest. You might hear your team call it a PICC or Hickman line.

- A PICC line enters the skin in your arm
- A Hickman line enters the skin in your chest

You may be able to choose which type of central line you prefer.

The central line runs underneath your skin and ends in a large vein near your heart. It can be used to give treatment straight into your veins, and to take blood samples.

A central line can stay in place for weeks or months. Having one fitted means:

- You don't have to have a tube put into a vein every time you go for treatment
- You don't need to have a needle put into your arm when you have blood tests
- Your treatment goes into larger, sturdier veins that are less likely to leak or be damaged

Pre-induction treatment

Before starting induction therapy, you will have a course of pre-induction treatment.

- Pre-induction treatment starts to treat your leukaemia. It also helps reduce your risk of developing a complication called tumour lysis syndrome.
- You usually stay in hospital to have it.
- You'll have steroids for 5 to 7 days, by mouth or through a drip. You might also have chemotherapy.
- Some people may also have chemotherapy injections into the fluid around the spinal cord.

Your medical team will let you know what pre-induction treatment you will have, and what to expect.

> "Induction is intensive, often scary, but the hospital staff and my CNS really helped me to understand the treatment, side effects and how my disease was responding, which made it all worthwhile."
>
> **Tara, diagnosed with ALL in 2023**

Induction

- Induction therapy aims to kill as many leukaemia cells as possible.
- You usually stay in hospital for several weeks to have it.
- You have chemotherapy and steroids, sometimes with a targeted medicine or antibody therapy.
- It includes a mix of medicines you have by mouth and medicines you have through a drip.
- You usually have two cycles or phases of induction treatment with time to recover in between.

There are many different treatments you may have during your induction phase. Your team will let you know exactly what treatments they recommend for you. They will explain what each is for, how you have it and what to expect. You can also ask them for a copy of your treatment plan.

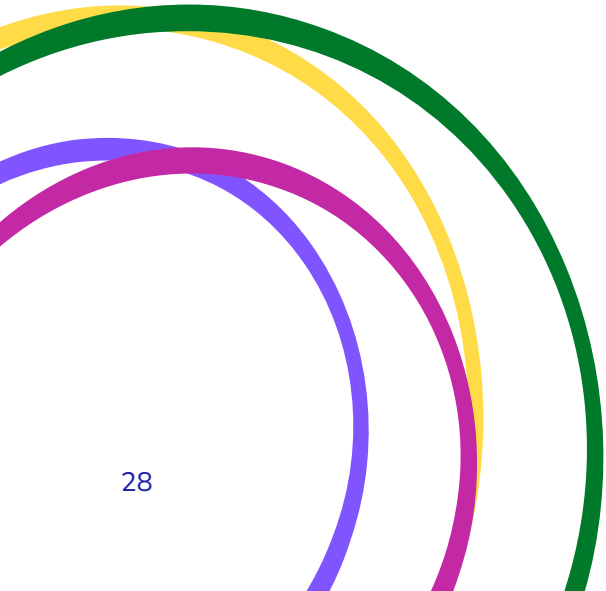
We have more **information on induction treatment for ALL**. Follow the link, scan the QR code or search 'induction treatment for ALL' at **leukaemiacare.org.uk**

Intensification and consolidation

After induction therapy, you might go on to intensification and consolidation. Or you might have a stem cell transplant (**page 30**).

There are many different treatments you may have. Your team will let you know exactly what treatments they recommend for you. They will explain what each is for, how you have it and what to expect.

We have more **information on intensification and consolidation treatment for ALL**. Follow the link, scan the QR code or search 'intensification and consolidation' at **leukaemiacare.org.uk**



- Intensification and consolidation aims to kill any leukaemia cells that might be left after induction and to stop them spreading to your central nervous system.
- Intensification and consolidation treatment usually lasts a few months. You have it in cycles or blocks with time in between to recover.
- During intensification you will have high-dose chemotherapy. Depending on your test results, you may also have targeted treatment or antibody therapy.
- You usually have treatment on a day unit and go home afterwards. Sometimes, you may need to stay in hospital for the treatment days of each cycle or to manage side effects.
- You might have chemotherapy and steroids, sometimes with a targeted medicine or antibody therapy. Or you might have an antibody therapy on its own.
- Consolidation therapy usually includes some medicines you have by mouth, some you have through a drip and some you have as an injection into your spinal fluid.
- Some people might have treatment through a portable drip that you go home wearing.

Stem cell transplant

Some people with ALL might have a stem cell transplant. Your team might recommend one if your ALL has a high risk of coming back or a well-matched stem cell donor is available for you.

A stem cell transplant involves having high-dose chemotherapy and sometimes radiotherapy. This kills the blood-forming cells in your bone marrow, called stem cells. These are then replaced by healthy stem cells.

For people with ALL, the healthy stem cells usually come from a matched donor. The donor cells gradually replace your whole immune system too. Your new immune system can help recognise and destroy the leukaemia cells.

A stem cell transplant is very intensive. It is only suitable for people who are fit enough to have it. Your team will let you know if it is an option for you. They will discuss it with you and give you a chance to ask questions.

We have more **information on stem cell transplants**. Follow the link, scan the QR code or search 'stem cell transplants' at **leukaemiacare.org.uk**

Maintenance

- Maintenance therapy aims to reduce the risk of your ALL coming back.
- It usually lasts around 2 years. During this phase you have most treatment at home and you can start getting back to your usual activities.
- You usually have low-dose chemotherapy tablets and a steroid that you take by mouth.
- You usually visit hospital every few months to have some chemotherapy medicines as a drip or an injection. You might also have occasional injections into the fluid around your spine.
- Depending on your results, you might also have targeted treatment that you have as tablets.

There are many different treatments you may have. Your team will let you know exactly what they recommend for you. They will explain what it is for, how you have it and what to expect.

We have more information on **maintenance treatment for ALL**. Follow the link, scan the QR code or search 'maintenance' at **leukaemiacare.org.uk**

Clinical trials

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is where new treatments or different ways of using existing treatments are tested to find out if they are better than standard treatments.

If there is a clinical trial suitable for you, your team should explain what it involves and the risks and benefits of it. It is your choice whether to take part.

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

Supportive treatment

You will also have treatment to prevent or manage symptoms or side effects. This is called supportive treatment. It does not treat ALL itself, but it helps you feel better.

Supportive treatment might include:

- Blood or platelet transfusions, if your blood counts are low.
- A procedure to remove some of your white blood cells, if your level is very high when your leukaemia is first diagnosed. This is called leukapheresis. It usually takes a few hours.
- Medicines to prevent or treat infections.
- Medicines to prevent or treat side effects.
- Medicines to reduce stomach acid.
- Medicines to prevent a complication called tumour lysis syndrome.
- Medicines to delay your periods, if you usually have them.

Supportive care is not only limited to the physical impact of ALL. It can include:

- Support with your emotions and mental health
- Support with exercise or physiotherapy
- Social support
- Complementary therapy or spiritual wellbeing

> “Treat each day of your treatment process as a small victory. The recovery from all three treatment regimens I experienced was a marathon, not a sprint.”
>
> **Julie, diagnosed with ALL in 2019**

Your haematology team should talk to you to find out what support they can offer you. Let them know if you have any symptoms, side effects or late effects that you are finding hard to cope with.

Measuring your response to treatment

You will have regular blood and bone marrow tests during your treatment to check how well your ALL is responding.

You usually have tests after each phase of treatment. The results of these tests help your haematology team work out the most suitable next treatment for you.

The tests will measure:

- Your blood cell counts. This is sometimes called your **haematological response**. It means your blood cell counts have returned to normal and specialists can't see any leukaemia cells under a microscope.
- The level of leukaemia markers or leukaemia genetic changes in your white blood cells. This is called your **molecular response**. It can detect very low levels of leukaemia cells. This is called **measurable residual disease** (MRD).

If you are MRD negative, it means sensitive molecular tests cannot find any leukaemia cells in your body.

Coping with treatment and side effects

Summary

- During your treatment, you usually need to stay in hospital for a few weeks, sometimes longer. You may need to arrange for someone to look after your home while you are away.
- You might want to pack things for a hospital stay or ask someone to bring your things to you.
- You may want to tell your place of work or education that you will be in hospital. You also may want to tell them you have ALL, and discuss how they might be able to support you.
- It can be hard dealing with treatment and its side effects. Tell your haematology team if you are struggling. They may be able to help.

We have separate information on **living well after a diagnosis of leukaemia**. Follow the link, scan the QR code or search 'living with' at **leukaemiacare.org.uk**

Preparing for treatment

After your diagnosis, you will likely need treatment straight away. There may be some things you need to get in order, but it can be hard to know where to start.

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

Staying in hospital

During your treatment for ALL you will probably need to stay in hospital for several weeks.

You might need to arrange for someone to look after your home while you are away. You may also need someone to look after your children, pets or water any plants you may have.

You may also want to pack some things to help make your stay at hospital more comfortable. You may need to ask someone else to bring them in for you. We list some of the things you might want to pack on the next page.

- [ ] Any medicines you take and details of any allergies
- [ ] Loose pyjamas or loose-fitting comfortable clothes
- [ ] Socks, slippers and underwear
- [ ] Flip flops, sliders or crocs to wear in the shower
- [ ] A bag to put dirty clothes in
- [ ] Your own pillow, sleep mask and ear plugs
- [ ] Your mobile phone, laptop or tablet, the chargers for them and headphones
- [ ] A notebook and pen
- [ ] Books, magazines, games or crafts
- [ ] Tissues and baby wipes
- [ ] Credit or debit card, small amounts of change or cash
- [ ] Something comforting, like a photo or favourite blanket
- [ ] Toiletries
- [ ] Period products
- [ ] Toothbrush, toothpaste, dentures, mouthguards or braces
- [ ] Hand and bath towels
- [ ] Glasses, contact lenses and solution
- [ ] Hearing aid and spare batteries
- [ ] Walking stick or orthopaedic shoes if you use them
- [ ] Your favourite tea, coffee or squash flavour

Work and education

Treatment for ALL can be intensive. You will probably need to stay in hospital for some time, so you will need time off work or education. Even when you are not in hospital, you'll need time off during your recovery and to attend appointments.

You may want to talk to someone about your needs and adjustments. This could be your manager, HR, occupational health, workplace union or student union. When talking to them you might want to:

- Explain what ALL is and how it may affect your work or education
- Ask about sick pay, occupational health and other policies
- Ask what support they may have or can offer you

Having cancer is a protected characteristic. This means you have certain rights and cannot be discriminated against due to your illness.

Our advocacy team can explain your rights and help you access support. Call **08088 010 444** or email **advocacy@leukaemiacare.org.uk**

Coping with side effects

ALL treatment kills leukaemia cells but it may also damage some of your healthy cells. This can cause side effects. These can be hard to cope with but your haematology team are there to help you. It's important to let them know if you are struggling as they may be able to offer treatments to help.

We have more **information on side effects of ALL treatment** in our resources for each phase.

- Induction
- Intensification and consolidation
- Maintenance

Follow the links, scan the QR code or search 'treatment for ALL' at **leukaemiacare.org.uk**

Sometimes you may have side effects after treatment finishes or that last a long time. These are called 'late effects'. Your haematology team will let you know what to look out for.

Tell your haematology team about any side effects or late effects you have. They may be able to suggest things you can do or give you medicines to help.

Words you might see or hear

Acute lymphoblastic leukaemia (ALL): a fast-growing type of blood cancer that affects blood cells called lymphoblasts.

Anaemia: a low red blood cell count.

Anaesthetic: a medicine to numb part of your body (local anaesthetic) or send you to sleep (general anaesthetic) so you don't feel any pain during medical procedures.

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

B cell or B lymphocyte: a type of white blood cell that makes antibodies.

***BCR-ABL1* gene:** a changed gene found in chronic myeloid leukaemia, some types of acute lymphoblastic leukaemia and some other types of blood cancer.

Bone marrow test: a test to take a sample of the spongy tissue from the centre of a bone, usually your pelvis.

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.

CD (followed by a number): proteins found on the surface of white blood cells.

Central line: a long, thin plastic tube used to give you medicines into your veins or take blood. It enters the skin in your arm or your chest and ends in a large vein near your heart.

Central nervous system: your brain and spinal cord.

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

Chromosomes: long strands of DNA inside your cells. Each chromosome contains lots of different genes.

Clinical trials: research studies that aim to find out what treatments work best for particular conditions.

Consolidation treatment: treatment that aims to kill any leukaemia cells that may be left after induction therapy.

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

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

Gene: a section of DNA that tells your cells how to make a particular protein.

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 or mutations.

Genetic: relating to genes.

Haematological response: how well leukaemia is responding to treatment based on your blood cell counts.

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

Induction treatment: treatment that aims to kill as many leukaemia cells as possible.

Intensive treatment: strong treatment that aims to cure your leukaemia.

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

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

Lumbar puncture: a test to collect a sample of the fluid that surrounds your brain and spinal cord through a needle in your back.

Lymph nodes: small, bean-shaped structures in your neck, armpits, groin and other parts of the body that are part of your immune system. They may become swollen when you are unwell.

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

Maintenance treatment: treatment that aims to reduce the risk of your leukaemia coming back.

Molecular response: how well leukaemia is responding to treatment based on the level of changed genes in your blood or bone marrow.

MRD (measurable residual disease): low levels of leukaemia cells left in your body after treatment. MRD negative means none can be detected.

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

Neutrophils: white blood cells that help you fight inflammation and infection.

PET/CT scan: a scan that uses a special dye containing a harmless radioactive sugar and specialised X-rays to take pictures of the inside of your body.

Philadelphia chromosome: a changed chromosome found in chronic myeloid leukaemia, some types of acute lymphoblastic leukaemia and some other types of blood cancer.

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.

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

Stem cell transplant: treatment that replaces damaged or abnormal blood forming cells in your bone marrow with healthy ones.

Steroids: medicines that reduce inflammation and have anti-cancer effects.

Supportive care: treatment to prevent or relieve symptoms or side effects.

Targeted treatments: medicines designed to block specific proteins on cancer cells.

T cell or T lymphocyte: a type of white blood cell that recognises proteins on the surface of other cells and can cause cell death.

Transfusion: having blood or blood products through a drip into a vein.

Tumour lysis syndrome: a serious side effect of some cancer treatments. It happens if a large number of cancer cells die quickly and release chemicals into your bloodstream.

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.

X-ray: a scan that uses low doses of radiation to take images of the inside of your body.

Useful contacts

Coping with ALL can be difficult. Here are some organisations you might find helpful.

Leukaemia Care

- Helpline: **08088 010 444**
  (weekdays 9am to 4.30pm)
- WhatsApp: **07500 068065**
  (weekdays 9am to 4.30pm)
- **leukaemiacare.org.uk**
- **support@leukaemiacare.org.uk**

Blood Cancer UK

- Leading charity into the research of blood cancers.
- **0808 2080 888**
- **bloodcancer.org.uk**

Macmillan

- Provide free, practical, medical and financial support for people facing cancer.
- **0808 8080 000**
- **macmillan.org.uk**

Cancer Research UK

- Leading charity dedicated to cancer research.
- **0300 1231 022**
- **cancerresearchuk.org**

Maggie's

- Offer free practical, emotional and social support to people with cancer and their loved ones.
- **0300 1231 801**
- **maggies.org**

Carers UK

- Offers advice, information and support for carers.
- **0808 808 7777**
- **carersuk.org**

Citizens Advice

- Offer advice on benefits and financial assistance.
- **0800 144 8848** (England)
- **0800 702 2020** (Wales)
- **0800 028 1456** (Scotland)
- **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

We've built an active community centred around emotional care, practical guidance, and raising awareness. We help people spot the signs, get diagnosed earlier, and feel supported through it all.

We can't do this alone. Whether you can give your money, effort, time or kindness, it matters. Your generosity means more people feel seen, understood, and less alone.

On the next few pages are some of the ways you can help.

For more information:

- Scan the QR code or visit **leukaemiacare.org.uk**
- Call **08088 010 444**
- Write to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**
- Email the addresses listed on the following pages

Tell us what you think

Follow the link or scan the QR code to complete **a short survey** about how we can improve our information.

We used an AI tool to help identify relevant evidence sources for this webpage, such as scientific journals and clinical guidelines. A human checked the reliability of these sources. Contact us if you'd like a list of the sources we used.

- Email **information@leukaemiacare.org.uk**

Share your story

Real stories shape our work. Sharing your story can help others in a similar situation. It can also help people understand ALL better.

- Email **communications@leukaemiacare.org.uk**

Volunteer with us

Our volunteers are at the heart of everything we do. Whether you can give a few minutes online or commit to a regular role, there are many ways you can get involved.

- Email **volunteering@leukaemiacare.org.uk**

Fundraise for us

Every fundraising activity or event, big or small, helps support people affected by leukaemia, MDS and MPN.

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

Contact our fundraising team:

- Email **fundraising@leukaemiacare.org.uk**

Donate to us

Whether you can give a little or a lot, your donation means faster diagnosis, all-rounded care, and better days ahead. There are so many ways you can give. Find one that fits you!

By bank transfer

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

By cheque

- Please make your cheque payable to **Leukaemia Care**
- Post it to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

- Visit **leukaemiacare.org.uk**

By phone

- Call **08088 010 444** to donate by debit or credit card

By text

- Text **LEUKCARE** to **70490** to donate £5

Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.

At Leukaemia Care, we support anyone affected by leukaemia because leukaemia can affect anyone. Whether you're living with it, loving someone through it, or coping with the impact of it, you're not alone.

Want to talk?

- Call our freephone Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Message us on WhatsApp: **07500 068065** (weekdays 9am to 4.30pm)
- Visit **leukaemiacare.org.uk**
- Email **support@leukaemiacare.org.uk**

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

Trusted Information Creator
Patient Information Forum

Leukaemia Care

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