Relapsed or refractory Acute Lymphoblastic Leukaemia (ALL)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

If you have relapsed and refractory ALL you will need further treatment. Treatment of ALL that has returned is hard to treat, but not impossible. If you have any questions about relapsed or refractor ALL and their treatments - this booklet covers the basics for you.

The booklet was written and updated by our Patient Information Writer, Isabelle Leach, and peer reviewed by consultant haematologists.

We are also grateful to our patient reviewers, Ross Happell, Meryl Simons and Karen Collier for their contribution.

Throughout this booklet, you will see QR codes that will take you to the relevant webpage for further support. Open the camera app on your phone and hover it over the QR code to open the link (suitable for Android, iPhone 7 and above).

Alternatively, if you are not able to use QR codes and would like to be sent the relevant webpages as URLs, or you would like the list of references used for this booklet, please email **communications@leukaemiacare.org.uk.**

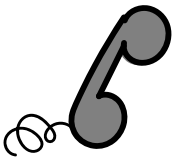
Version 2a
Reviewed: 06/2023
Updated: 04/2024
Review date: 06/2026

In this booklet

About Leukaemia Care

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.

Our services

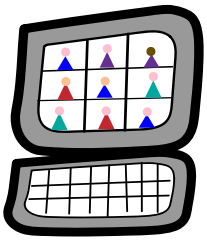


Helpline

Our helpline is available 9am to 5pm Monday to Friday. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9am to 5pm.

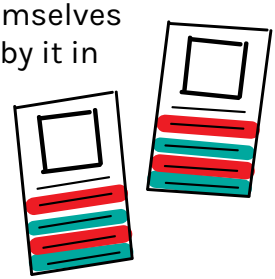
Support groups



Our nationwide support groups are a chance to meet and talk to other people who have been affected by a ALL diagnosis. For more information, scan this QR code:

Buddy support

We offer one-to-one phone support with volunteers who have had ALL themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**



Counselling service

Our counselling service helps ALL patients and their loved ones access up to six sessions of counselling. To apply, scan this QR code:

Advocacy and welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding a ALL diagnosis. These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.

Cost of living fund

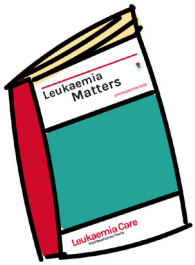
This fund provides grants to patients and families affected by ALL, to help with essential living costs. All applications must be made via the form which can be found by scanning the QR code:

Write a free will

Using our complimentary service, you can write a simple will so you know what happens to your estate when you die. To start writing your free will today, scan this QR code:

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe to our magazine, scan this QR code:



Glossary of medical terms

Acute leukaemia

Leukaemia which progresses rapidly and is generally aggressive. There are two types: acute lymphoblastic leukaemia and acute myeloid leukaemia.

Acute lymphoblastic leukaemia (ALL)

Leukaemia in which lymphocytes start multiplying uncontrollably in the bone marrow, resulting in high numbers of abnormal, immature lymphocytes. Lymphocytes are a type of white blood cell involved in the immune response.

Allogeneic stem cell transplant

A procedure where bone marrow stem cells are taken from a genetically matched donor and given to the patient through an intravenous line. The donor may be related or unrelated.

Autologous stem cell transplant (ASCT)

Transplant of stem cells derived from part of the same individual.

Blast cell

An abnormal (dysplastic), immature blood cell found in the bone marrow or peripheral blood. As they are not mature, these cells are unable to fulfil their intended function. AML develops from these blast cells.

Blood transfusion

A procedure in which whole blood or one of its components is given to a person through an intravenous line into the bloodstream. A red blood cell transfusion or a platelet transfusion can help some patients with low blood counts.

Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells, and platelets.

Chemotherapy

Therapy for cancer using chemicals that stop the growth of cells.

Clinical trial

A medical research study involving patients with the aim of improving treatments and their side effects. You will always be informed if your treatment is part of a trial.

Consolidation (phase)

Treatment following remission intended to kill any cancer cells that may be left in the body (also called intensification phase).

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly or it can be chronic and persistent.

Full blood count or FBC

A blood test that counts the number of different blood cells.

Graft-versus-host disease

Serious complication that occurs with allogenic stem cell transplants. It happens when the graft (donated marrow or stem cells) reacts against the host (patient receiving the stem cells).

Induction (phase)

First treatment after diagnosis intended to kill the majority of the leukaemia cells and stimulate remission.

Intrathecal therapy

Injection of chemotherapy into the cerebrospinal fluid that surrounds and protects the brain and spinal cord.

Maintenance

Treatment given to prevent cancer from coming back after it has

disappeared following the first-line treatment.

Monoclonal antibody

Man-made antibodies created from identical cloned immune cells so that they all bind to the same protein commonly found on the leukaemia cells such as CD20.

Neutropenia

A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Neutrophil

A type of white blood cell that helps fight infection.

Palliative care

Also known as supportive care, this is a type of care that focusses on improving the quality of life for a patient with a life threatening illness and their loved ones.

Platelet

A disc-shaped element in the blood that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate). Although platelets are often classed as blood cells, they are actually fragments of large bone marrow cells (megakaryocytes).

Platelet count

A normal platelet count in a healthy individual is between 150,000 and 450,000 per microlitre of blood. In general, low platelet counts increase bleeding risks. Normal platelet count 150-450 $x10^9$/L.

Red blood cells

Small blood cells that contain haemoglobin and carry oxygen and other substances to all tissues of the body.

Stem cells

Cells that have the potential to develop into many different or specialised cell types.

White blood cell

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils. Normal white cell count is 4-11x10^9/L.

What is relapsed or refractory ALL?

After your induction treatment, you may have one of three outcomes:

- **Remission:**
  - Blood cell counts return to normal
  - Less than 5% of leukaemia cells blasts are present in the bone marrow
  - There is no leukaemia detectable anywhere else in your body
- **Relapsed ALL:** Complete remission for six months or more but the ALL returns
- **Refractory ALL:** Remission is not reached or complete remission lasts for less than six months

If you have relapsed and refractory ALL you will need further treatment. Treating ALL that has returned is hard, but not impossible.

Treatment for relapsed/refractory ALL was traditional chemotherapy. The development of new targeted treatments has led to much improved outcomes. Your haematology team will explain your next steps to you.

As with the newly-diagnosed booklets, this booklet focuses on adult ALL including patients between 16 and 25 years.

What are my treatment options?

The aim of the treatment for relapsed or refractory ALL is to re-induce another remission. An allogeneic stem cell transplant (allo-SCT) can be used to try and consolidate the remission.

Treatment of relapsed or refractory ALL is harder than treatment of the initial ALL. Relapsed or refractory ALL treatment is usually more intensive or complex.

Treatment options available may be different for relapsed ALL and refractory ALL.

Relapsed ALL

If relapse of ALL happens after a long remission, you will receive the initial treatment again. It is possible that the chemotherapy combined with other drugs may induce remission.

If relapse of ALL happens after a short remission, you will receive other drugs.

The type of treatment you get will depend on:

- Your type of ALL (B-cell or T-cell)
- Location in the body where the disease is still present:
  - Bone marrow
  - CNS or testes
- Amount of time from initial diagnosis to detection of refractory ALL
- Results of your genetic testing from the leukaemia cells
- Previous treatments you have received for your ALL

Genetic testing at relapse may show different mutations from those present at your diagnosis. The results of genetic testing may alter your haematology team's treatment decision for you.

Please see our newly diagnosed booklets for B-cell ALL and T-cell ALL for details of genetic testing methods. Scan the QR code to order our booklets:

Resistance to drugs causes most relapses. This occurs because the leukaemia cells become tolerant to the drug treatments and survive. They then re-populate the blood and bone marrow in the future.

There are two types of drug resistance:

1. **Intrinsic drug resistance:** This is present before treatment. It means the leukaemia cells already had some genetic mutations that allow them to survive.
2. **Acquired drug resistance:** This occurs during or after treatment. Some cells become resistant after exposure to a drug.

Acquired resistance becomes evident as you experience a gradual reduction in the efficacy of the drug over time.

Intrinsic resistance will result in a more immediate lack of effect. Both can cause a return of ALL if the surviving resistant cells re-populate the blood again.

Refractory ALL

The aim of treatment for refractory ALL is to approach the ALL in a different way.

Your haematology team will use different combinations of drugs or different drugs to achieve remission. Other therapies may be added to increase the chances of remission.

The type of treatment you get will depend on:

- Your type of ALL (B-cell or T-cell)
- Location in your body where the disease is still present
- Results of your genetic testing of your leukaemia cells at relapse

- Previous treatments you have received for your ALL

To treat your refractory ALL, your haematology team will attempt:

- More intense doses of the initial chemotherapy drugs you had
- Different drugs

Treatments options for relapse or refractory ALL

The following treatments options for relapse or refractory ALL are:

- Chemotherapy
- Targeted therapy
- Immunotherapy
- Radiation therapy
- Central nervous system treatment
- Stem cell transplant
- CAR T-cell therapy

Chemotherapy

There is no standard chemotherapy treatment for refractory ALL. Chemotherapy is rarely used for relapsed B-cell ALL nowadays. The preferred choice of chemotherapy combinations for ALL include:

- FLAG: fludarabine, cytarabine, granulocyte FLAG colony-stimulating factor
- FLAG-IDA: FLAG and idarubicin

Combination chemotherapy with or without targeted therapy is an option. A TKI will be included for Philadelphia-positive patients.

Targeted treatment

Targeted treatments involve drugs that target specific proteins on the leukaemia cells. Targeted treatments limit damaging normal cells more than chemotherapy. They are also useful where

chemotherapy has not worked or caused a general resistance to treatment.

Tyrosine kinase inhibitors

Targeted TKIs focus on specific mutations such as the BCR-ABL1 gene mutation in patients with Philadelphia-positive ALL.

The Philadelphia chromosome is the most common genetic abnormality found in patients with ALL. Genetic testing may be repeated at the time of relapse, especially if it has not been done at diagnosis.

For more information on genetics in ALL we have a dedicated booklet. Scan the QR code to order or download the booklet:

The TKIs dasatinib or ponatinib often increase the rates of complete remission in ALL patients. The way each TKI works is a little different. Some TKIs may be able to respond to a mutation in a way that other TKIs cannot.

Immunotherapy

Monoclonal antibodies

An antibody is a protein that sticks to a foreign substance to remove it from your body.

The immune system makes large numbers of antibodies to bind to the foreign substance and remove it. The antibodies message your immune system to destroy the substance. Foreign substances may be bacteria, viruses or foreign proteins from a cancer cell.

In the case of your ALL, antibodies could target the proteins on the surface of your leukaemia cells. They need help to do so as your cells are not normally considered foreign.

Scientists modify your antibodies to make them only target the

protein on your leukaemia cells. This helps your antibodies target the leukaemia cells. The scientists then make numerous copies of that antibody. These are known as monoclonal antibodies. For example, they can be directed at different proteins on the surface of the leukaemia cells. These include CD19, CD20 and CD22.

Monoclonal antibodies stick to these specific proteins on the surface of the leukaemia cells. They can stimulate the body's immune system to destroy the leukaemia cells.

Scientists consider monoclonal antibodies as either:

- Targeted therapy because they work by targeting specific parts of the leukaemia cells, OR
- Immunotherapy because they use the natural immune system as a method of dealing with the leukaemia cells

They are considered as both targeted therapy and immunotherapies.

Examples of monoclonal antibodies are blinatumomab and inotuzumab ozogamicin.

Blinatumomab

Blinatumomab targets the CD19 protein found on B-cells. It also binds to the CD3 protein on T-cells.

Blinatumomab is indicated as monotherapy for:

Adults with CD19-positive relapsed or refractory B-cell ALL. Patients should have:

- Failed treatment with at least two TKIs
- No alternative treatment options

Adults with CD19-positive relapsed or refractory B-cell ALL, but negative for Philadelphia chromosome:

- Patients must be in their first or second complete remission with a measurable residual disease (MRD) greater than or equal to 0.1%.

MRD is a small number of leukaemia cells left in your body after treatment. It can be positive or negative.

Children aged one year or older with refractory or relapsed CD19-positive B-cell ALL. These children have to be negative for Philadelphia chromosome. They also have to have:

- Received at least two prior therapies
- Relapsed after receiving prior allo-SCT

Children aged one year or older with high-risk first-relapsed Philadelphia chromosome-negative CD19. But they also had to be CD19-positive B-cell ALL as part of their consolidation therapy.

For more information, we have a dedicated booklet on blinatumomab as a treatment for ALL. Scan the QR code to order or download the booklet:

Inotuzumab ozogamicin

Inotuzumab ozogamicin consists of an antibody coupled with chemotherapy drug ozogamicin. This chemotherapy drug is toxic to leukaemia cells. Inotuzumab ozogamicin binds to the CD22 proteins on leukaemia cells and the ozogamicin kills them.

For more information, we have a dedicated booklet on inotuzumab ozogamicin as a treatment for ALL. Scan the QR code to order or download the booklet:

CAR T-cell therapy

CAR T-cell therapy is a type of immunotherapy. Specialists remove your T-cells from your blood. They change the T-cells in the laboratory. As a result, the modified T-cells have chimeric antigen receptors (CARs) on their surface. These receptors recognise a specific protein or antibody on the leukaemia cells. The T-cells are then returned to you via your blood. Here they multiply, attack and destroy the leukaemia cells.

Tisagenlecleucel and brexucabtagene autoleucel are both approved in the UK to treat relapsed ALL.

Tisagenlecleucel is approved for children and young adult patients up to and including 25 years of age with B-cell ALL that is refractory, in relapse post-transplant or in second or later relapse.

Brexucabtagene autoleucel is indicated for the treatment of adult patients 26 years of age and above with relapsed or refractory B-cell precursor ALL.

For more information, we have a dedicated booklet on CAR T-cell therapy as a treatment for ALL. Scan the QR code to order or download the booklet:

Radiation therapy

You may receive radiation therapy before or during surgery. This will depend on the stage of your ALL and your haematology team's reason for treating you.

Radiation therapy involves receiving beams of high energy waves. Examples of these high energy waves are x-rays or gamma rays that will kill or shrink the leukaemia cells. Normal cells may also be radiated but most recover and resume their normal function.

Low-dose external beam radiation therapy is also available. It involves accurate delivery of targeted radiation beams. This can

help reduce symptoms due to the spread of ALL in your bone or brain and spinal cord.

Central nervous system treatment

The CNS consists of the brain and spinal cord. A fluid surrounds these organs to protect them. This is the cerebrospinal fluid (CSF).

The purpose of CNS treatment is to kill the leukaemia cells that have spread into your CNS. This may be the source of your relapsed ALL.

CNS prophylaxis is relevant because:

- You should have had a lumbar puncture at diagnosis to check if you already have leukaemia cells that have spread into your CNS. Your first treatment may not have been effective here.
- Your leukaemia cells can also spread into your CNS during your treatment.

CNS treatment may include one or more of the following:

- CNS chemotherapy treatment injected into your CSF. This injection occurs during a lumbar puncture. This is intrathecal chemotherapy. It includes methotrexate, cytarabine or a steroid such as prednisone.
- High-dose methotrexate given in a vein.
- Radiation therapy to the brain.

ALL patients receive intrathecal therapy throughout their whole treatment period.

For more information, we have a dedicated booklet on induction treatment, which covers intrathecal therapy. Scan the QR code to order or download the booklet:

Stem cell transplants

In general, you will receive an allo-SCT if you achieve a second remission. The goal is to:

- Reinforce the remission
- Reducing the risk of relapse for a second time

Before your allo-SCT, you will receive high-dose chemotherapy. This is to kill the leukaemia cells in your bone marrow. This is called myeloablative conditioning. Your bone marrow is then ready to receive the healthy stem cells from your donor.

You receive the healthy donor stem cells into a vein. The cells then migrate into your bone marrow where they form new blood cells to restore the bone marrow.

After the allo-SCT, you will receive drugs to prevent rejection of the donated stem cells. You may need to stay in hospital for four to six weeks.

While an allo-SCT can achieve a long-term remission, it does have significant risks. These include:

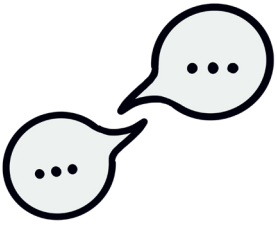
- Rejection of the transplanted cells
- Bleeding
- Infections

For more information, we have a dedicated booklet on stem cell transplants as a treatment for ALL. Scan the QR code to order or download the booklet:

This booklet is only a guide of what you might experience. Your haematology team will give you a copy of your specific treatment plan.

Summary: What is the prognosis for relapsed or refractory ALL?

- Long-term follow-up of patients with relapsed or refractory ALL shows survival rates in **10%-50%** of patients. The survival rates depend on prognostic factors. These prognostic factors affect your likelihood of further relapse and therefore your chances of survival. There are lots of other factors, including previous treatment response and genetics.
- Patients who cannot tolerate further intensive treatment often have a poorer prognosis. This is because it can be harder to treat ALL with non-intensive treatments.
- **Your prognosis will be discussed on multiple occasions.** It might change after each round of treatment depending on your response to treatment.
- You should also discuss prognosis if you cannot have or decide not to have more treatment. This will help you plan for the future.



What is the prognosis for relapsed or refractory ALL?

General prognostic factors

There are several factors that influence your prognosis or your chances of survival. This is based on your likelihood of future relapse. Factors for relapse include:

- Site of relapse – CNS disease is harder to treat
- Which treatment you receive – they work in different ways
- How well your last treatment worked – especially whether or not your measurable residual disease (MRD) was positive or negative. MRD is a small number of leukaemia cells left in your body after treatment.
- How long you were in remission after your first or last treatments
- Whether you had an allo-SCT as frontline therapy
- Genetic changes in your ALL since last treatment
- If you have B-cell or T-cell ALL
- Whether you were high or low-risk at diagnosis

The prognosis of patients with a Philadelphia chromosome depends on the timing and location of their relapse.

On average, survival rates for ALL range from 10% to 50% of patients alive at five years. This is heavily dependent on the prognostic factors.

Establishing an exact prognosis is important for the treatment of your ALL. Determining risk factors allows your haematology team to decide on the most suitable treatment for you. It also allows them to decide if an allo-SCT will benefit you.

You should also remember that the statistics on survival are an average made up of the experiences of lots of individuals. It is not possible to say exactly what will happen to you.

Being told your ALL isn't responding to treatment can be difficult. Our buddy scheme offers one-to-one support and the opportunity to speak to someone in a similar situation to you. Email **support@leukaemiacare.org.uk** or call **08088 010 444** to find out more.

Summary: Supportive care

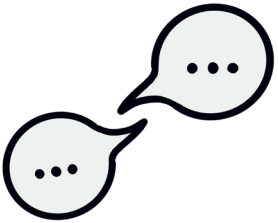
Supportive care is available at any time. It is a term that means any medication or medical care that is not given to treat your leukaemia. The aim is to **improve your quality of life**.

As well as your ALL treatment you are likely to need treatment for side effects (e.g. to treat nausea). You might be offered medication or different treatment strategies like counselling or physiotherapy. It depends on your situation.

Concerns you might experience include:

- Infection risk
- Fatigue
- Symptoms coming from not making other blood cells
- Mental health issues
- Challenges with work, money or dealing with issues at home

This section focuses on things that happen during treatment.



You can also get supportive care for symptoms when you are not actively receiving treatment. This applies even if you have not been treated for months or years. Your haematology team will work out if it is related to your ALL. Alternatively, your GP can help.

Make sure you talk to your healthcare professionals regularly. They will be able to help you if you need any treatment for physical symptoms or side effects.

Supportive care

ALL is an aggressive illness. Therefore treatment to deal with it has to be fairly intensive. During your treatment and afterwards, supportive care can improve your quality of life. It will help prevent, or treat, the symptoms of ALL as soon as possible.

Supportive care can also reduce the side effects caused by treatment. In this booklet, we focus on the immediate effects of diagnosis and treatment.

Supportive care is not only limited to the physical impact of your ALL. It will provide support for matters that are:

- Psychological
- Social
- Spiritual

In this section, we list some examples of supportive care. We also give you tips to help yourself.

Fatigue

A very common side effect of ALL treatment is fatigue. It can be caused directly by the drugs. It can also have other causes. One example is the psychological and emotional stress of diagnosis. Fatigue is often frustrating as it cannot be treated with medicines.

Solutions to decrease your level of fatigue are available. This includes pacing yourself or improving the quality of your sleep.

Make sure you discuss your fatigue throughout your treatment with your healthcare team. You can also raise it after treatment. It is very common for it to continue after treatment. There are fatigue services to help if it affects you long term or particularly severely, but waiting lists can be long.

Infection

You should be aware that you are vulnerable to infections whilst on treatment. This is because most treatments have an effect on other aspects of your immune system. You should be able to recognise symptoms of infections. Common symptoms of infection include:

- Fever – a raised temperature (38°C or higher)
- Aching muscles
- Diarrhoea
- Headaches
- Excessive tiredness

You should seek help as soon as possible if you experience any of these symptoms. Infections can progress more quickly if you are receiving active cancer treatment. Your haematology team should give you a specific phone number and instructions on what to do if you are aware of symptoms of infection.

Prevention of infections

Simple precautions can help you reduce your risk of infection. These are:

- Washing your hands after using the toilet and touching doorknobs and banisters.
- Limiting your time in crowds, especially if there is an epidemic of flu or other illness.
- Following food safety advice and not keeping food after use-by dates. Cleanliness in the kitchen is important.
- Neutropenic diets to protect you from infection are now no longer advocated nowadays. There is limited evidence as to whether they help to reduce your risk of infection.

Specific advice on how to protect yourself from COVID-19 infection is available on our website. It is constantly updated. Scan the QR code to take you there:

Antibiotics normally used to treat infections can also be used to prevent them where applicable. Most common antibiotics and antifungals used are:

- Trimethoprim/sulfamethoxazole (cotrimoxazole) for pneumocystis pneumonia prophylaxis
- Aciclovir to prevent viral infections

General wellbeing

Where possible you should eat a well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Recover without delays

You may lose weight while being treated due to changes in taste or appetite. This may also be due to the side effects of treatment, which includes sore mouth, or nausea and sickness.

Other digestive issues can also occur, such as constipation. These will be related to the treatments you are receiving.

Support with transfusions

Supportive care also includes:

- Blood transfusions (red cells or platelets). This is needed if your bone marrow is unable to make normal blood cells during your treatment. This might involve a different appointment.
- Treatment with antibiotics, antifungals or antivirals.
- Injections of growth factors will help you produce more white cells if you need that. Transfusion of white blood cells carries a high risk of side effects and will not be performed.

Mental health, emotional health, mood and behaviour changes

Being told your treatment is not working or has not worked can be upsetting. We recommend you treat the situation as if you were newly diagnosed again, taking things slowly and being kind to yourself. It's normal to feel emotions such as:

- Anger – Why has this happened to you
- Guilt – For being away from home for a long time
- Fear – Worrying about the future
- Confusion – Not understanding the new terminology

Talking to others can help. It can be difficult to talk to loved ones so you might need someone independent. This is where Leukaemia Care can help.

A diagnosis of ALL can be a lot to take in, especially when it comes to treatment options and prognosis. If you think you may benefit from counselling, we can offer funding for up to six sessions. Scan the QR code to fill in a form:

Work and money

Being in hospital for a long period is challenging for anyone. However, it may add additional stress for those patients who would otherwise be working. If you are diagnosed while you are at school or university, you will have to contact your place of education to defer your attendance while you are on treatment.

You will need to keep your employers informed. They are likely to be supportive. However, Leukaemia Care and other organisations can help you if they are not.

Your ALL may also affect your finances even if you are not working. Leukaemia Care are aware that being diagnosed with leukaemia comes with extra spending costs. We can offer financial support, including direct grants.

For more information about the financial help that we can provide, scan the QR code to take you there:

Home life

A diagnosis of leukaemia is likely to impact your home life. This stems from the long period of time you may need to spend in hospital which is very common for ALL patients.

Our newly diagnosed checklist can be useful in seeking help. Scan the QR code to take you there:

This should make you feel less stressed if you seek help early. Then you are able to focus more on your physical treatment.

Summary: End of life care

- Treatment for your ALL is not guaranteed to work. It includes intensive treatments and can occur at any stage of your treatment.
- This section on end of life care is designed to give you information if you have already been told your treatment has stopped working. If you are not sure, please ask your haematology team before taking any actions.
- End of life care may last days, months or years. End of life care will help you live as well as possible until you die. The aim of this section is to encourage you to enjoy a good quality of life, and die with dignity.
- Your haematology healthcare team will ask you about your individual wishes for your future care. They will treat you with this in mind.

If you would like support and advice about your ALL diagnosis, including end of life care, you can speak to someone on our helpline by calling **08088 010 444**. We're available from 9:00am – 5:00pm Monday to Friday.

End of life care

What happens if treatment stops working?

Your haematology team might explore other treatment options if treatments for your ALL are no longer working. However, they may give you a terminal diagnosis if there are no options left. They will discuss this with you first.

What happens next?

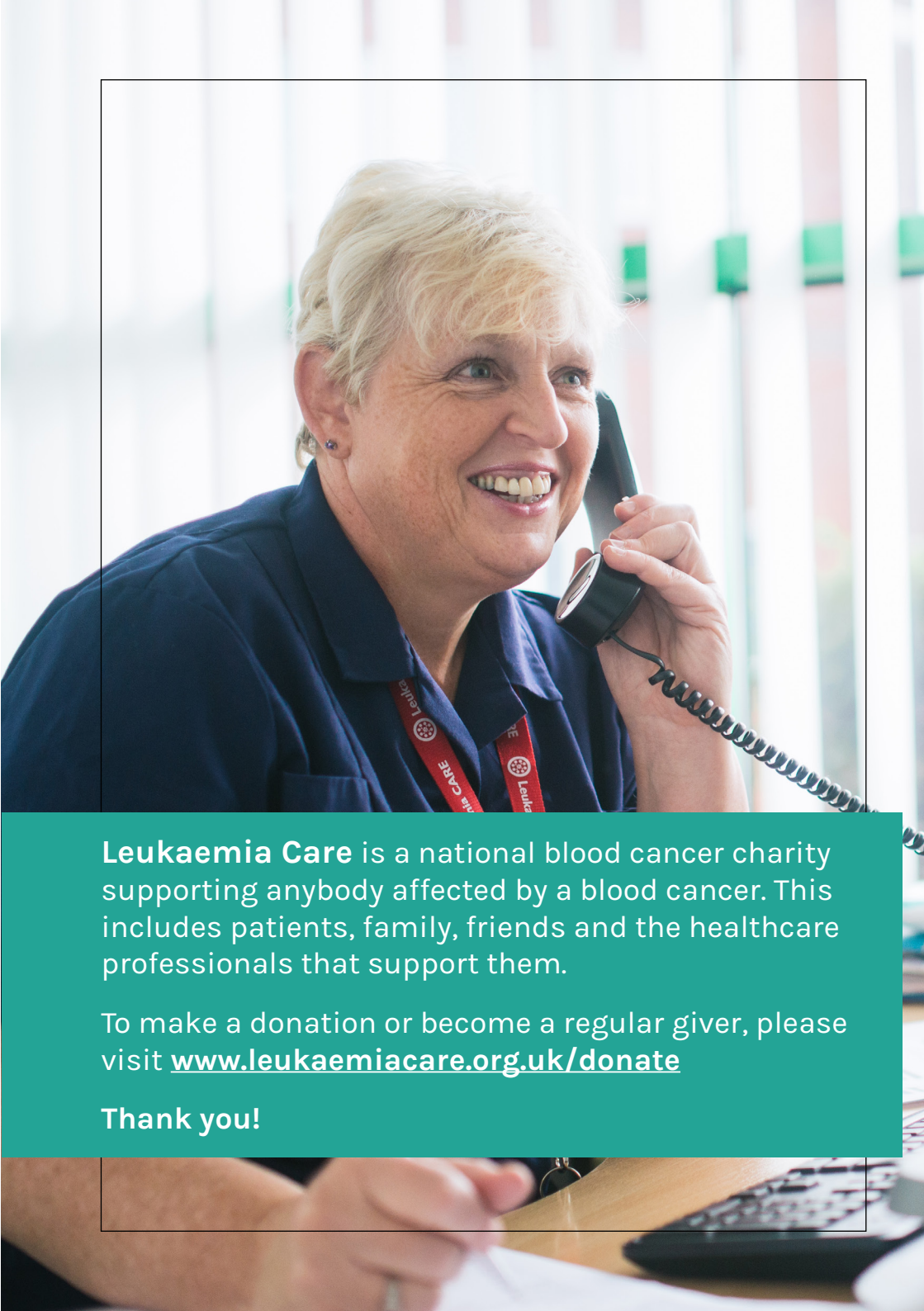
A terminal diagnosis means your team feel there are no more treatment options left that can cure or control your ALL. Other care to improve quality of life should continue. They will let you know when you need end of life care. End of life care may last days, months or years.

Your healthcare team should ask you about your individual wishes and how you feel over time. They will treat with this in mind. End of life care should help you live as well as possible until you die. The aim is to help you enjoy a good quality of life, and die with dignity.

Most hospitals have palliative care teams. They have experience in dealing with end of life and its related symptoms. You should have access to a community palliative care team if your local hospital does not have one.

Going through this process is often easier if you have made plans in advance. We recommend that you set up a will. This is a 'living will' in which you can express your wishes for care. You can also consider including a 'Do Not Resuscitate' (DNR) order. Creating a living will reduces stress for others if it is in writing and your family is aware.

Your haematology team should talk with you about your wishes for your future care. Sometimes your choices can be limited by the nature of your ALL. For example, blood transfusions and various supportive drugs can only be delivered in hospital. Options should be discussed with you regardless. Your haematology team will also provide support to your family, carers and loved ones.



Leukaemia Care is a national blood cancer charity supporting anybody affected by a blood cancer. This includes patients, family, friends and the healthcare professionals that support them.

To make a donation or become a regular giver, please visit **www.leukaemiacare.org.uk/donate**

Thank you!

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

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. We are here for everyone affected by leukaemia and related blood cancer types – such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). We believe in improving lives and being a force for change. To do this, we have to challenge the status quo and do things differently.

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

Blood Cancer UK

Leading charity into the research of blood cancers.

0808 2080 888
www.bloodcancer.org.uk

Cancer Research UK

Leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

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

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

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

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

How you can help us

If you've been affected by ALL, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications Team at communications@leukaemiacare.org.uk.

We are continually working to make sure our information is up to date and includes everything you need to help feel supported and empowered to advocate for yourself. With this, it is important for us to listen to any feedback you might have about our relapsed or refractory ALL booklet.

Scan the QR to take you to our shop to leave a review of our booklet:

Alternatively, you can email our Information Team at information@leukaemiacare.org.uk, call our office line on **01905 755 977** or write a letter to our Head Office at **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**.

Take on a challenge for Leukaemia Care

We have a range of fundraising challenges that you can get involved in to help us continue to provide care and support to those affected by a leukaemia, MDS or an MPN.

Running, swimming, cycling and adrenaline challenges are available to take part in, both in the UK and abroad. There really is something for everyone.

If you're interested in taking part in a challenge, speak to a member of our Fundraising Team by emailing fundraising@leukaemiacare.org.uk or calling **01905 755977**.

Alternatively, scan this QR code to find out all the ways you can get involved with Leukaemia Care:

"It was a pleasure to meet you and to take part in my first half marathon together with the Leukaemia Care team! I'm a scientist and work in immunology research. A dear family member passed away from leukaemia seven years ago this month, so I did this in his memory. I smashed my goal of under two hours with a final time of 1:53! I'm extremely happy, thank you so much for all your hard work and it was great to see you cheering us on along the track. I loved the look of the vests too! See you again, next year maybe!" **- Alexandru Bacita ran London Landmarks for Leukaemia Care in 2022**

Your gift today will ensure that Leukaemia Care can continue to offer support to leukaemia patients and those who love them

Yes, I want to make a regular gift to Leukaemia Care of £5 or £ ☐ a month starting on the 1st ☐ or the 15th ☐ of each month (please tick one).

Please note: the minimum for a direct debit is £2 a month.

Title: .....

First name or initial(s): ..... Surname: .....

Full home address: .....

.....

Postcode: ..... Phone: .....

Email: .....

☐ **Gift Aid Declaration: Please tick here if you want Leukaemia Care to reclaim the tax that you have paid on all your donations you make in the future or have made in the past four years.**

Instruction to your Bank or Building Society to pay by Direct Debit

Name of Account Holder(s): ..... / .....

Bank/Building Society account number: ☐

Branch sort code: ☐

Name and full postal address of you Bank or Building Society: .....

.....

Instruction to your Bank or Building Society: Please pay Leukaemia Care from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with Leukaemia Care and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s): ..... / .....

Date: ☐

This guarantee should be detached and retained by the payee.

The Direct Debit Guarantee

DIRECT Debit

This Guarantee is offered by all banks and building societies that accept instructions to pay Direct Debits.

The efficiency and security of the scheme is mentioned and protected by your own Bank or Building Society.

If the amounts to be paid or the payment dates change, Leukaemia Care will notify you 10 working days in advance of your account being debited or as otherwise agreed.

If an error is made by Leukaemia Care or your Bank or Building Society, you are guaranteed a full and immediate refund from your branch of the amount paid.

You can cancel a Direct Debit at any time by writing to your Bank or Building Society. Please also send a copy of your letter to us.

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?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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

Leukaemia Care is registered as a charity in England and Wales (no. 1183890) and Scotland (no. SC049802).

Company number: 11911752 (England and Wales).

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum