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# Maintenance treatment for Acute Lymphoblastic Leukaemia (ALL)

A Guide for  
Patients

# Introduction

**Maintenance is the third treatment phase of ALL. It consists of low doses of the chemotherapy used for consolidation in combination with a steroid drug. As a result, you can have maintenance treatment without needing to stay in hospital. If you have any questions about this phase of ALL treatment - 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@leukaemicare.org.uk](mailto:communications@leukaemicare.org.uk).

# In this booklet

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# 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

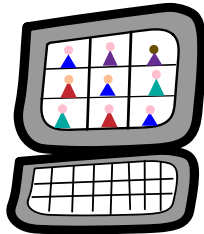
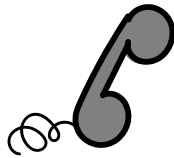
### Helpline

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.

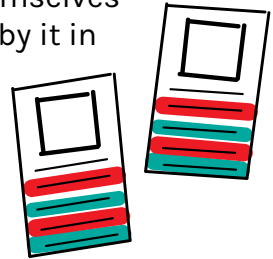
### Support groups

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@leukaemicare.org.uk](mailto:support@leukaemicare.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](mailto: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:



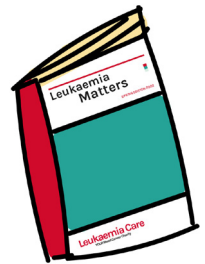
## Write a free will

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:



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# 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.

## **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.

## **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.

## **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.

## **Stem cells**

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

# Summary: What is maintenance treatment for ALL and its side effects?

- Treatment of ALL is divided into three separate phases:
  1. Induction treatment that destroys immature leukaemia cells to help achieve remission.
  2. Consolidation treatment that kills remaining leukaemia cells to strengthen remission.
  3. Maintenance treatment that destroys any remaining leukaemia cells that may cause a relapse.
- Maintenance is the third treatment phase of ALL. It consists of low doses of the chemotherapy used for consolidation in combination with a steroid drug. As a result, you can have maintenance treatment without needing to stay in hospital.
- In this booklet, we concentrate on the maintenance phase of treatment.

We have several booklets on the treatment of ALL, including induction and consolidation. Scan the QR code to order or download our booklets:



- Supportive care is available to help with symptoms of leukaemia and side effects of treatment.



# What is maintenance treatment for ALL and its side effects?

Maintenance is the third phase in the treatment of ALL. Maintenance treatment prolongs the remission achieved in the previous treatment phases.

## Duration of the maintenance phase

The optimal duration for the maintenance phase is 18-24 months. Increasing the maintenance phase to 36 months has not been shown to improve patient survival in clinical trials. This treatment duration of 36 months was common in the past, especially if you were male.

New treatments for ALL are more intensive. This means there is no need for treating boys longer than girls. Longer duration of intensive treatment would cause more harm without carrying any benefit. Longer duration for maintenance for boys is no longer recommended.

Giving maintenance chemotherapy for less than the established 18 months has been shown to increase relapse rates.

## Treatment used for maintenance

Maintenance treatment consists of low doses chemotherapy together with a steroid drug. These include:

- Mercaptopurine and methotrexate: These are the most commonly used drugs for ALL maintenance therapy. Mercaptopurine is given once a day and methotrexate once a week.
  - Mercaptopurine and methotrexate are anticancer chemotherapies.
  - Methotrexate stops cells making and repairing their DNA. It prevents leukaemia cells from growing and multiplying as normal.
  - Mercaptopurine interferes with the normal processes of cells. This leads to the death of the leukaemia cells.

- The doses of these drugs are low because of the long duration of treatment of the maintenance phase.
- The steroid drugs used are dexamethasone or prednisolone.

Both mercaptopurine and methotrexate chemotherapies are available as tablets for oral administration. This enables you to have your maintenance treatment at home. It is important to take your tablets as indicated. This is to make sure they work as well as possible for you.

Other maintenance treatments that may be beneficial for you can include:

- Steroids as part of your maintenance treatment. Steroids can:
  - Treat the leukaemia itself
  - Reduce inflammation
  - Help prevent an allergic reaction to leukaemia treatments
  - Reduce your body's immune response
  - Help reduce sickness and improve your appetite
- Monthly cycles of vincristine or another strong chemotherapy
- A tyrosine kinase inhibitor (TKI) if you have the Philadelphia chromosome. You are likely to have had a TKI throughout treatment. This will continue during maintenance treatment, or you might try a new type of TKI if needed.
- Intrathecal therapy: This treatment given as part of induction treatment may also be administered during maintenance treatment to:
  - Destroy leukaemia cells located in your brain and spinal cord.
  - Prevent any leukaemia cells from spreading into your central nervous system (CNS). The CNS comprises the

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

- Intrathecal therapy consists of methotrexate, cytarabine and a steroid injected into your CSF.
- ALL patients receive intrathecal therapy throughout the whole treatment period for ALL.

For find more details on intrathecal therapy, you can read our booklet on induction treatment for ALL. Scan the QR code to order or download our 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.

## **What are the side effects with maintenance treatment?**

Methotrexate and mercaptopurine can cause hepatotoxicity and myelosuppression. Hepatotoxicity means it can affect the function of your liver. Myelosuppression is where it stops the production of normal blood cells in the bone marrow. These side effects should not be too severe because of the low doses used.

Other side effects associated with the chemotherapy used in maintenance treatment are less severe for the same reason.

Common side effects with chemotherapy include:

- Increased risk of infection
- Fatigue
- Anaemia

- Bleeding
- Gastrointestinal (nausea, vomiting, diarrhoea and constipation)

You may only experience some of these side effects.

## Fatigue

This is a very common side effect of ALL treatment. It can be caused directly by the drugs. It can also have other causes. One example is the psychological and emotional stress of your 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 haematology team. It is very common for it to continue after treatment. There are fatigue services if it affects you in the long term or it is particularly severely, but waiting lists can be long.

## Infections

You should be aware that you are vulnerable to infections whilst on treatment. This is because most treatments have an effect on 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 have to 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 include:

- Washing your hands.
- 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.

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

# Summary: What happens after maintenance?

- After a successful maintenance, your haematology team will continue to follow-up with you at regular intervals. This is to pick up any symptoms of relapse or late side effects.
- If your ALL comes back, the symptoms will be similar to your initial episode of ALL. You will need further treatment. Your haematology team will discuss the availability of other treatments with you.
- Treatment of relapsed ALL is hard but not impossible. Your haematology team will select the treatment they feel will be most effective for you. This can be chemotherapy or the new targeted treatments which have led to very good outcomes.
- Your haematology team will explain your next steps.

# What happens after maintenance?

When your maintenance treatment is successful, it will have killed any remaining leukaemia cells in your body. After your last treatment, your haematology team will check that you are free of detectable leukaemia cells. This will help prevent you experiencing a relapse. Maintenance treatment will lengthen your remission.

Your haematology team will follow you up with regular appointments to check there are no signs of relapse or side effects of treatment. In the first year after maintenance you will have check-ups every two to three months. At each appointment, you will have blood tests. No more bone marrow tests will be needed if the blood test results are normal. Over time, the check-ups will become less and less frequent.

If your ALL comes back, the symptoms will be similar to those of your initial ALL. You will need further treatment. Treatment of relapsed ALL is difficult but not impossible. Treatment of relapsed ALL can be another cycle of chemotherapy. However, new targeted treatments have shown much improved outcomes.

We have a dedicated booklet on relapsed and refractory ALL and its treatment which you might find helpful. Scan the QR code to order or download our booklet:



# Summary: Supportive care

Supportive care describes any medication/medical care that is not intended to treat your leukaemia. Supportive care improves your quality of life.

Supportive care is not only available during maintenance treatment but at any time during your ALL treatment.

The main goal of supportive care is to help relieve symptoms from your ALL and the side effects of your treatment.

The most commonly used drugs for maintenance are mercaptopurine, methotrexate and steroids. Side effects of these drugs are similar to those in consolidation treatment, but less severe. Symptoms from your ALL are also less intense.



Methotrexate and mercaptopurine display only moderate hepatotoxicity and myelosuppression because the doses of these drugs are low.

Other side effects associated with the chemotherapy used in maintenance treatment are less severe for the same reason.

Common side effects with chemotherapy include:

- Increased risk of infection
- Anaemia
- Bleeding
- Fatigue
- Gastrointestinal (nausea, vomiting, diarrhoea and constipation)



# Supportive care

The increase in lymphocytes in ALL results in its symptoms. You may have experienced one, several, or all of the following symptoms. The most common symptoms and signs of ALL are:

- Weakness or fatigue
- Fever and night sweats
- Unexpected weight loss or anorexia
- Easy bruising
- Frequent chest or urinary tract infections

Treatments in the maintenance phase of ALL are similar to those used in the consolidation phase, but prescribed at much lower doses. The main drugs are mercaptopurine, methotrexate and corticosteroids. Side effects with these drugs are similar to those experienced with consolidation treatment, but they are less severe. Haematologists often administer these drugs in combination to help prevent the leukaemia cells from developing any drug resistance.

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

- Psychological
- Social
- Spiritual

For more information about side effects, we have dedicated booklets on the common side effects of treatment and late effects of treatment. Scan the QR code to order or download our booklets:



## Support with transfusions

Supportive care also includes:

- Blood transfusions of 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.

## How do you cope with an initial bad response?

Being told your treatment is not working or has not worked is disappointing. We suggest you view your position as if you were newly diagnosed again, taking things slowly and being kind to yourself.

Supportive care is not only limited to the physical impact of your ALL. It will provide you with support for concerns with an initial bad response such as :

- Emotional health
- Mental health
- General wellbeing/home life
- Work and money
- Support with transfusions

Information on the supportive care for the topics listed above are available in our newly diagnosed booklets for B-cell ALL and T-cell ALL. Scan the QR code to order or download our booklets:





**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](http://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](http://www.leukaemiacare.org.uk)**  
**[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)**

## Blood Cancer UK

Leading charity into the research of blood cancers.

**0808 2080 888**  
**[www.bloodcancer.org.uk](http://www.bloodcancer.org.uk)**

## Cancer Research UK

Leading charity dedicated to cancer research.

**0808 800 4040**  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## **Macmillan**

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

**0808 808 0000**

**[www.macmillan.org.uk](http://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](http://www.maggiescentres.org)**

## **Citizens Advice Bureau (CAB)**

Offers advice on benefits and financial assistance.

**08444 111 444**

**[www.adviceguide.org.uk](http://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](mailto:communications@leukaemiacare.org.uk).

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**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 maintenance treatment for 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](mailto: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](mailto: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



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](http://www.leukaemiacare.org.uk)

[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)

Leukaemia Care,  
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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

