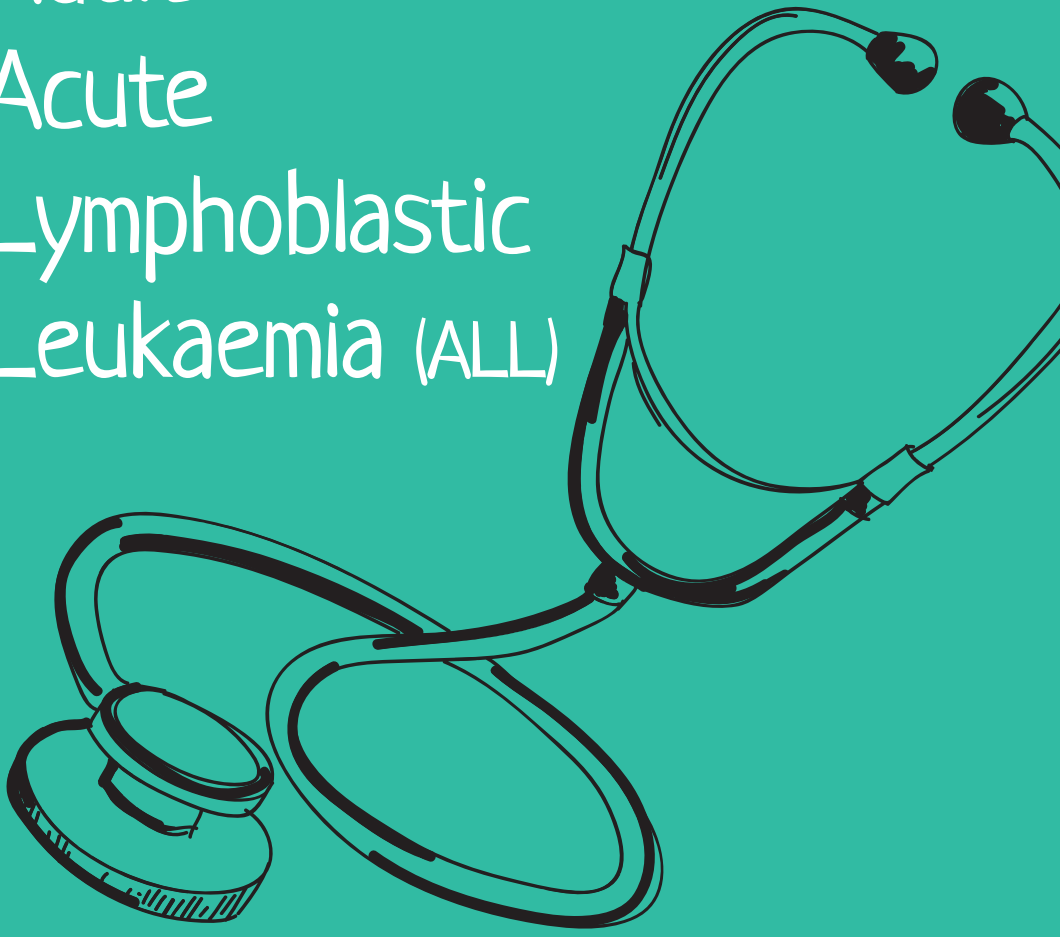
STEP BY STEP

Adult Acute Lymphoblastic Leukaemia (ALL)



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Introduction

Being diagnosed with acute lymphoblastic leukaemia (ALL) can be a shock, particularly when you may never have heard of it. If you have questions about ALL – what causes it, who it affects, how it affects your body, what symptoms to expect and likely treatments – this booklet covers the basics for you. For more information, talk to your haematologist, clinical nurse specialist (CNS) or hospital pharmacist. You'll also find useful advice about how to get the best from your haematologist, plus practical advice on how to help important people in your life understand such a rare condition.

This booklet focuses on adult ALL. For more information on childhood ALL, please refer to our other booklet, Step by Step on childhood ALL. Young adults, up to 25 years old, are usually treated in the same way as children. If you are a young adult with ALL, you should ask your specialist team about your treatment.

Booklet compiled by Ken Campbell, MSc (Clinical Oncology) and peer reviewed by Dr Clare Rowntree, Haematologist and Clinical Chair at Cardiff and Vale University Health Board. Thank you to patient reviewer Helen Laude for all your helpful insight.

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In this booklet

For a list of reference sources used in the writing of this booklet
email: info@leukaemiacare.org.uk

Useful personal information and contact details

This is a place for you to note down important information relating to your diagnosis and key contacts

Date of diagnosis	
My diagnosis	

Notes

	Name	Contact details
My hospital		
Consultant haematologist		
Clinical Nurse Specialist (CNS)		
GP		
Haematology clinic		
Haematology ward		
Emergency contact number / Out of hours contacts		

What is Acute Lymphoblastic Leukaemia (ALL)?

Acute lymphoblastic leukaemia (ALL) is a blood cancer which affects the lymphocytic cells, which are one type of white blood cell. When you have ALL, your body produces far too many leukaemia cells and does not produce enough healthy blood cells. The term acute does not describe how serious the leukaemia is. It refers to the fact that it develops rapidly and, if not treated, gets worse quickly. This contrasts with chronic leukaemia which develops and progresses slowly.

To understand ALL, it is helpful to understand how blood cells are normally produced. Blood cells are produced in the bone marrow, which is spongy tissue found inside bones. Each day, the bone marrow produces more than a trillion new blood cells to replace those that are worn out. Blood stem cells divide to produce either mature blood cells or more stem cells. Only about one in 5,000 of the cells in the bone marrow is a stem cell. A blood stem cell, also called haematopoietic stem cells, may become a myeloid stem cell or a lymphoid stem cell.

A myeloid stem cell becomes one of three types of mature blood cells:

- Red blood cells that carry oxygen and other substances to all tissues of the body.
- Platelets that form blood clots to stop bleeding.
- White blood cells that fight infection and disease. The shortest

lived white cells are called neutrophils.

A lymphoid stem cell becomes a lymphoblast cell and then one of three types of lymphocytes (white blood cells):

- B lymphocytes that make antibodies to help fight infection.
- T lymphocytes that help B lymphocytes make the antibodies that help fight infection.
- Natural killer cells that attack cancer cells and viruses.

People with ALL produce too many immature lymphoid cells (blast cells) which populate the blood and bone marrow. Over time, these abnormal cells will accumulate and begin to fill up the bone marrow, preventing it from producing healthy blood cells.

There are several different subtypes of ALL, about three out of every four cases of adult ALL affects B lymphocytes, and is known as B-ALL. Almost all the remaining cases affect T lymphocytes. Similar treatment protocols are used for B-ALL and T-ALL and the information in this booklet applies to both types.

How common is ALL?

ALL accounts for less than one in every hundred (1%) cases of cancer in the UK. Almost 350 cases of ALL are diagnosed in adults in the UK each year.

It can develop at any age but, unlike most types of cancer, it is most common in children. It affects young adults, but the incidence in adults increases with age. ALL is slightly more common in men than in women.

What causes ALL?

In most cases, there is no obvious cause of ALL. But there are certain things which are known to be linked to a higher chance of developing this illness.

Age
Adult ALL incidence increases with age.

Gender
Men are slightly more likely than women to develop adult ALL.

Genetic factors
In adults, there is little evidence of genetic risk factors for ALL. There are some known genetic conditions, including Down syndrome, which may be associated with an increased chance of developing ALL. There is no cause for anxiety, or for screening tests, for anyone with a family member who has ALL.

Environment
Some chemicals and high levels of radiation may increase the chance of developing leukaemia. Strict rules to limit occupational exposure mean that these factors play a very small part in causing ALL in the UK.

Previous treatment
Some patients can develop ALL after being previously treated with either chemotherapy or radiotherapy. This is uncommon and is called therapy-related ALL. People who develop leukaemia after cancer treatment are more likely to develop a completely different type of leukaemia called acute myeloid leukaemia (AML).

Symptoms of adult ALL

Before we discuss the symptoms of ALL, it's important to understand how ALL affects the body, compared to someone who doesn't have ALL.

In someone **without** ALL, bone marrow (the soft, fatty tissue inside your bones) contains blood stem cells that in time develop into mature blood cells – red blood cells (to carry oxygen to the tissues of your body); white blood cells (to fight infection and disease); or platelets (to help prevent bleeding by causing blood clots to form). Production of new blood cells is very closely controlled to balance the loss of worn-out cells or cells lost by bleeding or damage.

About one in 5,000 cells in the bone marrow is a blood-forming stem cell; these can divide to produce more stem cells or to develop into working blood cells. An average adult produces about one trillion new blood cells each day. The healthy number of different types of blood cells varies between people but is usually kept within fairly narrow limits. The white blood count may temporarily rise after exercise, but changes like this usually do not last very long and are perfectly normal.

In someone **with** ALL, there are very large numbers of immature lymphoid blood-forming cells (blasts) in the bone marrow. These are abnormal and do not produce healthy working blood cells. Very commonly, but not always, the blood contains immature (leukaemia) cells, including blast cells, which are normally present in the bone marrow, but not in the blood.

Due to the inability of the bone marrow to make enough working blood cells, ALL patients often have lower than normal numbers of red blood cells (anaemia), mature white blood cells (neutropenia) and/or platelets (thrombocytopenia). When all types of blood cells are lower than normal this is called pancytopenia. These changes lead to some of the symptoms of ALL which are described as follows.

What are the most common symptoms of adult ALL?

The majority of patients with ALL will have symptoms when they are diagnosed. However, not everyone experiences all of the symptoms together. Rarely, the condition may be found by chance when a routine blood test is carried out for something else. The most common signs and symptoms are caused by the bone marrow being unable to produce enough normal blood cells.

Symptoms which may be seen include:

- Fatigue
- Frequent and recurrent infections
- Fever and night sweats
- Malaise (general feeling of illness)
- Purpura (small purple spots on the skin)
- Unusual bleeding e.g. nose and gums
- Unexplained weight loss

Diagnosis of adult ALL

If, after a blood test, ALL is suspected, you'll have a further set of tests to confirm the diagnosis. If you're diagnosed with ALL, you will also have further tests to determine the right treatment for your cancer. It's important that you know and understand your diagnosis so you can ask questions and be fully informed of what to expect. Your consultant will be able to write it in the front of this booklet if that would help you.

Sometimes, test results can take a little while. This can be an anxious and worrying time but please remember that it is important that your medical team reach the correct diagnosis so that you can get the right treatment.

Tests may include:

1. Full Blood Count (FBC) – this is a simple blood test which measures the number of red cells, white cells and platelets in the blood. In ALL, there are typically more white cells than normal. Immature blood-forming cells (blasts) are seen in the blood; these are normally only found in the bone marrow.

2. Cytogenetics – Cytogenetics is the study of gene changes and investigates the genetic differences between ALL cells and normal cells. Cytogenetic results are important for the WHO (World Health Organization) classification of ALL and for risk classification. One of the most important cytogenetic abnormalities is called the Philadelphia chromosome – this forms when parts of chromosomes 9 and 22 are swapped over.

Philadelphia chromosome is most strongly linked to a type of leukaemia called chronic myeloid leukaemia (CML), but can also be seen in other blood cancers, including ALL.

The Philadelphia chromosome is much more common in adults with ALL than in children and is associated with poor results using standard treatment. Treatment results can be greatly improved by adding drugs called tyrosine kinases, which were originally developed to treat CML.

3. Bone marrow samples – In most cases, your doctor will take a bone marrow sample, where a small amount of bone marrow is taken from the hip bone using a needle (an aspirate), to look at the cells. You may also have a sample of bone marrow taken from the core using another larger needle (a trephine) to look at the structure of the bone marrow. This procedure is normally done under local anaesthetic.

4. Lumbar puncture - a sample of cerebrospinal fluid (CSF) is taken from the spine to see whether there are leukaemia cells in the nervous system. This test may be delayed until after treatment has started.

5. Other tests - may be done including X-rays, ultrasound or scans (CT or MRI), which are done to assess the impact of the leukaemia on organs of the body.

Blood tests, bone marrow samples and scans will be repeated throughout treatment to monitor response to treatment.
A test called MRD (minimal residual disease) will be done during treatment. MRD testing can detect even very small numbers of remaining leukaemia cells, which is important in planning the next phase of treatment.

If you want to know more about your tests and their results, you can ask your doctor or your specialist nurse. You can also find information about tests on the website Lab Tests Online UK **www.labtestsonline.org.uk**

Risk grouping

The most important part of classifying ALL is risk grouping. There are two risk groups in adult ALL; high risk and standard risk. You should ask your specialist about risk groups and what they mean for your treatment.

It is important to understand that risk groups refer to the outcome using standard treatments. By adjusting treatment according to risk groups the results can be improved.

High risk
High risk ALL is defined on the basis of age, white cell count, cytogenetics and response to initial treatment, as measured by MRD.

Standard risk ALL is defined as any patient who does not have high risk features.

What happens next?
Because ALL progresses rapidly, virtually all patients with ALL start treatment soon after diagnosis. You can refuse treatment at any time, but it is important that you understand clearly what might happen in this case. You can ask for a second opinion at any time. As far as possible, all decisions about treatment will take your wishes into account.

Treating adult ALL

Almost all patients will start treatment at, or soon after, the time of diagnosis. You may be asked to consider taking part in a clinical trial, which is a study comparing treatments to find out which is best. A clinical trial consists of two or more different arms.

One arm of a trial will be the best known current treatment, and the other arm(s) will be newer treatments. The treatment for an individual patient is chosen at random, to make sure that the trial does not have all the high risk patients in one arm. This process is referred to as randomisation.

You do not have to take part in a trial if you do not want to and you will be given detailed information and a chance to ask questions before you decide. Not all patients are able to take part in trials, for example if they have other medical problems. If you want to know about clinical trials, you should ask your specialist. All clinical trials have specific rules on which patients are eligible to be included; these are based on factors such as age, other medical conditions and whether you have previously been treated for any form of cancer.

If you are not taking part in a trial, your treatment will be based on the current gold standard treatment. Some of the factors considered in treatment planning are:

- Fitness levels and whether or not intensive chemotherapy would do more harm than good.
- Age – your age can affect how well your body responds to treatment.
- Whether there's a high risk of relapse with standard treatment.

If they are otherwise fit, even elderly patients can usually receive treatment. ALL is potentially curable but the proportion of patients who can be cured depends on the age, fitness of the patient at the time of diagnosis and the response to treatment.
You can find more information about drugs used to treat your ALL (and any other medicines you are taking) at the eMC Medicine Guides website **www.medicines.org.uk/guides**

Treatments for adult ALL

Initial treatment of ALL usually consists of chemotherapy, and is divided into phases known as induction, intensification, consolidation and maintenance. For younger/fitter patients a stem cell transplant may be considered.

If you may be able to have a stem cell transplant, you will be given detailed information about what this involves.

Induction treatment for adults normally lasts about 8 weeks and uses combinations of drugs.

Patients who are not having a stem cell transplant will have an extended phase of treatment called maintenance. If you are having a stem cell transplant, you will not receive maintenance chemotherapy; the stem cell transplant is done after completion of induction chemotherapy although some patients will receive intensification and consolidation as well before they have their transplant.

You'll receive your induction treatment as an inpatient in hospital, but you will normally have most of your other treatment as an outpatient. Most patients will need to be admitted to hospital from time to time due to complications such as infection. You'll be regularly monitored and will probably receive blood and platelet transfusions, if you need them to help support your body.

Treatment options for adult ALL

Chemotherapy
Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy will also damage some normal cells, which means that there are side effects. In ALL chemotherapy drugs are usually given in combination, you will be given details of your planned treatment and you can ask questions at any time.
The most common cell-killing drugs used to treat adult ALL are:

- Vincristine
- Mercaptopurine
- Methotrexate
- Daunorubicin
- Cyclophosphamide
- Cytarabine
- Doxorubicin
- Asparaginase

As well as the cytotoxic drugs, it has been found that steroids are very effective in treatment of adult ALL. The steroids used are artificial versions of natural substances made in your body. It is very important to understand that these steroids are very different from the drugs sometimes abused by athletes or bodybuilders. The steroid most commonly used for treatment of adult ALL is called dexamethasone. Some patients will be given a different steroid, called prednisolone.

For patients who have the Philadelphia chromosome, a type of drug called tyrosine kinase inhibitors are used along with the chemotherapy. These drugs are very effective at preventing the effects of the Philadelphia chromosome.

Immunotherapy
Immunotherapy uses monoclonal antibodies to attack and destroy ALL cells. Monoclonal antibodies are drugs that recognise, target and stick to specific proteins on the surface of cancer. They can stimulate the body's immune system to destroy these cells.

Another way to use the immune system is to modify immune system cells, called T-cells, to allow them to attack ALL cells more efficiently.

Stem cell transplant
A stem cell transplant involves the use of intensive treatment to kill as many leukaemia cells as possible. The patient is then given a transplant of healthy blood-forming (stem) cells. In ALL, the stem cells used are usually healthy stem cells from a sibling (brother or sister) or from an unrelated matched donor. This is called a donor (or allogeneic) transplant. Sometimes a patient may be given a transplant using their own healthy stem cells, collected after initial treatment. This is called an auto (or autologous) transplant – this type of transplant is not often used for ALL patients.

Pre-transplant treatment, called conditioning, may include high-dose chemotherapy plus whole body irradiation, to completely kill off the bone marrow. This is called myeloablative conditioning and is only suitable for younger, fitter patients, because of the high doses of chemotherapy. For older, and/or less fit patients, conditioning uses lower doses of chemotherapy without radiation. This is known as reduced-intensity conditioning and is more easily tolerated by older or less fit patients.

In ALL, a stem cell transplant is most often given as a form of consolidation, following induction therapy. It is usually considered for patients with high risk disease or for patients whose disease is difficult to control (refractory disease) or those who have a relapse.

The side effects of a stem cell transplant depend on the type of pre-transplant treatment and the source of stem cells. If you are being offered this type of treatment, you will be given detailed information and a chance to ask questions.

CNS treatment
In adult ALL, it is possible for leukaemia cells to get into the fluid around the brain and spine (cerebrospinal fluid or CSF). This is called central nervous system (CNS) disease and may be present at diagnosis or may develop later. Because drugs given

in the normal way cannot get into the CSF, it is necessary to give additional treatment to deal with this. This may be done at diagnosis, if there are signs of CNS involvement, or it may be given later in during induction treatment.

To prevent CNS relapse, you will have injections of drugs into the CSF by lumbar puncture during induction treatment. This is called intrathecal injection, or intrathecal therapy. You will be given detailed advice about lumbar puncture and about intrathecal injections, including possible side effects and how to avoid these. If you are not going to receive whole body radiation as part of a stem cell transplant, you may also have radiation to the head and spine to clear any remaining leukaemia cells.

You can find more information about drugs used to treat your ALL (and any other medicines you are taking) at the eMC Medicine Guides web site **www.medicines.org.uk/emc**

Side effects

Unfortunately, treatments do come with some side effects but you may not experience all of them. It's difficult to predict exactly what side effects you'll experience as different people react to treatment in different ways. Your medical team will be able to answer any questions you might have on any side effects you may experience.

Short term side effects
Short term side effects can last for a few days or weeks, but for some, can last for the duration of treatment. Short term side effects include:

- Fatigue – a common side effect of chemotherapy treatment. Fatigue isn't simply tiredness which passes with rest; you may feel generally tired all the time or you may tire very easily after doing normal, everyday tasks.
- Nausea and sickness – this can be well-managed with antisickness drugs (antiemetics).
- Infection - all patients with ALL will at some point get an infection which requires treatment with antibiotics.
- Bleeding – chemotherapy can make you more prone to bleeding especially from the nose or gums.

- Diarrhoea – this can usually be well-managed with medication.
- Constipation
- Sore mouth – chemotherapy can cause inflammation of the tissue inside the mouth.
- Loss of taste and appetite – your taste and appetite can be affected during treatment so it's important you drink plenty of fluids to stay hydrated. There are food supplements which can be taken to help maintain your energy levels.

- Organ dysfunction – chemotherapy can affect the functioning of your liver, kidneys or lungs.
- Hair loss – you may want to wear a wig or some form of headwear if you're affected by hair loss. Your healthcare team will be able to chat to you about your options.
- Bone pain with steroids
- Thrombosis and pancreatitis with asparaginase
- Headaches with lumbar punctures

Long term side effects

Fatigue
The fatigue will improve when treatment ends, but it may take months before you feel back to normal. After a transplant, it may take a year or longer for patients to feel recovered. Although fatigue cannot be completely prevented, there are ways of managing fatigue. Perhaps unexpectedly, resting a lot often can make fatigue worse, while remaining as active as you can manage often makes it easier to cope. If you are feeling tired, you should tell your healthcare team as they can offer help.

Loss of fertility
Some of the drugs used to treat ALL can cause temporary or permanent infertility. Your doctor will talk to you about this in more detail before treatment starts. The effect of treatment on fertility is a common concern that many patients have. However, as treatment for ALL usually needs to start as quickly as possible, there's not always enough time to store sperm or embryos.

If you're having treatment for ALL, at an age when you're thinking of having children, now or in the future, you should discuss options for protecting your fertility with your doctor. You can write down any questions you have so that you are clear about the treatment, and the effect it's likely to have on you, before it starts. Some drugs have less effect on fertility than others, and it is often possible for people successfully treated for ALL to later have healthy babies. Unfortunately, people who've had a stem cell transplant after high doses of chemotherapy or whole body irradiation are more likely to be permanently infertile. It's natural to worry about the effects of treatment on any children you might have after treatment. However, evidence from clinical studies has shown that any cancer treatment a parent has doesn't lead to an increased risk of cancer or other health problems in their children.

Heart damage

Some of the drugs (anthracyclines) used to treat ALL may affect the heart. This is rare because healthcare teams are careful to limit the doses you have. Your heart function will be carefully monitored during and after treatment, and the drugs you're given may be altered if any heart problems occur.

Stages of treatment of adult ALL

Induction

Remission induction, often just called induction, is the use of chemotherapy to induce remission, ideally complete remission (CR) which means that no leukaemia cells can be found in the blood or bone marrow, using standard tests. It is important to understand that remission, even CR, does not mean cure; if treatment stops at this point, almost all patients will relapse – their ALL will return. Induction is the same for most patients, apart from any trial variations. Patients who are Philadelphia chromosome positive or have CNS disease at diagnosis will have additional treatment to deal with this.

Remission induction for ALL uses combinations of chemotherapy drugs plus steroids. You will be given details of the drugs which you are going to receive during your treatment.
At the end of remission induction, special tests are carried out to look for minimal residual disease (MRD), which is the presence of very small numbers of leukaemia cells. MRD test results are very important in classifying patients as high risk (MRD positive, whether or not they have other risk factors) or standard risk (MRD negative and no other risk factors).

Intensification

This is a period of treatment based on use of high-dose methotrexate along with other drugs. As with induction, you will be given details of any drugs being used and what side effects you may experience. Intensification is intended to kill off any leukaemia cells which have survived induction treatment.

Consolidation

Consolidation treatment is given after remission induction to reduce the risk of a relapse. Several factors affect the choice of consolidation treatment, including age and risk status.

For patients who do not have a stem cell transplant, consolidation therapy will use similar combinations of drugs to those used for remission induction, but these are given in lower doses. You will be given detailed information about your planned consolidation therapy before this starts.

Maintenance

Maintenance therapy is low-dose chemotherapy and steroid treatment, given as an outpatient. Without maintenance therapy, there is a higher chance that the ALL will come back – a relapse. When this happens, it is often less responsive to treatment. Maintenance lasts for many months, with the total time from start of treatment being between two and three years.

Treatment of refractory/relapsed adult ALL

With modern treatment options, it is very uncommon to have no response at all to treatment, which is known as refractory ALL. When there is a good initial response but ALL returns this is known as relapsed ALL and again is less common with current treatments.

If you have refractory or relapsed ALL, your specialist will discuss your treatment options in detail. There are several new treatment approaches being studied – see under the heading "New treatments and treatments on the horizon". Often, newer treatments are initially introduced in clinical trials for treatment of refractory or relapsed ALL.

ALL treatment in older adults

In patients over the age of about 60 years, standard treatment may be too toxic. In this age group, treatment is chosen on an individual basis, depending on the patient's general health and any other health problems. If this applies to you, your consultant will discuss treatment options and you will have a chance to ask questions before any decisions are made.

Supportive care

Supportive care includes treatment to prevent infections and to manage them when they happen and treatment to deal with the side effects of adult ALL treatment. Improvements in supportive care have played a crucial part in improving the survival of patients with adult ALL.

Because both adult ALL and its treatment affect the body's ability to produce healthy blood cells, most patients with adult ALL need transfusions of red blood cells and often of platelets. It is not possible to transfuse white blood cells but it is now possible to have injections of growth factors, which help the body to produce more white cells. This will reduce the frequency and severity of infections.

Much of supportive care is based on good nursing care, but protecting yourself from infection outside the hospital is very important. You will be given information on this and will be shown how to recognise infection, or other complications, and who to contact and what to do.

Palliative care

During treatment, you may come into contact with a palliative care team who can help to control some of the symptoms you may be experiencing.

The palliative care team can provide additional advice and support when symptoms are not easily controlled. Their input can be temporary or for a longer period of time as some medical treatments can be fairly aggressive and call for equally aggressive palliative approaches to your care. Care provided by your palliative care team can help you tolerate the side effects of these treatments.

Not all treatments, sadly, are successful and sometimes patients have to be told that the disease is too progressive for any treatment to control it. That conversation will most likely be started by your medical team and most hospitals will have palliative care teams that have experience in dealing with end of life and related symptom control.

Follow-up

Once your treatment is finished, you'll need to have regular check-ups at the hospital. These may be frequent at first, probably one to two months, then every few months until they become yearly at five years or earlier. The exact frequency and timing will depend on the treatment you have received. The purpose of follow-up is to monitor you and look for signs of relapse or complications.

If you notice any new symptoms or something is worrying you, you should contact your medical team as soon as possible.
After treatment, you may still have some physical effects to cope with. It's important to remember that it can take some time for

you to fully recover, so try not to expect too much of yourself too soon. How quickly things improve will depend on the treatment you've had, your age and general health.

New treatments and treatments on the horizon

There are several new types of drugs being studied for the treatment of ALL. These classes are all more specific in their effects than standard chemotherapy. This is because they attack features of the leukaemia cells, while having much less effect on normal cells than chemotherapy.
Most of these fall into two groups:

Immune system based treatments

- Monoclonal antibody targeted at specific markers on ALL cells
    - Rituximab
    - Ofatumumab
    - Epratuzumab
- Monoclonal antibody linked to drug (drugs too toxic to use conventionally)
    - Inotuzumab
    - Denintuzumab
- Modified antibodies (which activate immune system cells to attack ALL cells)
    - Bispecific T-cell antibodies (BITE) Blinatumomab
- Modified patient immune cells
    - Chimeric antigen receptor (CAR) T cells (immune cells with Improved ability to attack ALL cells)

Tyrosine kinase inhibitor (TKI) drugs (for Philadelphia positive ALL)

- Tyrosine kinases are either abnormal proteins produced by leukaemia cells, or normal proteins produced in large amounts by leukaemia cells
    - Imatinib
    - Dasatinib
    - Ponatinib
    - Other TKIs – several are being tested in clinical trials

The aim of these newer, more targeted therapies is to reduce the amount of chemotherapy needed, which will reduce side effects. Some experts have suggested that it may eventually be possible to treat some patients without any chemotherapy.

A drug called nelarabine is showing promise in the treatment of T-cell ALL.

At present, these newer drugs (except TKIs) are either only available for ALL patients in clinical trials, or are not available on the NHS in the UK.

Your prognosis

Each patient with ALL will have a different outlook (prognosis) following treatment as it will depend on many factors such as age, overall fitness, your ALL subtype, how well you respond to treatment and your risk group. Every individual is different so your medical team are the best people to ask about your likely outlook.

Generally, the younger you are, the more likely you are to respond better to treatment. Younger people are better at coping physically with the very intensive treatments they have to go through.
It is important to remember that your prognosis can change, especially if you respond well to treatment.

Taking about your prognosis

Talking about your prognosis can be a daunting and difficult topic to discuss. You may find that whilst you don't want to know your prognosis, family members and friends do.

It is important to remember that your doctor cannot tell anyone else about your prognosis without your permission and only you can decide who you want to know about your condition. Everybody copes with it in different ways, and there's no right or wrong way to deal with it.

Everyday life and ALL

Being diagnosed with an aggressive blood cancer like ALL can be difficult physically, practically and emotionally. This chapter will talk about all of these aspects.

Emotional impact of ALL

Being told you have cancer can be very upsetting. It can be especially difficult with acute leukaemia as you often get ill suddenly, and have to start treatment quickly. There is usually very little time to take in information and start to cope with it.

Adult ALL is a rare condition and, because of this, you may need emotional as well as practical support. Being diagnosed with a rare disease can affect the whole of you, not just your body, and can impact you emotionally at any point of your 'journey'. It is likely that you will experience a range of complex thoughts and emotions, some of which may feel strange or unfamiliar to you. It is important to know that these feelings are all valid and a normal response to your illness.

Looking after you

Following a diagnosis of ALL, you may wish to make make changes to your lifestyle. It's important to know your limits and don't try to change too much at once. Exactly what you can do will vary and will depend on the treatment you have had, and how fit you were before your leukaemia. Adopting a healthy way of living is about making small, manageable changes to your lifestyle.

Diet

Diet plays an important part in coping with cancer and its treatment and recovery. A well-balanced diet can help you feel stronger, have more energy, and recover quicker.

If you're having treatment, you may notice that you lose weight, or your taste or appetite changes. This may be due to the side effects

of your treatment including sore mouth or nausea and sickness. Once your treatment has finished though, you should begin to feel better and be able to eat a normal diet. This can take a while after intensive treatment.

Exercise

With some of the side effects you may be experiencing, such as fatigue, the idea of getting out and being active may be the last thing you want to do. But it is important to try and stay as active as possible to make you feel better and reduce some of the symptoms or side effects you may be experiencing. Speak to your clinical nurse specialist about exercises that may be suitable for you.

Infection

One common problem following a diagnosis of ALL is infection. When you have ALL, your body is not able to fight infections as well as normal – this is known as immunosuppression. If you have immunosuppression, ordinary infections may occur more often and be more severe or longer lasting. You may also get ill from infections with germs which normally live in the body without causing problems but which grow more rapidly when your immune system is not working – these are called opportunistic infections.

If you think you may have an infection, you should contact your doctor straightaway. Common symptoms of infection include:

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

The signs and symptoms of infection may be less obvious when you have ALL, so if you are in any doubt it is best to contact your doctor and ask for advice.

You can help to reduce the risk of infection by taking some simple precautions. Wash your hands frequently, especially after using the toilet, and also if you have touched something like a door knob or banister which can be contaminated with lots of germs. Try not to spend more time than you can help in crowds; especially if there is an epidemic of flu or other illness. You should be very careful to follow food safety advice, such as cleanliness in the kitchen and not keeping food after use-by dates.

Vaccines

Vaccinations may not work as well when you have leukaemia, but it is still recommended that you have your annual flu vaccine. This will still reduce the risk of getting ill and will offer you some protection.

ALL patients should avoid having 'live' vaccines which are used for measles, mumps and rubella (MMR) and shingles. If a vaccine is recommended by someone other than your ALL specialist you should check that it is safe.

Shingles

If you have previously been exposed to chickenpox, you may develop a painful nerve condition called shingles. Even if it was a long time ago, the virus can live dormant for many years and surface when your immune system is suppressed. Patients are usually given a drug called aciclovir to protect against shingles during ALL treatment.

Talking about ALL

Talking to your haematologist

Adult ALL is a rare condition. It is important for you to develop a good working relationship with your haematologist so you are given the best treatment possible for you.

The following gives advice on working well with your haematologist:

- If it's an initial consultation, take along a list of your current medications and doses, and a list of any allergies you may have.
- If you have a complicated medical history, take a list of diagnoses, previous procedures and/or complications.
- Make a list of questions to take to your appointment. This will help the discussion with your haematologist. Suggested questions are available from the Leukaemia CARE head office and their contact details are enclosed in the Useful Contacts chapter.
- It can be useful to repeat back what you have heard so that you can be sure that you fully understood.
- Note information down to help you remember what was said.
- Be open when you discuss your symptoms and how you are coping. Good patient-doctor communication tends to improve outcomes for patients.

Other tips:

- Bring someone along to your appointment. They can provide support, ask questions and take notes.
- Don't be afraid to ask for a second opinion – most haematologists are happy for you to ask.

You need to tell your haematologist if...

You're having any medical treatment or taking any products such as prescribed medicines, over the counter treatments or vitamins. It is important to understand that treatments, including complementary therapies, which are perfectly safe for most people, may not be safe if you are being treated for ALL. Remember, if you choose to start any form of complementary therapy outside of your medical treatment, consult your haematology consultant or clinical nurse specialist, prior to beginning it. It is important to understand the difference between complementary therapies, used alongside standard treatment, and alternative therapies, used instead of standard treatment. There is no evidence that any form of alternative therapy can treat ALL.

Talking to other people

Telling people you have a rare condition like ALL can be hard to explain. You might find it useful to let your close family and friends, as well as your employer, know about your health condition. It might be easier to provide people with basic information and give them information leaflets about ALL if they want to know more in-depth details.

It is probably best to focus conversations on the symptoms that you are experiencing, how the condition affects you and how you feel about it. Often people misunderstand and, unfortunately, it will mostly fall to you to educate them as best as you can. Where possible, it's advisable to let people know what you find helpful and unhelpful, in terms of what others say and do. Often people make assumptions and do what they think helps. For example, saying you look well, recounting stories of others they know with a similar diagnosis, encouraging you to look ahead and stay positive, isn't always what people really want to hear. In many ways, the more you communicate with them the better.

These points may help you:

- Explain that you have a condition that means your bone marrow does not function properly, and this affects the number of blood cells it produces.
- Explain your symptoms (maybe you are tired, or have a lot of pain).
- Explain what you need (maybe more help day-to-day, or someone to talk to).

You could also consider the following when telling people about your diagnosis:

Find out more

Try to find out as much as you can about your condition, from reliable internet sources, charitable organisations or your consultant haematologist. The more you know, the more you can share.

Have a print-out to hand

It may help to have some information to hand to share with family and friends. This will take the pressure off you having to remember everything they may want to know. We have information on our website for you to print out.

Explain your needs

Try and be clear about what your needs may be. Perhaps you need help with the weekly food shop, help with cooking dinner, or someone to drive you to and from appointments. You may find that friends and family are pleased that they can do something to help you.

Be open about how you feel

Don't be afraid of opening up about how you feel, as people who care will want to help you as best they can. Talk as and when you feel comfortable, so those around you will know when you need them most.

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

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia CARE

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer. We provide emotional support through a range of support services including a 24 hour CARE Line, with access to a nurse, patient and carer conferences, support groups, informative website, one-to-one buddy service, high quality patient information and nurse led online forum.
Care Line: 08088 010 444 (Freephone 24 hours a day)
www.leukaemiacare.org.uk
care@leukaemiacare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They also offer support to patients, their family and friends through patient services.
020 7504 2200
www.bloodwise.org.uk
patientservices@bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040

www.cancerresearchuk.org

Macmillan

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

0808 808 0000

www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801

www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444

www.adviceguide.org.uk

Symptoms Tracker

Keeping track of how you are feeling and how your symptoms affect your lifestyle can be difficult. This is always important but particularly if you are on 'watch and wait' as changes in symptoms may affect when your haematologist recommends starting treatment. We have included symptom trackers, which may help you track any changes, so you can discuss them with your haematologist.

Identify the symptoms that are most troublesome to you. Think back over the past seven days, and consider how much each symptom gets in the way of your ability to sleep, interact with others, work, go about other normal daily activities, or generally enjoy your day.

Use the trackers in this booklet to mark the level that most closely describes how much that symptom has affected your life that week. Try and complete the tracker on the same day each week so you can compare how the symptom is affecting you.

Remember to share this information with your haematologist or CNS.

Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes:

Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes:

Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes:

Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes: .....

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Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes: .....

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Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
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None												

Notes: .....

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Symptom Tracker

Symptom:

Days:	1	2	3	4	5	6	7	8	9	10	11	12
Severe												
Difficult												
Moderate												
Mild												
None												

Notes: .....

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Glossary

Anaemia
A medical condition in which the red blood cell count or haemoglobin is less than normal.

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.

Central line
A tube which is inserted into a large blood vessel either in the chest or arm so blood samples can be taken easily and drugs can be given without the use of needles.

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

Full blood count or FBC
A blood test that counts the number of different blood cells.

Leukaemia
A cancer of the blood with many different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the blood, usually white blood cells, which stop the bone marrow working properly.

Neutropenia
Low levels of neutrophils (a type of white blood cell) in the blood, leading to increased susceptibility to infection.

Pancytopenia
Deficiency of red cells, white cells, and platelets in the blood.

Platelet
A disc-shaped blood cell that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate).

Spleen
An organ that filters the blood. It removes old blood cells and helps to fight infection. It sits under the ribs on the left of the body.

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

Thrombocytopenia
Deficiency of platelets in the blood.

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.

Notes

Notes

About Leukaemia CARE

Leukaemia CARE is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

CARE Line

Our 24-hour CARE Line is available any time of the day or night with access to a nurse specialist at set times.

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, www.leukaemiacare.org.uk, as well as speak to one of our CARE advisers on our online support service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia CARE is involved in campaigning for patient well-being, NHS funding and drug and treatment availability.

Journey magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals.

Online Forum

Our nurse led online forum allows patients , carers and health care professionals to talk about blood cancer and receive answers from a qualified haematology nurse.

Leukaemia CARE is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

CARE Line: 08088 010 444
(free from landlines and all major mobile networks)

Office Line: 01905 755977

www.leukaemiacare.org.uk

care@leukaemiacare.org.uk

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

Registered charity 259483 and SC039207

Blood and Lymphatic cancers
Leukaemia CARE
supporting a quality of life