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# T-cell Acute Lymphoblastic Leukaemia (ALL)

**A Guide for  
Patients**

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**Being diagnosed with T-cell acute lymphoblastic leukaemia (ALL) can be a shock, particularly when you may never have heard of it. If you have questions about T-cell 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 or hospital pharmacist.

Booklet compiled by our Patient Information Writer Isabelle Leach and peer reviewed by Dr Clare Rowntree, Cardiff and Vale UHB. Thank you to patient reviewer Helen Laude for all your helpful insight.

If you would like any information on the sources used for this booklet, please email [communications@leukaemiacare.org.uk](mailto:communications@leukaemiacare.org.uk) for a list of references.

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# 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

### Helpline

Our helpline is available 8:30am – 5:30pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:30pm.

### Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing [nurse@leukaemicare.org.uk](mailto:nurse@leukaemicare.org.uk) or over the phone on **08088 010 444**.

### Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at [www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/](http://www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/)

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to [www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/](http://www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/)

### Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer 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**

### Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

### 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**.

### Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemiacare.org.uk**

### Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

# What is T-cell ALL?

Acute lymphoblastic leukaemia (ALL) is a blood cancer where high numbers of abnormal, immature lymphocytes called blasts start over-multiplying in the bone marrow. Lymphocytes are white blood cells involved in the immune response. There are three types of lymphocytes:

- 1. B-lymphocytes (B-cells):** Formed in the bone marrow, B-cells produce antibodies that immobilise and label bacteria, viruses, and toxins which invade the body.
- 2. T-lymphocytes (T-cells):** Formed in the thymus gland behind the breast bone, T-cells destroy the invading organisms that have been labelled by the B-cells, as well as any cells that have become cancerous.
- 3. Natural killer lymphocytes (NK-cells):** Formed in the bone marrow, lymph nodes, spleen, tonsils, and thymus, NK-cells attack viruses and all types of cancer cells. NK cells are unique because they recognise cells under attack without needing antibodies to label them and therefore produce a much faster immune reaction.

Lymphoblastic cancers are classified as either lymphoblastic leukaemia or lymphoblastic lymphoma. Both are cancers of immature lymphocytes.

According to the 2016 World Health Organisation Classification of Tumours of Haematopoietic and Lymphoid Tissues, T-cell acute lymphoblastic leukaemia (T-cell ALL) is a subtype of ALL that begins in the bone marrow when the immature blast cells proliferate rather than developing normally into T-cell lymphocytes.

T-cell ALL is characterised by extensive bone marrow and blood involvement. If the condition occurs only as a body mass lesion, with little or no involvement of the marrow or blood, the term lymphoma is used.

If both a mass lesion and involvement in the marrow are present, the distinction between leukaemia and lymphoma is not necessarily made.

The bone marrow is always involved in T-cell ALL. Additionally, the skin, tonsils, liver, spleen, central nervous system (CNS – brain and spinal cord), testes and lymph nodes may also be

penetrated.

The treatment between the T-cell lymphoma and T-cell ALL is very similar, so the difference in diagnosis isn't vitally important. However, your doctor will be able to confirm your diagnosis based on the signs and symptoms you present.

## Who is affected by T-cell ALL?

Approximately 85% of patients with ALL are children under 15 years of age and the remaining 15% of ALL cases are adults, mainly aged over 50 years.

In children with ALL:

- 80% to 85% of ALL consists of early B-cells (also called precursor B-cell)
- 15% are early T-cells

In adults with ALL:

- 75% of cases are early B-cells
- 25% are early T-cells

Therefore, T-cell ALL accounts for approximately 15% and 25% of cases of ALL in children and adults, respectively.

T-cell ALL is more common in adolescents than in younger children and adults, although it can occur in any age group. In children, the incidence of T-cell ALL increases with age; for example, in patients aged one to 10 years, the incidence of T-cell ALL is 7%, whereas in patients aged 15-18 years, the incidence has risen to 29%.

The 2014 World Cancer report confirmed that the incidence of ALL was slightly higher in males than females. T-cell ALL occurs more commonly in male patients who tend to have very high white cell counts, enlarged lymph nodes in the chest, and rarely display hyperdiploidy, which is having more than the normal number of 46 chromosomes.

## What causes T-cell ALL?

The exact cause of T-cell ALL is unknown.

However, chromosome abnormalities are found in about 50 to 70% of patients with T-cell ALL, suggesting a possible correlation. The most common chromosome abnormalities can be found on page 12.

# Symptoms of T-cell ALL

For patients with T-cell ALL, the bone marrow is always involved. However, cancerous T-cells may also spread to the skin, tonsils, liver, spleen, CNS, testes and lymph nodes.

The most common signs and symptoms in patients with T-cell ALL are caused by the bone marrow being unable to produce enough normal blood cells. These include:

- Anaemia (lack of red blood cells)
- Weakness, tiredness, shortness of breath, light-headedness and palpitations
- Infections – due to a lack of normal white blood cells. Infections are more frequent, more severe and last longer
- Fever, malaise (general feeling of illness) and sweats
- Bleeding and bruising – due to a lack of platelets, which are a type of blood cell which helps to stop bleeding
- Purpura (small bruises in skin), nosebleeds, bleeding gums

In addition, T-cell ALL often features swollen lymph nodes in the middle of the chest.

Patients with T-cell ALL often present with very high white cell counts, involvement of lymph nodes and frequent infiltration of the CNS. CNS involvement in patients with T-cell ALL is relatively common, especially when compared with patients with B-cell ALL, and may also be present in patients who have relapsed (that is, if the leukaemia comes back).



# Diagnosis of T-cell ALL

The diagnosis of T-cell ALL is achieved by examining an aspiration or biopsy sample from the bone marrow. This will help determine the percentage of T-cells in the bone marrow and any abnormalities of the T-cells. Although there is no specific proportion of blasts (cancerous T-cells) which has to be present in the bone marrow, there is a general agreement that 20% of blasts or more should be present in the bone marrow to make the diagnosis.

The most reliable method for diagnosing T-cell ALL is immunophenotyping of the bone marrow sample.

## Immunophenotyping

This test analyses the types of antigens or markers on the surface of the cancer cells based on the antibodies drawn to them in the patient's blood. According to which antibodies are present, it is possible to identify the type of leukaemia.

Immunophenotyping can be

achieved rapidly and effectively using flow cytometry, which measures the size and internal cellular structures of thousands of cells, and assesses the characteristics of the antibody complexes that are present.

In flow cytometry, specific antibodies are labelled with fluorescent markers and mixed with the patient's blood or bone marrow fluid/tissue. The antibodies bind to corresponding antigens on the patient's white blood cells. A solution containing these cells is passed through the flow cytometer that shines multiple laser beams. According to the light changes, the flow cytometer will determine the number and characteristics of the cells.

## Chromosomal analysis

As previously mentioned, chromosome mutations are found in approximately 50 to 70% of cases of T-cell ALL. There are a large number of chromosome translocations or gene mutations within the chromosomes of

patients with T-cell ALL.

The chromosome mutations most helpful for making a diagnosis of T-cell ALL are:

- Mutations of the NOTCH1 gene and the FBXW7 gene, which are seen in most patients with T-cell ALL.
- Translocations of the T-cell receptor genes at chromosomes 14q11, 7q35 or 7p14 are seen in approximately 35% of patients.
- Mutations in genes known as JAK, such as JAK1 and JAK3. These are seen in around 2% of children, and 15% of adults.

## Other diagnostic evaluations

These include:

- **Complete blood count** with a differential white cell count (to determine which white blood cells are increased) and a blood smear to evaluate the types of white cells involved. In patients with T-cell ALL, levels of red blood cells, neutrophils and

platelets are typically reduced as the bone marrow is busy making cancerous T-cells. In contrast, the total level of white blood cells will be increased because of the increased numbers of cancerous T-cells.

- **Serum chemistry levels and coagulation tests** to check for any problems in the liver, kidneys or other organs.
- **Levels of uric acid, calcium, phosphate and lactate dehydrogenase** should be recorded to monitor for tumour lysis syndrome. Tumour lysis syndrome is an increase in blood uric acid levels following the rapid destruction of large numbers of white blood cells during treatment, which may cause damage to the kidneys, heart or liver.
- **Cerebrospinal fluid examination:** A lumbar puncture sample at the time of diagnosis is the standard of care for determining if there is CNS involvement. If the CNS is involved, magnetic resonance

# Diagnosis of T-cell ALL (cont.)

imaging (MRI) of the brain should be performed as well.

- **Chest X-ray, CT scans, ultrasound scans and MRI scans** may be performed to find any swollen lymph nodes, or other enlarged organs or affected sites if your medical team think these tests will be helpful in your case.

Blood tests, bone marrow samples and lumbar punctures are normally repeated throughout treatment to monitor response.



# Prognosis of T-cell ALL

The prognostic factors for patients with T-cell ALL are less clear-cut than those in patients with B-cell ALL. For example, a high white count does not appear to be a strong prognostic factor for patients with T-cell ALL. Therefore, it is important to remember that, while risk factors have been determined, they are not as accurate for prognosis as for those with B-cell ALL.

## Prognostic factors

In patients with T-cell ALL, the main factor which determines prognosis is the minimal residual disease measure at the end of the induction and consolidation treatment phases.

### Minimal residual disease

Minimal residual disease (MRD) is a measure of the presence of leukaemia at a molecular level rather than a cellular level, and can be measured using flow cytometry (which involves taking a bone marrow biopsy). Essentially, minimal residual disease is the remnants of the leukaemia at levels which are

only detectable by looking at antibodies to the cancerous T-cells rather than isolating the cancerous T-cells themselves. The lower the level of minimal residual disease, the better the prognosis. Minimal residual disease assessment is also useful to determine whether to follow induction treatment with consolidation and maintenance chemotherapy, or to consider allogeneic stem cell transplant. The presence of minimal residual disease following the induction treatment phase is an indication for considering an allogeneic SCT.

### Chromosome abnormalities

T-cell ALL patients with more than five chromosomal abnormalities have a lower overall survival, compared with patients with simple chromosomal abnormalities.

A good prognosis with an improved early treatment response and increased sensitivity to corticosteroid therapy is linked to having mutations in the NOTCH1 and/or

FBXW7 gene; however, this has not been shown to improve overall survival.

A poor prognosis is associated with a translocation of the MLL gene on chromosome 11q23 which occurs in T-cell ALL patients who have previously had chemotherapy. A mutation at the JAK1 gene is also linked to a poor prognosis.

### Relapse

Patients with T-cell ALL who relapse have a poor prognosis by default. Even with the recent improvements in the induction and consolidation regimens for T-cell ALL, up to two-thirds of patients will relapse in due course, particularly if they have high-risk factors.

### Other prognostic risk factors

Patients' response to early treatment has been recognised as being indicative of the prognosis value for both children and adults with T-cell ALL. Early response at the pre-phase therapy, day 15 of the induction phase and the

end of the induction phase has been associated with a better prognosis.

Other prognostic risk factors that are known to predict a poor prognosis are older age (>60 years), reduced tolerability to treatments and higher white blood cell count at diagnosis.

# Treating T-cell ALL

Ideally, treatment for patients with T-cell ALL aims to achieve a complete remission as quickly as possible with induction chemotherapy. Once your medical team see how well you respond to induction treatment they will be able to formulate a plan for further treatment based on factors including your age, white cell count at the start and response to treatment. Further treatments may include a stem cell transplant (SCT – also known as bone marrow transplant), or ongoing chemotherapy.

Complete remission is said to have occurred when the following conditions have been met:

- Blood cell counts return to normal
- Less than 5% of cancerous T-cells are present in the bone marrow
- There are no cancerous T-cells anywhere in the body where they were to begin with

## Treatment phases

The different treatment phases for ALL are as follows:

- **Induction therapy:** The aim of this phase is to kill all or the majority of the cancerous T-cells in the blood and bone marrow and to restore normal blood cell production which has been disrupted by the presence of the cancerous T-cells.
- **Consolidation therapy:** In this phase, any remaining leukaemia in the body, such as in the brain or spinal cord, is ideally destroyed.
- **Relapsed or refractory re-induction chemotherapy:** This is given to patients for whom T-cell ALL has returned (relapse) or those who did not respond to induction therapy (refractory).
- **Preventive therapy for the CNS:** During any of the treatment phases, additional treatment to kill cancerous T-cells located in the CNS may be given. The chemotherapy drugs are often injected directly into the fluid that covers the spinal cord.
- **Maintenance therapy:** This ongoing phase is intended to prevent any cancerous T-cells from multiplying again. Lower doses of therapy are given often

for years.

## Treatment types

The types of treatment you will receive will depend on the specific features of your leukaemia, your age and your general health. You will be able to discuss your treatment options and information of your treatment plan with your haematologist. The side effects of treatment vary between different types of treatment and different patients.

The types of treatment that patients with T-cell ALL may receive include:

## Chemotherapy

Chemotherapy drugs kill the cancerous T-cells or stop them from dividing. Chemotherapy is commonly used as induction therapy, but it can also be used as consolidation and maintenance therapies. Chemotherapy is the main type of treatment for patients with T-cell ALL, as unlike for B-cell ALL, there are no effective immunotherapy treatments for the treatment of T-cell ALL.

Since the outcome for patients

with relapsed T-cell ALL is poor, the main approach for treating patients with T-cell ALL is to prevent relapse by implementing the most effective treatment schedules in newly diagnosed patients as soon as possible.

Current survival rates for patients with T-cell ALL have dramatically improved compared with previous decades.

## Pre-treatment

Prior to induction treatment, patients may be given a pre-treatment of corticosteroids, or corticosteroids combined with vincristine, together with allopurinol and fluids for approximately five to seven days. This pre-treatment helps reduce the number of cancer cells and avoid tumour lysis syndrome. When necessary, supportive treatment to treat infections or to replace red blood cells is given.

## Induction

Induction therapy schedules have not been compared in clinical trials; however, using the current induction therapy approaches, remission rates of 80%–90% are being achieved. A

# Treating T-cell ALL (cont.)

typical induction chemotherapy regimen for patients with T-cell ALL would be the UKALL14 regimen which consists of vincristine, prednisone, doxorubicin and asparaginase being given through intravenous (IV). The regimen may also be modified to be less intensive while still remaining effective and can be used as induction, consolidation, and subsequent maintenance therapies.

Pegylated asparaginase is often added to a multi-drug induction schedule to improve clinical outcome and prevent relapse. Pegylated asparaginase is an enzyme which breaks down asparagine in the body and reduces its levels in the blood. All cells need asparagine to make proteins and stay alive. Normal cells have the ability to make asparagine for themselves. However, leukaemia cells are unable to make asparagine, and rely on the asparagine available in the blood for survival. By depleting the asparagine in the blood, pegylated asparaginase helps kill

the cancerous T-cells. Pegylated asparaginase can also be used as part of consolidation and maintenance therapies.

## Consolidation treatment

Following induction, patients will get further chemotherapy to consolidate their remission. After that, patients may have an allogeneic SCT if this is in the patient's best interests, or they may progress to further chemotherapy and maintenance treatment.

Drugs used for consolidation are generally the same drugs used for the induction regimen. High doses of drugs are used in consolidation therapy to ensure the levels are high enough to reach the cancerous T-cells which may be still be in the CNS.

## Maintenance treatment

Daily 6-mercaptopurine with weekly methotrexate is commonly used as a maintenance treatment and is normally continued for two to three years. This treatment will be taken orally.

Maintenance chemotherapy is the final and longest treatment phase in the treatment of T-cell ALL and is just as important as the more intensive induction and consolidation therapies.

### **CNS treatment**

Effective CNS therapy is also essential to your treatment to help prevent relapse. CNS prophylaxis treatments include:

- Intrathecal chemotherapy – An injection of methotrexate, or a combination of methotrexate, steroids and cytarabine, directly into the spinal fluid through the intrathecal space, usually during a lumbar puncture.
- Intravenous methotrexate can be used instead of or often as well as an intrathecal injection to protect patients against CNS disease developing.

### **Treatment for relapse**

Nelarabine has been specifically developed for patients with relapsed T-cell ALL and is often used in combination with other drugs. It is a chemotherapy drug

that kills dividing cells, such as cancer cells, and it has been approved since 2007. T-cells have been shown to be particularly sensitive to nelarabine.

Although SCTs represent the only chance of cure for patients with relapsed T-cell ALL, patients must have a successful remission following re-induction after their relapse, which is quite difficult to achieve. If they are successful in achieving a second remission, then patients who haven't had a SCT can have one. In some cases, patients who have had a transplant can have another one.

### **Stem cell transplantation**

SCTs can be used as consolidation therapy in patients who have a high risk of relapse, or for treating relapse if it occurs. SCTs help patients re-establish a healthy bone marrow. Patients receiving a SCT are given high doses of chemotherapy or radiation to destroy any cancerous T-cells. The recipient's bone marrow is then replaced by compatible bone

# Treating T-cell ALL (cont.)

marrow. There are two types of SCT:

- **Allogeneic stem cell transplantation (Allogeneic SCT):** Healthy stem cells from a matching donor are transplanted into the patient following the high dose chemotherapy. This is used for patients with a higher risk of relapse, even if they went straight into remission. Their risk will be based on a score that takes into account factors such as their age, white cell count and MRD state etc.
- **Autologous stem cell transplantation (ASCT):** Healthy stem cells are collected from the patients' bone marrow before they receive high-dose chemotherapy to kill the cancerous cells. This type of stem cell transplant is not used in patients with T-cell ALL, due to the aggressive nature of this disease type.

## Treatment by age group

### Treatment of adolescents and young adults

Several studies have shown that

adolescents and young adults with T-cell ALL achieve very good results when treated with the intensive chemotherapy regimens given to children with T-cell ALL.

The intensive chemotherapy regimens used in adolescents and young adults with T-cell ALL have been modified to include larger doses of corticosteroids, vincristine, L-asparaginase and CNS treatment compared with the treatments given to children.

### Treatment of adults

Not all adults are able to tolerate the intensive chemotherapy regimens used in adolescents and young adults. A typical chemotherapy regimen for these patients would be the UKALL14 regimen described previously. Despite being relatively intensive, this regimen is normally well tolerated in older patients with no other medical conditions. The UKALL14 regimen may also be modified to be less intensive while still remaining effective for patients with all types of ALL.

### Treatment of older adults

Older adults (>55 years) are able

to tolerate the T-cell regimen given to younger adults; however, they experience more side effects and toxicity and treatment-related death. The main risk of death in older patients comes from acquiring infections. Intensive supportive care, including prophylactic antibiotics and the use of granulocyte colony-stimulating factor (G-CSF) which stimulates the bone marrow should be provided.

Achieving complete remission should still be the main aim of treatment. Reduction of chemotherapy doses, particularly for doxorubicin and daunorubicin, is important because of the side effects. In fitter older patients, consolidation treatments can be intensified, and maintenance treatment is crucial. Elderly-specific regimens have been devised based on including fewer intensive therapies, such as corticosteroids, vincristine and asparaginase, and avoiding the more toxic chemotherapies such as cyclophosphamide to reduce early death related to treatment.

## New Targeted treatments

Targeted drugs attack the specific abnormalities present in cancer cells that allow them to grow and thrive. These drugs do not simultaneously harm healthy cells the way conventional chemotherapy drugs do. Targeted therapy may be used during or after chemotherapy.

These are being developed based on the knowledge of the chromosome abnormalities found in T-cell ALL such as NOTCH1, ABL1 and NUP214-ABL1:

- BMS-906024, an inhibitor of the enzyme gamma-secretase which is needed by the mutated NOTCH1 gene for survival, is being investigated in early trials.
- Tyrosine kinase inhibitors: Approximately 6% of adults with T-cell ALL have the fusion gene NUP214-ABL1, which results in a mutant tyrosine kinase enzyme and carries a poor prognosis. Tyrosine kinase inhibitors, which are effective in patients with B-cell ALL, have

# Treating T-cell ALL (cont.)

also been shown to induce rapid complete remission in a patient with T-cell ALL positive for the NUP214-ABL1 gene.

- Brentuximab (ADCETRIS®) is an anti-CD30 antibody which has shown efficacy in patients with peripheral T-cell lymphomas and T-cell prolymphocytic leukaemia. Up to 40% of patients with T-cell ALL are positive for the CD30 antibody. Given its efficacy in CD30 positive T-cell cancers, it is hoped that brentuximab will be a potential treatment for T-cell ALL.
- While the CD19 chimeric antigen receptor T-cell (CAR-T) therapy is achieving excellent results in patients with B-cell ALL, it is not yet available for patients with T-cell ALL.
- Bortezomib: an inhibitor of the faulty NOTCH1 gene, undergoing clinical trials for children and young adults with newly diagnosed T-cell ALL and in adults with relapsed/refractory ALL.



# Seeing your doctor

## Your symptoms

Whatever symptoms you or your child has, make sure you write a list of all of them to share with your doctor as they may be important to the treatment.

## Your appointment

Arranging an appointment with your GP will be one of the first things you will need to do when you start to notice symptoms. Pick a time convenient for you that you know you will be able to attend.

## Your preparation

It is important to know exactly what you would like to ask your doctor. Make a list of your questions and leave spaces for the answers so you can write them down when you see the doctor. This way you can go into the appointment ready and prepared.

Examples of questions to ask the doctor:

- What tests will be needed?
- What will the tests show?

- How long will it take to get the results back?
- How common is my or my child's condition?
- What sort of treatment will I or my child need?
- How long will the treatment last?
- How will I know if the treatment has worked?
- What will the side effects be?
- Are there any foods or medications that need to be avoided?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- Where can I get help dealing with my feelings?

## Talking to your doctor

Be honest with your doctors; there is no need to feel embarrassed about anything. If you saw your healthcare team before seeing your doctor, be sure to share with your doctor everything your healthcare team told you about

your or your child's condition, the blood tests that were performed, and the next steps in your or your child's T-cell ALL journey. Ask also if any intensive treatment or palliative care will be needed.

### **Your support**

If it helps, take a family member or friend in with you for support. Some people take a pen and paper in to make notes and repeat back to their doctor everything they have been told to ensure that they are on the same page, and that nothing has been missed or forgotten.

### **The next steps**

Always ensure that you leave the GP surgery, or the hospital, having shared everything you know about your or your child's condition, with all of your questions answered, and knowing exactly what the next steps are, whether it is more tests, further treatment or palliative care. You can ask for a summary letter of the consultation to have everything in writing. Your doctor will generally send a letter like this to your GP.

Furthermore, be sure to access all of the other support available to you as this may be able to help you with your feelings towards the diagnosis and treatment.

# Telling your family

## Planning who to tell

Telling your family and friends that you or your child has been diagnosed with T-cell ALL can be difficult.

You may want to create a list of people you want to tell, starting with close family and friends, and then extending it beyond, from your colleagues at work to friends in your neighbourhood.

## Planning what to say

It is important to know what you want to say and exactly how much you want people to know. Being clear in your mind about that before speaking to anyone will make this a much smoother experience. Know the story that you want to tell, the diagnosis, the prognosis, the next treatment steps, and what you expect things might be like, physically and emotionally. Be sure to speak to people in an environment where both of you can hear each other clearly and where there are likely to be no interruptions.

## How to say it

Using a conciliatory tone will help keep both yourself and the other person calm. Deliver what you have to say slowly, calmly, concisely, and sentence by sentence to allow the other person time to take in the information. Be sincere and hold their hands if you need to.

You can use the following sentences to help you articulate what you need to say:

- "This is going to be difficult, but I need to tell you something."
- "I've had some bad news but there's a good chance that everything will be okay after treatment."
- "You know I or my child have been feeling unwell for a while. Some tests have been done and they've found out what's wrong."

## How to respond

Naturally people will feel sad and concerned for you. Everyone deals with this type of news in their own way, from shock and silence, to questions and support. Invariably,

people respond positively, which in turn means you will respond back positively.

## Accepting help

Sometimes people feel guilty if they or their child gets cancer, that it's their fault, and that they will be a burden on those around them. This is where your loved ones come in, so make sure you do ask for and accept offers to help and support you. Do not try to cope on your own. If they offer to help, tell them that you will get in touch when you need them.

Repeating yourself to different people can become burdensome. Your network of family and friends can help you out by telling those beyond them about your current situation. You can receive help from us on how to deal with breaking the news to your family and friends. You can visit **www.leukaemiacare.org.uk**, or call **08088 010 444**, to find out more.

# Survivorship

Someone who is living with or is beyond a cancer diagnosis can be considered a cancer survivor. If your child has T-cell ALL, you may experience this process on their behalf as they may be too young to know.

Survivorship can be defined as:

"...cover[ing] the physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, secondary cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience."

When living with cancer, you or your child will face new challenges to cope with from physical to psychological and social ones. Survivorship aims to provide personalised care based on improving you or your child's health, wellbeing, quality of life, and your confidence and motivation, to help you manage. Survivorship also focuses on your

or your child's health and life with cancer after the end of treatment until the end of life. At this point, your routine of meeting frequently with healthcare professionals also ends, so you may feel a mixture of emotions from relief to fear, anxiety and uncertainty about the future. You may wonder how you will slot back into your life after coming through the treatment period.

Your survivorship pathway began at the point when you or your child was diagnosed with T-cell ALL. By this point, you will have been starting to receive support for work, finance, and personal relationships through to managing pain, fatigue and making positive lifestyle changes, such as starting a healthy diet and gentle exercising.

Your individual needs will be identified and addressed, including:

- Dealing with the emotional impact of receiving a T-cell ALL diagnosis which may have created feelings of uncertainty, fears of recurrence and difficulties in planning for the future. These will be discussed with you to develop your or your

child's individualised care plan with support from social care staff and therapists, as you need it.

- Improving your quality of life through efficient and co-ordinated care during treatment, with effective communication within the treatment team, and a positive attitude.
  - Taking care of any comorbidities – that is, other medical conditions and diseases – and offering a cancer rehabilitation based on your or your child's clinical needs as assessed by informed professionals and ensuring compliance with the National Cancer Rehabilitation Pathways and Rehabilitation Peer Review requirements.
  - Providing you with a treatment summary from the diagnosis of your or your child's condition to the end of treatment. This would include any ongoing medication and noting possible symptoms that may occur in the future. You would also be provided details of who to contact in addition to your GP for any concerns you may have.
- Preparing you fully for the impact of your or your child's T-cell ALL and treatment, the physical and physiological side effects of treatments and the psychological impact of T-cell ALL in general. You will be provided physical equipment and taught about various coping strategies to adapt to your or your child's new situation.
  - Supporting you with advice for social and financial difficulties, including caring responsibilities, your inability to participate in social activities, any debt and financial worries from not being able to work, and perhaps the need to return to work before you feel ready.
  - Receiving health and nutrition advice from a nutritionist on following a healthy and balanced diet to help improve your or your child's general health and wellbeing. The World Cancer Research Fund published a report for cancer survivors which suggests that even small dietary and lifestyle changes can produce large health benefits.

# Everyday life and T-cell ALL

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

## Emotional impact of T-cell 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.

T-cell 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 T-cell ALL, you may wish to make changes to your lifestyle. It is important to know your limits and do not 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 are 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.

However, once your treatment has finished, 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 T-cell ALL is infection. When you have T-cell 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 germs that 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 T-cell 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

# Everyday life and T-cell ALL (cont.)

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.

T-cell 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 T-cell ALL specialist you should check that it is safe.

## Work and finances

Being diagnosed with T-cell ALL means you will need to start treatment straightaway and so you, or someone you know, will need to contact your employer to inform them of your situation.

Your condition will mean that you will need to be at hospital a lot at first and may need to negotiate a reduction in working hours.

Your consultant or your GP can arrange letters to confirm your diagnosis and the effects it may have on your work life to your employer.

There are also a number of benefits you and your carer might be entitled to receive, which may help you if you are no longer able to work or have to reduce your hours after being given a cancer diagnosis.



# Managing your emotions

Being told that you or your child has cancer may be difficult for you to deal with.

You may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of the condition. However, you may experience a range of emotions, including uncertainty, isolation, anxiety, anger, sadness and depression. Understanding each emotion and developing ways that help you deal with them will help you move forward with your life.

## Uncertainty

You may think "what happens next?". You may be unsure about your or your child's health and what the future holds for you. You may or may not have had meetings with your healthcare team to discuss the next steps. Once you have a clear path set out in front of you, you will be able to develop a clearer picture of where you are headed. Gaining a sensible balance between being vigilant about your symptoms and carrying on with your life will help ease any anxieties. Help, care, kindness and support will be available to you from your healthcare team, and you will have access to counsellors and

therapists if you need it.

## Isolation

If you or your child has received a diagnosis of T-cell ALL, you may feel alone.

Alternatively, you may feel dealing with your or your child's cancer allows you to be around those closest to you. Being around those closest to you, such as your family and friends, can be positive and negative.

Let them know what you do and don't want to do, how you do and don't wish you or your child to be treated, and what you do and don't feel comfortable talking about. Sometimes, it is difficult for your family, friends and colleagues to understand what you are feeling and going through. Being clear will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

## Anxiety

Being fearful of the unknown, especially when we are feeling threatened, is natural. You may experience an increased heart rate, rapid breathing, and muscle tension. These things help us to face a danger or run away. These

changes in you are part of the 'fight or flight' response. Any feelings of discomfort, pain or even another appointment with your healthcare team may elicit such responses and give you sleepless nights or feelings of worry. This is completely natural.

Such reflexes and responses will ease over time with the building of daily routines and planning things for the future, which will help you to cope with the physical effects of anxiety. Cognitive behavioural therapy can help you deal with your worrying thoughts.

## Anger

Feeling angry after your or your child's diagnosis is natural and normal. You may be angry with yourself, with the healthcare team or with family and friends. You may display your anger as impatience, irritability and frustration with people and things that would not normally bother you.

Understanding exactly what is making you angry will help you deal with your feelings effectively. In addition, setting yourself or your child achievable but demanding goals will help reduce the anger and impatience, especially with each

passing success. Don't forget to congratulate yourself or your child for each successfully completed task, however small.

Physical exercise is a great way to release your anger and frustrations, and channel energy positively with no negative impact on the body. Talking about feelings and letting them out will also help stop you or your child lashing out at people and keep things calm.

## Sadness and depression

You may feel a sense of loss, and how safe you felt. You may also feel that your or your child's illness is a heavy burden on those around you. You might be feeling low, which is a natural effect of your situation and the illness, treatment and recovery process. However, if this low mood persists for more than several weeks, and you feel hopeless, and lose interest and pleasure with things in life, then you may have depression.

Your first steps should be to speak to your loved ones around you about your mood and state of mind, and then contact your GP. You may lift the way you feel by engaging in activities that

# Managing your emotions (cont.)

you were enjoying before the diagnosis and connecting back with your life. Only do as much as you can and try and talk about your thoughts and feelings. This will help lighten your burden and put things into perspective. If you have made any acquaintances or friends in the same position as you, talk to them over coffee as they will understand what you are facing.

## Self-confidence

Being forced to adjust from your daily routine during the visits to the hospital for treatment can take its toll. This interruption of your life can impact on how you feel about your appearance and how you feel emotionally. In turn, this can knock your self-confidence and self-esteem. Your feelings of relief, hope and optimism have just been replaced with their polar opposites.

You can gradually build your self-confidence and self-esteem back up by engaging in the activities you did before the diagnosis, and socialising with family, friends, and those in the same position as you. This will help create a

supportive atmosphere to get you back to your old self.

## Mindfulness and relaxation

Simple practices from mindfulness and relaxation techniques can help you calm the mind, release tension and ease any pain.

- Put yourself in a relaxing environment, sitting or lying down comfortably.
- Loosen your clothing so you can move more freely.
- Calmly breathe in through your nose, and out through your mouth, developing a steady natural rhythm, focusing on your chest and abdomen as you do so.
- Visualise that you are inhaling positivity and exhaling negativity.

By taking some time out of your day to do these exercises, you can help quieten your mind and remove the stress of coming to terms with your diagnosis, so you feel calmer and more relaxed.

# Palliative care

Palliative care, also known as supportive care, involves a holistic or "whole person" approach, which includes the management of pain and symptoms as well as psychological, social and spiritual support for you or your child and your loved ones.

Palliative care aims to reduce the symptoms, control the T-cell ALL, extend survival, and give you or your child and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps.

## Who provides palliative care?

Palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate the care.

These professionals can include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists, and

religious leaders, if you would like this. The palliative care services may be provided by the NHS, local council or a charity. You or your child may receive day-to-day care at your home and at the hospital.

## What is the clinical course?

You or your child will have a number of treatments and be prone to frequent infections because of the T-cell ALL and the impact of the treatments. The therapy may continue because of potential remission and/or useful palliation.

Various pains and other clinical complications can occur such as:

- **Bone pain:** Radiotherapy and/or oral steroids, and sometimes non-steroidal anti-inflammatory drugs (NSAIDs), may be used, although these are used with caution because they can interfere with the immune system and kidney function.
- **Bone marrow failure:** Blood and platelet transfusions are provided to prevent and fight recurrent infections and

# Palliative care (cont.)

bleeding episodes.

- **Oral problems:** Analgesic mouth washes and topical ointments may help with ulceration. Chewing gum, and mouth washes have been shown to help with dry mouth, tooth decay and oral thrush.
- **Night sweats and fever:** These can place a heavy burden on carers because of so many changes of night clothes and bedding.
- **Pathological fractures:** Orthopaedic intervention and subsequent radiotherapy, with consideration given to prophylactic pinning of long bones and/or radiotherapy to prevent fracture will be performed. This will reduce the likelihood of complex pain syndromes developing.
- **Spinal cord compression:** Immediate high single daily dose oral steroids will be given.
- **Back pain from wedge and crush fractures of the vertebrae of the spinal column:** Treatments can include

analgesics, antidepressants and/or anticonvulsant medication used in tandem with opioids.

- **Hypercalcaemia:** Treatment is usually with intravenous hydration and intravenous bisphosphonates.
- **Loss of appetite:** Low-dose steroids may temporarily boost the appetite, while small, frequent and appetising meals and supplement drinks will also help.

## End of life care

If the various treatment options have not worked and you are going through palliative care, end of life care may be offered. End of life care begins when it is needed and may last a few days, months or years.

End of life care is support for people who are in the last few months or years of their life. The aim is to help patients enjoy a good quality of life until they die, and to die with dignity. The professionals looking after you will ask about your wishes and

preferences on how to be cared for and put these into action. They will also provide support to your family, carers and loved ones. You will be able to decide where you will receive end of life care, be it at home or in a care home, hospice or hospital. The same will be true of where you would like to die. Wherever this is, you will receive high quality end of life care.

# Glossary

## Allogeneic stem cell transplant

A transplant of stem cells from a matching donor.

## Anaemia

A condition where the number of red blood cells, which contain haemoglobin and transport oxygen to body cells, are reduced. This may be due to a lack of iron, leukaemia, or sickle cell disease.

## Antibody

A large Y-shaped protein produced by B-cell lymphocytes in response to a specific antigen, such as a bacteria, virus, or a foreign substance in the blood. The antibodies neutralize the bacteria and viruses.

## Antigen

A toxin or other foreign substance which induces an immune response in the body, especially the production of antibodies.

## Autologous stem cell transplant (ASCT)

A transplant of stem cells derived from part of the same individual.

## Bone marrow failure

The term used when the bone marrow is unable to keep up with the body's need for white and red blood cells and platelets.

## Body mass lesions

An abnormal growth of cells in the body which can appear as a lump.

## Central nervous system (CNS)

Part of the nervous system which includes the brain and spinal cord.

## Chromosomes

Thread-like structures which carry the genes, and are located in the nuclei of every cell in the body. There are 46 chromosomes (23 pairs) in humans.

## Cytogenetic

Relating to the study of inheritance in connection with the structure and function of chromosomes.

## Cytoplasm

A jelly-like fluid that houses all the constituents required for survival and reproduction of the cell.

### Fatigue

Tiredness and weakness rendering the patient unable to work or perform usual activities.

### Genes

Genes are made up of DNA which stores the genetic information required to make human proteins.

### Haploidentical match

A modality of allogeneic transplantation where the donor is a relative of the patient, but the HLA compatibility is not ideal for transplantation purposes.

### HLA compatible

The degree of similarity between the HLA of the donor and patient.

### Human Leukocyte Antigen (HLA)

A unique protein signature expressed on the surface of most cells in the body of every person.

### Hyperdiploidy

Having more than the normal 46 number of chromosomes (23 pairs).

### Hypodiploidy

Having less than the normal 46 number of chromosomes.

### Lymph nodes

Components of the lymphatic system (part of the body's immune system) that contain lymphocytes which produce antibodies and macrophages to digest dead cells. Lymph nodes are swollen with cell fragments in the event of infection or cancer. They are located mainly in the neck, armpit and groin.

### Nucleoli

The small dense spherical structure in the nucleus of a cell.

### Philadelphia chromosome

The Philadelphia chromosome (BCR-ABL) is the most common genetic abnormality associated with adult ALL and has a very poor prognosis for both children and adults. It only occurs in 3 to 5% of patients with ALL, but less than 40% of them are cured with intensive chemotherapy.

### Platelets

One of the types of blood cells

# Glossary (cont.)

which help to stop bleeding.

## Prognosis

An indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or other timepoints in the disease.

## Radiation treatment

Cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumours.

## Refractory leukaemia

Leukaemia for which treatment does not result in a remission, or that gets worse within six months of the last treatment. However, the

leukaemia may be stable.

## Relapsed leukaemia

A relapse occurs when a patient initially responds to leukaemia treatment, but after six months or more, response stops. This is also sometimes called a recurrence.

## Translocation

In genetics, translocation is the transfer of one part of a chromosome to another part of the same or a different chromosome, resulting in rearrangement of the genes.

## Tell us what you think!

If you would like to give us some feedback about this patient information booklet, please hover over the code to the right using your phone or tablet's camera. Click the link as it appears and this will take you to a short web form to fill in.

Suitable for Android, iPhone 7 and above.



# 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 helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**  
**[www.leukaemicare.org.uk](http://www.leukaemicare.org.uk)**  
**[support@leukaemicare.org.uk](mailto:support@leukaemicare.org.uk)**

## Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

**020 7504 2200**  
**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

## Cancer Research UK

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

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

## Macmillan

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

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

**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)**

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?

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,  
One Birch Court,  
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Registered charity  
259483 and SC039207

**Leukaemia Care**  
YOUR Blood Cancer Charity

