

Treating Acute Lymphoblastic Leukaemia (ALL) - A Quick Guide



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This is a brief summary of the information on Treating Acute Lymphoblastic Leukaemia (ALL) from our website. You will find more detailed information on the website.

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Types of treatment for acute lymphoblastic leukaemia

The main treatment for ALL is chemotherapy. Other treatments you may have include steroids, growth factors, radiotherapy and bone marrow transplant or stem cell transplant. Treatment for acute lymphoblastic leukaemia varies depending on your type of ALL, your

general health, your age and level of fitness.

The phases of treatment for ALL
Doctors divide treatment for ALL into different phases. The first phase is called remission induction. You have treatment with chemotherapy and usually, steroids. The aim is to destroy the leukaemia cells and get you into remission. In remission, there are no leukaemia cells in your blood or bone marrow.

Then you have consolidation treatment to stop your leukaemia coming back. This may mean more chemotherapy, or a transplant of bone marrow or stem cells.

The last phase of ALL treatment is maintenance therapy. It helps to keep the leukaemia in remission for longer. It usually involves having low dose chemotherapy and short courses of steroids for up to 2 years.

Treating ALL that comes back or resists treatment

Sometimes leukaemia cells are left in the bone marrow after your treatment. This is called resistant leukaemia. You may have more chemotherapy, or possibly a stem cell transplant. If the leukaemia comes



back after a period of remission it is called a relapse. Again, you may have more chemotherapy or a stem cell transplant.

Statistics and outlook for acute lymphoblastic leukaemia

Outlook means your chances of getting better. Your doctor may call this your prognosis. The likely outcome with ALL depends on several things, including how advanced the leukaemia is when it is diagnosed, the type of ALL you have, and how well it responds to chemotherapy. Children tend to do better than adults.

On our website, we have quite detailed information about the likely outcome ALL. The statistics we use are taken from a variety of sources, including the opinions and experience of the experts who check every section of our patient information. They are intended as a general guide only. For the more complete picture in your case, you'd have to speak to your own specialist.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your leukaemia is unique. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

About chemotherapy for acute lymphoblastic leukaemia

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. You usually have chemotherapy directly into your bloodstream for leukaemia. You usually have a central line put in. It stays in for as long as you need it.

Getting rid of the ALL (induction)

Your first treatment aims to get your leukaemia into remission. It is called induction therapy. You have several different chemotherapy drugs and a steroid. The treatment causes side effects. Most people need to stay in hospital for about a month while they are having treatment and recovering.

Treatment to stop ALL coming back (consolidation)

When your leukaemia has gone into remission you have consolidation treatment. You may have high doses of chemotherapy. Or you may have intensive treatment, with a bone marrow or stem cell transplant.

Stopping ALL spreading into the brain or spinal fluid

Leukaemia cells can go into the brain and spinal cord. To try and stop this you have chemotherapy injected into the fluid that circulates around the brain and the spinal cord. This is like having a lumbar puncture.

Keeping the leukaemia away, long term Maintenance treatment is more chemotherapy, but in lower doses you will be able to have this as an outpatient. Including maintenance treatment, the whole ALL treatment course lasts for about 2 years.

Side effects of chemotherapy for acute lymphoblastic leukaemia

Most people with acute lymphoblastic leukaemia have a combination of 2 or more chemotherapy drugs. Our website lists the drugs you are most likely to have, and has links to information about their specific side effects.



ALL chemotherapy side effects

Drugs affect people in different ways. It is not possible to tell how you will react until you have a particular drug. The common side effects with treatment for ALL are

- Low numbers of white blood cells, red blood cells and platelets
- Feeling and being sick
- Complete hair loss but the hair grows back after treatment
- A sore mouth and mouth ulcers
- Diarrhoea
- Tiredness
- Changes in fertility- the treatment may make you infertile, temporarily or permanently

All the drugs used to treat ALL will make your blood cell counts fall. You will be at risk of infection for a few weeks after your treatment. During ALL treatment, most people will need antibiotics into a vein for infection at some time.

You may need blood transfusions to top up your red blood cells. You will also have a low platelet count at some point in your treatment. This means you are at risk of bleeding or bruising. You can have a platelet transfusion to top up your platelets.

Questions for your doctor about chemotherapy for acute lymphoblastic leukaemia

- Why do I need chemotherapy?
- How much treatment will I need?
- What will the side effects be?
- What can I do to help with side effects?

- Who can help me manage side effects?
- Can you prevent any of the side effects?
- Will any of the side effects be permanent?
- How long will the treatment take?
- When will you know if it has worked?
- What will happen if it doesn't work?
- What drugs are you going to give me?
- Is there written information I can have about these drugs?
- What should I do if I am at home and worried about a side effect?
- What should I do if I get a temperature?
- Will you give me growth factors and why?
- Will I have to stay in hospital and if so, for how long?
- Can I have any of this treatment as an outpatient?
- Will I need high dose chemotherapy and why?
- How long will I have to be off work / college etc?

Steroid therapy for acute lymphoblastic leukaemia

Steroids are substances made naturally in the body. They can also be made artificially and used as drugs. Treatment for ALL works better when you take steroids with the chemotherapy drugs. Steroids can be tablets or injections.

Side effects of steroids

Because you will not be taking the steroids for very long without a break, you are not likely to have bad side effects from them. But there are quite a few side effects you may notice. These can include increased appetite, increased energy and wakefulness, and indigestion.



When you have been taking steroids for some time you may notice some swelling in your hands, feet or eyelids. You may also put on weight. These symptoms are a result of water retention caused by the steroids.

Steroids are irritating to the lining of your stomach. You should not take them on a completely empty stomach. Try to have at least a slice of bread, or a glass of milk with them. If you can't manage food, your doctor may give you another tablet to stop the steroids damaging your stomach. You must tell your doctor if you get stomach pains after taking steroids. Your doctor will be looking out for other side effects of your steroids. These are raised blood pressure, and sugar in your urine or raised sugar in your blood.

It is important for any doctor treating you for any reason to know you are taking steroids. So you will be given a card to carry at all times to say you are taking steroids.

Growth factors for acute lymphoblastic leukaemia

Growth factors are natural substances that stimulate the bone marrow to make blood cells. Doctors can make some growth factors artificially and use them as treatments to increase the number of white blood cells and stem cells in the blood. A commonly used growth factor is filgrastim (G-CSF or Neupogen).

You have growth factors as an injection under the skin. This is usually in the tummy (abdomen), or into an arm or a leg. You may have growth factors as part of your treatment for two reasons

- To help you make white cells more quickly after chemotherapy
- To produce extra stem cells before having stem cells collected (a stem cell harvest).

Growth factor side effects

Growth factor injections can have side effects. Some people have itching around the injection site. You may have some pain in your bones after you have had a few injections. Your bone marrow is making so many blood cells that it can get quite crowded and make your bones ache. You can usually control the pain easily with a mild painkiller, such as paracetamol. It usually lasts a few days.

Some people get a high temperature (fever) when they have growth factors. Tell your doctor if this happens to you, because fever can also be a sign of infection.

Radiotherapy for acute lymphoblastic leukaemia

Radiotherapy uses high energy rays to treat cancer. Chemotherapy is the main treatment for ALL but, if the leukaemia has spread to your brain you may have radiotherapy to kill the leukaemic cells there. Even if they haven't found leukaemia cells there, your specialist may suggest radiotherapy to your brain and spinal cord to kill off any leukaemic cells that may be present but don't show up on tests. This type of preventative treatment is called prophylactic treatment.

Intensive treatment

You may have radiotherapy as part of intensive treatment – such as a bone marrow transplant. You have radiotherapy to your whole body (total body irradiation



or TBI). The radiotherapy kills off all your bone marrow, including the leukaemia cells. You then have donor marrow or your own marrow given back through your drip. You may have the radiotherapy as a single treatment or twice a day for 3 or 4 days.

ALL radiotherapy side effects

Whole body radiotherapy and treatment to the brain and spine most often cause sickness and tiredness. TBI can also have long term effects. You should not sunbathe for several months after treatment. Talk to your specialist about the exact precautions you should take. There is a risk of the lens of your eye clouding over (cataract) many years later. This can be easily treated with surgery.

Bone marrow or stem cell transplants for ALL

Bone marrow and stem cell transplants for ALL are part of treatments called intensive treatments. Intensive treatment is high dose chemotherapy, and sometimes total body radiotherapy. This treatment kills off all your bone marrow cells. The bone marrow is the spongy substance inside your bones. It contains the stem cells that make all your blood cells. Doctors need to replace the stem cells so you survive the treatment. You will most probably have the stem cells replaced by a drip of someone else's bone marrow or stem cells. Or you might have them replaced by your own bone marrow stem cells. But this is rarely used these days.

The choice between a donor transplant and having your own bone marrow or stem cells depends on a number of different factors, including

- The type of leukaemia you have
- Whether you have a close relative whose blood cells closely match yours

Having your transplant

After your chemotherapy and radiotherapy, you have the bone marrow or stem cells through a drip, into a vein. The cells find their own way to the centre of your bones. They begin to make blood cells after a few days or weeks. You usually have to stay in hospital for a few weeks while your blood cell counts are very low.

Biological therapy for acute lymphoblastic leukaemia

Biological therapies are treatments that use natural substances from the body, or drugs made from these substances. The body normally uses these natural substances to fight infection and disease.

Biological therapies and ALL

The main biological therapies used for ALL are tyrosine kinase inhibitors or TKIs. They block tyrosine kinases, which are chemicals that cells use to signal to each other. Some of these signalling systems tell the cancer cells to grow and divide.

Imatinib mesilate (Glivec) is a TKI drug which is used to treat Philadelphia positive ALL. You may have it with chemotherapy as part of your first phase of treatment (remission induction therapy).

Researchers are also looking at other types of TKIs to treat ALL, including dasatinib.

Side effects of biological therapies

All treatments have side effects. Everyone reacts differently to drugs and not



everyone will get every side effect. The main side effects of TKIs are

- Fatigue (tiredness)
- Diarrhoea
- Skin changes (rashes or reddening or darkening)
- A sore mouth
- Weakness
- Loss of appetite

ALL treatment side effects

Side effects are unwanted effects that happen as a result of medical treatment. They vary depending mainly on the type of treatment you've had, but also according to dose and from person to person. There are a lot of immediate side effects with acute leukaemia treatment, including tiredness, increased risk of infection, anaemia, bleeding and bruising, sickness, hair loss, a sore mouth and taste changes.

Long term side effects can come on months or years after your treatment finished. Again, the risk of these depends on the specific treatment that you had. Doctors are always working to reduce unwanted treatment effects. People treated for leukaemia these days are less likely to have long term effects than people treated in the past.

Long term side effects of ALL treatment

Long term side effects can develop months or years after you had treatment and may be permanent. Different types of treatment for leukaemia cause different problems. Not everybody gets long term side effects. Your risk of developing any effect depends on different factors including the type of treatment you had and the dose of those treatments.

Tiredness (fatigue) is the most common problem after cancer treatment and is especially likely in people who have had a bone marrow transplant or stem cell transplant. You are also likely to have lowered resistance to infection for at least 6 months to a year after your transplant.

People treated for ALL after puberty will probably be unable to have children (infertile).

Other less common long term effects include thyroid problems, lung problems, heart problems and clouding of the lens of the eye (cataract). There is a small risk of getting another cancer because of your treatment but this is rare.

Children can have growth problems because the treatment changes their hormone levels.

Questions for your doctor about ALL treatment side effects

- What short term side effects can I expect from my ALL treatment?
- What long term side effects can I expect from my ALL treatment?
- Are there treatment side effects that are permanent?
- Is there anything I can do to lower my risk of side effects?
- Are there any activities that I should avoid after treatment for acute lymphoblastic leukaemia – for example, crowded public places, contact sports?
- How long should I avoid these activities for?
- What infection precautions should I take and for how long?
- Is there anything I can do to relieve tiredness after treatment for ALL?



- What are my chances of being infertile?
- Is there anything I can do to preserve my fertility before I start leukaemia treatment?
- What are the most important signs of side effects to look out for and tell you about?
- Should I contact you between check ups if I'm worried about side effects?
- What number should I ring if I have an infection?
- Who should I ask for when I ring?

Acute lymphoblastic leukaemia follow up

After your treatment has finished, you will need to have regular check ups. This is because it is possible that the leukaemia could come back. And if you had intensive treatment, or are having maintenance therapy, your doctors need to keep an eye on you to make sure you don't have any complications.

How often you have check ups

Your check ups will continue for several years. You see your doctor every month while you are having maintenance treatment. A typical follow up schedule after this would be monthly for 3 months, then 2 monthly for 6 months, and then 3 monthly for up to 3 years after your treatment.

What happens during your check up

Check ups are likely to include blood tests and bone marrow tests. Your doctor will examine you and make sure you don't have any new symptoms. They will also ask about any side effects you may have from your treatment. Let your doctor or nurse know straight away if you are worried, or notice any new symptoms

between appointments. You don't have to wait until the next appointment.

Coping with worry

Many people worry about going for their check ups. You may find it helpful to tell someone close to you how you are feeling. It is common for people to have counselling after leukaemia treatment. To find out more about counselling, look in the coping with cancer section of our website.

What's new in acute lymphoblastic leukaemia?

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are safe are they tested in people, in clinical trials.

There is research looking into new chemotherapy drugs, resistance to chemotherapy, biological therapies and managing problems during treatment.

Questions for your doctor about treating acute lymphoblastic leukaemia

- What type of acute lymphoblastic leukaemia do I have?
- What treatment would you recommend and why?
- What are the risks and benefits of this treatment?
- Are there any other treatment options?



- How long will I be in hospital for?
- How often will I have to come back to hospital?
- What are the side effects of this treatment?
- How long will they last?
- What are the long term side effects?
- What do you expect the treatment to achieve?
- What is the chance of the leukaemia coming back after I have been treated?
- Will I be able to go back to work after this treatment?
- Will I still be able to have children after this treatment?
- Will the treatment cause an early menopause? If so, how will you treat this?
- Can you arrange sperm banking for me before I start my treatment?
- Will I have any hair loss? If so, when will my hair grow back?
- Can you arrange a wig for me on the NHS?
- Will I have difficulties with eating and

More information

For more information about acute lymphoblastic leukaemia, visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on 0808 800 4040 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in May 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666)