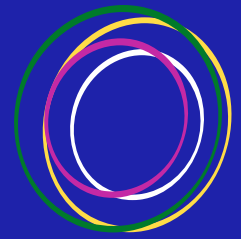


Maintenance treatment for acute lymphoblastic leukaemia (ALL)



Treatment for acute lymphoblastic leukaemia (ALL) happens in phases. Maintenance is the third main phase. It usually involves having chemotherapy and steroids. During this phase you have most of your treatment at home. Find out more about what maintenance treatment is, what it involves, and some of the more common side effects.

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional.

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This leaflet includes addresses and QR codes that link to webpages for further support. If you cannot access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.



Summary

- Treatment of ALL happens in phases. The third main phase is maintenance therapy. It aims to reduce the risk of your ALL coming back.
- Maintenance treatment usually lasts around 2 years. During this phase you have most treatment at home and you can start getting back to your usual activities.
- You usually have low-dose chemotherapy tablets and a steroid that you take by mouth at home.
- Depending on the genetic changes in your leukaemia cells, you may also have a targeted treatment that comes as tablets.
- Most people also visit hospital every month or every few months to have some chemotherapy medicines as a drip or an injection. You might also have occasional injections into the fluid around your spine.
- You'll also have medicines to prevent or manage symptoms or side effects.
- You will have blood tests to check how well your ALL is responding to treatment and how your body is coping with it.
- You may get some side effects while you are having your treatment. Some people have very few side effects, whereas other people experience more serious side effects.
- **Tell your haematology team about any side effects you have. They may be able to suggest things you can do or give you medicines to help.**

What is maintenance treatment?

Treatment of ALL happens in phases. The third main phase is maintenance treatment. It aims to reduce the risk of your ALL coming back.

Maintenance treatment usually lasts for around 2 years. During this phase you have most treatment at home and can start getting back to your usual activities.



The exact medicines you have can vary. There are a few different treatment options.

Your medical team will work out the most suitable treatment for you based on many factors. These include:

- Your age and overall fitness
- Your subtype of ALL
- The genetic changes and proteins in your leukaemia cells
- Any other medical conditions you have
- How you responded to earlier phases of treatment
- Your preference on how you wish to be treated

They will tell you what treatment they recommend for you and what you can expect.

Before treatment

Before starting maintenance treatment, you'll have tests to check how well your leukaemia responded to consolidation therapy. You'll also have tests to make sure your blood counts have recovered and that you're fit enough to have maintenance treatment. These tests might include:

- Blood tests to check your blood cell counts and liver and kidney function
- A bone marrow test to see how your leukaemia has responded to intensification and consolidation therapy
- A pregnancy test because some treatments can be harmful to unborn babies

The NHS have more [information on lumbar punctures](#). Scan the QR code, or search 'lumbar puncture' at [nhs.uk](https://www.nhs.uk).



Things to tell your haematology team

Before starting maintenance treatment, you should tell your haematology team if you:

- Are still experiencing side effects from your consolidation treatment
- Have any new health problems they are not aware of, including physical or mental health conditions
- Have or think you have an infection, or have been in recent contact with someone who has an infection
- Are due to have or recently had any vaccines
- Are pregnant or breastfeeding

Some medicines or drugs may interact with your maintenance therapy. It is important to tell your haematology team about any medicines or supplements you're taking. This includes prescribed medicines or medicines you have bought yourself without a prescription.

Having treatment

You have maintenance treatment in cycles. Each cycle is usually between 1 and 3 months.

You have most of your maintenance treatment at home. Once or twice in each cycle you are also likely to have treatment at a hospital day unit.

Most people have maintenance treatment for around 2 years. This sounds daunting, but this phase is less intense than induction, intensification and consolidation treatment. You'll probably be able to start getting back to your usual activities.

Your team should give you a copy of your treatment plan. If they don't, ask for it. This can help you keep track of what medicines you need to take, and when you need to go to appointments.

“ Treat each day of your treatment process as a small victory. The recovery from all three treatment regimens I experienced was a marathon, not a sprint. ”

Julie, diagnosed with ALL in 2019

Medicines you take at home

Most medicines you have for maintenance treatment are tablets or capsules you take at home. These include:

🕒 **Low-dose chemotherapy tablets.** Most people take a medicine called mercaptopurine every day. You might also have a medicine called methotrexate on some days of each cycle.

🕒 **Steroid tablets.** You usually take these for a few days each cycle.

If you have Philadelphia chromosome-positive ALL, you might have a targeted medicine called a tyrosine kinase inhibitor (TKI). Examples include imatinib, ponatinib and dasatinib. These are tablets that you take by mouth every day.

Your team will let you know what medicines you need to take and how often.

Make sure you know which medicines you take every day and which you only take on some days. Some people use a tablet organiser and set alarms to help them remember. Try to take your tablets at about the same time each day.

Medicines you have at a hospital day unit

You need to go to a hospital day unit for some treatments. This is usually only once or twice in each cycle. You can usually go home the same day.

Treatments you might have include:

- **A dose of chemotherapy as an injection or through a drip.** This is usually a medicine called vincristine.
- **Intrathecal medicines.** These are medicines you have through an injection into your lower back (a lumbar puncture). They aim to prevent ALL in your central nervous system. You may have a chemotherapy medicine called methotrexate. You might also have a steroid called hydrocortisone and another chemotherapy drug called cytarabine.
- **An antibody therapy called rituximab.** You might have this if you have B-cell ALL and your leukaemia cells make a protein called CD20. You have it through a drip.

Your team will tell you how often you need treatment on a day unit, and what you will have each time.

The NHS have more [information on lumbar punctures](#). Scan the QR code, or search 'lumbar puncture' at [nhs.uk](https://www.nhs.uk).



Medicines for symptoms or side effects

You'll also have medicines to prevent or manage symptoms or side effects. These might include:

- Blood transfusions
- Growth factor injections to boost your blood cell counts
- Anti-sickness medicines
- Medicines to prevent or treat infections
- Medicines to protect your bladder, kidneys and gut

Monitoring your treatment



You will have frequent blood tests during maintenance treatment to check your blood cell counts and liver and kidney function. These check how your body is coping with treatment.

You may have other tests and scans to monitor side effects from treatment.

During maintenance you will also have regular blood tests to check for any signs your ALL has come back. You may also have occasional bone marrow tests.

Your team use the results of these tests to see how treatment is working for you. This helps them decide if they need to change your treatment, or how often they monitor you.

You might hear your doctor talk about measurable residual disease or MRD. If you are MRD negative, it means sensitive molecular tests cannot find any leukaemia cells in your body.

Precautions during treatment

There are some precautions to be aware of when you are having maintenance therapy.

- Some treatments can cause side effects like dizziness, drowsiness, blurred vision or make you feel tired or confused. Take care if you are driving or operating tools or heavy machinery.
- Some treatments can make your skin more sensitive to the sun. Try to avoid the sun at peak times, if you can. If you need to go outside, try to cover up, wear protective clothing and use sunscreen with a high protection factor (SPF 50) on exposed areas.
- Some treatments can increase your risk of developing another type of cancer. Tell your team if you develop any signs or symptoms of cancer. It is important to go to any screenings you may be invited to. If you can, try to avoid smoking.

Cancer Research UK have more [information on the signs and symptoms of cancer](#). Scan the QR code, or search 'signs and symptoms' at cancerresearchuk.org



The NHS have more [information on quitting smoking and where to get support](#). Scan the QR code of search 'quit smoking' at nhs.uk



Contraception

The medicines used for maintenance treatment may harm unborn babies.

- If you could get pregnant, it is important to use effective contraception. You need to do this while you are having treatment, and possibly for some time after you stop treatment.
- If you could make someone pregnant, it is important to use effective contraception. You need to do this while you are having treatment, and possibly for some time after you stop treatment.
- If you think you might be pregnant, tell your haematology team as soon as possible. They may recommend stopping treatment for a while. They could also recommend switching to a different treatment.
- If you are planning to get pregnant, or make someone pregnant, tell your haematology team. They can discuss your treatment options with you.

How long you need to use contraception for varies based on what treatment you are having. Your haematology team will let you know how long to use contraception and what to do if you are pregnant or planning to get or make someone pregnant.

Breastfeeding

Scientists are not sure if medicines used for maintenance treatment pass into breast milk. If they do, they could be a risk for breastfed babies and children. You should not breastfeed while you are having treatment and possibly for some time after you stop treatment.

How long to avoid breastfeeding can vary depending on what treatment you are having. Your haematology team will let you know.

Possible side effects

Like all medicines, maintenance treatment can cause side effects. Some of these may be serious. Side effects are different for everyone, and we cannot predict what side effects you may or may not get.

Tell your haematology team about any side effects you have. They may be able to suggest things you can do or give you medicines to help.

If you are getting side effects that are difficult to cope with, your haematology team might suggest:

- Treatment to help manage your side effects
- Lowering your dose of treatment
- Changing how often you have treatment
- Stopping or changing one or more of your medicines

Here we cover some of the more common side effects of maintenance treatment. You may experience some of these side effects, or none at all. You may have different side effects altogether. Ask your team about side effects if you are worried.

Low blood counts

Some maintenance treatments can cause low blood cell counts. You'll have blood tests to check this.



If your red blood cell count is low, you may feel tired and breathless. You might get a fast or uneven heart rate. You may have blood transfusions to top up your red blood cells.



If your platelet count is low, you might bleed or bruise easily. You might get small blood spots on your skin. You may have platelet transfusions to top up your platelets.

Tell your medical team straight away if you have signs or symptoms of low blood cell counts.

Infections

Some maintenance treatments can cause a low level of white blood cells called neutrophils. This is called neutropenia. It means your body can't fight infections as well as usual. This means you have a higher chance of getting infections, and any infections you do get may be more serious.



Tell your medical team straight away if you think you have an infection.
Signs include:

- A high temperature (37.5°C or 38°C or higher). You may need a thermometer so you can check your temperature.
- Aching muscles, shivering or chills.
- Sore throat, blocked or runny nose or cough.
- Burning or stinging when you pee, or peeing more often than usual.
- Diarrhoea, being sick or tummy pain.
- Headache or stiff neck.
- Pain or redness around any cuts, wounds or drips.
- Feeling very tired or generally unwell.

Infections can get worse quickly if you have a weakened immune system, so it is important to get treatment as soon as possible.

Your haematology team should tell you who to contact if you think you have an infection. If you can't contact your team, you should go to your nearest emergency department and let them know you are having chemotherapy.

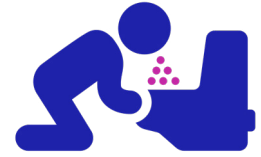
It is also important to contact your team if you feel unwell, even if your temperature is normal.

We have more [information on managing your infection risk](#). Scan the QR code or search 'managing infection risk' at leukaemiacare.org.uk



Feeling or being sick

Some maintenance treatments can make you feel sick or be sick. Tell your team if this happens. They may give you anti-sickness medicines to help.

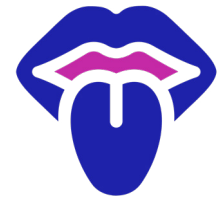


If you are feeling or being sick, you could try:

- Drinking plenty of fluids. This can include water, broth, fruit juices, ginger ale, tea or sports drinks.
- Avoiding foods that are greasy, spicy, sweet or have a strong smell.
- Eating little but often. Having smaller meals and snacks when you are feeling hungry can help.
- Eating cold and room temperature foods. Try foods like toast, rice, plain pasta, yoghurt, crackers, and biscuits.
- Avoiding lying down after eating.

Mouth ulcers, oral thrush and sore mouth

Some maintenance treatments can cause mouth ulcers, sores or mouth infections. This can be painful.



It's important to let your medical team know if your mouth is sore. They may be able to give you mouthwashes, gels or painkillers, as well as medicines to prevent mouth infections.

To cope with sore mouth or other mouth problems, you could try:

- Brushing your teeth with a soft toothbrush, at least twice a day.
- Using an antimicrobial mouthwash. Alcohol mouthwashes can dry your mouth, so it is best to avoid these.
- Sucking on ice chips and drinking water often.
- Chewing food slowly and drinking plenty of fluid with meals.
- Avoiding hot, spicy, acidic or hard foods, like crusty breads, pineapple or lemons.

Problems with your bones and muscles

Steroids can cause side effects that affect your muscles and bones.



You might get weak or painful muscles, bones or joints. Signs of muscle and bone problems include:

- Muscle weakness, especially in your shoulders, hips and upper thighs
- Muscle soreness, stiffness, pains or cramps
- Struggling with daily activities, like brushing your hair or getting out of a chair
- Feeling tired, especially after exercise or being physically active
- Unexplained back pain or muscle spasms
- A bent forward posture, you may feel like you are hunched over
- Height loss
- Pain in a bone or joint which is often worse when moving around
- A bone breaking when it usually wouldn't, such as from a minor fall

Tell your team if you have signs or symptoms of weak bones or muscles.

Your team may give you calcium and vitamin D supplements to help. They can also provide you with support and ways to help manage these side effects.

Early menopause

Sometimes, treatment for ALL can stop your ovaries from working properly, which can lead to early menopause.

Going through the menopause earlier than expected can be distressing. Let your haematology team know if you are struggling and they can discuss your options with you.

If you are experiencing menopause, there is support and treatment to help.

The Menopause Charity have more **information on menopause**, including available treatments and support and tips to manage your symptoms. Scan the QR code or visit themenopausecharity.org



Mental health and sleep problems

Some medicines for ALL might affect your mental health, sleeping and thinking.

This might include:

- Memory problems, feeling confused or finding it hard to concentrate
- Struggling to fall asleep or stay asleep
- Mood swings
- Feeling depressed, anxious or aggressive

Rarely people might get the following signs or symptoms:

- Hearing, seeing or feeling things that aren't really there, but feel real to you
- A strong feeling that you are being targeted, others are out to get you, or feeling suspicious of others

Talk to your team if you are having problems with your mental health or sleep. They can provide you with support and ways to manage these side effects.



If you need urgent mental health support, call 111 and select the mental health option.

The NHS have more [information on urgent mental health support](#). Scan the QR code or search 'urgent mental health' at [nhs.uk](https://www.nhs.uk)



Changes in your weight and metabolism

Steroids used to treat ALL can cause problems with your metabolism.

Signs include:

- Gaining weight, especially around your face, neck and tummy.
- Swelling of your hands, feet, ankles and tummy due to your body holding on to water.
- High blood sugar levels. Your team might notice this on a blood test. You may get symptoms like feeling thirsty, tired, or needing to pee often.
- High cholesterol levels. Your team might notice this on a blood test.



Other short-term side effects

This is not a complete list of side effects you might get. Your haematology team will give you information about your exact treatment, including possible side effects.

Other common side effects of maintenance therapy include:

- Changes in your liver or kidney function. Your team might notice this on a blood test. If it happens, they might adjust your treatment.
- Indigestion, heartburn, tummy pain or diarrhoea. Your team can give you medicines to help.
- Headaches.
- Itchy, dry, flaky or scaly skin.
- A flare up of hepatitis B if you have had it before.

Looking after yourself

Having treatment for ALL can impact you physically and emotionally.

We have more information on:



[Your emotions](#)



[Living well with leukaemia](#)

Scan the QR codes, or search 'your emotions' or 'living with leukaemia' at leukaemiacare.org.uk

When you finish maintenance treatment

You will have blood tests and sometimes bone marrow tests after your last cycle of maintenance treatment. This is to check your response and your blood counts.

If treatment has been successful

If you have responded well to treatment and there is no sign of ALL in your body, you move on to follow-up care.

- You will have regular blood tests and your team will check how you are doing.
- They will also ask how you are coping and can give you support if you are struggling with long-term side effects.
- Your team may also examine you and feel for swollen lymph nodes or a swollen spleen. Your medical team will let you know if you need any other tests or scans.

You have frequent follow-up appointments at first. Over time, you generally have appointments less often. Your team will let you know what to expect. They should also give you details of who to contact if you have any questions or concerns in between appointments.

When you finish treatment, it can be a difficult time, and you might not feel how you expected to.

We have more [information on your feelings when you finish treatment for blood cancer](#). Scan the QR code, or search 'feelings when you finish treatment' at leukaemiacare.org.uk



If treatment has not been successful

If maintenance treatment hasn't worked as expected, your haematology team will talk to you about your options. This is known as relapsed or refractory ALL.

We have more [information on relapsed or refractory ALL](#). Scan the QR code or search 'relapsed or refractory ALL' at leukaemiacare.org.uk



We'd like to thank the expert reviewers and patient contributors who helped us with this information:

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