Treatment for large granular lymphocytic leukaemia (LGLL)

Some people with large granular lymphocytic leukaemia (LGLL) may not need treatment. For those who do, treatment usually aims to control LGLL rather than cure it, but it is often effective. Find out about some of the common treatment options for LGLL.

Summary

- Many people with LGLL do not need treatment straight away. Instead, you will have regular check-ups and blood tests.
- If you need treatment, your team might recommend:
    - Medicines that lower your immune system
    - A clinical trial, if there is one suitable for you
    - Surgery to remove your spleen, if it is swollen and causing symptoms
    - Medicines to prevent or treat symptoms or side effects
- Side effects of some LGLL treatments include:
    - A higher chance of getting infections
    - Extreme tiredness (fatigue)
    - Low blood cell counts or changes in your liver or kidney function
    - Hair loss
- Your haematology team will monitor you closely so they can treat side effects promptly.
- **You should not become pregnant, make someone pregnant or breastfeed while you are having treatment for LGLL**

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Who might need treatment for LGLL?

If LGLL is not causing symptoms, you may not need treatment straight away. You will usually start treatment if you have low levels of healthy blood cells or if you start to develop symptoms.

Between 3 and 5 in every 10 people with LGLL never need treatment. Between 5 and 7 in every 10 people with LGLL have treatment at some point.

If you need treatment, your team will base this on many factors, including:

- Whether or not you have any symptoms
- Your age and overall fitness
- Whether or not you have any other medical conditions
- The genetic changes in your leukaemia cells
- The proteins on the surface of your leukaemia cells
- Your preference on how you wish to be treated

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Active monitoring

If your LGLL is not causing symptoms, you may not need treatment straight away. Instead, you might have regular check-ups and blood tests to monitor how LGLL is affecting you. This is called active monitoring. Some people call it watch and wait.

Active monitoring is a safe approach for slow-growing blood cancers. If you're feeling well, there is no benefit to starting treatment before you need it. This means you can avoid the side effects of treatment for as long as possible. Treatment is still available when you need it.

You are likely to start treatment if:

- Your blood tests show low levels of healthy blood cells
- You start to develop symptoms or your symptoms become worse

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Immunosuppressants

Most people with LGLL have medicines to lower the immune system. These are called immunosuppressants. You usually take them as tablets at home. They help improve your blood counts and reduce your symptoms. They may also reduce the number of abnormal lymphocytes in your body.

The main immunosuppressant medicines used to treat LGLL are:

- Methotrexate
- Cyclophosphamide
- Ciclosporin

Your haematology team will tell you what medicine they recommend, how to have it and what side effects you might get.

It can take at least 4 months to know if your treatment is working well.

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Other treatments

Sometimes your haematology team might suggest different treatment. This could include:

- A clinical trial, if there is one suitable for you
- Surgery to remove your spleen, if it is swollen and causing symptoms

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Supportive treatment

You might also need medicine to prevent or treat symptoms or side effects. This is called supportive treatment. It does not treat your LGLL itself, but it helps you feel better.

Supportive treatment might include:

- Blood transfusions or medicines called growth factors, if your blood counts are low
- Medicine to prevent or treat infections
- Medicine to prevent or treat side effects

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- Steroids, which can help with many different symptoms

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Monitoring during treatment

You will have regular blood tests during your treatment. Your team might also recommend other tests if needed. The tests check how well your LGLL is responding and how well your body is coping with the treatment.

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If LGLL does not respond

Sometimes LGLL doesn't respond well to treatment or comes back after treatment.

- Relapsed LGLL is when LGLL comes back after successful treatment.
- Refractory LGLL is when LGLL does not respond to your first treatment.

If this happens, your haematology team will talk to you about your treatment options. They might suggest:

- An antibody therapy such as rituximab or alemtuzumab. These are lab-made antibodies that stick to proteins on the surface of cancer cells. This helps your immune system recognise and destroy the cells. You usually have antibody therapy as an injection or through a drip.
- Chemotherapy medicines. These kill cells that are dividing rapidly, such as blood cells. If your doctor recommends chemotherapy, they will tell you what medicines they suggest and how you have them.

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Possible side effects

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

Your haematology team will monitor you for serious side effects. You'll have regular checks and blood tests. This means they can treat side effects promptly if they happen.

> **Tell your medical team straight away if you have any symptoms or side effects.**

Your haematology team will explain the side effects you might get with your treatment. Here, we cover some of the important side effects of LGLL treatment in general. It is not a complete list.

Infection risk

LGLL treatment can lower your white blood cell count. This is called neutropenia. It means your body can't fight infections as well as usual. So, you have a higher chance of getting infections, and any infections you do get may be more serious.

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

Contact your medical team straight away if you think you have an infection.

If your white blood cell count is low, there are things you can do to lower your risk of getting an infection. These include:

- Washing your hands frequently
- Avoiding crowded spaces
- Avoiding people who are unwell
- Storing and preparing food correctly to reduce the risk of food poisoning
- Making sure your kitchen is clean
- Regularly cleaning surfaces that you touch a lot, like light switches and door handles
- Having any vaccinations that you are eligible for

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Your haematology team might also prescribe medicines to help prevent infections.

Fatigue

LGLL and its treatment can cause fatigue. This is a feeling of physical or mental exhaustion that doesn't get better with sleep or rest.

Fatigue can be frustrating as it cannot be treated with medicines. But there are things you can do to help you manage it.

- Make plans and pace yourself.
- Prioritise things that are important to you and reserve energy for these.
- Build time to rest around planned busy periods.
- Allow yourself to rest as and when you need.
- Keep to a regular sleep schedule.
- Try to go to bed and wake up at around the same time each day.
- Keep your bedroom quiet and a comfortable temperature.
- Avoid eating or drinking alcohol, coffee, tea or chocolate before bedtime.
- Avoid using laptops, tablets or mobile phones before going to bed.
- Do regular, gentle exercise to maintain your fitness levels.
- Accept help with household tasks.

Make sure to tell your haematology team if you are experiencing fatigue. They may be able to suggest things to help or refer you for support if you need it.

Problems found on blood tests

You have regular blood tests during treatment to check your blood counts and your liver and kidney function.

- LGLL and its treatment can cause low blood counts. If this happens you might have blood transfusions or medicines called growth factors.
- LGLL can affect your liver and kidneys. If your blood tests find any problems, your team might reduce your dose or stop treatment for a while.
- LGLL can affect the level of fats in your blood.

Hair loss

Some treatments for LGLL can cause hair loss or thinning. Hair loss is usually temporary. It happens gradually. Some people prefer to shave their hair or cut it short. This can give you a feeling of control and reduce the emotional impact of it falling out. You could also cover

your hair loss, if you choose too. There are lots of options like hats, headscarves, wraps, turbans or wigs.

Cancer Hair Care UK has more information on hair loss, including how to care for Afro-textured hair during chemotherapy.

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Pregnancy, fertility and breastfeeding

Some treatments for LGLL may affect your fertility. If you think you may want to have children in the future, tell your haematology team. They can give you advice on sperm or egg storage before starting treatment.

- **Treatment for LGLL may harm unborn babies. Some treatments can damage sperm and eggs. You should not get pregnant, or make someone pregnant, while you are having treatment for LGLL.**
- **If you could get pregnant or make someone pregnant, you must use effective contraception during treatment and for several months after. It depends on what treatment you are having. Your team will tell you.**
- **Treatment for LGLL passes into breastmilk. You must not breastfeed during treatment.**

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Sources we used to develop this information

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

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