



Treating Chronic Lymphocytic Leukaemia (CLL) - A Quick Guide

Contents

This is a brief summary of the information on 'Treating Chronic Lymphocytic Leukaemia (CLL)' from CancerHelp UK. You will find more detailed information on the website.

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Staging chronic lymphocytic leukaemia (CLL)

What is staging?

When your doctors have all your test results, they will know more about how far your leukaemia has developed. This is called staging. To decide the stage of CLL, doctors look at the number of abnormal

white blood cells and whether any lymph nodes or the spleen are enlarged. The stage of your CLL helps your doctor to work out the treatment you will need.

The 3 stages of CLL

In the UK doctors use the Binet staging system. In the Binet system CLL has 3 stages – A, B and C. Your leukaemia is classed as

- Stage A if you have fewer than 3 groups of enlarged lymph nodes and a high white blood cell count
- Stage B if you have more than 3 groups of enlarged lymph nodes and a high white blood cell count
- Stage C if you have enlarged lymph nodes or spleen, a high white blood cell count, and a low red blood cell or low platelet count

Statistics and outlook for chronic lymphocytic leukaemia (CLL)

Outlook means your chances of getting better. Your doctor may call this your prognosis. The outcome of treatment for chronic leukaemia depends on a number of different factors. This includes the type of chronic leukaemia you have, how advanced it is when it is diagnosed and how well it responds to chemotherapy treatment.



On CancerHelp UK, we have quite detailed information about the likely outcome of CLL. The statistics we use are taken from a variety of sources, including the opinions and experience of the experts who check every section of CancerHelp UK. 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. 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.

Types of treatment for chronic lymphocytic leukaemia

Treatment in early CLL

You may have no symptoms when you are first diagnosed with CLL. So your specialist will probably suggest you do not have treatment at this time. If your CLL starts to get worse, your doctor will suggest treatment. Doctors generally treat for the following reasons

- Fast developing disease
- Bulky lymph nodes
- Bone marrow failure
- Fatigue, severe weight loss, drenching night sweats

The usual treatment is chemotherapy. Your doctor may also recommend radiotherapy if you have very swollen lymph glands, or surgery to remove a swollen spleen. The treatment can put CLL into remission – where you have no sign of CLL and no symptoms. With CLL a remission can last

for years. After some time the leukaemia may become active again and cause symptoms. This is called a relapse.

Treatment for relapse

When the leukaemia comes back, you have more treatment with chemotherapy or biological therapy or a combination. Many people with CLL can have further remissions. The remissions tend to get shorter, the more treatment you have.

Intensive treatment

After chemotherapy, some people have more intensive treatment to try to stop CLL coming back. This means having a bone marrow or stem cell transplant.

About chemotherapy for chronic lymphocytic leukaemia (CLL)

Chemotherapy is the main treatment for CLL. Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. As they circulate in the blood, the drugs can reach the leukaemia cells around your body. The most common chemotherapy treatments are

- Fludarabine and cyclophosphamide with the monoclonal antibody, rituximab
- Chlorambucil
- Bendamustine

If your CLL comes back after a period of remission, your doctor may suggest treatment with the same drug again. But if the chemotherapy is no longer controlling the CLL your doctor will recommend a different drug or combination of drugs.

There is more information in the main chemotherapy section of CancerHelp UK.



Chronic lymphocytic leukaemia drugs and side effects

The drugs most commonly used to treat CLL are a combination of fludarabine and cyclophosphamide, chlorambucil and bendamustine, and a drug combination called CHOP. Your doctor may also suggest that you have growth factor injections to help your white blood cell count increase more quickly.

Side effects

Chemotherapy drugs all have different side effects. Not everyone gets every side effect with every drug. The side effects that tend to happen with all chemotherapy drugs are

- Low blood cell counts, making you more likely to get infection, anaemia and bleeding or bruising
- Tiredness
- Possibility of harm to the developing baby if you get pregnant or father a child

Both fludarabine and chlorambucil can cause sickness, but this is usually mild. CHOP chemotherapy increases your risk of infection as well as causing sickness and hair loss. Other common side effects of CHOP include constipation, mouth ulcers and skin problems.

There are more detailed pages on the specific side effects of these drugs on CancerHelp UK.

What to ask your doctor about chemotherapy for chronic lymphocytic leukaemia (CLL)

- Why do I need chemotherapy?
- How much treatment will I need?
- Which drugs are you going to give me?

- How do you decide which drug to use?
- Is there written information I can have about these drugs?
- What will the side effects be?
- Will any of the side effects be permanent?
- What can I do to help with side effects?
- Who can help me manage the side effects?
- Can you prevent or reduce any of the side effects?
- How long will the treatment take?
- When will you know if it has worked?
- What will happen if it doesn't work?
- 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 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?
- What effect will this treatment have on my day to day life?

Steroids for chronic lymphocytic leukaemia (CLL)

Steroids are substances made naturally in the body. They can also be made artificially and used as treatment. If you have CLL, you may have steroids with chemotherapy, or on their own.

Your doctor may suggest high dose steroid treatment if your leukaemia has stopped responding to chemotherapy. You can have the steroids as tablets or through a drip. You normally have treatment for 5 days every month. The number of



treatments you have depends on how well it controls your leukaemia. Steroids increase your risk of infection, so your doctor may ask you to take antibiotics or antiviral drugs at the same time.

Side effects

There are several possible side effects of steroids. But the side effects vary a great deal depending on how long you are taking steroids for and on the dose. Common side effects may include having more of an appetite, having more energy, difficulty sleeping and indigestion.

Remember – you should never stop taking steroids, or change your dose without instructions to do so from your doctor.

Radiotherapy for chronic lymphocytic leukaemia (CLL)

Radiotherapy uses high energy rays to kill cancer cells. It is only used in particular circumstances in CLL. The main reasons why your specialist may recommend radiotherapy as part of your treatment are

- To treat a very large spleen that is causing symptoms
- To treat bulky lymph nodes that are causing symptoms
- Before a bone marrow or stem cell transplant

Side effects

Radiotherapy can cause a skin reaction, similar to sunburn in the treatment area, and tiredness. These side effects may be mild, depending on how much treatment you have. Other possible side effects depend on the area of the body having the radiotherapy. There is information about side effects to particular areas of the body

in the radiotherapy section of CancerHelp UK.

Surgery for chronic lymphocytic leukaemia (CLL)

Surgery is not often used to treat CLL because leukaemia is a systemic disease that affects the whole body. So the best treatment is one that treats the whole body, such as chemotherapy. But some people may need to have a minor operation to remove a lymph node for closer examination (lymph node biopsy).

Some people may have an operation to remove the spleen. This is called a splenectomy. Your doctor may suggest you have a splenectomy because your spleen

- Is so large it is making you uncomfortable or causing you pain
- Is destroying too many red blood cells or platelets
- Has not shrunk after chemotherapy

The spleen may be removed through a cut made just under the ribs on the left hand side. Or it may be done with keyhole surgery.

Without a spleen you will be more at risk of infection. To help prevent infection in the future, you will need to have some vaccinations before, or just after, the operation. And you will need to take antibiotics for the rest of your life. You should carry a card saying your spleen has been removed in case of a medical emergency.



Biological therapy for chronic lymphocytic leukaemia (CLL)

Biological therapy is treatment with substances that are made naturally in the body or change the way that particular substances work in the body. Doctors use a type of biological therapy called monoclonal antibodies (MAB's) for CLL.

The main biological therapies used for CLL are alemtuzumab and rituximab.

Rituximab (Rituxan)

Rituximab works by seeking out a protein that is found on normal and leukaemic white blood cells (lymphocytes). Once it has found the lymphocytes, it sticks to them and the immune system then targets the cells and kills them. Normal lymphocytes then grow to replace those that are destroyed. Rituximab, in combination with fludarabine and cyclophosphamide, is the most commonly used first treatment for people with CLL who are physically fit. The most common side effect is a reaction to the drug when you first have it

Alemtuzumab (Mabcampath)

Alemtuzumab works by finding and attaching itself to the cancerous white blood cells (lymphocytes) and then killing them. You are most likely to have alemtuzumab if your CLL has stopped responding to chemotherapy. But alemtuzumab may sometimes be useful as a first treatment for physically fit people with CLL. Alemtuzumab can lower your resistance to infection. To help protect you against infection while you are on this drug, your doctor will give you antibiotics to take.

Bone marrow and stem cell transplant for chronic lymphocytic leukaemia (CLL)

A small number of people have intensive treatment with a bone marrow or stem cell transplant for CLL, but this is still experimental.

The aim of a bone marrow or stem cell transplant is to keep the CLL under control for as long as possible. This type of treatment involves having your bone marrow cells killed off with high dose chemotherapy. You may also have radiotherapy to your whole body (TBI). This destroys the leukaemia cells but also your bone marrow cells. After the intensive treatment you will have donor bone marrow or stem cells through a drip. The stem cells move into your bone marrow and start to make new blood cells again.

This treatment is called a transplant because bone marrow or stem cells are removed from a donor and then transplanted into you. Doctors don't use this type of treatment very often for chronic lymphocytic leukaemia.

Mini transplants

Mini transplants don't use quite such intensive chemotherapy treatment. So your bone marrow is not destroyed. The chemotherapy still suppresses your immune system and allows donor blood cells to grow.



Follow up for chronic lymphocytic leukaemia (CLL)

Why have check ups?

Treatments for CLL usually aim to control rather than cure it. So your doctor will arrange for you to have regular check ups during treatment and afterwards.

Tests you may have

You will have blood tests at your check ups and your doctor will want to know how you are feeling. You may have a physical examination as well. Sometimes your doctor may want to do another bone marrow test.

If you are worried or notice any new symptoms between check ups, tell your doctor straight away. You do not have to wait for your next appointment.

Worrying about your appointments

Many people find their check ups quite worrying, especially at first. It may be helpful to tell someone close to you how you are feeling. It is common for people to have counselling after cancer treatment. To find out more about counselling, look in the coping with cancer section of CancerHelp UK.

Chronic lymphocytic leukaemia (CLL) research

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 likely to be safe to test are they tested in people, in clinical trials.

Research into CLL treatment is looking into what causes CLL. It is also looking at treatments with chemotherapy, biological therapies, transplants, and ways of finding remaining leukaemia cells.

What to ask your doctor about chronic lymphocytic leukaemia (CLL)

- What stage of CLL do I have?
- What sort of treatment do I need?
- Why are you recommending that treatment?
- What do you expect the treatment to do for me?
- Is there a choice of treatments?
- Will I be able to have another treatment if my disease flares up or comes back?
- How long will my treatment last?
- What will the side effects be?
- Can you arrange for me to have a second opinion?
- Is there a clinical trial that I could join?
- Will I still be able to have children after treatment?
- How often might you want to see me when my treatment is finished?
- When will I be able to go abroad for a holiday?



Notes

More information

For more information about chronic lymphocytic leukaemia (CLL), 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 November 2011. 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 2011. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).