



Treating Chronic Myeloid Leukaemia (CML) - A Quick Guide



Contents

This is a brief summary of the information on 'Treating chronic myeloid leukaemia (CML)' from CancerHelp UK. You will find more detailed information on the website.

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Staging chronic myeloid leukaemia (CML)

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. The stage of your CML helps your doctor to work out the treatment you will need.

Staging CML

The staging in chronic myeloid leukaemia (CML) is described in 3 phases. These are the chronic phase, the accelerated phase, and the blast phase.

In the chronic or stable phase, you will have symptoms that are mild and vague. These may include feeling tired, losing a little weight, and a slightly enlarged spleen. The number of white cells and platelets in your blood may be raised.

In the accelerated phase, your symptoms will be more obvious. You may notice that you are feeling more tired than usual or losing weight. Your spleen may be enlarged, which may cause an uncomfortable or painful feeling to the left of your stomach under your ribs.

The blast phase is also called the acute phase or blast crisis. In this phase, the leukaemia becomes more rapid and aggressive. Your symptoms will be troublesome and you will be feeling quite unwell.



Statistics and outlook for chronic myeloid leukaemia (CML)

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 the latest treatments, such as imatinib (Glivec).

On CancerHelp UK, we have quite detailed information about the likely outcome of CML. 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 myeloid leukaemia (CML)

The treatment of CML depends on the phase of the disease, your general health, your age and level of fitness.

Chronic phase CML

The preferred treatment for chronic phase CML is imatinib (Glivec). If imatinib doesn't work for you, there are other, newer biological therapies. Or you might have chemotherapy or interferon to keep the CML under control. Your doctor may

suggest intensive treatment with bone marrow or stem cell transplant. This treatment is not suitable for everyone, but it can cure some people with CML.

Accelerated phase

For accelerated phase CML, imatinib is usually the first choice of treatment. Generally you can only have imatinib if you didn't have it in chronic phase. If you were taking imatinib in chronic phase and your CML has progressed to accelerated phase, it will not continue to help you. Your doctor may suggest intensive treatment with a bone marrow or stem cell transplant. Or you may have chemotherapy or a newer biological therapy called dasatinib.

Blast phase

For blast phase CML, your doctor may suggest imatinib, if you haven't had it before. They may suggest chemotherapy with a combination of drugs that is usually used for acute leukaemia. Doctors are also developing new drugs that could work better than imatinib, if people have developed resistance to it.

Biological therapies for chronic myeloid leukaemia (CML)

Biological therapies are treatments that use natural substances from the body, or that change the way cells signal to each other. They can stimulate the body to attack or control the growth of cancer cells. A biological therapy called imatinib (Glivec) is the main treatment for most people with CML. It has largely replaced interferon combined with chemotherapy. Imatinib blocks a protein made by CML and stops the overproduction of white blood cells. Doctors are also developing new biological therapies, such as dasatinib and nilotinib.



They may work when CML has become resistant to imatinib.

Interferon for CML

Interferon is a type of immunotherapy. Interferon used to be the main treatment for chronic phase CML. If you are already on interferon and it is working for you, your specialist is likely to want you to carry on with it. If you have had a bone marrow or stem cell transplant for CML, but your leukaemia comes back, your doctor may suggest treatment with interferon. This may be combined with more chemotherapy.

The commonest side effects of interferon are a reaction similar to flu, with aching, temperature and weakness. You may feel sick or lose your appetite. Some people have depression and mood changes. All side effects tend to be more severe in older people.

There is more information about biological therapy in the 'cancer treatments' section of CancerHelp UK.

About chemotherapy for chronic myeloid leukaemia (CML)

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. It used to be the standard treatment for newly diagnosed CML. But now you are more likely to have treatment with imatinib. If, for some reason, you cannot take imatinib, CML also responds to treatment with chemotherapy or interferon alpha. The chemotherapy drug that most commonly used is hydroxycarbamide (it used to be called hydroxyurea).

If your CML doesn't respond well to imatinib, or develops resistance to it, your doctor may suggest intensive treatment

with a bone marrow or stem cell transplant. You will have to go into hospital and have high dose chemotherapy drugs through a drip. You will need to stay in hospital for a few weeks at least.

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

How you have CML chemotherapy

You may have hydroxyurea chemotherapy tablets at home. But if you have chemotherapy into your bloodstream, you will go to hospital for treatment. Unless you are having intensive treatment, you usually have chemotherapy in an outpatient clinic and go home the same day. You will have regular blood tests to check your levels of white cells, red cells and platelets.

Chronic myeloid leukaemia (CML) drugs and their side effects

These days, if you have early phase CML, you are more likely to have treatment with imatinib (Glivec) or interferon instead of chemotherapy. The most used chemotherapy drug for CML is hydroxycarbamide (it used to be called hydroxyurea). Another drug less often used is busulphan.

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

- A drop in your blood cell counts, increasing risk of infection, anaemia and bleeding or bruising
- Feeling tired and run down
- Loss of fertility



Some people have more intensive, high dose chemotherapy for CML, followed by a bone marrow or stem cell transplant. A variety of different drugs and combinations of drugs can be used for this treatment. High dose chemotherapy will always have more severe side effects than regular dose treatment.

There is more detail on the specific side effects of individual drugs in the 'cancer treatment' section of CancerHelp UK.

What to ask your doctor about chemotherapy for chronic myeloid leukaemia (CML)

- 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?
- How do you decide which drug to use?
- 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?
- Is there someone who can advise me about benefits?

Radiotherapy for chronic myeloid leukaemia (CML)

Radiotherapy uses high energy rays to kill cancer cells. Doctors generally only use radiotherapy for CML as part of a bone marrow or stem cell transplant. For this, you have radiotherapy to the whole body. This is called 'total body irradiation' TBI. Your doctor may also suggest radiotherapy if your spleen is very enlarged, uncomfortable or painful. Radiotherapy can help to relieve your symptoms by shrinking the spleen.

Side effects of TBI

If you have TBI, you are unlikely to have a skin reaction. But side effects include sickness, tiredness, hair loss and risk of infection. There are also some long term effects of TBI. There is more information about this in the cancer treatment section of CancerHelp UK.

Radiotherapy to the spleen

Radiotherapy to the spleen can cause a skin reaction in the treatment area. This is similar to sunburn. You may be increasingly tired as you go through the treatment.

You can read more about radiotherapy in the main 'radiotherapy' section of CancerHelp UK.



Bone marrow and stem cell transplant for chronic myeloid leukaemia

The aim of a bone marrow or stem cell transplant is to try to cure your chronic myeloid leukaemia or control it for longer. This type of treatment is mainly used for patients who have not responded to tyrosine kinase inhibitors. A bone marrow or stem cell transplant involves having high dose chemotherapy. You may also have radiotherapy to your whole body. This destroys the leukaemia cells but also your bone marrow cells. Bone marrow is the spongy substance inside your bones that makes all your blood cells.

After this intensive treatment you have donor stem cells through a drip into a vein. These then start to make new blood cells again. At the moment, the only known cure for CML for some people is a transplant with someone else's bone marrow or stem cells.

There is much more information about bone marrow and stem cell transplants (including auto transplant) in the 'about cancer treatment' section of CancerHelp UK.

Follow up for chronic myeloid leukaemia (CML)

Why have check ups?

Your doctor will often be trying to control CML rather than cure it. Even after intensive treatment and a long period of time in remission (being disease free), your leukaemia could come back. So your doctor will arrange for you to have regular check ups. These will continue for several years.

What will happen

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.

Check ups can be worrying

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. Having someone come along with you to your check ups may help. 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 myeloid leukaemia (CML) 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 are they tested in people, in clinical trials.

There is so much information on chronic myeloid leukaemia research it is not possible to include it all here. But there is research going on looking into biological therapies, transplants and finding leukaemia cells left behind after treatment.



What to ask your doctor about chronic myeloid leukaemia (CML)

- What type of leukaemia do I have?
- What stage of disease do I have?
- What sort of treatment do I need?
- Why would you recommend that treatment?
- Are you aiming to cure or control my disease?
- Is there a choice of treatments?
- 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 my fertility be permanently affected by treatment?
- Will I be able to have another treatment if my disease flares up or returns?
- How often might you want to see me when my treatment is finished?
- When will I be able to go abroad for a holiday?

More information

For more information about chronic myeloid leukaemia (CML), 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 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 September 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).