Chronic myelomonocytic leukaemia (CMML)

This fact sheet explains what chronic myelomonocytic leukaemia (CMML) is and how it's diagnosed and treated. It explains the different types of CMML and suggests places to go for more information.

What is CMML?

Chronic myelomonocytic leukaemia (CMML) is a rare form of leukaemia, which is a type of blood cancer.

Cells that make up your blood are made inside your bones in your bone marrow. CMML develops when blood cell production stops working properly.

The cells affected by CMML are a type of white blood cell called monocytes. CMML happens when too many monocytes are made.

> You can find out more about your blood and bone marrow at **bloodwise.org.uk**

CMML shares common features with two other types of blood disorders: myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). However, CMML is a separate condition with different treatment options because people with CMML can have features of both MDS and MPN.

> You can find more information about MPN and MDS in our booklets **Myeloproliferative neoplasms** and **Myelodysplastic syndromes**

Receiving your results or diagnosis

When you go to your second appointment, this may be the time that your doctor discusses your test results with you. Depending on your results, your doctor may be able to tell you if they have found out what condition is causing your signs and symptoms (give you your diagnosis). You may need to have further tests, such as a bone marrow biopsy, CT scan or MRI scan. Your doctor should make this very clear and should make sure that you have the opportunity to ask any questions you may have at this point.

Types of CMML

There are two different ways that doctors will classify your type of CMML. The type of CMML you're diagnosed with will affect which treatment option you're offered.

You'll have one of each type:

- CMML-1 or CMML-2,
- dysplastic CMML or proliferative CMML.

CMML-1 or CMML-2

People with CMML have abnormal monocytes in their blood. They're abnormal because they haven't developed properly – they are immature. These cells are also called leukaemia cells or blast cells. We'll call them blast cells in this fact sheet.

Whether you have CMML-1 or CMML-2 will depend on how many blast cells are in your blood and bone marrow.

- If you have CMML-1, you'll have less than 5% of blast cells in your blood and less than 10% in your bone marrow.
- If you have CMML-2, you'll have between 5 and 19% of blast cells in your blood and between 10% and 19% in your bone marrow.

The type you have can affect your treatment, outlook, and chances of your condition developing into another type of leukaemia.

Dysplastic CMML or proliferative CMML

Another way of classing CMML is to see whether your condition is more dysplastic (similar to MDS) or proliferative (similar to MPN). Your doctors will look at how high your white cell count is in your blood to work out which type you have.

People with proliferative CMML have a higher white cell count than those with dysplastic CMML.

- If you have dysplastic CMML, your total white cell count is equal to or less than 12 x 10^9/l (12,000 white cells per cubic millimetre of your blood).
- If you have proliferative CMML, your total white cell count is higher than 13 x 10^9/l (13,000 white cells per cubic millimetre of your blood).

Talk to your healthcare team if you'd like to know more about your blood counts and how this is measured.

If you have dysplastic CMML, you may receive treatments that are similar to those used to treat MDS.

If you have proliferative CMML, you'll receive a different type of treatment, usually to lower your white cell count.

Transformation

For some people, (between 15% and 30%) CMML 'transforms' into another type of leukaemia called acute myeloid leukaemia (AML).

Your diagnosis becomes AML if the number of blast cells in your blood rises above 20%. Your doctor will call this transformation. This happens in between 15-30% of people with CMML. Transformation may happen after a few months or after several years.

You can find more information about AML in our booklet **Acute myeloid leukaemia**

Who gets CMML?

The average age that people are diagnosed with CMML is 70 years old.

There's a very rare form of the disease which can develop in young children, called juvenile myelomonocytic leukaemia (JMML).

Cancer Research UK have more information about JMML on their website go to **cancerresearchuk.org** then search for '**JMML**'.

What causes CMML?

At the moment we don't know what causes CMML although we do know it's caused by changes that happen in the genes of some of the cells in your bone marrow. These genetic changes aren't inherited, so they can't be passed on to your children. Instead, these gene changes in your bone marrow cells are picked up over the course of your lifetime.

There aren't any lifestyle factors that are known to increase a person's risk of getting CMML. You may have a slightly higher risk of getting CMML if you've been treated with chemotherapy or radiation in the past. It's important to remember that nothing you've done has contributed to you developing CMML.

Signs and symptoms

CMML can cause a number of different signs and symptoms, including:

- fatigue,
- weight loss,
- fever,
- night sweats,
- infections,
- skin lumps,
- swollen gums,
- swollen lymph nodes,
- bleeding because of the low number of platelets (the cells that helps to form blood clots) in your blood,
- a high white cell count on your blood tests, and,
- an enlarged liver or spleen, especially if you have CMML-2; you may feel some discomfort in your upper stomach if this is the case.

Diagnosis

Your doctors diagnose CMML by looking at your blood, bone marrow and genes.

From a blood test, your doctors will be able to measure the amount of monocytes (a type of cell) in your blood. An unusually high number of monocytes can suggest that you may have CMML.

You'll also have a bone marrow biopsy taken from your hip bone. This sample can show if you have any blast cells (abnormal monocytes) and how many there are. If you do have blast cells, and the level of blast cells is lower than 20%, this can suggest that you may have CMML. In your blood and bone marrow, there may also be signs of dysplasia within some of your cells, which means your cells will look unusual when they're viewed under a microscope.

You can find more information about blood and bone marrow tests on our website **bloodwise.org.uk**

Your doctors may also do tests on your samples called cytogenetics or karyotyping. These tests look at changes in your chromosomes (your genes). An abnormal chromosome can confirm or rule out a diagnosis of CMML, or it may show that you have another type of leukaemia. Certain types of rare abnormal chromosomes found during these tests may also tell your doctors important information about your outlook and if you might benefit from a specific treatment.

Treatment

The treatment you'll receive will depend on a number of things, including:

- your age and fitness,
- your blast cell count (whether you have CMML-1 or CMML-2), and,
- whether you have dysplastic-CMML or proliferative-CMML.

The aim of most of these treatments is not to cure the disease but to reduce your blast cells, improve your symptoms, delay a possible transformation to acute leukaemia and give you the best quality of life for as long as possible.

An allogeneic stem cell transplant (a transplant using stem cells from a donor), may cure CMML but it's not suitable for everyone. A stem cell transplant is explained later in this fact sheet

Non-intensive treatment and supportive care

Everyone with CMML will receive supportive care. This means treatment that manages the symptoms of your condition and the side effects of your treatment. This may include red blood cell transfusions, platelet transfusions and antibiotics.

Non-intensive treatments are suitable for people who are older, or less medically fit. Most people with CMML will receive this treatment. Non-intensive treatment and supportive care may control your high white cell count and relieve your symptoms.

You may be given an oral chemotherapy drug called hydroxycarbamide. This, may lower your white cell count and help to shrink the size of your spleen and skin lumps. Most people find this treatment has few side effects. You can take hydroxycarbadmide at home or as an outpatient (which means not staying in hospital overnight).

Intensive treatment

An intensive chemotherapy treatment option for CMML is an allogeneic stem cell transplant. This is a treatment that involves collecting stem cells from a genetically matched donor, who may or may not be related to you, and giving the healthy cells to you with the aim of curing the CMML. This treatment is very intense and has lots of risks. So generally it's recommended for people under 60, who are in reasonably good health.

Treatment for people with a t(5;12) abnormality

For people diagnosed with a very rare form of CMML, which has a specific chromosome abnormality called t(5;12), doctors may recommend a type of drug called tyrosine kinase inhibitors (TKIs). These drugs are most commonly used for the treatment of chronic myeloid leukaemia (CML). An example of one type of TKI is imatinib (Glivec®). Your doctor will discuss this treatment with you if you have this type of CMML.

Treatment for people with CMML-2

If you're diagnosed with CMML-2, you may be given a drug called azacitidine. Generally this drug is injected under the skin for seven days, every 28 days for six or more cycles. This drug can be taken as an outpatient, which means you will not have to stay in hospital overnight. The injection is given by a doctor or a nurse. Azacitidine may improve your symptoms, blood counts and outlook.

Clinical trials

Your consultant might suggest you take part in a clinical trial. Clinical trials are done for many reasons, including to look for new treatment options and to improve existing treatments. In a clinical trial, the best current treatment is compared to one that could be better. Your safety and wellbeing is always the first priority in a clinical trial. Consider asking your healthcare team for more information about clinical trials.

You can find out more information about clinical trials in our booklet **Clinical trials**

Outlook

The outlook for people with CMML varies from person to person. One of the main factors affecting this is the blast cell count, so people with CMML-2 tend to have a poorer outlook (prognosis) than those with CMML-1. However, as life expectancy can vary a lot in CMML, it's important that you discuss your individual condition with your consultant.

Doctors can predict a person's outlook in a number of ways. They use something called a prognostic scoring system to take into account all aspects of your condition. However, these scoring systems may be less accurate for some people, for example, for people with a high white blood cell count. Your doctors can discuss this with you if you'd like to know more about these scoring systems.

Living with CMML can be difficult, both physically and emotionally. However, with supportive treatments you can feel better.

Finding out more

We offer information on many blood cancer types and topics, online and in free printed booklets. They cover everything from symptoms and diagnosis through to treatment and living with your condition. Go to **bloodwise.org.uk/information-and-support**

We also have an online community you may like to join **bloodwise.org.uk/our-community**

Or you can call our support line on **0808 2080 888** (Mon–Fri 10am–4pm). This is a freephone number.

See our website for more details of cancer information specialists and support groups. Go to **bloodwise.org.uk/living/where-get-help-and-support**

Other organisations

There's also other organisations who can offer you support such as the MDS UK Patient Support Group. Go to **mdspatientsupport.org.uk** (website and forum) **mds-uk@mds-foundation.org** **020 7733 7558**

About Bloodwise

We're the UK's specialist blood cancer charity.

We've been working to beat blood cancer since 1960.

We fund world-class research; provide practical and emotional support to patients and their loved ones; and raise awareness of blood cancer.

We'd like to thank Doctor Dominic Culligan and Doctor Eduardo Olavarria for their help and support in developing the content and checking for clinical accuracy. A list of references used in this fact sheet is available on request, please email information@bloodwise.org.uk.

Our factsheets contain general information. Always listen to the advice of your specialist about your individual condition – because every person is different.

Disclaimer

We make every effort to make sure that the information in this fact sheet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health.

Bloodwise can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

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