Juvenile myelomonocytic leukaemia (JMML)

Juvenile myelomonocytic leukaemia (JMML) is a very rare type of blood cancer. It affects babies and young children. Find out what it is, the signs and symptoms and how it is diagnosed and treated.

Summary

- Juvenile myelomonocytic leukaemia (JMML) is a very rare blood cancer that affects babies and young children. It affects white blood cells called monocytes.
- We do not know the exact cause of JMML. It is not because of anything you or your child have or have not done.
- JMML is diagnosed using blood tests and bone marrow tests.
- Sometimes, JMML might get better on its own. In this case, your child might not need treatment straight away. Instead they will have regular check-ups.
- If your child does need treatment, there are a number of treatment options your child's haematology team might consider. These might include:
    - Chemotherapy followed by a stem cell transplant.
    - Chemotherapy without a stem cell transplant.
    - A clinical trial.
    - Supportive treatment.

Download our factsheet on JMML

What is juvenile myelomonocytic leukaemia (JMML)?

JMML is a type of blood cancer called a myeloproliferative neoplasm (MPN). These are types of blood cancer that develop when cells in your child's bone marrow grow out of control and make too many blood cells.

JMML causes white blood cells called monocytes to divide uncontrollably.

Monocytes usually help fight infections. But in JMML, bone marrow makes too many immature monocytes that do not work properly. They build up in the bone marrow. This stops it making enough healthy red blood cells, white blood cells and platelets.

The immature monocytes can also build up in the spleen, liver or lymph nodes.

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Who gets JMML?

JMML is very rare. This is why you might not have heard of it before. It mainly affects babies and toddlers under 3 but it may affect children up to 6 years of age. It is more common in boys than in girls.

It is also more common in children with conditions called Noonan syndrome and neurofibromatosis type 1.

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What causes JMML?

> **We do not know the exact cause of JMML. It is not because of anything you or your child have or have not done. There is nothing you could have done to prevent it.**

Children with JMML have genetic changes in bone marrow cells called stem cells. Some of these may be passed down from a parent. But some happen by chance. We do not know why.

Stem cells usually make all the blood cells your body needs. The genetic changes in the stem cells cause a genetic switch to get stuck in the 'on' position. This means the stem cells keep making blood cells when they should not.

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Signs and symptoms of JMML

The signs and symptoms of JMML vary from child to child. If your child has JMML, you might notice the following signs and symptoms:



Swollen tummy, tummy pain or other tummy problems



Poor appetite



Not gaining enough weight or losing weight



Lumps in their neck, armpit or around the groin



Fever for no obvious reason



Frequent or long-lasting infections



Feeling tired or lethargic, sleeping more than usual or being more irritable than usual



Dry cough or rapid breathing



Pale skin, skin rash or other skin problems

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Diagnosis of JMML

JMML can take time to diagnose because it is so rare and the symptoms are similar to other conditions.

To get an accurate diagnosis, your child will have blood tests and bone marrow tests.



Your child will have blood tests to:

- Measure your child's numbers of red blood cells, white blood cells and platelets. If your child has JMML, they'll have high levels of monocytes. They may have low levels of healthy blood cells.
- Look at your child's blood cells under a microscope.
- Check how well their liver and kidneys are working.



Your child may have a bone marrow test to confirm their diagnosis. This involves taking a sample of your child's bone marrow, usually from the back of their pelvis. They have a general anaesthetic first so they will be asleep during the test.



Your child's doctor will send your child's blood and bone marrow samples to the lab for specialist tests. They may look for genetic changes in your child's stem cells, and test what proteins their blood cells make.



Your child may need other tests or scans, depending on their symptoms. Their medical team will let you know if this is the case.

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Treatment for JMML

Because JMML is so rare, it is difficult for researchers to carry out trials to work out the best treatment. So, at the moment, there is no standard approach to treatment.

> **Treatment varies from child to child.**

Occasionally, JMML might get better on its own. This can be difficult to predict. It depends on many factors, including the genetic changes in your child's blood cells.

If your child's team think this might happen, they may not recommend treatment straight away. Instead, your child might have regular tests and check-ups with expert supervision to see how JMML is affecting them.

> **If your child does need treatment, their medical team will discuss available treatment options with you. They should explain what the treatment is, how your child will have it and what to expect from it.**

There are a number of treatment options they might consider. These include:



Chemotherapy followed by a stem cell transplant. Chemotherapy kills the blood-forming cells in your child's bone marrow, called stem cells. These are replaced by healthy stem cells from a matched donor, sometimes a family member. A stem cell transplant has the potential to cure JMML, but it is intensive and has to be planned and timed carefully. Your child will usually stay in hospital for several weeks to have it.



Chemotherapy without a stem cell transplant. Your child may not need a stem cell transplant. Or it may not be suitable for them. Instead, their team might recommend chemotherapy on its own.



A clinical trial. This is where new treatments, or different ways of using existing treatments, are tested to find out if they are better than standard treatments. If there is a clinical trial suitable for your child, their team should explain what it involves and the risks and benefits of it. It is your choice whether or not your child takes part.



Supportive treatment, to control symptoms, side effects or slow the disease.

It is important to stay in contact with your child's medical team. They are there to support you and answer any questions or concerns you have.

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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.

Helpline and WhatsApp →

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