

Patient information from BMJ

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Sickle cell disease: what is it?

Sickle cell disease is a condition that some people are born with. It can cause pain and serious health problems, but many people with sickle cell disease feel well a lot of the time.

What is sickle cell disease?

Sickle cell disease is a condition that affects your blood. It's sometimes called sickle cell anaemia.

If you have this condition the red cells in your blood, which are usually disc shaped, turn into a sickle shape. This stops your blood from carrying oxygen as well as it should.

Sickle cells can't travel in your bloodstream as easily as ordinary red blood cells. They sometimes get stuck in your small blood vessels. This can stop blood reaching parts of your body, which can cause pain.

Sickle cell disease is most common among people whose families come from Africa. But people from a Mediterranean, Caribbean, Middle Eastern, or Asian background also can be affected.

Sickle cell disease is caused by a faulty gene. A child may be born with sickle cell disease if both their parents carry the faulty gene. It's possible to carry the sickle cell gene without having sickle cell disease.

You can have a blood test to find out if you have sickle cell disease or if you carry the gene. Most babies have this test soon after they're born.

What are the symptoms?

Pain is the most common symptom of sickle cell disease. Almost everyone with sickle cell disease gets pain at some point, but for some people it doesn't happen very often.

There are several other symptoms:

- Because sickle cell disease stops your blood carrying oxygen properly you may get tired or breathless easily.

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- You may be more likely to catch infections, especially when you're young.
- You might sometimes get swollen hands or feet.

What can I do to help myself?

There are several things you can do to help yourself.

Doctors may recommend that you avoid stress, drink plenty of fluids, and make sure you get enough rest.

Some people find that very hot or cold temperatures bring on attacks of sickle cell pain. So avoiding extreme temperatures might help.

Moderate exercise can be good for you, but very strenuous exercise might bring on an attack of sickle cell pain.

What will happen to me?

Everyone with sickle cell disease should have what's called 'genetic counselling'. This is because people with sickle cell disease may pass on the condition if they have children, through their genes.

So people with sickle cell disease who are thinking about having children should be given information and support by a trained counsellor.

Many people cope well with sickle cell disease and live full lives. Treatments can help with sickle cell pain and also help prevent problems such as infections.

But it is possible to get episodes of severe pain and other serious health problems. It's important to know about the problems you could get, and act straight away if you or your child gets ill.

To read about treatments for pain and other problems caused by sickle cell disease, see the leaflet *Sickle cell disease: what treatments work?*

Talk to your doctor about warning signs you need to watch out for. Signs that you or your child need medical help include:

- a fever
- pain that doesn't go away if you take ordinary painkillers
- pain in your abdomen that lasts a long time
- chest pain
- difficulty breathing
- trouble speaking
- changes in your vision
- weakness, pain, or swelling in your hands or feet
- headaches that don't go away.

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Men who get an erection that doesn't go away also need to see a doctor.

And some types of contraception are not suitable for women with sickle cell disease. Talk to your doctor about which type of contraception is best and safest for you.

Other longer-term problems related to sickle cell disease can include leg ulcers and gallstones.

Where to get more help

It might help to talk to people who've had experiences similar to yours. For example, in the UK you can get information and support from the Sickle Cell Society (sicklecellsociety.org).

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