

About Hairy Cell Leukaemia (HCL) - A Quick Guide

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This is a brief summary of About hairy cell leukaemia. You will find more detailed information on the website.

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The blood and hairy cell leukaemia

Hairy cell leukaemia is a rare type of chronic leukaemia. Chronic leukaemia is leukaemia that develops slowly, over months or years. Under a microscope, the abnormal blood cells in hairy cell leukaemia have hair like projections on their surfaces. This is where the name hairy cell comes from.

The blood and blood cells

Leukaemia is a cancer of the blood forming system. Your body makes blood cells in the bone marrow, which is the soft inner part of your bones. Most types of leukaemia cause the bone marrow to make abnormal

white blood cells. There are several different types of white cells. Hairy cell leukaemia develops from white cells called B lymphocytes.

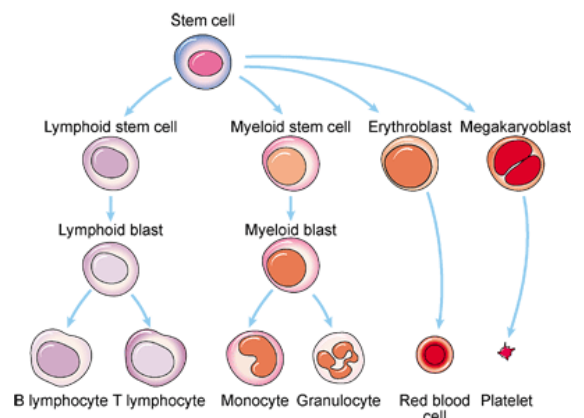


Diagram showing how blood cells are made © CancerHelp UK

How leukaemia affects you

White blood cells help fight infection. If your body is making abnormal white blood cells, they won't work properly. So you may be more prone to infections. It is also more difficult to get rid of infections once you have them.

If you have too many white blood cells, they can overcrowd the bone marrow. So there is not enough space for the other



types of blood cell, which are called red blood cells and platelets. Having too few red blood cells makes you tired and breathless (anaemic). And if you don't have enough platelets, you can have bleeding problems. Abnormal white blood cells can also build up in your spleen, lymph nodes and liver.

Hairy cell leukaemia risks and causes

Hairy cell leukaemia is rare. Altogether, around 190 cases are diagnosed each year in England, Scotland and Wales. Just under 7,000 cases of leukaemia are diagnosed each year in the UK, so hairy cell is one of the rarer types of leukaemia.

What risk factors are

Anything that increases your risk of getting a disease is a risk factor. Different cancers have different risk factors. Having one or more risk factors for a disease does not mean that you will definitely get it. And, although a risk factor can increase your chances of getting a cancer, it does not cause cancer.

Risk factors for hairy cell leukaemia

We don't know what causes hairy cell leukaemia. The only risk factors we know of are age and gender. Hairy cell leukaemia tends to be more common after the age of 30. The most common age for diagnosis is around 50.

It is more common in men. About 5 times as many men are diagnosed with this type of leukaemia as women.

Symptoms of hairy cell leukaemia

Usually people with hairy cell leukaemia (HCL) have mild symptoms at first that build up slowly and include

- Tiredness and breathlessness because of low levels of red blood cells (anaemia)
- Frequent infections due to low levels of white blood cells- if you have an uncontrolled infection, you may have very high temperatures and sweats

Some people may also have other symptoms such as

- Bleeding and bruising due to low levels of platelets- you may have nosebleeds, unexplained bruising or unusually heavy periods
- Swollen abdomen - an enlarged spleen is quite common and can make your abdomen uncomfortable or painful
- Weight loss – the leukaemia itself uses up energy, so you may lose weight, even if you are eating normally

Occasionally people with HCL don't have any symptoms. Their doctors might find it during a routine blood test for something else.

Screening for hairy cell leukaemia

Screening means testing people for the early stages of a disease, before they show any signs of having it.

Before screening for any type of cancer can be carried out, doctors must have an accurate test to use. The test must be reliable in picking up cancers that are there. And it must not give a positive result in people who don't have cancer.

There is no screening programme for hairy cell leukaemia. Leukaemia is not a common condition and hairy cell leukaemia is very rare. It is very expensive and not very cost



effective to screen everyone for a rare disease. It would be more cost effective to screen people who are thought to be at higher risk. But at the moment we don't know of any high risk groups for hairy cell leukaemia.

Should I see a HCL specialist?

Early symptoms of Hairy cell leukaemia (HCL) may include tiredness and getting more infections than usual. Occasionally people do not have very many symptoms. HCL is sometimes diagnosed through a routine blood test for something else.

It can be very difficult for GPs to decide who may have a suspected cancer and who may have something much more minor. But there are particular symptoms that mean your GP should refer you to a specialist straight away.

The NICE guidelines

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines for GPs to help them decide which patients need to be seen urgently by a specialist. You should ideally get an appointment within 2 weeks for an urgent referral. You may need an urgent referral if you have an enlarged spleen which your doctor can feel, is not getting better, and has no explained cause.

The guidelines also say that a GP should do some blood tests, and possibly refer you to a specialist, if you have a combination of symptoms including fatigue, weight loss, night sweats and unexplained fevers, itching, shortness of breath, bruising or unexplained bleeding, abdominal pain for no apparent reason, infections that keep coming back, bone pain and swollen lymph nodes.

If you are concerned that your GP is not taking your symptoms as seriously as you think they should, you could print this page and take it along to an appointment.

Questions for your doctor about hairy cell leukaemia

- How would I know if I had a form of leukaemia?
- Am I more likely to develop leukaemia than any one else?
- Is there anything I can do to reduce my risk of developing hairy cell leukaemia?
- Someone in my family has had hairy cell leukaemia. Does that increase my risk of getting it?
- Are there guidelines on when someone with leukaemia symptoms should see a specialist?



Notes

More information

For more information about hairy cell leukaemia, 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

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