

About Chronic Lymphocytic Leukaemia (CLL) - A Quick Guide

Contents

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

In this information there are sections on

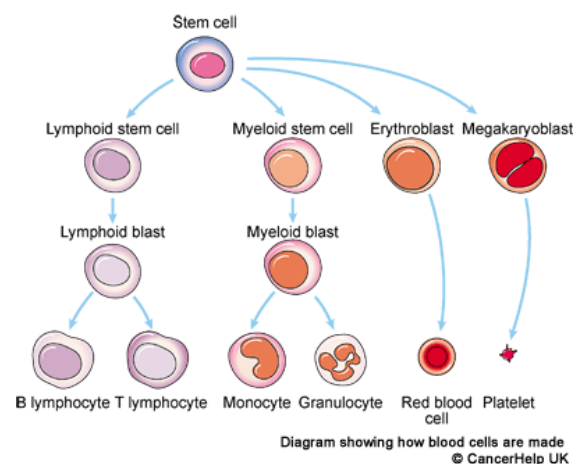
- About the blood and CLL
- CLL risks and causes
- Screening for CLL
- CLL symptoms
- CLL and types of chronic leukaemia
- Guidelines for seeing a CLL specialist
- What to ask your doctor

About the blood and chronic lymphocytic leukaemia (CLL)

Leukaemia

Leukaemia is cancer of the blood forming system. The blood forming system is found in the bone marrow, which is the soft inner part of some of your bones. In most types of leukaemia, abnormal white blood cells are made in the bone marrow. These do not develop properly so they do not give you the protection from infection that they should.

This diagram illustrates how blood cells form.



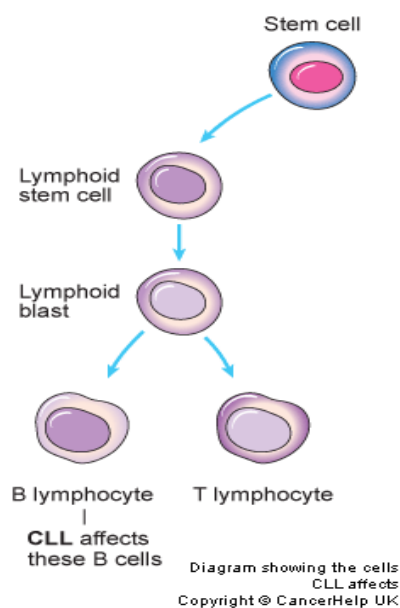
Because there are too many abnormal white blood cells, they stop the bone marrow producing enough healthy blood cells. The abnormal cells can build up in the lymph nodes and spleen, and cause swelling. They may also cause problems in the liver and central nervous system.

Chronic leukaemia tends to take longer to develop than acute leukaemia. You may have it for months or years without having many symptoms. It may be stable for months or years before it gets worse.



Chronic lymphocytic leukaemia (CLL)

There are two main types of chronic leukaemia – chronic lymphocytic leukaemia (CLL) and chronic myeloid leukaemia (CML). In CLL, it is a type of white blood cell called lymphocytes that are cancerous. (Lymphocytic in CLL is pronounced lim-fo-sit-ik.)



Chronic lymphocytic leukaemia (CLL) risks and causes

How common is CLL?

CLL is the most common type of chronic leukaemia, although still relatively rare. It mostly occurs in people over the age of 60 and is very rare in people under 40. Men are twice as likely to develop CLL as women. We don't know why that is.

Family history

There is some evidence of CLL running in families, but most cases of CLL do not have a family link. So far, we don't know of any

specific gene changes that increase a person's risk of CLL. It is much less common in some ethnic groups. Some people who have had particular blood disorders or other medical conditions are slightly more likely to develop CLL than the general population.

Screening for chronic lymphocytic leukaemia (CLL)

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

The aim of screening is to diagnose cancer

- At an early stage
- Before symptoms start
- When it is easier to treat
- When it is more likely to be curable

CLL is different from most cancers because it is not usually possible to cure it but it is a very slowly developing disease. And many people live for many years without symptoms or treatment. These people are monitored closely by their doctor. This monitoring is called watchful waiting. If the leukaemia starts to cause symptoms treatment can then control the CLL for a long time.

CLL affects mostly older people and most of them die from other causes. So for all these reasons there is no UK screening programme.

Chronic lymphocytic leukaemia (CLL) symptoms

About 40 out of every 100 people with chronic leukaemia (40%) won't have any symptoms at all. About 50 out of every 100 cases of CLL (50%) are diagnosed when a



person has a routine blood test for something else. In chronic leukaemia symptoms tend to be mild at first and get worse slowly. You may feel as if you have the flu.

Common symptoms of CLL

Many of the symptoms listed below occur in CLL but are more likely to be caused by other illnesses

- Swollen lymph glands
- Abdominal discomfort
- Weight loss
- Bleeding or bruising
- Infections that will not get better
- Tiredness from a shortage of red blood cells (anaemia)
- Fever

If you have any of these symptoms you must have them checked by your GP. But remember, they can all be caused by other conditions. For example, everyone's lymph glands swell up when they have a throat infection. Most people with these symptoms will not have CLL.

Rarely, some people with CLL have bleeding or bruising, but these people often have a bleeding condition as well as CLL. Some people whose CLL has changed (transformed) into a high grade disease have bone pain and night sweats.

CLL and types of chronic leukaemia

Leukaemias can be chronic or acute. Chronic leukaemias develop slowly and get worse slowly. In chronic leukaemia the cells are almost fully developed, but are not completely normal. They can still work, but not as well as they should do. Acute

leukaemias tend to develop quickly and get rapidly worse if they are not treated.

The two most common types of chronic leukaemia are chronic myeloid leukaemia (CML) and chronic lymphocytic leukaemia (CLL). If you are looking for information on chronic myeloid leukaemia, there is a section on CancerHelp UK. There is also a section about a very rare type of CLL called hairy cell leukaemia.

Over time, CLL may change into another type of leukaemia called prolymphocytic leukaemia. This happens to about 10 out of every 100 people with CLL. Doctors call this change from one disease to another transformation.

Rarely, advanced CLL can also change into a cancer of the lymphatic system (lymphoma) called Richter's syndrome.

Guidelines for seeing a CLL specialist

It can be difficult for GPs to decide if you may have cancer or not. Remember – CLL develops very slowly. Your GP can usually pick it up from a blood test, and it doesn't often need an urgent referral to a specialist.

The National Institute for Health and Clinical Excellence (NICE) have produced guidelines for GPs. The guidelines say that a GP should think about referring you to a specialist if you have a combination of symptoms such as

- Fatigue
- Weight loss
- Night sweats
- Itching
- Shortness of breath



- Bruising or unexplained bleeding

There are particular symptoms that mean your GP should refer you to a specialist urgently (within 2 weeks). These include the following

- Blood test results that suggest you have chronic leukaemia
- A swollen lymph node that is larger than 2cm across and has been there for more than 6 weeks
- Your GP can feel your liver or spleen is enlarged
- Lymph nodes that are increasing in size

If you have symptoms and do not think your GP is taking them seriously enough, you could print out this page and take it to your GP to discuss.

What to ask your doctor about CLL cancer

- How would I know if I had a type of chronic leukaemia?
- Am I more likely to develop leukaemia than anyone else?
- I have some swollen glands in my neck. How can you be sure that they are an infection and not leukaemia?
- Is there anything I can do to reduce my risk of developing chronic leukaemia?
- Someone in my family has had chronic lymphocytic leukaemia. Does that increase my risk of getting it?

- My family and I live near to an electricity pylon. Does this mean any of us are at risk of developing chronic leukaemia?
- Are there guidelines on when someone should see a specialist if they have symptoms that could be leukaemia?

More information

For more information about chronic lymphocytic leukaemia (CLL), 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 November 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).