

MONITORING CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL)

An information sheet for patients, families and whānau



WHAT IS CLL?

CLL is an overgrowth of white blood cells (a leukaemia). It is the most common type of leukaemia in adults in New Zealand, and it becomes more common as we get older. Most people with CLL are first diagnosed when they are over 60 years old, but it sometimes occurs in younger people. Not all leukaemias are the same. Unlike aggressive (or 'acute') leukaemias, CLL is called a 'chronic' leukaemia as it typically progresses very slowly over many years. This means that there are many New Zealanders living with CLL who do not have symptoms and who do not need treatment.

What causes CLL?

CLL is a cancer of the B-lymphocytes (B-cells). B-cells are a type of white blood cell and are part of the immune system. When we get infections, our B-cells divide quickly and make antibodies to help fight the infection. Once their job is done, normal B-cells reduce in number again. In people with CLL, B-cells develop genetic changes (mutations) that make them divide again and again, even when no infection is present. As a result, abnormal B-cells (CLL cells) gradually build up in the blood, bone marrow and lymph nodes.

The gradual build-up of B-cells often causes no symptoms at all and is only noticed when a person has a blood test for other reasons. However, sometimes the CLL cells stop the bone marrow from working properly and cause anaemia (low levels of red blood cells) or low levels of platelets. Sometimes the CLL cells build up in the lymph glands, causing them to swell.

How is CLL diagnosed?

Most people are diagnosed with CLL after they have a blood test for another reason. Your doctor may suspect CLL when the lymphocyte count is very high. A specialised blood test called flow cytometry can confirm that you have CLL. In most parts of New Zealand, your general practitioner (GP) can arrange this test for you.

If a diagnosis of CLL is confirmed, your GP may:

- Ask you about symptoms, such as drenching night sweats, weight loss, unexplained fevers or infections that keep coming back
- Ask you about other medical conditions, or a family history of other diseases
- Examine you to see if you have an enlarged spleen or lymph glands
- Arrange extra blood tests.

Monitoring by your GP

CLL does not usually need treatment when it is first diagnosed, and for many people it may never need to be treated. People with CLL that is not causing problems (early-stage CLL) are often monitored once per year by their GP. It may feel worrying to be told that you have leukaemia but that you do not need treatment or referral to a specialist right away. In many parts of New Zealand, GPs follow written pathways that have been developed with haematologists (blood specialists) according to international guidelines. These pathways help GPs to monitor CLL and to refer to a specialist at the right time. You may be referred to a specialist if you start having certain symptoms.

Symptoms that might mean your CLL is progressing

Many people never develop symptoms of CLL. For those who do, the symptoms are often mild, or progress very slowly over time. Because CLL often causes no symptoms, blood tests once or twice a year are usually recommended for monitoring CLL.

See your GP if you have any of the below symptoms (which may indicate CLL progression):

- Worsening shortness of breath when you exercise (e.g. when you climb stairs or walk uphill)
- Extreme tiredness (fatigue)
- Unexplained bleeding or bruising
- Unexplained weight loss
- Drenching night sweats (that cause you to have to change your pillowcase or bed clothes)
- Unexplained high temperatures (fevers)
- Lymph gland swelling that gets worse over four weeks or longer, or very large lymph glands (more than 2.5cm).

Many of these symptoms can be caused by other medical conditions, so they do not always mean that you have CLL or that your CLL is progressing.

It can be difficult to remember everything you want to ask and say when you see your doctor, so it may be helpful to take a support person with you. It can also help to write down your symptoms – including when they started, how often you have them and if anything makes them better or worse.

Indications for treatment

For most people, CLL is only treated when it causes significant anaemia (low red blood cell levels), low platelet counts, very large lymph glands, severe night sweats or weight loss. Sometimes the white blood cell count can rise to very high levels, but even very high white blood cell counts do not mean the CLL has to be treated, unless the white blood cell count is rising significantly and very quickly. If your CLL needs treatment, you should be referred to a haematologist for a review. Even if you are referred to a haematologist, you may not need treatment

straight away, and monitoring might be continued for some time. There are several very effective treatments for CLL (including chemotherapy) available and funded in New Zealand.

What can I do for my health?

There is no evidence that you can influence whether or not your CLL progresses. However, there are some things you can do to look after your health.

Skin cancers are common in people with CLL. Remember to wear sunscreen and a hat when outside and see your GP if you notice any unusual marks, moles or freckles on your skin.

People with CLL may be more likely to get sick. If you develop symptoms of an infection, such as a high fever or coughing up green or yellow phlegm, you should see your doctor as you may need antibiotics.

Many people with CLL notice reactions to insect bites. Consult a doctor if you have an insect bite that becomes very sore and tender, especially if you have a fever or redness that spreads around the bite.

You should receive the influenza (flu) vaccine every year. You should also talk to your GP about whether you should get the pneumococcal conjugate vaccine (PCV13, a vaccine against a type of pneumonia). This vaccine is not routinely funded for early-stage CLL in New Zealand but you might be eligible for it for other reasons, or you could choose to pay for it yourself.

We recommend that you have any COVID-19 vaccines offered to you. If you get symptoms of COVID-19, it is important that you get tested as you may be able to have different COVID-19 treatments due to your CLL.

People with CLL are at risk of shingles (varicella zoster). If you develop a rash with lots of small blisters, you should see a doctor urgently as you may need antiviral medicines. The Zostavax® shingles vaccine is not recommended for people with CLL because it contains a live virus and may cause side effects. The Shingrix® shingles vaccine does not contain a live virus and is safe for people



with CLL. Shingrix® is usually given as two doses, two months apart, and at the time of writing it is not funded by PHARMAC (so you will have to pay for it). You can ask a GP for the cost of the Shingrix® vaccination.

Other things you can do to look after your general health include:

- Eat a balanced diet with a variety of foods (see the Eating Well fact sheet on our website for more information).
- Move your body every day.
- Try to sleep at a similar time each night (see the Sleep fact sheet on our website for more information).
- Stop smoking. QuitStrong.nz and Quitline can provide support with this.
- Drink less alcohol.
- Take part in any cancer screening programmes that you are offered (e.g. mammograms, cervical smears, bowel screening).

Questions to ask your GP

- When do I next need a blood test? When do I next need to see you?
- How do I arrange an appointment if I develop new symptoms?
- What should I do if I develop an infection during the night or at the weekend?
- Is there anything I can do to help my general health?
- Will you contact me for the yearly flu vaccine?
- Am I eligible for the pneumococcal (pneumonia) vaccine? If not, how much would it cost me to have this?
- Am I eligible for any extra COVID-19 vaccine doses?
- How much does the Shingrix® vaccine cost?



Important information available online

For more information and to download other fact sheets, see our website www.leukaemia.org.nz

