

Monitoring of chronic lymphocytic leukaemia (CLL)



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 ('acute') leukaemias, CLL is called a 'chronic' leukaemia as it typically progresses very slowly over a long time, 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 malignancy of our 'B lymphocytes'. B lymphocytes are a type of white blood cell, and are part of our immune system. When we get infections, our B lymphocytes divide quickly and make antibodies to help fight the infection. Once their job is done, normal B lymphocytes reduce in number again.

In some people, B lymphocytes develop genetic changes (mutations), which make them divide again and again, even when no infection is present. CLL is the most common condition in which this happens. As a result, in people with CLL, abnormal B lymphocytes gradually build up in the blood, bone marrow and lymph nodes.

The gradual build up of B lymphocytes often causes no symptoms at all, and is noticed when someone has a blood test for other reasons. However, sometimes the CLL cells interfere with normal bone marrow function, and cause anaemia (low levels of red blood cells) or low levels of platelets. Sometimes, the CLL cells build up in the lymph glands, and cause them to enlarge.

How is CLL diagnosed?

Most people are diagnosed with CLL after they have a routine blood test for another reason. CLL is often suspected when the lymphocyte count is very high. A diagnosis of CLL can be confirmed using a specialised blood test called flow cytometry. Across New Zealand, most regions have specific pathways that a general practitioner (GP) can follow, to guide them in arranging this blood test.

If a diagnosis of CLL is confirmed, an initial assessment with your GP may include:

- Asking you about symptoms, such as drenching night sweats, weight loss, unexplained fevers or repeated infections.
- Asking about other medical conditions, or a family history of other diseases.
- A physical examination to see whether you have an enlarged spleen or lymph glands.
- Arranging additional blood tests.

Monitoring by your General Practitioner (GP)

CLL does not usually need treatment when it is first diagnosed, and for many people, it may never need to be treated. Across New Zealand, people with CLL that is not causing problems ('early stage' CLL) are often monitored annually (once per year) by their GP.

It may feel unsettling to be told that you have a type of 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 in conjunction with haematologists (blood specialists). These pathways provide specific guidance to GPs about monitoring of CLL, and when referral to a specialist might be needed.

There are particular symptoms or combinations of symptoms that mean your GP may need to refer you to see a specialist.



Symptoms that might indicate progression of your CLL

Many people never develop symptoms of CLL, and among those that do, the symptoms are often mild, or progress very slowly over time. Because CLL often causes no symptoms, blood tests (e.g. every 6 – 12 months) are usually recommended for monitoring CLL.

Symptoms that could indicate progression of CLL, and for which you should see your doctor, include:

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

It is important to note that 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 or 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

The pathways that GPs follow take account of international guidelines about when to treat CLL.

In practice, for most people CLL is only treated when it causes significant anaemia (low red blood cell levels), low platelet counts, very large lymph glands, or severe night sweats and 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 you develop features that indicate 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.

Haematologists have several very effective treatments for CLL. The treatment of CLL may include chemotherapy and other drugs which will depend on the latest medical evidence and the drugs that are 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, you can take other steps to look after your health.

Skin cancers are common in people with CLL. Remember to wear sunscreen and a hat when outdoors, and see your GP if you develop abnormal skin lesions.

People with CLL may be at increased risk of infection. You should visit your GP to receive the influenza vaccine every year. You should discuss the possibility of receiving 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. If you do develop symptoms of an infection, such as high fevers or coughing up green or yellow phlegm, you should seek medical advice, as you may need antibiotics.

Although people with CLL are at risk of shingles (varicella zoster), the Zostavax shingles vaccine is not recommended for people with CLL, in case it causes side effects. If you do develop a rash with lots of small blisters, you should see a doctor urgently, as you may need antiviral medicines.

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 it.





Because CLL often progresses slowly, and may never need treatment, it is important to look after your general health. Some ways to do so can include:

- Maintaining a balanced diet.
- Taking regular exercise.
- Striving for a normal sleeping pattern.
- Reducing or stopping cigarette smoking.
- Wearing sunscreen and a hat when outdoors.
- Taking part in any routine cancer screening programmes that you are offered (e.g. mammograms, cervical smears, bowel screening).

Questions you may want to ask your GP

- Am I on your list to be recalled for the annual influenza vaccine?
- Am I eligible for the pneumococcal (pneumonia) vaccine, and if not, how much would it cost me to have this?
- 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 do 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?

For more information please contact Support Services on 0800 15 10 15 or supportservices@leukaemia.org.nz

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