

FOLLOW-UP CARE AFTER LYMPHOMA TREATMENT

An information sheet for patients, families and whānau



FINISHING TREATMENT

After you complete treatment for your lymphoma, you may be followed up by your treatment team (a doctor or nurse specialist). Initially, this is to monitor for short-term side effects of treatment, and for early relapse of the lymphoma.

Early follow-up

The purpose of hospital clinic appointments soon after finishing treatment is to:

- Check the progress of your recovery after treatment
- Check for any symptoms or clinical signs of relapse of the lymphoma
- Discuss ways to reduce the risk of infections after treatment, such as vaccination
- Provide a chance for you to raise concerns about your physical and emotional well-being
- Monitor for emerging later side effects of treatment.

These follow-up appointments may include a physical examination and blood tests. The physical examination is usually to check for enlarged lymph glands, spleen or liver (or other features of lymphoma, depending on its type and where it was originally). Early after treatment, blood tests may include a blood count, and depending on the treatment given, measures of kidney or liver function.

Surveillance scans

It is not usual to offer 'surveillance' scans to monitor for a lymphoma coming back. Experts agree that

for most people, the risks of surveillance scans (which include radiation exposure, and unnecessary tests triggered by incidental findings) outweigh the benefits. However, your treatment team may recommend a scan if you have symptoms or findings on examination that raise concerns about possible lymphoma relapse.

WHAT TO EXPECT ONCE YOU HAVE BEEN DISCHARGED FROM SPECIALIST CARE

At some point after treatment, the chance of your lymphoma coming back may become small enough that routine hospital clinic appointments are no longer needed, and you will be discharged from the hospital clinic. When you are discharged from the hospital clinic, you and your GP should receive a copy of a clinic letter which details the type of lymphoma you had, the treatment you received, and any specific recommendations for your ongoing care.

What are the signs and symptoms of lymphoma coming back?

In some cases, lymphoma may come back (relapse) after treatment. The chance of a lymphoma coming back is different for every person, and depends on the type and stage of the lymphoma, the treatment that was used, the response of the lymphoma to treatment, and sometimes on other factors (such as genetic changes inside the lymphoma cells).

Like other people, you may develop new symptoms from time to time, and distinguishing benign

(not cancerous) symptoms from a lymphoma recurrence can be difficult. However, if you have any of the following symptoms, you should seek medical advice.

Possible symptoms of lymphoma:

- Lymph glands that continue to get bigger without another cause (such as an infection)
- Losing weight that is not explained by another cause (such as dieting or exercising more)
- Progressive pain that is not explained by another cause
- Frequent drenching night sweats (e.g. requiring change of pillow cases, sheets or pyjamas more than twice a week)
- Bruising easily, or red or purple pinhead sized spots on your skin (petechiae)
- Excessive bleeding (e.g. frequent nosebleeds, and minor cuts that take a long time to heal)
- Infections that last a long time or keep coming back.

It is important to note that the above symptoms do not necessarily mean your lymphoma is relapsing, as there may be many other reasons for them. If you develop symptoms like these, you should make an appointment with a doctor. This will normally be with your GP, but if you are still under hospital clinic follow-up, you may be able to contact your hospital clinic directly. A doctor can see and examine you, consider other causes of your symptoms, and arrange tests or refer you back to the hospital service if needed.

Side effects of treatment

Late side effects of treatment for lymphoma can occur due to damage to healthy cells from cancer medications and/or radiotherapy. They can appear months, years or even decades after treatment has finished. Being aware of potential late effects can help you monitor your health to detect problems early. Some common late side effects are detailed below but your medical team may provide information on specific side effects to look out for, based on your own treatment history.

Infection risk

The risk of infection is highest during and shortly after lymphoma treatment. However, certain

lymphoma treatments including fludarabine and bendamustine chemotherapies, and certain immunotherapies such as rituximab, obinutuzumab, bispecific T-cell engagers (BiTEs) and CAR T-cells, can increase your risk of infection for years after treatment. It is recommended that you are vaccinated against illnesses (see below for more information on vaccinations), and see a doctor quickly if you develop an infection.

Reduced fertility

Some chemotherapies and radiotherapy to your abdomen (tummy) or pelvis (groin) can affect your ovaries or testicles. This can lead to reduced fertility in both men and women, and to early menopause in women. If you are intending to try for a baby after lymphoma treatment, it is a good idea to discuss this with a healthcare professional as you may need to seek fertility support earlier than if you had not had lymphoma treatment. See our Blood Cancer and Fertility factsheets at www.leukaemia.org.nz

Heart disease

People who have had treatment for lymphoma are more likely to develop heart disease than the general population. Radiotherapy to the chest, and certain types of chemotherapy (including doxorubicin used for CHOP, ABVD, BEACOPP and EPOCH chemotherapy regimens) can cause damage to the heart muscles, valves and blood vessels. This can lead to hardening of the arteries (atherosclerosis), angina, heart attacks, valve problems and arrhythmias (problems with heart rhythm).

Lung problems

Radiotherapy that includes the lungs, or treatment with a chemotherapy drug called bleomycin (used in ABVD and BEACOPP regimens for Hodgkin lymphoma) can cause scarring (fibrosis) of the lungs. Mild damage does not usually cause symptoms, but more severe damage can cause shortness of breath and may affect your ability to exercise like you used to. Avoiding smoking can reduce the risk of these problems. If you have ever received bleomycin and you are due to have an anaesthetic, you should let the anaesthetist know that you have had bleomycin as they may want to avoid giving you very high oxygen concentrations.



Other (secondary) cancers

People who have had treatment for lymphoma have an increased risk of developing other cancers in the future. It is important to know that although you have a higher risk than the general population, this does **not** mean you will develop another cancer. Your risk will be higher as you get older, and if you have other risk factors including smoking, obesity, or a family history of cancer.

There is an increased risk of developing solid tumour cancers (cancers that are not blood cancers) after many chemotherapies, and in any parts of your body that were exposed to radiotherapy. For example, chest radiotherapy can increase your risk of developing breast, lung or oesophagus cancer. Radiotherapy to your abdomen may increase your risk of developing bowel, pancreatic or stomach cancer. Head and neck radiotherapy can increase your risk of developing head and neck cancers, including thyroid cancer. There is also an increased risk of developing skin cancers in the area of radiation treatment. There is an increased risk of developing a blood disorder, (such as myelodysplasia) or a leukaemia, after chemotherapy or radiotherapy.

We recommend you take part in all cancer screening programmes that are available to you. Note that if you have had radiotherapy to an area that includes your breast(s), you may need to have earlier or more frequent breast screening tests than normal—your radiation oncologist can advise on this.

Other problems

Other late side effects can include:

- Dental issues such as tooth decay if you had

radiotherapy near your mouth, teeth or salivary glands

- Eye problems, including cataracts, dry eyes or glaucoma if you had radiotherapy near your eyes, or if you had long-term high-dose steroids
- An underactive thyroid gland (hypothyroidism) if you had radiotherapy near your neck. If this is the case, your radiation specialist may advise yearly blood tests to check your thyroid function.

WHAT CAN I DO FOR MY OWN HEALTH?

- **Skin protection**—cover up, use SPF30+ sunscreen and stay in the shade to reduce your risk of skin cancer.
- **Stop smoking**—this reduces your risk of mouth, throat and lung cancers, and improves your heart health. Quitline (www.quit.org.nz) can help you to quit smoking, and local stop-smoking services may also be available.
- **Eat a healthy, varied diet**—this can improve your heart health, and may reduce your risk of secondary cancers. See the Eating Well fact sheet on our website for more information.
- **Drink less alcohol**—to reduce the risk of head and neck, liver, bowel and breast cancers.
- **Move your body every day**—aim for at least 2½ hours moderate-intensity exercise per week. This reduces the risk of secondary cancers and is beneficial for heart health. Regular exercise has also been shown to have a positive impact on emotional and mental health.
- **See your GP every 2–5 years for a heart health check**—particularly if you have received anthracycline chemotherapies or radiotherapy that includes your heart. You should have heart

health tests to check for high blood pressure, diabetes or significant cholesterol changes. This is because early treatment of these conditions can reduce your chance of developing heart disease later in life.

- **Participate in cancer screening programmes**—free screening programmes are available for breast, bowel and cervical cancers. If you have had radiotherapy to an area of your body that includes your breasts, your radiation oncologist may have made extra recommendations for enhanced breast cancer screening.
- **Get vaccinated**—a yearly influenza (flu) vaccine, and full Covid-19 vaccination are recommended for all patients after lymphoma treatment. Note that people who have had Hodgkin lymphoma, and people whose prior treatment includes fludarabine or bendamustine, or who have recently had a bone marrow transplant, should

avoid 'live' vaccines. Most vaccines are not live, but live vaccines in use in New Zealand include MMR, BCG, Zostavax and yellow fever vaccines. Talk to your GP about your options.

- **Connect with others**—this can help you process your experiences and improve your emotional well-being. It is normal to feel a range of emotions following treatment ending, including relief, uncertainty and worry. Spend time with family and friends and contact your local LBC Support Services Coordinator to discuss the supports available and opportunities for connection.



Important information available online

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

QUESTIONS & NOTES

Record details of your treatment here, along with any tests your medical team recommend.

Treatment	Recommendations

Important contact details

GP: _____

LBC Support Services Coordinator: _____

Call 0800 15 10 15 to connect with our Support Services team.