

What to expect – Hodgkin lymphoma and diffuse large B-cell lymphoma

What to expect during each stage of treatment and beyond



Lymphoma cancer support

For more information about these lymphomas and where to go for support and help call the Leukaemia Foundation on 1800 620 420 or visit www.leukaemia.org.au

Also, qualified cancer nurses at the Cancer Council can answer your questions about the effects of cancer, explain what will

happen during treatment and link you to support groups and other community resources. Call the Cancer Council on **13 11 20**.

If you need an interpreter, call TIS (the Translating and Interpreting Service) on 13 14 50. For support and advice for carers, call the Carers Association on 1800 242 636.

1. Initial investigations and referral

Your general practitioner (GP) will assess your symptoms (for example, a lump or mass), conduct a physical examination and arrange blood tests if needed.

Your GP may decide to wait for four to six weeks to observe any changes in your symptoms.

Your GP should also discuss your needs (including physical, psychological, social and information needs) and recommend sources of reliable information and support.

If lymphoma is suspected, you will be referred to a specialist for further testing. Your GP will provide the specialist with information about your medical history, whether there is a history of cancer in your family, and results of the initial tests.

It can be helpful to bring a family member or friend with you to your appointments.

You may have one or more of these tests::

Ultrasound scan

This uses high-frequency sound waves to make an image of a person's internal body structures.

Biopsy

A small sample of tissue is taken from the area of concern to examine under a microscope.

Computed tomography (CT) scan

Computer technology and x-rays are used to create detailed images of the body.

2. Diagnosis and staging

The specialist will discuss your test results with you and options for further testing. You should have a biopsy if you haven't already. This is to find out whether cancer is present and, if it is, its stage of development and if it has spread.

It can be helpful to contact cancer peer support groups and support groups for carers.

Further tests you may have:

Positron emission tomography (PET) scan

This produces a three-dimensional colour image that may show where cancers are located. A small amount of radioactive material is injected and the whole body is scanned.

3. Treatment

To ensure you receive the best care, your specialist will arrange for a team of health professionals to plan your treatment based on your preferences and needs.

The team will be made up of health professionals who have experience managing and supporting a person with lymphoma. Your specialist will tell you when the team will be discussing your case.

Your team should discuss the different treatment options with you including the likely outcomes, expected timeframes, possible side effects and the risks and benefits. Your doctor may also suggest you consider taking part in a clinical trial. You might want to ask for more time before deciding on your treatment.

Let your team know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment.

There are a number of ways to treat these lymphomas. In some cases, more than one type of treatment could be used to get the best outcome.

Treatment options:

Systemic chemotherapy is the most common treatment.

Radiation therapy (also called radiotherapy) may benefit patients when combined with chemotherapy.

For some people, very high doses of chemotherapy or radiotherapy are needed to effectively treat their lymphoma. As a side effect of these treatments, normal bone marrow and bone marrow stem cells are also destroyed and need to be replaced using an autologous stem cell transplant (also known as bone marrow transplant).

Autologous stem cell transplant is suitable for patients with recurrent lymphomas who are having high-dose chemotherapy. It involves collecting stem cells from your blood stream and storing them until after you have chemotherapy, when they are transplanted back into your bloodstream with the aim of restoring normal blood cell numbers.

3. Treatment cont'd

In some cases an allogeneic stem cell transplant (using a suitably matched stem cell donor) may be considered.

For more information about treatment and treatment side effects ask your doctor or **visit** www.cancer.org.au/about-cancer/treatment

Your doctor should discuss your needs with you during and after treatment (including physical, psychological, social and information needs) and may refer you to another service or health professional for different aspects of your care.

4. After treatment

After treatment is completed, your doctor should provide you with a treatment summary which details the care you received, including:

- diagnostic tests performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- support services provided to you.

You and your GP will should receive a follow-up care plan that tells you about:

- the type of follow-up that is best for you

- care plans for managing any side effects of treatment, should they occur
- how to get specialist medical help quickly if you think the cancer has returned or got worse.

Your doctor should:

- discuss your needs with you and refer you to appropriate health professionals and/or community organisations, if support is required
- provide information on the signs and symptoms to look out for that might mean a return of the cancer
- provide information on prevention and healthy living.

5. If cancer returns

Sometimes lymphomas can come back after treatment. This is why it is important that you have regular check-ups. Usually this will be detected at your routine follow-up appointments or if you notice symptoms are coming back.

6. Living with cancer

Side effects: Some people experience side effects (for example tiredness) that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished. For more information about side effects ask your doctor or **visit** www.cancervic.org.au/about-cancer/survivors/long-term-side-effects

Advance care plan: Your doctor may discuss with you the option of developing an advance care plan. An advance care plan is a formal way of setting out your wishes for future medical care. For more information about advance care planning ask your doctor or **visit** www.advancecareplanning.org.au/

Palliative care: This type of treatment could be used at different stages to help you with pain relief, to reduce symptoms or to or to help improve your quality of life. For more information about palliative care ask your doctor or **visit** www.palliativecare.org.au

7. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service, even if you have private health insurance.

You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have.

If you are experiencing financial difficulties due to your cancer treatment you can contact the social worker at your local hospital.

For more information about cost of treatment ask your doctor or **visit** www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment

For more information about accommodation and travel costs ask your doctor or **visit** www.cancercouncil.com.au/get-support/practical-support-services/

