

# Hodgkin and diffuse large B-cell lymphomas

## Your guide to best cancer care



### About this guide

Being told you have Hodgkin or diffuse large B-cell lymphoma or could have Hodgkin or diffuse large B-cell lymphoma can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

### Information and support

**Cancer Council:** For information and support, call Cancer Council on **13 11 20** to talk to an experienced healthcare professional or visit [www.cancer.org.au](http://www.cancer.org.au).

For more information about Hodgkin lymphoma look for Cancer Council's Understanding Hodgkin Lymphoma booklet and for more information on diffuse large B-cell lymphoma look for Cancer Council's Understanding Non-Hodgkin Lymphoma booklet.

**Leukaemia Foundation:** For information and support, call **1800 620 420** or visit [www.leukaemia.org.au](http://www.leukaemia.org.au).

**Lymphoma Australia:** For information and support, call **1800 953 081** or visit [www.lymphoma.org.au](http://www.lymphoma.org.au).

**Translating and Interpreting Service (TIS):** If you need a translator, call TIS on **13 14 50** or visit [www.tisnational.gov.au](http://www.tisnational.gov.au).

## Initial tests and referral

### Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what is making you unwell. They will ask about any symptoms you might be having. For example, you might have a lump or growth.

Your GP might decide to wait and watch what the lump or growth does. You will visit your GP again **within six weeks**.

### Initial tests you may have

**Blood test.** A sample of your blood is collected to check your general health.

**Ultrasound.** Soundwaves are used to make a picture of the inside of your body.

**X-ray.** An x-ray takes a picture of an area of your body to see if there is anything wrong.

**Computed tomography (CT) scan.** Computers and x-rays are used to make a detailed picture of the body.

**Excision Biopsy.** A small sample of the lump or growth is taken to check under a microscope.

### Referrals

If your GP has concerns, you will be referred to a specialist (haematologist) at a public hospital or in private practice for more tests. Haematologists are doctors who are highly trained in lymphoma and other conditions that affect the blood.



**You can bring a family member or friend with you to your appointments.**



### Timeframes

Your GP should refer you to a haematologist **within 72 hours** if Hodgkin or diffuse large B-cell lymphoma is likely or **within four weeks** if your test results are not too concerning.

If you can't get an appointment within this time, follow up with your GP.



### Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the haematologist I see?
- How much will appointments cost me?

## Diagnosis and staging

The specialist will do more tests to see if you have Hodgkin or diffuse large B-cell lymphoma. This process of working out if you have a medical problem is called making a **diagnosis**.

If you do have Hodgkin or diffuse large B-cell lymphoma, the tests will give the specialist more information about the cancer such as where exactly it is in your body, if it is growing or if it has spread and what stage it is. This is called **staging**. **Staging** helps to work out the best treatment for you.

You might have one test or a mix of tests:

**Excision biopsy.** If you haven't already had one.

**Bone marrow biopsy.** A doctor will put a long, thin needle into your hip bone. A sample of the bone marrow tissue will be taken. This is usually done with a local anaesthetic so you don't feel pain.

**Positron emission tomography—computed tomography (PET-CT) scan.** Computers and x-rays are used to make a detailed picture of the body. A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

**Lumbar puncture or spinal tap.** A doctor will put a needle into your lower back and take out a small amount of fluid. This is usually done with a local anaesthetic so you don't feel pain.



### Timeframes

Results should be available **within two weeks** from when you have the tests.



### Questions you might want to ask

- What is Hodgkin or diffuse large B-cell lymphoma?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

## Treatment

There are several ways to treat Hodgkin or diffuse large B-cell lymphoma. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

**Chemotherapy** uses drugs to kill cancer cells and stop the cancer growing.

**Autologous stem cell transplant (ASTC).** You might need a lot of chemotherapy or radiation therapy to treat your Hodgkin or diffuse large B-cell lymphoma if this is not your first episode of lymphoma. This is called a high dose therapy. The high dose therapy might kill some of your bone marrow and stem cells. This is a known side effect of treatment. You need these cells to make blood. An ASTC is where some of your blood is taken before you have chemotherapy. Cells called stem cells are taken out of this blood. Stem cells are cells that help the body grow new healthy cells. When your chemotherapy is finished, the stem cells that were collected are injected back into your bloodstream through a drip into a vein. You might have an ASTC to get your bone marrow and stem cells to grow back.

**Allogeneic stem cell transplant (allo-SCT).** An allo-SCT is where stem cells are collected from the blood of a suitable donor and put into your bloodstream through a drip into a vein. This is much less common.

**Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. It might be used with chemotherapy or before a stem cell transplant.

**Immunotherapy** is a type of cancer treatment that helps the body's immune system to fight the cancer.

**Targeted therapy** uses drugs to attack specific features of cancer cells and stop the cancer growing.

For more information visit

[www.cancer.org.au/cancer-information/treatment](http://www.cancer.org.au/cancer-information/treatment).

Supportive care (treatment or services that support you through a cancer experience) are also available.



### Timeframes

Treatment should start **within two weeks** of diagnosis and staging or **within 24 hours** of diagnosis in a case where your organs are in immediate danger of failing or where the cancer is spreading fast.



**You can ask your GP for a referral to another specialist for a second opinion.**

### Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au).

### Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.



#### Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



### Decisions around cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit [www.cancer.org.au/support-and-services/practical-and-financial-assistance](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance) and [www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment).

## Recovery

Cancer treatment can cause physical and emotional changes.

### Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other healthcare professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit [www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment](http://www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment).



#### Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

## Living with advanced cancer

### If cancer returns

Sometimes Hodgkin or diffuse large B-cell lymphoma can come back after treatment in the same place or cancer can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how widespread your lymphoma is, how fast-growing it might be and the symptoms you are experiencing.



#### Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

### Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

### Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

### Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit [www.palliativecare.org.au](http://www.palliativecare.org.au).

### Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit [www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment](http://www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment).



#### Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

Published in September 2021.

This resource is based on information from the optimal care pathway for people with Hodgkin and diffuse large B-cell lymphomas (2nd edition), available at [www.cancer.org.au/OCP](http://www.cancer.org.au/OCP).