



What to expect during each stage of treatment and beyond

Hodgkin lymphoma and diffuse large B-cell lymphoma

This information sheet tells you what you can ask for before, during and after your lymphoma treatment. You can ask your team for more information and support.

Working with your team means you can make sure you are getting the treatment, information and support that are right for you.

1. Your doctor visit

Your doctor should do a check up to see if they can find what is making you feel unwell. They will ask you about any symptoms you might be having. For example you might have a lump or growth.

Your doctor should work with you to make sure you have the information and support you need. You can ask your doctor about:

- What is happening in your body and why it could be happening
- What will or might happen
- How you are feeling and how to stay emotionally healthy
- Who you can talk to about getting the support you need
- Where you can get more information and support

Your doctor might decide to wait and watch what the lump or growth does. You will visit your doctor again in four to six weeks.

Your doctor might do tests to check for lymphoma:

Ultrasound

Sound waves are used to make a picture of the inside of your body

Biopsy

A small sample of the lump or growth is taken to check under the microscope.

Computed tomography scan (CT scan)

Computers and x-rays are used to make a detailed picture of the body.

Your doctor might send you to get more tests with a specialist. Your specialist is a doctor that is trained in working with people with lymphoma. Your doctor should give the specialist information on your health in the past, if someone else in your family has had cancer and your test results.

You can bring a family member or friend to your visits. You can ask your doctor for more information and support to make sure you have what you need.

2. Tests

The specialist should do tests to see if you have lymphoma. This is called a diagnosis. If you do have lymphoma, the tests will show how the cancer is growing or if it has spread. This is called staging.

You can ask the specialist:

- What tests you are going to have

- What will happen in the tests
- What the tests will tell you

You might have one test or a mix of tests:

Biopsy

A small sample of the lump or growth is taken to check under the microscope.

You will have a biopsy if you haven't already had one.

2. Tests cont'd

Position emission tomography scan (PET)

A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

You can ask your doctor about finding a cancer peer support group. It can help knowing that there are other people who understand what you are going through.

Your friends and family can talk to a support group for carers.

3. Treatment

Your specialist should work with a team. Your team is made up of people that understand lymphoma.

Your team will review your test results. They should ask you what you want and need. You should work together to make the best plan for your treatment.

You can ask your team:

- What treatment you are having
- Why you are having that treatment
- What will happen in that treatment
- What the treatment will do
- When your treatment will start and how long the treatment will take
- Risks and benefits of the treatment
- How you might feel during the treatment, side effects and what you can do to feel as well as possible
- What you can expect after the treatment

Your team might suggest you take part in a clinical trial. A clinical trial is used to test a new treatment, or to see if a treatment works better than another. You can ask for more time, or a second opinion before you decide on your treatment.

Complementary therapies include things like massage, acupuncture and meditation as well as other medicines you might take at the same time as your treatment. Some therapies might not work well with your treatment. Therefore, it is very important to talk to your team about any complementary therapies you are using, or would like to use.

You might have one treatment or a mix of treatments:

Chemotherapy or drug therapy is where drugs are used to stop the cancer growing.

It is the most common treatment for lymphoma.

Radiation therapy or radiotherapy is where radiation is used to stop the cancer growing.

It might be used with chemotherapy.

Autologous stem cell transplant or bone marrow transplant 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 in to your blood.

You might need a lot of chemotherapy or radiotherapy to treat your lymphoma. This is called a high dose. The high dose might kill some of your bone marrow and stem cells. This is a side effect of treatment. You need these cells to make blood. You might have an autologous stem cell transplant to get your bone marrow and stem cells back or if this is not your first lymphoma.

You could have an allogeneic stem cell transplant. This is where you will be injected with someone else's stem cells after chemotherapy. This is much less common.

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

Your team should talk to you about your needs before, during and after your treatment. You can ask for information and support at any time to make sure you have everything you need.

Your team can connect you with other services and health professionals to make sure you stay physically and emotionally healthy.

4. After your treatment

After your treatment is finished, your team should give you a treatment summary. Your treatment summary has all of the information on the treatment you received:

- Tests you had to diagnose your lymphoma, and the results of these tests
- Treatment you had, and when you had it
- Support services and other treatment plans you received

Your team should work with you to make a plan now that your treatment is finished. You and your doctor should receive a follow-up plan that includes:

- The follow-up that is best for you
- Plans for managing any side effects of treatment

- How to get help quickly if you think your cancer has come back or got worse

Your doctor should work with you and talk about:

- Finding more information and support to keep physically and emotionally well, and get what you need
- Signs and symptoms to look for that might mean the cancer is coming back
- Prevention and healthy living

Sometimes lymphoma can come back after treatment. It is usually found at a follow-up visit, or if you notice any symptoms come back. It is important to have regular check-ups. If you notice anything different go to your doctor. You can ask your doctor for a check-up and for information and support.

5. Living with cancer

Side effects

Some people get side effects during and after their treatment. Side effects are your body responding to the treatment you are having. They are normal, but can make you feel unwell. You might have side effects straight away, not at all, or months after your treatment.

You can talk to your doctor about your side effects or **visit** www.cancervic.org.au/about-cancer/survivors/long-term-side-effects

Advance care plan

Your team might work with you to make an advance care plan. An advance care plan is a way of setting out your wishes and making sure everyone knows what you want in future medical care.

You can talk to your doctor about making an advance care plan together or **visit** www.advancecareplanning.org.au

Palliative care

Palliative care is used at different stages of your treatment to help you feel well. Palliative care can help with pain relief, to reduce your symptoms and to improve your quality of life.

You can talk to your doctor about the type of

palliative care that is best for you or **visit** www.palliativecare.org.au

Cost

There are costs at every stage of your cancer including treatment, accommodation and travel. You might have costs if you are having treatment in a private health service even if you have private health insurance. You can talk to your team and your private health insurer if you have questions about the cost of each treatment you might have. You can also talk to the social worker at your hospital.


You can talk to your doctor about the cost of your treatment or **visit** www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment

You can talk to your doctor about the cost of accommodation and travel or **visit** www.cancercouncil.com.au/get-support/practical-support-services

There are a lot of things to think about when you have lymphoma. There is also a lot of information and support. It is important that you do what is right for you. You can work with your team to make sure you have the best care.

Information and support

Cancer Council

- You can talk to a cancer nurse: **13 11 20**
-  If you need an interpreter: **13 14 50**

Leukaemia Foundation

- Information and support: **1800 620 420**
- www.leukaemia.org.au

Carers Australia

- Information and support for carers:
1800 242 636

For more information visit
www.cancerpathways.org.au



Australian Government
Cancer Australia

