

Oral therapies in Lymphoma and Chronic Lymphocytic Leukemia

Lymphoma Australia
Nurse hotline: 1800 953 081
nurse@lymphoma.org.au

Learning about your lymphoma can be like learning a new language. It takes time and practice. Please keep this document handy so you can refer back to it as often as you need to. **It will become easier to understand the more you read it.**

Introduction

In the past, everyone needed to go to the hospital or a cancer clinic to have treatment for lymphoma or CLL through a drip in their vein (an infusion). Some people still need this, but many patients are able to have their treatment by taking an anti-cancer tablet at home. This is called an "oral therapy". Oral therapies are a different type of medicine than those given as an infusion. Depending on your type of lymphoma or CLL, anti-cancer tablets may be just as, or even more effective than having an infusion. Your doctor can talk to you more about your specific type of lymphoma or CLL.

Some oral therapies for lymphoma or CLL are a type of "immunotherapy". This means, instead of directly killing the cancer, the medicine strengthens your own immune system so it can fight the cancer more strongly. Your immune system is naturally made to fight infection and disease, but sometimes it needs a helping hand. Immunotherapy gives it that helping hand. Other oral therapies

are "targeted therapy". These tablets block signals or enzymes needed for the lymphoma to grow.

Oral therapies are good because you don't need to have an infusion. You don't need to spend much time at hospital, or pay for parking, and take time away from work or the things you love doing. You also won't need needles for your treatment. But they are still strong medicines and you may still get side-effects. The table on the next page has the side effects of the most common oral therapies.

Other things you need to consider and do when taking oral therapy:

- You might make a mistake and not take the right amount of the medicine at the right times. If you don't take the medicine the way your doctor ordered it, you might get serious side-effects, and you may need to go to hospital for treatment of these side-effects. Or the treatment might not work as well as it should.

- Keep track of when you take your medicine. Keeping track of your medicines can be confusing, especially if you also take other medicine. Some people find using a diary, or a special “pill container” helpful to keep track. If you would like a free diary to track your medicines and appointments, call the Lymphoma Nurses on 1800 953 081 or email us at nurse@lymphoma.org.au. Ask for the “Keeping track of my lymphoma and CLL” booklet. You can get a pill container from your local pharmacy and some supermarkets.
- You will have less contact with doctors and nurses at the hospital. Some of you may like this, while others may feel anxious about not having as much contact. Ask your doctor or nurse for the clinic or ward phone number to call when you need. They may not be available at night and on weekends, but can give you an “after hours” number to call.
- Find a local (GP) doctor you are comfortable with, and make regular appointments with them. You can also call the Lymphoma Australia nurse hotline on 1800 953 081, between Monday and Friday from 0800-1600 for advice.
- Call or make an appointment with your doctor or nurse if you become unwell or are concerned about side-effects. Do not wait until your next appointment, call as soon as you can. If

you have a fever of 38 degrees or more or are unwell – Go to your nearest emergency department.

- If you make a mistake with your oral therapies, or are not sure how to take it, contact the doctor who prescribed the medication, or the pharmacist who gave them to you for advice.

The Therapeutics Goods Authority (TGA) is an organisation within the Australian Government that controls what medicines are available in Australia. They look at how effective and safe the medicine is and put rules around who can have them. The Pharmaceutical Benefits Scheme (PBS) controls what medicines are partly funded by the government, and which ones you might need to pay full price for. If they are PBS listed, you will be able to get the medicine at a cheaper price, or may not need to pay for it at all. Your doctor or pharmacist will be able to tell you if your medicine is PBS listed. Some medicines that are not TGA approved or PBS listed can be accessed through clinical trials or compassionate access programs with the company that makes the medicine. If you are on a clinical trial or access program you may not need to pay anything.

Resources and Support

Lymphoma Australia has many ways we can support you. We have factsheets on many topics, including different sub-types of lymphoma and CLL, emotional and sexual wellbeing, living well after

your treatment and many more. We can also provide you with a diary to keep track of your appointments and medications. For more information on how we can help, please visit our website at www.lymphoma.org.au email us at

nurse@lymphoma.org.au or phone us on 1800 953 081. If you are on Facebook join our Facebook page “Lymphoma Down Under” to chat with other people living with lymphoma or CLL and get up-to-date information.

The table below lists some of the current TGA approved oral therapies for lymphoma and CLL:

Medicine name and type	How it works	What types of lymphoma/CLL it is used in	Most common side-effects
Ibrutinib BTK inhibitor	Blocks the signals lymphoma cells need to grow. No signal means lymphoma cannot grow.	Chronic Lymphocytic Leukemia, Small lymphocytic lymphoma and Mantle Cell Lymphoma	Diarrhoea, body aches and pain, respiratory tract infection, bruising, nausea, rash, decreased blood counts.
Acalabrutinib BTK inhibitor	Blocks the signals lymphoma cells need to grow. No signal means lymphoma cannot grow.	Chronic Lymphocytic Leukemia and Small lymphocytic lymphoma	Decreased blood counts, headaches, diarrhoea, fatigue, body aches and pains and bruising.
Idelalisib BTK inhibitor	Blocks the signals lymphoma cells need to grow. No signal means lymphoma cannot grow.	Waldenstrom's Macroglobulinemia and Marginal Zone Lymphoma	Infection, diarrhoea, abdominal pain, bruising, body aches and pains, bleeding, fatigue.
Lenalidomide Immunomodulator	Increases amount of immune cells. Helps your immune system to fight. Also stops blood supply to tumours, starving them to death.	Mantle Cell Lymphoma	Fatigue, diarrhoea, nausea, infection, low blood counts, low appetite, rash.
Panobinostat HDAC inhibitor	Block's enzymes your genes need to tell the lymphoma cells to grow.	Hodgkin Lymphoma and Cutaneous T-cell Lymphoma	Low blood counts, diarrhoea, nausea.

Medicine name and type	How it works	What types of lymphoma/CLL it is used in	Most common side-effects
Venetoclax BCL2 inhibitor	Blocks proteins that keep lymphoma cells alive. Acts as a "kill switch" for lymphoma cells.	Chronic Lymphocytic Leukemia and Small lymphocytic lymphoma	Tumour lysis syndrome, low neutrophils, infection.
Vorinostat HDAC inhibitor	Block's enzymes your genes need to tell the lymphoma cells to grow.	Cutaneous T-cell Lymphoma	Fatigue, diarrhoea, nausea, loss of appetite, low blood counts, infection.
Zanubrutinib BTK inhibitor	Blocks the signals lymphoma cells need to grow. No signal means lymphoma cannot grow.	Mantle Cell Lymphoma Waldenström's Macroglobulinemia	Low blood counts,rash, diarrhoea

Some questions to ask your doctor

- What subtype of Lymphoma do I have?
- Are there any other tests I need to work out the best treatment for me?
- What clinical trials am I eligible for?
- What are the best treatment options for my subtype of lymphoma?
- Are there any better treatments available, even if not TGA approved or PBS listed?

Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this factsheet is accurate and up-to-date. However, this information is intended for educational purposes only and does not substitute for medical advice. If you have any concerns about your health or wellbeing, please contact your treating team.