

Transformed Lymphoma (TL)

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

Lymphoma can be slow growing or fast-growing. Slow growing lymphomas are often called indolent lymphomas. These lymphomas can be identified under a microscope because they are quite small and grow slowly. If you have an indolent lymphoma, you will usually not be cured but you also may not have troubling symptoms. You can live well with an indolent lymphoma for many years without treatment. Whereas if you have a fast growing (aggressive) lymphoma, you may have more troublesome symptoms, but you may have a better chance of being cured because aggressive lymphomas often respond well to treatments. These lymphomas can be identified under a microscope because they are quite large and grow quickly.

Some people with an indolent lymphoma may develop new genetic mutations over the course of their disease. When this happens, the indolent lymphoma can “transform” into an aggressive lymphoma. That means, if you were

originally diagnosed with one subtype of lymphoma, you may later be diagnosed with another subtype. The small slow-growing lymphoma cells become large fast-growing lymphoma cells. Sometimes during this transformation, you may have both the indolent lymphoma cells and the aggressive lymphoma cells.

About 8 out of 10 people with an indolent lymphoma will never transform to an aggressive subtype. The risk of a transformation is highest in the first 10 years after you have been diagnosed with an indolent lymphoma. After 10 years the chances of a transformation are less, though it may still happen in rare cases.

For the 2 out of 10 people that do transform, the most commonly known indolent lymphomas, and the aggressive lymphoma they might transform into are listed below:

Follicular Lymphoma – May transform into a Diffuse Large B-cell Lymphoma or a Double or Triple hit lymphoma

Chronic lymphocytic leukemia/ Small cell lymphoma (CLL/SLL) –

May transform to Diffuse Large B-cell Lymphoma (DLBCL) or, rarely it may transform to Hodgkin lymphoma. When CLL/SLL transforms to DLBCL it is called “Richter syndrome”.

Waldenstrom Macroglobulinemia

– May transform to Diffuse Large B-cell Lymphoma

Marginal zone lymphoma - May transform to Diffuse Large B-cell Lymphoma

Nodular lymphocyte–predominant Hodgkin Lymphoma – May transform to Diffuse Large B-cell Lymphoma

Mantle cell lymphoma – May transform into blastic (or blastoid) mantle cell lymphoma

Mycosis Fungoides – May transform into Sezary syndrome

Fact sheets on all of these lymphoma subtypes can be found at our [website](#) or by calling our hotline on 1800 359 081 or emailing enquiries@lymphoma.org.au

How do I know if my indolent lymphoma has transformed?

If you have an indolent lymphoma and you develop new symptoms, or your symptoms get rapidly worse you should make an appointment with your medical team as soon as possible. Not all new symptoms will be related to your

lymphoma, but it is very important to get them checked to make sure. Some of the common symptoms experienced during a transformation include:

- A rapid increase in the size of your lymph nodes – A new lump often in your armpits, groin, neck or abdomen
- Losing weight without trying
- A high temperature or chills – often with drenching night sweats
- Changes to your blood tests – high calcium or lactate dehydrogenase (LDH)
- Your liver or spleen may become enlarged – Your doctor can often tell this by feeling your abdomen, or it may show up in scans. You may also feel quite full even if you haven't eaten much, or have some pain in your upper abdomen, back or shoulders.

Treatment options – what happens once my indolent lymphoma has transformed to aggressive lymphoma?

There is no “one size fits all” approach to treating transformed lymphoma. Treatment will depend on several things including:

- Your age
- What, if any treatment you have had for your indolent lymphoma
- How well you responded to any previous treatments
- Your general health

However, your treatment choices will be based on the regular treatment given for the aggressive lymphoma you now have. These may include treatments like:

Chemotherapy (chemo) – These medicines might be a tablet or given as a drip (infusion) in a cancer clinic or hospital. Chemo kills fast growing cells, so it can also affect some of your good cells that grow fast

Monoclonal Antibody (MAB) – Given as an infusion in a cancer clinic or hospital. MABs attach to lymphoma cells and attract other disease fighting white blood cells and proteins to the cancer. This helps your own immune system to fight the DLBCL.

Targeted therapy – taken as a tablet either at home or in hospital. Targeted therapies attach to the lymphoma cell and block signals it needs to grow and produce more cells. This stops the cancer from growing and causes the lymphoma cells to die off.

High dose chemotherapy followed by a stem-cell transplant – to learn more about stem cell transplants please see our factsheets

- transplants in lymphoma
- allogeneic stem cell transplants
- autologous stem cell transplants

Chimeric antigen receptor therapy (CAR T-cell therapy) – Please see our factsheet for more information on CAR T-cell therapy

Clinical trial – These may include targeted therapies and other treatments. Ask your doctor if you are eligible for any clinical trials.

Purpose of treatment – What to expect

The purpose of treating aggressive lymphomas is different to the purpose of treating indolent lymphomas. Currently, there is no known cure for indolent lymphomas. So the purpose of treating an indolent lymphoma is to decrease the amount of diseased cells and improve your symptoms. This is why many people with an indolent lymphoma do not have treatment when they are first diagnosed. If there are no troubling symptoms, and the disease is under control, then there is no benefit to having the treatment.

There is also no evidence to suggest that having treatment early for an indolent lymphoma will prevent a later transformation. People who have had early treatment for their indolent lymphoma, still transform as frequently as those who do not have early treatment.

Aggressive lymphomas on the other hand can quickly become life threatening if not treated, so treatment usually begins within a few weeks of diagnosis. Aggressive lymphomas tend to respond better to treatment, and the purpose of treatment is not only to save your life,

but in many cases also to cure you of the aggressive lymphoma.

Further information on different treatment protocols can be viewed at on our [website](#).

Clinical Trials

Clinical trials are important to find new medicines, combinations of medicines, or other treatments to improve results for people with transformed lymphoma in the future. They may also offer you a chance to try a new medicine or treatment, before it would otherwise be available. If you are interested in participating in a clinical trial, ask your doctor what clinical trials you are eligible for. You can also read our ['Understanding Clinical Trials' fact sheet](#) for websites to find a clinical trial;

Follow up

You will still see your doctor for blood tests and scans after your treatment ends. Your doctor will check you for signs and symptoms of the lymphoma coming back, and for side-effects you may have from your treatment.

Resources and support

Lymphoma Australia offers a wide range of resources and support for people living with lymphoma or CLL, and their carers. How to access our resources:

- **Visit** our website www.lymphoma.org.au for more information.

- **Phone** our Lymphoma Care Nurse Hotline on 1800 953 081.
- **Email** our Lymphoma Care Nurses nurse@lymphoma.org.au
- **Booklet:** Understanding Non-Hodgkin Lymphoma (NHL)
- **Downloadable information:** Visit our [website](#), or give us a call if you would like some more information on a variety of topics related to lymphoma
- **Join** our Facebook page [Lymphoma Down Under](#) (make sure you complete all the membership questions when you join).

Cancer Council offers a range of services, including free counselling, to support people affected by cancer, including patients, families and friends. Services may be different depending on where you live. You can contact them at www.cancer.org.au or by phone on 13 11 20.

Medicare Australia: Check with your GP if you are eligible for a Mental Health Treatment Plan (MHTP). This plan is funded by Medicare and can provide you with up to 10 sessions with a registered psychologist. More information can be found [here](#).

WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

Canteen provides support for young people aged 12-25 years who have cancer, or, who

have a parent with cancer. Find out more at their website here www.canteen.org.au.

Health Translations: A collection of health related information collected by the Victorian Government with resources in different languages. You can visit their website at www.healthtranslations.vic.gov.au.

Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this document 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.

