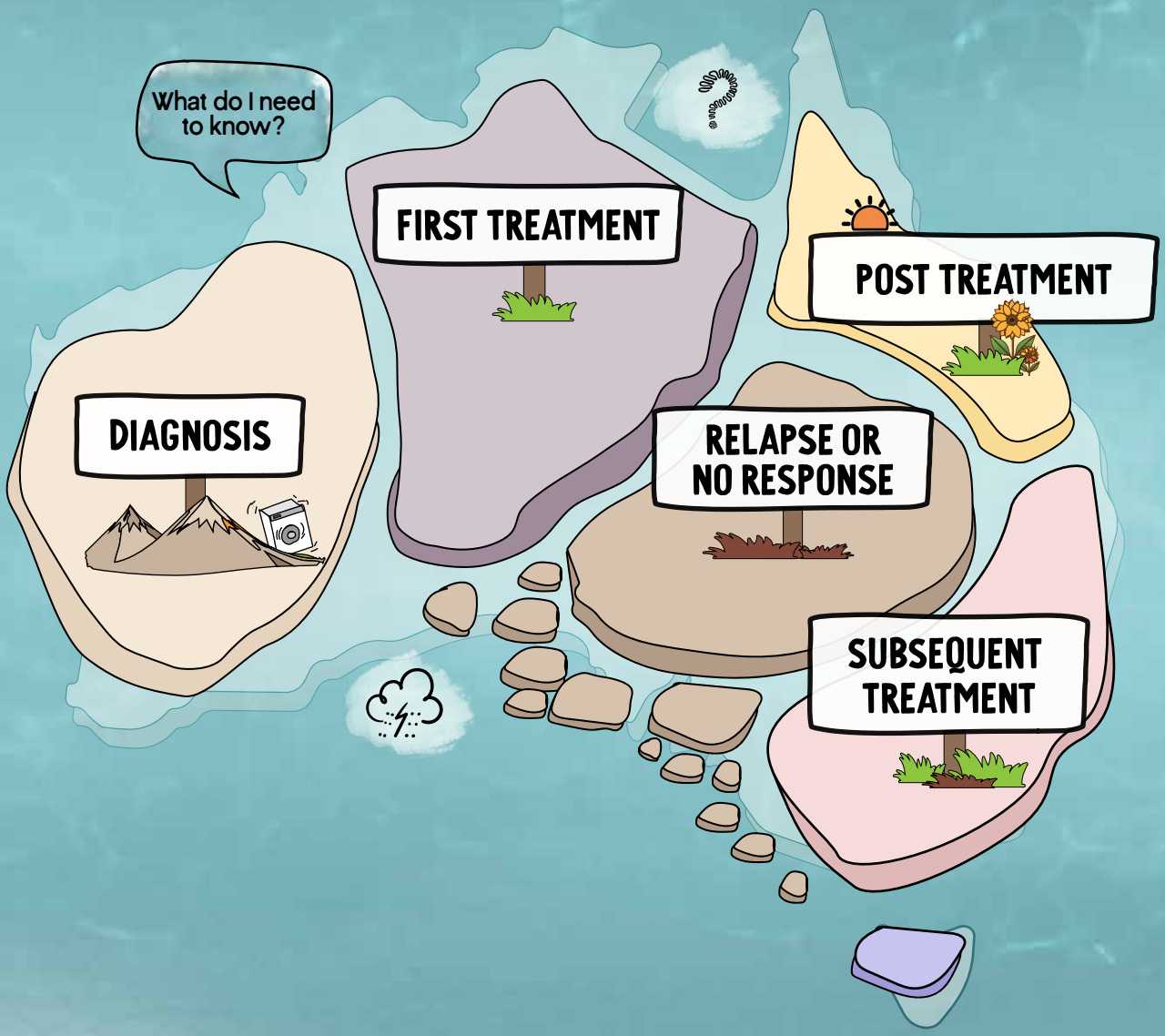
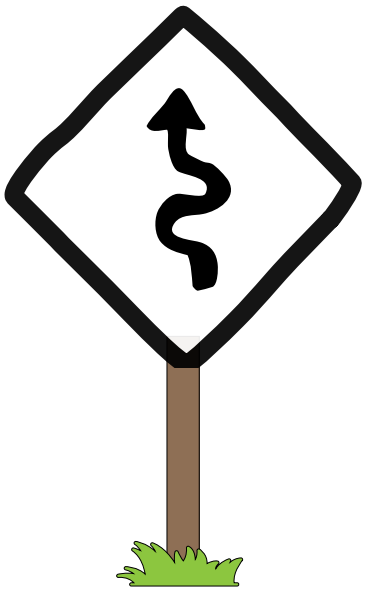
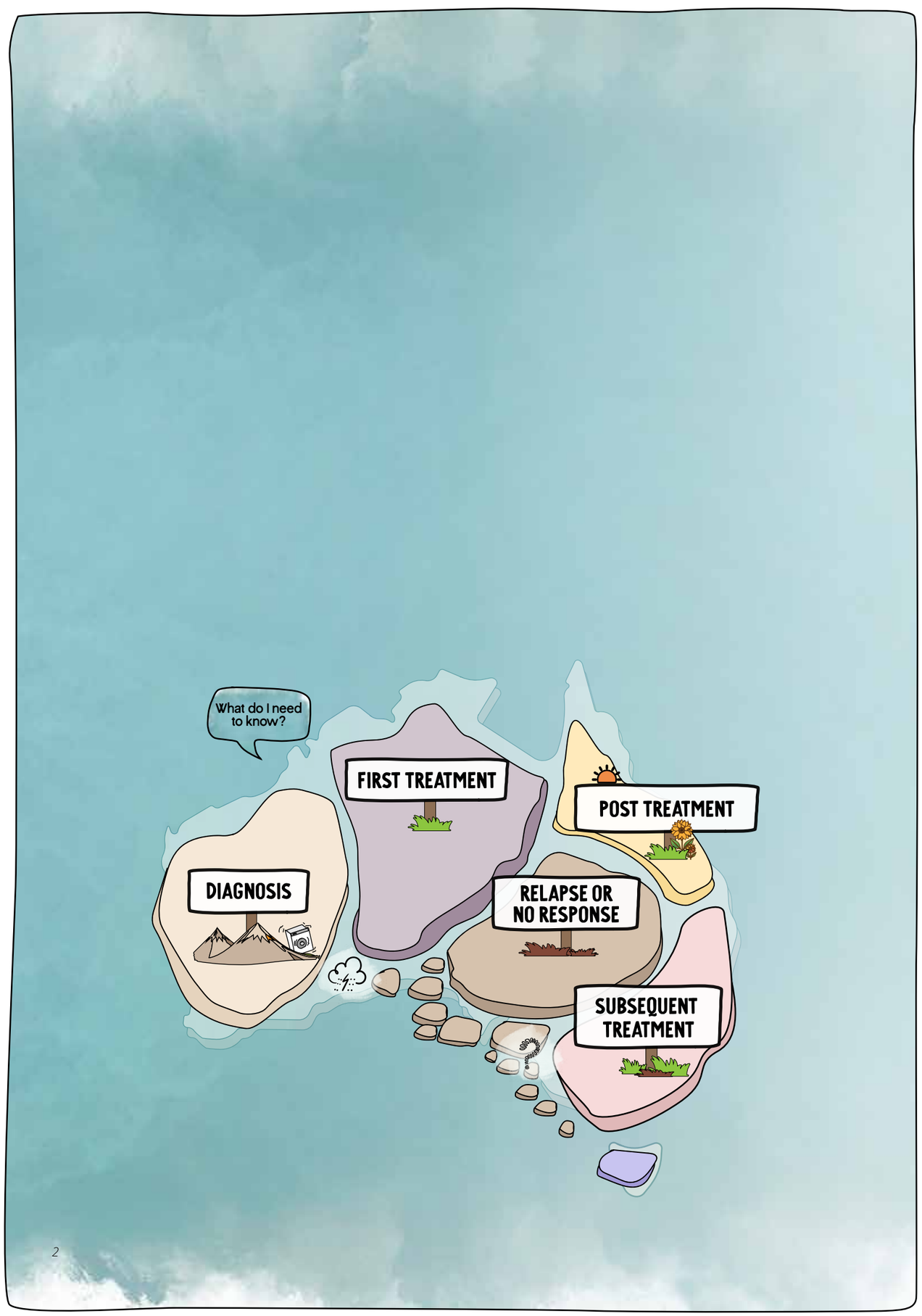


AGGRESSIVE LYMPHOMA ROADMAP





WHO IS THIS DOCUMENT FOR?

This document is for people who have been diagnosed with certain types of lymphoma (blood cancer) known as B-cell non-Hodgkin lymphomas. This includes aggressive types such as diffuse large B-cell lymphoma (DLBCL) and mantle cell lymphoma (MCL).

WHY DO WE NEED A LYMPHOMA ROADMAP?

Where you live in Australia and how far you are from a specialist hospital can influence your experience of care and access to treatment options and support. This should not be the case.

Aggressive lymphomas can grow quickly or cause troublesome symptoms and will require treatment. However, feedback from people with aggressive lymphomas has indicated there may be gaps in the information, support and treatment options offered by care teams.

This Roadmap is here to help.

- It recognises that everyone's experience of lymphoma is slightly different, so it can be hard to know what to expect.
- It recognises people like to receive information in different ways.
- It also recognises how people like to make decisions about their care and be supported also differs.

The Aggressive Lymphoma Roadmap is designed by people with their own experience of aggressive lymphoma, both personal and professional.

It provides their insights and expertise, along with links to resources that may be helpful at various points along the road.

The content provided is for informational and educational purposes only. Always seek the advice of a qualified healthcare provider with any questions you may have regarding your lymphoma and treatment. The appropriate treatment for an individual patient is for the healthcare professional to decide, in consultation with the patient.

Throughout this resource, recommendations on helpful resources and links to additional information and resources have been provided.

The intent of providing this further material is informational and not as advice. Any information provided by these sources should be discussed with your healthcare professional and does not replace their advice.

WHAT YOU NEED TO KNOW ABOUT LYMPHOMAS

NOT ALL LYMPHOMAS ARE THE SAME

Lymphomas are cancers that affect your blood cells.

We don't know what causes lymphoma, but we do know that many lymphomas can be cured.

There are around 80 different types (subtypes), and these are grouped into Hodgkin lymphomas and non-Hodgkin lymphomas.

It's important to know your lymphoma subtype - ask your doctor what your subtype is. This will ensure you can find information that is relevant for you and your type of lymphoma. It is also important when considering treatment approaches.

Ideally, any treatment will start after all your test and biopsy results have come back.

YOU HAVE OPTIONS

There are a range of treatment options available in Australia depending on your lymphoma subtype, stage (how much of your body is affected or how far it has spread from where it started), and any previous treatments you may have had.

There also continues to be advancements in lymphoma diagnosis, treatment and subsidised support.

Talk to your doctor about your chances of cure or long-term remission (decrease or disappearance of signs and symptoms). Some 'incurable' lymphomas can be treated effectively, so you can live well for many years with your lymphoma.

AGGRESSIVE LYMPHOMAS CAN BE FAST-GROWING

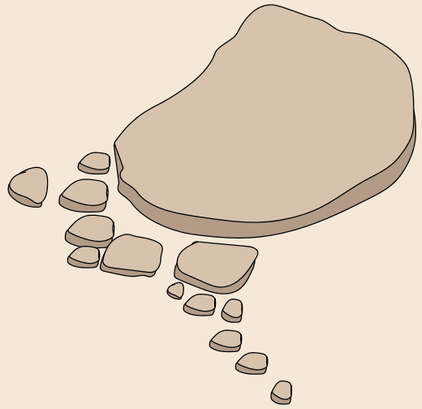
This Roadmap focuses on non-Hodgkin lymphomas and particularly aggressive B-cell lymphomas as they can grow fast, may cause severe symptoms, and usually need to be treated soon after diagnosis.

Understanding your options and what is available is important for making informed decisions with your lymphoma care team. If you have an aggressive lymphoma, you may need to make a decision fairly quickly.

Whilst some diagnosis tools, treatment options and clinical trials may not be available near where you live, this does not mean you cannot access them.

You should ask your doctor to tell you about the treatment options that are available in Australia. They may be available outside your local area or in other states.

Financial and social support options may be available if you need to travel to other hospitals. Talk to your doctor or other member of your care team about what's possible and available, even if it's outside your area.



HELPFUL RESOURCES

Lymphoma Australia: Questions to ask your doctor

Lymphoma Australia: What is Lymphoma?

Leukaemia Foundation: Non-Hodgkin lymphoma: the basics

Rare Cancers Australia: Types of non-Hodgkin lymphomas (aggressive B-cell).

WHAT YOU SHOULD EXPECT FROM YOUR LYMPHOMA CARE TEAM

Your lymphoma care team is more than just your treating specialist. It can include a haematologist, radiologist, lymphoma nurse, dietician, exercise physiologist, occupational therapist, social worker to name a few. This is often called your multidisciplinary team (MDT).

If you haven't had previous experience of cancer care, either personally or via someone close to you, it can be hard to know what to expect.

An expert Steering Committee and Advisory Council of patients and carers have created this helpful summary of what you should expect from your lymphoma care team.

Regardless of where you live, how old you are, or what personal support you have, you should expect:

- Clear, compassionate communication from your care team.
- Information about your type and stage of lymphoma and the treatment and support options available.
- The opportunity to discuss your options, needs and preferences before decisions are made.
- To be asked about your preferences for receiving information.
  - This may be written or visual resources.
  - You may need information in a language other than English.
  - You may want a lot of detail or just the important points.
- To be told about the practical and emotional support options available to you, your family and support people, at your hospital.
- To receive information about other practical and emotional support you may find helpful.

It is important to let your care team know if you feel you are not getting the information and support you need, or the opportunity to discuss your options. If you don't feel comfortable discussing this with your care team directly, the hospital will have a patient representative officer or complaints officer you can contact.

Most importantly, if your lymphoma care team is not offering you any of the above, you should feel comfortable seeking out a second opinion.

You can start with your own GP or search online for 'haematology hospital' to find an alternative hospital that specialises in blood cancer treatment that may offer telehealth. You can also reach out to patient organisations such as Lymphoma Australia, Leukaemia Foundation, Rare Cancers Australia or your local Cancer Council for information and support.

You may wish to join a private lymphoma patient group chat room for doctor recommendations.

HELPFUL RESOURCES

Leukaemia Foundation – Your healthcare rights

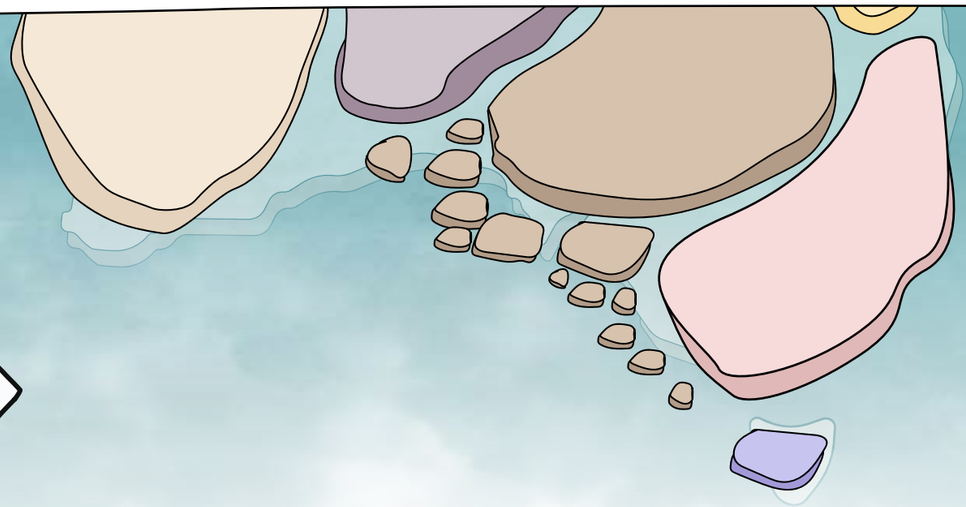
Lymphoma Australia: Types of treatment

Lymphoma Australia: Treatment updates

Leukaemia Foundation's blood cancer A – Z

Lymphoma Australia Support Line:
1800 953 081

Leukaemia Foundation Blood Cancer Support Coordinators:
1800 620 420

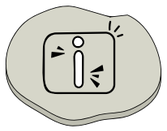


GOOD TO KNOW

YOUR CARE TEAM SHOULD ASK YOU HOW YOU LIKE TO RECEIVE INFORMATION, MAKE DECISIONS AND BE SUPPORTED

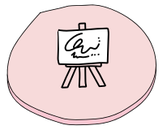
Everyone is different when it comes to how they like to receive information, make decisions and be supported.

YOU MAY LIKE FACTS AND STATISTICS .



OR, YOU MAY FEEL OVERWHELMED BY STATISTICS AND JUST WANT TO KNOW WHAT IS BEING RECOMMENDED FOR YOU AND WHY.

SOME PEOPLE TAKE IN INFORMATION BETTER WHEN THEY WRITE THINGS DOWN.



OTHERS PREFER VISUALS AND PICTURES.

If you know there are certain things that help you understand health information and make decisions, you should feel comfortable letting your care team know.

If you don't know what you might find helpful, that's OK. The important thing to remember is that it is OK to ask for more information, to ask for something to be explained more simply, or to ask for less information, if you are feeling overwhelmed.

YOU MAY LIKE TO TALK TO OTHERS

If you know you are someone who likes to talk to others with a similar experience, you can ask your doctor or lymphoma care team if your hospital has a support group.

Lymphoma Australia can connect you with a range of support groups, online forums, Facebooks groups and other resources. You might like to try the Lymphoma Down Under | Facebook group.

Having someone who can come with you to appointments, where possible, can also be helpful. They can help capture information for you and ask questions.

Remember, your information preferences and needs can change over time and at various points in your care. If you are not getting the information or support your need, it is important to let your care team know.

"When I was diagnosed I got a 90-page document. And I said to my mum, I'm not reading this. I'm going to go with the flow. Because the less I know, the less I freak out."

THINGS THAT HELP FROM PEOPLE WHO'VE BEEN THERE

- A care team that you know will answer all your questions and provide guidance. Specialist nurses (lymphoma, CAR T and transplant nurses) can be a great support and resource for you.
- Speaking with others with the same experiences. Try Lymphoma Down Under | Facebook to start.
- Clear written or printed information about your type of lymphoma and available treatment options and support that you can take home with you.
- Support from family, friends or advocates - whether that is attending appointments, helping with transport, household duties, childcare or moral support.
- Trusted online resources that offer information in a range of formats including visuals or diagrams, videos and personal stories.

NOT ALL WEBSITES HAVE INFORMATION THAT IS SUITABLE FOR AUSTRALIA

Information from overseas organisations may not be relevant for Australia as our healthcare system is different and the treatment options available may also differ.

It is recommended that you access information from reputable, trusted organisations based in Australia like Lymphoma Australia, Leukaemia Foundation, Rare Cancers Australia or your local Cancer Council.

"The Facebook groups were actually really helpful. I found people who'd been through the exact same treatment and could tell me what to expect."

AGGRESSIVE LYMPHOMA ROADMAP

KEEP YOUR HEAD WHERE YOUR FEET ARE

DIAGNOSIS

What type of lymphoma?
How do you like to receive information?

Information overload

What do I need to know?

Lots of different thoughts

A second opinion is OK

What should I expect?

FIRST TREATMENT

Advice from your doctor and care team

What about practical & financial needs?

Uncertainty is common

This can be harder than the original diagnosis

POST TREATMENT

Time to take a well-earned break.

Hopeful for the future

Be clear about what relapse or non-response means for you

RELAPSE OR NO RESPONSE

Your lymphoma has come back (relapsed) or not responded to treatment (refractory).

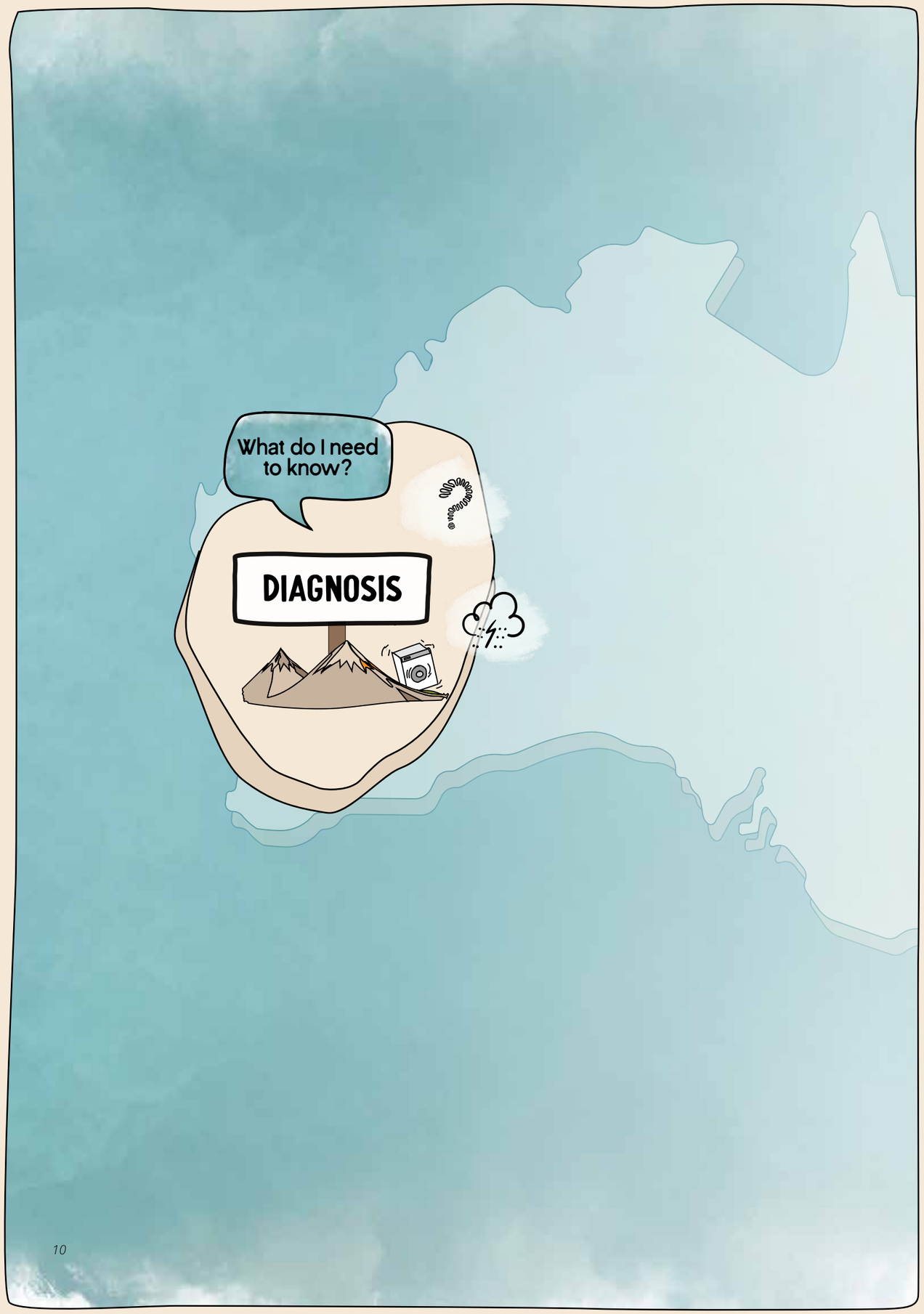
New treatment facility

Different treatment can add emotional and logistical challenges.

SUBSEQUENT TREATMENT

What should I do now...

Ask about all available treatment options



DIAGNOSIS

WHAT TO EXPECT

When you are first diagnosed with lymphoma you can expect to feel a range of emotions. Feeling uncertain is normal. It can be hard to process a cancer diagnosis.

Make sure you give yourself time to reflect and write down questions that come up. Some people like to use a pen a paper; others like to use the notes app on their phone. It can also be helpful for a family member or friend to capture questions for you and to write down any of their own questions as well.

Information overload is common, particularly at diagnosis. It's OK to tell your doctor or other members of your lymphoma care team if you are experiencing information overload. They can give you information to read or look at later and arrange a time to follow-up and answer your questions.

THINGS TO THINK ABOUT

DO YOU KNOW WHAT TYPE OF LYMPHOMA YOU HAVE?

Ask your doctor to tell you your lymphoma subtype.

HOW DO YOU LIKE TO RECEIVE INFORMATION, MAKE DECISIONS, BE SUPPORTED?

- If you are someone who wants all the information, statistics and options laid out, you may want to read a booklet on non-Hodgkin Lymphoma.
- If you prefer to be told critical information only e.g. "Just 'tell me when to panic otherwise I don't want to know," you may wish to share this preference with your lymphoma care team.
- If you find it hard to know which websites or other online information you can trust, ask your lymphoma nurse or other member of your lymphoma care team for sources they recommend.
- Do you want to hear the experiences of others? Check out Lymphoma Australia's story page.
- Do you want to connect with others? Visit Lymphoma Australia to find your preferred way to connect or look at Leukaemia Foundation, Rare Cancers Australia or your local Cancer Council.

DO YOU LIVE IN A RURAL, REGIONAL OR REMOTE AREA?

Make sure you read this information from Lymphoma Australia.

GOOD TO KNOW

IT'S OK TO ASK QUESTIONS OF YOUR DOCTOR AND CARE TEAM

You can and should be involved in decisions about your care. Write down any questions you have and bring them to your next appointment.

IT'S OK TO RECORD YOUR APPOINTMENTS ON A MOBILE PHONE

Just let your doctor know first. Having someone who can come with you to appointments, where possible, can also be helpful. They can help you record information and keep track of responses to your questions.

IT'S OK TO SEEK A SECOND OPINION

You can start with your own GP or search online for 'haematology hospital' to find an alternative hospital that specialises in blood cancer treatment that may offer telehealth.

You can also reach out to patient organisations such as Lymphoma Australia, Leukaemia Foundation, Rare Cancers Australia, or your local Cancer Council for information and support.

You may wish to join a private lymphoma patient group chat room for doctor recommendations.

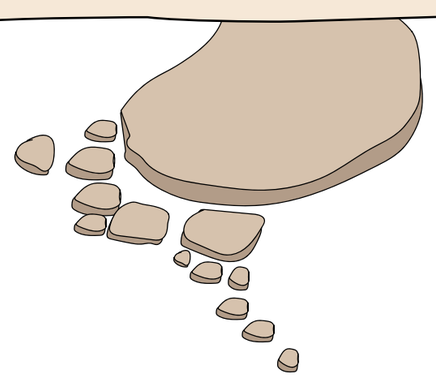
SUPPORT AND RESOURCES ARE AVAILABLE TO YOU BEYOND YOUR HOSPITAL TEAM

You should be told about Lymphoma Australia and their:

- Lymphoma Care Nurses – 1800 953 081, email nurse@lymphoma.org.au
- Support groups, online forums, Facebooks groups and other resources.

There's also support available via Leukaemia Foundation, Rare Cancers Australia or your local Cancer Council.

These organisations can also help you find support to manage hospital costs and other financial matters, if you have to take time off work. They also offer other resources that can help you as you travel along this road.



"If you're looking for information, go directly to your care team and ask. What you're receiving on the internet may not reflect what's happening to you."

CONNECTING WITH PEOPLE IN A SIMILAR SITUATION CAN BE HELPFUL

Try Lymphoma Down Under | Facebook or look at Lymphoma Australia's information on support groups to get started.

IT IS IMPORTANT TO LOOK AFTER YOURSELF

Looking after yourself before, during and after treatment is incredibly important. This includes your physical and mental health and the many things that influence them, including sleep, exercise, nutrition, relationships and practical matters.

Lymphoma Australia has a range of resources to help you live well with lymphoma, as does Leukaemia Foundation.

Your hospital may have information materials on how to look after yourself before, during and after treatment. They may also run education events focused on living well with cancer. These could be held at the hospital or online.

HELPFUL RESOURCES

IF YOU LIKE LOTS OF DETAIL:

What is Lymphoma? - Lymphoma Australia
Cancer Council's Understanding Non—Hodgkin Lymphoma Guide
Leukaemia Foundation's booklet on non-Hodgkin Lymphoma

IF YOU KNOW YOUR EXACT TYPE (SUBTYPE) OF LYMPHOMA VISIT:

Leukaemia Foundation's blood cancer A – Z
Lymphoma Australia's Lymphoma-types page

LOOKING FOR PRACTICAL INFORMATION ABOUT EVERYDAY LIFE OR NAVIGATING THE HEALTH SYSTEM?

Check out: Living with lymphoma, the practical stuff - Lymphoma Australia

LIVE AWAY FROM A BIG CITY OR TREATING HOSPITAL?

See Regional, Rural & Remote information - Lymphoma Australia

BEFORE YOU START YOUR FIRST TREATMENT

WHAT TO EXPECT

The decision regarding your first treatment will depend on your exact type of lymphoma (subtype), where it has spread in your body and how fast it is likely to grow.

Some types of lymphoma grow slowly, cause few symptoms and may not need to be treated urgently. Others grow more quickly, cause more severe symptoms and generally need to be treated soon after they are diagnosed.

For B-cell non-Hodgkin lymphomas including aggressive types such as diffuse large B-cell lymphoma (DLBCL) and mantle cell lymphoma (MCL), you might have one treatment or a combination of treatments.

These could include chemotherapy, autologous stem cell transplant, allogeneic stem cell transplant, radiation therapy, immunotherapy and targeted therapy.

Not all treatments are available for all subtypes of lymphoma. The appropriate treatment for you is for your doctor to decide, in consultation with you.

Your doctor and lymphoma care team should involve you in discussions about your treatment options and care.

Your doctor and lymphoma care team should prepare you for your first treatment by:

- Telling you the types of tests you need to do.
- Giving you information about the treatments you may need, how you will receive them, the time you will spend in or out of hospital and the number of visits you can expect to make to hospital.
- Giving you information on what to expect physically and emotionally.
- Telling you where you can access support at the hospital and beyond including Lymphoma Australia, Leukaemia Foundation and Rare Cancers Australia.

GOOD TO KNOW

IT IS OK TO ASK QUESTIONS

For example:

- How many people with this type of disease do you see and treat?
- Why are you recommending this treatment for me?
- Are there other options?
- Are there other options that could be available and personally funded at a private hospital as opposed to a public hospital?

IT CAN BE HELPFUL TO KNOW WHEN YOUR TEAM WILL DO SOME TESTS TO SEE IF YOUR TREATMENT IS WORKING

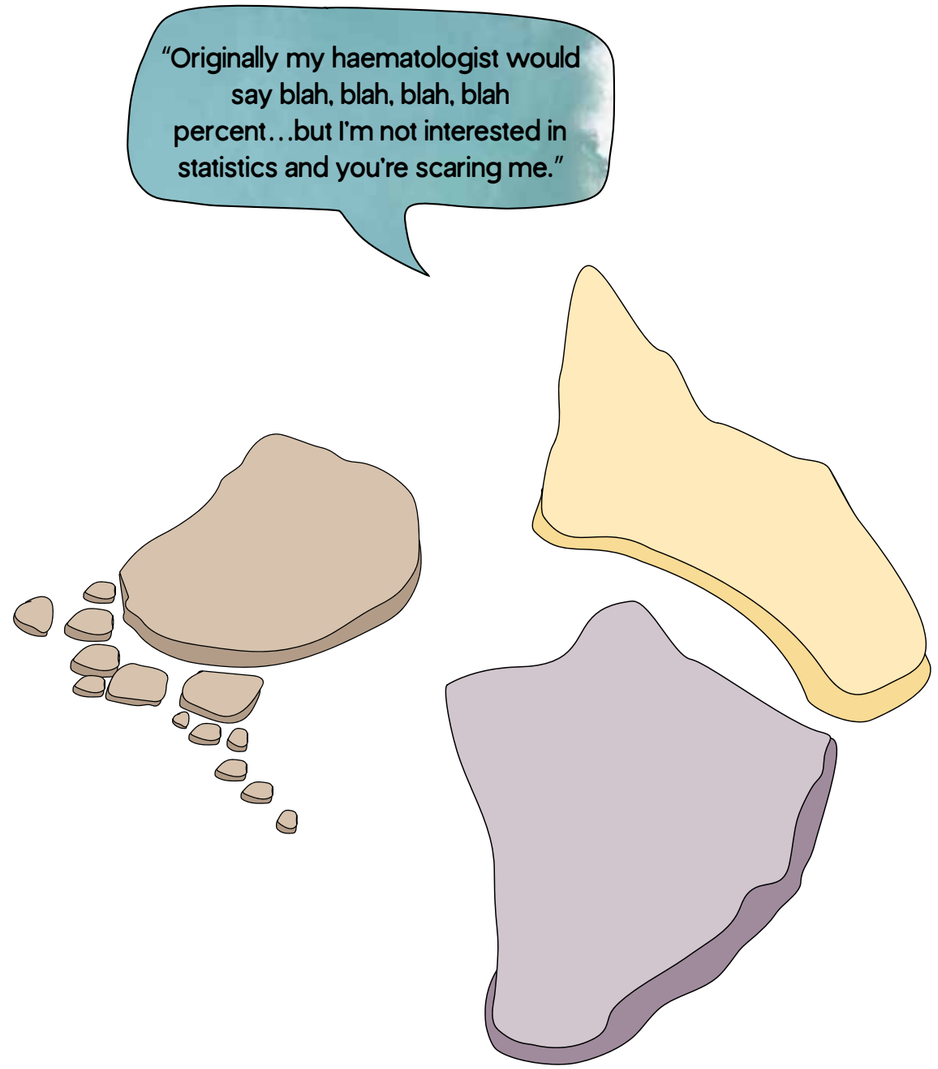
If you are someone who likes to plan for the road ahead, you may wish to ask your care team about what will happen if the tests show the treatment is not working and what your options are if that happens. Some treatments can only be used in a very specific time window or can only be used after other treatments. Working with your care team to know your options means you may be able to act quickly if you do need to move to another treatment.

GOING THROUGH TREATMENT CAN CREATE EMOTIONAL TURMOIL

It can be helpful to know the period before your first treatment can bring up a lot of emotions. Some might even surprise you.

Remember be kind to yourself. It can help to be curious about what you are feeling and experiencing. Some people want to share what they are feeling with family or close friends. Others prefer to talk to a professional or connect with someone going through a similar experience. It's important to know you are not alone, and there is support available.

If you would like more information or links to useful resources, visit Lymphoma Australia's Mental Health and Emotions page to start.



HELPFUL RESOURCES

Lymphoma Australia's Questions to ask your doctor
Leukaemia Foundation's Questions to ask your doctor

RELAPSE OR NO RESPONSE TO TREATMENT (REFRACTORY)

WHAT TO EXPECT

If your lymphoma has come back (relapsed) or not responded to treatment (refractory), you should expect your care team to:

- Be clear about what relapse or non-response means for you and what needs to be considered next.
- Use language that you can understand.
- Provide you with information in the way that works best for you.
  - This may include written and/or visual resources.
  - If you need information in a language other than English, you can ask for an interpreter.
  - It's OK to ask your lymphoma care team for more detail or less detail.
  - It's also OK to ask for time to process information before you make any decisions.
- Provide you with the opportunity to discuss your needs and preferences and provide your informed consent for treatment, before any treatment commences.
- Wait for you to seek a second opinion on the recommended treatment approach if you wish.
- Give you information on what to expect physically and emotionally during the next phase of treatment. This may include:
  - The potential side effects of treatments and practical guidance on how to manage these side effects and maintain daily routines.
  - Referral to support organisations like Lymphoma Australia, Leukaemia Foundation and Rare Cancers Australia for information, support and connection with other people with lymphoma.
  - Ensure you know where to access support at the hospital and beyond.

GOOD TO KNOW

YOU HAVE OPTIONS REGARDLESS OF WHERE YOU LIVE

Your lymphoma care team should talk to you about all available treatment options in Australia and why they are recommending a particular treatment approach for you. There may be treatment options available outside your local area. They may be available in other states.

Any treatments you have after lymphoma has come back or doesn't respond to the first treatment (second-line therapies) will depend on your type of lymphoma and may include chemotherapy, radiotherapy, stem cell transplant, CAR T, targeted therapy, bispecific immunotherapy, oral therapy and clinical trials.

Not all treatments are available for all subtypes of lymphoma. The appropriate treatment for you is for your doctor to decide, in consultation with you.

- For more information about the various treatment options for lymphoma you can visit Lymphoma Australia: Types of treatment and Lymphoma Australia: Treatment updates.
- You can access the consumer medicine information for any treatment you might be given via the Therapeutic Goods Administration website.
- For general information on potential side effects see Lymphoma Australia's page.

Financial and social support options may be available if you need to travel to other hospitals. Talk to your doctor or other member of your lymphoma care team.

YOUR CARE TEAM SHOULD TALK TO YOU ABOUT THE VARIOUS SUPPORTS AVAILABLE

Some treatment options may mean you need to be away from home for an extended period of time and/or change care teams.

If you do not live near your treating hospital, there may be options to have at least some of your medical appointments conducted by telehealth or via Hospital in the Home outreach programs.

There are also a range of financial, travel and accommodation support options available should you need them.

Talk to your doctor or other member of your lymphoma care team.

You can also speak to organisations like Lymphoma Australia, Leukaemia Foundation and Rare Cancers Australia.

"I found a quote that says keep your head where your feet are, which really helped me because it's easy to project into the future of what ifs and what could potentially happen. Whereas if you just stay where your feet are, it can help with the stress and the shock of everything."

COMMUNICATION CHALLENGES CAN OCCUR WHEN TRANSITIONING BETWEEN HOSPITALS OR DOCTORS FOR DIFFERENT THERAPIES, PROCEDURES OR CLINICAL TRIALS

If you need to change hospitals or doctors, there are some things that can make this transition easier for you and your care. These include:

- Knowing who the contact person is in your new care team and how to reach them.
- Ensuring your current medical and treatment information is shared with your new care team.
- Having access to your own medical and treatment information, so you can make informed decisions.

IT'S OK TO ASK QUESTIONS, ASK FOR SUPPORT TO MAKE DECISIONS OR SEEK A SECOND OPINION

It is important that you feel informed and supported by your lymphoma care team to make decisions about your care.

If you are not getting the information and support you need, or the opportunity to discuss your treatment and support options, you should feel comfortable seeking out a second opinion.

You can start with your own GP or search online for 'haematology hospital' to find an alternative hospital that specialises in blood cancer treatment that may offer telehealth.

You can also reach out to patient organisations such as Lymphoma Australia, Leukaemia Foundation, Rare Cancers Australia, or your local Cancer Council for information and support.

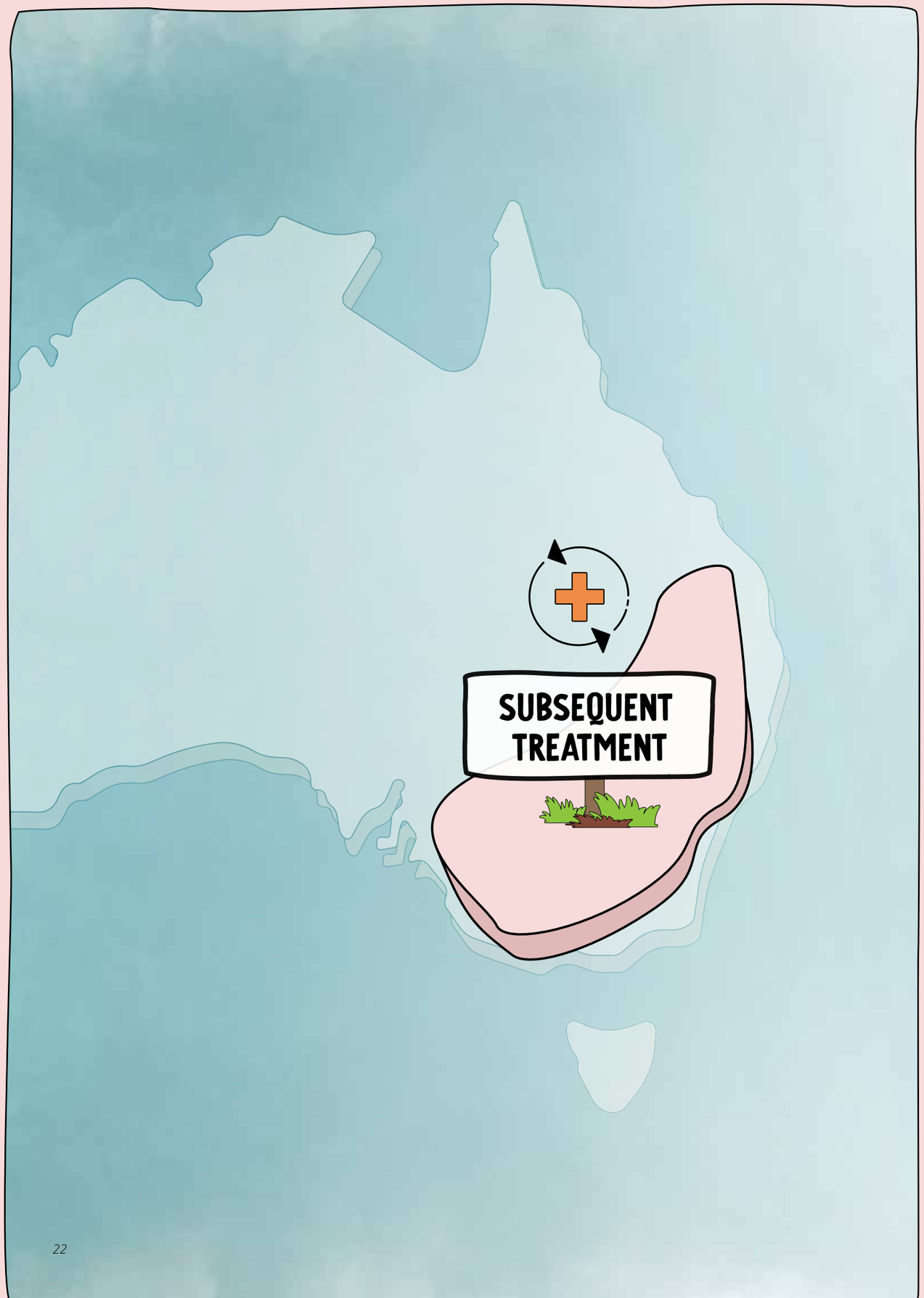
You may wish to join a private lymphoma patient group chat room for doctor recommendations.

HELPFUL RESOURCES

Lymphoma Australia's Questions to ask your doctor
Leukaemia Foundation's Questions to ask your doctor
Lymphoma Australia: Relapsed and refractory lymphoma
Leukaemia Foundation: Blood cancer treatment options

Lymphoma Australia Support Line:
1800 953 081

Leukaemia Foundation Blood Cancer Support Coordinators:
1800 620 420



SUBSEQUENT TREATMENT

WHAT TO EXPECT

If you need to have subsequent treatment, you should be given information on what to expect physically and emotionally during the next phase of treatment.

You should expect your lymphoma care team to:

- Be clear about what needs to be considered next.
- Use language that you can understand.
- Provide you with information in the way that works best for you.
  - This may include written and/or visual resources.
  - If you need information in a language other than English, you can ask for an interpreter.
  - It's OK to ask your lymphoma care team for more detail or less detail.
  - It's also OK to ask for time to process information before you make any decisions.
- Talk to you about all available treatment options in Australia and why they are recommending a particular treatment approach for you.
  - Options will depend on your type of lymphoma and previous treatments.
  - They may include chemotherapy, radiotherapy, autologous stem cell transplant, allogenic stem cell transplant, CAR T, targeted therapy, bispecific immunotherapy, oral therapy and clinical trials.
- Talk to you about the potential side effects of treatments.
  - You can access the consumer medicine information for any treatment you might be given via the Therapeutic Goods Administration website.
  - For general information on potential side effects see Side effects of treatment - Lymphoma Australia.

GOOD TO KNOW

IF YOU ARE CHANGING HOSPITALS OR CARE TEAMS, MAKE SURE YOU HAVE CONTACT DETAILS FOR YOUR NEW DOCTOR OR CARE TEAM LEAD

If you are transitioning hospitals or doctors to access a different therapy, clinical trial or procedure, you will need to know who you should contact at your new hospital. Ideally you should have the contact details for your new doctor or care team lead.

If this is not possible, ask to be given a copy of the medical and treatment information that is being given to your new doctor or care team.

THERE ARE SOME PRACTICAL CONSIDERATIONS IF YOU NEED TO BE AWAY FROM HOME AND/OR NEED TO CHANGE CARE TEAMS

Some treatment options may mean you need to be away from home for a period and/or change care teams.

This may mean there are some practical things to consider such as transport, accommodation and the people who can be with you and support you during this time.

There are a range of financial, travel and accommodation support options available should you need them.

Talk to your doctor or other member of your lymphoma care team first. You can also speak to organisations like Lymphoma Australia, Leukaemia Foundation and Rare Cancers Australia.

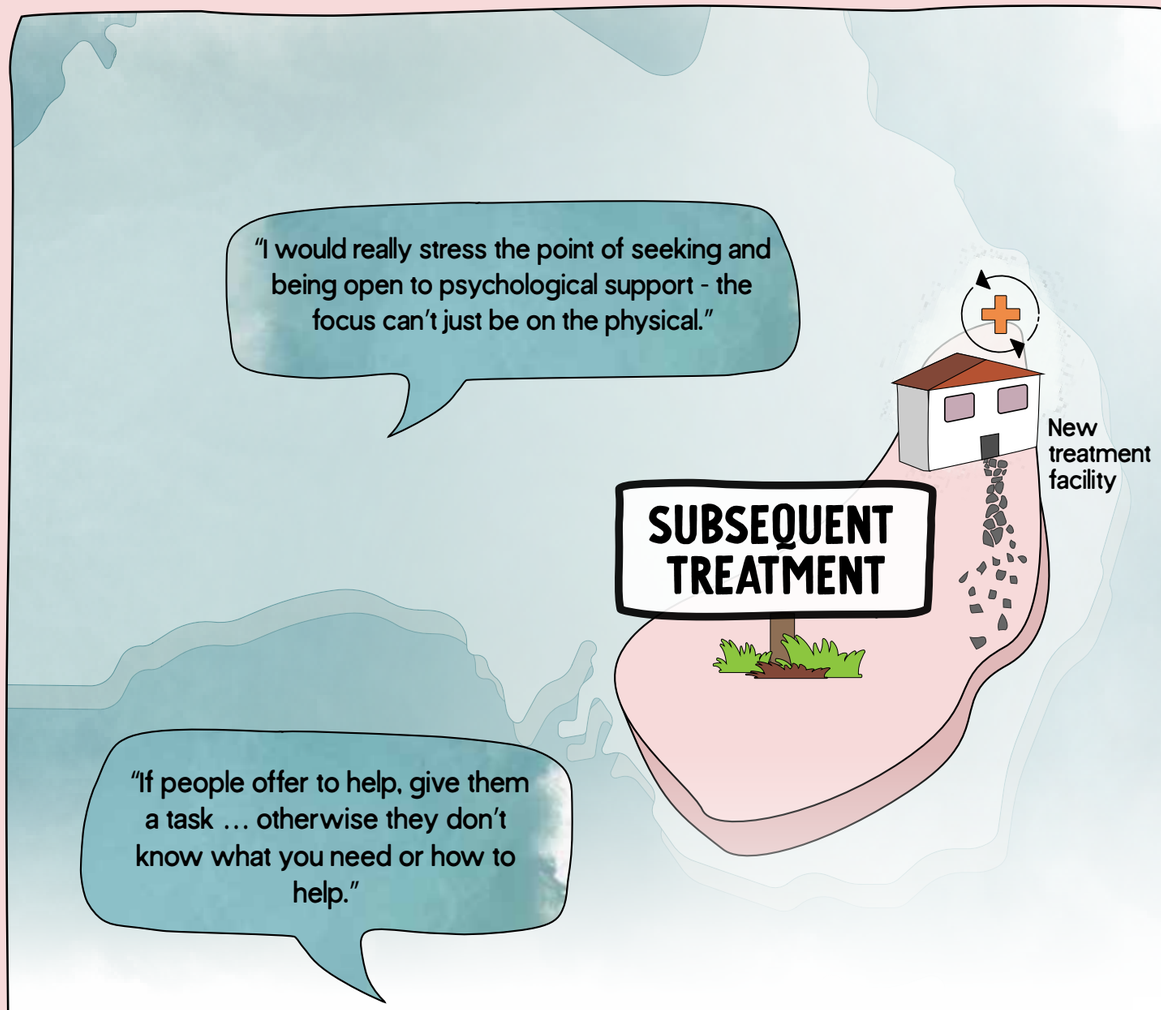
SUPPORT IS IMPORTANT FOR YOU AND YOUR FAMILY

If you have family or other support people in your life, it is important that they continue to be part of discussions regarding your treatment and ongoing care, so they understand your preferences, and what you will need.

It is also important to know there are other supports available to you, your family and other people who may be supporting you during this time.

If you haven't already, you can reach out to patient organisations such as Lymphoma Australia, Leukaemia Foundation, or Rare Cancers Australia. They can connect you with information, support or others with similar experiences to you.

They also offer support for family members and friends supporting someone with lymphoma.



HELPFUL RESOURCES

Lymphoma Australia: Relapsed and refractory lymphoma
Leukaemia Foundation: Blood cancer treatment options

POST TREATMENT

WHAT TO EXPECT

Finishing treatment for aggressive lymphoma is a major milestone.
It is normal to feel relief, pride and uncertainty all at once.

Recovery is phase of its own, and your care shouldn't stop once you stop treatment.

- You should expect regular follow-up with your specialist and check-ins with your GP to track your progress, manage any lingering effects and catch early signs if your lymphoma returns.
- You may also start thinking about parts of life you haven't been able to think about for a while.
- If fertility, sexual health or family planning is on your mind, ask for a referral to the right support.
- Returning to work or study or life in general is a gradual process. Pace yourself, ask for adjustments and try to rebuild your fitness slowly with gentle and regular activity.
- Anxiety around scans and appointments is real. Be kind to yourself and look to things that may help ease the worry. Many people find counselling, peer support, mindfulness, gentle exercise or planning something enjoyable to do just after an appointment can help.

MIXED EMOTIONS

Relief, uncertainty or worry about relapse can ebb and flow. This is part of finding your "new normal" after treatment.

CONTINUING CARE

You will see your specialist frequently at first (often monthly), then appointments usually space out to every 3-6 months, and later annually.

SIDE EFFECTS

Lingering side effects such as fatigue, changes in concentration or memory, altered taste or appetite, pain, weakness, numbness or tingling, and changes to periods or fertility can persist for a while. If you are experiencing any of these, tell your care team.

GOOD TO KNOW

There is support available post treatment. Ask your care team what is available and closest to you. Post treatment support centres (sometimes called survivorship or wellness centres) may offer complementary therapies, exercise and lifestyle classes and emotional support such as peer support, counselling or life coaching services for people who have finished treatment.

SOME OTHER THINGS THAT ARE WORTH CONSIDERING:

A POST TREATMENT PLAN

This is a written plan that outlines your follow up schedule, tests you may need (and how often), late effects to watch for and who best to contact in between appointments. Ask your care team if you don't have one.

KEEPING RECORDS

Keep copies of your treatment summary, scans, reports and blood results in case you need them in the future. It's also a good idea to share these with your GP if they do not have copies.

YOUR GP

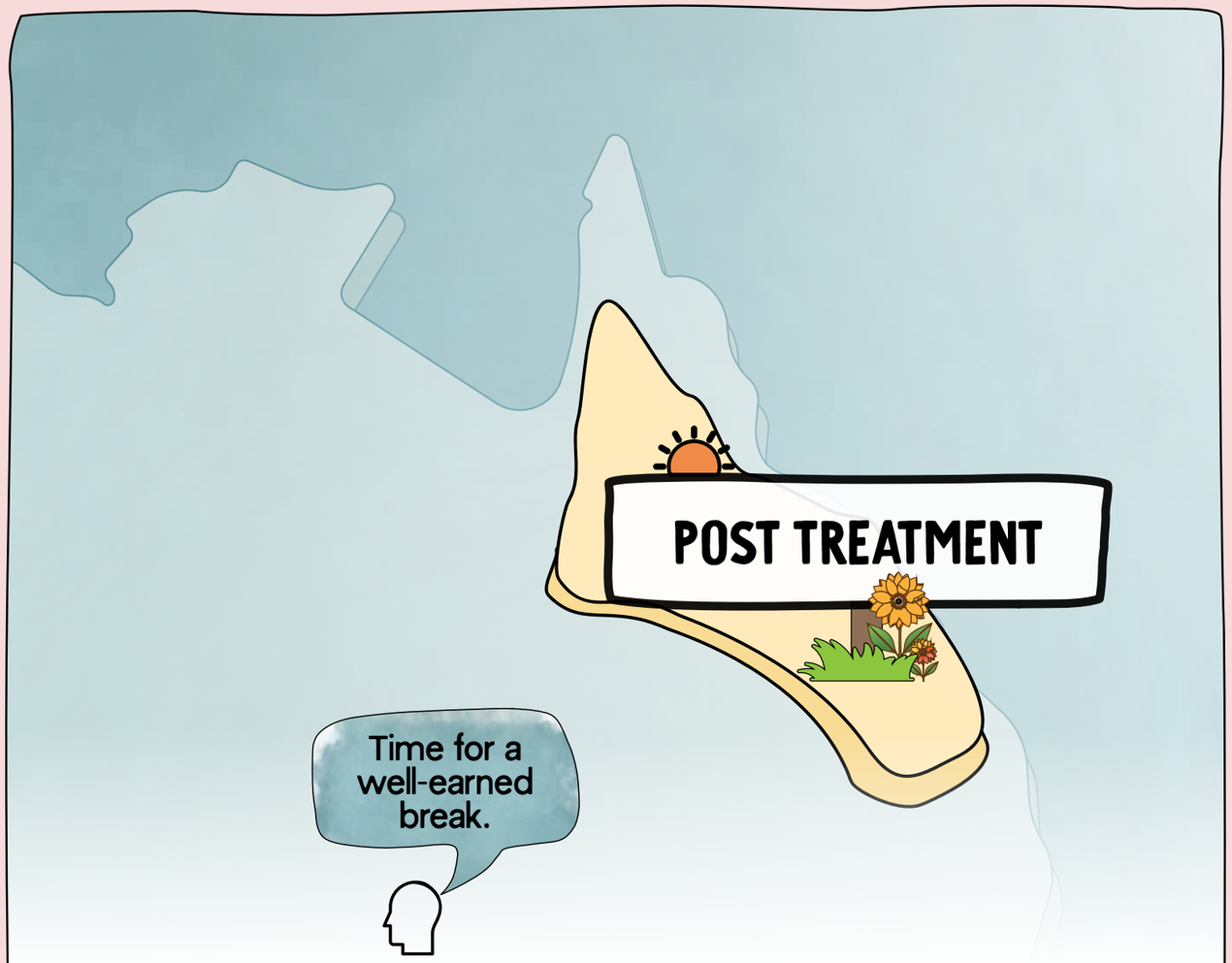
Keep regular contact with your GP. They can offer support and advice on a more regular basis and monitor your overall health.

KNOW WHEN TO CALL YOUR CARE TEAM

If you notice any new or enlarging lumps, have persistent fevers or night sweats, unexpected weight loss, unusual bruising or bleeding, shortness of breath or chest pain or severe or worsening fatigue, you should contact your care team straight away.

WHERE TO FIND SUPPORT

Support is still available to you, but it may come from different people. It could be your GP, a life coach or you can reach out to patient organisations such as Lymphoma Australia, Leukaemia Foundation, or Rare Cancers Australia.



HELPFUL RESOURCES

Lymphoma Australia: Finishing Treatment
Leukaemia Foundation: Going Home After Blood Cancer Treatment

DEFINITIONS

AGGRESSIVE LYMPHOMAS:
Types of lymphoma that are fast-growing.

CURE:
No more signs or symptoms of the disease. The lymphoma does not come back.

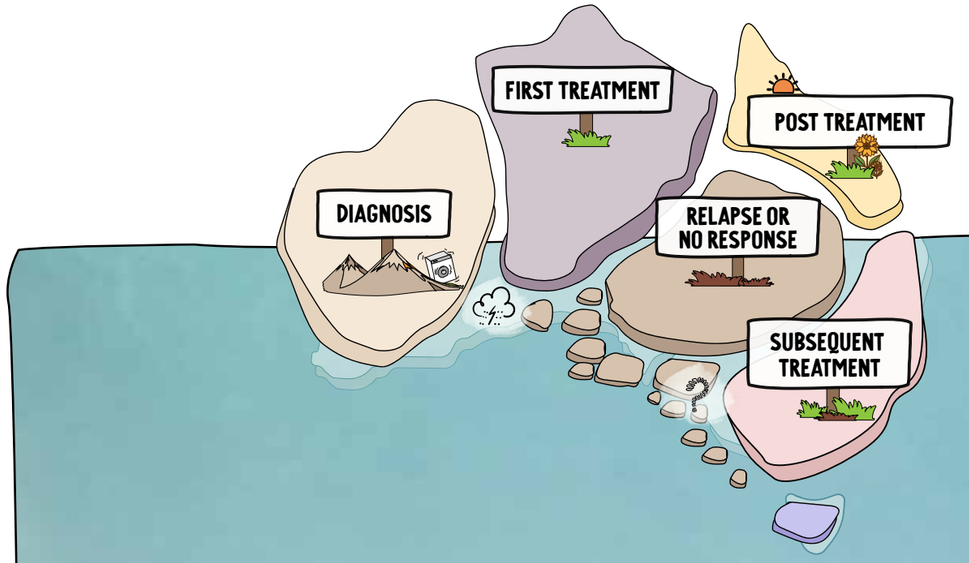
LYMPHOMA STAGE:
How much of the body is affected or how far the lymphoma has spread from where it started.

RELAPSE:
Signs or symptoms of lymphoma have come back.

REFRACTORY:
Lymphoma that does not respond or get better with the treatment given.

REMISSION:
Decrease or disappearance of signs and symptoms.

FOR MORE DEFINITIONS VISIT:
Lymphoma Australia: Aggressive B-cell non-Hodgkin Lymphoma.



ABOUT THE ROADMAP

The Aggressive Lymphoma Roadmap was built on the lived experience of Australians, personal and professional. This includes an Advisory Council of patients and carers who shared their experiences of diagnosis and treatment, what they have found helpful along the way and things they wished they knew.

The content was informed and reviewed by an expert Steering Committee of haematologists, lymphoma nurses and patient advocates to ensure the guidance and information represents best practice, evidence-based care.

The intention of the Aggressive Lymphoma Roadmap is to offer clear, supportive information at key timepoints.

It recognises that although everyone's road will be different, knowing what to look out for along the way can be helpful.

The Aggressive Lymphoma Roadmap should:

- Help you understand what to expect at each stage of your lymphoma journey.
- Be something that can be revisited over time, as your situation changes or questions arise.
- Recognise that everyone has different experiences and preferences for information and support and these may change over time.
- Acknowledge the physical and psychological impacts of lymphoma before, during and after treatment.
- Support you to have the conversations you want and need to have.
- Ensure you feel you are being presented with all available treatment and support options and can be actively involved in decisions about your care.

THANK YOU

Thank you to the Aggressive Lymphoma Roadmap Patient Advisory Council for generously sharing your experiences, insights and guidance. Without you this Roadmap would not exist.

Thank you also to our Clinical Steering Committee for your expertise and whole-hearted commitment to promoting greater equity in access to best-practice, patient-centred care.

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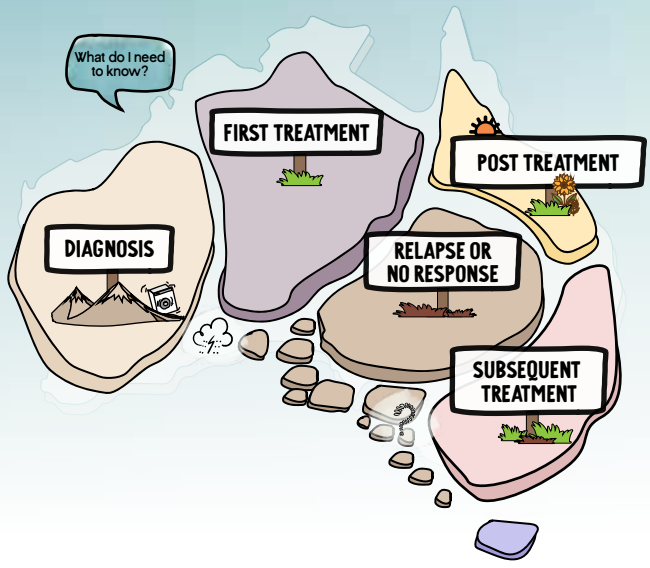

The Aggressive Lymphoma Roadmap has been funded and project managed by Gilead Sciences Pty Ltd with content co-created in partnership with the Clinical Steering Committee and Patient Advisory Council.

The Aggressive Lymphoma Roadmap content was co-created with Lymphoma Australia through their participation on the Clinical Steering Committee and Patient Advisory Council.