Questions to ask your Doctor: Regional, Rural and Remote Patients

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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.**

Navigating a lymphoma or CLL diagnosis while living in a regional, rural, or remote area presents unique challenges. Yet, knowing what questions you should ask can be difficult, especially when everything is new and you don't know, what you don't know.

Below, we've put together a list of essential questions to ask your doctor at each stage of your lymphoma journey, to ensure you receive the best possible care.

Before Diagnosis (If You Have Symptoms or Concerns)

1. Given my location, what's the fastest way to get tested for my symptoms?
2. Can I have tests done locally, or do I need to travel?
3. Can I travel to and from my appointments on the same day as my tests?
4. I live hours away. Can my tests be booked at a time that allows me time to travel safely.
5. What is the best way to coordinate my different biopsies and tests to avoid unnecessary travel?
6. How long will it take to get results, and who will explain them to me?
7. If I need a specialist, where is the closest one, and how do I get a referral?
8. Are there options for telehealth consultations instead of in-person visits?
9. If I need urgent tests or scans, can they be prioritised?
10. What financial assistance is available for travel and accommodation if I need to go elsewhere?

Just Diagnosed

1. What is my subtype of lymphoma, and are there any genetic factors that may impact my treatment options?
2. What exactly does my diagnosis mean, and what stage is my condition?
3. What are my treatment options, and where can I access them?
4. Is there a cancer care coordinator or rural health navigator to help me?
5. Can my local GP or hospital be involved in my treatment to reduce travel?
6. How will you keep all members involved in my care informed of my healthcare needs? (E.g. Communication between locums, GP, local health centre, treating team, local pharmacy).

7. Will I need to relocate temporarily for treatment? If so, for how long?
8. What support services (financial, psychological, social) are available to me?
9. What supportive services are available for my spouse, partner or children?
10. Can you connect me with a social worker to help me navigate these things?
11. How urgent is my treatment? Can I wait a little to organise logistics?
12. Is there a clinical trial that I might be eligible for?
13. Is the clinical trial available near my home or will I need to travel?
14. Is it safe for me to drink and bathe in rainwater from my rainwater tank?
15. Can I still.....
    - care for my animals?
    - work or go to school?
    - drive long distances?
    - care for young children even when they are unwell?
16. How can I ensure my wishes for future care are documented?

Starting Treatment

1. Can I have any of my treatments (e.g., chemotherapy, immunotherapy) closer to home?
2. How will my treatment be coordinated between specialists and my local healthcare providers?
3. If I have to travel, how often and for how long?
4. Are there accommodation or travel assistance programs available?
5. Will I need additional scans or tests, and can they be done locally?
6. How will my treatment affect my ability to work and care for my family or animals?
7. I have a septic tank at home, will my treatment affect this?
8. Can I drink and bathe in rainwater from my rainwater tank during treatment?
9. What is the safest way to dispose of contaminated waste while I'm having treatment?

Managing Side Effects and Getting Urgent Care in Regional, Rural, and Remote Areas

1. What side effects should I expect, and how can I manage them at home?
2. Which side effects will need urgent medical attention?
3. Where is the nearest hospital or medical facility that can handle cancer-related emergencies?
4. Can my local GP or nurse help with symptom management, or do I need to contact my specialist?
5. What medications can I keep on hand to manage side effects (pain, nausea, fever, etc.)?
6. If I experience severe side effects, who should I contact first—my GP, a specialist nurse, or the hospital?
7. Are there community nurses, palliative care teams, or other home-based support services available in my area?
8. What should I do if I can't travel for urgent care, and there are no ambulance services available to me? Are there emergency transport or telehealth options?
9. Is there an after-hours cancer support line I can call for advice?
10. Can the Royal Flying Doctor Service help in any of these situations?

On Watch and Wait (Monitoring Without Immediate Treatment)

1. What signs and symptoms should I watch for that indicate my condition is getting worse?
2. How often do I need check-ups, and can they be done locally?
3. Can my GP handle some of my monitoring to reduce travel?
4. What lifestyle changes can I make to stay as healthy as possible?
5. If my condition progresses, what is the next step in my care?
6. Who should I contact if I experience new or worsening symptoms?

Finishing Treatment

1. What follow-up care do I need, and how often?
2. Can I do my follow-up tests and appointments locally?
3. What are the chances of my lymphoma/CLL coming back (Relapsing), and how will we monitor for it?
4. What long-term side effects should I be aware of?
5. Are there rehabilitation or survivorship programs available in my area?
6. What lifestyle changes can help reduce my risk of recurrence?
7. Who do I contact if I have concerns between follow-up visits?
8. Are there mental health support services for cancer survivors?

Risk of Relapse or Refractory Disease

1. What are the early signs of relapse, and how can I monitor for them?
2. If my cancer returns, what are my treatment options?
3. Will I need to travel for further treatment, or are there local options?
4. Are there experimental treatments or clinical trials I should consider?
5. If treatment is no longer effective, what are my options for palliative care?
6. How can I access pain and symptom management services in my area?
7. What support is available for my family and caregivers?
8. How can I ensure my wishes for future care are documented?

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 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 at www.canteen.org.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.

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