Waldenström’s macroglobulinaemia

Your guide to best cancer care

About this guide

Being told you have or could have Waldenström’s macroglobulinaemia (WM) can be overwhelming. A lot can happen quickly, and you might have many questions. This resource can help to guide you, your family, and friends through this experience.

Information and support

For more information about WM, visit the Leukaemia Foundation website **www.leukaemia.org.au/blood-cancer/waldenstroms-macroglobulinaemia/**.

Cancer Council: for information and support, call **13 11 20** to talk to an experienced healthcare professional or visit **www.cancer.org.au**.

Leukaemia Foundation: To speak with an experienced healthcare professional who can provide you with disease-specific information, answer your questions, talk through your concerns, and connect you to blood cancer support groups, call **1800 620 420** or visit **www.leukaemia.org.au**. The team can also help with practical concerns such as accommodation close to treatment, transport to appointments, and financial assistance. The Leukaemia Foundation also have a WM Network Facebook support group where people can share their experiences, information, and research news **www.facebook.com/groups/WaldenstromsLF/**.

Lymphoma Australia: Lymphoma Australia nurses can help patients and their families understand their diagnosis and treatment options, navigate the lymphoma journey, and connect patients with others and appropriate support networks. Call **1800 953 081** or visit **www.lymphoma.org.au** for education, support, and awareness for lymphoma and WM.

WMozzies: is an Australian community support group providing information and support for people living with WM and their caregivers. This is their website **www.wmozzies.com.au**.They are a national affiliate of the International Waldenström’s Macroglobulinaemia Foundation based out of USA; more information can be found on the website **www.iwmf.com**.The associated connect group, **iwmfconnect@groups.io**, provides the opportunity to connect with other WM patients mainly in USA. WMozzies lead a global patient-derived database which you can join and publishes the collective lived experience of hundreds of patients with WM.

More information is available in the ‘Resources’ section of the optimal care pathway for Waldenström’s macroglobulinaemia. **www.cancer.org.au/OCP**.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit **www.tisnational.gov.au**.

Initial tests and referrals

Symptoms

Your general practitioner (GP) or other primary care physician will do a check-up to see if they can find out what is making you unwell. They will ask you about any symptoms you might be having such as fatigue (most common), cramps, night sweats, fevers, unexplained weight loss, headaches, shortness of breath, nose bleeds, numbness or weakness, or blurred vision. Almost half of all patients diagnosed with WM do not have any symptoms and diagnosis is made when a blood test comes back with abnormal results.

Australian Government
Cancer Australia

Leukaemia Foundation

Initial tests you may have

Physical exam. Your doctor will check to see the cause of symptoms such as those noted above and will pay particular attention to your skin including your lymph nodes.

Blood tests. A sample of your blood is collected and sent to a laboratory for full blood examination. This will determine whether you have a low level of red blood cells (called anaemia) and whether your white blood cells have started to produce a high amount of an antibody called Immunoglobulin M (IgM).

Imaging such as CT or X-rays may be completed.

Referrals

If your GP thinks you may have WM, they'll refer you to a haematologist or medical oncologist (specialist) at a public hospital or in private practice for more tests. Haematologists are highly trained in conditions that affect blood and bone marrow. Oncologists are highly trained in the diagnosis and treatment of cancers.

It can help to have a family member, carer, or friend attend appointments with you for support.

You can let your doctor know what is most important to you in a specialist (e.g., that they specialise in WM, cost, location, bedside manner, expertise).

Timeframes

The timing of your specialist appointment will depend on your initial results of tests performed by your doctor. For a small number of patients, an urgent appointment or hospital admission may be required, but for most people there is not an urgent need for a specialist appointment straight away, your doctor will discuss appropriate timeframes with you.

Ask your GP to recommend trusted sources of information and support — you can share these with your family and friends too.

Talk to your GP/specialist about how to manage any other health conditions you may have during your blood cancer treatment and let them know if you have any concerns.

Questions you might want to ask your doctor

- Are there any symptoms and signs that I should watch out for while I am waiting for my appointment to see a specialist?
- Can I choose the specialist I see?
- What emotional and mental health support services are available and how do I access them?
- Can I choose whether I go to a public or private hospital?
- What are the differences of being treated in the public versus private system?
- Is WM curable?

It's a good idea to bring a list of questions for your GP or specialist as we often forget some of the questions we have.

It's a good idea to keep a written diary or digital record of treatment details and appointments with your GP and specialists. You can ask permission to record your appointments on your phone/device. It's also helpful to ask for a written treatment plan.

Don't ignore new signs and symptoms. Alert your GP or specialist. Trust yourself. It's OKAY to be persistent.

Travel to access tests, treatment, and care

You may have to travel to see a specialist, undergo tests or access treatment, especially if you live in a rural or regional area. In some cases, you may have to leave home for an extended period of time. Accommodation and transportation support services are available, and it is encouraged to have family support with you whilst you undergo treatment. You can ask about what patient travel subsidy schemes are available to you.

Mental health and emotional wellbeing

A blood cancer diagnosis can affect your mental and emotional wellbeing. Patient support organisations, your GP, or another health professional such as a psychologist or social worker, can help you develop strategies to cope. They can help you access a mental health treatment plan if required. There may be local cancer support groups where other people with cancer support each other in a safe setting. Cancer Council can assist with finding out if there is a group near you and you can contact them by phoning **13 11 20**.

Diagnosis, staging and treatment planning

The haematologist/specialist will do more tests to see if you have WM, to check how advanced it is, and to help determine the best treatment for you.

You may have one or a combination of these tests:

- **Blood tests** to see whether blood results are within normal parameters, in particular checking for red blood cell levels and the level of IgM protein in the blood.
- **Bone marrow or lymph node biopsy.** For a bone marrow biopsy, a doctor will put a needle into your hip bone. A sample of the bone marrow tissue will be sent to a laboratory for examination. This is usually done with a local anaesthetic, and inhalational pain relief or mild sedation. For a lymph node biopsy, a doctor will put a thin needle into your lymph node to remove a small sample of cells which will then be sent to a laboratory for examination.
- **Chest X-ray** to check the heart, lungs, and CT scan to assess for any enlarged lymph nodes.

Timeframes

You should have most results back **within four weeks**.

Questions you might want to ask

- What is WM and where can I find more information about it?
- What tests will I need and why?
- Will my follow-up appointments be face-to-face or by tele/video health or a combination?
- What's my prognosis? Alternatively, you can let your doctor know if you don't wish to know your prognosis.
- How much will appointments and tests cost and how much will I have to pay?
- Can I choose where I have treatment?
- Are there any clinical trials near me that I may be eligible for?
- Will I need to start treatment straight away?
- How long will the treatment last?
- How will my disease be monitored?
- Is there information that I can share with my family or friends?
- Is there any genetic association with WM?
- What support services are available to me?
- The 'Questions to ask a haematologist' from Cancer NSW can be a helpful resource available at **www.cancer.nsw.gov.au/about-cancer/document-library/haematologist-question-list**.

Treatment

Your specialist will talk to you about your treatment options for WM. You may need more than one treatment type to get the best results, and it is most likely that you will require ongoing treatment to manage your WM for the rest of your life.

You may have one or a combination of these treatments:

- **Watch and Wait.** Many patients newly diagnosed with WM experience no symptoms and have a slow growing disease that does not warrant treatment at this time and can avoid side-effects that treatment brings. Monitoring is through clinic appointments and blood tests every few months. Leukaemia Foundation have a Watch and Wait webinar with some helpful tips available at **www.leukaemia.org.au/webinar-videos/**.

- **Chemotherapy.** Drugs that are used to kill cancer cells to stop the cancer growing.
- **Immunotherapy** is a type of cancer treatment that helps the body's immune system fight the cancer. Rituximab, an immunotherapy drug, is often used alongside chemotherapy as an in initial treatment for WM.
- **Targeted therapy** is a drug treatment that targets specific features of cancer cells to stop them growing and spreading. Zanubrutinib is used in patients who do not respond well to or are not appropriate for immunotherapy-chemotherapy approaches.
- **Plasma exchange.** A treatment to temporarily reduce the IgM protein from the blood.

For more information visit **www.cancer.org.au/cancer-information/treatment**.

Your haematologist may also discuss participating in a clinical trial which provides you access to new treatments.

Supportive care (treatment or services that support you through a cancer experience) are also available, often delivered through a multidisciplinary team that may include nurses, pharmacists, psychologists, physiotherapists, and dietitians. You can ask your GP or haematologist if you have a multi-disciplinary team and whether they have been involved in decisions regarding your cancer care.

Timeframes

By evaluating your symptoms and test results, your specialist will determine when your treatment should start. Once a decision has been made that you need to start treatment for WM, it will generally be started **within four weeks**. There may be instances where your treatment could be delayed beyond this timeframe. If this occurs your specialist will discuss this with you.

Clinical trials

Your specialist may recommend participating in a clinical trial (or you can ask if you are eligible for any clinical trials if this discussion is not prompted by your doctor or specialist). Clinical trials often provide access to promising new treatments that are not yet available to the public. Many people with cancer are now living longer, with a better quality of life, because they have been on clinical trials.

For more information about the types of trials available and information on participating in a trial, visit **www.australiancancertrials.gov.au** or **www.clintrialrefer.org.au/** or search the Australian New Zealand Clinical Trials Register **www.anzctr.org.au**.

Complementary therapies and other medications

Speak to your doctor or healthcare team about any dietary supplements, vitamins, herbal remedies, and other medications that you use or would like to use, including prescription and over-the-counter medicines (e.g., paracetamol or ibuprofen). Some medicines, complementary therapies, vitamins, and foods may interact with your treatment.

Fertility and sexual health

Blood cancer and blood cancer treatment may cause fertility problems for both men and women. This will depend on age, the type of blood cancer and the treatment received. If this is relevant, get advice from your treating team about contraception before, during, and after treatment. Discuss having children whilst undergoing treatment and the need for referral to a fertility specialist and options for fertility preservation before starting treatment. Diagnosis and treatment may affect your sex life or overall sexual health. For support and, if necessary, referral to counselling services, contact the Leukaemia Foundation on **1800 620 420** or visit **www.leukaemia.org.au** and type 'relationships and sex' in the search bar.

You can ask for more time to think about your treatment options.

You can ask your GP for a referral to another specialist for a second opinion.

Questions you might want to ask

- What are my haemoglobin and IgM (Immunoglobulin M) levels to help me map the progress of my WM and its treatment?
- What treatment do you recommend and why?
- Are there alternatives? If so, what is the course of treatment, side-effects, and effectiveness of the alternatives?
- What will happen if I don't have treatment?
- How long will I need to be on treatment?
- How long does my treatment last before it stops working?
- What will treatment cost and how much of the cost will I have to pay?
- What activities/exercise will help me during and after treatment?
- Is there any specific diet I should follow during treatment?
- Is it okay to consume alcohol?
- How will the treatment affect my day-to-day life, and can I still work?
- Who is in my treatment team and who is the main contact person if I have any questions or feel unwell?
- What side effects could I have from treatment and how should I manage them?
- Will treatment affect my ability to have children, and if yes, what options should I consider?
- Can I travel overseas?

Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel, or parking.

Speak with your GP, specialist, or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs, talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation and/or transport during treatment
- the possible financial impact of your treatment and financial support schemes you may be able to access
- how your treatment might impact your ability to work.

For more information about financial and practical support call the Cancer Council on **13 11 20** or visit **www.cancer.org.au/support-and-services/practical-and-financial-assistance**, or contact the Leukaemia Foundation on **1800 620 420** or visit **www.leukaemia.org.au/how-we-can-help/practical-support-services/**.

Care during treatment

WM is a highly treatable low-grade lymphoma but is not curable with current therapies. Patients with WM may need multiple courses of therapy over their lifetime, given the relapsing nature of the lymphoma. Discussing keeping vaccinations up to date with your haematologist, such as with the COVID vaccine, is important due to the effects of blood cancer on your immune system. Monitoring for late effects and second malignancies, which are more common in patients with WM, is required, and primary prevention and risk minimisation strategies are encouraged. Important supportive measures include monitoring for low iron stores and nutritional support, particularly for patients with relapsed WM.

Survivorship

Current therapies mean that most people with WM will go on to live long healthy lives and you may need regular ongoing follow-up appointments and care.

Your specialist and healthcare team will talk to you about your needs and can refer you to other health professionals and community support services. Other information you get might be about:

- the side effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of staying well.

For more information visit **www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment**.

?

Questions you might want to ask

- Who should I contact if I'm feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?
- What vaccinations are safe for me to have?

Living with relapsed or progressive disease

Most patients with WM will relapse after responding to initial treatment. Access to the best available therapies, including clinical trials and treatment with a multidisciplinary team, are crucial to achieving the best outcomes for relapsed disease.

In managing people with relapsed or progressive WM, considerations include:

- the choice of second and subsequent lines of treatment – this is strongly influenced by the previous treatment regimens and duration of response.
- the risk of infection rises due to the side effects of therapy on the immune system (the body's way of fighting infection).

?

Questions you might want to ask

- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there an appropriate clinical trial available?
- What financial, practical, or emotional support is available?

Advance care planning

Your GP or healthcare team may talk with you, your family, and carer about future treatment and medical needs. It is important to have this conversation so that you can make your wishes and decisions about your treatment and care known to your doctors and family.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and medical team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. There are also sections in the document where you can make comments in your own words, and you can change your mind. For more information visit **www.advancecareplanning.org.au**.

Symptom and palliative care management

Palliative care can help you to live as well as you can including managing pain and symptoms, psychosocial support, and assistance in identifying care goals. This care may be at home, in a hospital, or at another location you choose. Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with blood cancer or if their blood cancer returns. Speak to your GP or haematologist/specialist or visit **www.palliativecare.org.au**.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You can always change your mind about your treatment. Just talk to your specialist. For more information visit **www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment**.

Questions you might want to ask

- What can be done to reduce my symptoms?
- Can I see a dietician to manage my significant nutritional needs?
- Are there any exercise programs available to me? or where can I go to receive a tailored program?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?
- What support services are available to me to help manage the ongoing nature of my blood cancer?
- What emotional support services and tools are available if I have concerns, experience anxiety or emotional distress?

Published in May 2024.

This resource is based on information from the optimal care pathway for people with Waldenström's macroglobulinaemia (1st edition), available at **www.cancer.org.au/OCP**.

Australian Government
Cancer Australia

Leukaemia Foundation