

1. What medicines are available to treat Primary Progressive Multiple Sclerosis (PPMS)?

There is only one medicine, Ocrevus® (ocrelizumab), that has been approved by Medsafe to treat primary progressive MS (PPMS).

From 1 October 2023, PHARMAC will fund Ocrevus® (ocrelizumab) for people living with PPMS, subject to certain criteria. This means that ocrelizumab would be the first funded targeted medicine for this type of multiple sclerosis.

However, in addition to this disease-modifying therapy (DMT), a wide range of medications and rehabilitation strategies are used to manage symptoms of PPMS.

2. What is Ocrevus used for?

Data shows that for some people with PPMS, Ocrevus can improve quality of life, slow progression and enable people to live more independently for longer.

Ocrevus is not a cure but has been shown to effectively slow the worsening of PPMS and helps manage symptoms including cognition and fatigue.

However, Ocrevus is not suitable for everyone, and is more effective when given earlier in your disease course.

It is important that you discuss with your doctor or nurse whether this medicine is right for you based on your individual circumstances.

Before talking with your MS Nurse or Neurologist we recommend considering what your treatment goals are so that you can be clear around what you would consider to be treatment success or otherwise.

3. Will I be eligible for treatment with Ocrevus® from 1 October?

To access PHARMAC funded Ocrevus for the treatment of PPMS, you must meet the following criteria:

1. Have a neurologist confirmed diagnosis of PPMS.
2. Have an Expanded Disability Status Scale (EDSS) score between 2.0 and 6.5 (inclusive). An EDSS score of 6.5 means you can walk around 20 metres with one or two aids (crutches, sticks or walkers) without stopping for rests.
3. Have no history of relapsing remitting multiple sclerosis (RRMS).

4. How do I check if I'm eligible for treatment for 1 October?

If you are unsure whether you meet these criteria, and whether Ocrevus is right for you, you can either:

- 1) Contact your MS Nurse Specialist if you have their contact details.
- 2) Contact your local GP who will be able to refer you to a neurology service.

You can also contact your local MS Community Advisor to talk you through the criteria in general. They are not clinical staff so are unable to give any individual treatment advice.

5. What if I don't know my EDSS score?

The EDSS is a way of measuring how much someone is affected by their MS. Predominantly it measures walking ability. Your neurologist or MS Nurse Specialist will give you a score on the scale based on what they find after examining you and asking you questions about how your MS affects you. The higher your score, the more MS is affecting you.

As an example, an EDSS score of 6.5 means you can walk around 20 metres with one or two aids (crutches, sticks or walkers) without stopping for rests.

If you're unsure of your EDSS score, please contact your MS Nurse Specialist or your local GP who will be able to discuss further with you and refer you to a neurology service if required.

6. What if I'm not sure what type of progressive MS I have?

PPMS is generally characterised by a fairly steady and gradual change in functional ability over time - most often related to walking initially - without any episodes of relapse followed by periods of remission or improvement. Approximately 10-15% of people with MS in New Zealand have PPMS. PPMS can be harder to diagnose, often only after a long onset of neurological symptoms with visible lower-limb disability.

If you have a history of relapses, and have been on a DMT in the past, it is more likely that you will have Secondary Progressive MS. If so, you unfortunately won't qualify for treatment at this time. MSNZ is advocating for the availability of funded treatments for all types of MS.

If you're unsure what type of MS you have, please contact your MS Nurse Specialist or your local GP who will be able to refer you to a neurology service.

7. How is Ocrevus given?

Ocrelizumab is administered as an intravenous (IV) infusion, which means it is usually given to you in a hospital clinic.

Typically, the initial treatment involves two separate infusions given two weeks apart. After that, follow-up infusions are given every six months.

Initial infusions can take up to 6 hours. Subsequent infusions can take between 4-6 hours.

8. What are the risks/side effects of using Ocrevus?

There are some side effects and risks to be aware of when receiving Ocrevus.

The most common side effects of OCREVUS are infusion-related reactions (IRR). Infusion reactions can be serious, so you'll be carefully monitored throughout your infusion and for at least one hour afterwards.

However, because IRRs can happen for up to 24 hours after a dose of Ocrevus, it's important that you tell your doctor or go to the Accident and Emergency at your nearest hospital if you notice any unusual symptoms.

Ocrevus increases your risk of getting upper respiratory and lower respiratory tract infections, skin infections, and herpes infections. Tell your healthcare provider if you have an infection or have any of signs of infection.

There have been reports of a rare, serious brain infection called PML (progressive multifocal leukoencephalopathy) in patients receiving medicines for MS. PML can cause severe disability or even death- it is mostly associated with risk factors, such as age and use of other medicines that affect your immune system.

We recommend having a robust conversation with your neurology team to ensure you are aware of all the benefits and potential risks/side effects. Together, you should make an informed decision about whether Ocrevus is right for you. Before commencing treatment ensure you are alert of potential side effects you may experience and when and how to report these.

9. Who can prescribe Ocrevus

Under the criteria 'any relevant prescriber' can make a Special Authority Application for MS DMTs if they feel this is within their scope of practice. As it is a complex decision making process, in most cases a neurologist will make the Special Authority Application.

A neurologist needs to confirm a PPMS diagnosis which meets the 2017 McDonald MS diagnostic criteria. Confirmation may not necessarily require a re-visit to a neurologist but could be confirmed via previous clinic letters from a neurologist.

If your GP or other relevant prescriber is making an initial or renewal application but has any concerns, it is recommended they reach out to their local Neurology team.

Once established on treatment 'any relevant prescriber' could re-prescribe providing they know and understand the treatment and monitor patients for potential complications.

Please contact your MS Nurse Specialist or your local GP who will be able to discuss further with you and refer to a neurology service if required.

10. I've heard there are significant wait times, is there anything I can do?

Wait times across the country are significant in most areas for neurology appointments, infusion clinics and MRIs.

While you are waiting, ask your GP and Neurology team whether there are any vaccinations that you can get in advance of starting treatment. Ocrevus is a B-cell depleting treatment as due to how it works there is a recommended vaccination schedule. Your health care team can support you through this and it will reduce any further delays for starting treatment.

If you haven't seen a neurologist in a while, contact your GP for a neurology referral.

If you feel you would be eligible for treatment based on this information, but are struggling to navigate the system, reach out to your local MS Community Advisor who may be able to support you with the process.

11. Where can I find out more information about Ocrevus?

You can find more information about Ocrevus in the Consumer Medicine Information <https://www.medsafe.govt.nz/consumers/cmi/o/Ocrevus.pdf>

Visit www.getonwithlife.co.nz to learn more about Ocrevus

Watch more about Ocrevus: <https://www.youtube.com/watch?v=SX7kHhmrell>

If you still have further questions or want to understand if Ocrevus is right for you, speak to your MS Nurse specialist or doctor.

12. Next Steps

Step 1: Check you meet all of the following criteria:

- I have a neurologist confirmed diagnosis of PPMS.
- I can walk 20 metres or more with **one or two** aids (crutches, sticks **or walkers**) without stopping for rests.
- I have no history of relapsing remitting multiple sclerosis.

Step 2: Make Contact:

- If you know your local MS Nurse at the hospital, give them a call to discuss your potential eligibility and if a GP referral is required.
- If a GP referral is required, visit them as soon as possible. Ask them to provide as much detail as possible in your referral regarding your diagnosis, symptoms, progression, current mobility, interest in being assessed for Ocrelizumab. Where possible they should send the referral to the attention of the leading MS Neurologist in your Region. More detailed information will assist with triaging cases where wait times are significant.
- Speak to your MS Community Advisor and let them know you are interested in accessing funded Ocrevus. They may be able to check in with your local Neurology Team to provide any further information. It is also a timely opportunity to check in with them about any other needs you may have, or any additional support they may be able to help put into place.

Notes:

EDSS 6.5 - Requires two walking aids – pair of canes, crutches, etc. – to walk about 20m without resting.

References:

www.msnz.org.nz

<https://www.nationalmssociety.org/What-is-MS/Types-of-MS/Primary-progressive-MS/Frequently-Asked-Questions-about-PPMS>

[Proposal to widen access to medicines for haemophilia A and multiple sclerosis - Pharmac | New Zealand Government](#)