

Purpose & Service Value

Why consider genetic counselling or testing?

Genetic counselling can help you understand whether genetic testing may be useful for you, what results might mean, and how they may relate to your family.

What does a genetic counsellor do?

A genetic counsellor provides information and support about genetic testing, inheritance, family risk, and possible implications for you and your relatives. They also support informed decision-making about whether genetic testing is right for you.

What is the difference between genetic counselling and genetic testing?

Genetic counselling is a discussion with a specialist about genetics and your options.

Genetic testing is a laboratory test that looks for genetic changes linked to MND.

Some people attend for genetic counselling, but do not proceed with testing.

Do I have to pursue genetic testing?

No. Genetic counselling is about understanding your options and making the decision that is right for you and your family. Some people prefer the idea of DNA storage for future potential testing rather than proceeding with genetic testing.

Can genetic testing help with treatment or research?

In some cases, yes. Certain treatments and clinical trials may be linked to specific genetic changes.

Will genetic testing affect insurance or employment?

Recent changes in Australia mean there are now stronger protections in place regarding the use of genetic test results in life insurance. On 1 April 2026, the Australian Parliament passed legislation making it illegal for insurers to use genetic test results to adversely affect applications for life, income protection or trauma insurance. These protections will come into effect on 8 October 2026.

Eligibility & Scope

What is the service?

The MND Genetic Counselling Service is 12-month pilot partnership between MND Victoria and Monash Health. It provides specialised support to people with MND and their families to access prompt genetic counselling and testing with minimal delays.

Who can access the service?

Victorian residents living with MND, and their unaffected family members, may access the service irrespective of family history.

Can I access the service if I live outside of Victoria?

At this stage, the genetic counselling pilot is for Victorian to support evaluation of the service model and ensure feasibility. There is potential for future expansion pending funding and capacity.

If you live outside Victoria, we recommend discussing your situation with your local medical team and referring to the Human Genetics Society of Australasia (HGSA) to locate a genomics service in your area (<https://www.hgsa.org.au/>) or speaking with the Monash Genetics team for guidance.

Should I explore genetics if there is no family history of MND?

Genetic changes can still be found in a patient with MND, even without a family history. Exploring genetics is a personal choice, and the service can help you understand the options, potential benefits, and considerations before deciding whether genetic testing is right for you.

Can I access the service if my relative with MND has died?

Yes. Family members are still able to access genetic counselling and may be eligible for genetic testing, depending on individual circumstances.

Can I access the service if I have already had genetic testing or received results?

Yes. The service can still help explain results, discuss implications for family members, and support next steps or future planning.

What to Expect

What happens in an appointment?

You will speak with a genetic counsellor who will provide information about genetic testing, discuss possible outcomes and implications for you and your family, and support decision making around genetic testing. Genetic counselling is tailored to your needs.

What is presymptomatic testing?

Testing for people who do not have symptoms but may have an inherited risk of MND. This is only available if the genomic cause of MND has already been identified in a family.

What is DNA storage?

Storing a DNA sample for possible future testing. This is a good option for those who may be unsure about genetic testing and important to consider while still alive to provide your family with the option of genomic testing for the future.

How long is the process?

The length of the process can vary depending on individual circumstances and whether genetic testing is pursued. It usually involves around 1-3 genetic counselling appointments, as needed.

If genetic testing is undertaken, testing is typically initiated within 1-3 weeks of referral. Once a sample is collected, results are usually available within approximately 3-8 weeks.

Referrals & Access

How do I access the service?

A referral is required from a GP, neurologist, or other medical specialist via Monash Health's electronic referral system; [HealthLink](#). Patients and family members are welcome to call or email us with enquiries, even before a referral has been made.

Can MND Victoria refer me?

No. A medical referral is required, but MND Victoria can provide referral guidance.

Is there a cost?

No. The genetic counselling service is free. In most cases genetic testing is also funded.

Is the service available outside Metro Melbourne?

Yes. Appointments are available statewide, either via telehealth or in person, with face-to-face appointments predominantly held at Monash Health, Clayton.

Your Appointment Experience

Can family members attend appointments?

Yes, in fact we encourage a support person to attend.

What if I feel overwhelmed?

Genetic counsellors provide emotional support and can link you with additional services if needed. MND Victoria can also support you here.

Additional Information

Is this an ongoing service?

This is a 12-month pilot program. Future continuation depends on evaluation and funding.

Who can I contact for more information?

The Monash Health MND Genetic Counselling Service team can be contacted for service-related queries.

MND Victoria staff can assist with general enquiries and guidance.

Referral & Service Enquiries

Monash Genetics (Monash Health)

☎ (03) 9594 2026

✉ geneticsintake@monashhealth.org



MND Victoria

☎ (03) 9830 2122

✉ geneticsupport@mnd.org.au

