

Monash Health Referral Guidelines – MND Genetic Counselling Service

Referrals to be sent to Monash General Genetics for the MND Genetic Counselling Service via **‘Healthlink’**, Monash Health’s online referral system by the patient’s GP, Neurologist, or other Medical Specialist. Referrals can be addressed to Head of Unit: Dr Andrew Fennell.

Referral triaging will be completed by the general genetics, MND genetic counsellors or neurogenetics staff at Monash Genetics, via the Monash General Genetics referral pathway.

Eligibility:

The MND Genetic Counselling Service supports people with a confirmed diagnosis of MND and their relatives, prioritising those needing urgent guidance on genetic testing, DNA storage, or family planning.

Patients with MND as well as their unaffected family members are eligible for referrals to this service.

If patient is symptomatic, patient must be under the care of a neurologist or a referral to neurologist should also be made for management of their condition. Please attach correspondence/results confirming the MND diagnosis and any genetic testing (if completed). This information is required prior to the appointment.

For unaffected relatives requesting pre-symptomatic testing, please provide family genetic test results, or the name (and DOB) of their MND affected relative, where known.

Urgent / Priority

Person with MND diagnosis (regardless of family history)

- Patient rapidly deteriorating, considered advanced or with time-pressure for DNA sample (blood / saliva)
- Patient in psychological distress – requiring clarity about genetic testing implications or decision making to alleviate emotional state
- Patients with MND (at any stage) with a family member who is pregnant or undergoing IVF and whom hasn’t yet had genetic testing

Relative of patient with MND

- With time-critical need for genetic counselling input and advocacy due to medical, reproductive or psychological reasons (i.e. pregnant, IVF)

Routine / Lower Priority

Person with MND diagnosis (regardless of family history)

- With questions or concerns about genomic testing and DNA storage options
- With questions about eligibility for trials or treatment options

Relative of patient with MND

- Wishing to explore presymptomatic testing to inform reproductive decision prior to pregnancy planning
- Requesting information on DNA storage options and genomic testing of an affected family member
- Requiring clarity of genetic status in family (please provide name and DOB of MND affected relatives)

Referral Submission:

HealthLink:

<https://monashhealth.org/health-professionals/referrals/referrals-for-community-based-services/healthlink-referrals-for-gps/>

Referral Support:

- Monash MND Genetic Counselling Service: ph. (03) 9594 2026 or monashgenetics@monashhealth.org
- MND Victoria: ph. (03) 9830 2122 or geneticsupport@mnd.org.au