

Information and support at diagnosis



Information about diagnosis, prognosis and management of MND should be given by a neurologist with knowledge and experience of treating people with MND, including:

- symptoms, types, possible causes and progression of MND
- treatment options and how they may be affected by progression
- crisis prevention, such as acute hospital admission, and advance care planning
- opportunities to be involved in research
- likely needs and concerns of people with MND, their family and carers.



Provide information about MND and support at diagnosis or when the person asks. Determine:

- how much information they wish to receive
- their preferences for involving family members and carers
- whether they want you to share the information with their family/carers.



Set aside time to discuss concerns, such as:

- What will happen to me?
- Are there any treatments or a cure?
- How long will I live? How will I die?
- What will the impact on my day-to-day life be?
- What will happen next with my healthcare?
- Will my child get MND?
- How do I tell my family and friends?



Forge links:

- Provide a single point of contact in the MDT.
- Provide a plan on what to do if there are concerns between appointments, during out of hours, emergencies, or if there's an equipment issue.
- Offer a face to face appointment within 4 weeks of diagnosis.
- Inform the GP of the suspected or confirmed diagnosis and the likely prognosis.
- Refer to social services if necessary.
- Advise carers about carer assessment, respite care and support.

Information should be written and oral, and may include:

- what MND is, types and possible causes
- likely symptoms, progression and management options
- where the person's appointments will take place and which professionals will be involved in their care
- expected waiting times for consultations and treatments
- local services (such as social or palliative care), support groups, online forums, charities and how to contact them
- legal rights, including employment rights and benefits
- requirements for disclosure, such as notifying the DVLA
- opportunities for advance care planning.