

Information and support at diagnosis

How a person receives their diagnosis can affect their experience of living with MND.

Neurologist knowledge and expertise:

- symptoms of MND
- types and possible causes of MND
- treatment options
- how MND may progress & that may affect the treatments offered
- crisis prevention e.g. an acute hospital admission
- opportunities for people with MND to be involved in research
- likely needs and concerns of people with MND and their family members and/or carers
- advance care planning.

Support at or around the time of diagnosis

Information about the diagnosis, prognosis and management of MND should be given by a consultant neurologist with up-to-date knowledge and experience of treating people with MND.



Leave time for questions which may include:

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

Determine how much info the person wants and if they want to involve family members and / or carers. Provide information oral or written - at diagnosis or when asked for:

Information may include the following:

- what MND is
- likely symptoms and management
- progression
- treatment options
- where appointments will take place
- healthcare professionals and social care practitioners that will provide care
- expected waiting times for consultations, investigations and treatments
- local services (inc. social care and specialist palliative care services) and how to contact them
- local support groups, online forums and national charities, and how to contact them
- legal rights, including social care support, employment rights and benefits
- requirements for disclosure, e.g. DVLA
- opportunities for advance care planning.

Forge links:

- Provide a single point of contact in the MDT.
- Provide a plan for what to do in an emergency or out of hours, between assessments or appointments, problems with equipment.
- Offer a face to face appointment within 4 weeks of diagnosis.
- Inform GP - with information and likely prognosis.
- Refer to social services for assessment if necessary.
- Advise carers of their right to Carer Assessment.