

After a Motor Neurone Disease Diagnosis

An MND diagnosis can bring profound uncertainty and anticipatory grief. Information should be paced, person-centred and focused on both present needs and future choices.

A diagnosis can create grief as well as questions

Life-changing diagnoses can involve grief for health, certainty, identity, independence, work, relationships, plans or the way you expected your future to unfold. Relief at finally having an explanation can exist alongside fear or sadness. There is no correct emotional response.

Take information at your own pace

Many national charities now provide newly diagnosed packs, helplines, peer groups, online communities, webinars, practical guidance and accessible information. You do not have to absorb everything at once. Write questions down, take somebody you trust to appointments if you want to, and ask clinicians to explain information again when needed.

The shock of diagnosis

The shock of diagnosis can become an important part of adjusting to a diagnosis. Try to separate what is known today from fears about what might happen later. Notice the losses that deserve acknowledgement as well as the strengths, choices and support that remain available.

A useful approach is to identify one immediate need, one question for your clinical team and one practical action. This keeps the diagnosis from becoming one enormous problem that has to be solved all at once.

Anticipatory grief and uncertainty

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Communication and independence

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Relationships and family conversations

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Planning while still living now

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Work, money and practical support

A diagnosis may affect attendance, energy, travel, concentration or the tasks you can comfortably do. Before making irreversible employment decisions, consider occupational health, reasonable adjustments, flexible working, sick pay, benefits advice and Access to Work where relevant. Condition-specific charities may also provide money, benefits or employment guidance.

Emotional and psychological support

Not everyone needs therapy, but counselling can provide somewhere to process fear, identity change, anger, grief and relationship strain. Peer support can reduce isolation because other people may understand experiences that are difficult to explain. If distress becomes persistent, severe or affects safety or daily functioning, speak with your GP or clinical team.

Practical worksheets to use with this guide

- Questions I want answered now
- Questions I am not ready for yet
- My communication preferences
- People I want involved
- Practical priorities
- What matters most to me

A simple worksheet: What do I need right now?

Area	What is happening?	My next small step
Medical / appointments		
Emotional wellbeing		
Home / daily living		
Work / money		
Relationships / support		

Questions I want to take to my next appointment

1.

2.

3.

4.

5.

Recommendations and specialist support

Motor Neurone Disease Association - MND Connect. Look for their newly diagnosed information, helpline or advice service, peer/community support and condition-specific practical guidance. Your NHS specialist team, GP, specialist nurse and relevant allied health professionals can also help you understand treatment and local services.

For work and money questions, Citizens Advice, GOV.UK benefits information and Access to Work may be useful depending on your circumstances. For urgent medical symptoms use the emergency advice given by your clinical team or NHS services.

A Message From Me

A diagnosis can change the story you thought you were living. You may feel frightened, relieved, angry, practical, numb or all of those things at different times. You do not have to become an expert overnight and you do not have to turn every difficult feeling into positivity. Give yourself time to understand what this diagnosis means for you, not just medically but emotionally, practically and personally.

With warmth,

Maggie

Space to Breathe Therapy