

Think family



Consider asking the person with Motor Neurone Disease (MND):

- **Who lives in your house?** – Helps understand the family set-up.
- **Is there a child in the family?** – Recognises the different family structures.
- **Is support needed for your parenting role?** – Acknowledges any issues.
- **Who helps you and who is important to you?** – Helps identify the support network.
- **Is there anyone you provide care and support for?** – Acknowledges that they “care about” and “care for” others.



Sharing diagnosis: How and when is an individual choice. There might be some apprehension about sharing it with children. Provide information about MND and how to share the diagnosis, so that they can make an informed decision about telling children.

Recommend that the parents read any literature before sharing it with children. Our resources for children and young people can help: mndassociation.org/cyp.



Maintaining quality of life: Find out what is important to the person with MND (for example, work or hobbies) and support them to continue doing these things, where possible, to maintain their social activities and lifestyle.

Financial impact of MND: Help the person consider how to maximise their income and access all their benefit entitlements. The MND Association also offers support funds for both people with and affected by MND: mndassociation.org/benefits.



Help at home: Under the Care Act 2014, adults with MND can have an assessment for care and support services. Carers, young carers and children also have a right to a formal assessment of their needs. Contact the Local Authority to request an assessment.



Contingency planning: When symptoms change, the person may need more equipment and the impact of MND may be more apparent. Check on the children’s wellbeing and whether they need more information or support. Also check what their school knows.

Changes in symptoms also provide an opportunity to discuss contingency planning. Encourage caregivers to make a plan and share it with their children.



Memory making: Making and storing memories does not have to be formal. Photographs, and objects can be stored in any container. It is important to talk, share stories, family history and spend time together.



Bereavement: Knowing the family helps to provide better, informed bereavement support. Signpost to appropriate sources of support: mndassociation.org/bereavement, ataloss.org childbereavementuk.org.