

When you come into contact with person with motor neurone disease consider asking the following questions

## 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 and supports you and who is important to you?

Helps identify support networks.

## Is there anyone you provide care and support for?

Acknowledges that they 'care about' and 'care for' others.

## Sharing diagnosis

How and when is individual choice. Possible apprehension about sharing the diagnosis with children.

Provide information about MND and how to share diagnosis, this allows them to make an informed decision about telling children. Recommend parents read any literature before sharing with their children.

## Impact of MND and maintaining quality of life

Financial impact - Income maximisation – ensure people are in receipt of all their benefit entitlements.

Social and lifestyle – Find out what is important to the person with MND and support them to continue doing these things where possible. Eg continuing to drive, work or sustain hobbies.

## Grants

Check for sources of grant funding. Most MND Association grants may be applied for by the person living with MND, a family member, volunteer or health and social care professional. (The MND Support (Care) Grant must be applied for by a health and social care professional.)

Link [www.mndassociation.org.uk](http://www.mndassociation.org.uk)

## Help at home

Adults with MND can have an assessment for care and support services under the Care Act 2014. Contact the Local Authority to request an assessment.

## Changing symptoms

This is a time when the person may need more equipment. Eg a hospital bed. Impact of MND may be more apparent and children may be anxious about this.

Now is a good time to check out

How are the children with this?

Do they need more information?

Does school or college know?

Consider Young Carer support

## Contingency planning

Changing symptoms provide an opportunity to discuss contingency planning. Some parents may not have thought this through or have limited support networks. Encourage care givers to make a plan and share this 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

This accumulated knowledge of the family helps to provide better informed bereavement support. Signpost to appropriate resources and sources of support eg MND Association information 'Finding your way with bereavement', Ataloss.org

Specialist support for children eg [www.winstonswish.org.uk](http://www.winstonswish.org.uk)