



5: Family, children and friends

This section will help you to manage difficult conversations as people close to you adjust to your diagnosis of MND.

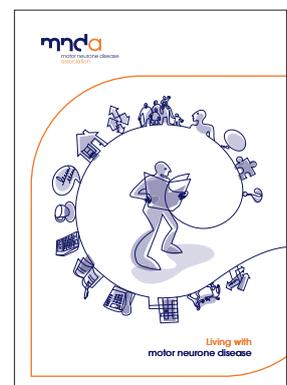
The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: **www.mndassociation.org/publications**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



Living with
motor neurone disease

5: Family, children and friends



This section will help you to manage difficult conversations as people close to you adjust to your diagnosis of MND.

Sharing the news of your diagnosis may feel very difficult to do.

The reactions of other people to your diagnosis will vary greatly, influenced by their own circumstances, their relationship with you, their age and the way they respond to crises. These reactions are natural responses to troubling news that will bring change and emotional impact.

How do I tell people about this?

How and when you inform others about your diagnosis is up to you. You should do what feels right for you. You may feel that:

- you need time to adjust before telling anyone else
- you only wish to tell your immediate family while you adjust
- you want all close contacts to be aware.

MND is progressive and the effects will be visible to others. The more people know, the easier it is for them to adjust too. It can also help them to understand how to offer support in ways that suit you.

“ My way of telling my workmates was to use a humorous approach with the ‘good news, bad news’ idea. The good news is we finally know what’s wrong and the bad news is there’s no cure yet. I found it broke the ice nicely.”

You may not want to explain the situation over and over again if this feels stressful. If you are married, or in a relationship, this may also be true for your partner. A close friend may be prepared to communicate on your behalf to reach a wider circle. There are many ways they can do this, perhaps by email or sending information about MND with their message.

It may help to keep any initial conversations quite simple in case people feel overwhelmed. As time goes on, you may wish to give more detail about how the disease is affecting you, so that people know how to support you.

Changing roles

Living with MND can result in normal routines and lifestyles being turned upside down. This can lead to significant emotional changes for everyone in your immediate circle.

Tasks that were traditionally yours may be taken on by someone else, careers may be put on hold and money worries can increase. Your own sense of purpose may need to adapt rapidly, but family roles can all change, and this is not always easy.

If your main carer is also your partner, this may cause strain, although some people find it strengthens their relationship. However, it cannot be emphasised enough how important it is for your carer to consider their own well-being, as MND is progressive and your need for support will increase.

See *Further information* at the end of this section for publications designed to support family carers.

See Section 14: *How we can help you for information about MND Support Grants, including grants for carers.*

“ There never really seems to be time to shift from talking about symptoms to the emotions that come up.”

Many will try to hide their own feelings to protect you and it may take time to develop open communication. Try to recognise when people close to you need to share their feelings and encourage open conversations. This will enable understanding and help you all to develop better ways of coping as a team.

Accepting external support for some of your care can be very beneficial. This may help you to hold on to what was unique about close relationships before you had MND. It can also provide a rest for your main carer, as their well-being can come under pressure through fatigue and worry.

If your main carer is your partner, you may each have concerns about how MND will affect intimacy and sexual expression. Again, open communication is very helpful and you may find it beneficial to talk to your health and social care team about specific worries.

See Further information at the end of the section for information sheets on sex and relationships.

Feelings of isolation

People with MND, and their main carers, often talk about a sense of growing isolation, for various reasons:

Social networks may grow smaller:

Physical hobbies and certain types of employment may become difficult as the disease progresses. There may be ways to do things differently, if you wish to remain involved. This can help to maintain relationships based on these activities.

Speech and communication may become affected:

This can make social interaction more difficult. There are therapies and communication aids to assist, but you may need to explain to others how to listen and respond to you in different ways.

See Section 8: *Speech and communication.*

Some friends may retreat:

There could be many reasons for this, including fear of saying or doing ‘the wrong thing’. It is also possible they lack understanding, for example, if you are affected by emotional lability and they are unaware of this symptom.

See Section 4: *Emotional impact.*

“ We made a strategic decision to relocate, to be closer to our relations and our family roots.”

Where people do continue to visit and maintain contact, you may find it helpful to:

- keep them informed of changes so they know what to expect (MND is rare and they may not fully appreciate the impact of the disease)
- let them know the best times of day to visit, as your routines may change and you may feel more energised at certain times
- let them know how long to stay, to help you avoid fatigue
- make a list of tasks that others might be able to help with (people like to offer practical support and a ready list gives them choice and saves you trying to think of instant tasks)
- open difficult conversations to give them ‘permission’ to ask about things that may concern them
- encourage your inclusion at social gatherings for as long as you feel this is right for you.

You may find new ways to develop social contacts by exploring different types of social activity. This could include new hobbies, or joining a local branch or group of the MND Association. Meeting other people in a similar situation and sharing experiences can help to remove the feeling of isolation for both you and your carer. Not everyone feels this is appropriate for them at first, but you can join a branch or group at any point.

“ I have had a one-to-one conversation with someone else with MND. This was very useful at a low time.”

If you have access to an Association visitor in your area, they can contact you by telephone, email or visit face to face, to provide support and helpful information.

See Section 14: How we can help you.

The MND Association online forum also provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can also view the forum conversations without joining if you prefer. This can still help to reduce isolation. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips.

See Further information at the end of this section for contact details.

Communicating about MND to children and young people

It is natural for any parent to want to protect their children from distress or worry. Yet even young children notice far more than we realise. Without information and explanations, children may:

- feel isolated and forgotten
- rely on their imagination to provide answers,

which can be far more damaging and distressing than reality

- think their thoughts or actions can influence the wider world and, seeing someone they love gradually get worse, they may feel it is somehow their fault
- try to find out more information on their own, which may not be from an accurate source.

When communicating sensitive issues to children, start by talking about things the child will already have noticed. For example, if leg muscles are affected, explain how this will make it increasingly difficult to walk. If facial muscles have been affected, explain how it may be difficult to smile, but this does not mean you are angry.

You may be worried about getting upset, but this can give children and young people permission to release some of their own emotions. By talking about MND you are clearly demonstrating it is not a taboo subject, but one that is safe to discuss.

“ I wish we had talked more because a lot of my worries would have been dealt with.”

There is no need to give all the information at once. How much and how often you should talk to children will depend on their age and how quickly the disease is progressing. However, it is important to be clear in your explanations to avoid misunderstanding.

It may help to use information about MND specifically for young people:

See Further information at the end of this section for publications we have produced to help adults and children communicate about MND.

If teachers at the child's school are told how the disease is affecting the family, they can be a source of support for the child.

As they get older, children gain a different level of understanding. They may seek information on their own and know more

than you realise, but still need to talk to you. If they shoulder a heavy responsibility as a young carer, they may also feel torn between home and student life.

Encouraging young people to maintain their links with the outside world is vital. Reassure them that their friends and activities are essential in maintaining a balanced life.

See Section 14: How we can help you for information about grants for young people affected by MND.

Key points

- There are specialist services and organisations that can help you, your family and those close to you to work through sensitive and difficult issues.

See Further information at the end of this section for examples and for contact details of MND Connect who can direct you to a wide range of support

- Try to find out what children think is happening, as it may be worse than you expect and you can help them to understand.
- Working together to keep things as open and positive as possible can really help to improve quality of life.

Further information:

We have a range of numbered information sheets, including:

- 4A:** *Communicating about MND with children and young people*
- 13A:** *Sex and relationships for people living with MND*
- 13B:** *Sex and relationships for partners of people living with MND*

Publications specifically to help children and young people:

When someone close has MND

an activity workbook for children aged four to ten, to help a trusted adult communicate about MND at a pace they feel is appropriate for the child and for the child to explore ways of coping.

So what is MND anyway?

a publication for young people and young carers, with input from young people who have been affected by MND.

We also provide the following publications:

Caring and MND: support for you

a comprehensive guide focused on the well being of family and unpaid carers.

Caring and MND: quick guide

a small A5 booklet to help someone new to the caring role become aware of available support.

Most of our publications can be downloaded from our website: **www.mndassociation.org** or you can order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 14: How we can help you.

Online forum:

http://forum.mndassociation.org hosted by the MND Association for you to share information and experiences with other people affected by MND.

Samaritans:

Telephone: **116 123**

Childline:

Telephone: **0800 1111**

The Carers Trust:

support for all family carers at **https://carers.org**

Carers UK:

information and advice for all family carers at:

www.carersuk.org

0808 808 7777 (England)

02890 439 843 (Northern Ireland)

02920 811 370 (Wales)

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The MND Association has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org