



5: Family, children and friends

This section can help you manage difficult conversations about MND, with those close to you.

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

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Sharing news of your diagnosis may feel difficult, as it brings change and emotional impact. Reactions will vary too, depending on each person's own circumstances and relationship with you, their age and the way they respond to situations.

How do I tell people about this?

You should do what feels right for you. Following diagnosis, you may:

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

As MND progresses, the effects will be visible. The more people know, the easier it is for them to adjust and offer support.

“ Tell your friends and colleagues when you feel able...give them something positive to do, so they have a sense of helping.”

If you find it stressful to keep explaining the situation, ask a close friend to help tell your wider circle. This can be done through private messages or email, with information attached. We also have a short animation called *What is MND?* that people find helpful at: www.mndassociation.org/MNDfacts

It may help to keep early conversations simple in case you or those close to you feel overwhelmed. You can offer more detail over time, so that people know how to support you and your changing needs.

You may find people try to hide their emotions to protect you, which can prevent open communication. If you sense someone needs to share their feelings, encourage conversation.

“ 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.”

Changing roles

Living with MND can result in your routines and lifestyle being turned upside down. There can be significant changes for everyone in your immediate circle.

You may find that:


- someone else has to take on tasks that you can no longer do
- your own sense of purpose and family roles begin to change
- you may need to think about whether to continue working
- money worries can increase.

None of this is easy. Unwanted change can take time for everyone to accept, but it can help if you find ways to work like a team.

It's also essential to help your main carer consider their own wellbeing, as care demands with MND will increase.

See *Further information* at the end of this section about our resources for carers.

See Section 12: *How we can help you about our MND Support Grants, including grants for carers.*

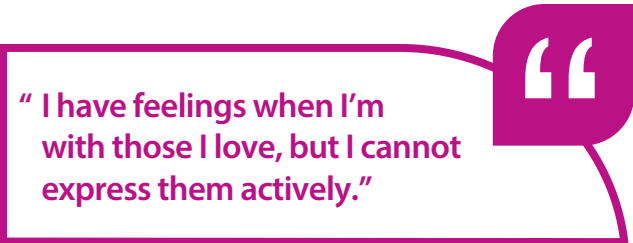


“ We feel for our carers as they do us. We are all sharing a terrible situation. The idea of sharing helps – it gives a feeling of togetherness.”

Accepting external support for some of your care can be valuable. It can:

- help you hold on to what was unique about close relationships before you had MND
- provide rest for your main carer, as the care demands increase
- allow your main carer time for activities beyond the caring role.

If your main carer is your partner, the demands of MND may strain your relationship. It can also bring you closer, but you may both have concerns about the effect on intimacy and sexual expression.



“ I have feelings when I'm with those I love, but I cannot express them actively.”

You may have similar concerns if you are single and would like to begin a relationship or find a sexual partner.

If you have any worries about sex and relationships following your diagnosis, ask your health and social care team for guidance.

See *Further information* at the end of this section about our resources on sex and relationships.

Feelings of isolation

People with MND and their main carers often talk about a sense of growing isolation. This can happen for various reasons:

Social networks may grow smaller:

As MND symptoms progress, hobbies and job roles can become more difficult to do.

You may want to think about equipment and other ways to prolong independence, for activities you'd like to continue. Staying involved helps maintain social contacts, but explore new interests too.

Speech and communication may become affected:

MND can make communication more difficult, but there are therapies and communication aids to assist. You may need to explain to others how they can best support you in conversation.

See Section 8: *Speech and communication.*

Wider family members and friends may retreat:

People sometimes stop contacting someone who is ill. This can be through fear of saying or doing 'the wrong thing'. They may also lack understanding.

Where people do keep in contact, it can help to:

- keep them informed of changes so they know what to expect when they see you
- let them know when to visit and how long to stay, if you feel more energised at certain times
- keep a list of tasks they can help with if they offer support (a list gives choice and saves trying to think of instant tasks)
- open conversations that give them permission to share concerns
- try to join social gatherings for as long as this feels right for you.

“ Be flexible with routine, as things can change from day to day and night to night.”

Meeting people going through similar experiences can also help you and your family, and ease any sense of isolation. Not everyone wants this at first, but you can join one of our MND Association branches or groups at any 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 12: How we can help you.

Our online forum also provides a safe place share to share support and tips with others affected by MND. You can just view or join forum conversations, at:

<http://forum.mndassociation.org>

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

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

Communicating about MND to children and young people

Protecting children from distress or worry is a natural instinct, but even young children notice more than we realise. MND will become more visible as time goes on and without explanation, children may:

- feel isolated and forgotten
- use imagination to find answers, which can be more distressing than reality
- think their thoughts or actions can influence the wider world and feel they are to blame
- try to find out information on their own, which may not come from an accurate or sensitive source.

When communicating about MND with children, start with things the child has already noticed. For example, if leg muscles are affected, explain how this makes it more difficult to walk. If facial muscles have been affected, explain how this makes it more difficult to smile, but that doesn't mean you're angry.

You may worry about getting upset in front of children and young people, but this can give them permission to release their own emotions. Openly discussing MND means it's not taboo and can help children feel safe enough to ask questions.

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

There is no need to give information all at once. How much and how often depends on a child's age and the speed at which your symptoms progress.

However, it's important to be clear and avoid misunderstanding. This includes asking questions to check how much they understand.

“ We told them we would explain everything, but we needed to be honest. As you can imagine there were floods and floods of tears...When they were ready, I gave them information. They asked a few questions, and I could answer them because I had read the content.”

As they get older, young people develop greater understanding. They may seek information on their own and know more than you realise, but still need discussions with you.

See *Further information* at the end of this section for our resources to help communicate about MND with children and young people.

Teachers can also be a source of support if they know what's happening. If a child or young person takes on responsibility at home as a young carer, they may feel torn between home and student life. In this situation, it can really help to keep their school or college informed.

However, keeping children and young people involved in care support can be helpful. It enables them to feel included, maintain a strong relationship, build good memories and to contribute. This can help them build resilience.

“ The balance of care and support is not always perfect in our house, and for our teenage children, dealing with daddy's illness is a tricky landscape.”

If the care demands are overwhelming, external support may be needed. Where children and young people live in the same household, any needs assessment considers the whole family. Care plans should include the needs of young carers.

See *Section 10: Finances, work and social care* on needs assessment.

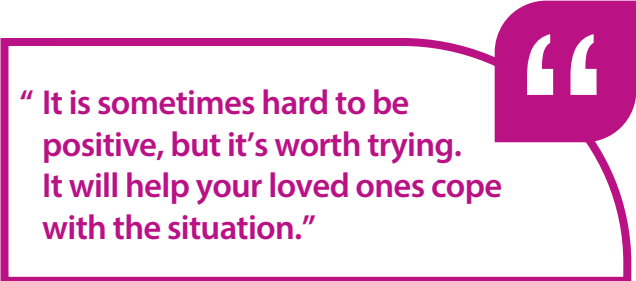
Encourage young people to maintain links with the outside world. Reassure them that their friends and activities are essential to maintain a balanced life. This can help them have time, where they can just be themselves.

See *Section 12: How we can help you about grants for young people affected by MND.*

Key points

- Try to find out what children think is happening, so you can help them understand.
- When children and young people are included in discussions and care tasks, it can help them build good memories and strengthen their resilience.
- 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* next or **Section 13: Useful organisations**.



“ It is sometimes hard to be positive, but it’s worth trying. It will help your loved ones cope with the situation.”

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 4A:** *Communicating about MND with children and young people*
- 10G:** *Support for families with children*
- 11D:** *Managing fatigue*
- 13A:** *Sex and relationships for people living with MND*
- 13B:** *Sex and relationships for partners of people living with MND*

From our guides and other publications:

Making the most of life with MND: a booklet about how to maintain interests and adapt.

MND Checklist: a questionnaire that helps you think about your condition and how to plan and prepare for your care needs.

Understanding my needs: a booklet in which you record your needs and preferences to guide all those involved in your care.

Caring and MND: support for you: a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide: a booklet to help someone new to the caring role.

Information for children and young people:

Website: See our pages for children aged 4 to 10 and young people aged 11 to 18 at: www.mndassociation.org/cyp

When someone close has MND: an activity workbook for children aged 4 to 10, 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.

Information to pass to your health or social care professionals:

Caring for a person with MND – a guide for care workers

Supporting children and young people close to someone with MND

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**.

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

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at:

<http://forum.mndassociation.org>

Samaritans:

A listening service for confidential support.

www.samaritans.org

Telephone: **116 123**

Childline:

A free, confidential helpline for anyone under the age of 19 at **www.childline.org.uk**

Telephone: **0800 1111**

The Carers Trust:

Information and advice for all family carers at

<https://carers.org>

Telephone: **0300 772 9600** (England)

Telephone: **07826 930508** (Northern Ireland)

Telephone: **0300 772 9702** (Wales)

Carers UK:

Information and advice for all family carers at

www.carersuk.org

Telephone: **020 7378 4999** (England)

Telephone: **02890 439 843** (Northern Ireland)

Telephone: **029 2081 1370** (Wales)

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For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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**This resource has been evidenced,
user tested and reviewed by experts.**



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