



4A

Communicating about MND to children and young people

Information for people with or affected by motor neurone disease

Telling other people that you have motor neurone disease (MND) may feel very challenging. This can be particularly difficult with children or young people, as our natural instinct is to protect them from upset.

However, with MND things will change. Children and young people may become frightened if they don't understand. Clear explanations can help them feel included, avoid confusion and help them feel supported.

This information sheet offers suggestions that may help, in the following sections:

- 1: Why do children need to be told about MND?**
- 2: How do I explain what is happening?**
- 3: How do I manage the emotional responses?**
- 4: Who else can help?**
- 5: How do I find out more?**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



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

www.England.nhs.uk/tis

1: Why do children need to be told about MND?



“Although we were a close family, we didn’t talk much about what was happening or what might happen in the future. I wish we had talked more because a lot of my worries would have been dealt with.”

When someone close is very unwell, children will wonder why. Helping a child to understand can prepare them for what lies ahead and reduce any sense of shock. It can also give them the opportunity to talk about what is happening, which can help their understanding. Without information and explanation, they may:

- feel isolated and forgotten
- rely on their imagination to provide answers, which may be far more damaging and distressing than reality
- feel it is somehow their fault
- try to find out more information on their own, which may not be accurate
- be told by someone else, in a way you would not have wanted
- worry that other people, including themselves might become ill.

What if I am not the child’s parent or guardian?

Whether you are a parent, guardian, grandparent, relative or friend, this information sheet can help you explain about MND to children. However, we recommend involving the child’s parents or guardians before the discussion takes place. They may have to answer more questions later, and will be able to help decide at what pace information should be given to their child. Sharing this information sheet with them may be helpful.



“During this time we have had four grandchildren. The oldest, who is now six, has asked why Grandpa can’t walk anymore and why he doesn’t speak like the rest of us. I have just said that he has MND and that causes these problems. The younger ones seem to accept that Grandpa is different, but as they get older I am sure they will want to know more.”

When should I tell them?

Children often sense the anxiety and distress of adults around them, even those trying hard to hide their feelings. This can be confusing for a child or young person. It is best to discuss MND with them as soon as you feel able, to ensure they feel included and can ask questions if they need to.

It is helpful to plan what you are going to say in advance. Choose a time and place where there are few distractions and interruptions. Make sure you have plenty of time, as they may have questions or need to be comforted. If there is more than one child in the family, try to tell them all at once. This ensures everyone knows the same information.

2: How do I explain what is happening?

When discussing MND with a child or young person, the following may be helpful:

Be open and honest – by talking about MND to a child, you are making it clear that it is not a taboo subject, but one that is safe to discuss. Explanation can help them cope, and seeing you cry or get upset can help give them permission to do so too. This can help them to release some of their emotions.



"Our children wanted to avoid the 'MND' talks. But sometimes they are necessary and unavoidable."

Be aware of fear and distress – children may get frightened if they see a loved one becoming increasingly dependent, and at times upset or angry. Gently encouraging them to discuss what they are feeling can help the child to share their fears and worries. Reassure them that they are still allowed to have fun, as well as being sad sometimes.

Be clear and straightforward – finding the right words can be difficult, but it is important that children don't get confused or misunderstand. Tell them as much as they want to know in any particular discussion, using simple language they understand.



"It was a weird time, I didn't feel like a child because I was doing all this stuff to help care for her, and then the next minute my mum and dad would say I was too young to understand and not tell me things. I think they were trying to protect me, but it was really frustrating and I'd get really angry."

Dispel embarrassment – most children don't want to be thought of as 'different' and they may feel embarrassed about a parent who is becoming increasingly disabled. The more they understand that their loved one is the same underneath, the better they will deal with it. Their normal routines, such as friends coming round, should be retained for as long as possible.

How much should I tell them?

How much and how often you should talk to children about MND will depend on their age, maturity and how quickly the disease is progressing.

It can be helpful to ask the child what they already know, and what they want to know. This gives them permission to talk about things that are worrying them. This can help you assess their level of understanding or any misunderstandings they might have. Their questions may be very different to the ones you think they will ask.

Children tend to absorb information in bite-size pieces, so tell them a bit at a time. They may need to talk repeatedly about what has happened or ask questions at inappropriate times. This may impact on how you feel, but is natural for the child.

Sometimes they might not want to know anything or talk about the illness. This may be their way of coping and is not a sign that they don't care about what is happening.

How do I explain the disease to a child?

When discussing MND, it is important to use its name rather than saying the person is poorly or unwell. This can help them to avoid confusion or worry when someone has a less serious illness, such as a cold.

It can help to explain that the muscles aren't working properly, so the child can understand why someone is changing and growing weaker. You can start with things the child will already have noticed. For example, if the legs are affected, explain how this will make it increasingly difficult to walk.

We have publications specifically designed for children and young people of different ages to help them to understand more about the disease:

 See: *When someone close has MND* - a workbook for children aged four to ten, and *So what is MND anyway?* - a guide for teenagers

Explain how MND may affect communication. If someone with MND begins to speak differently or their facial expressions change, it might be misunderstood by a child. You can help by explaining, eg 'Uncle John is happy to see you, but he might not be able to smile in the same way.'

 *"I could understand my mum even when other people couldn't. Sometimes we'd just look at each other and I'd know what she was thinking. Then we'd start giggling."*

 For more information about communication and MND, see: Information sheet 7C - *Speech and communication support*

Explain if MND has affected thinking or behaviour, as up to half of people with MND may experience some changes to how they think and behave. These changes affect people in different ways. The changes are usually subtle and have little or no effect on daily life, but for some, the changes may be more apparent. Explain to the child that this is part of the disease, eg 'Gran might not act the same, but she can't help it. This is part of how MND affects her. She still cares about you but might not be able to show it in the same way.'

 For more information about how MND can affect thinking and behaviour, see: Information sheet 9A - *Will the way I think be affected?*
Information sheet 9B - *How do I support someone if the way they think is affected?*

Although it can be challenging, try to keep the child's routine as consistent as possible. If family routines need to change, explain why to avoid confusion.

What if my children are teenagers?

As they get older, children have a different level of understanding. They may seek out information on their own and may already know more than you realise. However, they still need to talk to you. Encourage them to share any information they have discovered. You can then check if the information is from a reliable source and if they have understood it correctly.

They may have feelings of responsibility as a young carer, or they may be at college and feel torn between home and student life. Encourage them to maintain their links with the outside world. Reassure them that their friends and activities are an important part in maintaining a balanced life.

 *“I found with my teenage son that I was dreadfully hurt by some of the comments he made. However, I realised over time that I was obsessing over my MND too much rather than accepting he was a teenager, who was likely at times to be surly and uncooperative and say hurtful things to a parent, no matter what the circumstances. In time I came to view this poor behaviour in a positive way, ie he was treating me as his dad!”*

Older children and teenagers often need to talk to their parent about their plans for when they grow up. Although these conversations can be difficult, they are likely to be glad to have had the chance in the future.

How do I explain about dying?

 *“When my mum told me that Gramps had MND I thought he would get better, but then she told me that they couldn’t cure him.”*

Telling children that someone close to them is going to die can be very difficult for you both. It is natural to want to protect your child from any distress – and yourself from dealing with that distress too. However, it is important for the child to understand what is happening and to feel included.

 *“The most important thing to know is that they won’t get better. That’s the main thing, even if it’s hard to tell young people and children. But we need to know or it’s going to be a huge shock.”*

What you say will be determined by the child’s age, maturity, experiences and the stage of the disease. Sometimes they may know more than you think. Whatever they understand, it is important for them to realise that even though someone they love will die, they can remember them and talk about them. They should be reassured that they are allowed to ask about their future after the person with MND has died, and can ask them for their advice and suggestions.

It is worth remembering that children have a very different sense of time – anything described as ‘in the future’ could mean tomorrow, so try to be aware of how they may interpret what you say.



“My son was aged 8 when I was diagnosed and we thought we had prepared him, but several years later he still thought I would get better. Sensitive subject but important to articulate early.”

It is important to dispel any fears your child might have about the actual process of dying. They may have no experience of someone close to them dying, and their only experience may be violent death in films or on the news. They should be reassured that this is not what happens with MND.



When you feel ready, we provide detailed information in our End of life guide, including Section 7: *Discussions with family and children*.

What should I do if they keep asking questions?

Children need to feel included in any situation that will directly affect them. Being able to ask questions and receive responses helps children to feel safe. It also helps them to start making sense of what is happening.

Children will often dictate how quickly you give them information by asking questions, especially if they feel comfortable to do so.

Younger children have shorter attention spans so may need to ask the same questions several times to help them understand more fully. This is a part of normal development.

When answering questions, it can help to:

Be truthful – don't be afraid to admit that you don't know an answer. If you promise to find out an answer you don't know, do this as quickly as possible. Don't claim not to know something simply to avoid the subject. Children can pick up very quickly if you are hiding something.

Be specific – answering one question at a time is often all that's needed. It is best not to use one question as the starting point for a whole range of information that might overwhelm them.

Be understanding – initially, a child might find it easier to talk to someone other than a parent, for fear of causing worry or distress. Another person can help the child to see that it is alright to talk openly and to share their feelings within the family.

Be open – children have vivid imaginations and it is difficult to predict what will worry them. For example, they may have practical concerns about who will take them to school, whether they can still go on holiday and so on.

Check their understanding – ask the child whether you have answered their question, or if they need more information. Be aware that as the child matures, their understanding will change. They are likely to ask more complex questions and expect more detailed answers.

What should I do if they don't ask any questions at all?

Some children can be frightened to ask questions if they are worried about upsetting you, or think they will get into trouble for asking. It may also be a form of self-protection – eg 'If I don't say anything, it might go away'. Telling them about how you feel and naming the emotions can help them to express their feelings.

A lack of questions should not be mistaken for a lack of interest – a child may need gentle encouragement to tell you how they feel and for you to find out the things they want or need to know. If you think this might be the case, ask gentle questions about how they feel. This may be all the permission they need to ask questions in return.

To help them open up, you could make a question box together. An old shoe box is ideal and can be decorated so it feels familiar and owned by the child. The child can write down any questions or concerns and 'post' them through a slit in the lid of the box.

You can then provide answers and help the child to discuss any fears. This can help by taking away the pressure of asking the question out loud. Some children may prefer for you to post your answers back in the box, so that they can read and digest the information in a time and space that feels safe for them.

It is important to remember to keep checking the box to see if they have 'posted' any new questions.

3: How do I manage the emotional responses?

Can I share my feelings?

Sharing your feelings with your child will help them to understand their own. Encouraging openness and sharing will help them at times of pain and sadness. This can strengthen the bond between you and bring you even closer as a family.



"The bit about showing emotion is very important I think. I admit, I wasn't able to do this, certainly not at first anyway. I felt as a parent I was supposed to be fireproof."

Don't be afraid to cry – for children, crying is very natural. If you are worried about distressing the child, it can help simply to let them know that you do cry in private and that this helps you.



For more information about managing the emotional impact of MND, see: Information sheet 9C – *Managing emotions*

How can I support them emotionally?

It is very difficult to predict how a child will respond to the situation, and it may be difficult to judge how they are feeling.

Children use a range of ways to let out their feelings, such as play and drawing. Watching their activities may be an effective way to begin to understand how they are feeling. It may be useful to ask teachers at the child's school about they are getting on and whether there are any concerns about their schoolwork or behaviour.

They may experience a range of emotions. Children might use anger to express their fears or anxiety, or even display jealousy at the attention their loved one is getting. Others may use denial as protection - they may withdraw or refuse to talk about the situation, hoping it will go away. This is a normal reaction.

The following suggestions may be helpful when supporting a child to come to terms with someone close to them having MND:

Special time – children need to be shown they are loved. If a parent suddenly cannot play with them or take them to school, they may interpret this to mean they no longer love them. It may help to ensure you have special times together.

Special tasks – finding ways for children to help their parent is a great way to make them feel involved and important.

Maintain routines for the child – keeping daily life as normal for the child as possible can help them to feel secure. Show them that life must go on and, if necessary, get outside help with routine things so that you have more time to spend with your child.

Memory books and boxes – many children and parents find comfort in putting together a special book or box filled with photographs and mementos of happy times. This will be a wonderful source of good memories for the child in years to come.



"Sometimes we do really cool stuff 'just because'. Like once we didn't have to go to school and we all went for a tour of Wembley stadium. That's a really good memory."

Digital legacies – you may wish to record video messages for your child, documenting your experiences and memories for them to view in the future. There are a range of websites that can help you create a digital legacy online, including suggested topics you may want to include. See *Useful organisations* in section 5: *How do I find out more?*

4: Who else can help?

Other trusted adults or appropriate organisations can help provide children with an outlet for any distress they may be feeling. Children and young people sometimes find it helpful to talk to someone outside of the immediate family.

This can be particularly important if the child has any difficulties outside of the home. For example, some children may experience bullying as a result of the situation and feel awkward telling you in case they upset you.



“You are supposed to tell your form teacher stuff, but I don’t like him so I talk to the science teacher instead and she is really understanding.”

Support and services are available to help children and young people through this difficult time:

School: inform the school of the situation as early as possible. It is possible that the staff won’t be aware of MND, and may need to access further information and support. Our helpline, MND Connect, can provide publications and guidance to help.

Teachers, school nurses and pastoral staff at your child’s school can be a real source of both emotional and practical support, such as:

- adjustments that help parents stay involved, such as a home visit instead of having to attend parent’s evening
- managing academic workloads
- advice about funding for school uniforms, lunches, school trips etc
- arranging transport with the local authority
- flexibility with time-keeping
- special consideration during exams
- signposting to further support
- linking the family with young carers organisations
- managing the child’s emotional and physical wellbeing.

Health and social care services: if the child’s parent or guardian has MND, an assessment from health and social care services should be arranged for the child, known as a young carer’s needs assessment. This will look at what help the whole family may need, and whether any children or young people need support or services, which can provide valuable help and information. You can find out more from your local authority in England and Wales, or from your local health and social care trust in Northern Ireland.

Young carers support: if the child is a young carer, there are support groups and projects offering support, information and activities across the UK. Contact your local authority, or in Northern Ireland, your local health and social care trust to find out what is available in your area.

Counselling: this talking therapy is used to help people come to terms with problems they are facing. GPs and school nurses can refer children to counselling services for emotional support. There may be a waiting list and sometimes there may be a charge for counselling services. School nurses may be able to provide some counselling and emotional support. There may be local services for bereaved children in your area and your GP can advise.

Some young people may need additional support from the local child and adolescent mental health services (CAMHS) if they are not coping with the situation. They offer assessment and treatment when children and young people have emotional, behavioural or mental health difficulties. Be aware there may be a waiting list.

Hospices: Some hospices employ staff who are trained to listen and help people make sense of their feelings. These services are not simply for the person who is living with MND, but for the family too. Ask your GP for a referral.



"I used to go see Marilyn at the hospice. She'd listen to how I was feeling and I could tell her things 'cos I knew she wouldn't get upset or tell anyone else."

The MND Association: Our MND Connect helpline offers a Young Connect service for children and young people. The team can provide information or simply listen:

Telephone: 0808 802 6262

Email: youngconnect@mndassociation.org

Some of the MND Association's local branches and groups offer family support. Contact MND Connect to find out what is available in your area.

Young Person's Grant: Our Support Services team offer grants to help young people affected by MND, up to the age of 18. Up to £250 can be awarded to a young person in any one year. This can be used for a range of purposes, such as a special day out to build a family memory or to redecorate the child's room. Contact the team for details:

Telephone: 01604 611802

Email: support.services@mndassociation.org

5: How to find out more

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin to search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see Further information at the end of this sheet for details).

Barnardo's

A charity supporting children across the UK, including services for young carers.

Address: Tanners Lane, Barkingside, Ilford, Essex IG6 1QG

Telephone: 0208 550 8822 (England)

029 2049 3387 (Wales)

028 9067 2366 (Northern Ireland)

Email: through the website contact page

Website: search for *young carers* at: www.barnardos.org.uk

Bullying UK

Help on bullying issues, with advice for children and young people.

Telephone: 0808 800 2222 (confidential helpline)

Email: through the website contact page

Website: www.bullying.co.uk/advice

Babble (for young carers up to age 18)

By Carers Trust, Babble is an online community for young carers up to age 18, providing an online space for friendship, support, advice and fun. See also *Matter* in this list.

Website: <https://babble.carers.org>

Child and adolescent mental health services (CAMHS)

Specialist NHS children and young people's mental health services, offering assessment and treatment when children find it emotionally hard to cope with daily life. Your child's GP or school can help you to access the service, or search online for Child and adolescent mental health services in your area.

Child Bereavement Charity

Support for families, children and young people during bereavement.

Address: Clare Charity Centre, Wycombe Road, Saunderton HP14 4BF

Telephone: 0800 0288840

Email: support@childbereavementuk.org

Website: www.childbereavementuk.org

Childhood Bereavement Network

Can direct you to support for bereaved children, young people and families across the UK. They have a directory of all local services for bereaved children.

Address: 8 Wakley Street, London EC1V 7QE

Telephone: 020 7843 6309

Email: cbn@ncb.org.uk

Website: www.childhoodbereavementnetwork.org.uk

Childline

Counselling and a free 24-hour helpline for children or young people in distress.

Address: 42 Curtain Road, London EC2A 3NH

Telephone: 0800 1111

Email: through website confidential login (does not need your real name)

Website: www.childline.org.uk

The Children's Society

Support and services for children, including young carers.

Address: Edward Rudolf House, Margery Street, London WC1X 0JL

Telephone: 0300 303 7000

Email: supportercare@childrenssociety.org.uk

Website: www.childrenssociety.org.uk

The Children's Society – Include Programme

Support and services for young carers.

Address: Edward Rudolf House, Margery Street, London WC1X 0JL
Telephone: 01962 711511
Email: through the website contact page
Website: www.youngcarer.com

Grief Encounter

Support for bereaved children and their families.

Address: The Lodge, 17 East End Road, London N3 3QE
Phone: 020 8371 8455
Email: contact@griefencounter.org.uk
Website: www.griefencounter.org.uk

Matter (for young adult carers 16 to 25)

By Carers Trust, Matter is an online space for young adult carers aged 16 to 25 to connect, share their experiences and access trusted support. See also *Babble* in this list.

Website: <https://matter.carers.org>

RecordMeNow

A free, downloadable app, for people to leave video messages for after their death, for children and family members.

Email: director@recordmenow.org
Website: www.recordmenow.org

Winston's Wish

Support for bereaved children, young people and their families.

Address: 3rd Floor Cheltenham House, Clarence Street, Cheltenham GL50 3JR
Helpline: 08452 030405
Email: info@winstonswish.org.uk
Website: www.winstonswish.org.uk

Young Minds

For guidance about the emotional wellbeing and mental health of children and young people. They do not operate a helpline for children, but can advise parents and guardians.

Address: Suite 11, Baden Place, Crosby Row, London, SE1 1YW
Helpline: 0808 802 5544 (for parents)
Email: ymentquiries@youngminds.org.uk (general enquiries)
Website: www.youngminds.org.uk

Youth Access

A national membership organisation for young people's information, advice, counselling and support services.

Address: 1-2 Taylors Yard, 67 Alderbrook Road, London SW12 8AD
Telephone: 020 8772 9900
Email: admin@youthaccess.org.uk
Website: www.youthaccess.org.uk

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References

References used to support this information are available on request from:
email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Further information

We provide the following publications to help children and young people find out about motor neurone disease:

When someone close has MND: a workbook for children aged four to ten - an activity workbook to help children understand about the disease and develop ways to cope, with guidance from a trusted adult.

So what is MND anyway? A publication informing young people about MND from the point of someone's diagnosis and throughout their journey. This resource was developed with contributions from young people affected by MND in their family.

This is also available as a web app at: www.mndassociation.org/ypapp

We also have a web page for young carers, which gives details about these publications, our services and ChildLine: www.mndassociation.org/ypinfo

If young people would like to talk about MND with our helpline, MND Connect, they can contact the team.

Telephone: 0808 802 6262

Email: youngconnect@mndassociation.org

You can download most of our publications from our website at: www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support:



MND Connect

MND Association, PO Box 246, Northampton NN1 2PR

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association website and online forum

Website: www.mndassociation.org

Online forum: <http://forum.mndassociation.org> or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25

Or request a paper version by email: infofeedback@mndassociation.org

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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