MND Association | For professionals

Supporting children and young people affected by MND

About Motor Neurone Disease

Today, six people

will be told they have MND and six people will die from the disease. There is no cure.

MND is a fatal, rapidly progressing disease.

It affects the nerves in the brain and spinal cord that control muscles.

A third of people will die within a year of diagnosis.

More than half will die within two years.

People may lose movement, speech, swallowing and breathing.

This affects quality of life for them and those around them.

MND doesn’t discriminate.

It affects people from all backgrounds and at all ages.

People with MND may experience changes in thinking and behaviour.

Some develop frontotemporal dementia, with more severe changes.

MND affects everyone differently.

Symptoms progress at different speeds and a different order for everyone.

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Introduction

Motor neurone disease (MND) is a progressive, fatal disease that attacks the motor neurones, or nerves, in the brain and spinal cord. It can affect how people walk, talk, eat, drink, breathe and think, however not all symptoms affect everyone. There is no cure for MND, but symptoms can be managed to help improve quality of life.

A diagnosis of MND can feel overwhelming for the whole family. Children and young people close to someone with MND may seek out a trusted adult to ask questions about the disease. However, the adult family members may need time to come to terms with the diagnosis before explaining to a young person.

This guide has been developed to help professionals working with children and young people to understand the disease and its impact, and help the family access appropriate support. It may be particularly useful for school staff, youth workers and social workers.

It is important to find out how much the child understands before trying to offer support. They may not be aware of the diagnosis or that MND is a terminal disease.

Contact our MND Connect helpline if you have any questions about MND. Call 0808 802 6262 or email mndconnect@mndassociation.org

A note to parents and guardians

Although this guide has been written for professionals, we hope you will find it useful too. It can signpost you to further support. You may also find it helpful to share a copy of the guide with your child's school or any professionals working with them.

Please note that some of the language used in this guide is deliberately direct to have maximum impact with professionals. The resources listed on the next page have been specifically designed for children, young people and families and use gentler language.

Helpful resources

The MND Association has a wide range of information and support for people with MND, as well as their carers and families.

Telling people about MND: How to open conversations about MND with family, children, friends, colleagues and health or social care professionals. This guide includes information on difficult conversations, planning ahead and using advocates.

Information sheet 10G: Support for families with children: Information sheet to help families with children access extra help and financial support.

When someone close has MND: Our activity workbook for 4—10 year olds to enable a trusted adult to talk to a young child about MND.

So what is MND anyway?: Our guide about MND for young people and young carers aged 11—18. It is also available as a web app.

MND Buddies: Our online activity hub can help young children find out about MND in a gentle way, through games and stories. **mndbuddies.org**

Storybook - Why are things changing?: Features families affected by MND. The three stories can also be listened to on the MND Buddies activity hub above.

Children and Young People's (CYP) Team: The MND Association's CYP team delivers holistic, trauma-informed support for children, young people and families affected by MND, including:

- national 1:1 support for families with children and young people (up to age 25), pre- and post-bereavement
- specialist counselling tailored to MND-related grief, anticipatory grief and emotional wellbeing
- memory boxes and memory days to help families create and preserve meaningful memories

- working with schools and colleges to promote understanding, stability and appropriate pastoral care
- age-appropriate conversations about MND, dying and bereavement to help children and young people understand and process what's happening
- volunteer-led emotional and practical support
- collaborating with health and social care professionals to ensure families receive high-quality co-ordinated care.

Find further resources for families affected by MND at **mndassociation.org/cyp**, or email CYP@mndassociation.org for further information and support. See page 35 to learn how to download or order printed publications.

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The effects of MND

This section describes the effects of MND to help you understand what the child or young person may be experiencing and trying to cope with, either now or in the near future. MND affects each person differently. People can be affected by any of the possible symptoms listed below, at any time and in any order.

We have a wide range of publications about the symptoms of MND. See page 35 and **mndassociation.org/publications** to find out more.

Movement and getting around

When nerves are affected by MND, messages from the brain no longer reach the muscles, making it difficult for the person to control or use those muscles. If muscles are no longer used, they tend to decrease in mass, known as wasting. This causes weakness and can affect balance and posture. The person may experience painful cramping and spasticity, which causes the muscles to become stiff and tight, making them harder to move.

Muscle wasting cannot be reversed. As MND progresses, more nerves and muscle groups are affected. The person is likely to use a walking frame, wheelchair, or other mobility aids to get around.

Breathing

With MND, the muscles involved in breathing can weaken, leading to shortness of breath and fatigue. Breathing difficulties can become severe over time and are a common cause of death in MND.

The person may use a machine known as a ventilator to help them breathe. Some people may wear a face or nose mask (known as non-invasive ventilation or NIV). A small number may have a breathing tube inserted directly into their neck (known as tracheostomy).

Communication

For some people with MND, muscles in the throat, mouth and chest become weak. This can cause speech to become slow, slurred and unclear. Weakened breathing can cause speech to become faint.

The person may use a communication aid or rely on support from others to communicate. Communication aids can be as simple as a pen and paper, or they can be high-tech computerised systems, depending on the person's needs.

It is important to ensure that health and social care professionals offer a range of ways to communicate and check what method the person prefers. They should also help the family with using the communication methods chosen by the person with MND. Text messages, emails or letters may be more appropriate than phone calls if speech is affected.

Swallowing problems

As the muscles in the throat and mouth become weaker, swallowing can become difficult. This can affect the person's ability to eat, drink and clear saliva. They may dribble saliva, food or drink from the mouth.

Some people may cough or choke when eating or drinking. These episodes can be distressing for both the person with MND and those around them. People with MND may use a feeding tube which passes specially prepared liquid feed directly into the stomach. This is known as a gastrostomy, or PEG.

Thinking and behaviour

Around half of people with MND experience changes in how they think and behave. It can also affect their use of language. These changes affect people in different ways. For many people, these may be subtle and the person may compensate or work around these issues. For others, the changes may be more apparent.

A few people also develop frontotemporal dementia (FTD), which involves severe changes to behaviour and use of language.
FTD is different from other forms of dementia such as Alzheimer's disease and it doesn't usually involve memory loss.

When someone experiences cognitive or behavioural changes, they may find it harder to think, focus, interact with others or plan like they used to. They may show a lack of empathy, which can make them seem selfish or uncaring of others' emotions. Sometimes, they might become disinhibited and act in socially inappropriate ways.

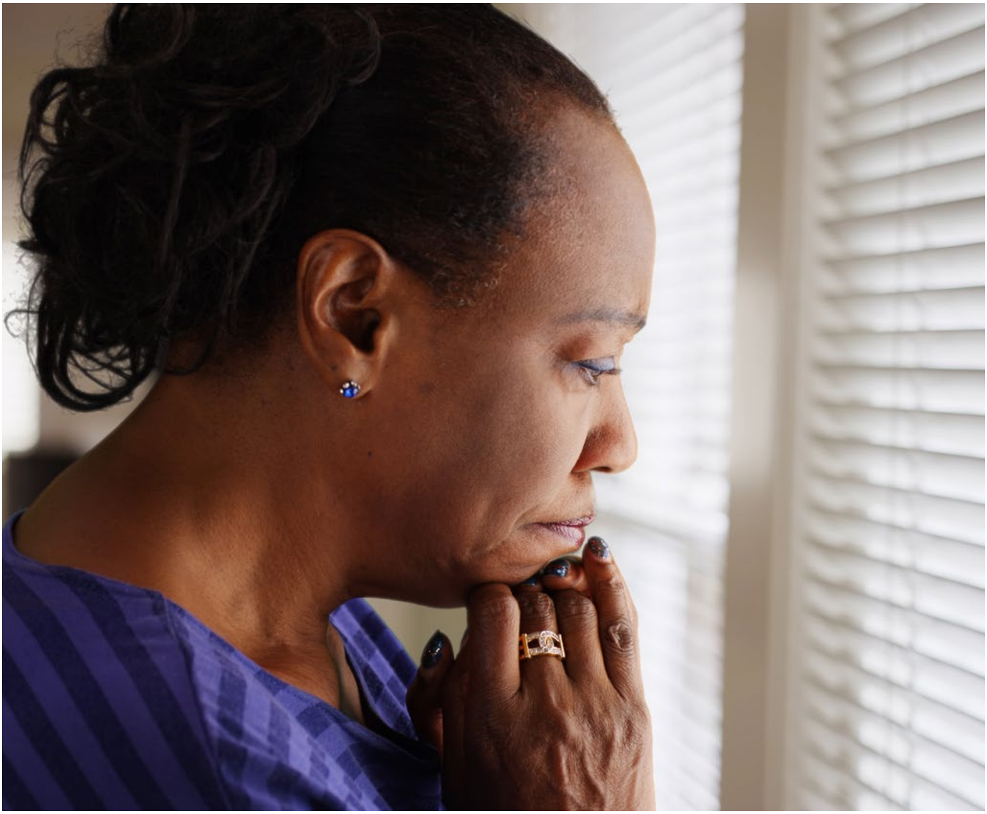
These changes can be difficult for the people around them, and they might be confusing and upsetting to the young person. It's important to provide support and reassurance, and explain that these behaviours are not personal, but a symptom of MND.
See page 14 to learn more about approaching conversations about MND.

Some people experiencing behavioural changes may become irritable, verbally aggressive or physically aggressive. This can be very difficult for the entire family. Sometimes, it can also pose a safeguarding concern.

Emotional lability

People with MND might experience emotional lability, known as pseudobulbar effect. This causes them to uncontrollably laugh or cry at inappropriate times. These reactions are involuntary and do not reflect what the person is actually feeling. For example, the person might laugh during a funeral or when they are in pain.

These reactions can be embarrassing and upsetting, and they might seem callous or unfeeling. They might also be confusing for a young person. Explaining that emotional lability can be part of MND and helping understand this symptom can be reassuring. However, for some people, emotional lability may be limiting and affect what they comfortably do or where they go.



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Providing support

Emotional support

Communicating to anyone about MND is not easy, but this can feel particularly challenging when children and young people are involved.

Information for people affected by MND:

Booklet – Telling people about MND
Booklet section – Family, children and friends (“Living with motor neurone disease”, section 5)
Booklet section – Support for children and young people (“Caring and MND: support for you”, section 9)

See page 35 to order publications

Why do children need to know about MND?

Wanting to protect children from upsetting news is natural. However, helping them to understand what is going on can reduce feelings of shock and support them to prepare for the future.

Without appropriate information and understanding, children and young people may:

- use their imagination to provide answers, which can be far more distressing than reality
- feel left out of conversations
- think that it is somehow their fault that someone has MND
- search for information on their own, which may not come from a trustworthy source
- find out from someone else
- worry that they or other people will also become ill.

How do I approach conversations about MND?

How to approach conversations with children and young people will depend on their age, maturity and how quickly the disease is progressing. It is important to use language appropriate to their age and level of understanding. The following suggestions may help:

Check what they already know: it can be helpful to ask children or young people what they know and what they want to know. This gives them permission to talk about things that are worrying them. Their questions may be very different to what you expect.

Older children may seek out information on their own. Encourage them to share what they know, so you can see whether it has come from a reliable source and has been understood correctly. Try asking the child or young person simple questions to check whether they have understood what you have said. This can also help them ask more questions, and it can help you assess what else needs explaining.

Use clear language: when discussing MND, it's important to use its name rather than saying the person is poorly or unwell. This can help avoid confusion or worry when someone has a less serious illness, such as a cold. Use age-appropriate language to help them understand, and avoid using euphemisms. Find age-appropriate resources on **mndassociation.org/cyp**

Provide information piece by piece: try not to tell them everything at once. They may ask questions when they are ready to know more, or you can try telling them another small chunk of information at a later time. They may need to talk about something repeatedly, or ask questions at inappropriate times. This is natural for a child but may be difficult for you at first.

Be honest: although protecting children from feeling upset seems the kindest thing to do, they may pick up on parts of conversations or people's emotions. Being honest with them and not providing false reassurance will help them trust you and feel included.

Gently prepare them for the future: it may help to explain what might happen in the future, so that they can understand that MND will get worse. This may also help reduce a sense of shock if they see the person change both physically and mentally.

Explain what they can see: it can help to explain that the muscles are not working properly, so the child can understand why the person is changing and growing weaker. Start with things they will have already noticed. For example, if the person's legs are affected, explain how this will make it harder to walk. Explaining what they can still do may help keep conversations positive but maintaining gentle honesty about future changes is important.

Explain speech and communication difficulties: MND may affect communication or facial expressions. Explain that if this happens, it's caused by MND and it's not how the person feels about them. Some families gradually create their own way of communicating, where certain body or eye movements mean different things.

Explain changes to thinking and behaviour: as these changes can be very upsetting, acknowledge and validate how it makes them feel and reassure them that this is part of the disease. For example "Your 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".

Dispel embarrassment: most children do not 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.

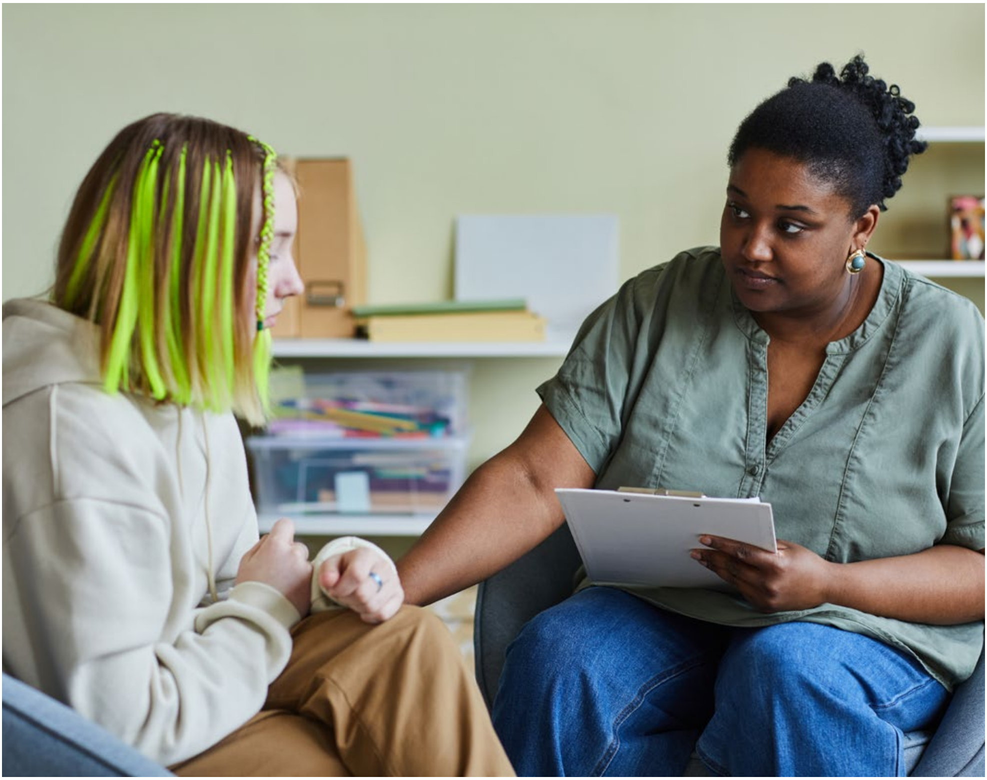
Reassure them: children may get frightened if they see a loved one becoming increasingly dependent, and at times upset or angry. Gently encouraging them to discuss what they are feeling can help the child to share their fears and worries. Reassure them that they are still allowed to have fun, as well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

What if they don’t want to talk?

Sometimes the child or young person might not want to know anything or discuss the illness. This may be their way of coping and is not a sign that they do not care about what is happening.

Some children may be frightened to ask questions if they are worried about upsetting others or think they will get into trouble for asking. It may also be a form of self-protection along the lines of, “If I don’t say anything, it might go away”.

Try to gently ask the child or young person how they are feeling. This may be all the permission they need to ask questions about MND in return. They may want to talk but be afraid of how to start the conversation. It can be useful to try to talk to them while you are doing something together, such as on a walk or while playing.



Support at school

Schools, colleges and universities can offer a wide range of support to a child or young person affected by a parent having MND. It can be very helpful to highlight the family's situation, and ensure the staff know about MND. It may be helpful to give them a copy of this guide.

Parents and guardians gain positive benefits from continued involvement in their child's education. The increasing challenges and care demands of MND may make this more difficult as time goes on.

If you are a member of the school staff:

- be prepared to change meeting arrangements to meet the family's needs. It may not be possible for a parent or guardian to attend parents' evening, so a home visit or video call may be necessary
- if the child is providing care, ensure they are introduced to the school's young carers' lead and acknowledged as a young carer, if they want to
- anticipate and plan contact between the school and home
- keep in regular contact with the family
- provide early access to an individual and flexible academic plan that allows more time for homework or coursework, and extra help if needed
- budget and plan for any specialist services, for example bereavement support
- know how to contact and make a referral to local services
- communicate with colleagues about any potential challenges that could affect the child or young person
- offer enrichment activities such as sport, music, art or drama, but be aware that some children might not want to engage in these if it makes them feel they stand out as being different from their peers

- plan any absence you might need to ensure continuity of support, including informing colleagues of arrangements
- consider an event to raise awareness of MND. However, this may make the child or young person feel like they stand out so investigate with them and their family on what they feel comfortable sharing or how the event can be run without openly disclosing their situation
- include information about bereavement, children's rights and young carers in the curriculum. Ensure the family are aware of the specific lessons to avoid shocking or upsetting them.

Work with the family to develop a care emergency plan or crisis plan. It can help if there is:

- an emergency involving the child or young person at school
- an emergency at home, for example the person with MND needs urgent medical help.

This plan should contain a list of emergency contacts, including the child or young person's GP. It should also state that the person with MND may not be able to take or collect their child, and what to do in this situation.

Early help assessment

A good working relationship with the family can give early insight into any difficulties or potential problems. A wide range of interventions may be required to support a child. As MND progresses, support should be flexible to meet an ever-changing environment at home.

An assessment of need and a good support package can help children and families to access appropriate support as early as possible. This can help them maintain their quality of life and address any problems that could prevent a child from reaching their expected milestones.

Families can be referred for an early help assessment, which identifies children and young people who require additional support, and their needs. Any service aware of a child or young person who has additional needs can request this through the local authority, or Health and Social Care Trust in Northern Ireland. This should be discussed with the family.

An early help assessment ensures that there is a team of people around the young person who ensure their needs are met as planned. The support package might include:

- help with parenting, where a parent's physical ability makes this difficult, such as preparing a meal or getting a child ready for school
- interventions that support emotional wellbeing, such as group sessions delivered by appropriately trained specialists
- help with benefits and entitlements
- identification of potential problems or risks that might need future intervention. For example, support with speech and language development for very young children where a parent has deteriorating speech.

Supporting young carers

We offer a wide range of support for unpaid or family carers of people with MND. This includes publications, other resources and access to our services, such as support funds for carers.

Visit **mndassociation.org/carers** for further information.

What is a young carer?

Young carer: someone aged under 18 who provides care or support to a family member or friend with an illness or disability, mental health condition or an addiction.

Young adult carer: a young person aged 16–25 who provides unpaid care or support to a family member or friend with an illness or disability, mental health condition or an addiction.

It is important to be aware that children and young people may not identify or recognise themselves as carers, and may not feel comfortable with this label.

What care might young people be providing?

Care needs for people with MND will significantly increase as the disease progresses. Statutory services may struggle to keep up with the person's needs, which may change rapidly. This increases the burden of care on families.

Children and young people who live in a household where someone has MND are likely to provide a level of care at some point such as:

- offering emotional support, comfort and help with hobbies and leisure activities
- helping the person with MND to communicate when speech is affected or absent
- managing household finances, such as paying bills and budgeting

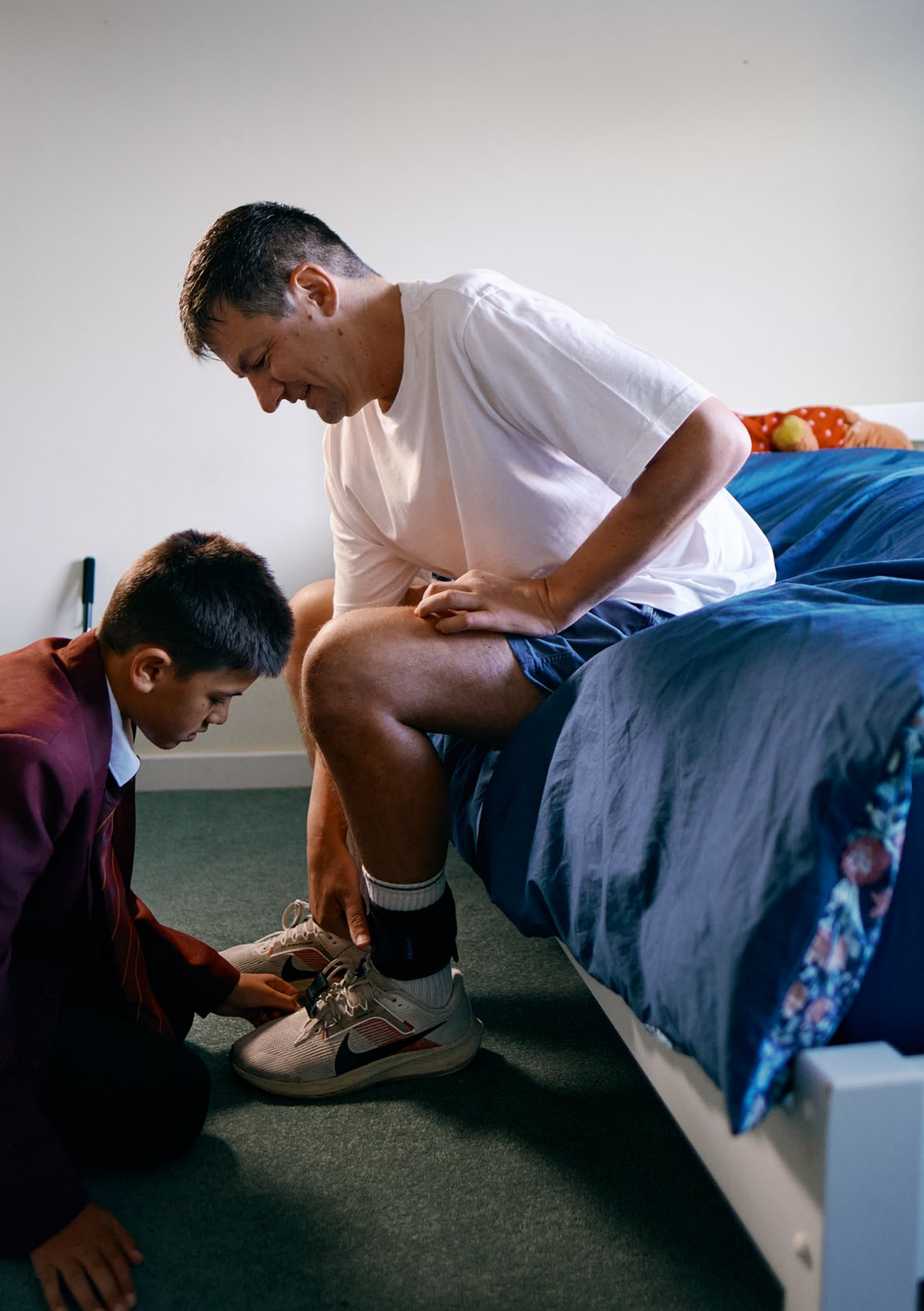
- providing advocacy on behalf of the person, for example telephone calls, contacting services and support organisations
- liaising with health and social care professionals, making appointments and accompanying the person with MND
- collecting prescriptions, administering medication or assisting with medical equipment
- shopping, managing housework, laundry, gardening and home maintenance
- caring for younger siblings or looking after visitors
- preparing meals or assisting with tube feeding
- lifting, hoisting, providing care at night and delivering personal care, such as bathing and dressing
- supporting a person who has cognitive changes or dementia.

Young carers' needs assessment

Young carers are entitled to a young carers' needs assessment from the local children's social care services department, based within their local authority, or Health and Social Care Trust in Northern Ireland. They have a legal duty to assess the young carer's needs if the child or their parents ask them to. This may help the young carer and the person they care for to access practical support and information about other sources of help, including local carer organisations.

Young carer and young adult carer groups may offer help and guidance to children, young people and adults who work with or support them. Referral to a local young carers' group can be a great way for young people to have shared experiences which can reduce feelings of isolation.

Some groups offer opportunities to attend trips and events with other young people of a similar age, providing respite and support. It's important to include the child in discussions about the referral to ensure they want to become involved.



Financial support

When a parent or guardian has MND, the household income may reduce significantly. A parent or guardian with MND may be unable to continue working, if they were previously doing so. Their partner or spouse, if they have one, may need or choose to give up work to provide care, or take up work to support the family financially. Older children may need to help subsidise the family income by working.

Families may struggle to provide essentials. Days out, holidays and treats are likely to reduce or disappear. Quality and standard of life may be affected for all family members. Effects could include:

- a reduced income compared to a family unaffected by MND
- an increasing reliance on benefits
- reduced standard of living
- resentment, sadness or anger about the circumstances
- anxiety and embarrassment.

What help is available?

You could talk to the family about benefits to support their child's education. This can help them plan and manage a decreasing income, reducing anxiety and worry. Remember to approach conversations about financial support sensitively, as these may cause feelings of stigma.

A family experiencing severe financial crisis may benefit from referral to a local food bank and local authority social care services for additional emergency support. This can be a very sensitive subject and must be handled with care.

You may also need to assist the family to apply for extra support or signpost them to services that can help, including local charities or organisations providing academic funding or financial support, such as hardship grants or loans.

Young carers aged 16 or older may be entitled to financial benefits, such as the Carers Allowance, provided they are not in full-time education. As this could affect other benefits that they or the person they care for receive, it's important to always seek advice. The MND Association offers information about benefits and financial support that people with MND, their carers and families may be entitled to. For further details, visit **mndassociation.org/benefits**

We also offer a Benefits Advice Service, where qualified advisers can help the person with MND, carers and families identify what they are entitled to and how to claim. This service is confidential, impartial and free. Learn more on **mndassociation.org/benefitsadvice**

Additionally, we are able to offer some financial support to help with:

- cost of living, including food costs and household bills
- equipment, technology and services that people with MND have been assessed as needing, including respite care, communication aids, contributions towards adaptations
- improving the wellbeing of people with MND, non-paid carers and young carers, children and young people, including holidays, school trips, home maintenance and driving lessons.

The support funds are not in place of any statutory funding, equipment or services that should be available. We can assist with obtaining funding from other charitable organisations. Visit **mndassoc.org/supportfunds** for details.

The child or young person's education provider will likely have access to a range of funding and support that may help the family, such as:

- free school meals
- help to buy school uniforms
- funding for school trips
- arrangements for travel to and from school
- discretionary school funds.

Supporting health and wellbeing

Children and young people have their own health needs. Childhood illness, dental care, health checks and immunisations are part of normal life. Challenges to the child or young person could be:

- missed routine appointments as MND becomes the focus
- increased risk of physical injury due to inappropriate levels of care
- severe cognitive and behavioural changes, posing potential safeguarding issues
- poor nutrition due to irregular or unbalanced meals (they may be preparing their own meals)
- lack of sleep, due to care responsibilities or worries
- increased susceptibility to illness, infection and injury as a result of fatigue and poor nutrition
- missing out on activities with peers, which can affect their sense of self, identity and mental wellbeing
- poor mental health, which could also impact physical wellbeing
- increased risk of being bullied by their peers.

How can I support a child or young person’s physical health?

Every child or young person should be able to attend their personal health appointments in order to keep well. These may include GP, dentist, health visitor, immunisation or development check-ups.

Families may need referral or support to make and attend appointments for their child. Maintaining good communication between all professionals and home may help identify what support is needed for a child or young person to remain well.

Using resources that are already available within the environment can be beneficial. Exercise is good for physical wellbeing and mood. Support to attend activities, such as dance or sport may help.

It may be possible to support a young person to access free or reduced sports centre membership. This could also give respite from caring. It may be difficult for the family to get the child to and from the centres, so travel arrangements should be considered.

Be aware that some children may not want to engage in these activities because they are worried about their parent and don’t want to be away from home.

It’s important to validate their feelings. Reassure them that it’s okay not to participate, encourage them to express their feelings and what they might want to do instead.

Bereavement support

Despite being aware that MND will end the life of a loved one, the reality of death can come as a huge shock. For families where MND has progressed rapidly, there may have been little time to come to terms with the diagnosis. For some families, death can feel like a relief from the disease and the burden of caring.

The family may have become accustomed to a busy household full of equipment and visiting professionals. Once the person has died, the equipment is removed, and the visitors stop. This may also trigger an emotional response.

Very young children may not understand that death is final and may be expecting the person to return. The child or young person's response to bereavement will be individual. Support to help them express emotions and ask questions is beneficial.

Offering the family time to come to terms with their situation is essential. The family will need time and space to grieve. For younger children, the routine and normality that school offers may help them to build resilience and manage their emotions. Providing flexibility, a period of absence and reducing non-essential academic tasks, study or exams may also reduce pressure.

It is normal for academic performance and concentration to be affected in the first few weeks or months (or longer, in some cases) following a bereavement. Good communication among professionals in contact with the young person may help prevent difficult, embarrassing or upsetting situations that could occur.

After the death of the person with MND, certain dates or anniversaries may trigger an emotional response. Curriculum areas may present a challenge, such as Father's Day or Mother's Day.

A child may still wish to participate in celebrating their relationship to the person who died, but be mindful that they may need support. Taking part should not be discouraged. It can help a child feel close to the person who has died.

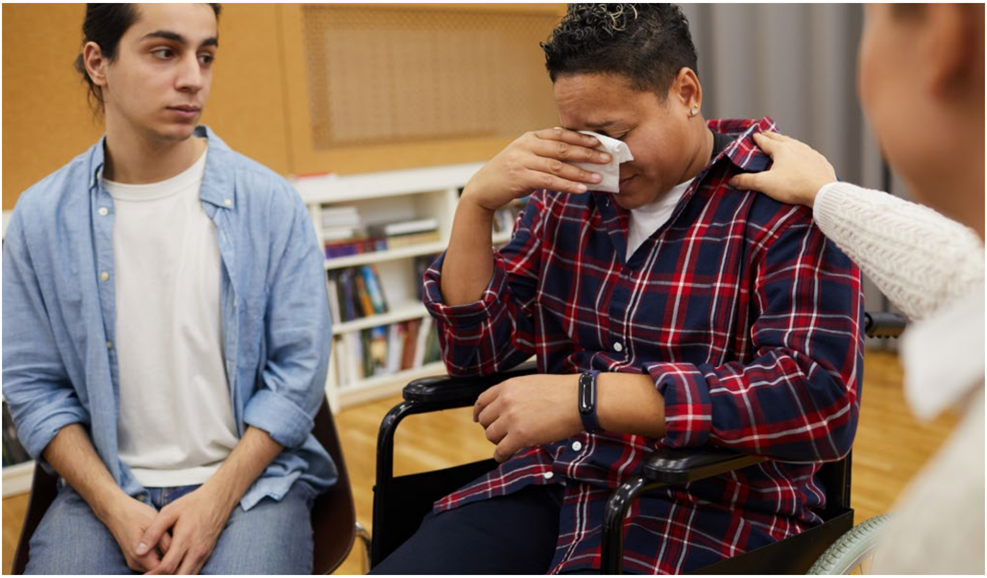
We have a range of information and support for people experiencing bereavement. Our MND Connect helpline can signpost to information, offer a chance to talk and provide guidance about any relevant services, including external ones.

Visit **mndassociation.org/bereavement** for details on the support available.

Information for people affected by MND:

Booklet – Finding your way with bereavement
Booklet section – Discussions with family and children
("End of life: a guide for people with MND", section 7)

See page 35 to order publications



Useful organisations

See other useful websites at: **mndassociation.org/usefulorgs**

Social care services (Children's or Adults')

Contact your local authority, or Health and Social Care Trust if you live in Northern Ireland, who can provide advice and access to social care assessments and services.
Website: **gov.uk** (England and Wales)
nidirect.gov.uk (Northern Ireland)

Barnardo's

A charity supporting children across the UK, including services for young carers.
Telephone: 020 85508822 (England)
029 20577074 (Wales)
028 90672366 (Northern Ireland)
Website: **barnardos.org.uk**

Child and adolescent mental health services (CAMHS)

NHS services that assess and treat young people with emotional, behavioural or mental health difficulties. A referral can be made by a professional, such as the GP or school.

Search online for child and adolescent mental health services in your area or your local NHS trust website should have the details. If you live in Northern Ireland, you can ask your local Health and Social Care Trust for details.

Childhood Bereavement Network

This organisation can direct you to support for bereaved children, young people and families across the UK.
Website: **childhoodbereavementnetwork.org.uk**

Child Bereavement UK

Support for families, children and young people during bereavement.
Telephone: 080 00288840
Email: ask@childbereavementuk.org
Website: **childbereavementuk.org**

Childline

Counselling and a free 24-hour helpline for children or young people under 19 in distress or danger.
Telephone: 0800 1111
Website: **childline.org.uk**

The Children's Society

Support and services for children, including young carers.
Telephone: 0300 3037000
Email: supportercare@childrenssociety.org.uk
Website: **childrenssociety.org.uk**

MND Scotland

Support for people affected by MND in Scotland.
Telephone: 014 13323903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

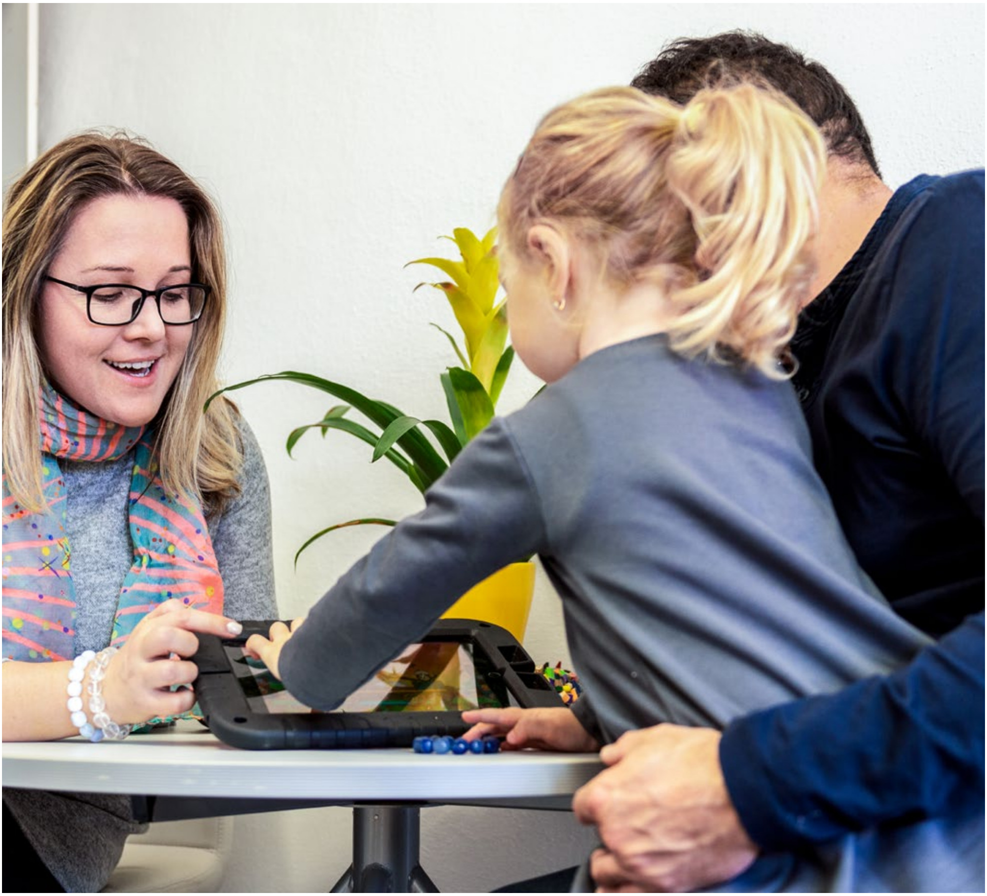
Young Minds

An organisation providing guidance about the emotional wellbeing and mental health of children and young people.
Telephone: 080 88025544 (Parents Helpline)
Telephone: 020 70895050 (General enquiries)
Email: ymenquiries@youngminds.org.uk
Website: **youngminds.org.uk**

Youth Access

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

Email: admin@youthaccess.org.uk
Website: **youthaccess.org.uk**



How we can support you

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide information about our services mentioned below.
Email: mndconnect@mndassociation.org
Tel: 0808 802 6262

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for health and social care professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals’ Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of support funds for people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on research for people with or affected by MND.
mndassociation.org/research

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We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to **education@mndassociation.org**.

If you would like to help us by reviewing future versions of our information resources, please email us at **education@mndassociation.org**.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call **0808 802 6262** or email **mndconnect@mndassociation.org**.

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**Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.**