

## Supporting children and young people close to someone with motor neurone disease (MND)



**Information for professionals working with children and young people in education, training or employment.**

## Who is this guide for?

This booklet is for any professional working with children or young people who have a parent, guardian, grandparent or close relative with motor neurone disease (MND). Families have told us they need more support to help their children cope when a relative has MND. They would like more help to access services that may benefit their child's future aspirations, health and wellbeing.

You may work within a setting such as:

- teaching
- private or sessional tutoring
- school nursing
- pastoral support services
- social work
- student support services
- spiritual support
- youth work
- an organisation offering traineeships and apprenticeships
- a workplace that employs young people.

This guide will give you information about MND and the impact that a relative's diagnosis may have on a child or young person. It is designed to help you support a young person to stay in education, training or work and, if relevant, how you can ensure a person with MND remains included in their child's education. It can support you to help the young person achieve positive outcomes in education, health and wellbeing.



"I was 10 when he was diagnosed. I think repeated messages and really clear explanations might help at this age. You need someone to help you understand ... young people have creative minds. I used my imagination to fill the gaps and created scenarios."

- a young person affected by MND

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# What is MND?

Motor neurone disease (MND) is a progressive disease that attacks the motor neurones, or nerves, in the brain and spinal cord that control how muscles work. This means that messages gradually stop reaching the muscles, leading to stiffness, weakness and wasting.

MND can affect how people walk, talk, eat, drink, breathe and think. However, not all symptoms happen to everyone and it is unlikely they will all develop at the same time, or in any specific order. There is no cure for MND, but symptoms can be managed to improve quality of life.

## **Key facts about MND:**

A person's lifetime risk of developing MND is up to 1 in 300.

MND affects up to 5,000 adults in the UK at any one time.

Around 35% of people with MND experience mild cognitive change, which can cause difficulties with planning, decision-making and language.

A further 15% of people with MND show signs of a form of dementia resulting in more pronounced changes in thinking, language and behaviour called frontotemporal dementia (FTD).

MND kills a third of people within a year and more than half within two years of diagnosis.

Six people are diagnosed and a further six die from MND every day.

MND affects people from all communities.

## The effects of MND

MND affects each person differently and not everyone will have all of the symptoms. People can be affected by any of the possible symptoms, at any time and in any order.

### Movement and getting around

When motor neurones are affected by MND, messages no longer reach related muscles. If a muscle or group of muscles are no longer used, they tend to decrease in mass, known as wasting. This causes weakness and can affect balance and posture. Muscle wasting cannot be reversed. The person may experience:

- falls
- painful cramps
- twitching in the muscles
- lack of co-ordination
- inability to move parts of the body independently.

As MND progresses, the person is likely to use a walking frame, wheelchair, or other mobility aids to get around. They may also use a head support or arm supports to help their posture.

### 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
- speech to sound hoarse, low pitched and monotonous
- weakened breathing, which causes speech to become faint
- difficulty making certain sounds.

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.

## 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 from the mouth. They may:

- lose weight
- dribble saliva, food or drink from the mouth
- cough or choke when eating or drinking.

The person may require support from a carer to eat or drink if their arms are affected. They may use a feeding tube which passes specially prepared liquid feed directly into the stomach.

## Breathing

With MND, the muscles involved in breathing can weaken. This can lead to:

- shortness of breath
- morning headaches or daytime sleepiness
- higher risk of chest infections
- increased sleeping
- everyday routines becoming increasingly tiring.

The person may use a ventilator to help them breathe.

## Mental and emotional wellbeing

For most people, a diagnosis of MND can feel devastating. They may experience a range of emotions and feel overwhelmed. Some people may experience depression.

Some people with MND experience a symptom known as emotional lability, where they tend to laugh or cry at inappropriate times. This can cause embarrassment or distress for both the person with MND and others.

## Planning, decision-making and language

Up to half of people with MND experience some changes to how they think and behave. These changes affect people in different ways. For many people, the changes are usually subtle and have little or no effect on daily life. For some, the changes are more apparent and intensive support may be needed to manage daily routines.

The person may experience changes to their:

- thinking and learning
- language and communication
- behaviour and emotions.

It can become difficult for the person to make and carry out plans. They may lack empathy and have difficulty recognising emotions in others.

A small number of people with MND develop frontotemporal dementia. This can have a major effect on the person's behaviour, and they may become aggressive at times.

## What support can help the person with MND?

Although there is no cure, support is available to help manage the symptoms of MND and improve quality of life. A person with MND and their family are likely to be in contact with a wide range of support services. This could include:

- a multidisciplinary team of health and social care professionals to help manage symptoms
- mental wellbeing services
- social care and help to access equipment
- help with claiming benefits and entitlements
- services that support people before and during bereavement
- palliative and end of life care specialists.

## **Information to share with the family:**

We provide a wide range of information sheets to support people living with MND to manage their symptoms. These include:

*7A – Swallowing difficulties*

*7C – Speech and communication support*

*8A – Support for breathing problems*

*9A – Will the way I think be affected?*

*9C – Managing emotions*

*11D – Managing fatigue*

We also have core guides about MND:

### ***Living with MND***

This is our main guide to support people living with MND, which has been developed to help manage daily routines and achieve the best possible quality of life from diagnosis onwards.

### ***Caring and MND: support for you***

Comprehensive information for carers supporting someone living with MND. This guide is designed to support individual needs during the caring role.

### ***So what is MND anyway?***

A comprehensive guide about MND for young people, including young carers.

### ***When someone close has MND***

An interactive workbook to help a trusted adult communicate about MND with children aged between four and ten years.

**If you or the family need more information about any aspect of MND, contact our MND Connect helpline on 0808 802 6262.**

# The impact of MND on a child or young person

MND can affect many aspects of life for the whole family. The increasing needs of the person with MND, possible reduced family income and changed quality of life can all impact on children. The transition to adulthood for some young people can be complicated and more stressful than it may be for their peers.

Families may become inward-looking, with the focus on MND. A child or young person may experience:

- an increased feeling of isolation and of being different
- reduced freedom to act on impulse, such as visiting a friend or a going for a drink after college or work
- missing out on activities that cost money
- limited social and recreational time due to caring responsibilities
- problems making and keeping friendships
- difficulties fitting in due to their responsibilities and experience at home
- anxiety about situations where talk turns to MND
- falling behind with their studies
- not being able to cope in social situations as self-esteem may be affected
- panicking at school.



“Dad couldn’t drive anywhere and I couldn’t have my friends around because so much was going on in the house. So I didn’t really have much of a social life.”

- A young person affected by MND

Some young people may already be separated from a parent by death, divorce or as a result of care proceedings. For these children and young people, the additional challenges of MND in the family can be vast and may lead to an even greater sense of isolation.

A diagnosis of MND can feel overwhelming for the whole family and there will be a period of readjustment. A parent or guardian may need time to come to terms with the diagnosis before explaining to a young person.

Finding the right words and choosing the right time can be difficult. However, if the situation is not explained, children may make their own conclusions. This can lead to greater worry and they may even blame themselves. Some families may need support following this conversation.



*“Mum says she told me about the diagnosis, but I don’t remember it at all. I think I blocked it out.”*

**- A young person affected by MND**

The person diagnosed could be a parent, guardian, grandparent or another person that the child or young person feels close to. Understanding the relationship between the child and the person with MND can be helpful.

Children and young people who are adopted, fostered or from single parent families may have higher anxieties about their own future. This may be about where they will live and who will care for them once the person has died.

A child or young person who lives apart from their family may struggle as the disease progresses. They may be living in care or being educated away from home. They may find it difficult to accept changes in the person between visits or have anxieties about being able to see their loved one as they approach the end of life.

Young people may find it difficult to accept that a relative won't get better and will die. Therefore, end of life can still come as a huge shock, regardless of length of illness or progression.

Gentle honesty is very important when helping a child in this position, as any lack of clarity may be taken the wrong way and give false hope. This can then make the death more traumatic.

Children or young people may seek out a trusted adult to ask questions about MND. This could be you. Understanding the disease and its impact will support you in conversations with a young person.

### **Information for adults:**

Information sheet 4A – *Communicating about MND to children and young people*

### **Information for children or young people:**

*When someone close has MND* - a workbook for children aged four to ten

*So what is MND anyway?* - a guide for teenagers

## **What changes might I notice in their behaviour?**

Finding out that the person will die can be unsettling for a child or young person. They may have many questions or concerns about the person or the effects on their own life. This can influence their ability to engage in education or training. The young person may be:

- worrying and needing to check home frequently, resulting in poor concentration
- struggling to meet deadlines for homework or coursework
- feeling different to peers or being bullied
- avoiding group activities to limit conversations
- having difficulties travelling to school or college, or arriving late

- needing time off for caring responsibilities, to attend appointments or liaise with health or social care professionals
- experiencing low mood and lacking motivation, which can lead to loss of ambition and low performance
- feeling tired
- confused about how and where to get help
- experiencing lack of empathy or understanding from adults around them
- missing out socially as home life becomes more challenging
- using school, higher education or employment as respite from their caring role.



“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.”

- a young person affected by MND

## What can I do to help?

Children and young people may need different types of support depending on their circumstances, during studies or during work, apprenticeships or internships.

Knowing more about MND and its impact will help you anticipate the needs of the young person you support. Planning in advance and providing services promptly when they are needed can have a positive outcome on a young person’s future.

Establish a good working relationship with the family as early as possible. Your approach should be sensitive and consider current and future challenges for the person with MND.

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.

It can be helpful to encourage the child to inform others about the MND diagnosis as soon as possible, so they can be aware, offer practical support and be there for the child to talk to. For example, if they attend a youth club they may be able to talk to the staff there.

### **For children and young people at school:**

- 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 may be necessary
- if there is a young carer's lead at the school, ensure the child is introduced and acknowledged as a young carer
- 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
- provide interventions to help strengthen protective factors; examples might include a support programme to help develop skills to manage or control emotions and behaviours
- 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
- plan any absence you might need to ensure continuity of support, including informing colleagues of arrangements
- offer enrichment activities such as sport, music, art or drama
- consider an event to raise awareness of MND
- include information about bereavement, children's rights and young carers in the curriculum.

Work with the family to contribute to the development of a care emergency plan or crisis plan. This involves contribution from the various individuals supporting a child or young person and includes the family. It should help planning if there is:

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



“He’d fallen and I wasn’t strong enough to lift him on my own, so I had to leave him there while I fetched someone else. I hated feeling so helpless when he needed help so badly.”

- a young person affected by MND

This plan should contain a list of emergency contacts, including the child or young person’s GP. It should also state why the person with MND may not be able to take or collect their child.

A planned approach to communication and support arrangements may help relieve pressure for the child or young person, which can reduce the risk of under achievement. Helping a child or young person to focus on their strengths can be a positive way to help them engage in the world around them.

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.



“At school you hope no-one even mentions MND, but at times you also want teachers to be aware and give you a bit of leeway... it’s difficult for them though. They’re supposed to treat you the same and keep things as normal as possible. It’s a bit of a balancing act I guess, but there are times you need help.”

- a young person affected by MND

## **For young people at college or university:**

- offer a flexible timetable
- be more lenient with deadlines
- offer additional support at meetings
- involve decision makers, including those responsible for agreeing budgets or additional academic support
- work together to develop a plan to support emergencies
- plan for reasonable adjustments – for example, extra time in exams and extensions on coursework
- liaise with and refer to other agencies who can support carers
- offer advice and support about career options
- guide conversations and introductions to services that can provide support to reduce any anxiety about asking for help.

## **For young people in traineeships, apprenticeships and work:**

- offer a flexible work roster if possible
- provide information about policies and procedures that support young carers. Consider creating these policies if they are not in place
- work with the young person and family to develop a plan to support emergencies
- allow mobile phone access to enable the young person to check in at home
- liaise with and refer to other agencies who can support carers
- offer advice and support about career progression
- provide information and access to carer's leave.

# Supporting young carers

## What is a young carer?

**A 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.

**A 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.

## What care might a young person be providing?

It is important to be aware that care needs for people with MND will increase as the disease progresses. The rate of progression varies from person to person and, in some cases, can be rapid. Statutory services may struggle to keep up with the changing needs of a person with MND. 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 some level of care at some point such as:

- offering emotional support and comfort
- helping the person with MND to communicate when speech is affected or absent
- managing household finances eg paying bills, budgeting
- providing advocacy on behalf of the person, for example telephone calls, emails and letters
- liaising with health and social care professionals
- collecting prescriptions and administering medication
- shopping

- managing housework, laundry, gardening and home maintenance
- caring for younger siblings
- preparing meals or assisting with tube feeding
- lifting and hoisting
- delivering personal care, such as bathing, dressing, toileting and feeding
- keeping the person safe
- assisting with medical interventions such as non-invasive ventilation (NIV), suction machines or devices to assist a weakened cough
- supporting a person who has cognitive changes or frontotemporal dementia
- providing care at night
- making appointments and accompanying the person with MND
- contacting other services and support organisations
- looking after visitors
- supporting the person with hobbies or leisure activities
- translating complex medical or care information for a person who has a low literacy level or does not speak or read English.



“I helped with mum’s feed. I’d use the syringe to pump it into the tube. We’d joke that it was roast beef and Yorkshire pudding, or steak and chips going in.”

**- a young person affected by MND**

Caring duties can have a major impact on young people, both now and in the future. Young adult carers:

- continue to be the largest group of young people not in employment, education or training
- may find it difficult to pursue a course, job choice or chosen career due to a caring role
- are often drawn into careers in care. Care and support jobs tend to be low paid and often lack long-term security.

# What support is available for young carers and young adult carers?

## Early help assessments

An early help assessment can support identification of children and young people who may take on a caring responsibility. An assessment of need and a good support package can help reduce the negative impact of care.

The assessment aims to enable children and families to access appropriate support as early as possible, to help them maintain their quality of life and provide support for any problems that could prevent a child from developing emotional and physical resilience.

A support package might include:

- help with parenting, where a parent's physical ability makes this difficult eg preparing a family meal or helping a child get ready for school
- interventions that support emotional wellbeing eg group sessions delivered by appropriately trained specialists
- help with benefits and entitlements
- identification of potential problems or risks that might need future intervention to give the child the best chance in life eg support with speech and language development for very young children where a parent has deteriorating speech.

If you are aware of a child or young person living in a family where someone has MND, referral for assessment should be done as soon as possible. Any service aware of a child or young person providing care can request assessment through the local authority or social care service. This should be discussed with the family and young person.

This type of assessment provides the young person with choices about their involvement in care and may prevent them from taking on too much. Reassessment can be requested at any point if circumstances change or support is not adequate.

## 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.

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 them 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 is important to include the child in discussions about the referral to ensure they want to become involved.

## What should children and young people know about their rights?

Children have rights. Knowing about these rights can support a young person to make informed choices. It is a young person's right to:

- have the same life choices and chances as their peers
- receive information about circumstances that affect them
- be protected from harm
- receive services that will help them to maintain and build resilience for a positive future.

The Children and Families Act, and Care Act 2014, came into force in April 2015. Both significantly strengthen the rights of young carers.

Through the Children and Families Act:

- young carers under the age of 18 have a right to an assessment
- a young carer has the right to an assessment based on the appearance of need.

The Care Act reinforces these rights and directs local authorities to:

- take a whole family approach to assessing and supporting adults so that a young carer's needs are identified too
- ensure that adult's and children's social care services work together to ensure assessments are effective.

### **Young carers' rights in England**

In England, all young carers under the age of 18 have a right to assessment regardless of who they care for, what type of care they provide or how often they provide it.

### **Young carers' rights in Wales**

A young carer under the age of 18 with significant caring responsibilities is recognised as a child in need in Wales. A Children Act Assessment is required. For young people aged 16 or over, a full carer's assessment can be requested.

### **Young carers' rights in Northern Ireland**

In Northern Ireland, young carers up to the age of 18 are assessed using a process called Understanding the Needs of Children in NI (sometimes known as UNOCINI). An assessment can be requested through the local health and social care trust.

When supporting a child or young person living in Scotland, contact MND Scotland for guidance. See *How can I find out more?* at the end of this guide.

It can help the child or young person to understand their rights. The UN Convention of the Rights of the Child (UNCRC) outlines these. Some of the rights included in the UNCRC are important to UK laws that support young carers. For example, children have the right to:

- a childhood
- an education
- health and access to relevant health services
- be heard, listened to and believed
- be protected from physical and psychological harm
- privacy and respect
- have their views taken into account when decisions are made that affect their lives.

It can be helpful for adults working with children to provide support and advocacy to help them exercise their rights. The local authority children's services department may be able to offer support to interpret these rights.

The child's needs are paramount, and their needs and wishes should be put first, so that they receive the support they require before a problem escalates. All professionals who come into contact with children and families have a duty of care to be alert to their needs and any actual or potential risks to a child's wellbeing.

A combined plan may be suggested by the local authority. This encourages professionals supporting a child to work together with shared goals. It also outlines where responsibilities for specific interventions lie. This may be a combination of professionals from education, social care and health, dependent upon the child's needs.

Understanding about rights and being heard may support a child, young person or the family to engage with any interventions outlined in a support plan.

# The financial impact of MND

## What financial changes might the family experience?

When a parent or guardian has MND, the household income may reduce significantly.

Over time, or on confirmation of diagnosis, 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 be:

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



“Money can cause arguments for many families, but MND creates such pressure. Our finances were stretched and I know mum felt guilty because she couldn’t always give us what we wanted or needed as kids”

- a young person affected by MND

## What help is available?

### School aged children and young people

You could talk to the family about benefits, financial help and other funding to support their child’s education. This can help families to plan and manage a decreasing income, reducing anxiety and worry. You should remain sensitive to conversations about financial support, which may cause embarrassment or feelings of stigma.

Options you may wish to discuss:

- free school meals
- assistance with the purchase of school uniform
- funding for school trips
- arrangements for travel to and from school
- discretionary school funds.

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

MND can be all-consuming. Families may appreciate additional help, as it can reduce delays in access to services for the child or young person.

If relevant, consider applying for additional funding to support the child or young person, such as pupil premium. This can be requested by the school, and is paid by the local authority.

Pupil premium can be used by the school to offer support including:

- equipment for home working, such as a laptop or tablet
- in-class teaching support
- extra tuition
- school clubs or trips
- emotional or wellbeing support
- enrichment activities.

## College or university students

A young person may not be aware of the support available. It can be hard to work out what might help and what is needed. You may be able to provide help, guidance and agree a support plan, which can be flexible as MND progresses. Support needs may change over time, depending on disease progression and increasing caring responsibilities at home.

Funding support that could be considered includes:

- scholarships, bursaries, grants and awards
- university and college hardship funds
- learner support funds
- welfare benefits and entitlements
- other sources of funding, such as local and national charities.

You could support a young person to access:

- careers advice
- centres offering free retakes of GCSEs and A levels
- free NVQ level 1, 2 and 3 courses and exams.

A young person or 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.

# Supporting emotional health and wellbeing

## How might emotional health and wellbeing be affected?

Life may seem overwhelming for a child or young person who is managing their own emotions and learning about MND. The young person may display a range of emotions.

Emotion or behaviour	Possible causes
stress	<ul style="list-style-type: none"><li>• juggling care, study and work responsibilities</li><li>• changing routines, roles and activities</li><li>• increased responsibility</li></ul>
worry and anxiety	<ul style="list-style-type: none"><li>• the person's deteriorating health</li><li>• looking after younger siblings</li><li>• managing finances</li><li>• thinking about how the person with MND will die</li><li>• wondering what will life be like afterwards</li></ul>
lethargy and reduced motivation	<ul style="list-style-type: none"><li>• emotional exhaustion</li><li>• not sleeping or disturbed sleep</li><li>• physical exhaustion</li></ul>
low mood or depression	<ul style="list-style-type: none"><li>• overwhelming or fluctuating emotions</li><li>• lack of motivation</li><li>• poor coping</li></ul>
guilt	<ul style="list-style-type: none"><li>• wishing it was someone else with MND</li><li>• thinking it is their fault that the person is ill</li></ul>

Emotion or behaviour	Possible causes
embarrassment	<ul style="list-style-type: none"> <li>• the way a parent talks, walks, appears or eats has changed</li> <li>• equipment in the home</li> <li>• not being able to afford the same things as their friends</li> </ul>
fear	<ul style="list-style-type: none"> <li>• high levels of uncertainty</li> <li>• lack of understanding about what is happening</li> <li>• thoughts of losing the person with MND</li> <li>• feeling alone</li> <li>• fear that they will get MND</li> </ul>
frustration	<ul style="list-style-type: none"> <li>• loss of control of the situation</li> <li>• being ignored or feeling invisible</li> <li>• others not understanding</li> <li>• friends issues seeming frivolous and irritating in comparison</li> <li>• why me?</li> </ul>
anger and resentment	<ul style="list-style-type: none"> <li>• reduced finances</li> <li>• missing out socially</li> <li>• having to do more to help</li> <li>• missing out on fashions and latest gadgets</li> <li>• feeling different and why me?</li> <li>• anger at MND</li> </ul>
jealousy	<ul style="list-style-type: none"> <li>• all the attention going elsewhere</li> <li>• comparing themselves to friends who have 'normal' lives</li> </ul>

Families can rapidly become isolated, unaware of and unable to access services that may help them. A child or young person may feel embarrassed to seek support from their own peer group. This can compound feelings of being alone.

Sometimes the peer group is unsupportive because they do not understand and cannot empathise with the young person.



“We were living in the MND bubble and it was really difficult to think about anything else.”

**- an adult whose parent died of MND during childhood**

The emotional and psychological wellbeing of the child or young person may be affected by their ability to cope with changes, their age and development. Life changes, such as the transition to adulthood, can also be significant. Loss of ambition and feeling resigned to a changed life can affect short and long term outcomes.

If the person with MND has cognitive impairment or frontotemporal dementia (FTD), the changes can be confusing for a child or young person. They may struggle to adapt to this new relationship.

In these circumstances, the person with MND may experience a lack of empathy or interest for those around them. This can feel like living with a stranger. For example, they may respond to the noise of a child playing with agitation and irritability, which could result in aggressive behaviour.



“I lived near to another family with MND and their father wanted to be involved with his children, as his thinking and behaviour weren’t affected. It was different for us. Our dad was like that before, very affectionate, but then he didn’t want anything to do with us.”

**- a young person affected by MND**

Because of the nature of MND, typical childhood protective factors may be weakened or non-existent. Protective factors are the conditions, circumstances and strengths that protect and support healthy emotional and physical development of a child or young person.

Children may experience disruption in their home life for many reasons. Without intervention, this can reduce normal protective factors and increase a family’s chance of poor outcomes.

For families affected by MND, the risk factors could be:

- loss of friendships
- decreased family finances and increased debt
- parental mental ill health
- loss of a relationship, where the person has cognitive change or frontotemporal dementia
- death of a loved one or parent.

There may be subtle or significant changes in the child or young person's mood and behaviour. These could happen at any stage of the disease. In some cases, changes may appear long after the death of the person.

The young person may present with difficult behaviours, including aggression as they may not yet have the skills to identify and express their emotions effectively. It is helpful to respond to this in a supportive way.

Losing a loved one to MND is devastating at any age. Lack of understanding and communication about the child or young person's history can be detrimental.



“At school you hope no-one even mentions MND, but at times you also want teachers to be aware... In one lesson, a teacher was talking about young carers... I sat there thinking it's a bit more serious than that. I tried to explain how young people often care for someone who is dying, and do all sorts of things. The teacher dismissed it, as if it wasn't true.”

- a young person affected by MND

## How can I support emotional wellbeing?

School, university or work life can give a sense of normality and security. Good quality and timely support can have a positive effect on emotional and psychological wellbeing. This can help prevent anxiety and depression. Emotional wellbeing includes being happy and confident. Psychological wellbeing is being able to:

- experience empathy
- manage emotions
- develop autonomy
- problem solve
- develop resilience
- engage with the world around you.

The child or young person may require emotional or psychological support. A support programme should consider early access to talking services, pre-bereavement, to improve resilience.



“Most of my support came from my family, but some young people don’t get that. Some professional support, like a nurse to tell you what was going on, would help.”

- a young person affected by MND

### Activities

Opportunities that support both emotional and social wellbeing can be valuable. This may provide a break from thinking about MND. You may want to support a young person to enjoy leisure pursuits and hobbies. Attending a lunch club or a local young carer group may also be helpful.

A child or young person may find it daunting to talk to someone about their feelings. Meeting up with someone regularly can help build a relationship and trust. This can enable a child or young person to talk when they are ready.

You might consider supporting a child or young person to record memories and positive events during the person’s life.

A young carer may have limited time to join in with recreation or social events due to care responsibilities. Raising awareness of young carers can have positive benefits for the young person, including improved understanding and empathy from peers.

## Talking

For many families, the grieving process begins at diagnosis. A safe environment may provide an opportunity for a child or young person to express their emotions. Talking can help a child or young person to work through emotions and make sense of their situation and changing life.

The child or young person may be able to begin to prepare for the death of their loved one. Having a positive relationship with a loved one before their death can reduce the risk of poor mental health in later life. Good emotional and psychological support can help a young person to maintain this relationship before and after the person's death. Help to find the words or a way to communicate their feelings to the loved one may be helpful.

A child or young person will often want to feel 'normal' and to have the same experiences as their peers. They may not want others to know about their home circumstances, so these discussions should remain private.

## Planning

Planning may be needed to support the young person to access wider support. In collaboration with the young person, you may wish to consider referral to:

- a school nurse
- pastoral support, including spiritual advisors
- student support
- school, college or university counselling services
- local pre and post bereavement services
- commissioned talking or counselling services.

Other options for support could include:

- referral to local young carers' or young adult carers' services
- regular meetings to review the support plan with the child or young person
- regular review of the support plan to help reduce misunderstandings
- regular communication with home to identify problems as they occur
- access to nurture clubs and non-directive play therapy for younger children
- providing permission cards or a system to support time out for a child or young person to regain emotional control
- support from local hospices who may offer outreach services for young carers, including counselling or support groups.

A good plan outlines agreed actions to support a child or young person's mental and emotional wellbeing, maintain or improve academic achievement and support attendance.

## Post-bereavement

Despite being aware that MND will end the life of a loved one, the harsh 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 health and social care professionals. Once the person has died, the equipment is removed and the visitors stop. This may also trigger an emotional response.



“People seemed to disappear as if all our problems must be over now, but they don't just go away”.

- a young person affected by MND

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 can be 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 following a bereavement. Good communication among staff in contact with the young person may help prevent difficult, embarrassing or upsetting situations that could occur.

If a child is having difficulty managing emotions, or becomes withdrawn or insecure, they may require more specialist support to grieve. See the next section *What if the child or young person needs more intensive support?*

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 record of significant events can be helpful for lesson planning. This record should accompany the child, especially when changing schools.

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

Young people in training or employment could be directed to the Human Resources department for more guidance and support.

# Supporting physical health and wellbeing

## How might physical health be affected?

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 giving
- severe cognitive changes in the person with MND, increasing the risk of direct injury to carers and family
- poor nutrition due to irregular or unbalanced meals (they may be preparing their own meals)
- lack of sleep, due to care responsibilities or worry
- increased susceptibility to illness, infection and injury as a result of fatigue and poor nutrition
- poor mental health, impacting on physical wellbeing.



“Sometimes we had to cancel stuff because dad had an appointment or was really tired. My mum had a massive calendar on the wall with all the appointments on it.”

- a young person affected by MND

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

Every child or young person should be able to attend their own 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. Young people may need support to make arrangements to attend and manage their own health needs.

Adopting a whole family approach describes how the wider needs of the family are considered, including children and young people. A joined up approach enables good support and access to services for all members of the family, not just the adult needing care.

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.



“Sport was the one thing that made me feel better. It was a release. My coach was aware of what had happened and helped me channel my anger and focus my energy in a structured way.”

- a young person affected by MND

# What if the young person needs more intensive support?

If there are concerns about the health and wellbeing of a child or young person, these should be raised in line with your safeguarding policy.

A child or young person may experience problems coping and need more help. The negative impact on psychological wellbeing may gradually emerge over time.

Feelings can sometimes intensify for years following bereavement. Unresolved grief can have an impact on the future mental wellbeing of a young person. It is critical that you highlight any concerns as early as possible.



*“My younger brother struggles in his new school because they’re not really aware of him losing his dad. It was some time ago, so even if they do know, it’s like it’s all over. But it stays with you...”*

**- a young person affected by MND**

Arranging a meeting with relevant professionals and the family can help you anticipate and plan specialist services. These services may support a child or young person to develop resilience. Developing healthy behaviours can support:

- emotional wellbeing
- psychological wellbeing
- social wellbeing
- physical wellbeing
- educational attainment.

Other positive steps could include:

- providing information about MND within the curriculum
- sharing information, raising awareness of the disease and its impact amongst your colleagues
- helping the young person to make and maintain friendships
- supporting the family to fundraise, campaign, volunteer or raise awareness of MND (this can help families take some control and give them purpose and focus)
- raising awareness of young carers
- engaging with local young carers' groups to deliver individual support to a young person
- finding out how to refer to bereavement services
- finding out more about children's rights, the Care Act 2014 and the Children and Families Act 2014
- training on reducing risk and improving protective factors
- increasing your understanding of the link between childhood bereavement and future mental health problems.



“You need someone to tell you it will be okay in the end. Not that there will be a cure or anything, but that you will find a way to get through the sadness and live your own life. Because you will.”

- a young person affected by MND

# How can I find out more?

Our section at the end of this guide, *How the MND Association can support you*, contains information about our services. There is also a list of other organisations and resources.

MND can impact on anyone providing support or services to affected families. You may need to think about where you will access personal support at work and at home.

## Resources for children and young people

**The MND Association has specific resources for young people:**

*So what is MND anyway?* is a guide for teenagers and young people affected by MND. It includes a section on being a young carer.

Visit [www.mndassociation.org/ypinfo](http://www.mndassociation.org/ypinfo) to view and download a PDF copy of *So what is MND anyway?* It is also available as a web app.

*When someone close has MND* is an interactive workbook for 4-10 year olds, which enables a trusted adult to communicate with a young child about MND at a speed that feels appropriate.

A selection of reading lists is available to support conversations about loss and bereavement.

These resources can be ordered from MND Connect (see overleaf).

## How the MND Association can support you

We support people living with MND, their carers and families, and support health and social care professionals to provide the best possible care and services. We do this in a number of ways:

### MND Connect

Our helpline offers information, support and signposting to other services and agencies.

Phone: 0808 802 6262

Email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

We also offer support to young people.

Phone: 0808 802 6262

Email: [youngconnect@mndassociation.org](mailto:youngconnect@mndassociation.org)

### Information resources

We produce high quality information resources for people with and affected by MND, as well as the health and social care professionals who support them.

Most of our publications are available from our website.

[www.mndassociation.org/publications](http://www.mndassociation.org/publications) or you can order publications directly from the MND Connect team.

### MND Association website

Access information to support children and young people.

[www.mndassociation.org/ypinfo](http://www.mndassociation.org/ypinfo)

### MND Association membership

Join us now to help fight MND. It is free for people with MND and for carers, spouses or partners of people living with MND.

Call 0808 802 6262 or email [membership@mndassociation.org](mailto:membership@mndassociation.org)

### Young Person's Grant

We offer grants to help young people close to someone with MND. Up to £250 can be awarded to a young person in any one year.

The grant can be used in many ways, for example, to help fund a day out with family to build a special memory. A member of the family or a health or social care professional can apply for a grant on behalf of a young person. Email [support.services@mndassociation.org](mailto:support.services@mndassociation.org) or call 01604 611802.

## Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Call 01604 611880 or email [research@mndassociation.org](mailto:research@mndassociation.org)

Alternatively, visit [www.mndassociation.org/research](http://www.mndassociation.org/research)  
For the latest research news, visit our research blog at [www.mndresearch.wordpress.com](http://www.mndresearch.wordpress.com)

## Awareness and fundraising material

We produce a wide variety of resources to help you raise awareness of MND, as well as fundraise for the MND Association. We produce a school fundraising pack called Silence Speaks, which includes suggestions for lesson plans for across the curriculum. Call 01604 611860 or email [fundraising@mndassociation.org](mailto:fundraising@mndassociation.org)

## Local support

### Regional care development advisers

Our network of regional care development advisers (RCDAs) have specialist knowledge of the care and management of MND. They work closely with local services and care providers to ensure effective support for people affected by MND, provide education for health and social care professionals in MND, and are champions at influencing care services.

## **MND care centres and networks**

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

## **Branches and groups**

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

## **Association visitors (AVs)**

Association visitors are volunteers with experience of MND who provide one-to-one local support to people affected by MND.

## **Useful organisations and resources**

You can find links to other useful websites at [www.mndassociation.org/usefulcontacts](http://www.mndassociation.org/usefulcontacts)

## **Bereavement**

### **Child Bereavement UK**

Support and guidance to families and professionals during bereavement.

Phone: 0800 028 8840

Email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Website: [www.childbereavementuk.org](http://www.childbereavementuk.org)

### **Childhood Bereavement Network**

Can direct you to support for bereaved children and families.

Phone: 020 7843 6309

Email: [cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)

Website: [www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

### **Cruse Bereavement Care**

Support, advice and information for bereaved people.

Phone: 0808 808 1677

Email: [info@cruse.org.uk](mailto:info@cruse.org.uk)

Website: [www.cruse.org.uk](http://www.cruse.org.uk)

### **Grief Encounter**

Support for bereaved children and families, and training for professionals.

Phone: 020 8371 8455

Email: [contact@griefencounter.org.uk](mailto:contact@griefencounter.org.uk)

Website: [www.griefencounter.org.uk](http://www.griefencounter.org.uk)

### **RecordMeNow**

A free app for people to record video messages for children and family.

Email: [director@recordmenow.org](mailto:director@recordmenow.org)

Website: [www.recordmenow.org](http://www.recordmenow.org)

### **Winston's Wish**

Support for bereaved children, young people and their families.

Helpline: 0845 203 0405

Email: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

Website: [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

## **Emotional and psychological wellbeing**

### **Child and adolescent mental health services (CAMHS)**

Search online for services in your area or your local NHS trust website.

If you live in Northern Ireland, ask your health and social care trust.

### **Childline**

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

Phone: 0800 1111

Website: [www.childline.org.uk](http://www.childline.org.uk)

### **Matter**

An online space for young adult carers aged 16 to 25 to connect, share their experiences and access trusted support.

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

### **MindEd**

Information to support adults working with young people to identify those at risk of mental health problems and how to support wellbeing.

Email: [minded@rcpch.ac.uk](mailto:minded@rcpch.ac.uk)

Website: <https://www.minded.org.uk>

### **NHS Choices – Youth mental health**

Comprehensive health information with articles, videos and tools.

Website: [www.nhs.uk/youthmentalhealth](http://www.nhs.uk/youthmentalhealth)

## **Place2be**

Provides emotional support to children in schools, including counselling training, advice and support for professionals.

Phone: 020 7923 5500

Email: [enquiries@place2be.org.uk](mailto:enquiries@place2be.org.uk)

Website: [www.place2be.org.uk](http://www.place2be.org.uk)

## **Rethink mental illness**

This charity provides information on how you can look after your mental health. It provides a section for young people and young carers.

Phone: 0300 5000 927

Email: via website contact page

Website: [www.rethink.org](http://www.rethink.org) and search 'support for young carers'

## **Young Minds**

Provide guidance about the emotional wellbeing and mental health of children and young people. They can advise parents and guardians.

Helpline: 0808 802 5544 (for parents)

Email: [ymentquiries@youngminds.org.uk](mailto:ymentquiries@youngminds.org.uk)

Website: [www.youngminds.org.uk](http://www.youngminds.org.uk)

## **Young carers and young adult carers**

### **Action for Children**

Provide practical and emotional support to young carers and vulnerable children.

Phone: 01923 361 500

Email: [ask.us@actionforchildren.org.uk](mailto:ask.us@actionforchildren.org.uk)

Website: [www.actionforchildren.org.uk/youngcarers](http://www.actionforchildren.org.uk/youngcarers)

### **Babble**

An online community for young carers up to age 18.

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

### **Barnardo's**

Supporting children across the UK, including young carers.

Phone: 020 8550 8822 (England)

029 2049 3387 (Wales)

028 9067 2366 (Northern Ireland)

Email: through the website contact page

Website: [www.barnardos.org.uk/young\\_carers](http://www.barnardos.org.uk/young_carers)

## **Bullying UK**

An organisation providing advice and resources to tackle bullying.

Phone:: 0808 800 2222 (confidential helpline)

Email: via the website contact page

Website: [www.bullying.co.uk](http://www.bullying.co.uk)

## **Carers Trust**

Information and support for young and adult carers . Offers signposting to local young carers' services and a school toolkit.

Phone:: 0300 772 9600

Email: [support@carers.org](mailto:support@carers.org)

Website: [www.carers.org](http://www.carers.org)

Step-by-step Guide for Leaders, Teachers and Non-teaching Staff:

<https://professionals.carers.org/stepbystep>

## **Carers UK**

Information and support for young carers and young adult carers.

Phone: 0808 808 7777

Email: [advice@carersuk.org](mailto:advice@carersuk.org)

Website: [www.carersuk.org](http://www.carersuk.org) and search for 'young carer'

## **Children's Society**

Support and services for children, including young carers.

Phone: 0300 303 7000

Email: [supportercare@childrenssociety.org.uk](mailto:supportercare@childrenssociety.org.uk)

Website: [www.childrenssociety.org.uk](http://www.childrenssociety.org.uk)

## **Children's Society – Include Programme**

Support and services for young carers, including a Young Carer Festival.

Phone: 01962 711511.

Email: through the website contact page

Website: [www.youngcarer.com](http://www.youngcarer.com)

## **Gov.UK**

Online information for young people on education and training options.

Website: [www.gov.uk/browse/education](http://www.gov.uk/browse/education)

## **Learning and Work Institute**

A programme to support carers aged 16-24 in education or work.

Telephone: 0116 204 4200

Email: [enquiries@learningandwork.org.uk](mailto:enquiries@learningandwork.org.uk)

Website: [www.learningandwork.org.uk/youngadultcarers](http://www.learningandwork.org.uk/youngadultcarers)

### **MND Scotland**

Provides care, information and research funding for people affected by MND in Scotland.

Phone: 0141 332 3903  
Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)  
Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

### **National Career Service**

Provide information about options for further education opportunities.

Phone: 08000 968 336  
Email: via website contact page  
Website: <https://nationalcareersservice.direct.gov.uk>

### **Prince's Trust**

Supports children and young people 13-25 with education and training.

Phone: 0800 842 842  
Email: via website contact page  
Website: [www.princes-trust.org.uk](http://www.princes-trust.org.uk)

### **Queen's Nursing Institute**

Free online resources for school nurses, to enable them to identify and support young carers, including an app.

Phone: 020 7549 1400  
Email: via website contact page  
Website: <http://qni.org.uk> and search for 'school nurse'  
App: [www.qni.org.uk/supporting\\_carers/mobile\\_app](http://www.qni.org.uk/supporting_carers/mobile_app)

### **Royal College of Nursing**

Has produced a toolkit for school nurses supporting young carers.

Email: via website contact page  
Website: [www.rcn.org.uk](http://www.rcn.org.uk) and search for 'young carers'

### **Spurgeons**

A charity providing advice, information, support and mentoring for carers aged up to 25. Also provides education and training support.

Phone: 01933 412412  
Email: [info@spurgeons.org](mailto:info@spurgeons.org)  
Website: [www.spurgeons.org/young-carers](http://www.spurgeons.org/young-carers)

### **Youth Access**

Information, advice, counselling and support services for young people.

Phone: 020 8772 9900  
Email: [admin@youthaccess.org.uk](mailto:admin@youthaccess.org.uk)  
Website: [www.youthaccess.org.uk](http://www.youthaccess.org.uk)

# Feedback form

Please send us your feedback on *Supporting children and young people close to someone with motor neurone disease (MND)*

**Thank you for taking the time to provide your feedback on this information resource.**

This questionnaire can be accessed online if preferred, using the following link: <https://www.surveymonkey.co.uk/r/supportingCYP>

**What is your profession or specialism?**

---

**Did you find this resource useful?**

Yes    Somewhat    Not really    No

Please explain your answer

---

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**Will this information resource help you to provide children or young people close to someone with MND with any of the following? (tick all that apply)**

- an increased understanding of MND
- access to support for young carers or young adult carers
- access to learning support
- support with the financial impact of MND
- support for emotional health and wellbeing
- support for physical health and wellbeing
- improved quality of life

*Continued overleaf*

*Feedback form continued*

**Were there any particular topics that were useful to you?**

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**Was there any information that you didn't find useful or relevant?**

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**Are there any other MND-related topics you would like more information about?**

---

**Would you be happy to help us improve our information by becoming an expert reviewer?**

Yes (please include your email address below)    No

**Do you have any experiences of working with children and young people close to someone with MND you could share as an anonymous quote or case study for future resources?**

Yes (please include your email address below)    No

Please return your completed form to:

Education and information team

MND Association

PO Box 246

Northampton NN1 2PR

Name:

---

Email:

---

## References

References used to support this information are available on request.

Email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback

MND Association

PO Box 246

Northampton

NN1 2PR

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Patrick Buckingham, Education Adviser, Action for Carers, Surrey

Dr Rachel Fearnley, Independent Researcher/Consultant specialising in children's experiences when a parent is at the end of life

## About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

## Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

## MND Association

PO Box 246, Northampton NN1 2PR

Tel: 01604 250505

Email: [enquiries@mndassociation.org](mailto:enquiries@mndassociation.org)

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



@mndeducation



/mndassociation



## About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.

**mndconnect**  
**0808 802 6262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)