

mnda

motor neurone disease
association

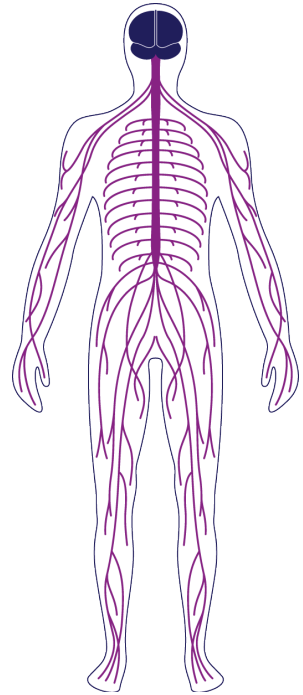
For professionals
working with children
and young people



**Supporting children and
young people close to
someone with MND**

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.
- It can leave people locked in a failing body, unable to move, talk and breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years.
- 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.



Would you like to find out more?

Contact our helpline MND Connect if you have any questions about MND or want more information about anything in this booklet.

mndconnect
0808 802 6262
mndconnect@mndassociation.org

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This guide has been endorsed by the MND Professionals' Community of Practice.

A note to parents and guardians

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

Please note that some of the language used in this guide may be hard-hitting to have maximum impact with professionals.

The useful resources listed on the next page have been specifically designed with children, young people and families in mind, and use gentler language.

Introduction

MND is a fatal, rapidly progressing disease. Children and young people close to someone with MND may seek out a trusted adult to ask questions about the disease.

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.

A diagnosis of MND can feel overwhelming for the whole family and the adult family members may need time to come to terms with the diagnosis before explaining to a young person.

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

Information resources for children, young people and families

The MND Association has a wide range of information and support for families affected by MND. Visit www.mndassociation.org/cyp

Our Children and Young People's Team offers individual family support alongside specialised counselling, memory boxes and family fun days. Email CYP@mndassociation.org for further information and 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 (www.mndbuddies.org)

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

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.

Information for people with or affected by MND

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.

Most of our publications can be downloaded from www.mndassociation.org/publications, or contact MND Connect to order hard copies. Email mndconnect@mndassociation.org or call 0808 802 6262.



**Section one:
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 and not everyone will have all of the symptoms listed below. People can be affected by any of the possible symptoms, at any time and in any order.

Information for parents and guardians

We have a wide range of publications about the symptoms of MND discussed in this section.

Visit www.mndassociation.org/publications, or contact our MND Connect helpline to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Movement and getting around

When nerves are affected by MND, messages from the brain no longer reach the 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. 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. 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. 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. Text messages, emails or letters may be more appropriate than phone calls if speech is affected.

Breathing

With MND, the muscles involved in breathing can weaken, leading to shortness of breath and fatigue. Breathing problems can make the person more prone to chest infections, and respiratory failure is the most 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), and others may have a breathing tube inserted directly into their neck (known as tracheostomy).

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.

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

Up to half of people with MND experience some changes to how they think and behave. It can also affect their use of language. These changes affect people in different ways. For many people, the changes are usually subtle and they may find ways to compensate or work around these issues. For some, the changes are more apparent, and a small proportion of people with MND are affected by dementia.

The type of dementia people with MND are more likely to get is known as frontotemporal dementia (FTD). It is different from the more common forms of dementia such as Alzheimer's disease, which usually begin with memory loss.

With FTD, people experience changes to their behavior and use of language. FTD can cause the person to act differently from how they normally do, and they might become disinhibited or not seem to care about other people's emotions. This could be confusing and upsetting to the young person, and you may need to provide reassurance. See *How do I approach conversations about MND?* on page 11.

Some people may become aggressive, which can be very difficult for the entire family, especially if they don't understand this is a symptom of MND. Be alert to possible warning signs that the person is becoming agitated.

Emotional lability

Some people with MND experience a symptom that causes them to laugh or cry. This may not reflect how they feel and may be inappropriate at times eg laughing at a funeral or when in pain. This can cause embarrassment for the person with MND and others, and may be confusing for the young person.

Some people find understanding the symptom helps them to manage the impact, but others find it limits where they go and what they do.



Section two: Providing support

Emotional support

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

Information for parents and guardians

Our guide, *Telling people about MND*, is designed to help open conversations about MND with family, children, friends, colleagues and health or social care professionals.

Visit www.mndassociation.org/publications, or contact our MND Connect helpline to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

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. This can also aid their understanding, as they may ask more questions.

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 about MND 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.

Use clear language: when discussing MND, it is 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.

Provide information piece by piece: younger children tend to take in information in small pieces, so try not to tell them everything at once. They may ask questions when they are ready to know more, or you can try another small chunk of information. They may need to talk about what has happened 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, children 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 too, 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 speech and communication difficulties: MND may affect communication or facial expressions. Explain that if this happens, it is caused by MND and it is not how the person feels about them. Some families gradually create their own 'language', where certain body or eye movements mean different things.

Check understanding: ask the child or young person simple questions to check whether they have understood what you have said. This will also gently help them start talking about MND. This will also give you the opportunity to assess how much the child knows.

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.

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.

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.



Be aware of changes to thinking and behaviour: explain 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'.

We have publications specifically designed for children and young people of different ages to help them understand more about MND. See page 5 for details.

What if they do not 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'.

You may need 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 engaged in a mutual task such as playing or walking.



Support at school

Information for parents and guardians

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 your family's situation, and ensure the staff know about MND.

You may wish 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.

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 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
- 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 then means 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
- 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 should 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 action to take in this situation.



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.

Early help assessments

An early help assessment can identify children and young people who require additional support to meet their needs.

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.

This type of assessment provides the young person and their family with choices about their involvement in the support package.

The support package might include:

- help with parenting, where a parent's physical ability makes this difficult eg preparing a meal or getting a child 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 needed, referral for assessment should be done as soon as possible. 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 are a team of people around the young person who are aware of their needs and ensure that the plan is adhered to.

Supporting young carers

Information for parents and guardians

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

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

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.

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 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 a 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 and dressing
- assisting with medical equipment such as ventilation, suction machines or devices to assist a weak cough
- supporting a person who has cognitive changes or 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.

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

Financial support

Information for parents and guardians

We have more detailed information about benefits and financial support, as well as a Benefits Advice Service. For further details, visit www.mndassociation.org/benefits

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
- feelings of resentment, sadness or anger about their circumstances
- anxiety and embarrassment.

What help is available?

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.

The MND Association has a Benefits Advice Service. Qualified advisers can help identify benefits the person with MND and carers may be entitled to, and advise on how to claim. This service is confidential, impartial and free.

Visit www.mndassociation.org/benefitsadvice for further 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
- 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, such as local charities or organisations providing academic funding or financial support, such as hardship grants or loans.

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.

MND Association support grants

The Association is able to offer some financial support to help with funding for:

- equipment and services that people with MND have been assessed as needing
- children and young people aged 18 or under living with someone with MND
- unpaid carers and young carers supporting someone living with MND (available up to 12 months post-bereavement)
- improving quality of life for someone living with MND.

These are not in place of any statutory funding that should be available, however we can assist with obtaining statutory funding or funding from other charitable organisations.

Visit www.mndassociation.org/supportgrants for more information.

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 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
- missing out on 'normal' activities with peers, which can affect their sense of self, identity and mental wellbeing
- poor mental health, impacting on physical wellbeing.

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. 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.



Bereavement support

Information for parents and guardians

We have a range of information and support for people experiencing bereavement.

Our MND Connect helpline can help you with information, support, a chance to talk, and guidance about our services and external services to suit your needs. Call 0808 802 6262 or email mndconnect@mndassociation.org

Visit www.mndassociation.org/bereavement for details of the support available.

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.

Further information about bereavement support is available at www.mndassociation.org/bereavement



Useful organisations

You can find links to other useful websites at:
www.mndassociation.org/usefulcontacts

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: www.gov.uk (England and Wales)
www.nidirect.gov.uk (Northern Ireland)

Barnardo's

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

Telephone: 0208 550 8822 (England)
029 2049 3387 (Wales)
028 9067 2366 (Northern Ireland)
Email: through the website contact page
Website: www.barnardos.org.uk

Bullying UK

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

Telephone: 0808 800 2222 (confidential helpline)
Email: through the website contact page
Website: www.bullying.co.uk/advice

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.

Child Bereavement Charity

Support for families, children and young people during bereavement.

Telephone: 0800 0288840

Email: support@childbereavementuk.org

Website: www.childbereavementuk.org

Childhood Bereavement Network

This organization can direct you to support for bereaved children, young people and families across the UK.

Telephone: 020 7843 6309

Email: cbn@ncb.org.uk

Website: www.childhoodbereavementnetwork.org.uk

Childline

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

Telephone: 0800 1111

Email: through the website contact page

Website: www.childline.org.uk

The Children's Society

Support and services for children, including young carers.

Telephone: 0300 303 7000

Email: supportercare@childrenssociety.org.uk

Website: www.childrenssociety.org.uk

The Children's Society – Include Programme

Support and services for young carers.

Telephone: 01962 711511

Email: through the website contact page

Website: www.youngcarer.com

MND Scotland

Support for people affected by MND in Scotland.

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

Winston's Wish

Support for bereaved children, young people and their families.

Helpline: 08452 030405
Email: info@winstonswish.org.uk
Website: www.winstonswish.org.uk

Young Minds

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

Helpline: 0808 802 5544
Email: [ymenquiries@youngminds.org.uk](mailto:ymentquiries@youngminds.org.uk)
Website: www.youngminds.org.uk

Youth Access

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

Telephone: 020 8772 9900
Email: admin@youthaccess.org.uk
Website: www.youthaccess.org.uk

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Kelly Taylor, Head of Year 10, The King's School, Wolverhampton

How we can support you

MND Connect

Our helpline offers help, information and support to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Benefits Advice Service

Qualified advisers can help identify benefits the person with MND and carers may be entitled to, and advise on how to claim. This service is confidential, impartial and free.

www.mndassociation.org/benefits-advice

Information resources

We produce high quality information resources for people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

www.mndassociation.org/professionals

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

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

www.mndassociation.org/research

MND Register

The MND Register aims to collect information about every person with MND to help researchers focus their knowledge and expertise in the right areas.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.

www.mndassociation.org/care-centres

Branches and groups

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

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND.

www.mndassociation.org/associationvisitors

We value your feedback

We would greatly appreciate your feedback on this guide. Please visit www.smartsurvey.co.uk/s/mndprofessionals or email your comments to infofeedback@mndassociation.org

Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

MND Association

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