

# Telling people about MND

Conversations with family, children  
friends and professionals



**“It all helps when we discuss  
our condition with others.”**

Person living with MND

# Contents

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<b>How can this booklet help me?</b>	<b>4</b>
<b>1: How do I begin to tell people I have MND?</b>	<b>5</b>
<b>2: How do I approach conversations about MND?</b>	<b>8</b>
<b>3: How do I manage emotional conversations?</b>	<b>13</b>
<b>4: How do I communicate about MND with children and young people?</b>	<b>20</b>
<b>5: How do I raise awareness of my needs with health and social care professionals?</b>	<b>25</b>
<b>6: How can someone else help raise awareness of my needs?</b>	<b>30</b>
<b>7: How do I find out more?</b>	<b>34</b>



This symbol highlights quotes from people living with or affected by MND.



Patient Information Forum

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

**<https://piftick.org.uk>**

## How can this booklet help me?

Telling those important to you that you have motor neurone disease (MND), is likely to be one of the most challenging things you ever have to face.

This booklet gives suggestions on how to open conversations about MND, in a way that feels right for you. It includes guidance on how to raise awareness of your needs when seeking support.

**See *Further information* in section 7: *How do I find out more?* for a list of other resources and how to order them.**



# 1: How do I begin to tell people I have MND?

You may not want to tell others about your diagnosis at first. You may need time to adjust.

However, those close to you will begin to notice the effects of the disease and are likely to ask questions.

Friends and family often want to support, but they can only do this if they know what is going on. When given an opportunity to process the news, everyone can begin to adjust to the diagnosis and think about how to help each other.

## When do I tell people?



**“My husband found it helpful to tell people as soon as possible about his diagnosis. Reactions were mixed but it allowed everyone to talk about it.”**

There is no right time to tell people about your diagnosis. When you feel ready may depend on:

- your personality
- your relationship with those you are telling
- how you are adjusting to the diagnosis yourself
- how quickly the disease is progressing
- your circumstances
- what’s happening at the time.

However, it's important to have these conversations as early as possible, as MND can cause:

- weakness in the tongue, lips, vocal cords and chest, causing most people's speech to become faint, slurred or unclear
- fatigue, which can make speaking and concentrating on conversations very tiring
- changes to thinking and behaviour for some people, which can affect communication.

## Who do I tell?

You may feel comfortable telling people about your diagnosis.

If you find it overwhelming, you may only want to tell your closest family and friends at first.

When you feel ready, you can explain what's happening to your wider network of family or friends. If needed, ask a trusted friend or relative to help.

We provide a short introduction in an animation called: *What is MND?* found at: **[www.mndassociation.org/MNDfacts](http://www.mndassociation.org/MNDfacts)**  
Sharing this web link by email or online messaging can save having to repeat your explanation.

We have a wide range of information resources at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or contact our MND Connect helpline to order printed copies:

Telephone: **0808 802 6262**

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



## Should I tell my employer and colleagues?

If you are currently working, consider telling your employer that you have MND as soon as possible. If you want to stay at work, they may be able to support you to do this.

You can also discuss whether you want your colleagues to know about your diagnosis. If so, how would you like this news to be communicated?



**“I decided to tell three people a day at work, as I had chosen to leave. I wrote their names down and phoned each one over a period of about a week.”**

If you feel that stopping work is best, your employer may be able to help you leave in a way that feels right for you and those close to you.

**For more detail, including your rights as an employee, see: Information sheet 10E – *Work and MND*.**



## 2: How do I approach conversations about MND?

MND can affect the way you speak and use gesture. This can make it harder to manage conversations. We provide a range of information about the way MND can affect speech and communication.

**See Information sheet 7C: *Speech and communication support* and 7D: *Voice banking and message banking*, also section 8 of our *Living with motor neurone disease guide*, which covers these topics.**

However, when discussing a life-shortening illness, one of the biggest challenges is managing feelings. You may not want to get upset, or upset other people.



***“It’s an intriguing dilemma...a fellow worker asked what MND is, so I explained in simple terms and she burst into tears. I have since learned to be more tactful and weigh up the person asking first.”***

Yet, having conversations about MND can help other people feel more included. You can then all start planning how to manage daily life with the condition and seek support when needed.

It can feel hurtful if people try and avoid you or the subject. This is usually because they feel uncomfortable about upsetting you.

Using a question to open a conversation can help, as this gives the other person the option to join in or not. If they do, explain that MND affects each individual in different ways.



**Is there anything you  
have been wondering  
or want to ask me?**

**I've been discussing  
MND with my doctor.  
How would you feel if we  
had a chat about it now?**

**Last time we had a conversation  
about my diagnosis, we started  
to discuss \_\_\_\_\_.  
Could we carry on with this?**

There is no right or wrong way to communicate about MND. How you do this is your choice, but the following may help:

**Try to do it as early as possible:** have conversations about how you would like your treatment and care provided, as early as you can. Over time, these discussions will become more tiring. If this feels overwhelming, cover one subject at a time.

**Be clear:** telling people what's happening with clear and simple words can help avoid misunderstandings. This helps everyone, but especially children or young people. Also people with learning difficulties, dementia or where their first language is different to yours.

**See *Introductory information at:***  
[www.mndassociation.org/careinfo](http://www.mndassociation.org/careinfo)

**Share your feelings:** sharing your emotions can give other people permission to open up. This can help if they have been hiding their emotions to protect you from getting upset. Don't be afraid to cry or laugh, as these reactions can help release tension and built-up feelings.



**"It all helps when we discuss our condition with others."**

**Be open and honest:** by discussing MND, you show that it's safe to discuss and not a taboo subject. If people around you understand the disease and what's likely to happen, it may help them cope better too. If it feels right for you, tell them as much as they want to know. Don't be afraid to say that you don't know the answer to something.

**Reduce distractions:** help everyone concentrate by switching off phones, television or other distractions. This is also helpful if your speech is unclear or faint.

**Check understanding:** when people are in shock, they may not take in information as easily as expected. Gently check the person's understanding with simple questions about things you discuss. This can also help them feel more relaxed about discussing MND.



## What is emotional lability?

Emotional lability, also known as pseudobulbar affect, is a symptom that can happen with MND.

It can cause intense emotional responses, or responses that don't match your feelings. For example, you may laugh uncontrollably when sad, or cry when happy.

This can be distressing for you and those around you, but does not affect everyone with MND.

If it does happen, sensitive conversations can feel harder, as they may trigger emotional lability.

Explaining that these responses are part of the disease can help you and those close to you find ways to ease the symptom. You may find it useful to carry a note about this, in case you have an emotional response and someone else offers support.

This symptom usually reduces over time, but do ask your GP for support if needed. Medication and other assistance may help.

If your GP is not familiar with emotional lability, ask for referral to a health professional with neurological experience.

***See our booklet, [Emotional and psychological support](#).***

### 3: How do I manage emotional conversations?

**This section contains sensitive information on decision making for future care and end of life. Read when you feel ready to do so.**



*“With MND I might be lucky and have several years. I don’t know for sure, but I’ve got the chance to say to my loved ones, ‘I love you’ and that’s worth a lot.”*

With MND, you may need to think about:

- breathing support, known as assisted ventilation
- alternative ways to eat and drink if swallowing becomes difficult, such as tube feeding
- your preferences for care if you can no longer stay at home
- end of life decisions.

Find out your options for treatment and care. Discuss these with your health and social care team and those close to you. This will help you make informed decisions.

These conversations may feel emotional, but they can help all those involved feel prepared. This gives everyone more confidence that they are supporting you in the way you want.

At appointments, agree how much you want to discuss. Family members may wish to follow up with further questions, but you can take time out from the conversation if needed.

## Why are these conversations important?



**“No one advised us about end of life care or signs. It was only through reading online guides that I was able to recognise and come to terms with my father approaching the end of his life.”**

Conversations about treatment interventions and future care can feel emotional. End of life discussions even more so, especially with children and young people. It means facing up to difficult decisions and unwanted change. There may be cultural or religious reasons why certain subjects feel sensitive. Yet, being open about your wishes for advanced care, future treatment and end of life is helpful, both for practical and emotional reasons.

**See our information to help decision making in:  
*End of life: a guide for people with motor neurone disease.***



**“Reading about end of life allowed me and my husband to discuss sensitive issues and put plans in place to enable us to move on and live with MND.”**

It can be a relief, for all involved, once discussions happen. When everyone understands how you want to be supported in the future, you can focus on living.

If your speech and communication are affected, communication aids can help. A mix of methods may suit different situations. For example low tech solutions, such as alphabet or image boards or high tech, such as computerised speech apps.

**See information sheet *7C – Speech and communication support* and *7D - Voice banking and message banking.***





**“Of course, complete understanding is impossible, but most of those close to me have a remarkable ability to understand.”**

Those close to you are more likely to understand how you communicate, than people you don't meet regularly. Knowing your wishes can help if they need to guide health and social care professionals, who won't know you in the same way.

Your specific wishes for treatment, future care and end of life can also be written down to guide professionals. This is known as advance care planning. You can change your mind at any time. You can even record treatments you do not want or would want withdrawn under certain circumstances. When completed correctly on an official Advance Decision to Refuse Treatment (ADRT) form, this becomes legally binding for professionals. See section 5 later in this booklet: *How do I raise awareness of my needs with health and social care professionals?*

**See information sheet 14A – Advance Decision to Refuse Treatment and advance care planning, which also covers appointing someone you trust as power of attorney to make decisions on your behalf.**

## **What if we don't agree?**

Family, friends and professionals may have differing views about your treatment or care than yourself. Ask your health or social care professionals to help ensure all views are considered and understood. It's important that everyone involved in your care is included in these discussions. The professional guiding these conversations should be someone you see regularly, who knows you well. For example, an MND care centre or network co-ordinator, or a professional from your care team or local neurological service.



## How do I communicate about end of life?

Section 2 of this booklet may help when discussing end of life, but the following approaches may be particularly useful:

**Allow yourself to show emotion:** you may worry about upsetting others, but showing emotion gives them permission to share feelings too. This can help everyone feel supported.

**Share feelings of grief:** from diagnosis, MND can cause a sense of ongoing loss for you and those around you, known as 'anticipatory grief'. This can feel very challenging as symptoms get worse and plans change. Sharing these feelings with family and friends can help everyone feel closer and less isolated.

**Use clear language about end of life:** words like death and dying can feel upsetting, but help understanding. When death is shown on television or in films, it is often dramatic or violent – it may help to reassure others that this is not what usually happens with MND.

**Use information to open conversations:** sharing relevant resources shows that you want to make decisions. It gives others permission to discuss end of life with you. This can also help professionals, who may not realise that you are ready to discuss something sensitive.

**See our *End of life guide* for candid help with emotional conversations, anticipatory grief and decision making. Access the full guide or one section at a time at [www.mndassociation.org/eolguide](http://www.mndassociation.org/eolguide)**

## Who can I discuss end of life with?

If family, friends or carers find end of life conversations too difficult, your health and social care team can discuss it with you. This is supported in the NICE guideline on MND, which recommends that your health and social care team should:

- offer an opportunity to discuss future care, plans and concerns about end of life
- give support and advice about planning for future care.

For more information on the NICE guideline, see section 5 of this booklet: *How can I raise awareness of my needs with health and social care professionals?*

**See our booklet, *What you should expect from your care*. This pocket sized guide is based on the NICE guideline recommendations, to help open conversations about MND with health and social care professionals.**

Health and social care professionals are human too, and some may struggle to talk about end of life.



**“It is almost as if professionals are embarrassed about mentioning anything in case I get upset.”**

If this is the case, ask a professional that you feel particularly comfortable with. The following people may be helpful:

**Hospice and specialist palliative care professionals:** these experts are trained to discuss end of life concerns openly and with empathy.



**“I discussed end of life issues at the hospice and with family. My decisions were taken with great respect.”**

They also provide a wide range of help to improve quality of life for people with life-shortening conditions. This includes symptom management, practical advice and emotional support.

**For more detail on this type of care, see:  
Information sheet 3D – Hospice and palliative care**

**MND care co-ordinator:** if you attend an MND care centre or network, or local neurological service, you may have an MND care co-ordinator. They usually act as a link between you, your multidisciplinary team (MDT), other community services and the MND Association. They have regular contact with people affected by MND and can help with many questions.



**“The MND co-ordinator was excellent at discussing end of life care with us and did it in a professional and empathetic way”**

**MND Connect:** the helpline team at the MND Association can discuss all aspects of MND with you. They also provide emotional support, guidance and help to find further support, if needed. See *Further information* at the end of this booklet for contact details.

**Association visitor (AV):** our AVs are trained volunteers who provide free, confidential support for you and those close to you. Where an AV is available in your area, this support can usually be given by home visit, telephone or email. If it feels right for you both, they may be able to discuss sensitive topics with you, such as end of life. If you would like to be supported by an AV, contact our helpline MND Connect (see *Further information* at the end of this booklet for contact details).



## 4: How do I communicate about MND with children and young people?

### Why do children and young people need to know about MND?

Wanting to protect children from distress is natural. Yet, telling them what's happening can help them prepare for change.

Without understanding, children and young people may:

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

### How do I approach conversations about MND with a child?

How to tell children and young people about MND depends on their age, maturity and how quickly the disease is progressing. Using the tips mentioned in section 2 of this booklet can help with a child or young person, as with an adult. However, it is important to use language appropriate to their age and level of understanding. The following suggestions may help.



**Check what they know:** ask children or young people what they already know and want to know. This gives them permission to talk about things that are worrying them. Their questions may be different to those you expect. Older children may seek information about MND on their own. Encourage them to share what they find out, so you can see if it's 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 you are poorly or unwell. This can help avoid confusion or worry when someone has a less serious illness, such as a cold.

**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 over and over, or ask questions at inappropriate times. This is natural for a child, but may sometimes feel challenging for you.

**Be honest:** protecting children from upset may feel kind, but children can overhear things or pick up on emotions. Be honest without false reassurance to help them trust you. Explain what you are still able to do with MND to help keep conversations positive, but gentle honesty about future change is important.

**Gently prepare them for the future:** it can help to explain what's likely to happen next, so they understand that MND gets worse. This helps reduce the sense of shock as things change.

**Explain what they can see:** for example, if your legs are affected, explain how this makes it harder to walk. Let them know that your muscles are not working properly, so the child understands why you may be getting weaker.

**Explain speech and communication difficulties:** MND can affect communication and facial expression. Explain that if this happens, it will be caused by MND not by how you feel about them. You and the child or young person may gradually create your own 'language', where movements mean different things.



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

**Be aware of changes to thinking and behaviour:** up to half of people with MND experience changes to thinking and behaviour. This is usually subtle with little effect on daily life, but for some, changes are more severe. If you support someone with MND who shows these changes, explain to children or young people who know them that it's part of the disease. For example 'This is one of the ways MND affects Gran. She still cares about you, but might not be able to show it as she did before'.

**Discuss feelings:** name emotions when discussing how you feel, as this may help the child or young person express themselves as well. For example, "I'm disappointed the weather was too bad for me to get outside today." or, "I'm so happy to see you!"

**Dispel embarrassment:** most children don't want to be seen as 'different' and may feel embarrassed if a loved one visibly changes. If they understand the person with MND is the same underneath, they are more likely to manage this. Although challenging, try to keep the child's routine as much as possible. Where things change, explain why to avoid confusion.

**Reassure them:** children may be frightened if they see a loved one becoming dependent, or upset or angry. Gently encourage them to share their fears and worries. Reassure them that having fun is still okay, as well as being sad sometimes.

**Check understanding:** ask questions to check understanding and gently help children and young people chat about MND.

**See our MND resources to help children and young people:**

- *MND Buddies*, our online hub at: [www.mndbuddies.org](http://www.mndbuddies.org) with games, stories and MND facts for young children
- *Why are things changing?* our storybook for children
- *When someone close has MND*, a workbook for children aged four to ten
- *So what is MND anyway?* our guide for young people up to the age of 18



## What if they don't want to talk?

If the child or young person doesn't want to talk about the illness, it may be their way of coping. A little like, 'If I don't say anything, it might go away'. They may worry about upsetting you or think they'll get into trouble by asking.

**Ask how they're feeling:** gently ask the child or young person how they feel about the changes that are happening. This may be all the permission they need to ask MND questions in return.

**Use a question box:** making a question box together can help a child who doesn't want to ask things out loud. A plain shoe box is ideal and can be decorated. Questions can be posted through a slot in the lid of the box. You can then discuss any fears, or post answers in the box for the child to read when they choose.

**Ask professionals to help:** teachers, social workers and health professionals can all help if needed.

**See our booklet *How to support children and young people, to help professionals, parents and guardians.***

**Record things they may want to know:** if children are too young to understand or discuss MND at the moment, try to record things they might want to know at a later date. Video or voice messages help in case your speech becomes affected, or text messages with photos. The free, downloadable app **[www.recordmenow.org](http://www.recordmenow.org)** can help you answer questions about your life in video format. Your recorded memories can be very helpful for children and young people as time goes on.

**See also information sheet 7D - *Voice banking and message banking, on how to preserve the sound of your voice for use with communication aids.***

## 5: How do I raise awareness of my needs with health and social care professionals?

In the UK, people are becoming more involved in decisions about their health and social care. The aim is that you have more conversations, choice and control over the support you receive.

However, if your speech and communication are affected by MND, it can be harder to make your views known. It can help to plan, or record messages and questions on a mobile device before important conversations.



**“Before an appointment with a doctor, I make a list of things I want to mention and hand it to them”**

Be clear how much information you want from the professionals you meet. You may want as much as possible to prepare. Or you may want to take in information at your own speed.



## How do I open conversations about my needs with professionals?



**“When my husband’s condition changes, I find out information to explain what’s happening. This means I can confidently discuss the issues and help we need.”**

Our information resources can help you start conversations. Taking information to appointments can help with subjects that feel uncomfortable and provide prompts to guide discussion.

**See our pocket guide, *What you should expect from your care, to help discussions at appointments.***

Health and social care professionals should take your views into account when supporting you.

If you find it difficult to communicate your needs and preferences, use our *Understanding my needs* form to record:

- information about you and how MND affects you
- the care and medication you need
- your main health and social care contact details
- other key contacts, such as your main carer.

Having these details to hand avoids having to repeat them at every appointment. This form is particularly helpful when guiding hospital staff or care workers about your care.

**See *Forms and resources to help communicate your needs* at: [www.mndassociation.org/careinfo](http://www.mndassociation.org/careinfo) which also explains our MND alert card and MND alert wristband.**



## How do I explain my needs in assessments?

With MND, you may need support from adult social care services for daily tasks, like getting washed and dressed. You have the right to a needs assessment, to work out if you need care services. In Northern Ireland, this is known as a community care assessment. Give as much detail as you can to the assessor.

### **Example of how to answer the questions:**

#### **Don't say:**

'I find it difficult to get dressed.'

#### **Do say:**

'I cannot do up buttons or zips now. Even with help it takes over an hour to get dressed and I find it very tiring.'

Your assessment will look at how MND affects your daily life and independence. With MND, ability can be affected by levels of tiredness and symptom do get worse over time. Explain the support you need on a bad day. It may help to keep a diary leading up to the assessment, to track when you need help and for how long. This also shows how symptoms progress, so future needs can be considered.

You can also ask how to access urgent care support, if your carer is unable to help for any reason, and whether you may be eligible for certain benefits.

It may help to have someone with you who knows MND and how it may affect you at either of these assessments. This could be an Association visitor (AV) or you may wish to ask your MND nurse to be present, if you have one.

At some point, you will need to have a financial assessment to work out how much you may need to pay towards any agreed services. This is known as a 'means test'.

You can choose to have services arranged for you or receive direct payments to select and arrange your own. If you use direct payments, you need to account for the money spent. You may need to take on the role of employer if you select a regular care worker through direct payments (known as a personal assistant). However, there are ways to get help with this.

Your carer also has the right to a carer's assessment, to work out if any services can support them in their caring role.

**See Information sheet 10B – *What is social care?* for more on needs assessment, carer's assessment, social care and direct payments. See also 10A – *Benefits and entitlements* and 10D - *NHS Continuing Healthcare*, about funded health and social care through the NHS.**

## **How can I check if my treatment and care are appropriate?**

With MND, you will need support from a wide range of professionals, which can feel daunting. The NICE guideline on MND provides recommendations to health and social care professionals about how to provide appropriate care.

**See our web page at: [www.mndassociation.org/mycare](http://www.mndassociation.org/mycare) which includes two resources based on the NICE guideline:**

- **Information sheet 1A – *About the NICE guideline on MND***
- **a pocket guide, *What you should expect from your care.***

## The Accessible Information Standard



**“When you struggle with speech, it’s got to be 50:50 with health and social care professionals. They need to adapt their communication style at appointments.”**

In England, organisations providing NHS healthcare or adult social care have a duty to support your communication if you are disabled. This includes providing information in a format you can access and understand. This might be in large print or Braille if you are sight impaired, or through support from a communication professional, such as with sign language.

Search for *Accessible Information Standard* at **[www.england.nhs.uk](http://www.england.nhs.uk)**



## 6: How can someone else help raise awareness of my needs?

Using a communication aid can help you raise awareness of your needs, but sometimes you may prefer to have spoken support from another person. This person is referred to as an 'advocate'.

### What does an advocate do?

An advocate can help ensure your views are heard and taken into account during health and social care appointments, meetings or conversations.



**“Having an advocate present at healthcare meetings suggests there may be some conflict. Yet really it’s more about having my voice heard and acted upon.”**

Although disagreements are unlikely at appointments, it may get more challenging to raise awareness of your needs. If so, an advocate may be helpful.

An advocate is someone who:

- knows you, your preferences and wishes for your care
- can support you to make your views known to others and speak for you, if needed.



**“Being heard is a very real issue, especially if I have written something – people will always hear the verbal voice first.”**

## Who can be an advocate?

An advocate can either be someone who already knows you, or someone from an independent organisation.

**Family member or friend:** someone who knows you well can be an advocate, if they:

- want to be your advocate
- know your wishes and preferences for care
- do not let their own views affect what they say on your behalf (known as being impartial).



**“I cannot speak, so use an iPad. Sometimes I feel frustrated that I am not being listened to, but my carer speaks on my behalf.”**

**Assigned advocate:** in England and Wales, your local authority may assign a free, independent advocate if you find it challenging to communicate your wishes ,and:

- you do not have family members or friends able to act as your advocate
- or you cannot make decisions about your health or care (known as ‘lacking mental capacity’.

If you live in Northern Ireland, contact your local health and social care trust for more information.

**Paying for an independent advocate:** if needed, you can pay for an independent advocate from an advocacy organisation. A professional care worker can speak on your behalf within their role, but you cannot pay them to be an independent advocate.

## How can I ensure I'm included in the conversation?

If conversations are moving too quickly or your advocate is not representing your views, you may feel a loss of control. It can help to arrange the following in advance of any meeting.

**Create a list:** it may be helpful to note down everything you want to discuss. You can signal to the list if you feel the conversation is moving off topic.



**“Every sentence or paragraph I write should be acknowledged by one of the professionals there and repeated aloud or summarised as we go along. This slows down the conversation and highlights what I have said.”**

**Use a communication aid:** in case spoken conversation moves too quickly, prepare a statement in advance through your communication aid. For example, ‘Please slow down, I want to say something.’ This ensures the other person waits while you input what you want to say. Some communication software apps have this option built-in.

**Agree a signal or code:** if you do not have a communication aid with you or cannot use one for any reason, agree a set of signals or movements. These can help you show that you want to pause conversation or disagree with something that is being said.





I love the way to



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# 7: How do I find out more?

## Useful organisations

We cannot endorse organisations, but this list may help you search for further information. Contact details may change between revisions. If you need help to find an organisation or have questions, contact our MND Connect helpline (see *Further information* at the end of this booklet for details).

### Organisations to support adults:

#### Conversations for life

Ways for families and professionals to start discussions about end of life care.

Email: [info@conversationsforlife.co.uk](mailto:info@conversationsforlife.co.uk)  
Website: [www.conversationsforlife.co.uk](http://www.conversationsforlife.co.uk)

#### Dying Matters

Hosted by Hospice UK, Dying Matters offers resources to help people start conversations about death and dying.

Email: [info@dyingmatters.org](mailto:info@dyingmatters.org)  
Website: [www.hospiceuk.org/our-campaigns/dying-matters](http://www.hospiceuk.org/our-campaigns/dying-matters)

#### Marie Curie

Support for people with a life-shortening illness, and their carers, including information about discussing a diagnosis.

Telephone: 0800 090 2309 (support line)  
Website: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

## **MND Scotland**

Support if you are living with MND in Scotland.

Telephone: 0141 332 3903

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

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

## **POhWER**

Advice and advocacy in the Midlands and South of England.

Telephone: 0300 456 2370

Email: [pohwer@pohwer.net](mailto:pohwer@pohwer.net)

Website: [www.pohwer.net](http://www.pohwer.net)

## **RecordMeNow**

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

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

## **Organisations to support children and young people:**

### **Barnardo's**

Supporting children and young carers across the UK.

Website: search for *young carers* at: [www.barnardos.org.uk](http://www.barnardos.org.uk)

### **Include**

Service run by the Children's Society for young carers.

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

### **Hope Support Services**

For young people close to someone with life-shortening illness.

Telephone: 01989 566317

Email: [help@hopesupport.org.uk](mailto:help@hopesupport.org.uk)

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

## YoungMinds

Supporting emotional and mental health for children and young people, with a helpline for parents and guardians, and a crisis textline for young people.

Parent helpline: 0808 802 5544  
Crisis Messenger: text SHOUT to 85258  
Website: [www.youngminds.org.uk](http://www.youngminds.org.uk)

## Youth Access

Find local youth information, counselling and support services.

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

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**Rachel Thomson**, Co-ordinator, Sussex MND Care and  
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## References

References used to support this information are available on request from: email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information Feedback

MND Association

Francis Crick House (2nd Floor)

6 Summerhouse Road

Moulton Park, Northampton NN3 6BJ

## Further information

You may find some of our other publications helpful.

***Living with MND*** – our main guide on daily life with MND, including sections on speech and communication.

***Information sheet 7C – Speech and communication support.***

***Information sheet 7D – Voice banking and message banking.***

***Supporting a child or young person close to someone with MND***  
– guidance for professionals, parents and guardians.

***Why are things changing?*** – family-based storybook to help young children begin adjusting to the changes that MND can bring.

***When someone close has MND: a workbook for children aged four to ten*** – activities for younger children to help a trusted adult communicate with them about MND.

***So what is MND anyway?*** – to help support young people who are affected by a diagnosis of MND in their family.

***End of life: a guide for people with motor neurone disease*** – support for challenging conversations around end of life and getting affairs in order.

**MND Buddies** – our online activity hub for young children close to someone with MND, with facts, games and stories at:  
**[www.mndbuddies.org](http://www.mndbuddies.org)**

We also have a web area for children, young people, parents and guardians at: **[www.mndassociation.org/cyp](http://www.mndassociation.org/cyp)**

Young people can also contact our helpline, Young Connect:

Telephone: **0808 802 6262**

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

You can download most of our publications at:  
**[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or order printed copies from our MND Connect helpline team, who can provide additional information and support:

### **MND Connect**

Telephone: **0808 802 6262**

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

### **MND Association website and online forum**

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

Forum: **<https://forum.mndassociation.org>**



## **We welcome your views**

Let us know what you think of this booklet. We'd love to hear what you think we did well and where we can improve the content for people with or affected by MND. Your anonymous comments may also be used to support and influence, as they help us share real MND experience and raise awareness in our resources, campaigns and applications for funding.

Please use our online feedback form at:

**[www.smartsurvey.co.uk/s/TellingPeopleBooklet](http://www.smartsurvey.co.uk/s/TellingPeopleBooklet)**

or contact by email: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**

or write to:

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