

Changes to thinking and behaviour with MND

a guide for people with or affected
by motor neurone disease (MND)



**“I feel that I am not the person
who outwardly behaves
in the way that I do.”**

Person living with MND

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



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

<https://piftick.org.uk>

How can this booklet help me?

If you have been diagnosed with motor neurone disease (MND), you may be worried about possible changes to the way you think and behave. This can affect some people with the disease.

This booklet can help you identify changes that may happen and how to get support if they do. We have also included information to help family and carers.

All quotes are from people with or affected by MND.

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



1: Will my thinking and behaviour change with MND?

Up to half of people with MND have changes to thinking and behaviour, known as cognitive change. In the later stages of MND, this increases to 8 out of 10 people.

For most, these changes have little or no effect on daily life, but may affect:

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

Where changes are more severe, frontotemporal dementia (FTD) may be involved and extra support needed.

See section 4 for more on frontotemporal dementia (FTD).

A diagnosis of MND is emotionally challenging and changes to thinking and behaviour are often mistaken for depression. However, if you experience unusual changes to the way you think or behave, seek advice from your GP or neurologist.

Friends or family may recognise these changes before you do, possibly before MND was even diagnosed. It may help to understand the effects are due to the disease.



“His behaviour was not about depression from diagnosis, but something to do with changes to the way he was thinking.”

How do I get checked for these changes?

A health professional, such as a neurologist, can help identify changes to thinking and behaviour through 'screening'.

Screening is a question and answer technique that shows if you need referral to a clinical psychologist or neuropsychologist for a full assessment.

More detailed testing can then look at the way changes may impact on daily life for you, your family and carers. The psychologist or neuropsychologist will work with you and your carers to help manage these symptoms.

However, changes can take time to become clear. This means it may not be possible to give an instant diagnosis, such as frontotemporal dementia.

The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is designed for use with MND, but there are various other screening methods.

Contact your nearest MND care centre or network, or your local neurological clinic to find out about different types of screening.

See information sheet 3A - MND care centres and networks.

Can changes to thinking and behaviour be caused by something else?

Yes, temporary changes may be caused by some medications or the impact of other MND symptoms.

See our resources on symptoms and emotions.

Contact your health team if you have any of the following:

- shortness of breath, disturbed sleep or extreme tiredness
- pain or cramp
- dehydration, especially from swallowing difficulties
- infections, especially of the chest or bladder
- persistent difficult emotions or depression.

What is emotional lability?

Some people with MND get emotional lability (known as pseudobulbar affect). With this symptom, you may laugh or cry at inappropriate times, which can be distressing and difficult to stop. These responses may not match how you feel. For example, you may laugh when sad, or cry when happy.



“It doesn’t help when people say things like ‘Get control of yourself’. The more I try to do that, the harder it gets. It feels as though something is using my body against my will.”

These outbursts are usually short and emotional lability usually reduces over time. Seek advice from your GP or a neurologist if you would like support to manage this symptom. Medication may help.

For more on managing emotions and emotional lability, see our booklet: *Emotional and psychological support*.

With changes to thinking and behaviour, it is more common to experience emotional lability. However, emotional lability can happen as a separate symptom and does not mean your thinking and behaviour will definitely change.

2: What changes could happen?

With MND, changes to thinking and behaviour can vary for each person. Not all of the following may happen.

How could thinking and learning be affected?

You may find it becomes more difficult to:

- make plans and finish tasks
- do things in the right order
- focus on more than one thing at a time
- process new information or solve problems
- make decisions and understand their consequences
- recognise other people's feelings.

How could behaviour and emotions be affected?

You may find that you:

- lack drive or interest in things
- find it hard to manage emotions, including aggression
- behave inappropriately in social situations
- repeat the same activity over and over
- become self-centred and dismissive of other people
- make impulsive decisions and take more risks
- crave sugary or junk food, and binge-eat.



“I feel as though I am in conflict with another individual inside me, but not part of me. It’s as if an unknown force is taking possession of my body and gradually pushing me out.”

How could my communication be affected?

MND can affect how you physically speak, and how you use gesture or expression. An assessment by a speech and language therapist can help you work out suitable solutions and communication aids.

See our resources on speech and communication, voice banking and message banking.

If the way you think changes, your use of words and language can change too. You may find that you:

- need support to follow conversations
- take more time to communicate and respond
- misspell words or find it more difficult to read or write
- have difficulty thinking of words or use wrong names.



“He became very frustrated, as he thought his writing made sense, but it didn’t.”

3: What can I do to manage these changes?

If you do experience changes to thinking and behaviour, try to build clear routines. The following suggestions may help you feel more in control of daily life.

For professional support, see section 6: *Who can help?*

How can I communicate my needs?

- get assessed by a speech and language therapist if you have problems with speech and communication
- take your time when raising awareness of your needs
- carry notes to explain the support you need
- use pictures, or gestures if you can, to help explain
- use image based communication aids if it becomes difficult to read or spell words.

We provide a form to help you explain your needs, called: *Understanding my needs*. If needed, ask your carer to help fill this in. Give the completed form to care workers or hospital staff to guide them about your care.

We also provide MND alerts, such as a small card to carry with you or a wristband that you can wear at all times.

See the option for *Forms and resources to help communicate your needs* at www.mndassociation.org/careinfo or *Further information* in Section 7, about ordering our resources.

ALERT! I have MND

How can I maintain focus better?

If you find it difficult to concentrate, try to:

- use a notebook or diary to keep track
- sit in a quiet, comfortable space without distractions
- do more difficult tasks when you have most energy and take regular breaks.

How can I manage my finances?

If you become more impulsive with spending, try to:

- stop and think carefully before buying things
- limit what you spend to a daily or weekly amount
- set up direct debits to pay bills on time
- avoid situations that might tempt you to gamble
- ask someone you trust to help with your finances.

How can I manage family responsibilities?

If you need help for your family, try to:

- discuss how to share tasks with family members
- ask schools about their support if you have children
- seek a needs assessment from adult social care services, as they can consider your whole family in their approach (including things like getting children to school or to a child-minder).

How can I do things more safely?

To stay safe, try to:

- get advice from an occupational therapist on how to manage daily routines and helpful equipment
- have safety equipment fitted, like smoke alarms, and keep dangerous items out of reach
- get support for cooking or cleaning
- have someone travel with you for road safety
- ask for help if needed with taking medicines.

What can I do to make appointments feel easier?

If you find appointments difficult, try to:

- list questions in advance, so you don't miss any out, and email questions to the person in advance
- tell the person you're meeting in advance if you need communication support arranged
- ask for a longer appointment in advance, if needed
- try to relax before an appointment to avoid feeling tense
- ask if you can record their answers to listen to later or see if someone can make notes for you
- ask someone to go with you for support or as an advocate to help explain your needs.

See our booklet *Telling others about MND for more on using advocates.*

How do I maintain personal care and hygiene?

If personal care and hygiene begin to feel less important to you, try to:

- agree how carers will prompt you about these routines
- add pictures or large labels on products to help you use them correctly
- store high risk toiletries out of reach, such as aerosols
- ask for guidance if you make mistakes, such as drying your body before rinsing off the soap
- get assessed by an occupational therapist for supportive equipment in the bathroom.

How can I manage behaviour changes?

If you experience behaviour changes that feel inappropriate, try to:

- seek guidance from your GP, nurse specialist or neurologist
- let those close to you know that your behaviour changes are caused by MND and what to expect
- avoid situations that tend to make you behave in an inappropriate or impulsive way
- keep your environment calm and familiar
- encourage your carer to seek guidance from healthcare professionals
- agree with carers how you want to be supported if you act inappropriately.



How do I manage changes to eating habits?

If you find that the way you eat becomes more impulsive, try to:

- ask your speech and language therapist about swallowing difficulties, and your dietitian about nutrition
- avoid or keep certain foods out of reach, where advised to do so by your health professionals - such as sugary foods, those that tempt you to gorge or that you find difficult to swallow
- have someone with you at mealtimes to help you control portion sizes, eat small mouthfuls and eat slowly
- attach pictures to containers, and keep things you find more difficult to identify away from food or drink - such as medicines.

See our resources on swallowing, eating and tube feeding.



How do I check if I can still drive?

If you are diagnosed with MND or dementia, you must:

- inform your driving licensing authority as soon as you can
- ask your GP if you can continue driving while waiting for confirmation from your driving licensing authority
- attend a driving assessment if asked to do this.

Warning: Not telling your driving licence authority about your diagnosis is a criminal offence. Please note, you may be fined and could be prosecuted if you are involved in an accident as a result. Contact the DVLA in England and Wales, or the DVA in Northern Ireland.

See Useful organisations in section 7: How do I find out more?

How do I plan ahead for future care?

Changes to thinking can increase over time, so try to plan ahead as early as you can. This can bring peace of mind in case you become unable to communicate your wishes or make decisions for yourself.



“I can still talk but find it hard to concentrate or hold complex discussions. The advice on having these difficult discussions as early as possible is crucial.”

See our resources on planning ahead and advance decisions.

You can plan ahead in various ways, including the following.

Advance care plan: this records how you want to receive care in the future and what's important to you. Although not a legal document, an advance care plan can guide others in all aspects of your care.

Advance Decision to Refuse Treatment (ADRT): if completed correctly, this document is legally binding in England and Wales. It states which medical treatments you do not wish to receive, in specific circumstances in the future. It only becomes valid if you lose the ability to make or communicate those decisions.

You cannot ask for anything to deliberately cause death, but you can refuse life-sustaining treatment. You can change or cancel an ADRT at any time.

Power of Attorney: you can give a trusted friend or relative legal power to make decisions on your behalf, in case you become unable to do this. There is a fee for this and you may need legal assistance.

In England and Wales, this is done with a Lasting Power of Attorney (LPA), through the Office of the Public Guardian. You can allow someone to make decisions about your property and finance. You can also give them permission to make decisions about your health and personal welfare.

In Northern Ireland, this is done with an Enduring Power of Attorney (EPA), through the Office of Care and Protection. An EPA can only apply to decisions on property and finance.

See Useful organisations in section 7: How do I find out more? for contact details.

4: What is frontotemporal dementia (FTD)?

A small number of people with MND are affected by frontotemporal dementia (FTD). You may not be aware that you have changed if you are affected in this way.

FTD mainly affects behaviour, thinking and language. The changes are similar to those previously explained in this guide. However, the impact is more severe and gets worse over time. This needs more intense support.

Memory is not usually affected in the same way as with Alzheimer's disease, the more common type of dementia. However, FTD can make it harder to take in and recall new information.

What causes FTD?

With FTD, changes in the frontal and temporal lobes of the brain cause brain cells to die faster than normal. About a third of those affected have a change in their genes (known as a mutation), but the cause in other cases is not known.

Can I pass on the gene?

There is a chance of passing the changed gene to your children. You can find out more through genetic counselling.

Although sensitively done, genetic counselling is not a form of psychotherapy. Instead, facts are explained, including options such as genetic testing. Genetic testing shows if you carry the gene, but not how it will affect you or your children.

Deciding about testing can feel difficult, as it affects your wider family and may raise questions about options for pregnancy. Your genetic counsellor can help you make a decision that feels right for you. Ask your GP or neurologist for a referral.

See our research sheets on genetic testing.

What help is available for FTD?

There is currently no cure for FTD, but the following can help:

- support from a neuropsychologist who can work with you on ways to manage symptoms
- a calm, structured environment, with safety in mind
- care support to meet changing needs from adult social care services, including support for carers
- maintaining social contacts to avoid isolation
- medication to help control some behaviours.

With FTD, there may come a time when you are no longer able to make or communicate decisions. Planning ahead ensures your wishes are known for future care.

FTD will have a major impact on carers and family members. It's important that your carers have the right support.

See Section 5: *What if I'm a carer for someone with changes to thinking and behaviour?* and our comprehensive guide for carers: *Caring and MND: support for you*

Don't be scared to ask health and social care professionals about changes in your thinking or behaviour. The support you'll need depends on what's changing and how else MND affects you.

You can get help from:

- health and social care professionals, including specialists in neurology, psychology and neuropsychology, or specialist dementia nursing (such as Admiral nurses)
- an occupational therapist, for advice on equipment, home adaptations and different ways of doing things
- adult social care services, who can assess your needs for care support and services – contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

**See also section 6: *Who can help?*
and section 7: *How do I find out more?***



5: What if I'm supporting someone with MND who has changes to their thinking and behaviour?

MND makes increasing demands on carers, but becomes more complex if thinking or behaviour are affected. Although these changes can be mild, the problems can be more severe if the person with MND develops frontotemporal dementia (FTD).

For example, they may show less empathy for others, including awareness of your feelings. Try not to take this personally. Keep in mind that it's the disease causing these changes.



"It's easier to manage a caring role when you acknowledge that changes to thinking or FTD are part of the disease. Once you get your head around this, you find ways to cope and place structure into each day."

See the previous sections to find out what to expect and a range of suggestions on support, but this will vary. If someone with MND has changes to their thinking and behaviour, support has to be tailored to the person's needs.



"I worried if he would forget me with dementia. Would he forget his family? But FTD doesn't work like this. It was more about behaviour change than his memory."

What support can I give?

First, read through the guidance in section 2: *What can I do if my thinking and behaviour change?* You may find the suggestions help you as a carer too.

You may be able to help the person with MND to act on these suggestions, if the changes they experience are mild. If more severe, they will need support to manage daily routines.



“I was his carer and a constant in his life. I knew how to cope with him and he sensed that. He depended on me.”

If thinking and behaviour are affected, the person may not be aware of the changes happening, but will need more support.



“He’s aware he has MND, but not of any changes to personality or approach. He’s definitely not aware he has FTD.”

Advice from the person’s health and social care team is essential to help you manage problems caused by changes to thinking and behaviour. They may also be able to provide guidance about seeking appropriate care services that understand MND.



In addition, try to:

- keep calm and display the behaviour you want to see
- aim for a structured routine, with one activity at a time.

Think about the following, where relevant:

Driving: ensure the person has informed the DVLA in England and Wales, or the DVA in Northern Ireland, about their diagnosis of MND or dementia. They may still be given permission to drive, but failure to inform their driving licence authority is a criminal offence. While waiting for confirmation, the person's GP can advise them whether they should continue to drive.

Safety around the home: ask an occupational therapist about practical support and adaptations for safety, including smoke detectors and carbon monoxide detectors. Keep dangerous substances and household appliances out of reach if the person finds it hard to identify them or might use them incorrectly. Use large image labels on products they need to identify.



“I had sensor lights around the house, so if he moved at night the alarm would wake me up.”

Safety outside the home: if someone with MND and FTD becomes less aware of safety, they may need support with tasks like crossing the road. It can also help to inform neighbours and local shops so they can support the person's needs. You may want to leave your contact details with trusted local contacts in case of an urgent situation. The person with FTD can also wear identification, such as an identity bracelet, to help if they get separated or lose their way.

Communication: MND can affect speech and communication. Changes to thinking may also make it hard to read, spell, use the right words, follow conversation or interpret facial expression. If the person with MND is less able to show facial expression or empathy, it can be difficult to know how they're feeling.

Try to:

- give the person time to listen
- check understanding
- watch their body language for clues
- avoid open questions – offer a choice of two things
- speak in short, steady sentences
- use pictures or gestures to help get your point across, and encourage them to do the same
- give gentle reminders
- break down complex information into small chunks
- ask a speech and language therapist for advice.



“He can understand simple instructions, but gets confused if more than one idea is thrown at him.”

If behaviour or empathy are affected, there may be aggression, which can be upsetting for everyone involved.

If it's not the way the person would usually behave, then it's not as personal as it may feel. However, you may need support. Ask the health and social care team for advice.

Try to:

- spot warning signs or triggers, such as tiredness or pain
- keep a calm, structured routine and avoid arguments
- use calm body language, facial expression and voice
- distract the person or change the subject
- keep a safe distance and let the person calm down
- ask a health professional about medication to help.

Children: keeping children safe is a priority. If you have children, their noise levels and behaviour may irritate the person with MND. Be alert to possible warning signs that the person is becoming agitated. It may help prevent incidents if the person is supervised when children are present.

If needed, contact your local authority's Safeguarding Children team for advice and support. Services supporting the person with dementia should work together with the Safeguarding Children team to put extra help in place.

If the affected person or anyone else is at risk of serious harm, call emergency services on 999. Ensure that you inform them that the person has a condition that affects the way they think.

What can I do to help myself in a caring role?

MND symptoms get worse, including changes to thinking and behaviour. No matter how difficult, you must consider your own needs as a carer. Without support and rest, you could become ill yourself. You may be unable to remain in your caring role, even if this is something you want to continue.

Let your GP know you are a carer, so you can access regular health checks and flexible appointments. You may also be able to get support at home as a carer.

See next heading: *Getting your needs assessed and our carer's guide, Caring and MND: support for you, for more on carer wellbeing, including guidance from carers.*

Health and social care professionals who support people with MND and FTD, also advise carers. You can guide them too, as no-one knows the challenges of care better than you.

Keep useful professional contacts to hand and keep them informed. MND is not a common disease, which means not all health professionals and care workers are familiar with the care needs. Experience may be even more limited where FTD is involved, so ask about possible referrals to appropriate support.

Support with FTD is usually available from either an MND care centre or network, or dementia services. This might include a community mental health nurse (CMHN) or dementia specialist nurse (which may include Admiral nurses who work with the whole family).

Keep in touch with your nearest MND care centre or network, or your local neurology service. This is important for specialist advice and referrals when needed. They provide co-ordinated care, with neuro specialists working together as a team.



“As professionals learn more about FTD and the link to MND, the support keeps getting better. There’s a way to go, but progress is being made.”

Where medical needs become complex or urgent, the person with MND may need to move into a nursing care home. This can be a difficult decision, but the need for advanced care and medical support is not a reflection on the care you provide.

Getting your needs assessed



“Exhaustion can creep up on you when you least expect it and tasks that would normally be easy or simple can become very fraught.”

You can ask for a carer’s assessment and a needs assessment for the person with MND. Contact adult social care services, through your local authority in England and Wales or your local health and social care trust in Northern Ireland. An assessment may result in support and an opportunity to find out about care services, voluntary help, benefits advice and assistance with travel. You can also ask about local support, respite care, emergency support and nursing care.

For detailed guidance on preparing for a carer’s assessment, see our carer’s guide, *Caring and MND: support for you*.



Respite care is where someone takes care of the person with MND while you take a short break, or longer holiday. This may be through a day care or support group, often at a local hospice. Respite care can also be provided at home, or in a residential or nursing care home. Even if family and friends help out, external care support is worth exploring.

However, MND and FTD can make it more difficult to find suitable care providers. Check their experience before choosing providers and be clear what the person with MND needs. This may include helping with medical equipment, such as assisted ventilation for breathing support or tube feeding.

Can I talk to other carers affected by MND?

Your experience is unique, but meeting other carers can help you share support. The MND Association has branches and groups across England, Wales and Northern Ireland. They offer a warm welcome and chances to get together with others affected by MND. Many hold specific meetings for carers.

If you find it difficult to attend a meeting, there are sometimes opportunities to join online.

Or find our online forum for people with or affected by MND at: **<https://forum.mndassociation.org>**

If joining a branch or group doesn't feel right at the moment, you can join at any time. Find your nearest one at: **www.mndassociation.org/branchesandgroups** or contact our MND Connect helpline.

See contact details in [Further information](#), in section 7: [How do I find out more?](#)

6: Who can help?



“It really can’t be emphasised enough to listen to professionals who have helped people go through this before.”

Seek support from the following health and social care professionals, or services.

GP: for guidance and appropriate medication, if needed. Also for referral to other services and specialists, as in this list.

Multidisciplinary team (MDT): for co-ordinated care through a team of specialists. This can usually be found through an MND care centre or network, or a local neurological service.

Psychologist: for in-depth forms of mental health therapy covering a wide range of emotional and behavioural issues.

Neuropsychologist: for support where the relationship between the physical brain and way someone thinks and behaves has changed. The work of psychologists and neuropsychologists can overlap.

Community mental health nurse (CMHN) or dementia specialist nurse: for support of mental health care in the community. Specialist dementia nurses may include Admiral nurses who work with the whole family.

Occupational therapist: for assessment and support to prolong independence, safety in the home, equipment, adaptations and different ways to do everyday activities.

Speech and language therapist: for assessment on speech and communication. This may help you source communication aids that are appropriate if there have been changes to thinking.

Adult social care services: for needs assessment, information and help to arrange care services. Contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

Specialist palliative care or hospice care: for practical and emotional support to achieve the best possible quality of life with a life-shortening illness. It includes day therapies and home visits in some cases. This type of care brings benefit from the point of diagnosis, but there is sometimes a waiting list.

Spiritual or religious guidance: for this type of support, contact your local faith leader or ask a social worker for advice. You can also find this type of support through specialist palliative care services.

NHS Continuing Healthcare: for a package of nursing and personal care, fully funded by the NHS. This is only provided where healthcare needs are complex and urgent. Continuing healthcare works in a similar way in England and Wales – there is no formal guidance in Northern Ireland, but health and social care trusts are encouraged to refer to the same criteria.

See information sheet 10D: *NHS Continuing Healthcare.*

MND Association: for guidance, information, services and emotional support, including regional support.

See section 7: *How do I find out more? for details about how we can help you and other useful organisations.*

What do the words mean?

You may hear healthcare professionals use the following words when discussing possible changes to thinking and behaviour with MND.

Aphasia: difficulties with speaking, understanding speech and finding the right words.

Cognition: your mental and thinking abilities.

Disinhibition: behaviour that others find inappropriate and you may find difficult to stop.

Echolalia: repeating a word or sound you just heard.

Emotional lability: also known as pseudobulbar affect, which is laughing or crying that may not match how you feel. See Section 1 for more on this symptom.

Impulsivity: acting without thinking about consequences, such as spending money impulsively, or behaviour that puts you or others at risk.

Mental capacity: the ability to make and communicate decisions for yourself.

Perseveration: continually repeating words, phrases, actions or movements.

Pseudobulbar affect: see *emotional lability* above.

7: How do I find out more?

Useful organisations

We cannot endorse organisations, but the following may help you search for further information. Contact details may change between revisions. Our MND Connect helpline can help you find organisations (see *Further information* in this section).

Alzheimer's Society

For information about support for any type of dementia.

Telephone: 0333 150 3456

Email: through the website contact page

Website: www.alzheimers.org.uk

BBC Music Memories

A BBC site to help you find music you love by decade and type.

Website: <https://musicmemories.bbcrewind.co.uk>

Carers Trust

Information and support for carers.

Telephone: 0300 772 9600

Email: info@carers.org

Website: www.carers.org

Carers UK

Information and support for carers.

Telephone: 020 7378 4999 (England) or 029 20811370 (Wales)
or 02890 439 843 (Northern Ireland)

Email: through the website contact page

Website: www.carersuk.org

Dementia UK

Information about dementia and specialist Admiral Nurses.

Telephone: 0800 888 6678

Email: info@dementiauk.org

Website: www.dementiauk.org

DVA

Driving licence authority for Northern Ireland.

Website: www.nidirect.gov.uk/motoring

DVLA

Driving licence authority for the UK.

Telephone: 0300 790 6806 (for medical condition enquiries)

Website: www.gov.uk/driving-medical-conditions

FTD Talk

Updates on recent research findings about FTD.

Website: www.ftdtalk.org

GOV.UK

Online government information on benefits and support.

Email: see website for subject related emails

Website: www.gov.uk (England and Wales)

www.nidirect.gov.uk (Northern Ireland)

Headspace

Membership site with meditation and mindfulness exercises.

Website: www.headspace.com

Health in Wales

Online information about NHS services in Wales.

Email: through the website contact page

Website: www.wales.nhs.uk

Health and social care online (Northern Ireland)

Health and social care online information for Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

Medic Alert

Identity bracelets or necklets with a 24 hour telephone service.

Telephone: 01908 951045

Email: info@medicalert.org.uk

Website: **www.medicalert.org.uk**

The Mental Health Foundation

Online information to help protect and sustain mental health.

Website: **www.mentalhealth.org.uk**

Mind

Information and support on mental health.

Telephone: 0300 123 3393

Email: info@mind.org.uk

Website: **www.mind.org.uk**

MND Scotland

Support if you are living with MND in Scotland.

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

NHS (online)

Health information about NHS services in England.

Telephone: 111 for urgent, but non-emergency medical advice 24-hours a day, 365 days a year

Website: **www.nhs.uk**

NHS 111 Wales

Online health advice in Wales.

Telephone: 111 for urgent, but non-emergency
medical advice

Website: **<https://111.wales.nhs.uk>**

Office of Care and Protection

For Enduring Power of Attorney (EPA) in Northern Ireland.

Telephone: 0300 200 7812

Website: Search for *EPA* at: **www.justice-ni.gov.uk**

Public Guardianship Office

For Lasting Power of Attorney (LPA) in England and Wales.

Telephone: 0300 456 0300

Email: customerservices@publicguardian.gov.uk

Website: search for *LPA* at: **www.gov.uk**

Rare Dementia Support

Information and FTD support.

Email: contact@raredementiasupport.org

Website: **[www.raredementiasupport.org/
frontotemporal-dementia](http://www.raredementiasupport.org/frontotemporal-dementia)**

Safeguarding children team (through social services)

Contact your local authority in England and Wales or your local health and social care trust in Northern Ireland.

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Professor Jonathan Rohrer, Professor of Neurology, Dementia Research Centre, UCL Queen Square Institute of Neurology and National Hospital for Neurology and Neurosurgery

References

References used to support this information are available on request from: email: **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

For more support, see the following guides:

What you should expect from your care: using the NICE guideline on motor neurone disease (MND)

Information sheet 3A - MND care centres and networks

Emotional and psychological support

Living with motor neurone disease (MND)

Caring and MND: support for you

End of life: a guide for people with motor neurone disease (MND)

You can download most of our publications at:

www.mndassociation.org/publications or order printed copies from our MND Connect helpline team (see next page), who can provide additional information and support.

MND Connect

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Our helpline team can provide information, guidance and emotional support. They can explain our services and grants, and introduce you to our local our Association visitors, regional staff contacts, branches and groups. They can also help you search for external organisations.

MND Association website and online forum

Website: **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 how 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/ThinkingandFTD

or contact by email:

infofeedback@mndassociation.org

or write to:

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