



9B

How do I support someone if the way they think is affected?

Information for carers of people with motor neurone disease

Up to half of people with motor neurone disease (MND) experience changes to their thinking and behaviour, but this can affect them in different ways. For many, the changes are subtle and have little effect on daily life. In a small number of people, the changes may be more apparent and additional support may be needed to manage daily routines.

If you are caring for someone with MND, you may be concerned about what to expect if their thinking is affected. This information sheet looks at the possible changes, how to access support and adjustments that may help.

The content includes the following sections:

- 1: **What changes might happen to thinking and behaviour?**
- 2: **What is frontotemporal dementia?**
- 3: **How can the person with MND get support?**
- 4: **Who can support me as a carer?**
- 5: **How can I help someone to manage changes in thinking and behaviour?**
- 6: **How do I find out more?**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

The suggestions given may not be suitable for everyone, and depend on how the person is being affected, so ask your health and social care team for individual advice.

What do the words mean?

Your health and social care team may use medical terms. Here are some words you may hear when discussing changes to thinking and behaviour.

Aphasia: using the wrong sounds or words when speaking or writing.

Cognition: all of your mental abilities and knowledge, including memory, language, attention, problem-solving, decision-making and thinking.

Disinhibition: behaviour that others find inappropriate and that you may have difficulty stopping yourself doing.

Echolalia: repeating a word or sound you have just heard.

Emotional lability: also known as pseudo-bulbar affect. It causes laughing or crying, sometimes at inappropriate times. It can be difficult to stop and may not match how you feel. See section 3: *What is emotional lability?*

Frontotemporal dementia (FTD): a type of dementia that affects your thinking, behaviour and use of language. See section 5: *What is frontotemporal dementia?*

Impulsivity: acting without thinking about the consequences, including risky or dangerous behaviour and making decisions quickly.

Mental capacity: the ability to make and communicate decisions for yourself. See section 7: *How do I plan for future care?*

Perseveration: continually repeating words, phrases or movements.

Pseudo-bulbar affect: see emotional lability above.

1: What changes might happen to thinking and behaviour?

Changes to thinking can range from very mild to more severe. People affected by these changes may experience difficulties with:

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

You or other people close to the person with MND may notice the changes first, as the affected person may not be aware of the changes.

If you recognise the changes described in this information sheet, contact the person's health and social care team for advice. You may wish to share this information sheet with them, as they may not be familiar with the links between MND and changes to thinking and behaviour.

In a small number of cases, people with MND develop frontotemporal dementia which can have a major impact on daily life and may require a higher level of support. See section 2: *What is frontotemporal dementia?*

What else might be causing changes to thinking and behaviour?

Physical health problems may cause temporary changes to thinking and behaviour. It is important that these are addressed, as the changes may be reversible. Get advice from the person's health and social care team if you think they might be experiencing:

- dehydration, especially if eating and drinking have become difficult
- disturbed sleep due to stress, discomfort etc
- breathing difficulties
- infections, especially of the chest or bladder
- side effects of certain medications
- low mood or depression.

Speech and communication difficulties caused by the physical effects of MND can make it difficult to understand whether or not the person's thinking has changed. Ask the person's health and social care team for a referral to a speech and language therapist for advice.

How might thinking and learning change?

If the person you are supporting experiences changes to their thinking and learning, they may find it becomes more difficult to:

- make and carry out plans
- think of things to do
- carry out activities in the right order
- do more than one thing at a time
- process information and solve problems
- make decisions after considering the options and consequences carefully
- concentrate and take in new information
- finish tasks.

How might language and communication be affected?

The person with MND may experience speech and language difficulties due to the physical effects of MND on the ability to move the mouth, throat and vocal cords. However, the person you care for may also have difficulties with language and communication due to changes to their thinking.

You may find that the person with MND:

- communicates more slowly
- has to think more about what has been said and how to respond
- struggles to think of a particular word
- has difficulty spelling words
- finds it harder to recognise words when reading or writing
- finds it difficult to follow conversations and take in what someone is saying.

What changes might affect behaviour?

If the person you are caring for experiences changes to their behaviour, they may:

- find it difficult to manage their emotions, including aggression and irritability
- lack drive and show less interest in things
- behave inappropriately in social situations
- repeat the same activity over and over
- become self-centred and dismissive of others' feelings
- make decisions based on emotions and take more risks
- binge-eat, crave sugar and experience changes to taste.

They may experience a range of difficult, mixed emotions following a diagnosis of MND. This is a normal reaction to a difficult situation, and is different to the changes listed above.

 For more information about emotions and MND see:
9C – *Managing emotions*

What is emotional lability?

This is a symptom that some people experience with MND. It causes laughing or crying at inappropriate times, and may not reflect how they are feeling. It is difficult to stop and can be distressing. In many cases it is a temporary symptom that reduces over time.

 *“Sometimes I knew he wanted to laugh, but it came out as tears. Friends would think they had upset him and I had to explain it was just a response he couldn’t help.”*

Recognising this as a symptom and making others aware of this may make it easier to manage. If it is persistent and causing distress, speak to your health and social care team as medication may help.

People with MND who are affected by changes to their thinking are more likely to experience emotional lability. However, emotional lability is not in itself a sign of changes to their thinking.

 For more detailed information about emotional lability in MND see:
9C – *Managing emotions*

2: What is frontotemporal dementia?

A small number of people with MND are affected by frontotemporal dementia (FTD). FTD gets worse over time, and the person may not be able to recognise that they have changed.

FTD can have a major impact on the independence and daily life of the affected person, on you as a carer, the wider family and social relationships.

It is important to note that FTD has very different symptoms to Alzheimer’s disease, which the most common type of dementia. With FTD, memory is not usually affected. However, some people may appear to have problems with their memory due to difficulties with concentration and taking in new information.

What causes FTD?

FTD is caused by changes in the frontal and temporal lobes of the brain that cause brain cells to die at a faster rate than normal. For some people the condition is inherited. Around a third of people who develop FTD have a change (mutation) in their genes that is passed down in families. The cause of FTD in other cases is not known.

If you are worried that the person with MND may have the genetic form of FTD, ask their GP for a referral to a genetic counsellor. The role of the genetic counsellor is to explain the facts as clearly as possible, and provide accurate information on the potential implications for the family. This will include information about options such as genetic testing which can show if someone carries the gene, but it cannot predict how or when someone might be affected.

 Although focussed on MND, and not FTD, further information about genetic testing is available in our research information sheet *B: Inherited MND*

How could FTD affect the person I care for?

FTD mainly affects behaviour, thinking and language. The changes are similar to those already described in this information sheet, but are more apparent and require more support. People with FTD may not be aware of the changes they are experiencing.

 *"He was aware he had MND, but not of any changes to personality or approach. He was definitely not aware he had FTD".*

FTD can affect someone's ability to make decisions, and there may be a time when they can no longer make or communicate decisions. You may want to help the person plan ahead to ensure their wishes are known and respected during future care.

There is currently no cure for FTD, but there are a number of important things that can help. These might include some or all of the following:

- a calm, caring environment
- a regular routine
- a support package that increases to meet their changing needs
- ensuring safety around the home with advice from health and social care professionals
- avoiding isolation and maintaining social contacts
- medication which may help to control some behaviours
- planning for the future early
- ensuring care staff understand the person's needs
- support for you, as a carer.

How could FTD affect me as their carer?

FTD will have a major impact on you as a carer, as well as the wider family. It can cause anxiety and stress. Simple everyday tasks can become more difficult and you may need extra support to manage caring for someone. The level of care needed will increase, so it is important that you and the person with FTD both have the right support. See section 4: *Who can support me as a carer?*

 For detailed information for carers see our guide: *Caring and MND: support for you*

3: How can the person with MND get support?

It's important to discuss changes to someone's thinking, language or behaviour with a health or social care professional to ensure they get the right support.

How can they get a diagnosis?

The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is a screening tool that health or social care professionals can use to help identify changes to thinking. It helps the professional decide if a detailed assessment by a clinical psychologist or neuropsychologist is needed.

Ask your MND Care Centre or neurological clinic for more information about ECAS. They may not be aware of the tool, but it may be worth encouraging them to use it. Other screening tools are in use, but ECAS specifically looks at the types of changes that people with MND may experience. It includes a carer's questionnaire, so that you can provide information about changes you have noticed.

The person with MND may be referred to a neurologist or neuropsychologist for further assessment, such as:

- a full assessment of their symptoms and family medical history
- blood tests to exclude other causes
- detailed testing of their thinking
- brain scans to look for changes to the brain's structure
- testing the fluid from around the spine, known as lumbar puncture
- testing to see if there is a known cause in the genes.

There is no single test to diagnose these changes. At first, it may not be possible to get a firm diagnosis, as it can take time for the changes to become clear.

Who can help the person whose thinking has been affected?

Occupational therapist (OT)

Occupational therapists support people to remain as independent as possible through equipment for daily living, adapting the home environment and showing people different ways to do everyday activities. Ask a health or social care professional for a referral.

Speech and language therapist

Speech and language therapists can assess the communication needs of someone with MND and give advice about swallowing, speech and communication aids. Ask a health or social care professional for a referral.

Adult social care services

It is essential that the person affected has the right level of support. If they are receiving care from the NHS, adult social care services or health and social care trust in Northern Ireland, they should be made aware of these changes so that they adjust the level of care as needed. Contact adult social care services or your health and social care trust in Northern Ireland for an assessment or review. See section 6. *How do I find out more?* for contact details.

Neuropsychologist

Neuropsychologists can assess the nature of changes to thinking and behaviour using a range of tests. An assessment with a neuropsychologist can be arranged by your GP or other medical professionals. This may follow completion of the ECAS screening assessment. See heading *How can they get a diagnosis?* earlier in this section.

Specialist dementia nurse

These nurses who give practical and emotional support to the person whose thinking has been affected and their family. They provide families with the knowledge to understand the condition and its effects. Specialist nurses are available through the NHS so ask your health and social care team to help arrange this. Charities such as Dementia UK also provide this support. See section 6: *How do I find out more?* for contact details.

4: Who can support me as a carer?

No matter how difficult it might be when providing care, you need to consider your own needs too, which can be difficult to balance with the caring role. Without rest, you may reach a crisis point that will prevent you from continuing to care.

Let your GP know you are a carer. Some GP practices offer regular health checks for carers and have more flexibility when making appointments. It is important to maintain your wellbeing.

The same professionals who help the person with MND and FTD can also give you advice as the carer and should treat you as part of the health and social care team. No-one knows the daily challenges better than you do.

It may be helpful to keep useful contacts including important health and social care professionals close at hand in case you need emergency support.



You may find it helpful to refer to our full carer's pack:
Caring and MND – support for you

How can a carer's assessment help me?

A carer's assessment enables you to tell social services how they can make caring easier for you. Ask your local adult social care services or health and social care trust in Northern Ireland for an appointment. See section 6: *How do I find out more?* for contact details.

Your circumstances, your income and the number of hours in which you provide care, may affect your eligibility for specific services or support, but a carer's assessment will help you find out about:

- statutory care services, benefits advice and voluntary sector services
- planning for respite or emergency care
- assistance with travel
- suggestions for counselling or support groups.

How can respite care help me?

Caring for someone with MND and changes to their thinking and behaviour can be tiring and challenging. Respite care can help you take a break as care is provided by someone else to give you time for rest, a holiday or other activities. This can sometimes be provided by friends and family, but you may need external care support.

Respite care can be provided at home, in a residential or nursing care home, a day centre, hospital or hospice. Check the provider can meet the needs of the person with MND. Hospices can usually advise where to find specialist care.

A community care assessment for the person you support, and a carer's assessment for yourself, may help you plan for future respite and alleviate worries. Contact your local adult social care services or health and social care trust in Northern Ireland for more information. See section 6: *How do I find out more?* for contact details.

How can residential and nursing care help me?

There may come a time when the person you support requires more care than can realistically be provided at home, and residential or nursing care may need to be considered. This can be a difficult decision for the person you support and for you as a carer.

However hard the decision might be, there are times when a person may require advanced support and you need to recognise that this is not a reflection on you or the care you provide.

If you are considering residential or nursing care, contact your local adult social care services or health and social care trust in Northern Ireland to request a Community care assessment for the person you support. See section 6: *How do I find out more?* for contact details.

5: How can I help someone to manage changes in their thinking and behaviour?

The suggestions in this section may not be appropriate or suitable for everyone. The support that someone needs will depend on the changes they are experiencing and how else MND affects them. Always get individual advice and support from the person's health and social care team.

A few key tips to help you are:

- display the behaviour you are trying to encourage
- aim for a structured routine
- focus on one activity at a time
- give calm, patient reminders often
- break down complex information into smaller chunks
- understand that the changes to behaviour and thinking are due to a problem in the person's thinking and try not to take things personally.



"It's easier to manage when you acknowledge that FTD is part of the disease. Once you get your head around this, you can find ways to cope and place structure into each day".

How can I help keep the person safe?

Someone experiencing changes to their thinking may need support to keep safe, as they might not recognise risks and act without thinking about consequences.

Driving

The person's driving licensing authority must be informed of a diagnosis of MND or dementia. Discuss with the GP whether the person you support should continue driving while you wait for confirmation from DVLA or DVA in Northern Ireland.

Failure to inform them of an illness is a criminal offence and can result in a fine, or prosecution if they are involved in an accident as a result. See section 6. *How do I find out more?* for contact details for the DVA and DVLA.

Safety around the home

Get advice from an occupational therapist, as they can offer practical support, aids and adaptations that may help to keep the person safe.

Consider keeping dangerous substances and household appliances somewhere safe, as the person may not understand what they are for and use them incorrectly. Ensure that any safety devices around the home are working correctly. Smoke detectors and carbon monoxide detectors can help reduce the risks of accidental fires.

Safety outside the home

Depending on the person's needs, they may benefit from being with someone else whilst in the community, for example some people may cross the road without considering their safety.

Make sure the person carries some form of identification. Bracelets (such as MedicAlert) and awareness cards are available. See section 6: *How do I find out more?* for contact details. These can help if you and the person become separated. It may also help to inform neighbours and local shops about the person's needs and give them your contact details in case they need to contact you about the person.

What can help someone to concentrate?

If lack of concentration is an issue, it may help to:

- sit somewhere quiet and make sure there are no distractions
- make sure the person is as comfortable as possible
- adjust temperature and brightness of the room if needed
- encourage them to take regular breaks from the activity they are focusing on.

How can I support someone to take care of their personal hygiene?

Personal hygiene may not feel as important to the individual as before, and they may start to neglect it. They may use products incorrectly or do things in the wrong order, for example drying their body before rinsing off the soap.

It may help to:

- agree in advance when and how you will prompt them to take care of their hygiene
- add pictures to bottles and containers to help them to use them correctly
- store dangerous toiletries such as aerosols out of reach
- get advice from an OT as they can support with this .

What can I do to help with communication?

The person affected may find communicating challenging due to difficulty finding the right words and not being able to follow what you are saying.

Some people with FTD can find it difficult to understand facial expressions, and show less facial expressions themselves. This can make it difficult for you both to recognise how the other is feeling, which can make open communication difficult.

The following may be helpful:

- allow enough time for them to take information in and check they have understood
- limit choices to one or two alternatives, and avoid open ended questions
- speak slowly using short sentences
- use pictures or gestures to help get your point across, and encourage them to do the same
- ask for a referral to a speech and language therapist for advice.



"His perception of the world and what was said to him had changed. He could understand simple instructions, but was easily confused if more than one idea was thrown at him".

How can I help someone with unwanted behaviours?

The person you care for may say or do things that cause embarrassment, distress or confusion. This can be difficult for everyone involved.

It may help to:

- ensure that people understand that this behaviour is a part of MND
- try to identify any triggers and help to avoid them
- keep the environment as calm and predictable as possible
- ask the person how they would like you to support them during these times.

If none of the above work, discuss this with the GP as to whether medication would be helpful.

How do I support someone with aggressive behaviour?

Some people with changes to their thinking may become more aggressive. This can be scary and upsetting for everyone involved. Remember that this behaviour is not personal, it is a part of the disease.

Try to:

- spot warning signs or triggers, such as tiredness or pain
- maintain a calm, structured routine
- avoid getting involved in an argument
- stay calm in your body, facial expressions and tone of voice
- change the subject or distract the person
- keep a safe distance and let the person calm down
- get advice from health and social care professional as medication may help.

If you have children, their noise levels and behaviour may lead to the person with MND getting agitated and irritable and this may result in aggressive behaviour. Preventing this and keeping the child safe is a priority. It may help to prevent incidents by ensuring that the person is supervised when children are present and being alert of any triggers or warning signs that the person is becoming agitated.

You can contact your local authority's Safeguarding Children team for advice and support. See section 6: *How do I find out more?* for contact details. The services supporting the person with dementia and the Safeguarding Children's services should work together, and extra help can be put in place.

If changes to thinking place the affected person or anyone else 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.

How can I help manage changes to eating?

Many people experience changes to their eating due to the physical effects of MND. However, changes to the brain can affect eating in other ways too, such as sugar-cravings, binge-eating and putting too much food in the mouth at once.

If the person you care for has difficulties with swallowing, this could be particularly risky. Ask for a referral to a speech and language therapist and dietitian.



“He couldn’t eat safely anymore, but would try to gorge. If food was left out for other people, he’d seek it out as he was mobile”.



For more information about swallowing difficulties with MND see:
7A – Swallowing difficulties

The person you care for may also have problems recognising different foods, for example using salt instead of sugar and not being able to tell that they have used the wrong one.

To help manage changes to someone’s eating, consider whether it would help to:

- keep foods that pose a risk out of reach eg if they have been advised to eat a soft diet, remove foods they have difficulty eating
- eat together to support them with portion sizes and eating slowly
- make sure that similar items are not kept near each other
- attach pictures to containers to make it easier to understand.

How can I support someone to plan for the future?

Many people with progressive illnesses fear losing control and not being able to make or communicate their decisions. Planning ahead can give you both peace of mind and may be especially important if there are changes to thinking.

Advance care plan

This is a record of the person’s preferences about care in case they become unable to make their wishes known. It is not a legal document, but health teams will take note of choices about where they wish their care to take place, spiritual or religious beliefs and how they would like your care provided.

Advance Decision to Refuse Treatment (ADRT)

An ADRT is a legal document that states which medical treatments someone does not wish to receive and in what circumstances in the future. It only becomes valid if they lose the ability to make or communicate those decisions. An ADRT cannot be used to request treatment to deliberately speed up death, but it can include refusing life sustaining treatment.

The person can change or cancel an ADRT at any time.



For more information about ADRT see:
14A – Advance Decision to Refuse Treatment

Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA)

These legal documents allow a trusted friend or relative to make decisions on someone's behalf about property and finances if they became unable to make or communicate decisions. The LPA or EPA must be done while they person still has the ability to make and communicate decisions.

LPAs are used in England and Wales. There is also an LPA that allows someone to make decisions about the person's health and personal welfare. The LPA must be registered with the Office of the Public Guardian (OPG), for which there will be a cost.

In Northern Ireland, EPAs are used and only apply to decisions concerning property or finance. EPAs are registered through the Office of Care and Protection.

6: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Alzheimer's Society

For information about supporting someone with dementia. Offer help cards for people with dementia.

Note: Alzheimer's Society support people with all forms of dementia, not only Alzheimer's disease.

Address: Devon House, 58 St Katharine's Way, London E1W 1LB
Telephone: 0300 222 11 22
Email: enquiries@alzheimers.org.uk
Website: www.alzheimers.org.uk

Carers Direct (part of NHS Choices)

Online information, help and advice about care and support, including advice for carers. For Northern Ireland, see NI Direct.

Telephone: 0808 802 0202
Email: through the website contact page
Website: search for guide to care and support at: www.nhs.uk

Carers Trust

Support for carers.

Address: 32-36 Loman Street, London SE1 0EH
Telephone: 0844 800 4361
Email: support@carers.org
Website: www.carers.org

Carers Trust (young carers)

Support for young carers – see also Carers Trust.

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

Carers UK

Information, advice and campaigning for the rights of carers.

Address: 20 Great Dover Street, London SE1 4LX

Telephone: 0808 808 7777 (England and Wales)
02890 439843 (Northern Ireland)

Email: through the website contact page

Website: **www.carersuk.org**

Dementia UK

Provide Admiral Nurses, specialist dementia nurses who give practical and emotional support to families affected by dementia.

Address: Second Floor, Resource for London, 356 Holloway Road, London, N7 6PA

Telephone: 020 7697 4160

Email: info@dementiauk.org

DVA

Find out if a health condition will affect whether the person you support can continue to drive and keep their driving licence. Contact details for Northern Ireland.

Address: Drivers Medical Section, Castlerock Road, Waterside, Coleraine, BT51 3TB

Email: dva@doeni.gov.uk

Website: **<http://www.nidirect.gov.uk/motoring>**

DVLA

Find out if a health condition will affect whether the person you support can continue to drive and keep their driving licence. Contact details for England and Wales.

Address: Drivers Medical Group, Swansea SA99 1DL

Telephone: 0300 790 6806 (if you are a car or motorcycle licence holder)

Telephone: 0300 790 6807 (if you hold a bus or lorry licence)

Email: eftd@dvla.gsi.gov.uk

Website: **www.dft.gov.uk/dvla/medical.aspx**

The Frontotemporal Dementia Support Group

Information and advice for people caring for someone with FTD. Awareness cards are available.

Address: 3 Fairfield Park, Lyme Regis, DT7 3DS

Telephone: 01297 445488

Email: frontotemp@aol.com

Website: **www.ftdsg.org**

FTD Talk

Provides jargon free online updates of recent research findings in FTD.

Website: **www.ftdtalk.org**

GOV.UK

Online government advice on a variety of topics, including support for people with disabilities and contact details for local councils.

Email: email addresses are provided on the website, related to each enquiry

Website: **www.gov.uk**

www.nidirect.gov.uk (Northern Ireland)

Health in Wales

Information on NHS services in Wales, including a directory of Welsh health boards. This is an online service only.

Email: through the website contact page

Website: **www.wales.nhs.uk**

Medic Alert

An identification system for individuals with medical conditions, usually in the form of bracelets or necklets, supported by a 24 hour emergency telephone service.

Address: 327-329 Witan Court, Upper Fourth Street, Milton Keynes MK9 1EH

Telephone: 01908 951045

Email: info@medicalert.org.uk

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

MND Scotland

Support for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

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

NHS Choices

Online health information including the Information Prescription Service, for information according to need.

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

Email: through the website contact page

Website: **www.nhs.uk**

NHS 111

The NHS online/telephone help and support service, providing health advice and information, 24-hours a day, 365 days a year.

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

Email: through the website contact page (see NHS Choices)

Website: **www.nhs.uk**

NHS Direct Wales

Similar to NHS Direct, but particular to Wales and the Welsh NHS structure.

Telephone: 0845 46 47

Website: **www.nhsdirect.wales.nhs.uk**

NHS Northern Ireland

Online information about NHS services in Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

Office of Care and Protection

Information about Enduring Power of Attorney for Northern Ireland.

Address: Room 2.2A, Second Floor, Royal Courts of Justice, Chichester Street,
Belfast, BT1 3JF

Telephone: 028 9072 5953

Website: search for office of care and protection at: **www.courtsni.gov.uk**

Public Guardianship Office

Information about Lasting Power of Attorney and the Mental Capacity Act.

Address: PO Box 16185, Birmingham B2 2WH

Telephone: 0300 456 0300

Email: customerservices@publicguardian.gsi.gov.uk

Website: search for lasting power of attorney at: **www.gov.uk**

Safeguarding children's team (often called social services)

Contact details for your local Safeguarding Children's team can be found through your local authority, local council or local telephone directory. You may also find the following online information from GOV.UK useful:

Website: **<https://www.gov.uk/find-your-local-council>**

Young Dementia UK

National source of information and support specifically about young onset dementia (under 65 years old).

Address: PO Box 315, Witney, Oxfordshire, OX28 1ZN

Telephone: 01993 776295

Email: mail@youngdementiauk.org

Website: **www.youngdementiauk.org**

References

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

email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Jill Walton, Support Group Coordinator, FTD Support Group

Further information

We have related information sheets you may find helpful:

7A – Swallowing difficulties

9A – Will the way I think be affected?

9C – Managing emotions

12A – Driving

12B – Choosing the right vehicle

14A – Advance Decision to Refuse Treatment

You can also refer to our main guides:

Living with motor neurone disease – our guide to MND and how to manage its impact, including guidance about your finances

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at:
www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support:



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<http://forum.mndassociation.org/>** or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/infosheets_1-25**

Or request a paper version by email: **infofeedback@mndassociation.org**

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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