



9A

Will the way I think be affected?

Information for people with or affected by motor neurone disease

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

If you have been diagnosed with MND, you may be concerned about these possible changes. This information sheet provides information about the changes that some people experience and adjustments that may help.

The content includes the following sections:

- 1: What changes might happen?**
- 2: What is frontotemporal dementia?**
- 3: How can I get support?**
- 4: What can I do to manage these changes?**
- 5: How do I plan for future care?**
- 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 in this information sheet may not be suitable for everyone, so ask your health and social care team for individual advice.

This information may not be suitable if your reading ability has been affected by any changes. If this is the case, your health and social care team may be able to give you guidance.

What do the words mean?

Your health and social care team may use medical terms. Here are some words you may hear when you discuss 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?

The possible changes to thinking can range from very mild to more severe. In a small number of cases, people with MND develop frontotemporal dementia which can have a major impact on daily life and requires a higher level of support. See heading 2: *What is frontotemporal dementia?*

You may experience changes to your:

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

Friends or family may notice the changes first, as you might not be able to tell anything has changed.

If you, or those close to you, recognise the changes described in this information sheet, contact your 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.

What else could it be?

It is important to rule out other causes and get appropriate support. The changes may be temporary if they are caused by other symptoms.

Get advice from your health and social care team if you think you 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.

If you experience changes to speech and communication due to the physical effects of MND, conversations can become difficult and frustrating. Other people may not understand and react as if your thinking or behaviour has changed, which may not be the case. Ask your health and social care team for a referral to a speech and language therapist for advice.

What changes might affect my thinking and learning?

If you experience changes to your thinking and learning, you may find it becomes more difficult to:

- make and carry out plans
- think of things to do
- do 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
- recognise other people's feelings
- finish tasks.

What changes might I experience to my language and communication?

You may experience speech and language difficulties due to the effect of MND on your mouth, throat and vocal cords. These are physical symptoms. However, you may also experience problems with language and communication along with changes to your thinking.

You may find that you:

- communicate more slowly
- have to think more about what has been said and how to respond
- have difficulty spelling words
- use the wrong names for people or objects
- find it harder to recognise words when reading or writing
- find it difficult to follow conversations and take in what someone is saying.

How could changes to my behaviour affect me?

Changes to your behaviour may mean you:

- lack drive and show less interest in things
- find it difficult to manage your emotions, including aggression and irritability
- 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 sugary or junk food and experience changes to your sense of taste.

You 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:
Information sheet 9C - *Managing emotions*

What is emotional lability?

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

Recognising this as a symptom and making others aware of this may make it easier to manage.

 *"Laughing can be embarrassing at the wrong moment, but at the right time it means I enjoy the joke longer and set people around me laughing as they say 'He's off again!'"*

If it is persistent and causing distress, speak to your health and social care team. Although not helpful to everyone, there is medication that may help.

If you have changes to your thinking, you are more likely to experience emotional lability. However, emotional lability is not in itself a sign of changes to your thinking.

 For detailed information about emotional lability in MND see:
Information sheet 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 you may not be able to tell that you have changed.

How could dementia affect me?

FTD mainly affects behaviour, thinking and language. The changes with FTD are similar to those already described in the previous sections of this information sheet, but are more severe.

It is important to note that FTD has very different symptoms to Alzheimer's disease, which is 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.

It can have a major impact on your independence and daily life, and on your carers and family members. There is currently no cure for FTD, but there are a number of important things that can help.

This could include some or all of the following:

- a calm, structured caring environment
- a support package that increases to meet your changing needs
- ensuring safety around the home
- support for carers
- avoiding isolation and maintaining social contacts
- medication to help control some behaviours
- planning for the future early (see section 7: *How do I plan for future care?*).

Simple everyday tasks can become much more difficult and you may need much more support. FTD can affect your ability to make decisions, and there may be a time when you are no longer able to make or communicate decisions.

You may want to plan ahead to ensure your wishes are known and respected during your future care. See section 7: *How do I plan for future care?* for more information.

How would FTD affect my family and carers?

FTD will have a major impact on family and carers and may cause anxiety and stress. The level of care and support you need will increase, so it is important that your carers have the right support.

 For information for carers about changes to thinking see:
Information sheet 9B – *How do I support someone if the way they think is affected?*

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

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. 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.

Have I inherited the gene?

If you have a genetic change that causes FTD, you have a chance of passing it on to your children. If you are concerned about a family history of FTD and what this could mean for those close to you, you may wish to seek genetic counselling.

Although sensitive to the emotional aspects of the situation, genetic counselling is not a form of psychotherapy. A genetic counsellor will explain all the facts to you as clearly as possible, and give you accurate information on the potential implications for your family.

This will include information about options such as genetic testing, to help you decide whether or not this is something you wish to do. You may find this decision difficult, as it affects the wider family and may raise questions about options relating to pregnancy. Genetic testing can show if you carry the gene, but it cannot predict how you or your children might be affected.

3: How can I get support?

Don't be scared to ask questions about things that happen that are not normal for you. It is important to discuss changes that you, or someone close to you, has noticed in your thinking, language or behaviour with a health or social care professional.

How can I get a diagnosis?

Health or social care professionals can use a range of screening tools to help identify changes to thinking. These help the professional decide if you need a detailed assessment by a clinical psychologist or neuropsychologist.

The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is a screening tool that specifically looks at the types of changes that people with MND may experience. 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 commonly used, such as ACE III, but ECAS specifically looks at the types of changes that people with MND may experience.

There is no single test to diagnose these changes. If you are referred to a neurologist or neuropsychologist for further assessment, this may include:

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

At first, they may not be able to give you a firm diagnosis, as it can take time for the changes to be clear.

Who can help?

Occupational therapy (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 therapy

Speech and language therapists can assess your needs and give you advice about swallowing, speech and communication aids. Ask a health or social care professional for a referral.

Care services

It is essential that you get the right level of support. If you receive care services from the NHS, Adult Care Services or Health and Social Care Trust if you live in Northern Ireland, they should be made aware that you are having these changes so that they adjust your care to meet your needs. If you are not currently receiving a care package, contact Adult Care Services or your Health and Social Care Trust for an assessment.

4: What can I do to manage these changes?

The suggestions in this section may not be suitable for everyone. The support you need will depend on the changes you are experiencing and how else MND affects you. Always get individual advice and support from your health and social care team.

Some key tips to help you:

- get into the habit of breaking tasks into smaller steps
- use checklists with all the steps of an activity and follow them in order
- follow set routines
- use a notebook, schedule or diary to keep track
- do difficult things earlier in the day when you have more energy.

It is important that people close to you know how best to support you. You may want to ask them to read the following information sheets for more information.

 For information for carers about changes to thinking see:
Information sheet 9B – *How do I support someone if the way they think is affected?*

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

What can help me concentrate?

If you find it difficult to concentrate, it may help to:

- sit somewhere quiet and make sure there are no distractions
- make yourself as comfortable as possible
- adjust temperature and brightness of the room if needed
- take regular breaks from the activity you are focusing on.

How can I prepare food and manage chores safely?

If you are finding it difficult to manage food preparation and household chores, you could consider:

- cooking or cleaning with support from a family member or carer
- asking someone else in your household to do these tasks
- getting support from your Adult Care Team or Health and Social Care Trust
- asking for a referral to an OT, as they can advise you about equipment and methods to help.

How can I take care of my personal hygiene?

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

If you are finding managing your hygiene difficult, you might find it helpful to:

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

How can I manage my family responsibilities?

If you have childcare and other family commitments, these may become difficult to manage. You could consider:

- talking to your family about your roles and responsibilities, as another member of the family may be able to take on some of these tasks
- getting extra help such as a child-minder or a driver to take children to school
- asking for help from your local adult social care services or health and social care trust in Northern Ireland.

How can I manage my finances?

You may find yourself having financial difficulties due to spending money more impulsively, or forgetting to pay bills. It may be useful to:

- consider what you are buying or spending your money on carefully
- set up direct debits to ensure your bills are paid on time
- carry only as much cash as you will need
- leave bank cards and large amounts of cash at home
- ask your bank to reduce your daily withdrawal limit to prevent overspending.

If you find it confusing to manage your money generally, you may want to consider arranging a Lasting Power of Attorney, or Enduring Power of Attorney (EPA) if you live in Northern Ireland. See section 4: *How do I plan for future care?*

What can I do to help my communication?

If you experience changes to the way you think, you may find it difficult to find the right words and follow what someone is saying. MND can also affect how you physically speak and communicate.

You may want to consider:

- asking for a referral to a speech and language therapist for advice
- carrying a card that explains your needs and how people can support you
- taking your time
- using pictures or gestures to help get your point across.

How can I make appointments feel easier?

Appointments and meetings can become challenging. You may find it difficult to remember what has been discussed and take in the information.

It may help to:

- prepare in advance by taking some notes of questions you want to ask
- email the person ahead of time with your questions
- make sure the person is aware of your needs
- ask for a longer appointment if you need it
- ask someone to go with you to support you
- ask the person you are seeing to write things down or record them.

How can I control unwanted behaviours?

You may say or do things that cause embarrassment or confusion for yourself and others. This can be distressing for you and those around you.

It may help to:

- ensure that those close to you understand that this behaviour is a part of MND
- consider medication to help you control some behaviours
- identify any triggers and avoid them
- keep your environment calm and predictable
- agree with family or carers how they will support during these times.

How can I manage changes to my eating?

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

If you are having difficulties with swallowing, this could be particularly risky. In all cases, ask for a referral to a speech and language therapist and dietitian.

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

You may also have problems understanding the meaning of tastes, for example using salt instead of sugar and not being able to tell that you have used the wrong one.

To help manage changes to your eating, consider whether it would help to:

- ask family or carers to keep foods that pose a risk to you out of your reach eg if you have been advised to eat a soft diet, remove foods that you have difficulty eating
- have someone with you when you are eating to support you 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.

Can I still drive?

Having a medical condition or disability does not automatically mean you cannot or will not be allowed to drive. However, you must inform your driving licensing authority as soon as you are diagnosed with MND or dementia.

You will need to discuss with your GP whether you 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 you can be fined up to £1,000. You may be prosecuted if you are involved in an accident as a result.

 For more information about driving with MND see:
Information sheet 12A - *Driving*

 For more information about driving assessments see:
Information sheet 12B - *Choosing the right vehicle*

5: How do I plan for future care?

Many people with progressive illnesses fear losing control and not being able to make or communicate their decisions. Planning ahead can give you peace of mind and may be especially important if you experience changes to your thinking. It is important that this is done early as it may become more difficult to make or communicate decisions for yourself.

What is an advance care plan?

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

What is an Advance Decision to Refuse Treatment (ADRT)?

An ADRT is a legal document that 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. An ADRT cannot be used to request treatment to deliberately speed up death, but you can refuse life sustaining treatment.

You can change or cancel an ADRT at any time.



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

What is Lasting Power of Attorney (LPA) or Enduring Power of Attorney (EPA)?

These legal documents allow a trusted friend or relative to make decisions on your behalf about your property and finances if you became unable to make or communicate decisions for yourself. These documents must be completed and signed before you lose the ability to make decisions for yourself, so it can be helpful to consider it early.

LPAs are used in England and Wales. You can also have an LPA that allows someone to make decisions about your health and personal welfare. The LPA must be registered with the Office of the Public Guardian, for which you will be charged a fee.

In Northern Ireland, EPAs are used and only apply to decisions on your behalf concerning property or finance. EPAs are registered through the Office of Care and Protection. See *Useful organisations* in section 6: *How do I find out more?* for contact details for the Office of the Public Guardian and 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 organization, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Alzheimer's Society

Offer a wide range of services to support people with all forms of dementia including information, care services, support and befriending services.

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
Helpline: 0300 222 1122
Email: enquiries@alzheimers.org.uk
Website: www.alzheimers.org.uk

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
Website: www.dementiauk.org

DVA

Find out if your health condition will affect your driving and if you will be able to keep your driving license. Contact details for Northern Ireland.

Address: Drivers Medical Section, Castlerock Road, Waterside, Coleraine, BT51 3TB
Email: dva@doeni.gov.uk
Website: www.nidirect.gov.uk/motoring

DVLA

Find out if your health condition will affect your driving and if you will be able to keep your driving license. Contact details for England and Wales.

Address: Drivers Medical Group, DVLA, 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

Address: 3 Fairfield Park, Lyme Regis, DT7 3DS
Telephone: 01297 445488
Email: frontotemp@aol.com
Website: **www.ftdsg.org**

FTD Talk

Website providing 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 (see also NHS Direct Wales).

Email: through the website contact page
Website: **www.wales.nhs.uk**

NHS Choices

The main online reference for the NHS, including information on Continuing Healthcare.

Address: Customer Services, Richmond House, 79 Whitehall, London SW1A 2NL
Telephone: 0207 210 4850
Email: through the website contact page
Website: **www.nhs.uk**

NHS 111

The NHS online/telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England)

NHS Direct Wales

Health information and advice for Wales.

Telephone: 0845 4647
Website: **www.nhsdirect.wales.nhs.uk**

NHS Northern Ireland

Online information on NHS services in Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

NI Direct

The equivalent of GOV.UK for Northern Ireland, providing government information on a variety of subjects, including health services and support for disability.

Email: through the website contact page

Website: **www.nidirect.gov.uk**

Office of Care and Protection

The department handling Enduring Power of Attorneys in Northern Ireland.

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

Telephone: 028 9072 4733

Website: **www.nidirect.gov.uk/office-of-care-and-protection**

Office of the Public Guardian

Protects people in England and Wales who may not have the mental capacity to make certain decisions. LPAs are registered here.

Address: PO Box 16185, Birmingham, B2 2WH

Telephone: 0300 456 0300

Email: customerservices@publicguardian.gsi.gov.uk

Website: **<https://www.gov.uk/government/organisations/office-of-the-public-guardian>**

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: **<http://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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Further information

We have related information sheets you may find helpful:

7A – *Swallowing difficulties*

9B – *How do I support someone if the way they think is affected?*

9C – *Managing emotions with MND*

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

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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