Cognitive impairment in motor neurone disease (MND): information for carers

Initially, it was thought that motor neurone disease (MND) only affected the nerves we use to control our muscles. However, we now have much more knowledge and understanding of the changes in the brain that can affect thinking, emotion and behaviour in some people with MND. We describe these changes as cognitive and behaviour change.

This leaflet aims to help your understanding of cognitive and behaviour change in MND and offers useful information about the support available for you and the person you care for.

What does cognitive change mean?

Cognition refers to a range of brain functions that include the ability to learn and remember, think through and plan activities, concentrate and carry out tasks, and understand what we see and hear. Cognition also includes verbal communication, such as the ability to say words, interact and respond appropriately to other people.

With regard to cognition, people living with MND appear to fall into one of four groups:

- No cognitive change
- Subtle cognitive and behaviour change
- Severe cognitive and/or behaviour change where the person develops frontotemporal dementia (FTD)
- People with FTD who go on to develop motor impairments where MND is diagnosed after dementia.
Some people experience very mild changes, whilst others may experience changes that are more noticeable.

FTD is a type of dementia involving severe cognitive and behaviour change. Around 5% of people with MND will develop FTD. This type of dementia is different from Alzheimer’s disease, the most common type of dementia.

The effects of cognitive changes

Cognitive changes can appear in a variety of forms. Some people find it difficult to:

- Concentrate, eg when reading or dealing with household bills
- Learn new activities or use new equipment
- Start conversations
- Hold a conversation if background distractions are present
- Plan ahead or manage a sequence of activities
- Start activities or tasks
- Finish tasks through to conclusion
- Do more than one thing at a time, eg ironing while watching television
- Know how to respond to people in social situations
- Find the names of items that they would have previously known
- Understand complex sentences.

Some behaviour changes may result in people:

- Feeling restless
- Lacking drive or initiative
- Acting impulsively without thinking things through
- Eating lots of sweet things and cramming food
- Becoming fixated on one activity or routine
- Lacking empathy and appearing indifferent, eg when you or someone else close to the person with MND is distressed.
Social awareness and loss of insight

There may be loss of insight, ie the person affected may not be aware of changes going on. This can be distressing for everyone close, eg family members, especially if they have noticed changes in behaviour.

Because you are caring for the person with MND, you are likely to be the first to notice changes in their behaviour. This can be really confusing and upsetting and you may wonder what the cause might be, eg could it be MND, depression, frustration or fatigue?

Therefore, it is important to rule out other possible causes that can also affect the ability to concentrate and function. For example changes in breathing, or the presence of an infection.

What else could it be?

Mood
It is only natural that adapting to changes caused by MND may lead to changes in mood. Many people with MND will experience feelings of frustration and upset.

For a small number of people these feelings can be overwhelming and as a result, they become depressed.

If someone finds it difficult to engage with a task or concentrate on things, it may be due to feeling low, rather than cognitive change. Some people may choose to take certain medication when they feel like this, eg anti-depressants or they may seek counselling.

Emotional lability
Some people with MND experience ‘emotional lability’. This can result in uncontrollable laughter or crying in response to something that is only moderately funny or sad, for example a television programme. This can seem inappropriate at times and cause confusion.

Breathing
If MND is affecting breathing, it can affect sleep quality. This can cause changes in concentration and memory.

If a ventilator is being used to help with breathing, it is important to check the settings and make sure the ventilator is working properly.

Infections
Chest or urine infections may lead to confusion or muddled thinking. It is important to note that this would be a more rapid onset accompanied by signs of infection e.g. a high temperature, feeling unwell.
**Who can help?**

If you recognise the changes described in this leaflet or have any concerns, we encourage you to contact your GP or a member of the health team providing care and support. This will enable them to understand more about what these changes are, the effect they are having and the impact on you and other members of the family.

Knowing that cognitive change is part of MND can often come as a relief to those who have noticed changes in thinking and behaviour since diagnosis. Seeking advice, support and information is important, for everyone in the family.

Because MND is uncommon, your GP may not be familiar with these symptoms in relation to MND.

It may be helpful to show this leaflet to your GP so your GP can see the source of information you have read. Whilst awareness of cognitive change in MND is increasing, not all GPs will necessarily have experience in this area.

You can also contact MND Connect to talk through any concerns you have (Please find contact details at the end of the leaflet).

**What will happen next?**

The GP or member of the health team may advise an assessment. This will help identify the cause and suggest ways to minimise any confusion and frustration that may exist. They will also offer practical suggestions to overcome some of the everyday difficulties.

They may offer helpful advice for you and other family members about the sort of questions to ask, eg asking questions that require yes or no answers and avoiding complex sentences that require a lot of explanation.

A variety of options will be considered to help simplify communication and daily tasks. The aim is to help the person affected feel more in control. This can also be beneficial to you and other family members.

Enabling everyone close to understand the cause of behaviour changes may empower, support and help them to care more confidently.

The management of people with MND affected by cognitive impairment is about forward planning and helping to organise appropriate support for them and their families/carers.
An Advance Decision to Refuse Treatment (ADRT)

An ADRT (previously known as a Living Will) is a decision someone can make in advance to refuse specific treatments in certain circumstances in the future. This can include the right to refuse life sustaining treatment.

Many people living with progressive illnesses such as MND fear losing control and not being able to tell healthcare professionals their decisions themselves.

An ADRT tells people about those decisions and becomes active when the person loses the ability to make decisions. For many people, an ADRT can give them peace of mind and may be especially important if severe cognitive change becomes evident.

To find out more information about ADRTs, contact the MND Connect team or visit the MND Association website to access our ADRT publications (see the end of this sheet for contact details).

Other organisations

Build-UK
This online forum can be used to contact others who are affected or interested in MND. Please see Further information at the end of this sheet for details of the MND Association Online Forum.

Website: www.build-uk.net

PatientsLikeMe
Another online forum for sharing information with people who may have experience of a similar condition. It is also accessible for carers or health professionals. Please see Further information at the end of this sheet for details of the MND Association Online Forum.

Website: www.patientslikeme.com

Healthtalkonline
A website database of personal and patient experiences, including a series of interviews with people affected or living with MND.

Healthtalkonline
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Email: info@healthtalkonline.org
Website: www.healthtalkonline.org/Nerves_and_brain/motorneuronedisease
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Further information

If you have any questions about the information on this sheet, please contact the MND Connect team.

Downloads of all our information sheets and most of our publications are available from our website. You can also order our publications direct from the MND Connect team, who will also be able to advise on individual needs:

MND Connect
MND Association, PO Box 246, Northampton NN1 2PR
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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:
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