

Emotional and psychological support for people with or affected by MND





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



Patient Information Forum

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

<https://piftick.org.uk>

How can this booklet help me?

When diagnosed with an illness like motor neurone disease (MND), you may feel overwhelmed. Those close to you will also be affected. The challenges ahead may cause mixed emotions that feel hard to manage.



“I try to see the glass as being half full, but...”

Your circumstances, culture and beliefs will affect how you respond. A diagnosis of MND can feel devastating, but you are not alone. This booklet can help you find ways to cope, including how to find professional support if you need it.

See Further information in section 6: How do I find out more? for a list of other resources and how to order them.



1: What can I expect?

You may need time to adjust. Emotions can be mixed, such as anger and guilt. This can be confusing, but work through emotions at your own pace. Try to review your life and plans in a way that feels right for you and those close to you.



“You grieve on diagnosis. I was inconsolable for about a month, but then it got much better.”

No matter how bleak something may feel, emotions tend to come and go. There can still be positive times, with victories won and shared moments. Give yourself permission to laugh and cry when needed.

MND symptoms can affect mood. Ask your GP or health and social care team for guidance if you experience:

- shortness of breath, extreme tiredness or problems with sleeping
- pain, stiffness or cramps
- problems with speech
- problems with swallowing or loss of appetite
- changes to your thinking and behaviour.

See Further information in Section 6: How do I find out more? We have a range of resources on symptoms.

Your experience is individual, but natural responses to a difficult diagnosis are to be expected and may include the following.

Shock: can cause physical reactions, like nausea, shaking, difficulty sleeping, heart palpitations or exhaustion. You may be more at risk of illness or infection, but shock usually calms.

Denial: is a common defence to block negative thoughts. You may need time, but facing the challenges ahead can help you feel more prepared.

Frustration or anger: frustration is likely if MND affects communication, mobility or your sense of independence. You may feel 'Why me?', or angry if you can't easily get the support you need or others don't seem to understand.

Fear, anxiety or panic: are to be expected, as not knowing what will happen next can be distressing. With a life-shortening disease, you may feel anxious for yourself and those close to you. Watch for physical signs of anxiety, such as increased heart rate, sweating, muscle tension or finding it hard to focus.



"It's like living in a giant hand that's slowly closing."

Feelings about sense of self: you may worry about how you are perceived, or your purpose, health, relationships and whether you're letting others down. It is unlikely anyone else takes the same view, so try to have open conversations.

Unexpected emotional responses: some people with MND have emotional outbursts that don't match their true feelings, or find it harder to control responses to negative news or events.

See section 3: *How do I manage emotional lability?*

Guilt: you may worry how your illness will impact on others. Discuss this with those close to you. Health and social care support can help solve a range of problems.

Sadness and grief: these are rarely constant feelings, but can come in intense bursts. You may feel sadness due to your diagnosis and anticipated grief for the losses ahead, including changes to life goals.

Depression: you may feel persistently sad, anxious or worthless, or have lost interest in things you once loved.



“I have lost confidence in doing anything independently and find it difficult to imagine the place where this disease is taking me.”

See section 2: *How do I manage challenging emotions?*

Suicidal thoughts: can sometimes happen with depression, fear, or worrying about burden of care on others. Practical, medical and emotional support can help bring ease of mind. Try discussing any concerns with:

- your GP or a specialist palliative care professional
- a friend, family member or someone you trust, such as a religious or spiritual leader
- our MND Association helpline, MND Connect: **0808 802 6262** or **mndconnect@mndassociation.org**
- an adviser through the NHS helpline, **NHS 111**
- Samaritans 24-hour support service on **116 123**, or appropriate local helplines.

When you feel ready, see our *End of life guide* for more support with planning future care and ways to find support.

Why does telling other people feel so hard?

You may be worried about getting upset or upsetting other people when explaining your diagnosis.

It may seem that discussing MND somehow makes it more real for them and yourself. You may not feel ready for the questions that could be raised about the future.

However, MND will become visible and questions will be asked. Give yourself time to adjust – you may only want immediate family to know at first.

Try having simple conversations to start with. As time goes on, give more detail, so others can adapt. Help them understand how best to offer support.

See our booklet: *Telling others about MND.*



“I took a humorous approach at work with the ‘good news, bad news’ idea. The good news is we finally know what’s wrong and the bad news is there’s no cure yet. It broke the ice.”

If you find it upsetting to keep repeating the news, a friend may be prepared to tell your wider circle. Sharing information about MND can help.

See our short animation, *What is MND?* and a link to our guide, *An introduction to motor neurone disease*, along with basic facts at: www.mndassociation.org/mndfacts

How can I explain MND to children and young people?

Explaining your diagnosis to children and young people can feel challenging. Our natural instinct is to protect them from upset, but children also see the effects of MND. Without explanation, they may even blame themselves for what's happening.

Sharing your feelings gives them permission to release their own emotions. Being open also shows it's safe to ask questions and seek you out if they feel troubled.

Start with things the child may have noticed. For example, if facial muscles have been affected, explain that it may be difficult to smile, but this doesn't mean that you're angry.



You don't have to give all the information at once. How much and how often depends on a child's age and how quickly your symptoms progress.

See our booklet: *Telling others about MND*, which provides guidance on how to communicate about MND with children and young people.

Find our resources for children, young people, parents and guardians at: www.mndassociation.org/cyp



Will I experience changes to thinking and behaviour?

Up to half of people with MND have changes to thinking and behaviour. This increases to 8 out of 10 people in the late stages of MND.

These changes usually have little or no effect on daily life. Friends or family are likely to notice what is happening before you do.

If affected, you may experience changes to:

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

For a small number of people with MND, these changes are more severe and develop as frontotemporal dementia (FTD). If this happens, more intensive support may be needed.

See our booklet: *Changes to thinking and behaviour.*



“I have suspected dementia so cannot always make informed choices as to healthcare.”

MND can also affect speech and communication, and cause extreme tiredness. If you experience these symptoms, or any changes to thinking and behaviour, try to have complex or sensitive conversations as soon as you feel ready to do so.

2: How do I manage challenging emotions?

Remember that emotional reactions are natural when facing challenges. Our emotions tell us what really matters and help guide our choices.

Try to make space for painful feelings that may have value. Share them with others, let yourself cry or write things down. These actions can help you work things out and connect with others.

Taking positive action can bring a sense of control and lift mood. Various therapies are also available. You may find some of the following suggestions helpful.

Find new ways to do things:

Prolong independence: stay active for as long as possible. An occupational therapist can advise on equipment, new ways to do things and how to adapt your environment. For example, with adapted switches to operate controls.



Make new plans: as life changes, make new goals that feel achievable, such as planning positive events.



“While I am restricted in the activities I can pursue, there are many things I can still do to give myself a good quality of life.”

See our booklet: *Making the most of life with motor neurone disease (MND)*

Be aware of your needs:

Become informed: when ready, find out about MND and what to expect. Knowing facts and choices can reduce fear, help you make informed decisions and give a sense of control.

Be prepared for change: MND does progress. For some this is slower and the changes more gradual, but it can be rapid. Some challenges are likely to be upsetting – but these may be different for each individual. It can help to acknowledge and accept that change is inevitable, so that you can prepare.



“My Motability vehicle increases my quality of life, but I am getting weaker and may have to stop driving. This will be an upsetting time for me.”

Plan for the next change: try to plan ahead, rather than wait until you need specific equipment or support, as it may take time to arrange and no longer be appropriate when it arrives. This can be costly and frustrating. An occupational therapist can assess your home and your changing needs. They can advise on how to plan, adapt and find suitable equipment, which may save you money. They may be able to offer some equipment on loan too.

Find out about benefits and social care: financial challenges, along with the need for care support, can cause stress.



“We only have moderate income due to my wife continuing to work, but we will definitely struggle when she has to give up work to care full time for me. This is an emotional pressure that causes me unnecessary stress.”

It can help to:

- find out if you qualify for any benefits or financial support
- get your needs assessed for care support at home, including personal care, equipment or urgent care cover.

You can get a needs assessment if you are living with MND, or a carer’s assessment if you are supporting someone with MND. Contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

A financial assessment works out if you need to pay towards any agreed services and by how much. Services can then be arranged for you, or you can receive direct payments to make your own arrangements.

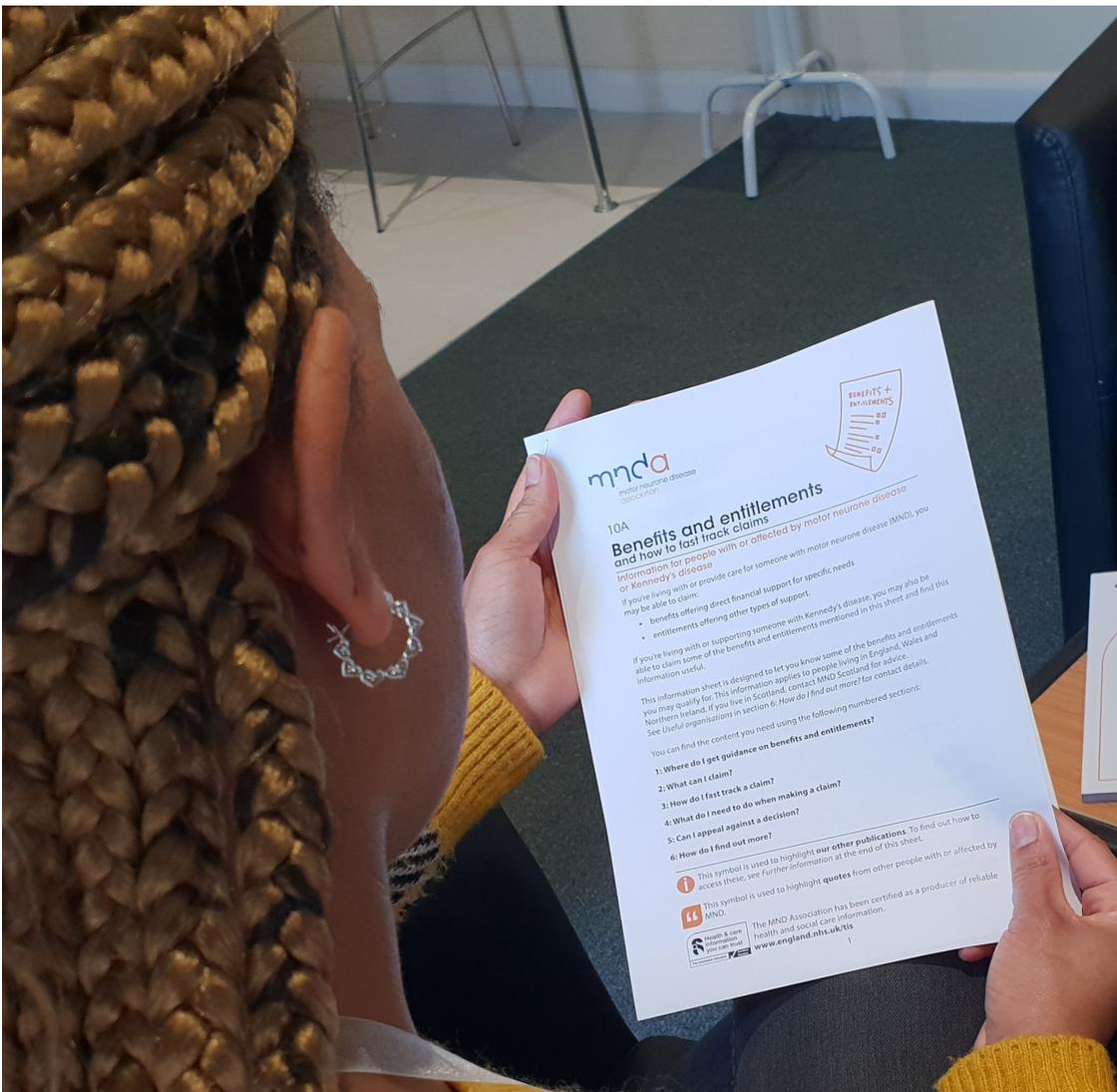
For more information on benefits, social care and direct payments, see information sheets 10A-10G and our guide for carers, *Caring and MND: support for you.*

For government guidance on benefits and entitlements, see **www.gov.uk** in England and Wales, or **www.nidirect.gov.uk** in Northern Ireland.

We also provide a Benefits Advice Service for people with or affected by MND or Kennedy's disease.

See Further information in section 6: How do I find out more? about our services and contact details.

See guidance for family and carers in section 4: How can I get help if I support someone with MND?



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association



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Benefits and entitlements and how to fast track claims

Information for people with or affected by motor neurone disease (MND) or Kennedy's disease

If you're living with or provide care for someone with motor neurone disease (MND), you may be able to claim:

- entitlements offering direct financial support for specific needs
- entitlements offering other types of support.

If you're living with or supporting someone with Kennedy's disease, you may also be able to claim some of the benefits and entitlements mentioned in this sheet and find this information useful.

This information sheet is designed to let you know some of the benefits and entitlements you may qualify for. This information applies to people living in England, Wales and Northern Ireland. If you live in Scotland, contact MND Scotland for advice. See Useful organisations in section 6: How do I find out more? for contact details.

You can find the content you need using the following numbered sections:

- 1: Where do I get guidance on benefits and entitlements?
- 2: What can I claim?
- 3: How do I fast track a claim?
- 4: What do I need to do when making a claim?
- 5: Can I appeal against a decision?
- 6: How do I find out more?

1 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.

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

Health & care information you can trust
The MND Association has been certified as a producer of reliable health and social care information.
www.english.nhs.uk/is

Do what you enjoy: things that you find meaningful can lift your mood, like listening to music.

Music or art therapy may help, or complementary therapies, such as massage and reflexology. Ask your GP about local registered practitioners, or specialist palliative care and hospice services.

If you need help to get out and about, find out what support is available. A change of environment can help reset emotions.

See our booklet, *Getting around*.





“I go to the local hospice one day a week, which is very enjoyable.”

Digital innovations can also help, such as *virtual reality therapy*. This type of virtual reality often involves visiting a different environment or location, such as a museum, art gallery or scenic area.

Think about things in ‘small pieces’: you may find it less daunting to tackle challenges in small pieces. Planning ahead can ease fear, but you don’t have to do it all at once.

If you have limited energy, let go of non-essential tasks and focus on things you really want to do.

See our booklets on *Personal care and Making the most of life with MND*.



“If I have a two hour rest in the afternoon, I feel better in the evening.”

Spiritual reflection: whatever your beliefs, religion or faith, you may want to reflect on inner thoughts. A faith leader, or a local specialist palliative care or hospice team can help you explore your questions.



“My faith helps me a great deal.”

Maintain relationships:

Have open conversations: sharing highs and lows helps everyone in your immediate circle to support each other. If your speech is affected, a speech and language therapist can advise on communication.

Share your feelings: allow yourself to express anger, tears, and laughter to release tension. Strong emotions can get more intense if you hide them.

Adjust to changing roles: as symptoms progress, someone else may have to do tasks you usually do and sense of purpose can be shaken. Those supporting you also have to adjust. This can be emotional, but try to think like a team.



“I can no longer be what I spent my life trying to be ... MND makes us the opposite of what we wish.”

Seek relationship support: if needed, ask your GP for referral to a relationships counsellor. You may have to pay for this service. They may need to understand the challenges of MND.



“Counselling and a listening ear help with the trauma ... this is paramount for families from onset.”

Ease anticipatory grief: you and those close to you may feel grief in anticipation of losses to come. Being open with each other can help ease any sense of dread.

Reduce isolation: social networks may grow smaller if personal interests and employment are difficult to maintain.



“Some previous hobbies are now denied me, but I’m finding new ones.”

Wider family and friends can also retreat, often from fear of doing the wrong thing. Help them feel less wary by explaining:

- the best times to visit when you have energy, and how long to stay to help you avoid fatigue
- any changes, so they know what to expect
- what aspects of MND you are happy to discuss
- tasks they can help with
- any support you may need at social gatherings.

Make new memories: being with family and friends can help you share positive memories and communicate feelings. This can also help resolve any past differences that may exist.



“Family and friends are making my journey in life so much better.”

Seek support if you live alone: finding appropriate support and professional care will become vital if you live on your own.

See earlier heading in this section, *Find out about benefits and social care, on getting your needs assessed.*

At your assessment, emphasise that you live alone, especially if you are single or do not have a close network of support.

Be clear if you need particular support to maintain social activity, get out and about, or take part in an interest or hobby.



“I am single...Every outing has to be planned.”

Accept paid care support to help you and your carer: your main carer may also be your partner, a relative or close friend. Support from paid care workers can help carers rest and give time for what’s special about relationships.



“Although love and wanting compels you to do your very best as a carer, sometimes taking a step back and accepting or asking for help, can help you not to lose your relationship within it all.”

See earlier heading in this section, *Find out about benefits and social care on care support, section 4: How can I get help if I support someone with MND?* and our comprehensive guide for carers, *Caring and MND: support for you.*

Seek out others affected by MND: our branches and groups offer support and opportunities to meet others affected by the disease. If you don’t feel this is right for you yet, you can join at any time. Find your nearest branch or group at: **www.mndassociation.org/branchesandgroups** or contact our MND Connect helpline. The helpline team can also explain our other services, including Association visitors (AVs). Where available, these trained volunteers can provide guidance and support by telephone, email or home visit.

See Further information for our helpline details, in Section 6: *How do I find out more?*

You can also find support and shared experience from others affected by MND through our online forum at: **<https://forum.mndassociation.org>**



Be open about intimacy and sexuality: you may be worried about MND affecting intimate relationships, due to symptoms, medical interventions or assistive equipment, such as use of a head support (an example is pictured above). For many, touch and intimacy are important ways to share affection and support. Sex may also be significant to your emotional life.



“I have feelings...but cannot express them actively.”

MND doesn't affect sexual function, but reduced mobility can make sexual expression more difficult. If you feel a lack of confidence, open discussion with your partner can help. Try not to feel embarrassed about asking your health and social care team for guidance – if they don't have the relevant knowledge, ask to be referred to a specialist.

See our information on sex and relationships with MND, for support if you are single or have a partner.

How can I stop worrying about my future care?

When thinking ahead, you may worry about:

- how to manage the later stages of the disease and the impact on those close to you
- losing ability to communicate your needs and wishes
- receiving care that is not appropriate for MND.

These worries can cause emotional stress – sometimes through fear of the unknown. You may not feel ready to discuss your future care yet, but knowing the facts can reduce fear and help everyone feel more prepared.



“When thinking about the future, it’s important to have a say in what you want. You may not want what your partner or family think you need.”

MND can also cause fatigue, problems with speech and communication, and changes to thinking. This can make emotional conversations more challenging. Try to plan ahead as early as you can and involve all those involved in your care, so they know your wishes. You can change your mind at any time. If you use communication aids, signals or recorded phrases can let people know when you want to review or amend decisions.



“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.”

Your health and social care professionals can help you note down advance care plans and any guidance on future care you want to receive.

This may include support to record legally-binding advance decisions about treatment you do not want, or would like withdrawn in specific circumstances, including life-sustaining treatment. Once done, it can bring peace of mind.



“There is a sense of relief it’s now in place and not something still to be tackled.”

See our resources about planning ahead and making advance decisions.

Which therapies can help with challenging emotions?

Many symptoms and practical problems can be eased with the right support. This can reduce worry and help you manage challenging emotions, when they arise. Seek professional help for any concerns.

See Section 5: *Who can help? about specialists.*

Your GP may be able to prescribe medication to help with challenging emotions. However, many therapies focus on emotional and mental health. Ask your GP for guidance on psychological services in England, Wales or Northern Ireland.



“Online programmes like mindfulness (which are usually cost-free) can be helpful, but you have to be willing to use them. Meeting people socially can help you remain positive and therapies such as reflexology can be beneficial.”

The following examples may give you a starting point.

Talking therapies: this describes a range of psychotherapies and counselling techniques that use discussion, such as Acceptance and Commitment Therapy (ACT) – see below. Talking therapies cannot make problems go away, but can help you cope with them. In England, focus on ‘talking therapies’ has increased through the Improving Access to Psychological Therapies (IAPT) pathway.

Acceptance and Commitment Therapy (ACT): this form of psychotherapy is thought to have some positive impact with neuro conditions like MND. It helps you accept difficulties, rather than using avoidance. Ask your GP for referral to a psychological service to explore this. With ACT you learn to:

- **Accept** your reactions and be present (being aware of yourself and your environment in the moment).
- **Choose** a valued direction.
- **Take** action.

Cognitive Behaviour Therapy (CBT): where a psychologist or counsellor helps you reduce your distress through:

1. identifying the things that trouble you
2. realising your thoughts, feelings and beliefs about these
3. recognising thoughts that are negative or inaccurate
4. challenging those thoughts and exploring different ways to think about the situation.

Mindfulness techniques: these simple meditation techniques can reduce stress and depression. They help you focus on how you feel in the moment, without judgment. It may help to explore what’s most important to you.

Some mindfulness exercises use breathing techniques, which may be more difficult if MND affects how you breathe. Ask your GP to help you find suitable mindfulness techniques for MND.

Physiotherapy: a physiotherapist can recommend an exercise programme, including assisted or passive exercise, where someone helps move your limbs. Exercise cannot stop or reverse MND, but it can strengthen unaffected muscles, ease pain and stiffness, and help range of movement. Many find exercise brings a sense of control and positivity.



“I was a wee bit of a gym junkie. I found it difficult to deal with physiotherapy at first, because I couldn’t see any progress...In time, I came to see the benefits of even the smallest amount of exercise.”

Complementary therapies: ranging from simple massage, to acupuncture and aromatherapy, these therapies work alongside conventional medicine. Some people find they can help ease symptoms, anxiety and feelings of stress. Private therapists or practitioners will charge a fee. Hospices and specialist palliative care teams often provide some complementary therapies free or at a low cost.



“I have complementary therapy – massage, reflexology...”

See information sheet 6B – *Complementary therapies.*



3: How do I manage emotional lability?

Emotional lability (known as pseudobulbar affect) affects some people with MND. It's more common if there are problems with swallowing and speech.

With this symptom, you may laugh or cry at inappropriate times, or in an exaggerated way. This can be distressing and difficult to stop. Those nearby may not understand, but these outbursts are usually short. In most cases this symptom reduces over time.



“I get very upset, as I know it upsets others, and frustrated and angry with my own body.”

What causes emotional lability?

MND can affect the pathway between the outer layer of the brain and the brain stem. This causes emotional lability, which is an abnormal motor response rather than emotional.

This is why your responses may not match how you feel. For example, you may laugh when sad, or cry when happy. Something small, that didn't trouble you in the past, may now lead to an overwhelming or unexpected emotional response.

Some people with MND experience changes to thinking and behaviour. In these cases, it is more common to experience emotional lability, but emotional lability is not necessarily a sign that your thinking and behaviour is going to change.

What can I do?

Once you know what's happening, you may feel more able to manage emotional lability.

If it limits what you do, medication may help - ask your GP for guidance or referral to a neurological specialist.

If you let those supporting you know that you may have an outburst, they will be less likely to think they've upset you.



“The more people that know this problem is due to my disease, the less of a problem it feels to me.”

Also explain how you want to be supported if it happens. For example, do you find it easier if they ignore an outburst until it passes? Or will it help if they distract you?



“The best way to help me is to quickly take me away from people. After a few minutes I regain composure.”

Emotional lability affects people in different ways. Guide others to do what feels right for you.



“I have an advice sheet with me that I can give to people if I break down, as when this happens, I cannot speak or communicate.”

4: How can I get help if I support someone with MND?

If you are in a caring role, the previous sections in this guide can help you consider someone's emotional needs with MND. This can be very different for each individual, depending on their own feelings, beliefs and symptoms. Your relationship with them will also affect how you offer support. You may also need support when facing the challenges ahead.

Finding ways to work together as a team can help you support each other. Being aware of each other's mood, having open conversations and sharing feelings can help.



If the person with MND experiences changes to thinking and behaviour, they may become less aware of your feelings than before. Try not to take this personally, as it is a symptom of the disease. However, this can feel challenging and you may need professional support.



“My husband had changes in his thinking and became unable to problem solve or fully understand how his illness was affecting me. It was hard at times, but once I accepted this, I found support from others and things got better.”

See our guide on *Changes to thinking and behaviour*.

As a carer, no-one knows the challenges of providing MND care better than you. You can help guide the health and social care professionals who support the person with MND, but they can advise you too. Keep useful contacts to hand. Your nearest MND care centre or network, or your local neurology service, provide co-ordinated care. This means that different specialists work as a team and support for carers is part of their offering.

What can I do to help myself?

As the care demands increase with MND, physical and emotional stress can impact heavily on carers.



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

As an unpaid carer, you may be the partner, relative or friend of the person with MND. You are likely to face challenging emotions too.

This may include sadness, anticipated grief, loss or anger. Guilt is a common emotion too, even when carers tell us they are doing all they can to support the person with MND.



“Sometimes heavy discussions make me feel I’m not doing enough, and I feel guilty.”

In the midst of this, you must consider your own needs no matter how impossible that seems. Without support and rest, you may become unable to continue your caring role.

Let your GP know you are a carer, so you can access regular health checks and flexible appointments.

You may also need a referral to counselling. If there is a waiting list, specialist palliative care and hospice teams often provide similar support, which is also open to carers and close family.



Getting your needs assessed

Ask your local adult social care services for a carer's assessment. This is through your local authority in England or Wales, or your health and social care trust in Northern Ireland. The person with MND can also have a needs assessment. Assessment may result in support and help you find out about:

- care services, voluntary sector services
- how to get benefits advice and assistance with travel
- suggestions for counselling or support groups
- respite care, emergency care and nursing care.

Even if family and friends help out, external care support is worth exploring. This may include respite care, where someone takes over to give you time out. This can help you take regular short breaks from the caring role or a longer break for a holiday.

Respite care can be provided at home, in a residential or nursing care home, a day centre, hospital or hospice. However, MND can make it more difficult to find suitable providers.

Check the experience of the provider first to ensure they offer appropriate care, which might include support for:

- moving and repositioning for comfort
- personal care for dressing, washing and getting to the toilet
- speech and communication difficulties
- tube feeding to top up or replace eating and drinking

- assisted ventilation for breathing problems
- changes to thinking and behaviour - which may involve frontotemporal dementia (FTD) for a small number of people with MND.

See our form, *Understanding my needs to help the person with MND guide care workers and hospital staff.*

If medical needs become complex or urgent, the person with MND may need to move into a nursing care home.

This can be emotional for you both, but a need for advanced care and medical support is not a reflection on the care you provide.

See our full carer's guide, *Caring and MND: support for you for more about carer wellbeing, support and getting a carer's assessment.*

Recommendations about professional psychological and social support are given in the NICE guideline on MND, produced by the National Institute for Health and Care Excellence.

**We have resources on how you can use the guideline.
See *Further information in Section 6: How do I find out more?***

See the next section about *Who can help?* for descriptions of support that can help with managing emotions.

5: Who can help?

Some professionals specialise in emotional support, but many can help ease worries and anxiety.



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

You may see a wide range of health and social care professionals with MND, including a:

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

Counsellor: to help manage challenging emotions. There may be a waiting list with the NHS, but specialist palliative teams and hospices usually offer similar help. Ask your GP about registered practitioners if you wish to pay for sessions privately.

Psychologist: for exploration of how the mind affects your behaviour, emotions, perception and learning ability. This can help you challenge negative responses.

Neuropsychologist: for support where the relationship between the physical brain and the way someone thinks and behaves has changed. The roles of psychologist and neuropsychologist often overlap.

Multidisciplinary team (MDT): for a team of specialist health and social care professionals who work closely to provide co-ordinated care. This can usually be found through an MND care centre or network, or a local neurological service.



Specialist palliative care or hospice team: for practical and emotional support to achieve the best possible quality of life with a life-shortening illness. There may be a waiting list, but where available, try to access this type of care from the point of diagnosis. This can help you gain most benefit, and includes outpatient therapies and home visits in some cases.

Occupational therapist: for equipment, adaptations and ways to prolong independence, which can reduce frustration.

Speech and language therapist: for help with any speech and communication difficulties, so that you can raise awareness of your physical and emotional needs. They can also help with swallowing problems.

Dietitian: for help with nutrition and extra calories if you are losing weight with MND, or feeling frustrated at mealtimes.

Complementary therapist: for a range of therapies that work alongside conventional healthcare, such as massage and acupuncture. Some people find these can help ease certain symptoms, stress or anxiety.

Adult social care service team: 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 if you live in Northern Ireland.

Link worker: for help with personalised care, on what really matters to you. This includes connecting you to community groups and services for practical and emotional support. Ask your GP about this type of support in your area.

Spiritual or faith leader: for support or guidance about your beliefs, faith or sense of spirituality. A social worker or a specialist palliative care team can also usually advise and help you discuss your thoughts, hopes and worries.

NHS Continuing Healthcare: for a package of nursing and personal care, fully funded by the NHS in England and Wales. This is only provided following assessment, where healthcare needs are complex and urgent.

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

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

See section 6: *How do I find out more?* for details about how we can help you and a list of other useful organisations.

What do the medical words mean?

When meeting professionals, you may hear the following words used when discussing changes to emotions with MND.

Cognition: your mental and thinking abilities.

Emotional lability: also known as *pseudobulbar affect*, which causes laughing or crying that may not match how you feel. See Section 3 for more about this symptom.

Frontotemporal dementia (FTD): a type of dementia that affects thinking, behaviour and language.

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

Pseudobulbar affect: see *emotional lability* above.

See also our booklet: *Changes to thinking and behaviour.*



6: How do I find out more?

Useful organisations

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

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

See our guide, *Caring and MND: support for you* for more carer organisations.

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 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**

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>**

Samaritans

A 24-hour confidential emotional support service.

Telephone: 116 123

Email: jo@samaritans.org

Website: **www.samaritans.org**

Acknowledgements

With thanks for their kind support on this guide:

Jane Leicester, MND Service Improvement Practitioner, Greater Manchester MND Care Centre, Salford Care Organisation (part of the Northern Care Alliance NHS Group).

Amanda Mobley, Consultant Clinical Neuropsychologist, Neuropsychology Services, Newtown Hospital, Worcester

Dr. Rachel Woolrich, Principal Clinical Psychologist, Oxford MND Care and Research Centre, Oxford Centre for Psychological Medicine, John Radcliffe Hospital, Oxford University Hospitals NHS Foundation Trust.

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 help with emotional support, see the following guides:

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

Telling others about MND

Changes to thinking and behaviour

Making the most of life with MND

Living with motor neurone disease (MND)

Caring and MND: support for you

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

Finding your way with bereavement

See also **MND Buddies** our online activity hub for young children close to someone with MND, with facts, games and stories at: www.mndbuddies.org

We have a web area for children, young people, parents and guardians at: www.mndassociation.org/cyp

Young people can also contact our helpline, Young Connect:

Telephone: **0808 802 6262**

Email: **youngconnect@mndassociation.org**

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 emotional support and guidance. They can explain our services and grants for people with MND, their carers, and children or young people affected by MND. They can also introduce you to local support – including Association visitors, regional staff contacts, and branches and groups where you can meet others affected by MND. If needed, the helpline can help you search for external organisations.

MND Association website and online forum

Website: **www.mndassociation.org**

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

Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance:

0808 802 6262

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/emotions

or contact by email:

infofeedback@mndassociation.org

or write to:

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Created: November 2023
Next Review: November 2026
Version: 1

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