

Making the most of life

with motor neurone disease





“This is John and I at Latrigg summit overlooking Derwent water. We were able to hire the all terrain wheelchair. Fell walking was one of our dreams when we thought of moving to Cumbria.” Margaret

Contents

How can this booklet help me?	4
1: How might MND affect me?	6
2: How can I do the things I want to do?	7
Communication and having conversations	11
Eating and drinking	13
Getting around	15
Using your hands	17
Breathing	19
Saving energy	21
Staying positive	23
Relationships	25
Work and employment	27
3: Where can I get support?	28
4: How can the MND Association help me?	31
5: How do I find out more?	35



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.

How can this booklet help me?

We're all different, and the things that make us happy vary from person to person. The things we enjoy make us who we are.

With motor neurone disease (MND), it is likely to become difficult or more tiring to do things. This can affect everyday routines, your social life, interests and hobbies. If you're living with Kennedy's disease, you may have similar symptoms and also find this booklet useful.

You might need time to adjust, but finding new ways to do things may help you continue doing what you enjoy, or try something new.

Knowing what to expect and where to find support when needed is a good starting point.

To help you with this, *Making the most of life with MND* includes:

- how MND may affect you
- how adaptations can help
- where to find support for the challenges you may face.

Our aim is to help you:

- find ways to adapt and save energy
- feel more prepared so that you can plan ahead
- know where to find further information when needed
- see examples of how others have continued doing things they want to do with MND.



“I need help finding new interests with examples.”

It would be impossible to list the huge number of interests people might enjoy in this short booklet. However, knowing where to begin your personal search for support may help you make the most of life with MND or Kennedy's disease.

Discuss your interests with your health and social care professionals, as individual needs are so varied. You may find personalised guidance helps you find new ways to do things.

Whether you enjoy sports, crafts, live performance, eating out, social clubs, travelling, cooking, gardening or a more specialised hobby, there are many ways to maintain your interests. You may also want to try something new.



“Eventually MND got to my legs, so I can't run anymore but I find alternatives, like wheelchair racing.”

Further information and publications

Throughout this booklet we will direct you to our resources for further information, where appropriate. You can download them from our website at: **www.mndassociation.org/publications**

or order them in hardcopy from MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

All quotes have been provided by people living with or affected by MND. Some are anonymous, but we have provided names where people have contributed directly to the booklet.

1: How might MND affect me?

MND affects the nerves in your body called motor neurones. These control how your muscles work. Over time, the motor neurones stop carrying messages that tell your muscles how to move, causing muscle weakness, stiffness and wasting.

MND can change how you walk, talk, eat, drink or breathe. It's likely you will also get tired and find things take more effort and energy. Some people also experience changes to thinking, behaviour and emotions. Not all symptoms happen to everyone, or in the same order, but disability will increase as symptoms progress. Kennedy's disease is a separate condition to MND, but has similar symptoms.

See our guide: *Living with motor neurone disease, for comprehensive information and pointers on how to manage the impact of MND. If you are living with Kennedy's disease, see also information sheet 2B - Kennedy's disease.*

What is meant by quality of life?

Quality of life can be different for everyone, but usually refers to general wellbeing, life satisfaction or sense of self. For many of us, spending time with friends and family is important for our quality of life. We may also find satisfaction in our work.

Yet our personal interests and hobbies can have a powerful and lasting impact on how we feel. They lift our mood and sense of wellbeing. We choose what we want to do in our leisure time for personal satisfaction, entertainment, pleasure or relaxation.

You don't have to stop all of your interests because of MND, but you may need to approach them in a different way.

2: How can I do the things I want to do?

People with MND share their experiences with us about activities they continue to enjoy. Often they have approached activities in a different way or found new interests since diagnosis.



“I have fitted a lot into my life since I was diagnosed and I advise anyone who has MND to do the same. You have to stay positive and enjoy life - you only get one chance at it.”

There are many ways to remain involved in your interests. It may take a little arrangement and planning. You may need to take things slower, do it differently, or accept support. For example:

- If you want to access computer applications but can no longer operate a keyboard, then adapted switches or voice recognition software may help. Some software enables you to use eye movement to operate a computer.
- If you want to take part in a walk or run but have problems with mobility, then a running partner, mobility aids or a wheelchair may enable you to get involved in other ways.
- If direct involvement gets too tiring, you may want to attend events or clubs to support others. This can help you maintain social contact with people who share your interests.
- If you enjoy visiting the countryside, look out for accessible walking routes and trails for wheelchairs or mobility scooters.

You may feel ready to begin taking part in adapted activities, or the thought of this may be overwhelming. Whatever you are feeling, it is important to know these feelings are natural and there is support available to assist you.

How can equipment and adaptations help me?



“I remain determined to get on with my modified life... my outlook, by necessity, is having to change.”

Over time activities and tasks are likely to become more difficult as MND progresses. You may need time to adjust to the idea of using equipment or seeking support. However, it could free up time and energy for you and your carer to continue enjoying your hobbies and interests together.

See information sheet 11C - *Equipment and wheelchairs* and our booklet, *Personal care for more about equipment and support*.

Assistive equipment includes:

- communication aids
- apps for tablets and smartphones, and computer software or modifications
- aids to help with dressing and washing
- aids to help with cooking, eating and drinking
- home adaptations
- mobility aids, manual and powered wheelchairs, and adapted vehicles.



“The thing about MND is the goal posts are constantly moving... but you just have to adapt as you change. It’s all about living life to the full.”

Seek advice from an occupational therapist before buying any equipment. When the time is right for you, they can assess your needs and advise on suitable items, such as aids, equipment or wheelchairs. Your needs can be reviewed too, to ensure your equipment is still suitable. If you don't currently have an occupational therapist, ask for referral from your GP or wider health and social care team.

Having an assessment is important, as needs can change quickly. It can be costly and frustrating if you purchase something that isn't suitable, or only helps for a short time. Some equipment may also be available free, or on loan from the NHS or adult social care services.

You may feel that equipment or aids aren't needed yet. However planning ahead is important, and some time may be needed to arrange certain items. They can be put aside until needed.

See section 4: *How can the MND Association help me? for our support grants and equipment loan service information.*

Try to ask for help when needed, and accept it when offered, even if this feels difficult at first. Support may come from people you know, adult social care services, or organisations like the MND Association.

Planning and making decisions

If your thinking or behaviour is affected by MND, it may make planning and making decisions difficult. This can make it harder to do the things you want to do, and you may need extra support from those close to you and your health and social care team.

For more information see our booklets, *Emotional and psychological support* and *Changes to thinking and behaviour*.

Support from health and social care professionals

Health and social care professionals can help you manage your symptoms and the impact of MND or Kennedy's disease on your life. Throughout this booklet, we have suggested the professionals who can support you. If you would like to be assessed by a specific professional, ask your GP or another member of your health and social care team for a referral. They can help you get an appointment.

For more guidance, see section 3: *Where can I get support?*



“When diagnosed with MND life goes on, but it is different. We live in the 21st century and we can adapt in ways that were not possible 10 years ago. The future will bring more and more.” Lee

*Lee has created a blog about living with MND: www.onein300.com
Lee also features on the cover riding his recumbent trike, which allows him to continue cycling now he can no longer ride a two wheeled bike.*

Communication and having conversations

The challenge: with MND you may experience changes to your speech, voice, gesture and facial expression at some point. You may also experience some of these changes with Kennedy's disease. This can make having conversations more difficult. It may also impact on relationships, social life, interests and confidence.

What might help?

Communication aids range from simple tools like alphabet boards, to high tech software apps and devices. Your individual needs and preferences will be important, but a choice of aids may be needed. For example, if your speech volume is low, a voice amplifier can help in a noisy social setting like a pub.

See information sheet 7C - *Speech and communication support.*

You may be able to 'bank' your voice before it is largely affected, to create a computerised version of it. This can then be used on a powered communication aid in the future, to sound more like you.



I haven't needed to use my created voice for general communication yet, but it has been banked and can be installed on a range of devices for when I do need it."

See information sheet 7D - *Voice banking.*

Who can help?

A speech and language therapist can assess your needs, help you use your own voice for as long as possible, and advise on any communication aids that can assist.

The Communication Aids Service at the MND Association can also support you by providing guidance on services and equipment, including information and support with voice banking.

See section 4: *How can the MND Association help me?*



“I’ve always enjoyed my food and drink and I was a very good cook, there isn’t any food or drink I don’t like. The only thing we have to do these days is check the wheelchair access and toilet facilities in restaurants.” Ian

Eating and drinking

The challenge: with MND, and sometimes with Kennedy's disease, swallowing difficulties and restricted movement may affect the way you eat and drink. These symptoms can get worse over time and clearing saliva can also become difficult. Keep well nourished and try to continue eating and drinking socially, for as long as you wish to.

What might help?

Gadgets and adapted utensils can help with cooking, eating and drinking. You may also need to adapt the types of food and drink you have, for easier swallowing. If you enjoy eating out, check restaurant menus and facilities in advance to see if they are accessible and suitable for your needs.

See our guide *Eating and drinking with MND*, for information, tips, tasty, easy-swallow recipes and guidance on eating out. See also information sheets, *7A - Swallowing difficulties* and *7B - Tube feeding*.

You may also wish to ask your health and social care team for information about tube feeding. Being fully informed about your options can help you make timely decisions that are right for you.

Who can help?

A speech and language therapist can advise on effective swallowing techniques and the best food and drink consistencies. A dietitian can advise on how to keep well nourished, and increase your calorie intake if you have lost weight.

If eating and drinking are difficult due to arm or hand weakness, an occupational therapist can advise on posture, equipment or aids that may be able to help.



“There’s a reservoir not far from us that has a wheelchair path around it and picnic areas, it’s great we’ll be able to take our grandson there during his summer holidays.” Nigel

Getting around

The challenge: MND or Kennedy's disease usually affect the movement in your arms and legs, which can make getting around difficult and tiring. This can make social contact, employment and active hobbies and interests more challenging.

What might help?

Home adaptations like hand rails or ramps can help you get around the house more easily. Wheelchairs and adapted vehicles can make getting out and about easier too.



"We've got a wheelchair access vehicle, (WAV) now, it's like having a new life."

Many holidays, activities and hobbies can be made accessible by using specialist equipment or wheelchairs.

See our booklet, *Getting around and information sheet 11C - Equipment and wheelchairs*

Who can help?

An occupational therapist can assess your needs, and provide guidance on mobility aids or equipment to help you get around. A physiotherapist can advise on exercise or assisted exercise to help you maintain movement in muscles not already affected by MND or Kennedy's disease.

See information sheet 6A - *Physiotherapy*.

Local authorities in England and Wales, health and social care trusts in Northern Ireland, voluntary organisations and the internet also provide lots of information on accessible activities, hobbies and holidays that may be suitable for someone living with MND or Kennedy's disease.



“I use a computer with eye gaze, not just to communicate, but to do online shopping, use social media and even make art, something I’ve been passionate about my whole life.”

Sarah

The artwork in the image above shows some of Sarah’s artwork, created using eye gaze technology, on display.

Using your hands

The challenge: weakness in the muscles from MND or Kennedy's disease makes it harder to move your arms and grip things with your hands. This can affect daily tasks and taking part in hobbies, interests or activities you enjoy.



“When I lost the movement in my hands, I couldn't access my computer and felt really isolated.”

What can help?

Gadgets, adapted switches and voice control technology can help if your arms and hands are affected. Accepting aids or help from other people may enable you to continue doing the things you want to do, and save energy too.

Many activities and interests can be adapted to suit your needs. Contact your local authority in England or Wales, your health and social care trust in Northern Ireland, or local disability organisation to find out about accessible activities near you.

Who can help?

A physiotherapist can assess your needs and advise on exercise or assisted exercise that may maximise the movement in muscles not yet affected by MND or Kennedy's disease. An occupational therapist can assess your needs and advise on any equipment or aids that may help you remain independent for as long as possible.

See information sheet 6A - *Physiotherapy*.

Other people living with MND or Kennedy's disease can also help by giving advice and tips on how they approach problems with hand movement and grip.

See section 4: *How can the MND Association help me?* for how to meet other people living with MND and our online forum.



“I try not to dwell on negative thoughts. I do a lot of visualisation, in which we are all together as a family on that day and far beyond. It’s so important to me to stay positive and we dream of taking our family back to Disneyland Paris.” Emma

Breathing

The challenge: many people with MND experience changes to their breathing. This may be subtle at first, and you may not even notice a difference. However, breathing difficulties can cause your energy levels and appetite to decrease, and affect your sleep, which may make it harder to do the things you want to do.

What can help?

Breathing exercises, physiotherapy, positioning and medication can all help. You could ask your health and social care team about ventilation, where a machine supports your breathing. Some people find ventilation reduces the impact of symptoms like fatigue and anxiety when doing the things they enjoy.



“I rely on life support ventilation 24 hours a day, life is still absolutely worth living.”

In some cases ventilation equipment can be taken out and about with you, in a car or on a plane if you enjoy travelling. Have an early discussion with a respiratory specialist before you consider travelling with ventilation equipment, so that they can help you plan.

However, using ventilation is not suitable for everyone and it is your choice whether this feels right for you or not.

For more on breathing support see information sheets 8A-8D.

Who can help?

A respiratory consultant can assess your breathing and advise on techniques, treatments or therapies that may help. They can also help you determine your options and assist you in making informed decisions about supported breathing. A physiotherapist can advise on breathing exercises that may help. An occupational therapist can advise on positioning and support aids to help breathing.



“I was on a six hour annualised contract...I didn’t work two consecutive shifts as I found I was tired after six hours at work and needed an easy day the following day. It meant that some weeks I could work more hours over several days and then have the ability to go off and do some travelling.” Alison

Saving energy

The challenge: many people with MND or Kennedy's disease experience extreme tiredness, known as fatigue. This can happen due to loss of physical function, as a result of other symptoms, or because of disturbed sleep. Fatigue can make you feel more tired than usual following an activity or even while resting. If you are tired a lot, it can affect seeing friends or family, following hobbies and working.

What can help?

Storing or 'budgeting' your energy can help you manage the impact of fatigue. This might mean planning activities at the times of day when you usually feel more energised, and taking time out to rest when you don't. It might also mean using assistive equipment that can help you and your carer save energy.



"Listen to your body. Perhaps do tasks in small steps rather than all at once. This way, you achieve the task in the end but without the frustration of tiredness."

Prioritise tasks that you really want to do over those that can wait or that somebody else can help with.



"It's important to emphasise – pick activities you enjoy against activities you feel obliged to take part in."

Who can help?

Other symptoms, like breathing difficulties or lack of nourishment, can cause fatigue. The professionals who help manage these symptoms can advise on managing fatigue too. An occupational therapist can also support you by advising on suitable equipment to make everyday tasks easier, or help you find ways to adapt how you do things. Your health and social care team can support you to find ways to improve your sleep.

For more on managing fatigue see our booklet, *Personal care*.



“I was determined to make the most of the possibilities the wheelchair gave me. I saw my niece dance at the Royal Opera House and I visited Hampton Court Flower Show. I even co-ordinated my mother of the bride outfit with my purple chair for my daughter’s wedding.” Claire

Staying positive

The challenge: living with MND or Kennedy's disease can involve many emotional challenges. The range of emotional responses to diagnosis can include anger, relief, fear and sadness. These emotions along with other symptoms can lead to feelings of anxiety. You may experience emotional lability with MND, which causes responses that don't match your emotions, like laughing when you feel sad. This may make you feel like withdrawing from social situations or holding back from doing things you enjoy.

What can help?

Doing the things you enjoy can have a positive, therapeutic effect on how you feel. Whether this is spending time with others or focusing on a hobby or interest.



“I have a great support network of family and friends. My home is always full of people popping by - to say hello, or walk the dog.”

Acknowledging your emotions can help loved ones understand and support you better, and share their feelings too. If you become anxious, taking time out with something you enjoy can distract. Such as listening to music or spending time in the garden. Ask your GP about therapies or medications that may be helpful.

If you experience emotional lability, recognising this as a symptom of MND can help you manage its impact. Medication may also help.

Who can help?

Your health and social care team can refer you to a clinical psychologist or counsellor, who can help you work through emotions. Palliative care specialists also provide counselling and complementary therapies, which may help reduce anxiety.

See our booklets, *Emotional and psychological support*, *Telling people about MND*, and section 4 of our guide, *Living with MND*.



“My nieces decided they wanted to do a fundraising challenge, I’m so proud of both of them. My sisters have been great too helping out cleaning, cooking, shopping, keeping me company and making me laugh. They are part of a very small support bubble.” Mark

Relationships

The challenge: MND or Kennedy's disease can change the existing roles in family and social circles. If your partner is also your main carer, you may be worried about how this might affect your relationship. It may also be harder to maintain the social side of life. Fatigue or reduced mobility may make visiting people difficult or tiring. Some symptoms can also affect being intimate with your partner.

See our booklet, *Sex and relationships for information on intimacy.*

What can help?

Having early, open conversations with loved ones can help them feel informed about what to expect with MND. This is important for children and young people too, as clear explanations can help them feel included and supported, and avoid confusion.

See section 5 of our *Living with MND guide and booklet, Telling people about MND.*

You may feel like withdrawing from social situations if you feel awkward or different around friends as your symptoms become more obvious. However, spending time with others can have an effect on wellbeing. Take part in social gatherings for as long as you want to, and let others know the best time of day to visit. You could adapt the activities you do with others, such as when you're spending time with children in the family.



"I have good friends who don't treat me any differently. I do feel very lucky."

Who can help?

Depending on how MND or Kennedy's disease challenges you, your healthcare team may be able to help with how your relationships are affected. Other people with or affected by MND or Kennedy's disease may be able to share their experiences about ways they have maintained their relationships with others.



“Employers are often unclear about their obligations towards disabled employees. A little bit of knowledge before discussing your needs with an employer can be very helpful indeed.”

Work and employment

The challenge: work can be important to identity, sense of purpose and quality of life. You may wish to stay at work for as long as possible, or decide to leave sooner if your symptoms make it difficult. This important decision will depend on your needs, preferences and situation.



“I decided to carry on with my life as normally as possible for as long as I could. Remaining in employment was part of this plan.”

What can help?

Accessing the support mentioned in this booklet may help you manage your symptoms and save energy to continue working for longer. You may also be able to adapt the type of work you do, maybe changing from physical to desk-based work activities. Ask your employer about the Access to Work scheme for more information.

If you wish to leave work, discuss this with those close to you or an independent adviser. You may also want to ask your employer about your options, such as taking paid or unpaid leave or early retirement.

See information sheet 10E - *Work and motor neurone disease*.

Who can help?

Having early conversations with your employer can help them make arrangements to help you stay at work for as long as possible. A member of your health and social care team, such as an occupational therapist, can assess your ability to work and help you save energy.

If you wish to leave work, an accountant or financial adviser can help review your finances and options before leaving. Our Benefits Advice Service can also advise on benefits you may be entitled to with MND. See section 4: *How can the MND Association help me?* for details.

3: Where can I get support?

There are people and organisations who can help you remain independent and continue doing things you enjoy for as long as possible.

Local authorities in England and Wales, or health and social care trusts in Northern Ireland: can help you find out about assisted activities in your local area. They also often have directories of services, support and information for disabled activities.

Ask your local authority for a needs assessment and for your carer, a carer's assessment. This helps identify any home support or services that you both may need. They may also provide certain types of equipment and aids to help you continue doing the things you enjoy.

See our information sheets 10A-10G for more about social care and financial support.

Your GP: is a first contact for questions about health, but also the person who usually refers you to other specialists. However, other members of your health and social care team can do this too. GPs may also be able to advise on community contacts for disability support.

Health and social care professionals: provide specialist support in a range of areas. Many may not have a lot of experience of MND or Kennedy's disease, however MND care centres and networks (part-funded by the MND Association) and local neurological services offer specialised help, usually through a multidisciplinary team.

See our guide, *Living with MND* section 13: *How health and social care professionals can help you.*

Multidisciplinary team (MDT): a group of professionals from different disciplines, who provide co-ordinated care and linked services. For example, with MND, this usually includes a neurological consultant, occupational therapist, speech and language therapist, dietitian and physiotherapist, but there may be other consultants, specialist nurses and local care support too. The number and type of professionals in your team will depend on your needs and the services available in your area.

Hospices and palliative care specialists: aim to help you and those important to you achieve the best possible quality of life, through symptom management, services, practical guidance, and emotional and spiritual support. Ask your GP, or wider health and social care team for referral as soon as possible after diagnosis.

See information sheet 3D - Hospice and palliative care.

Clubs and societies: enable people with similar interests to share ideas, experiences and social events. If you're already a member of a club or society, find out if they offer accessible services or help. If you wish to explore a new interest, contact your local authority if you live in England or Wales or your health and social care trust in Northern Ireland to find out the options near you. There are many clubs and societies run for and by disabled people.

Faith leaders: offer religious or spiritual support, which can often include activities and support groups for disabled people. Contact your local faith leaders for further information.

Internet sites: can provide information and support about accessible venues, restaurants, holidays, days out, experiences and interests. Sites often provide links to other reputable and relevant websites where you are more likely to find trustworthy information. Search for *accessible activities* at: **www.nhs.uk** for some examples of reputable websites for disabled people.

See Useful organisations in section 5: How do I find out more?

Voluntary organisations: provide all kinds of support, including advice, financial guidance and linking through to other services. Many of these exist to support disabled people, by providing access to activities, sports and other ways to stay involved. Search the internet for voluntary organisations that may be able to provide assistance for your individual needs.

Other people with or affected by MND: people who will understand the challenges you face and can offer their support. MND Association branches and groups, and local neurological support groups offer the chance to meet with others and share experiences. If this doesn't feel right for you at the moment, you may find it helpful in the future. Local clubs and organisations may provide wider opportunities to meet other disabled people too.



“The regular support meetings held by my local branch are invaluable – people affected by MND are the only ones who can really ‘tell it as it is!’”

See section 4: *How can the MND Association help me?* for information about our services, including regional support, branches and groups, our online forum and membership.

4: How can the MND Association help me?

The MND Association is dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. Scotland is supported by a different organisation called MND Scotland. See section 5: *How do I find out more?* for details.

MND Connect

Our helpline provides information and support, and can connect you with our own or other appropriate services.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Equipment loans and MND support grants

If statutory funding is not available, or is taking too long, we may be able to provide a support grant or some equipment on loan. Grants may be given to help with aspects of care or quality of life, for people with MND or Kennedy's disease, their carers and younger members of the family. Applications for some support grants or equipment loan need to be made by a relevant health or social care professional.

Telephone: **0808 802 6262**

Email: **support.services@mndassociation.org**

Website: **www.mndassociation.org/getting-support**

MND Association website

You can find lots more information, support and news on our website: **www.mndassociation.org**

Local and regional support

To find out who your local contacts are for any regional support, contact MND Connect, details above.

Regional staff for local support: Our regional staff have knowledge about the management and care of people with MND. They work with volunteers and affected families, or help to influence local service providers. Their aim is to help ensure care and support is made available at the right time.

Association visitors (AVs): are trained volunteers who can provide information and guidance about MND and local services by phone, email and home visits. AVs may not be available in all areas, so contact MND Connect to find out if there is an AV near you.

Branches and groups: are volunteer-led and provide local support, practical help and an opportunity to get together with others living with or affected by MND.



“Two years after diagnosis, my husband decided to attend a branch support meeting. In no time, he became involved in raising awareness of MND, writing the branch newsletter and setting up their website and social media accounts. This kept him up to date with his skills and gave him a purpose in life... incidentally his motto was ‘make every day count.’”

MND care centres and networks: we part-fund and develop care centres and networks across England, Wales and Northern Ireland. These offer specialist clinical expertise from diagnosis onwards, and co-ordinated care across a range of disciplines. Local neurological services provide similar co-ordinated services if you find it difficult to reach a care centre or network.

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**

Communication Aids Service

Help for people affected by MND or Kennedy's disease, and health and social care professionals, with queries about communication aids. It provides limited financial support or some items on loan if unavailable or delayed through health and social care services.

Telephone: **0808 802 6262**

Email: **communicationaids@mndassociation.org**

Membership

As a member of the MND Association, you'll be able to contribute to an active and supportive community.

Telephone: **01604 611855**

Email: **membership@mndassociation.org**

MND Association forum

Our online forum is a safe place to share experiences with other people living with or affected by MND. You don't have to join the forum if you only wish to view rather than post. You can access the forum at: **<https://forum.mndassociation.org>**



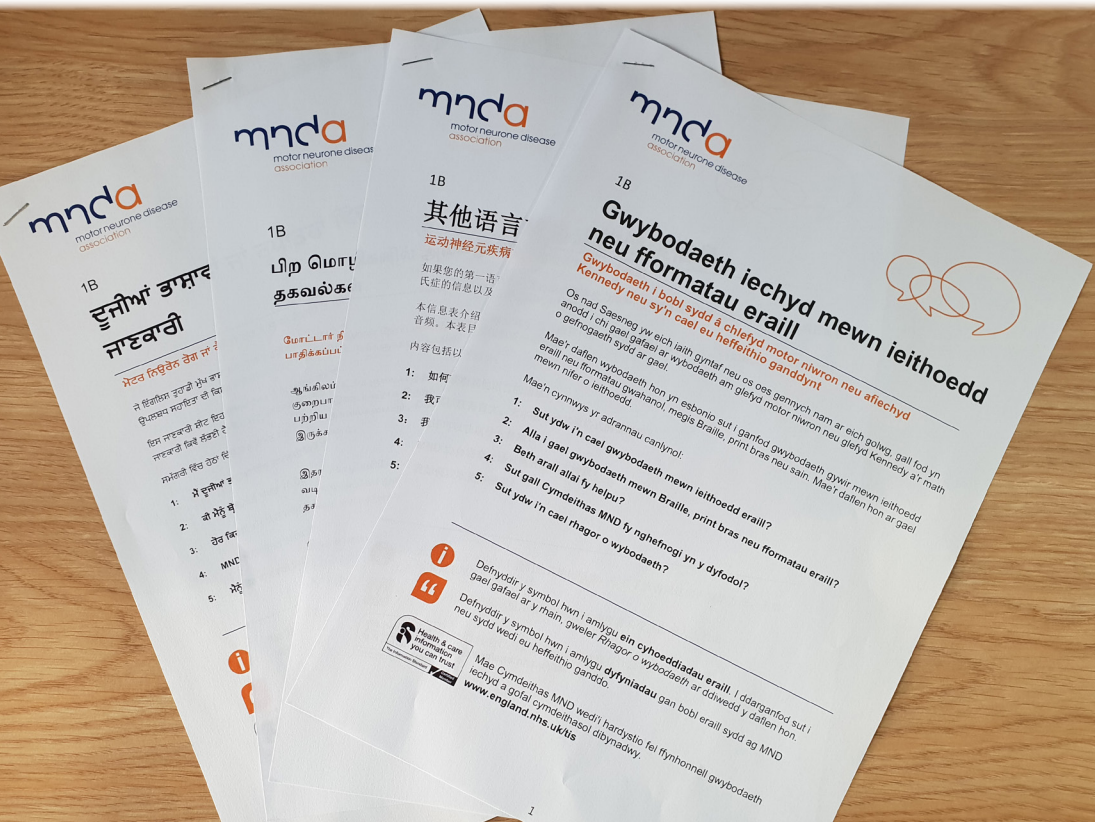
“The online forum can be such a help to those people who may feel isolated in everyday life, giving access to a new social circle and peer support.”

Support for minority and ethnic groups

We are here for everyone living with or affected by MND or Kennedy's disease in England, Wales and Northern Ireland. We acknowledge that people have differing needs, backgrounds, culture, beliefs and faiths. We support equality in all our services. Please ask the service supporting you for help if you have any preferences or needs you wish to be considered.

Information in other languages

We provide introductory information in languages other than English, with a limited translation service for further care publications. Contact MND Connect or ask someone to contact them on your behalf for support. We can also arrange for an interpreter to join a call with MND Connect or our Benefits Advice Service, if needed, or look on our website: www.mndassociation.org/languages



5: How do I find out more?

Useful organisations

We cannot endorse organisations, but the following may help your search for further support and information. Find more links at: **www.mndassociation.org/usefulorgs** Contact details may change between revisions. Our MND Connect helpline can help you find services, (see *Further information* in this section).

Adult Social Care Services

To arrange a needs assessment or a carers assessment, contact your local authority in England or Wales. Search for, *find your local council* at: **www.gov.uk**

In Northern Ireland, search for, *health and social care trusts* at: **www.nidirect.gov.uk**

British Red Cross

For a variety of disability living aids and equipment hire.

Telephone: 0344 871 11 11

Website: **www.redcross.org.uk**

The Calvert Trust

Outdoor adventure activity centres in the UK for disabled people.

Website: **www.calvert-trust.org.uk**

Care & Repair Cymru

Helping older people in Wales live independently.

Telephone: 02920 107580

Website: **www.careandrepair.org.uk**

Care & Repair England

Helping older people in England live independently.

Telephone: 0115 950 6500

Website: **www.careandrepair-england.org.uk**

Ceiling Hoist Users Club

For details of hotels, guest houses and other accommodation that contain a ceiling track hoist, in the UK and overseas.

Email: admin@chuc.org.uk

Website: www.chuc.org.uk

Changing Places

Accessible toilets that feature hoists and extra space for wheelchairs.

Telephone: 07701 373 565

Website: www.changing-places.org

Disability Action

For services to help disabled people in Northern Ireland.

Telephone: 028 9029 7880

Website: www.disabilityaction.org

DisabledGo

Provides access information on venues around the UK.

Telephone: 01438 842 710

Website: www.accessable.co.uk

Living made easy

For a wide range of support and aids for disabled people.

Telephone: 0300 999 0004

Website: www.livingmadeeasy.org.uk

Euan's Guide

Reviews by disabled people of venues around the UK and abroad.

Telephone: 0131 510 5106

Website: www.euansguide.com

GOV.UK

Online government advice for people with disabilities.

Website: www.gov.uk

Leonard Cheshire Disability

Supports disabled people around the world.

Telephone: 020 3242 0200 (England)
01633 422583 (Wales)
07895 207 659 (Northern Ireland)

Website: **www.leonardcheshire.org**

MND Scotland

Providing support for people affected by MND in Scotland.

Telephone: 0141 332 3903

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

Motability

Helping people with disabilities continue driving and getting around.

Telephone: 0300 456 4566

Website: **www.motability.co.uk**

NI Direct

Online government advice for disabled people in Northern Ireland.

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

Regional Driving Assessment Centre

For driving assessments and vehicle adaptations advice.

Telephone: 0300 300 2240

Website: **www.rdac.co.uk**

REMAP

A voluntary organisation making bespoke aids for disabled people.

Telephone: 01732 760209

Website: **www.remap.org.uk**

The Rough Guide to Accessible Britain

A free guide on accessible days out for disabled people.

Website: **www.accessibleguide.co.uk**

SpecialEffect

Ways for disabled people to play video games.

Telephone: 01608 810 055

Website: **www.specialeffect.org.uk**

Tourism For All UK

A website that provides information on accessible travel.

Telephone: 0845 124 9971

Website: **www.tourismforall.org.uk**

Welcome by Neatebox

An app that enables you to communicate your needs to customer service teams before you arrive at a venue. If your favourite venues don't currently provide this service, you can use the app to request they download it.

Website: **www.neatebox.com/welcome-user**

The Wheelyboat Trust

For wheelchair accessible boats around the waterways of the UK.

Telephone: 01798 342 222

Website: **www.wheelyboats.org**

Acknowledgements

With special thanks to:

- our review group of people with MND, Kennedy's disease, carers and ex-carers for their support on this project
- all those who shared their images, experiences and quotes which are featured in this booklet.

We would like to thank the following for their guidance in the development of this booklet:

Helen Copsey, MND Care Network Co-ordinator, Norfolk and Norwich University Hospital, Norfolk

Haf Holden, Occupational Therapist, Posture and Mobility Service, Bryn Y Neuadd, Llanfairfechan, Betsi Cadwaladr University Health Board

Dr Emma Husbands, Consultant in Palliative Medicine, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire

Amanda Mobley, Consultant Clinical Neuropsychologist, Worcester Health & Care NHS Trust, Worcestershire

Rachel Thomson, Care Network Co-ordinator, Sussex MND Care and Research Network, Sussex

Ingrid Unsworth, BSc (Hons) Specialist Occupational Therapist, Posture and Mobility Service, Wrexham, Betsi Cadwaladr University Health Board

References

References used to support this information are available on request.
Email us at: infofeedback@mndassociation.org

Or, write to us at:

**Care information feedback, MND Association,
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ.**

Further information

For more support, see our following resources:

Guides and booklets:

Living with motor neurone disease (MND)

Caring and MND – Support for you

Personal care

Eating and drinking with MND

Emotional and psychological support

Telling people about MND

Changes to thinking and behaviour with MND

Sex and relationships with MND

Understanding my needs

Throughout this booklet we have highlighted a number of information sheets that can provide further information.

You can download them from our website:

www.mndassociation.org/careinfo

or, order printed copies from our helpline MND Connect:

MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

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

We welcome your feedback

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/Makingthemostoflife

You can also email your comments to us at:

infofeedback@mndassociation.org or write to us:

**Care information feedback, MND Association,
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ**



Created: November 2021
Next Review: November 2024
Version: 2

Registered Charity No. 294354
Company Limited by
Guarantee No. 2007023
© MND Association 2017

