Making the most of life with motor neurone disease (MND)
“I’ve just got back from a trip with my daughter to an activity centre for disabled people. The activities we sampled in just three days included: canoeing, horse riding, tandem cycling on tracks, crate stacking, wheelchair abseiling, zip wire, archery and finally going in the swimming pool and jacuzzi to help tired muscles... it’s never too late to learn new tricks.” Sally
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We’re all different, and the things that make us happy vary from person to person. Yet, 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 in finding new interests with examples.”

It would be impossible to list the huge number of interests that 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.
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 within this booklet 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 this booklet._

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

Dave, living with MND
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.

“Yes, you’ve got this condition… but with appropriate support you can still have a fulfilled life and you can still enjoy it.” Paula, carer
Many people with MND have shared 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.

“Don’t assume you can’t do something: think about what you would like to do. Perhaps something that you used to do in the past and see if it can be adapted to your present abilities.”

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. Where suitable, some software even 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 be 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 that 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.”"

If any activity becomes difficult with MND or Kennedy’s disease, assistive equipment can make a huge difference. This may feel like ‘giving in’ at first, and you may need time to adjust to the idea.

However, support and equipment can help you and your carer save more energy for the things you really want to do.

See Information sheet 11C – Equipment and wheelchairs for examples of equipment and aids that can help with managing symptoms and different needs.

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.

See also Information sheets 7C, 11B-11C and 12A-12B.

“The thing about MND is that 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 to ensure your equipment is still suitable. If you don’t currently have an occupational therapist, ask for a 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 the equipment or aids your health and social care team are suggesting aren’t needed yet. However planning ahead is important, as time may be needed to arrange certain items. If your equipment does arrive before you are ready to use it, it can be kept to one side ready for when it is needed.

See section 4: How can the MND Association help me? for information about our MND Support Grants and equipment loan service.

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 other organisations, such as 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 on changes to thinking and behaviour that some people experience with MND, and adjustments that may help, see Information sheets 9A and 9B.

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?
Lee

Lee is 53 and a lover of technology. Since being diagnosed with MND in 2014, he’s created a blog about life with the condition. He decided to bank his voice for use on a communication aid in the future. Lee also features on our front cover riding his recumbent trike, which enables him to continue getting out and about now that he can no longer ride a two wheeled bike or walk any distance.

“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
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 if you are living 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 can help. These range from simple tools like alphabet boards, to technical objects such as electronic and software devices. The best solution for you will depend not only on your individual needs, but your preferences too. Different aids may be needed for different places, eg a voice amplifier in a noisy 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.”

Lee, living with MND

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?
Brian

Brian lives in Northamptonshire with his wife Janette. They enjoy eating out and have found that checking out restaurants in advance helps when you’re living with MND.

“You still want to eat out with MND. Why not? It’s a social thing that I want to enjoy.” Brian
Eating and drinking

The challenge: Usually with MND, swallowing difficulties and restricted movement affect the way you eat and drink. You may have similar symptoms if you have Kennedy’s disease. If you are affected in this way, keeping well nourished, enjoying food and drink as social activities, and clearing your mouth of saliva can become difficult. This can have an impact on your energy levels, confidence and social life.

“Knowing what is available out there, such as thickening agents for swallowing difficulties, is invaluable.”

Brian, living with MND

What might help?

Gadgets and adapted utensils can help with cooking and eating. You may also need to adapt the types of food and drink you have, for easier swallowing. If you enjoy eating out, check out 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.
Michael

Michael is from West Yorkshire, he was diagnosed with MND in 2012. Adaptations have helped him continue to get around, both in and outdoors.

“I have a Motability car with hand controls on it so I can still drive. It has a huge boot so we can get the two wheelchairs, a dog and luggage into the back and it’s very comfortable for me to drive.” Michael
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?
There is a huge range of aids and equipment that can support you. 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.

“He got his battery operated wheelchair and shot down the road laughing, with me chasing after him.”

See Information sheet 11C: Equipment and wheelchairs.

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

See Information sheets 12A-12D for holiday and travel information. See also Useful organisations in section 5: How do I find out more?

Who can help?
An occupational therapist can assess your needs, and provide guidance on aids or equipment to help you improve your mobility and 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 or health and social care trusts, 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

Sarah
Sarah lives in London and was diagnosed with MND in 2000. Assistive technology has helped her continue doing things she enjoys, and in 2012 she began using eye gaze technology to paint. The image above shows some of her artwork 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 may enjoy.

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

Sarah, living with MND

**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, health and social care trust or local disability organisation to find out what accessible activities are available 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 details about meeting other people living with MND and our online forum.
Max is from Wrocław, Poland. After moving to the UK in 2005, he was diagnosed with MND in 2010. He now lives in Cambridgeshire with his wife Agnieszka. Max uses a ventilator, which is portable and enables him to get involved in the things he wants to do.

“We don’t drive or have a car, so I use my laptop to stay in touch with the outside world. I also use it to speak to others affected by MND on the MND Association forum, as well as stay in touch with my family in Poland.” Max
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 can directly 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 may wish to ask your health and social care team for some information on ventilation, where a machine supports your breathing. Some people find ventilation reduces the impact of symptoms like fatigue and anxiety on doing the things they enjoy.

“Wearing my [non-invasive ventilation] ventilator 24 hours a day allows me to lead what I call a ‘normal’ life and doesn’t stop me from doing what I want to do.”

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

In some cases ventilation equipment can be taken out and about with you, eg 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 determine your options.

See Information sheets 8A-8D for detailed information on breathing support.

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 also advise on breathing exercises that may help. An occupational therapist can advise on positioning and support aids for easier breathing.
Alison

Alison was diagnosed with MND in 2012. After diagnosis, she continued to work as a nurse practitioner for four and a half years. She has also taken up volunteering with a local hospice.

“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
Feeling tired

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 meeting up with others, following interests or hobbies, and work.

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 be delayed, 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, eg 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 the way you do things. Your health and social care team can support you to find ways to improve your sleep.

See Information sheet 11D: Managing fatigue.
Dave and Paula live in Northamptonshire. Dave was diagnosed with MND in 2015. After getting over the emotional response to the diagnosis, they have focused on raising awareness of MND and supporting others who have been diagnosed by sharing their experience.

“Always look on the bright side of life. Focus on what you can do, don’t worry about what you can’t do.” Dave

“When Dave was diagnosed, it felt like he’d died… it’s like a bereavement. But after a few weeks, I realised that he isn’t dead, he’s still here, he’s still Dave and it’s really important to carry on with all the things we love doing and not to just hide away.” Paula
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. When these emotions are paired with other symptoms, it can lead to feelings of anxiety. You may also 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 may have a therapeutic effect on how you feel. Whether this is spending time with others or focusing on a hobby or interest, prioritise doing things you enjoy over things that can wait or someone can help you with.

Acknowledging and discussing your emotions can help loved ones understand and support you better, and share their feelings too. If you experience emotional lability, recognising this as a symptom of MND may help you manage its impact. There may also be medication that can help with this symptom.

“To me, talking about MND is a therapy. I’ve had so much help because I’m open about it.”

Dave, living with MND

If you become anxious, taking time out to try to calm down, or distracting yourself with something you find relaxing may help. This may be listening to music or spending time in the garden. There may also be talking therapies or medications available to 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 negative emotions. Palliative care specialists also provide counselling and complementary therapies, which may help reduce anxiety.

See Information sheet 9C: Managing emotions and Living with MND section 4: Emotional impact.
Ricardo and Vicky

Ricardo was diagnosed with MND in 2010. He lives with his wife Vicky, daughter, son-in-law and two granddaughters in Walthamstow.

“I have support, especially from my family, they take turns.” Ricardo

“We all live here together and we share food together, pray together and do lots of things together. We go on holiday together too.” Vicky
**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 aspect of relationships with others. For example, fatigue or reduced mobility may make visiting people difficult or tiring. Some symptoms can also affect being intimate with your partner.

See Information sheets 13A and 13B for information on intimacy with your partner.

**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 Information sheet 4A and section 5 of our Living with MND guide.

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 a big effect on quality of life. Take part in social gatherings for as long as you want to, and let others know the best time of day to visit.

You may also need to adapt the activities you do with those important to you, eg when spending time with children in the family.

“We used to play computer games with dad. When he couldn’t use the controls anymore, he’d still enjoy watching us play and would get involved that way.”

**Who can help?**

Depending on how MND or Kennedy’s disease challenges you, the professionals mentioned in this booklet 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.
Gemma is a Senior Environmental Consultant from Nottinghamshire. She was diagnosed with MND in 2016. Since diagnosis she has been raising awareness of MND, including in her workplace.

“I’ve helped to organise some education in the workplace. I think it is important for them to be made aware and hear things from a health or social care professional, so they understand how it could affect me.” Gemma
Work and employment

The challenge: Work may have a big impact on your identity and quality of life, especially if you’re close to your colleagues. Symptoms will make it increasingly difficult to continue working, and it is likely you’ll have to leave work at some point. You may wish to stay at work for as long as possible, or decide to leave sooner. This important decision will depend on your needs, preferences and situation.

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, eg changing from physical to desk-based work activities. Ask your employer about the Access to Work scheme for more information.

“I have a new chair at work to support my head a little more and brakes on it to stop it from rolling away when I try to get up.” Gemma, living with MND

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, eg taking paid or unpaid leave or early retirement.


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 you review your finances and options before leaving. Our Benefits Advice Service may be able to advise on any benefits you could be entitled to with MND. See section 4: How can the MND Association help me? for details.
There are many 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**

These can help you find out about assisted activities going on in your local area. They also often have directories of services, support and information for disabled activities.

Your local authority will have an adult social care services department that can offer you a needs assessment and your carer a carer’s assessment. This helps identify any home support or services that you both may need. Ask your local authority or health and social care trust for these assessments. Adult social care services may also provide certain types of equipment and aids that can help you continue to do the things you want to do.

*See our information sheets 10A-10G on social care and financial support.*

**Your GP**

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**

These professionals provide specialist support in a range of areas. Many professionals may not have a lot of experience of MND or Kennedy’s disease, due to their rarity. 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* **Living with MND section 13: How health and social care professionals can help you.**
Multidisciplinary team (MDT)
This team is 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
The aim of hospice or palliative care is 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.

Disability organisations
These organisations provide support, services, information and advice on a local and national level. They may also provide opportunities to get involved in accessible activities.

Clubs and societies
These 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 adapted equipment. If you wish to explore a new interest, contact your local authority, health and social care trust or local disability organisation to find out the options near you. There are many clubs and societies run for and by disabled people, who meet on a regular basis.

Faith leaders
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
Websites provide a great deal of information and support about accessible venues, restaurants, holidays, days out, experiences and interests. Many internet sites are designed by and for disabled people. These 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
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
These people 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.

We provide a number of services that can support you by providing information, support and opportunities to get together with others. To find out more about these, contact our MND Connect helpline, or see section 14 of our Living with motor neurone disease guide.

**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**
**Information resources**
Throughout this booklet, we have signposted to information resources for further information, where appropriate. We provide information resources for people living with or affected by MND or Kennedy’s disease, and for the health and social care professionals who provide support. You can order printed copies of our publications from MND Connect (see previous heading), or you can access and download most of our publications at: [www.mndassociation.org/publications](http://www.mndassociation.org/publications)

**MND Association website**
You can find lots more information, support and news on our website, at: [www.mndassociation.org](http://www.mndassociation.org)

**Local and regional support**
To find out who your local contacts are for any regional support, contact MND Connect (see previous heading).

**Regional care development advisers (RCDAs):** Our network of regional care development advisers have specialist knowledge of the care and management of MND. They work closely with local service providers to ensure care and support is available at the right time.

**Association visitors (AVs):** Association visitors 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:** 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
The MND Association Benefits Advice Service provides free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: 0808 801 0620 (England and Wales) 0808 802 0020 (Northern Ireland)

Email: Through the website contact page, at: www.mndassociation.org/benefitsadvice

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
Membership with the MND Association is free for people with MND or Kennedy’s disease, their partners and carers. It enables you to join a community of people who all share the same vision of a world free from MND. By becoming a member, you can access benefits such as our quarterly magazine Thumb Print, which features the latest news on care, research, campaigns and fundraising. It also includes articles about how others with MND continue to do things they enjoy or pick up new interests.

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:

http://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
Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline. See section 4: How can the MND Association help me? for details.

Adult Social Care Services

If you need to arrange a needs assessment for yourself or your carer would like a carer’s assessment, contact your local authority in England and Wales.

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.

Address: 44 Moorfields, London EC2Y 9AL
Telephone: 0344 871 11 11
Email: contactus@redcross.org.uk
Website: www.redcross.org.uk

The Calvert Trust

For activity centres in the UK that enable disabled people to try out different outdoor adventure activities.

Website: www.calvert-trust.org.uk
Care & Repair Cymru
For services to help older people in Wales live independently in their own homes for longer.
Address: 1st Floor, Mariners House, Unit A, Trident Court, East Moors Road, Cardiff CF24 5TD
Telephone: 02920 107580
Email: Through the website contact page
Website: www.careandrepair.org.uk

Care & Repair England
For services to help older people in England live independently in their own homes for longer.
Address: Unit 9, The Renewal Trust Business Centre, 3 Hawksworth Street, Nottingham NG3 2EG
Telephone: 0115 950 6500
Email: info@careandrepair-england.org.uk
Website: http://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
For details on accessible toilets that feature hoists and extra space for wheelchairs.
Telephone: 020 7803 2876
Email: changingplaces@musculardystrophyuk.org
Website: www.changing-places.org
Disability Action
For services to help disabled people in Northern Ireland.
Website:  www.disabilityaction.org

DisabledGo
Provides access information on venues around the UK.
Address:  Unit 7, Arlington Court, Arlington Business Park, Stevenage SG1 2FS
Telephone:  01438 842 710
Email:  enquiries@disabledgo.com
Website:  www.disabledgo.com

The Disabled Living Foundation
For a wide range of support and aids for disabled people.
Address:  Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE
Telephone:  0207 289 6111
Email:  info@dlf.org.uk
Website:  www.dlf.org.uk

Euan’s Guide
Website and app where disabled people review venues around the UK and further afield for their disabled access and facilities.
Address:  CodeBase, 38 Castle Terrace, Edinburgh EH3 9DZ
Telephone:  0131 510 5106
Website:  www.euansguide.com

GOV.UK
Online government advice on a variety of topics, including benefits and support for people with disabilities and contact details for local councils.
Website:  www.gov.uk
Inclusive Britain
Website and app that allows you to locate hotels, restaurants, pubs, shops, museums and more, based on your specific access requirements and location within the UK.
Website:  www.inclusivebritain.com

Leonard Cheshire Disability
Supports disabled people around the world to live the life they want to live.
Address:  66 South Lambeth Road, London SW8 1RL
Telephone:  **020 3242 0200** (England)
            **01633 422583** (Wales)
            **028 9024 6247** (Northern Ireland)
Website:  www.leonardcheshire.org

MND Scotland
Provides care, information and research funding for people affected by MND in Scotland.
Address:  2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone:  **0141 332 3903**
Email:  info@mndscotland.org.uk
Website:  www.mndscotland.org.uk

Motability
A scheme that allows disabled people under 65 to lease a car, scooter or powered wheelchair by exchanging their mobility allowance from certain disability-related benefits.
Telephone:  **0300 456 4566**
Website:  www.motability.co.uk
NI Direct
Online government advice on a variety of topics, including benefits and support for people with disabilities in Northern Ireland.
Email: through the website contact page
Website: www.nidirect.gov.uk

Regional Driving Assessment Centre
For assessment if you are older or disabled to work out your driving capability. They can also offer advice on driving adaptions, if required.
Address: The Gee Centre, Holborn Hill, Birmingham, B7 5JR
Telephone: 0300 300 2240
          0121 359 4222
Email: info@rdac.co.uk
Website: www.rdac.co.uk

REMAP
A voluntary organisation making bespoke aids for disabled people.
Address: D9 Chaucer Business Park, Kemsing, Sevenoaks, Kent TN15 6YU
Telephone: 01732 760209
Email: through the website contact page
Website: www.remap.org.uk

The Rough Guide to Accessible Britain
Free downloadable guide to accessible days out in Britain, produced by and for disabled people in association with Motability.
Website: www.accessibleguide.co.uk

Shopmobility
Many large shopping centres and retail parks offer schemes where you can phone ahead and book a wheelchair. Search for Shopmobility online.
**SpecialEffect**
An organisation that uses accessible equipment and technology to help people with physical disabilities play video games.

Address: The Stable Block, Cornbury Park, Charlbury, Oxfordshire OX7 3EH
Telephone: 01608 810 055
Email: info@specialeffect.org.uk
Website: www.specialeffect.org.uk

**Tourism For All UK**
A website that provides information on accessible travel.

Address: 1 Pixel Mill, 44 Appleby Road, Kendal, Cumbria LA9 6ES
Telephone: 0845 124 9971
Email: info@tourismforall.org.uk
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.

Address: North Lodge, Burton Park, Petworth, West Sussex GU28 0JT
Telephone: 01798 342 222
Email: info@wheelyboats.org
Website: www.wheelyboats.org
Further information
We provide the following guides that may be useful:

Living with motor neurone disease
Eating and drinking with motor neurone disease (MND)
Caring and MND: support for you – a guide for carers of people living with MND
Caring and MND: quick guide – the summary version of our information for carers

If there are children or young people in your family, we provide the following guides:

So what is MND anyway? – a guide for young people close to someone living with MND to help them understand the condition better and the support available to them.
When someone close has MND – an activity workbook for children aged four to ten, to help a trusted adult communicate about MND and for the child to explore ways of coping.

Throughout this guide we have highlighted a number of information sheets that provide further information on the areas we have touched upon. You can download them from our website: www.mndassociation.org/careinfo
or, order them in hardcopy from MND Connect:
Telephone: 0808 802 6262
Email: mndconnect@mndassociation.org

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

Or write to:
Information feedback,
MND Association, PO Box 246, Northampton NN1 2PR
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 whose images and quotes are featured in this booklet.
- Lee Millard, for his kind permission to use quotes and images from his blog. See his blog at: www.onein400.com

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

We welcome your feedback

If you would like to provide feedback about our *Making the most of life with MND* booklet, please use our online feedback form at:

www.surveymonkey.co.uk/r/MMObooklet

or alternatively, please contact us at:

infofeedback@mndassociation.org

or by post to:

**Care information feedback,**
MND Association, PO Box 246, Northampton NN1 2PR
“MND has affected my life, but I won’t let it define it.”

MND Association
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Registered Charity No. 294354
Company Limited by Guarantee No. 2007023
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Created: 11/17 Next review: 11/20 Version: 2

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