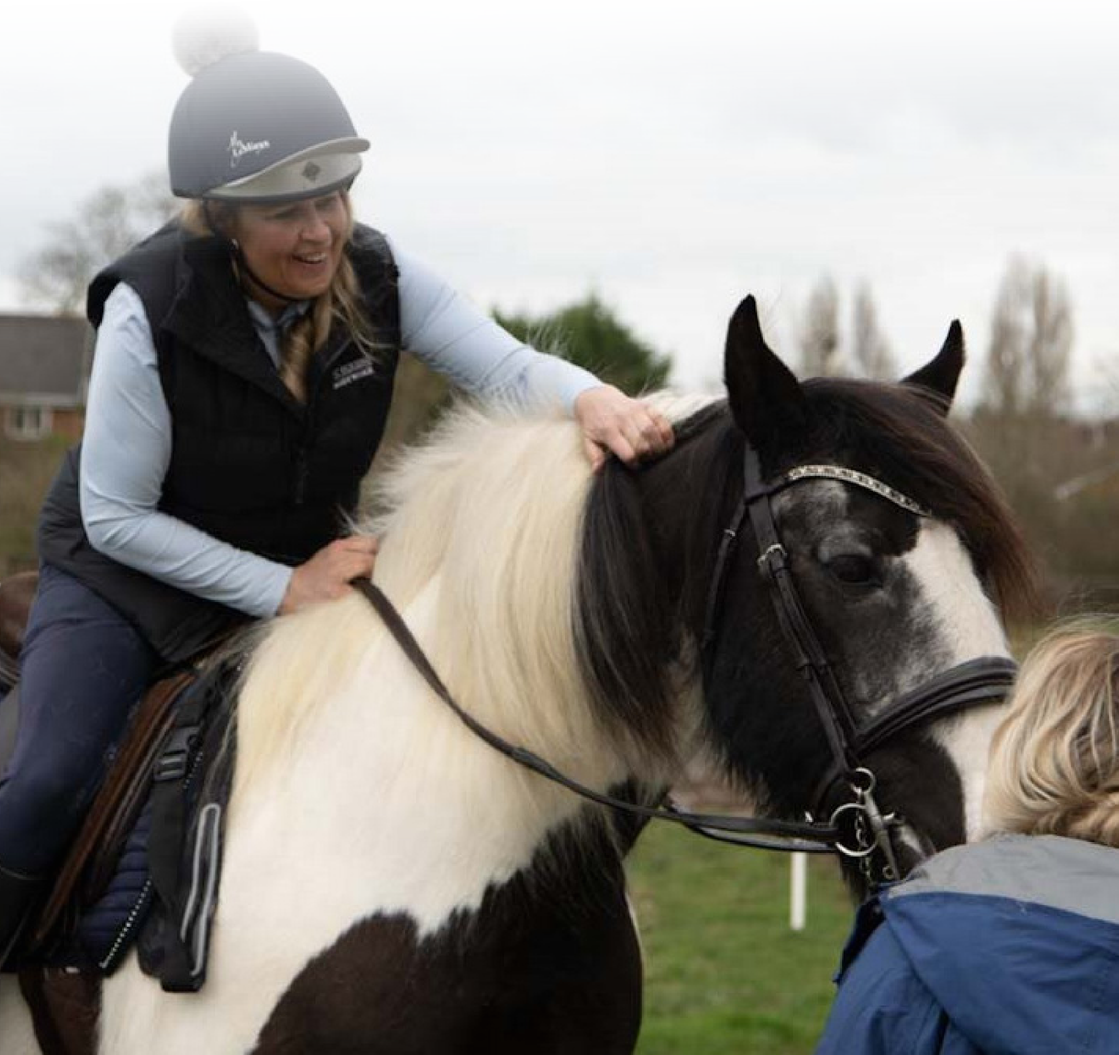
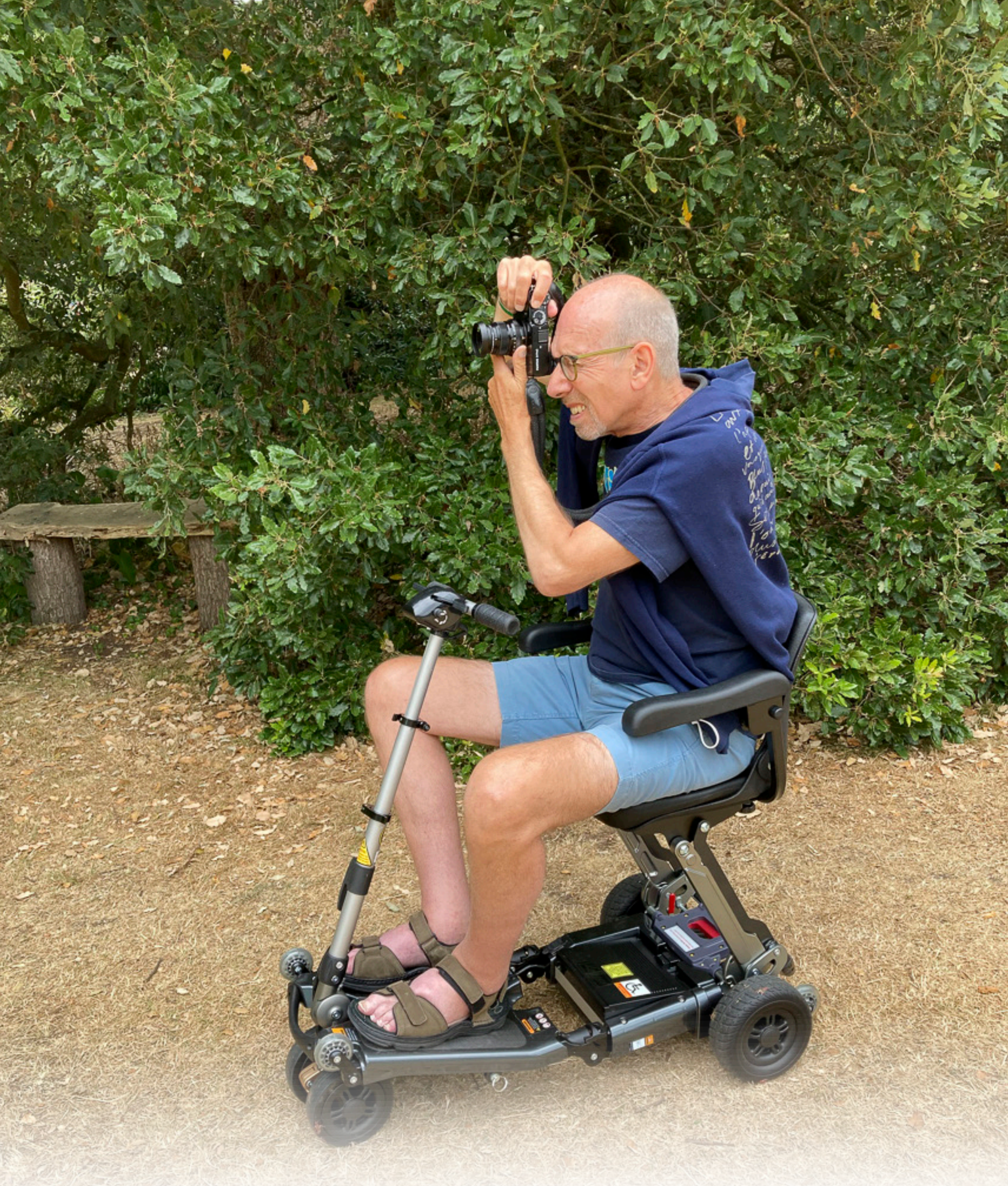
motor neurone disease
association

Making the most of life

with motor neurone disease or Kennedy's disease





“I am a very keen photographer ... Being able to position myself to take pictures has once again made photography manageable and enjoyable for me.” Nigel

Contents

See *Further information* at the end of this booklet to find out more about ordering our resources.

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

Trusted Information Creator
Patient Information Forum

This information has been evidenced, user tested and reviewed by experts. https://piftick.org.uk

How can this booklet help me?

With motor neurone disease (MND) or Kennedy's disease, mobility and movement are usually affected and you may also get very tired. This can affect everyday routines, your social life, interests and hobbies.

Take time to adjust after diagnosis, but finding new ways to do things can help you continue to do what you enjoy or find new activities.

"I need help finding new interests with examples."

It would be impossible to list the huge number of hobbies and interests available, but others living with MND have shared experiences in this booklet. Knowing where to begin may help you find the support you need.

Ask your health and social care professionals for guidance, as they can help you find ways to adapt.

Further information

Download our resources from our website at:
www.mndassociation.org/publications

or using our care information finder at:
www.mndassociation.org/careinfofinder

You can also order printed copies from MND Connect:

Telephone:	**0808 802 6262**
Email:	**mndconnect@mndassociation.org**

1 How might MND or Kennedy's disease 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. You're likely to get tired if things take more effort and energy. Some people also have 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 *Living with motor neurone disease* guide for a complete overview of MND. If you are living with Kennedy's disease, see our *Kennedy's disease* booklet.

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.

With MND, maintaining your interests can help your wellbeing, but you may need to do things in new ways.

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

> **“I have done a lot in 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.”**

Your activities may take a little more planning with MND. You may need to take things slowly, get involved in a different way or accept support. For example:

Using computers and devices: may be easier with adapted switches or voice recognition apps. Some software enables you to use eye movement to operate a screen.

Walking and running: may feel safer with a walking or running partner if your mobility is affected. Walking aids help as symptoms increase. Look out for accessible walking routes for outdoor powered wheelchairs or mobility scooters.

Events, sports or social clubs: may feel less appealing if it’s harder to join in, but you can still attend to support others. This helps you maintain social contact with others who share your interests.

How can equipment and adaptations help me?

> **“I remain determined to get on with my modified life... my outlook, by neccessity, 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. It could free up time and energy for you and your family, friends, or carer to continue enjoying your hobbies and interests.

See our *Personal care* booklet and our information on equipment, wheelchairs and environmental controls.

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 powerered 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.”**

Your needs with MND are likely to change. 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 for free, or on loan from the NHS or adult social care services.

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

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.

Planning ahead helps with larger items of equipment and home adaptations, as they may take time to arrange.

See *Further information* 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.

Does MND affect thinking and behaviour?

Thinking and behaviour may be affected for some people with MND. Although this doesn't usually affect daily living or decision making, these changes can be more severe. This makes it harder to do things, but health and social care professionals can help with assessment, guidance and extra support for these needs.

See our booklets:

- *Emotional and psychological support*
- *Changes to thinking and behaviour.*

Support from health and social care professionals

When seeking help with symptoms, treatment or personal care, your health and social care professionals can provide wider guidance too. Let them know how MND or Kennedy's disease impacts on your social life and interests. They may be able to tailor their support.

We have suggested relevant professionals in this booklet. Ask your GP or another member of your health and social care team about referral to a specialist, if needed. They can help you get an appointment.

How do I get my needs assessed?

Adult social care services can assess your needs with MND or Kennedy's disease, or as a carer.

The assessment explores support services, but your social needs and interests are also part of this discussion.

The assessor may be able to provide local guidance to help you.

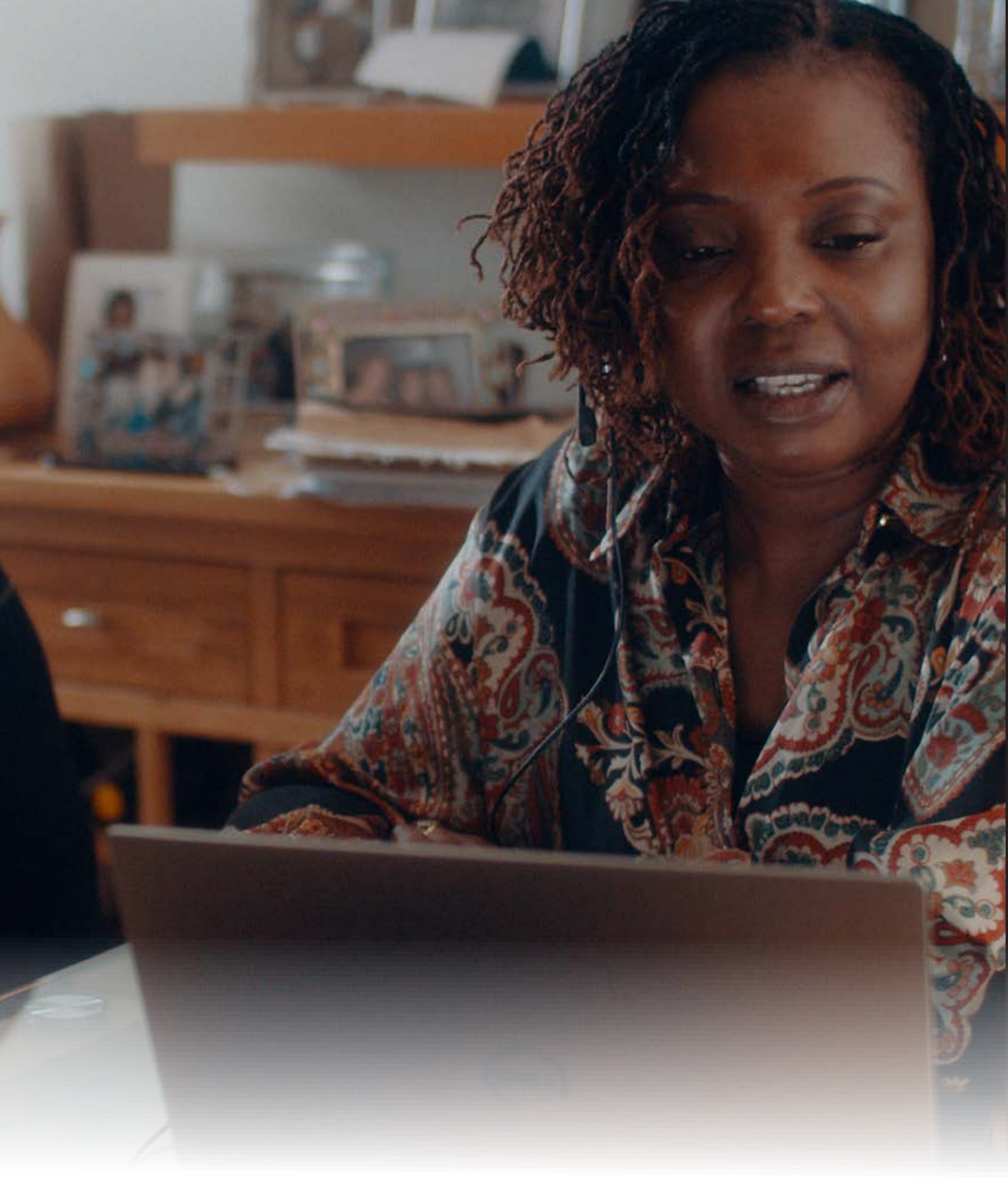
To arrange an assessment:

In England and Wales, contact your local authority:
www.gov.uk/find-your-local-council

In Northern Ireland, contact your local health and social care trust:
Search for health and social care trusts at: **www.nidirect.gov.uk**

In Scotland, contact your local council:
www.careinfoscotland.scot/find-my-council

See our booklets on *Personal care* and *Types of care* for more guidance, and information sheet 10B *What is social care?*



“Because I’m quite a character with my friends and family, if my voice goes and I’m using the banked voice...my family and friends will immediately recognise it as me, which is just so important.” Yvonne

Communication and having conversations

With MND or Kennedy's disease, you may experience changes to the way you speak and communicate. You may find conversations harder or more tiring. This can 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 setting like a pub.

You may be able to record or 'bank' your voice before it is largely affected, to create a computerised version of it. This can 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."**

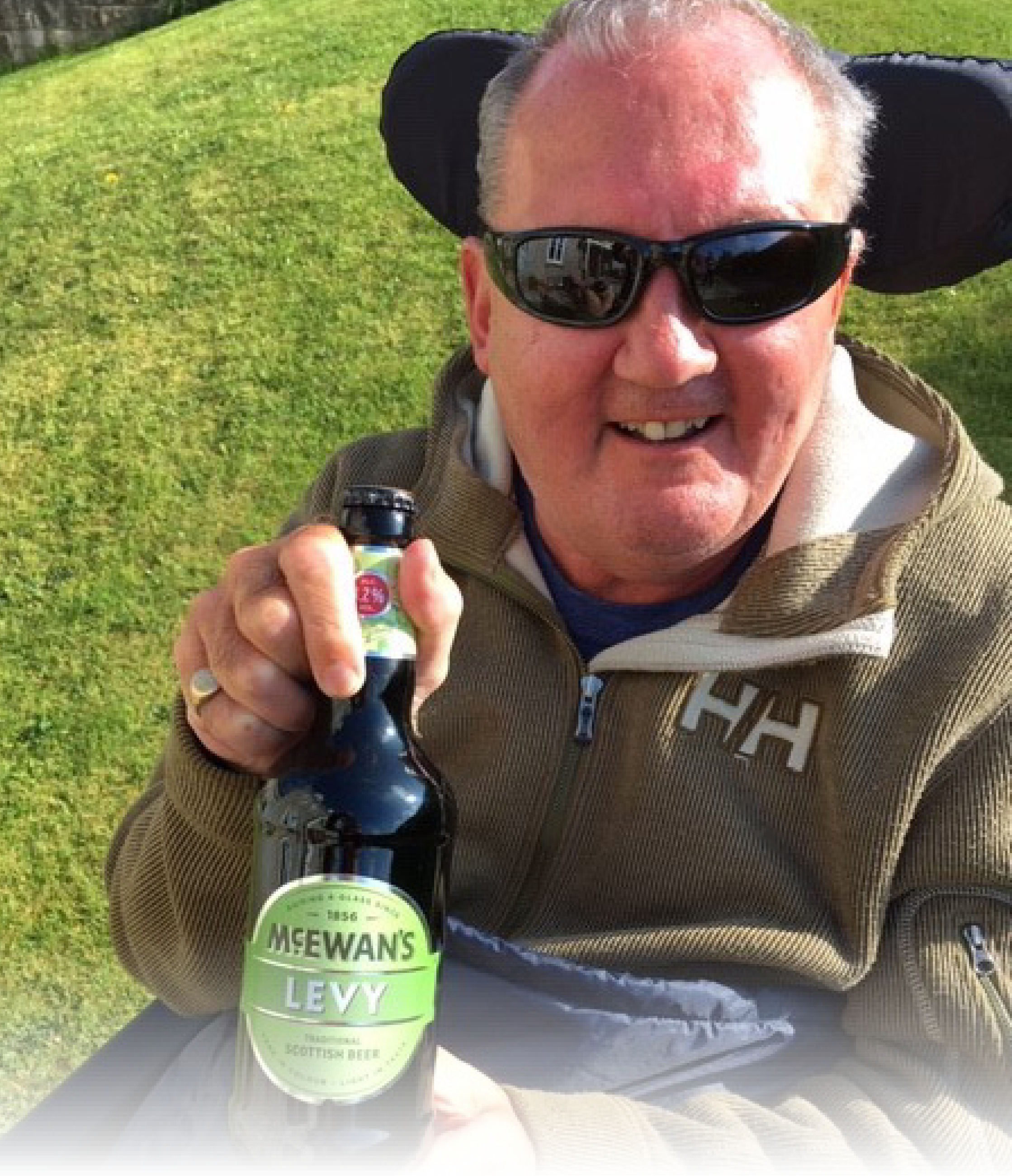
See our resources:

- 7C - *Speech and communication support*
- 7D - *Voice and message banking*
- *What is voice and message banking?* animation
- on environmental controls.

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.

Our MND Connect service can also support you by providing guidance on services and equipment, including information and support with voice banking.



“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

With MND, and sometimes with Kennedy's disease, you may have swallowing difficulties and restricted movement. These symptoms can get worse over time and affect how you eat and drink. Clearing saliva can also become difficult. Keep well nourished and 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 resources:

- *Eating and drinking with MND*
- 7A - *Swallowing difficulties*
- 7B - *Tube feeding.*

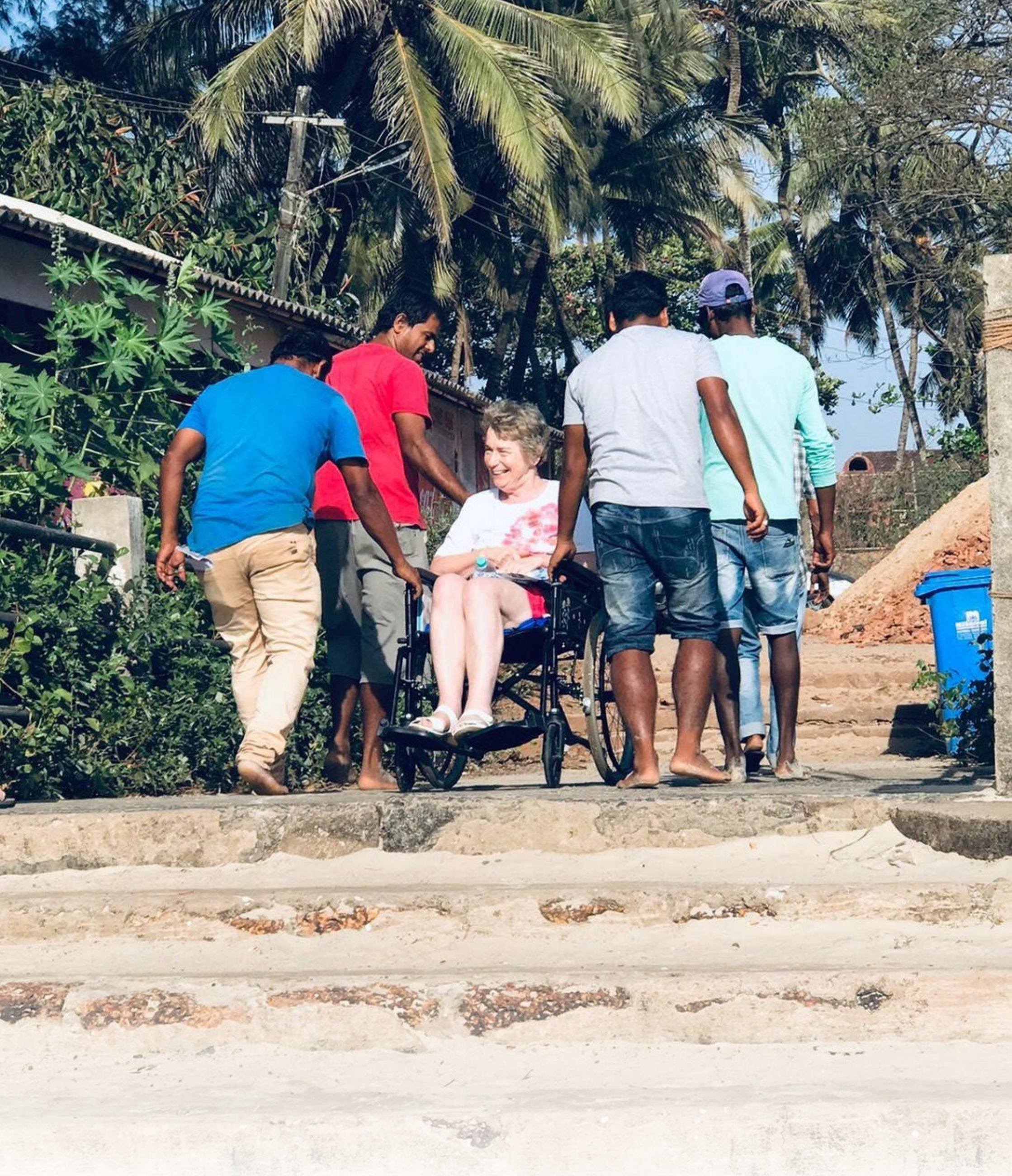
Ask your health and social care team for information about tube feeding. Being fully informed about your options can help you make timely decisions that are right for you.

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.

An occupational therapist can advise on posture, equipment or aids that may be able to help with eating and drinking.



“I was diagnosed with MND almost 10 years ago and although I can’t speak and can’t walk unaided, we cope quite well. We’d travelled a lot to India... We’ve been over 30 times.” Christine

Getting around to do things

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 our information on equipment and wheelchairs.

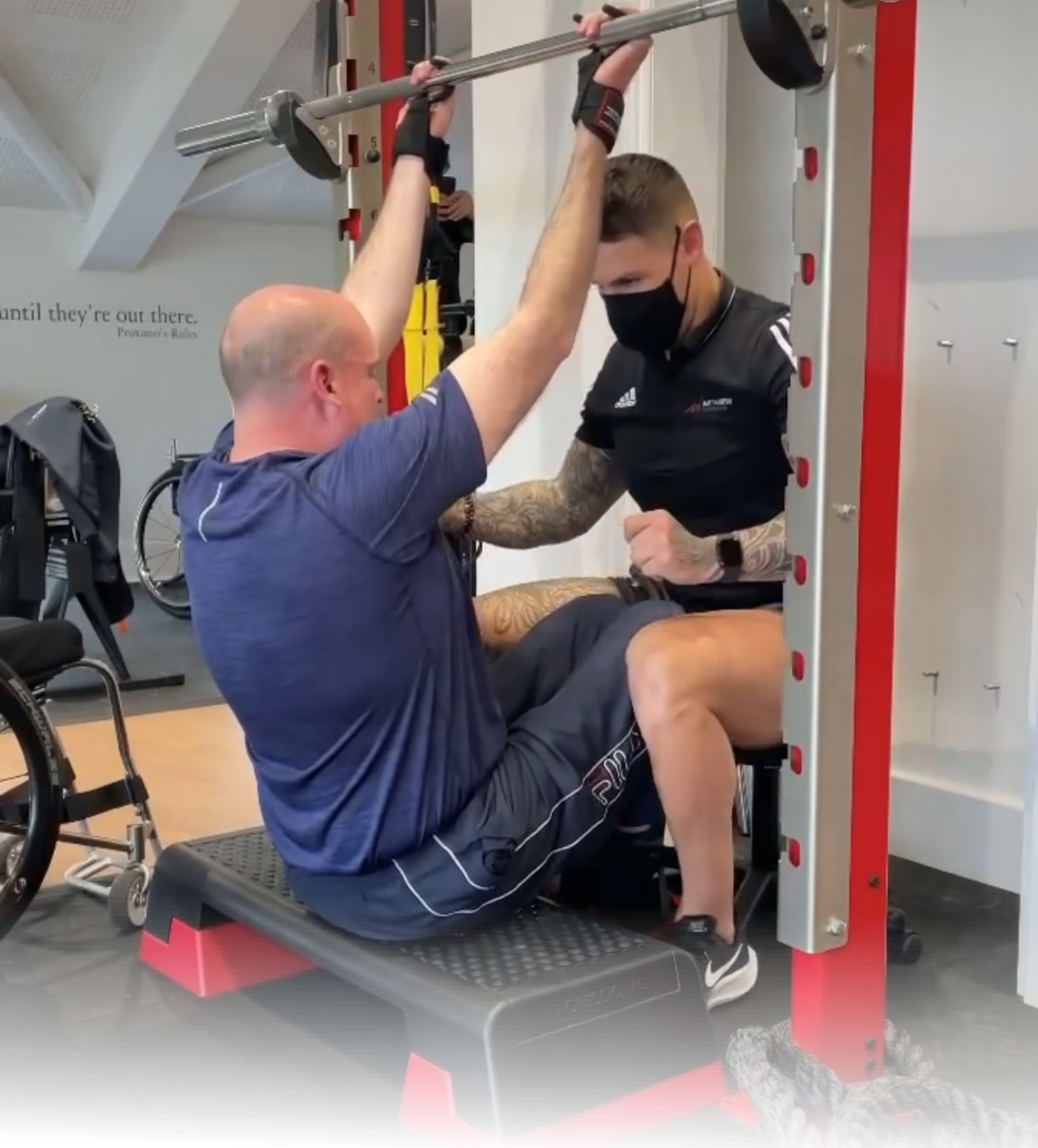
Who can help?

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.



"My wrists and forearms are thin and my hands don't function as they used to, but there are still ways of cracking on and doing everything that I did before. It's just a case of finding a different way to do them. I notice that the weakness becomes more evident when there are large gaps between exercising. " David

Using your hands

Muscle weakness 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, environmental controls and voice control technology can help if your arms and hands are affected. Accepting assistive 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 accessible activities near you.

Who can help?

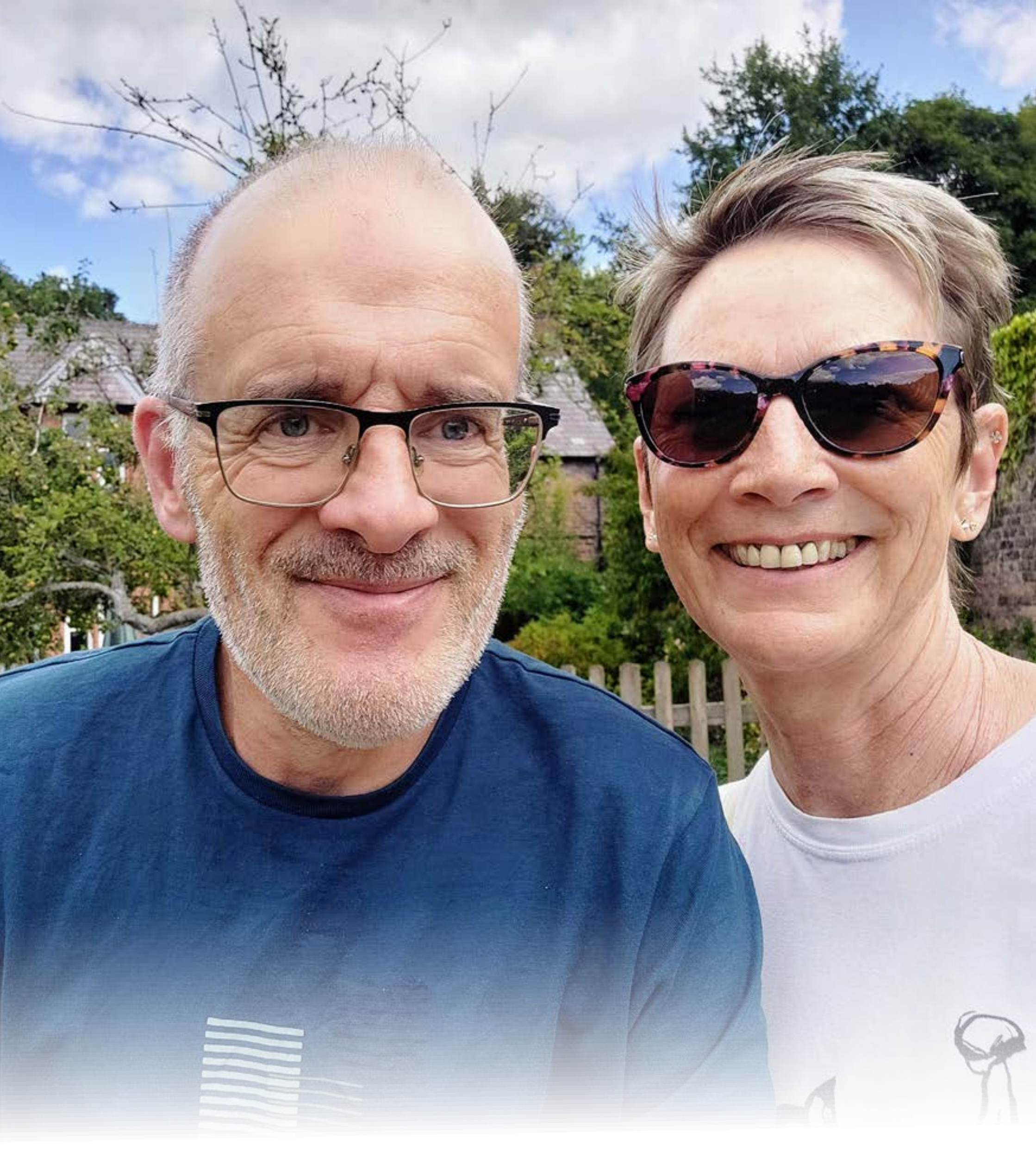
A physiotherapist can assess your needs and advise on exercise or assisted exercise. This cannot reverse symptoms, but helps maximise movement in muscles not yet affected by MND or Kennedy's disease.

An occupational therapist can assess your needs and advise on any equipment or aids. They can 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 tips on how they approach problems with hand movement and grip.

See *Further information* on how to meet other people living with MND and our online forum.



“It must be hard for him to wake up every day with a mask on his face, but it’s working as his carbon dioxide levels have gone down. Simon hasn’t really been suffering with tiredness, the NIV was needed because his breathing changes when he goes into deep sleep.” Donna

Breathing support

If your breathing is affected by MND or Kennedy's disease, it may impact on your sleep and energy levels. It can 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 started with just using NIV for an hour each day and slowly increased and so found it easy when I used it all night."**

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.

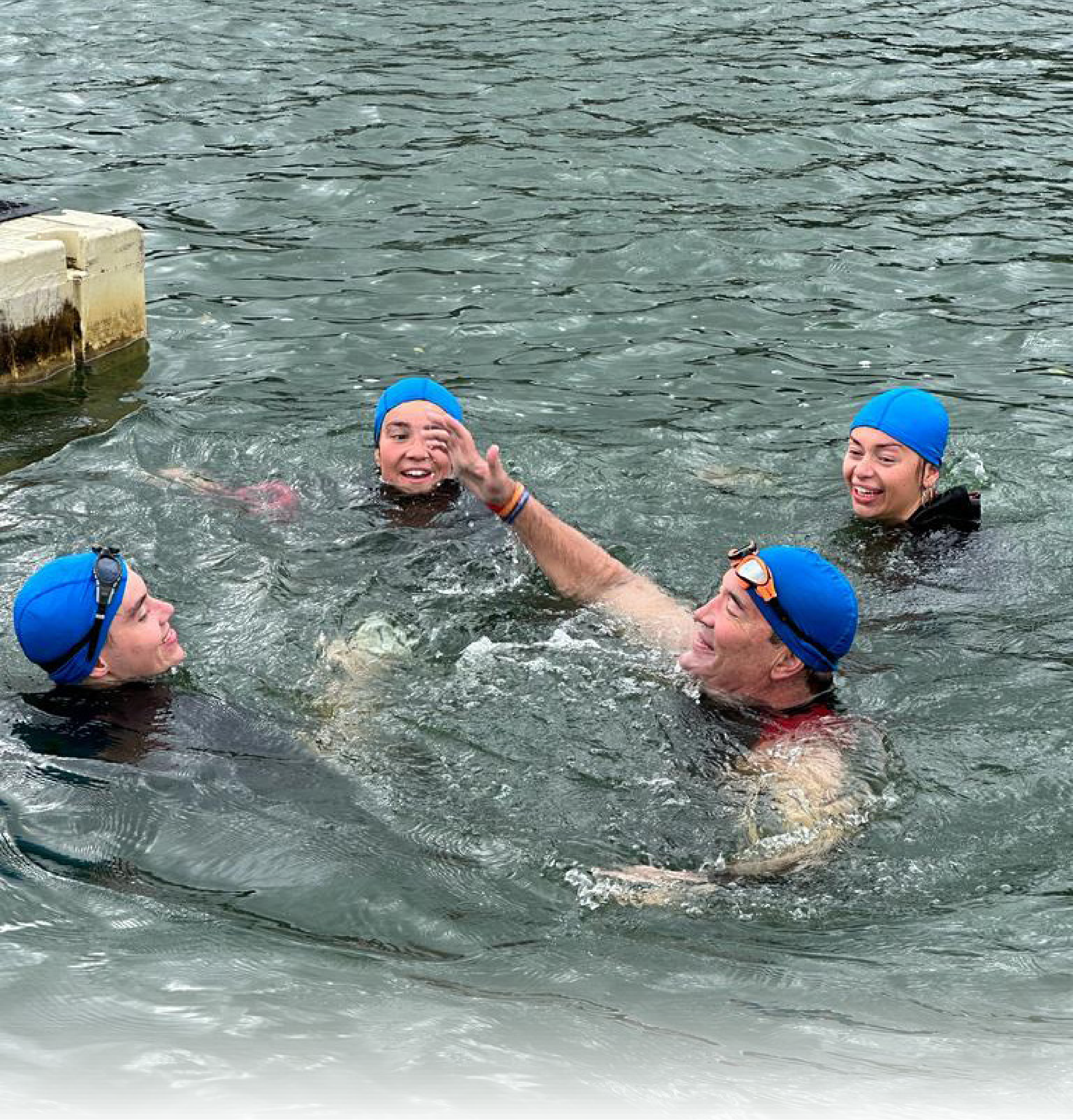
See information sheets 8A-8D on breathing support.

Who can help?

A respiratory consultant can assess your breathing and advise on techniques, treatments or therapies.

A physiotherapist can advise on breathing exercises.

An occupational therapist can advise on positioning and support aids to help breathing.



“I think also understanding that it’s okay to have a bad day. Sometimes when you wake up in the morning, you’re not sure how you’re going to feel, regardless of how much sleep you get. And it’s mentally getting to that place where it’s okay to have a sofa day, it’s okay to be tired. That took a long time to get used to that.” Mark

Saving energy

With MND or Kennedy's disease, you may feel extreme tiredness following an activity or even while resting. This is known as fatigue and may happen with muscle weakness, breathing problems or disturbed sleep. This type of tiredness can impact on your work, relationships and social life.

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.

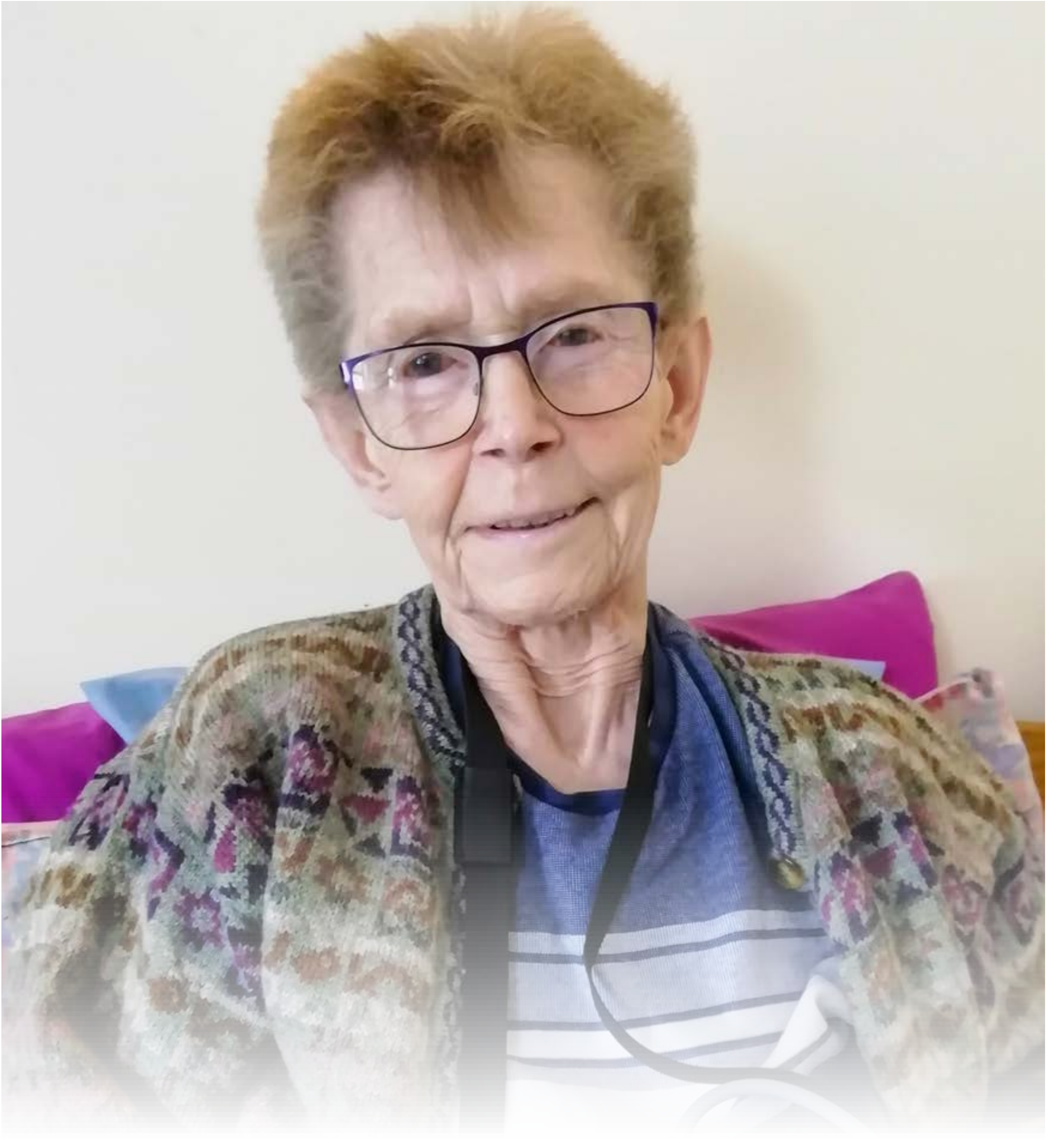
> **"It's important to emphasise – pick activities you enjoy against activities you feel obliged to take part in."**

Who can help?

Professionals who help with symptoms related to tiredness will advise on fatigue and sleep too.

An occupational therapist will also give you support on fatigue as well as support on equipment that can help make things easier.

See our *Personal care* booklet for more on fatigue.



“I can’t tell you the gratitude I felt after the first support group meeting with the Oxfordshire Branch and meeting people who devote their lives to helping others and being able to laugh together. Even if you have this dire disease, you can still have fun and tell jokes.” Ellen

Staying positive

You may feel a range of emotional challenges following your diagnosis, which can lead to anxiety. You may also experience emotional lability with MND, which causes responses that don't match your emotions, like laughing when you feel sad. You may be tempted to avoid social events or 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."**

Sharing your emotions can help loved ones understand and support you better, and share their feelings too. Doing things you enjoy helps lift mood, such as listening to music or spending time in the garden.

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?

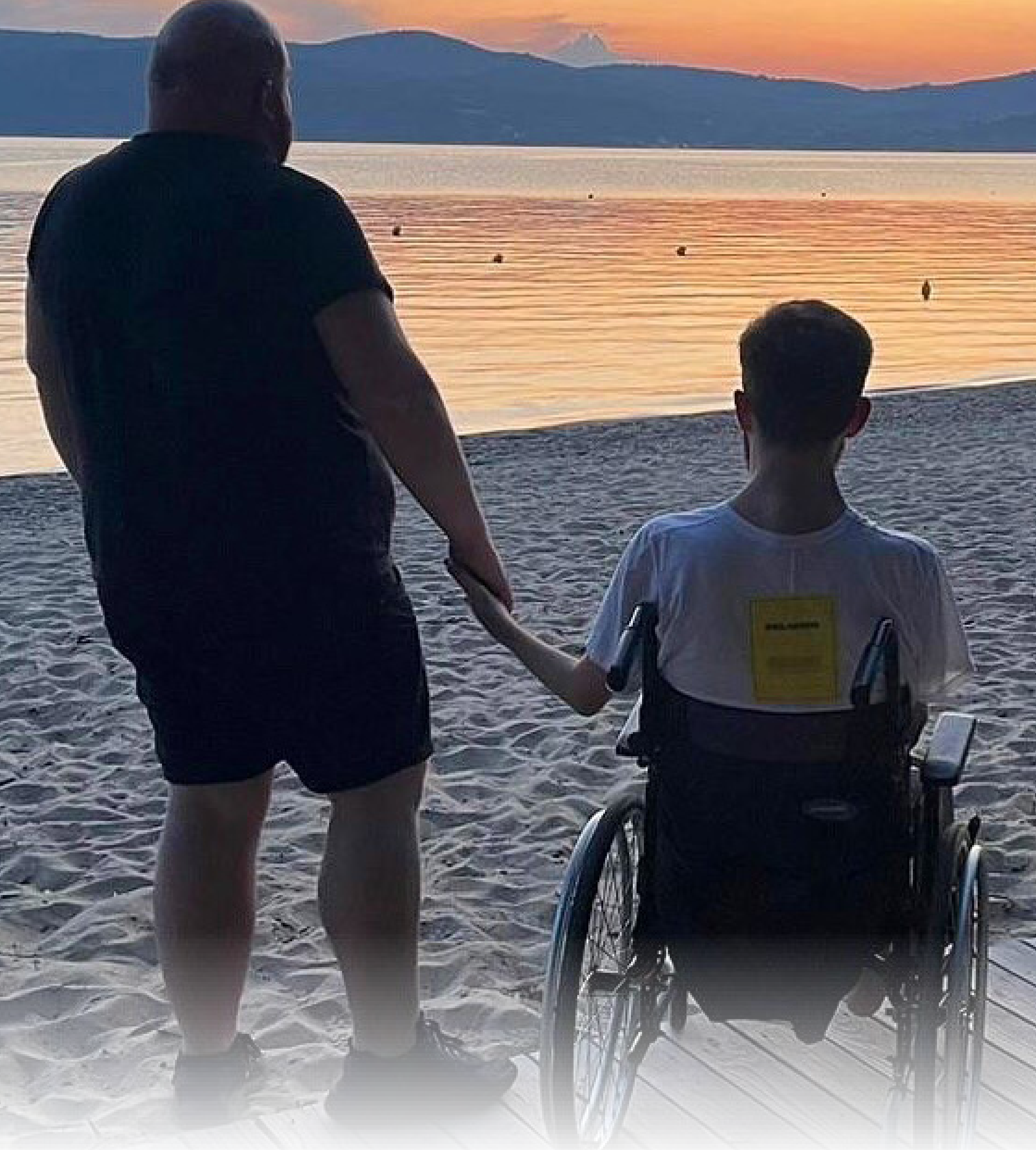
Your GP and other professionals can refer you to therapies or advise on medications that may help.

A psychologist or counsellor can help you work through emotions.

A complementary therapist offers therapies that work alongside traditional medicine to ease symptoms and anxiety.

See our booklets:

- *Emotional and psychological support*
- *Telling people about MND.*



“Me and my husband and my parents went to Iceland in 2022 and when we booked that we weren’t sure if I was going to be able to do much, but when it came around to it, I went on hikes, and it was fun. That was a really nice trip to go on. We got to see the northern lights. Then we decided to get married.” Mark

Staying connected

You may find roles or sense of purpose change in family and social circles, due to the challenges of MND or Kennedy's disease. If your partner is your main carer, you may worry about the affect on your relationship or intimacy. Spending time with family and friends can also be more tiring.

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 helps children and young people too, as clear explanations can help them feel included and supported, and avoid confusion.

See our booklet, *Telling people about MND* and *Further information* for resources for children, young people, parents and guardians.

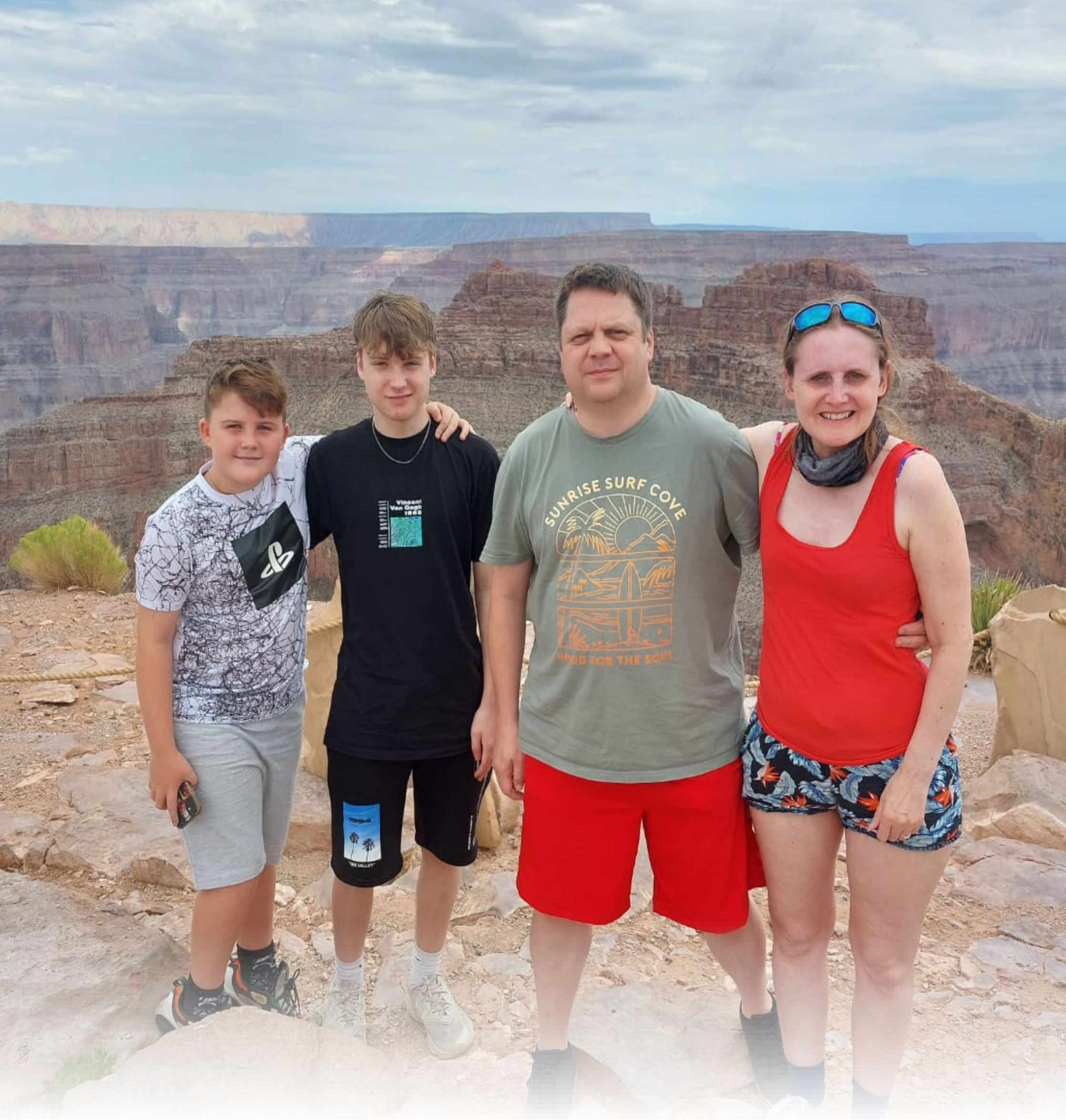
You may feel like withdrawing from social situations as your symptoms become more obvious. However, spending time with others is positive for wellbeing. Take part in social gatherings for as long as this feels right for you. Let others know the best time of day to visit, and if any activities need to be adapted for you.

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

Who can help?

Ask your healthcare team for guidance if your relationships are affected. They may have advice, tips or links to local organisations.

See section 3 *Where can I get support?* for guidance on finding shared experiences with others affected by MND or Kennedy's disease.



“My manager told me to take a couple of weeks off around the diagnosis period, and I did... Following my time off, it was agreed with my GP that I need to be signed off work due to my caring responsibilities ... Luckily, I’d had the foresight to get critical illness cover in place as well.” Gareth

Work and employment

If you work, this may form a large part of your identity, sense of purpose and standard of living. You may wish to stay at work for as long as possible. Choosing to leave may depend on your symptoms or a wish to explore other areas of your life. As a carer, you may also be thinking about how to balance this with employment.

> **“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.

Explore your options, such as the Access to Work scheme, taking paid or unpaid leave, flexible working or early retirement. Take time on major decisions as one may affect another. For example, early retirement may affect how you claim for any benefits.

See information sheet 10E - *Work and MND*.

Who can help?
Your employer can help you with options to stay at work or leave in a way that feels right for you.

Your health and social care professionals, such as an occupational therapist, can assess your ability to work and help you save energy.

An independent financial adviser can help review your finances and options before leaving work.

See section 4: *How can the MND Association help me?* for details about our Benefits Advice Service.

3 Where can I get support?

Your main contacts will likely include:

Adult social care services: for assessment of your needs and those of your carers. Contact your team through your local authority or council in England, Wales and Scotland, or your local health and social care trust in Northern Ireland. They may also be able to advise on assisted activities in your area, with directories of services.

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

GP: for guidance, symptom management and medication, and referral to specialist services. GPs may also be able to advise on community contacts for disability support.

Health and social care professionals: provide a range of support, often through a multidisciplinary team for co-ordinated care and linked services. MND care centres and networks (part-funded by the MND Association) and local neurological services offer specialist help. Specialist palliative care teams and hospices also provide a wealth of services and activities to support quality of life. Social care professionals aim to improve your daily life at home, including helping you to maintain your interests and social connections.

See our booklet *Types of care* and information sheet 3D - *Hospice and palliative care*

Clubs and societies: provide experiences, social events and a chance to share ideas. Find groups near you through your local authority or council in England, Wales or Scotland, or your health and social care trust in Northern Ireland. Many are 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. Search for *accessible activities* at: **www.nhs.uk** for some examples of reputable websites for disabled people.

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.

Other people with or affected by MND and Kennedy's disease: are likely to face similar challenges and can offer you support and knowledge. MND Association branches and groups and local organisations 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.

See *Useful organisations* in section 4 *How do I find out more?*

"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'."

4 How do I find out more?

Useful organisations

We don’t endorse organisations, but these may help your search or see: **www.mndassociation.org/usefulorgs.** If you need help to find services where details have changed, contact our MND Connect helpline.

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**

Ceiling Hoist Users Club

For holiday accommodation details containing a ceiling track hoist.
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**

National information
Online government or national guidance for disabled people.
Website: **www.gov.uk** (England and Wales)
www.nidirect.gov.uk (Northern Ireland)
www.mygov.scot (Scotland)

Leonard Cheshire Disability
Supports disabled people around the world.
Telephone: through website contact page
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**

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 communicates your needs to venues before you arrive:
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**

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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)
Living alone with MND or Kennedy's disease
Caring and MND – Support for you
Personal care
Eating and drinking with MND
Types of care
Getting around
Emotional and psychological support
Telling people about MND
Changes to thinking and behaviour with MND
Sex and relationships with MND
MND Checklist
Understanding my needs
What you should expect from your care

For children, young people, parents and guardians:
www.mndassociation.org/cyp

Download our resources from our website at:
www.mndassociation.org/publications

or using our care information finder at:
www.mndassociation.org/careinfofinder

You can also order printed copies from MND Connect:

Telephone:	**0808 802 6262**
Email:	**mndconnect@mndassociation.org**

MND Association Benefits Advice Service
Find details at: **www.mndassociation.org/benefitsadvice**
or contact MND Connect.

MND Association online forum
Our online forum is a safe place to share experiences and ideas with other people living with or affected by MND. You can access the forum at: **https://forum.mndassociation.org**

Our financial support
We provide a range of financial support for care needs, quality of life, carers and young people. Some applications 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/financialsupport**

We welcome your feedback

Let us know what you think of this booklet at:
www.smartsurvey.co.uk/s/Makingthemostoflife
or email your comments to: **infofeedback@mndassociation.org**
or post to Infofeedback at the address shown below.

Your anonymous comments help us share real MND experience and raise awareness in our resources, campaigns and applications for funding.

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