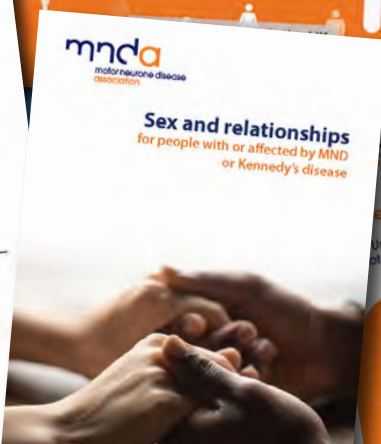
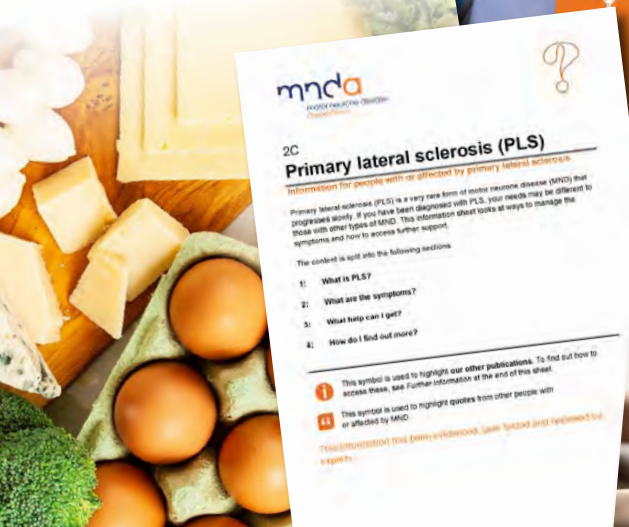
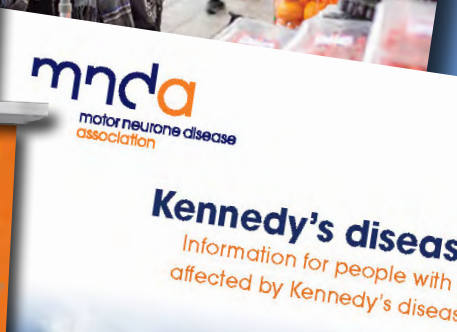
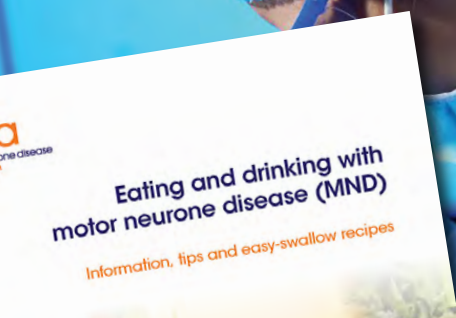


# Care information Review 2024

For people living with motor neurone disease (MND)  
or Kennedy's disease, their families and carers





## Welcome to our yearly information review and what a packed edition for 2024.

A great deal has been accomplished, with an extraordinary number of revisions, new launches and web page improvements for our care information.

***“People living alone might be fiercely independent and not know how to ask for help. Or they could be lonely and overwhelmed. Pointing people to advice in a safe environment is key to their future quality of life.”***

Person affected by MND on our new booklet: *Living alone with MND or Kennedy’s disease*

Our aim with our care information resources is to help everyone affected by MND or Kennedy’s disease feel informed and supported, without bias or opinion.

This can help people diagnosed with the conditions make informed decisions, that feel right for them as individuals and for their loved ones.

We hope this intent is reflected in these pages, for our guidance on healthcare, social care, practical support or quality of life.

**We couldn't achieve the work we do without the support of people with MND, Kennedy's disease, their families and carers. So many share their insight and experience to help with our information.**

We're incredibly grateful – especially to our User Review Group who give so much, each and every year.



Another huge thank you to the many health and social care professionals who help us.

Our **Community of Practice** brings together professionals with a special interest in MND who educate and raise standards of care, and help review our content. We learn from their guidance, as led by their patients. It's reassuring to see a shared desire for clear and accessible information, with inclusive language and empathy.

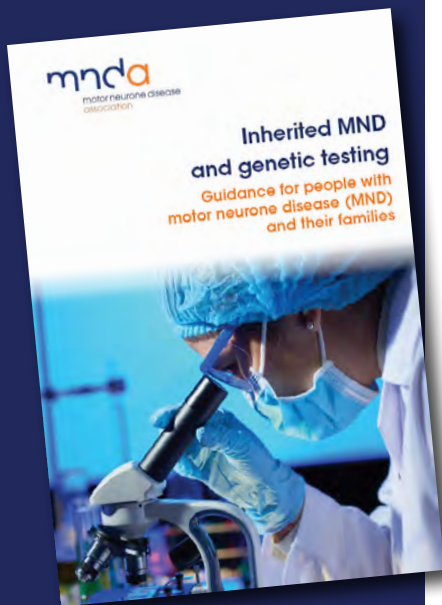
We maintain a strong relationship with the **Patient Information Forum**, as successful members of their national PIF Tick accreditation. They assess our process to help our development of quality assured resources.



Our wider MND Association colleagues and volunteers also support us. Their interactions with our membership, external services, and health and social care systems, add much value to our content.

**Collaboration is vital. As information specialists, we seek feedback to ensure our content is both accurate and effective. We can only improve and grow through listening to you all.**

**Thank you**



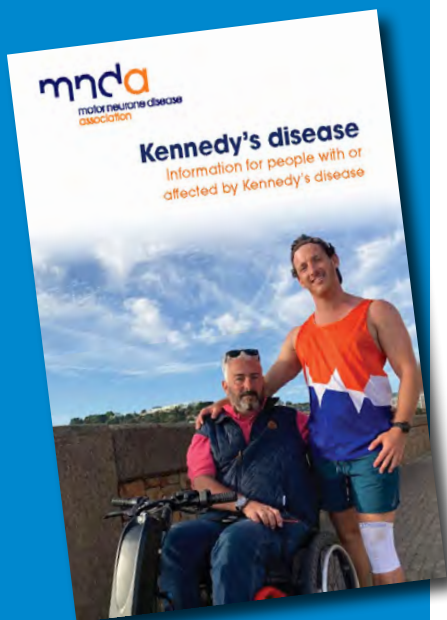
# New work in 2024

## Inherited MND and genetic testing booklet

Launched in April, this popular resource required a reprint within the first month. *Inherited MND and genetic testing* explores how genetic counselling can help prepare people for the possibility of genetic testing, whether they have been diagnosed or have a blood relation with MND. Watch out in January 2025 for a companion overview, with our new animation *What is genetic testing?*

***"I think the booklet is well set out. It is clear and informative without being frightening."***

Person affected by MND

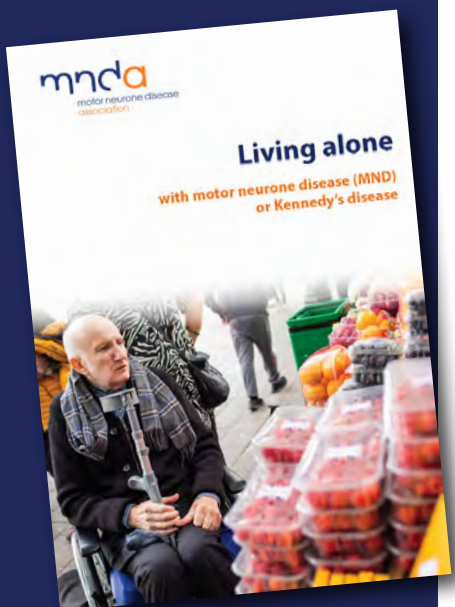


## Kennedy's disease

Kennedy's disease is a rare genetic disorder that affects motor neurones. Although not strictly a form of motor neurone disease, the MND Association supports people living with or affected by Kennedy's disease. Developed with support from people affected by this condition and the Kennedy's Disease Clinic in London, this booklet replaces our previous information sheet.

***"It is very clear, engaging and packed with useful information."***

Dr Louie Lee, Clinical Specialist Neuromuscular Physiotherapist, University College London



## Living alone with motor neurone disease or Kennedy's disease

This overview explores the likely emotional and practical challenges for people living alone with these conditions, to help them plan ahead. We are grateful to our target audience for their input and the national project on living alone with neurodegenerative disease and dementia, led by the NIHR Policy Research Unit in Dementia and Neurodegeneration (DeNPRU Exeter).

***"It shows there is a lot of help out there and you're not alone if you're prepared to open the door to support."***

Person with MND

## Eating and drinking guide

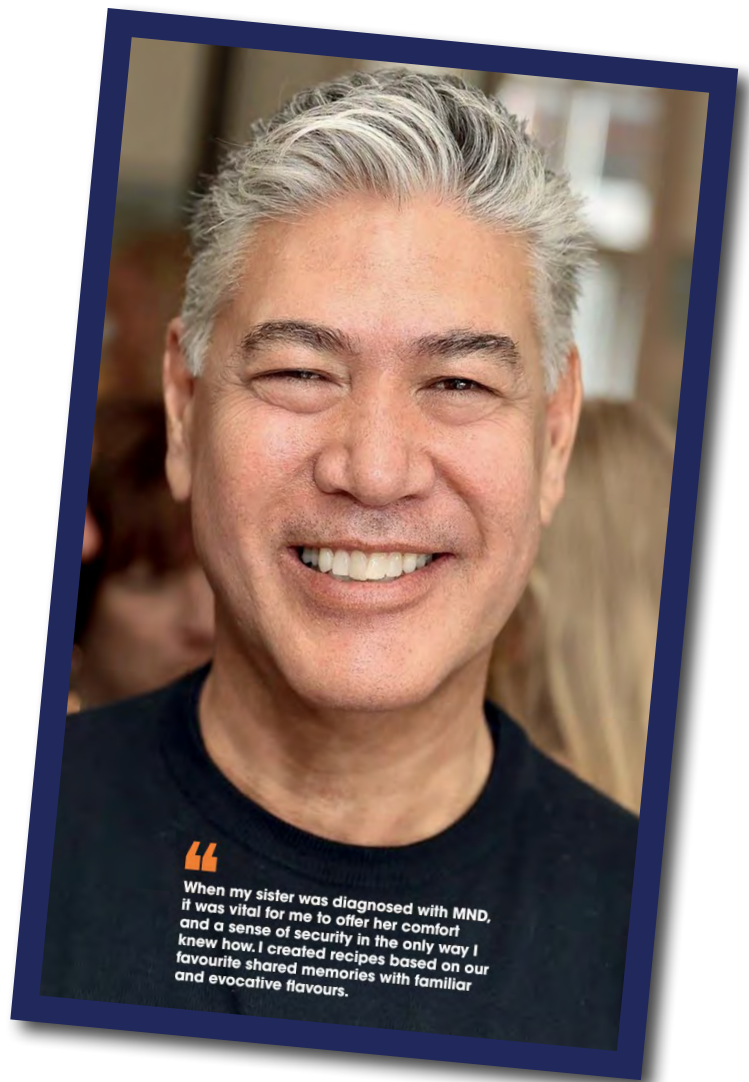
We gave our popular Eating and drinking guide (and companion web app) a refresh this year.

It now includes more recipes from around the globe and all our dishes are provided by affected families, health professionals and television chefs.

Our new version has a foreword and featured recipe from celebrity cook Jonathan Phang, who helped care for his sister with MND.

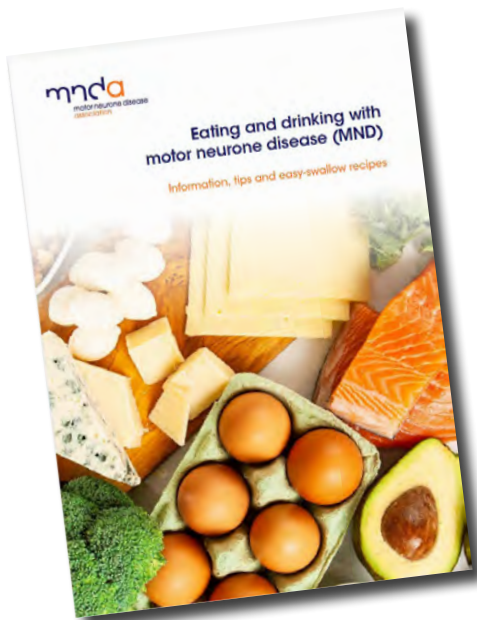
He feels that the guide, "is an essential support to MND carers and a creative and resourceful cookbook you will treasure forever."

*Thumb Print membership magazine article - Autumn 2024*



The guide has been endorsed by The British Association for Parenteral and Enteral Nutrition, BAPEN:

***"This is a wonderful resource which will be hugely helpful for those with MND, family, carers and healthcare professionals – BAPEN are delighted and proud to endorse it."*** Nick Thompson, BAPEN President



As well as the recipe range, the content explores eating out, food preparation, different consistencies and how to maintain weight with swallowing difficulties.

***"Amazing collaborative resource – well done!"***

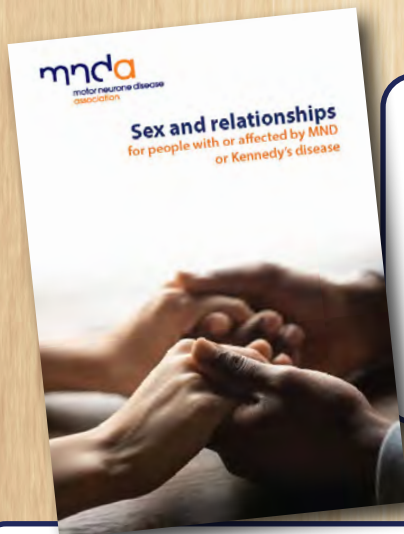
Carer supporting a person with MND

***"A fantastic book. So much more than just recipes. As one who suffers with chewing and swallowing, section 2 – 'Will my diet need to change with MND?' was just brilliant. Thank you."***

Person with MND

# Updated resources

We have updated the following resources in 2024 to ensure they remain fit for purpose:



## Guides and booklets

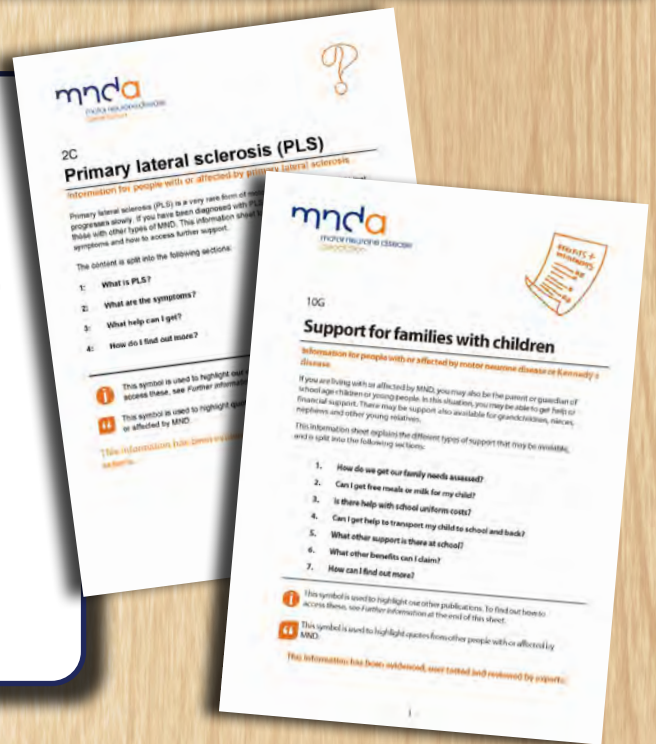
- What you should expect from your care - pocket guide
- Sex and relationships booklet
- Eating and drinking guide (see previous page)

We are also currently redeveloping our End of life guide.

## Information sheets

- 1D - How we use your information
- 2C - Primary lateral sclerosis (PLS)
- 2D - Progressive muscular dystrophy (PMA)
- 3D - Hospice and palliative care
- 6B - Complementary therapies
- 7A - Swallowing difficulties
- 10A - Benefits and entitlements
- 10E - Work and MND
- 10G - Support for families with children

Several other sheets are currently under review and will also be relaunched in early 2025.



## Other resources

- Publication order form
- MND Checklist (both in print and online)

# Our online work

We have been busy on our care information web pages too.

We've developed a new page to give easy online access to our *MND Checklist*, to match the revised print version.

Updates have been made to:

- our introductory animation, What is MND?
- various information web pages
- our Care information finder to help you search for resources by need:  
[www.mndassociation.org/careinfinder](http://www.mndassociation.org/careinfinder)



## Care information finder



We've also worked hard to make our web page on *Languages and other formats* more accessible.

Each drop down option now enables the reader to find their specific language and when opened, provides an introduction to the translation service in the selected language.

[www.mndassociation.org/languages](http://www.mndassociation.org/languages)

Work continues on a new digital version of *Understanding my needs* – our form to help guide your care. Development has been extended to ensure safeguards around security of personal data.

# Engaging with our readers

Our User Review Group members are all living with MND or Kennedy's disease, or they are carers or former carers.

Their experience helps us develop and improve our information. They've helped with a range of resources this year, including new booklets, our *MND Checklist* and more.

We also meet people at events, hold interviews with user mentors, liaise with our Association personal stories specialist and look carefully at wider feedback, website responses and other MND Association surveys.

Without lived experience, our information would be just facts. With insight, it becomes identifiable, and covers aspects that might otherwise have been missed.



## In 2024...



we sent out

**33,000**

printed publications  
for care information



with another

**32,000**

downloads of our  
resources from our website.

### How to get involved with our information

We welcome new members to our User Review Group. Our only requirements are:

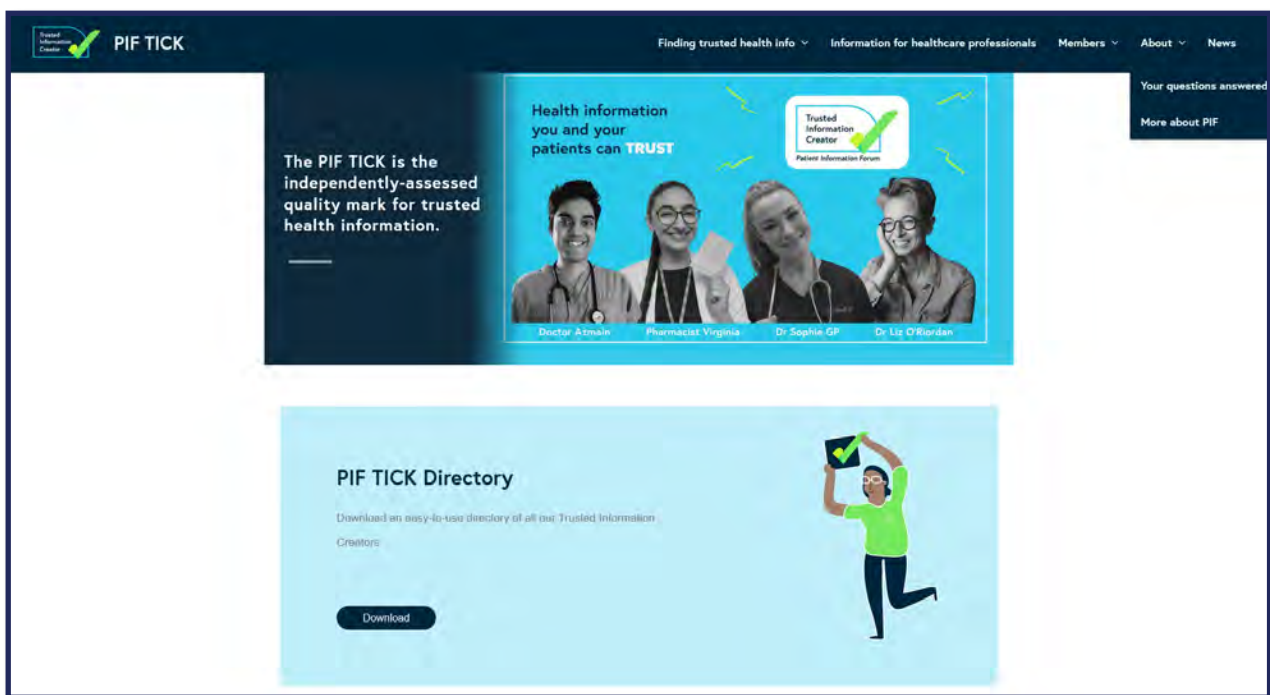
- you are living with MND or Kennedy's disease, or you are a carer or former carer for someone of either disease
- you have access to email and internet.

A range of opportunities are provided each year to feed into different content and formats. Pick and choose which tasks you want to work on and make a difference from the comfort of your own home.

Contact: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)



# What's new with the PIF Tick?



## Our national accreditation with the Patient Information Forum has been through some changes.

Their PIF Tick scheme now includes more checkpoints, including how you translate resources and other requirements.

Find out more about the accreditation at: <https://piftick.org.uk>

We're heading into re-assessment in early 2025 and following lots of preparation, we anticipate a successful pass under the new criteria.

PIF Tick checks that our information production is based on reputable evidence, user engagement and expert review. Our joint aim is to ensure we provide trustworthy and accessible content, that readers can both understand and apply when thinking about health and social care.



# What's new for 2025?

**We will be reviewing and updating a wide range of resources in 2025, along with new development.**

Key work will include:

- A major project involving video interviews with people living with MND and with Kennedy's disease, and their carers.
- Redevelopment and streamlining of our larger core guides.
- A new small summary of our *End of life guide*.
- A new booklet about *equipment and wheelchairs*.
- Expansion of our audio guides, to provide an accessible range of our decision-making information in voiceover.
- A series of new two-page prompt sheets with questions to ask at appointments for specific topics.
- 25 planned revisions to ensure existing resources remain fit for purpose.



**As always, our goal is to continue making a positive difference through the power of trusted information. Your support means so much.**


If you would like to view a resource mentioned in this report, see: [www.mndassociation.org/careinfo](http://www.mndassociation.org/careinfo) or use our Care Information finder:

**Care information finder**

**Thank you from  
the Education and Information Team**





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