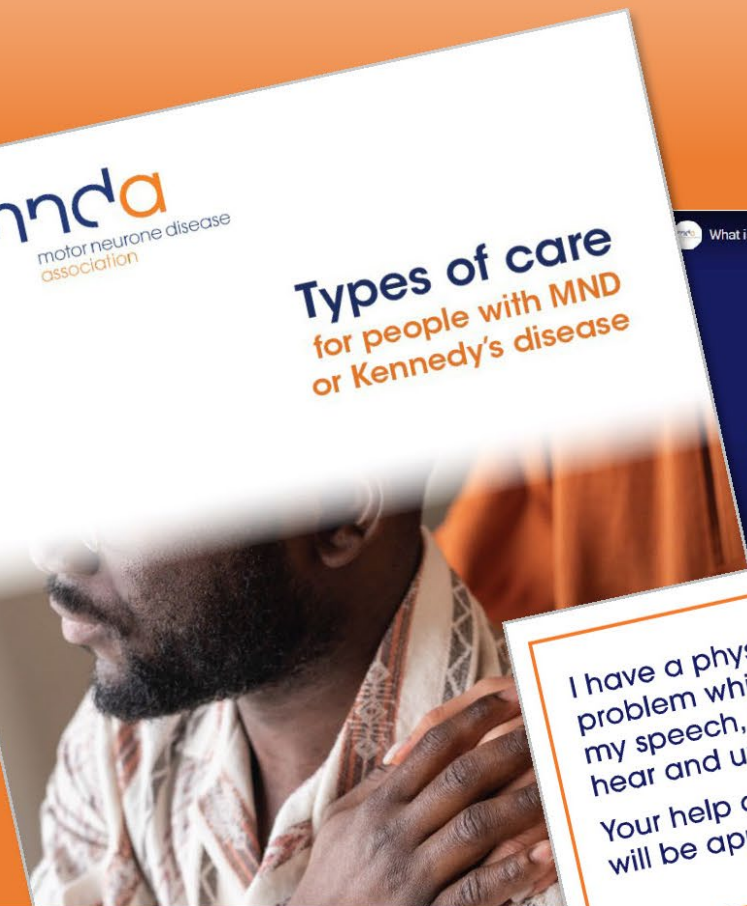
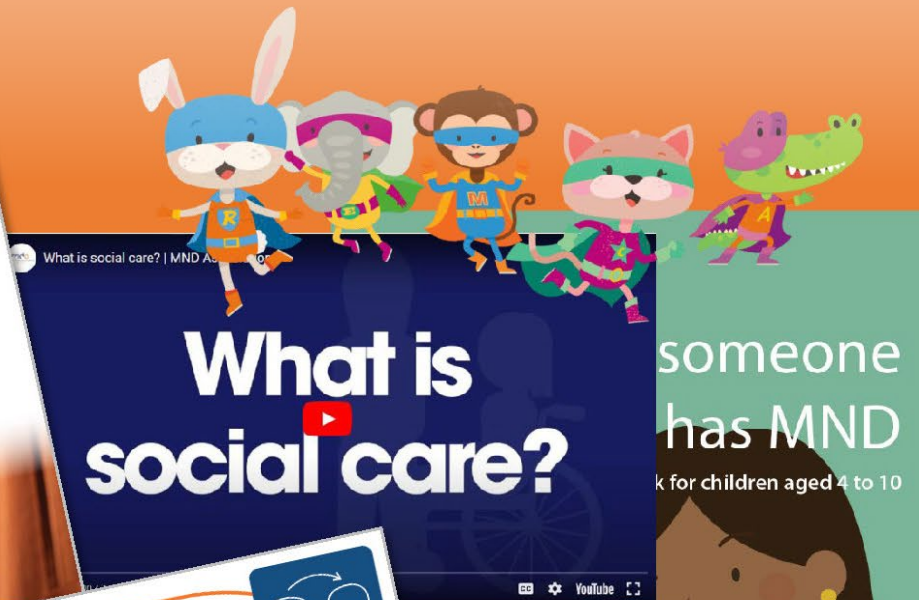


Review of the year 2023

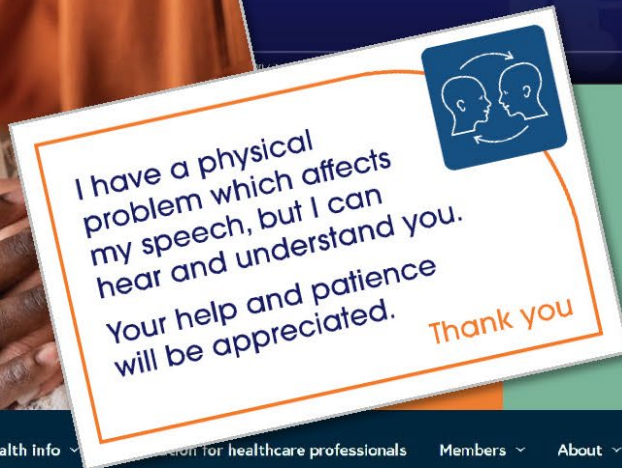


Types of care for people with MND or Kennedy's disease

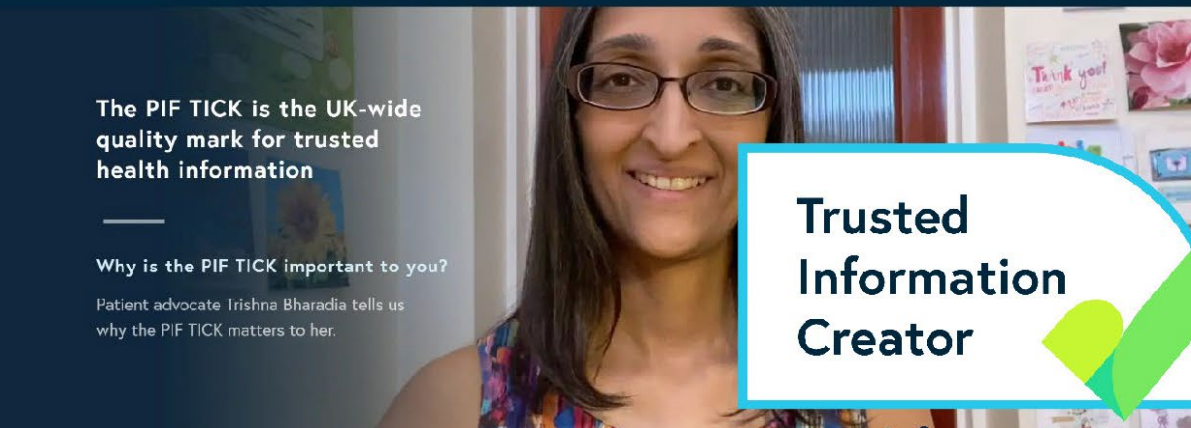


What is social care?

someone has MND



I have a physical problem which affects my speech, but I can hear and understand you. Your help and patience will be appreciated. Thank you



Trusted Information Creator

The PIF TICK is the UK-wide quality mark for trusted health information

Why is the PIF TICK important to you?

Patient advocate Irishna Bharadia tells us why the PIF TICK matters to her.

6A

Physiotherapy and exercise with MND

Information for people with or affected by MND or Kennedy's disease

Motor neurone disease (MND) affects people in different ways with movement, mobility and posture. If you have MND, you may be affected in a similar way and find it difficult to move.

Physiotherapy helps maintain movement and function. It is achieved through movement, exercise, education and advice. Although physiotherapy can help you maintain your independence for as long as possible.

This information sheet explains how physiotherapy can help you access this support.

The content is split into the following sections:

- 1: How can physiotherapy and exercise help you?
- 2: How do I access physiotherapy services?

PIF Tick national accreditation

Having maintained the **PIF Tick** marker in 2022, we were fully re-assessed in December 2023, through the Patient Information Forum. This in-depth certification happens every three years, with an external assessor.

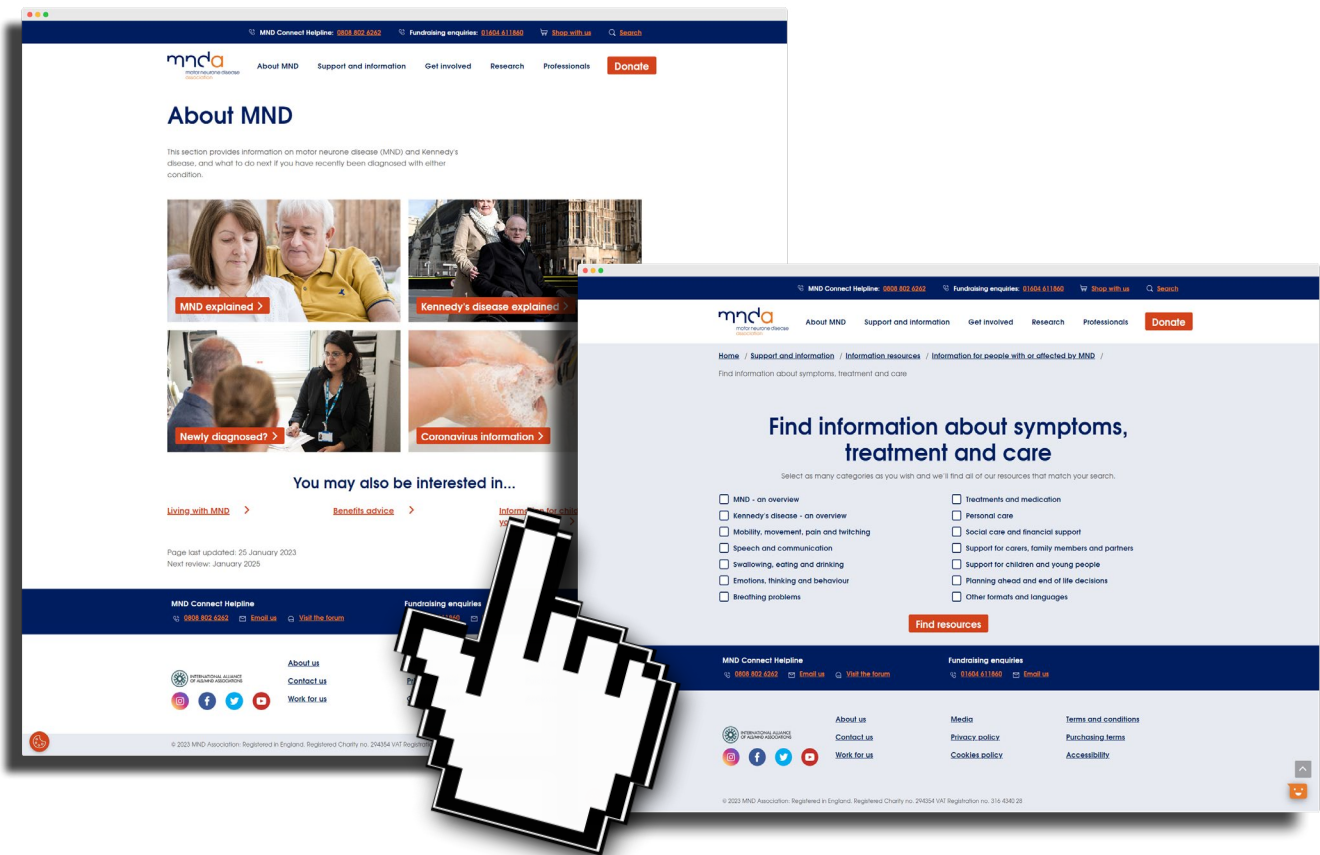
PIF Tick checks that our information production is based on reputable evidence, user engagement and expert review, to provide trustworthy and accessible content.

Using their new online system, we had to submit a range of supporting evidence about our process, followed by an interview with the assessor. Not only have we passed, but our work was marked as going 'above and beyond' both for, a) team training on the information process and b) how we involve independent clinical and social care professionals as expert reviewers.



Our thanks to everyone involved, especially our user reviewers living with or affected by motor neurone disease (MND) or Kennedy's disease. Also to external experts and funders for their generous input – and our colleagues who support with internal validation, funding bids and the ongoing delivery of our printed resources.

Website work



In 2022, we assisted our Digital team with the migration of our website to a new platform, which meant rebuilding our care pages and links. The launch of the new platform happened in February, and we have continued refining the refreshed hubs and pages throughout 2023. This work has included improvements to our **Care information finder** search facility and we have now added the following button to all of our care information pages:

Care information finder

The *Care information finder* helps you search for our content by need, so you can't miss any relevant resources.

Also the introduction of three new content sections or web pages:

- **Cost of living**
- **Safety at home**
- **What do all the words and initials mean?**

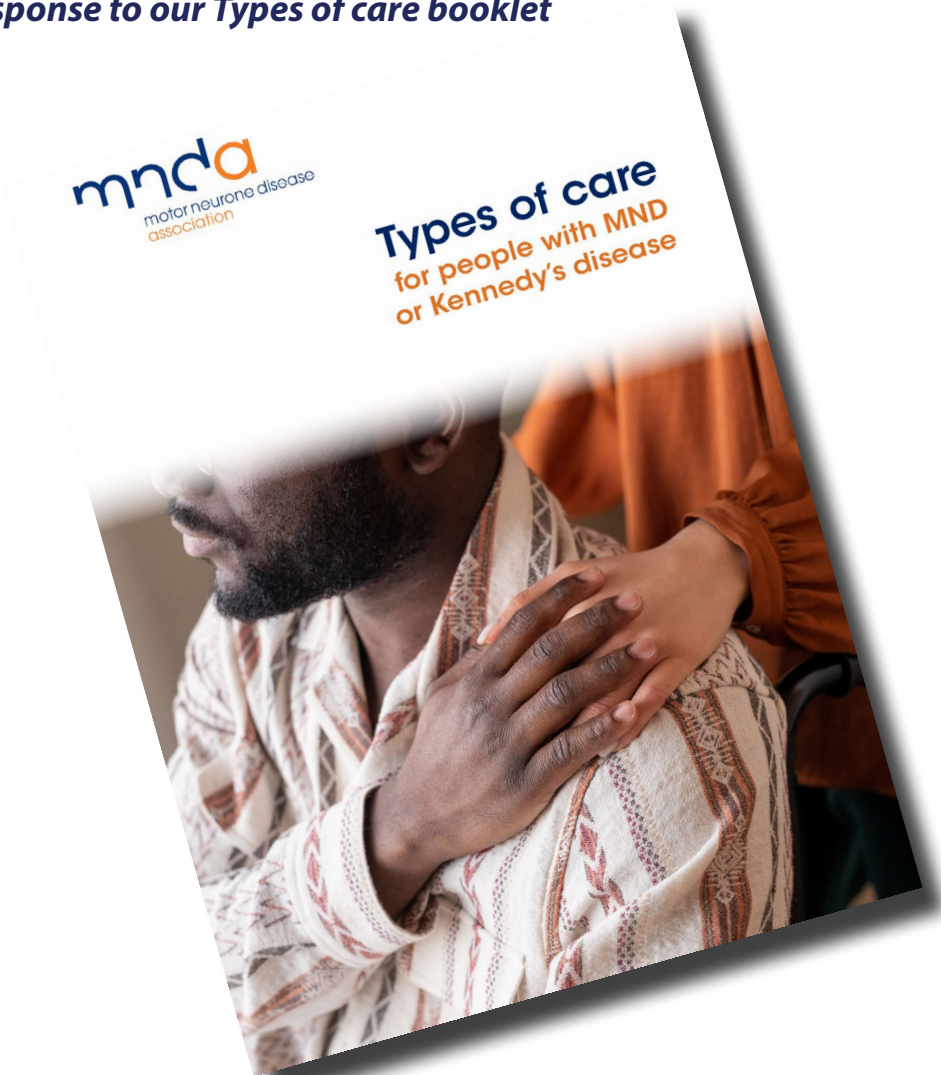
We have updated various other web resources, such as our **What is social care animation**, our web page about **Coronavirus**, our **MND Buddies** activity hub for young children and our **web hub for children, young people, parents and guardians**.



New resources

“I think it will help people to navigate what is a very complex and off putting system. I think the main thing to stress to people embarking on this journey is the importance of finding someone who can be your care co-ordinator so you are not alone. Signposting this role to patients and carers is essential.”

Example response to our Types of care booklet



In addition to new web pages and content, we have produced a new booklet on ***Types of care*** to explain the wide range of clinical and social care support available with MND or Kennedy's disease.

Work has started on another new booklet, *Living alone with MND* and an information sheet on *Inherited MND and genetic testing*.

We are also developing digital interactive versions of:

- ***Understanding my needs*** – a form to help guide care for someone with MND, in hospital or other care settings.
- ***Motor neurone disease checklist*** – a series of prompts to help someone think about their needs.

Reviews and revisions

We have updated the following resources in 2023 to ensure they remain fit for purpose:

Information sheets

- 5A – Riluzole
- 6A – Physiotherapy
- 7C – Speech and communication
- 7D – Voice banking and message banking
- 10A – Benefits and entitlements

Five other sheets are currently under review and will also be relaunched in early 2024.

Guides and booklets

- An easy read guide to motor neurone disease
- Telling people about MND
- Emotional and psychological support
- Changes to thinking and behaviour with MND
- When someone close has MND – workbook for children aged 4-10

Other items

- How to find out more leaflet
- MND Speech card
- Fresh **translations** for our Introduction to MND and our sheet on Tube feeding

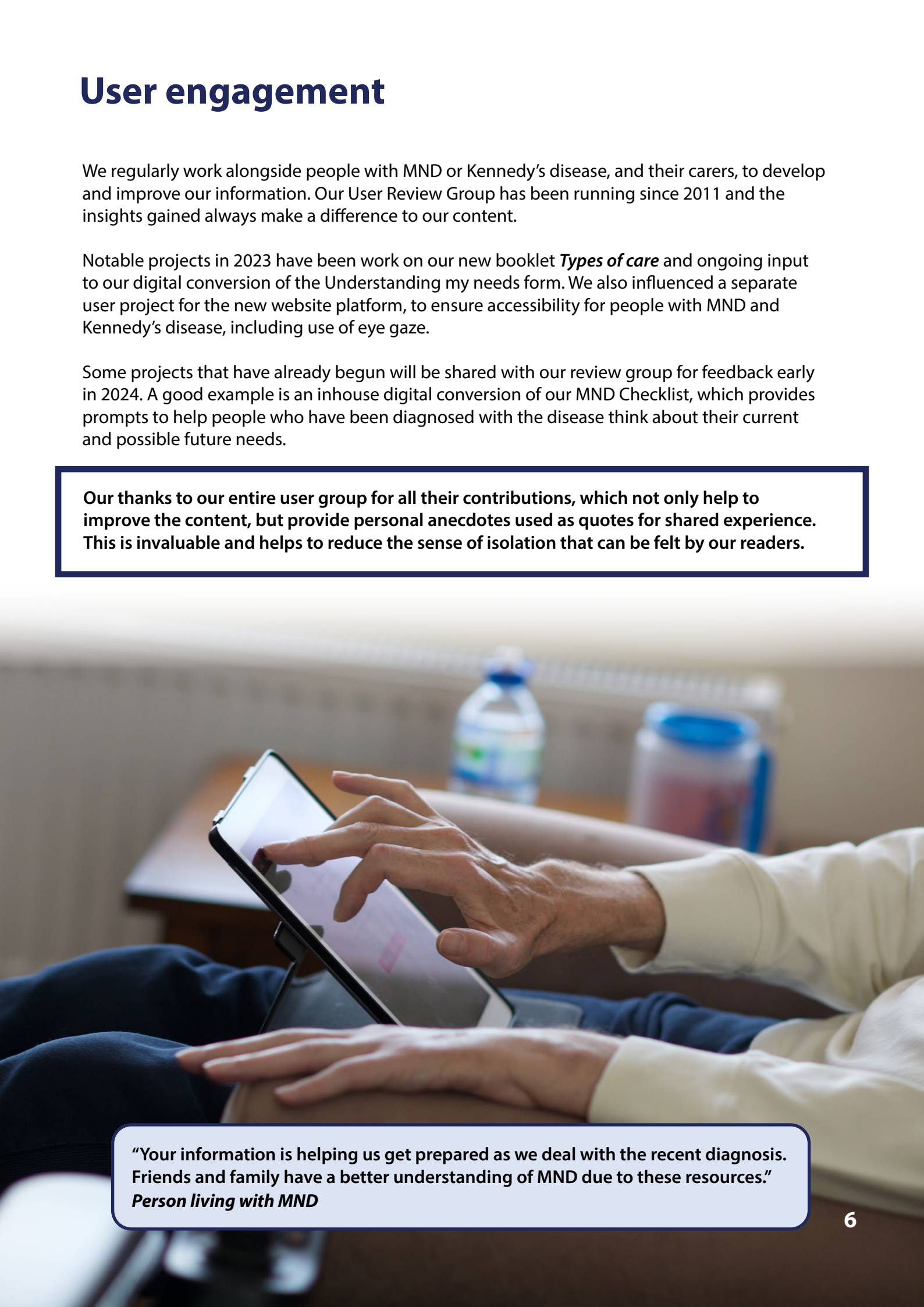
User engagement

We regularly work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information. Our User Review Group has been running since 2011 and the insights gained always make a difference to our content.

Notable projects in 2023 have been work on our new booklet *Types of care* and ongoing input to our digital conversion of the Understanding my needs form. We also influenced a separate user project for the new website platform, to ensure accessibility for people with MND and Kennedy's disease, including use of eye gaze.

Some projects that have already begun will be shared with our review group for feedback early in 2024. A good example is an inhouse digital conversion of our MND Checklist, which provides prompts to help people who have been diagnosed with the disease think about their current and possible future needs.

Our thanks to our entire user group for all their contributions, which not only help to improve the content, but provide personal anecdotes used as quotes for shared experience. This is invaluable and helps to reduce the sense of isolation that can be felt by our readers.

A photograph showing a person's hands interacting with a tablet computer. The person is wearing a light-colored long-sleeved shirt. In the background, there is a water bottle and a blue container on a table. The image is slightly blurred, focusing on the hands and the tablet.

**"Your information is helping us get prepared as we deal with the recent diagnosis. Friends and family have a better understanding of MND due to these resources."
*Person living with MND***

User engagement

2023 has seen record take up on our information:



In our work, we not only engage with our user reviewers for insight, but listen to public feedback too. Where it's appropriate to make suggested changes, we do, either with a version change or as we approach a full revision for a relevant resource.

Everyone who responded to our core guide *Living with motor neurone disease* felt it was useful or very helpful. We feel strongly that our user involvement helps others identify and trust in our content.

“Good source of information post diagnosis.”
Person living with MND

Getting involved

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.

You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home.

Find out more by contacting: infofeedback@mndassociation.org

What's cooking in 2024?

We will be conducting more than 25 revisions this year, to update information sheets, booklets, guides and other resources, along with new development. Notable projects will include:

- a refresh of our ***Eating and drinking guide***, with at least five new recipes
- the redesign of our ***End of life guide*** and a new summary booklet to help people plan ahead
- the conversion of our ***Understanding my needs*** form into an interactive online facility
- the conversion of our ***MND Checklist*** to a webpage for better mobile access
- a new booklet on ***Living alone with MND***
- a new information sheet ***4A – Inherited MND and genetic testing***


An ambitious and wide range of work, that we hope will help our information to continue making a difference.

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

Care information finder

“It has provided all the information and support I needed. It is the BEST quality information and support anyone could ever receive. I wish I had contacted you earlier.” *Person affected by MND*



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 **www.mndassociation.org**