



Neurocare KnowHow

Thank you for considering taking part in the Neurocare KnowHow project.

You can help us to create this new and exciting learning tool.

This information sheet tells you about what is involved.

What is Neurocare KnowHow?

Neurocare KnowHow is a new **online learning tool for care workers who support people with neurological conditions**. These conditions can seem challenging, and specialist learning can be helpful for care workers.

It covers a range of conditions, such as Parkinson's, Multiple Sclerosis, Motor Neurone Disease and more. Because there are so many different conditions, the learning is grouped by common symptoms, such as communication, movement, nutrition and more.

It will be **quick and easy to use 'on the go'**, on your phone or a tablet. It will have a mix of short texts, videos and mini-podcasts for 'bite size' learning. You can find reliable answers and advice quickly, and develop your skills.

Why is Neurocare KnowHow needed?

Supporting somebody with a neurological condition can be daunting. The symptoms can seem complex and difficult to manage. There are many different conditions and lots of them are quite rare.

The Neurological Alliance did a study looking at the care that people with neurological conditions received in the community. They found that paid carers can feel anxious delivering care to these people.

They recommended better training to build carer workers' confidence and understanding. This is why we are making Neurocare KnowHow.

Who is Neurocare KnowHow for?

Neurocare KnowHow is aimed at paid care workers. This includes personal assistants, homecare visit staff and care home staff.

These care workers can find themselves looking after new people with neurological conditions. They may feel anxious or uncertain about what to do.

Some of the content will also be available for unpaid carers - the family and friends of people with neurological conditions. This can help them as they adapt to the diagnosis and the changes it brings.

What has been done already?

We ran a small pilot project in summer 2019. We worked with people with neurological conditions, a nursing home and care workers. This helped us to understand the problem better. The group told us what they wanted from a learning tool.

We made a pilot website with some simple content. This helped to prove we had a good idea. You can see an introduction page here: www.neurocareknowhow.co.uk

We have now been awarded funding from Ufi, a charity who support vocational learning projects. This will help us develop a bigger website by the end of summer 2021.

Who is making Neurocare KnowHow?

We are a collaboration between:

- **The University of Sheffield** Neuroscience researchers and clinicians
- **NIHR Devices for Dignity MedTech Co-operative** Specialise in supporting people with disabilities
- **Amba** Technology company who create learning tools
- **Optical Jukebox** Filmmakers who specialise in health education

We previously collaborated to make the award winning myTube and myBreathing websites: www.mymnd.org.uk

These learning tools helped support people living with Motor Neurone Disease to make decisions about support for their breathing and nutrition.

Why do you need me to help make Neurocare KnowHow?

We want to develop Neurocare KnowHow **with** the people who will benefit from it. Your experiences are key. Only **you** can tell us what we need to make this work. You can tell us:

- What you wish you had known before
- Any problems you had
- What worked well for you

Who do you need to help make Neurocare KnowHow?

We want a range of people to take part in the workshops:

- Paid carers, especially Personal Assistants (PAs)
- People living with a neurological condition
- Their family members

We'd love to have a range of people involved, for example from across age and ethnic groups, and with different learning needs (e.g. dyslexia).

Because of Coronavirus, we feel it is safest to involve people who live at home with their own PAs. **All of the project will take place online for safety.**

We are looking for pairs or small groups of people (max of four). This can include:

- A person living with a neurological condition
- One or two of their PAs
- Also perhaps a partner or family member who is an unpaid carer

What will be involved?

We would like you to take part in **two online workshops**, with some short follow up emails or phone calls. This will help us to develop the content and design.

We will ask you about your experiences to help us understand **what people need to learn**. We will also ask you about **how you prefer to learn**, such as ways of using video, audio and text.

When will it happen?

- **Week of 19th October 2020:** Workshop 1 - online, 2 hours
- **October and November 2020:** Follow-up phone calls and emails

- **February 2021 (date TBC):** Workshop 2 - online, 2 hours
- **March and April 2021:** Follow-up phone calls and emails

What do I need to take part?

You can use a mobile phone, tablet or a smartphone. We recommend you use an internet connection for a reliable video call. We will use a free app for the calls and send details of this to you in advance.

What is in it for me?

This is a really important question! Why should you give up your time to take part? Here are some benefits of taking part:

- **Learn new skills** - being part of the workshops involves teamwork, communication and creative skills
- **Good on your CV** - you can put your role in the project down as a key skill
- **Free access to Neurocare KnowHow** - to say thank you for taking part
- **Sense of pride** - your experiences and ideas will shape the project

What happens next?

Thank you for considering taking part. Please think carefully if the project would suit you.

Talk with the people who you would like to take part with. We can answer any questions they may have. We can do this via phone call or email.

Call:

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