

# Are you interested in supporting someone who is caring for someone living with MND?

By taking part in this study, you could make a huge difference to people living with MND and their carers.

## The Study:

This research study aims to find out the usefulness of a 12-week virtual support programme for people caring for someone with MND. We will look at the impact caring has on wellbeing and try to understand how user friendly and acceptable the online peer support programme is to family carers in the study.

**This is an exciting opportunity to become a peer supporter.**

## What's involved?

**You must have lived experience as a carer for someone with MND.** As a peer supporter, the research team will link you via an app with a family carer of someone with MND. This app is a bit like WhatsApp but more secure and can be used on your smartphone, tablet, or computer. These family carers are part of the research study and you'll be helping them.

The role is a 12-week commitment. During this time, you will need to check-in (contact) with your allocated family carer a minimum of once a week for each of the 12 weeks. This can be done through text or audio/video call (or both) via the app called aTouchAway. You will also need to reply to texts or calls from your allocated family carer.

In your role, you can share your personal experiences and your knowledge of resources or tips on useful carer strategies you have learnt. However, you are not expected to provide specific advice related to medical treatment or medical technologies.

## The role will suit you if:

- you are a good communicator
- You are happy to use the app (like WhatsApp) for communication and have access to your own device suitable for this
- you can develop and maintain supportive relationships
- you are non-judgmental and respectful of diverse lifestyles
- you understand the need for confidentiality and the importance of data protection
- You can assess when extra support is needed

You will also join in a weekly discussion forum via a Zoom link through sharing your carer experiences and knowledge. Here is the list of topics for discussion each week.

Promoting self-care and how you look after yourself as a carer	Caring for your loved one	Setting boundaries as a carer	Navigating the health and social care system	Caregiving and other relationships	Ask the Expert
Managing stress	Social Activities	Finding joy in caregiving	Navigating technology	Ask the Expert	Experiences with peer support programme

The research team will give you with one-on-one training (via Zoom) on how to use the app to send text messages and make audio or video calls, at a time that suits you. You will also receive three one-hour group training sessions (via Zoom) on peer support. The research team will be there to support you throughout the 12 weeks including check in/debrief sessions at 6 and 12 weeks.

**How can I take part?** - For further information, please contact the trial team at: [peersupport@kcl.ac.uk](mailto:peersupport@kcl.ac.uk)