What happens next?

- 1. We will contact you (by phone or email) to answer any questions you may have and to make sure that you are happy to take part.
- 2. If you decide to participate in the study, we will ask you to sign a consent form.
- 3. We will arrange a time to have the interview, either face-to-face or online.
- 4. We will store your information on a secure database

All information and data collected from you as part of this study is strictly confidential and kept in compliance with the Data Protection Act (2018).

The information we collect will enable us to understand how carers of people living with MND manage emotionally the changes that might occur in daily life when caring for the person with MND.

If you would like to take part in this study, or have questions or concerns, please contact the researcher at any time:
Email: mnd.research@uea.ac.uk
Phone: +44 (0) 7825 863389

If you decide to take part in the interview, but change you mind later, you can withdraw at any time without having to give a reason. Or if you don't want to join right now, you can also decide to participate at a later stage.

Sponsored by the University of East Anglia

Neurodegeneration Network Queen's Building Norwich Research Park Norwich Norfolk NR4 7TJ





Factors Affecting Family Carers' Wellbeing in Motor Neurone Disease – interview study

Leaflet for potential participants



IRAS No: 281943 Leaflet v.1, 16 February 2022

What is this study for?

People that support a relative who has been diagnosed with Motor Neurone Disease (MND) are invited to participate in this study.

We aim to understand better how the experiences of being a family carer for someone living with MND impact the carer's wellbeing. We are particularly interested in how family carers emotionally manage the changes that MND might bring to everyday life.

This research aims to help us learn how to better support family carers of people with MND.

What would I have to do?

If you decide to take part in the study, we will invite you to participate in an interview about your experiences of caring for the person you support and how you are coping with changes in the person you care for and in your daily routine.

The interview will be held either face-to-face or online, for example using a platform like zoom, and will take approximately 30-90 minutes.

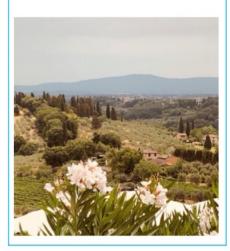
How do I join the study?

Either:

- Complete the slip attached to this leaflet and return it by post.
 Give us a call on 07825863389.
- Email mnd.research@uea.ac.uk

What will happen if I don't want to join the study?

You do not have to take part. Whether you take part or not, your medical care or participation in other studies will not be affected at all. Participation in this study is for research purposes and is entirely voluntary.



Vour name

If you would like more information or would like to take part, please fill the following slip

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Return to: Eneida Mioshi, Queen's Building, School of Health Sciences, University of East Anglia Norwich NR4 7TJ