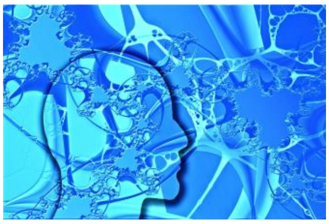
Exploring end of life decision making with patients with Motor Neurone Disease (MND) using home mechanical ventilation: The perspectives of people with MND



People with MND: Information Sheet

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Name of Researcher: Eleanor Wilson (Chief Investigator)

I am a researcher from the University of Nottingham, and I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. Please read the information sheet and talk to others about the study if you wish. **Please ask me if there is anything that is not clear.**

What is the purpose of the study?

To understand:

- decisions about the use of home ventilation (such as NIV, Nippy, tracheostomy) for MND
- how these decisions were made including how people can be supported by professionals and how they might share this information with those involved in your care
- your thoughts about discussions and decisions to stop or continue using ventilation at the end of life

Why have I been invited?

You have been invited to take part in this study because you have identified as someone who is **using ventilation at home to alleviate the symptoms of MND and can no longer effectively breathe without it (dependent)**, and, who may be willing to share their experiences. You may have seen one of my adverts seeking participants and contacted me to ask for more information. I am inviting 20 people to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you are still **free to withdraw at any time** and without giving a reason. This would not affect either your healthcare or your rights.

What happens if I take part?

If you decide to take part in the study you will be asked to provide your consent, either in a written form or recorded verbally, to indicate that you agree to take part in **an interview that will be tailored to suit you**. This can take place over the phone, a video chat or via email exchanges. This can be as one interview of approximately 1 hour or several shorter chats, to suit you. If, in the future in-person contact becomes possible I would be happy to visit and speak to you at home, if you prefer.

The interview will be **about your experiences** of using home ventilation. I would like to find out:

- about your decision to use home ventilation
- what it is like to live with home ventilation
- what your thoughts are about your use of home ventilation in the future

With your permission, I would like to audio record the interview. Interview recordings will be transcribed, and any information that could identify you will be removed. However, you can still take part in the study even if you do not want me to record the interview.

*The information you give will be used for research purposes only, and cannot form any or part of a living will or documentation of your wishes.

Personal information about you, such as your name and contact details, will be stored securely on the University server in a password protected file. This will be destroyed once your involvement with the study is over. The information that I collect from you will be held securely for seven years after the end of the study, in line with University of Nottingham practice. All such research data will be given a code and it will not be possible to identify you from it.

What are the possible benefits of taking part?

The information I collect may help understanding of peoples' use of home ventilation towards the end of life. This will **help to improve the care and support provided in future** by health and social care professionals. I hope participants will find involvement in the study to be an interesting experience. Some people find it helpful to have the opportunity to reflect on, and share, difficult things, such as experiences of serious illness and care, with someone who is not directly involved.

What are the possible disadvantages and risks of taking part?

I understand that talking about issues relating to your own illness and the end part of your life may be difficult and upsetting. I ask you to consider very carefully how you would feel about sharing this experience with the researcher. It is important that you understand what is involved and have the opportunity to discuss this fully with the researcher and others that you may choose to before you decide to take part. It is possible that you may feel upset at times during the interview. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. **You can stop the interview, take a break, or withdraw from the study, at any time.**

Expenses and payments

Participants will not be paid to take part in the study. However, should you need additional child or home care in order to participate in the study please do let me know as this can be paid for.

Will my taking part in the study be kept confidential?

Yes. You will not be identified in any reports or other outputs arising from the research. A unique code, rather than your name, will be used on interview notes or transcripts that are part of the study data. I will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, I will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password-protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means I am responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as I need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights I will use the minimum personally – identifiable information possible.

You can find out more about how I use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx. Or by contacting: Data Protection Officer,
Legal services, A5, Trent Building, University of Nottingham, NG7 2RD, 0115 748 7179.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. Authorised people may also look at them from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

Information about you that leaves the University of Nottingham will have your name and address removed and a unique code will be used so that you cannot be recognised from it. By giving your consent you agree to the above.

The University of Nottingham will keep your contact information for 3 to 6 months after the end of the study so that I am able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

The only circumstances under which confidentiality would be broken would arise if the researchers were made aware of actions or situations resulting in serious risk of harm to yourself or others. The researchers would discuss this with you and consider the need to raise the matter with the appropriate authorities.

What will happen if I don’t want to carry on with the study?

Your participation is **voluntary and you are free to withdraw at any time**, without giving any reason, and without your health care or legal rights being affected. If you withdraw then the information collected so far, including any personal identifiable data, will not be erased from the secure University of Nottingham server. Anonymised data may still be used in the project analysis.

What if there is a problem?

If you have a concern about any aspect of this study, please ask to speak to me and I will do my best to answer your questions. My contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the FMHS Research Ethics Committee Administrator E-mail: FMHS-ResearchEthics@nottingham.ac.uk

What will happen to the results of the research study?

The results of the study will be used to help inform our understanding of patients’ and families’ experiences and perspectives on the use of home ventilation towards the end of life in MND and will enable the improvement of the care and support provided to patients and family members. I will provide yearly **reports** for the funders, University of Nottingham. The results of the research will be made more widely available through professional and academic journal publications and conference presentations, and **publicly accessible via the study website**. With your permission, I may include direct quotations from the interviews. However, these will not include your name or any personal details. You will not be identified in any report or publications resulting from the research. All participants will be sent a summary of the findings at the end of the study if they would like to receive this.

With your agreement, I may use the data collected in this study to support other research in the future. In this case the data would only be shared anonymously with other researchers.

Who is organising and funding the research?

This research is organised and sponsored by the University of Nottingham and is funded by their Anne McLaren Research Fellowship scheme.

Who has reviewed the study?

All research involving people as participants is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and approved by University of Nottingham’s School of Medicine and Health Sciences Research Ethics Committee.

What do I have to do?

Please let me know if you are interested in taking part in the study, or would like to discuss this further. You can contact me using the details given below by email or by phone.

Contact details

Dr Eleanor Wilson
Anne McLaren Research Fellow
School of Health Sciences
University of Nottingham
Phone: 07971 036520
Email:eleanor.wilson@nottingham.ac.uk
Twitter: @DrElliWilson

I have been a researcher in palliative and end of life care for a number of years, and have a particular interest in neurological conditions. My background is in anthropology so for this study I am working with experienced clinicians with expertise in MND, palliative care, respiratory disease, home mechanical ventilation and physiotherapy.

Further information

If participating in the study raises any issues that would you like to discuss further please get in touch with your care team. Further resources can also be found at:

https://www.mndassociation.org/support-and-information/living-with-mnd/breathing-and-ventilation/

http://mybreathing.mymnd.org.uk/

The MNDA also provide a helpline that can be contacted on 0808 8026262 or mndconnect@mndassociation.org further details can be found on their website at: https://www.mndassociation.org/support-and-information/our-services/mnd-connect/