

UNDERSTANDING TRACHEOSTOMY VENTILATION (TV) FOR MND

TVLIFE RESEARCH SUMMARY



University of
Nottingham
UK | CHINA | MALAYSIA



Thank you to everyone who took part in TVLife

Between February 2023 and April 2024, we spoke to:

- **14 people living with MND** who use TV
- **16 family members** who support someone living with MND to use TV
- **24 health professionals** with experience of TV for people living with MND

In this report, we share some of the key findings from our research. Thanks to you, we have increased our understanding of the process of initiating TV for people living with MND, the benefits and challenges of everyday life, and the impact on quality of life for people living with MND and family members. We hope you find this report interesting. If you have any questions or comments on TVLife, you are welcome to get in touch at:

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INTRODUCTION

In the UK, non-invasive ventilation (NIV) is commonly used by people with MND who need help to breathe. Some people are unable to tolerate NIV, or as the disease progresses, they need to wear the mask all the time. Tracheostomy ventilation (TV) can be an alternative way of supporting breathing. TV may not be suitable for everyone who has MND and is not always offered to people with MND in the UK. Until now, there has been a lack of information on what living with TV in the UK is like for people with MND and their family members.

RESEARCH TEAM:

- **Eleanor Wilson**
 - **Nicola Turner**
- with
- **Christina Faull**
 - **Jonathan Palmer**
 - **Martin Turner**
 - **Scott Davidson**

The TVLife research study aimed to:

- explore how decisions about TV are made
- understand the reasons for using TV
- explore the experiences of people electing to have TV and those for whom it was placed in an emergency
- understand the impacts and demands of living with TV from the perspectives of people living with MND and family members
- identify the key issues of TV for people living with MND from the perspective of health professionals

STARTING TO USE TRACHEOSTOMY VENTILATION

Findings show that people living with MND and health professionals discuss the use of TV before it is required, but that access to, and timing of, elective surgery is challenging. Six of our participants with MND started TV following a planned operation, whereas for eight people, TV was the outcome of an emergency hospital admission.

Needing a life-saving operation in an emergency can be traumatic, especially when someone may not be able to fully express their wishes. Some family members found themselves having to act as advocates to ensure the tracheostomy went ahead.



This junior doctor said to me, he was trying to ask me whether [husband] had a DNR, but I had no idea what he was talking about. ... Eventually I realised he was trying to say, do you want us to try to save your husband or let him die? So I was really upset by this question, seriously upset. I was like get in there and try and do everything, he's a father, he's a husband ... You get in there and you do everything that you can to save his life.

(Tess, Family member)

As TV is not a common procedure in the UK, many health professionals we spoke to had limited experience, with some having supported only one or two people to use TV even after many years of working with people living with MND.



Image: <https://mybreathing.mymnd.org.uk>

Some people with MND did their own research

I wish the respiratory consultant and nurses could offer more information about TV and on the rehabilitation process. It was only based on my own research on the subject and information from the friend who had TV to help me to make decisions, and Google.

(Chin, Person with MND)

Others felt their discussions with HCPs did not prepare them enough for the procedure, potential difficulties following the procedure, or for the day-to-day reality of living with TV:

I guess I feel they gave me their best advice, and I accept there's always a risk to any operation. But on the other hand I do wonder whether my MND and ventilation consultant, between them perhaps hadn't had quite as much experience of doing traches with MND patients and weren't as fully aware of the risks as they could have been.

(Colin, Person with MND)



People living with MND and their families want sufficient, timely information on all aspects of TV to help make informed decisions on future care

I think that my discussions around the trache before the hospital admission, it would have been nice to have had a greater sense of what the actual process was going to be like, focussing on what's it going to be like living with the trache, carers etc., but we never discussed this is how it actually is, if you've got a tracheostomy, this is the process you're going to have to go through.

(Owen, Person with MND)

People should be told about the potential, really told what it's like to live with it as far as possible, so they can make a very informed choice... I think it's important that that choice is made available together with an understanding of what it really means, because it's not an easy choice and you have to adjust.

(Anne, Family member)



Guidance for health professionals on when and how to discuss TV with people living with MND would help ensure sufficient, timely information is made available

All names used in this report are pseudonyms

QUALITY OF LIFE FOR PEOPLE WITH MND WHO USE TV

The most frequently reported benefit of TV is that it prolonged the life of the person with MND, enabling them to continue spending time with family and friends.

I had two options; have the trache or lose my life, and I wasn't ready to die. We had four grandsons at the time... So the kids don't know me without it. And there's nothing more that I want than to get in the water with them when they're out swimming, but I can't, but I can watch.
(Gordon, Person with MND)

Tracheostomy ventilation meant that people no longer struggled to breathe, and it helped them to deal more easily with symptoms such as secretions.

I'm not struggling to breathe anymore. I hated the feeling before that I was unable to take a breath. Chest management - how easy is to clean secretions from my chest. Now we are calm, the kids are not crying from seeing me struggling. We can go outside and enjoy time.
(Yusuf, Person with MND)

People living with MND were used to having to 'accept and adapt' as their illness progressed. Most chose to focus on the positive activities and relationships they were able to enjoy and found purpose through continuing to engage with others.

I don't think it's curtailed my life, I think I feel more normal because I don't have the mask over my face all the time...I manage to go to theatres, go to football matches, go to restaurants, go to shops.
(Owen, Person with MND)

ADVICE TO PEOPLE CONSIDERING TV

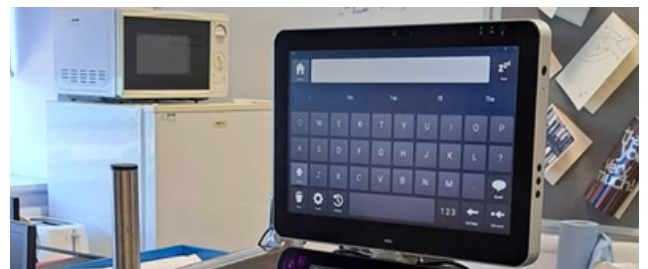
I would say to people that the first month or six weeks is very difficult, and it takes a lot of adjustment and determination and patience, but if you retain your ability to speak and to swallow it's a great advantage, I think. But you need to consider your own circumstances and whether you can accommodate two strangers living with you 24 hours a day. So I think that people need to really think seriously about the effect it'll have on their life, but if they want to live longer, then I think it is worthwhile.
(Owen, Person with MND)

Having to get used to the constant presence of paid homecare workers was one of the biggest drawbacks of living with TV.

I find it very difficult if I'm sad or upset, I don't feel comfortable expressing those emotions where everyone would know my business. It's quite lonely always having people around you not really being able to behave like you want to. Don't get me wrong, my carers are amazing people, some have been with me ten years, but it's difficult not having any real alone time.
(Luke, Person with MND)

TV also has an impact on the person's ability to communicate. Some people were no longer able to communicate verbally and relied on the use of communication aids.

The hardest thing is particularly now with my speech, because to follow the rhythm of the trache breathing, people have to wait for my voice to come around, and a lot of people find that impossible. They leap in and anticipate when I'm going to speak. So I've had sometimes people trying to put words into my mouth or telling me what it is that I'm going to say. Wait a while, I can speak, just give me a chance.
(Colin, Person with MND)



Many people with MND who use TV had adjusted their understanding of 'quality of life' to focus on taking pleasure in everyday activities and experiences.

My favourite part of the day is either when family or friends visit or I am outside either in the garden or going for a stroll down my village where I see the sea and people I know. My least favourite is suction of saliva and the wash routine, though my care team make it work well. I can't communicate during the personal care routine due to not having eye gaze then.
(Marcus, Person with MND)



Living with TV requires major adjustment but for most people with MND the overall benefits to quality of life outweighed the challenges

For family members, 'quality of life' was sometimes more difficult to describe

- The extensive changes required to the home to accommodate the equipment and workforce needed to support TV could be difficult for family members to adjust to. Sometimes, it was not possible for people living with MND to return home, which meant extra effort was required to maintain family relationships.
- However, like people living with MND, family members had grown used to adapting and focusing on simple things that still gave pleasure, such as watching a favourite TV programme together. Support and information sharing with others in a similar situation was valued.
- The challenges of caring for someone using TV were made both better and worse by having to navigate relationships with paid homecare workers. When experiences of homecare were largely positive, family members felt able to take time to focus on their own needs.

The carers were like how did you manage to do this yourself? But you know from probably speaking to other relatives, you don't even think about it. You don't realise what you're doing until you stop doing it...So now I don't have the pressure of, like I can go to the gym in the morning, the days I'm not working, and not feel guilty about leaving him for any length of time.

(Fiona, Family member)



It is essential to carefully consider the home space as a place of care and how to build relationships that can foster good homecare

I've still got my husband and I've still got a very positive man. Where there's not too many people like that, but the ones that are have got to be given that choice. He's here, he loves his garden, he loves his surroundings, he loves going for a walk, he loves his grandchildren which he wouldn't have had. Just seeing all that is enough for me to know it's all worthwhile - but not for everyone.

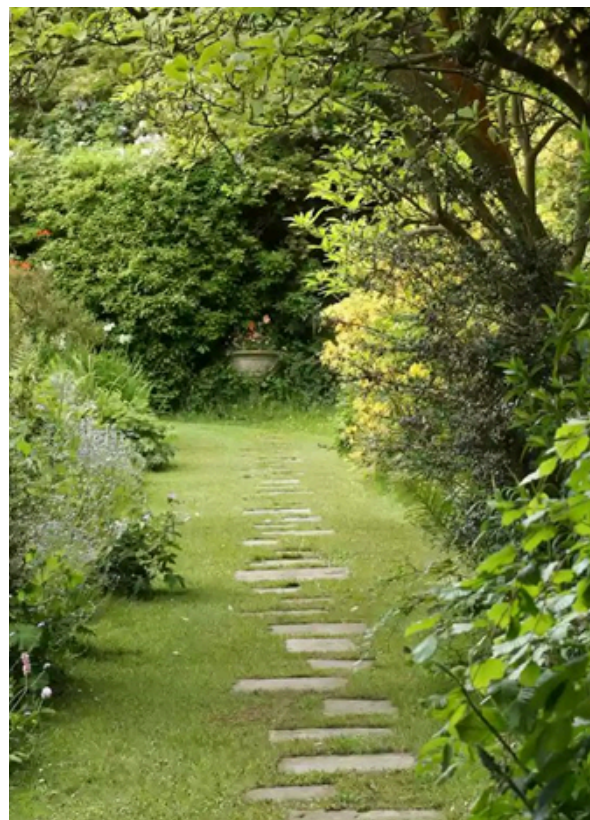
(June, Family member)

William and I have this little mantra, life goes on. It's not what we planned but life goes on. It's just a different normal...and when we have family round, we move the table near the bed or near the chair where he sits and we still have family meals...and he's on his PEG feed, and so that sense of normality, that brings a lot of joy.

(Jan, Family member)

Thank god for the MNDA. Thank god for all the in-hospice care and the nursing team. They've become part of you because they've seen, they've felt, you know, like people that have gone through it ourselves, and experienced it in many different ways, but there's a commonality. There's a common empathy and it's allowed us to survive on.

(Alison, Family member)



More opportunities for peer support would be valued, especially for people living with MND who use, or are considering using TV

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