

# Tracheostomy ventilation in MND

Many people living with MND are understandably concerned about the life-shortening effects of the progression of respiratory muscle weakness. Non-invasive ventilation (NIV, sometimes called NIPPV) is a highly effective way to manage many of the symptoms associated with this phase of MND and also increases overall survival. It is routinely available for all those who might benefit.

Some people consider an invasive method of breathing support through what is called a tracheostomy and ventilation machine. This is a more complicated undertaking and is not part of routine practice in most countries. Oxford team members led a recent review of the topic ([Tracheostomy in motor neurone disease](#)). It is important to discuss the issues around tracheostomy ventilation with your MND care team, and we have meanwhile listed some of the common questions with brief answers below.

## What is tracheostomy ventilation?

A tracheostomy is an opening in the windpipe made by a surgical operation. A plastic tube is inserted through the opening which is connected to a mechanical ventilator machine to assist breathing. Having a tracheostomy involves a stay in hospital, usually in the intensive care unit, and needs a full anaesthetic to undergo the operation.

## Would a tracheostomy extend the length and quality of my life?

It is not possible to know this definitely for an individual. Although some people undergoing tracheostomy ventilation live for years after the procedure, some do not. Some people who choose not to have tracheostomy ventilation, but continue using NIV, also live for many years. On average, people having tracheostomy ventilation for MND live longer than those who don't, but there are several factors that have been shown to influence this, the main adverse one being older age. It also seems to be more effective in people with what is called a mainly lower motor neurone type of MND (where there is more muscle wasting than muscle stiffness), though more work is needed to understand this.

Information on individual quality of life after tracheostomy ventilation is very limited and difficult to generalise. People with MND and tracheostomy have reported greater, lesser or similar quality of life after the procedure, but their initial view sometimes changes with time.

## Would my MND continue to progress after tracheostomy?

Tracheostomy ventilation does not stop the continued progression of MND. Experience from countries like Japan, where the procedure is done more regularly, shows that people eventually completely lose the ability to move their limbs with time. They may also lose the ability to control eye movements which then makes communication of their wishes very difficult. A lot of research is ongoing to try to connect brain activity directly to a computer in order to communicate without the need for movement, but this is not yet possible reliably.

Lastly, someone's wider thinking processes and their personality might also decline due to progression of MND in the long term.

## What about aftercare and potential complications?

The hospital stay after tracheostomy is often very prolonged (several weeks or more) while the complex arrangements are put in place to support the use of home ventilation equipment safely. The training for the individual, their family and other carers, plus the ongoing support and troubleshooting any issues arising with the tracheostomy ventilation, will inevitably increase the potential to spend significant time in a facility that is not the person's home. This must be weighed very carefully against the greater convenience of using NIV.

Common complications of tracheostomy are managing secretions that might otherwise block the tube and dealing promptly with any chest infections. Rarer complications such as a collapsed lung or blocked windpipe can be very serious and may be life-threatening.

## Would I still be able to talk after a tracheostomy?

The tracheostomy tube prevents the outgoing air moving over the vocal cords to allow speech. A speaking valve can be attached to redirect the outgoing air over the vocal cords, but this is not always successful and many people with MND may already have significant problems with their speech due to muscle weakness. Communication with limb or eye movements is more usually the case.

## Would I still be able to travel outdoors or even abroad?

Portable ventilation units (wheelchair-mounted) are available. It is necessary to ensure adequate back-up equipment plans for travel, such as batteries and spare tubes for longer trips. Travelling abroad usually requires insurance to cover any medical care or emergency repatriation and the cost of this may be extremely high.

## May a person with a tracheostomy tube ask to have it removed?

Someone who fully understands the implications can ask for the removal of their tracheostomy tube and the doctor helping would be acting within UK law. Communication of an individual's wishes may be very difficult in the later stages of MND, and a person may choose to create an Advanced Directive to outline a future situation in which they would not want to continue with tracheostomy ventilation. Removal of the tube in advanced MND will usually lead to death within hours to days, even if NIV is attempted as a replacement, and so it needs support to manage any symptoms so that the individual is kept comfortable.