
MOTOR NEURONE DISEASE

FACT SHEET No 12

Ventilation in MND

WHAT IS VENTILATION?

Ventilation is assisted breathing. The purpose of ventilation is to assist breathing for people who are having difficulty, or to breathe for the people who cannot breathe for themselves.

It can be non-invasive, using a mask, or invasive, using a tracheostomy (a breathing tube placed into the windpipe under local anaesthetic). Air or oxygen is delivered either using a gas cylinder or through a pump.

THE NEED FOR VENTILATION

Most people with MND will have problems related to weakness of the muscles used to breathe and cough. This can result in:

- Difficulty breathing
- Ineffective coughing
- Disturbed sleep
- Morning headaches
- Day time drowsiness
- Susceptibility to chest infections

Ventilation can be an effective tool to relieve problems associated with not being able to breathe adequately. Ventilation options should always be discussed on an individual basis, taking full account the wishes of the individual and family, and the clinical circumstances.

TYPES OF VENTILATION

Night time oxygen

Oxygen is not a form of ventilation, but some people with MND may benefit from supplementary oxygen. This may be of particular value at night when breathing is naturally shallower. Prior to commencing oxygen it is recommended that an arterial blood gas is taken to ascertain the level of oxygen in the blood and to ensure that there are no contraindications.

Bipap

Bi-level intermittent positive air pressure is often used at night. It reduces the work of breathing and can reduce the effects of increasing weakness of breathing muscles.

This system consists of a closely fitted mask joined to a ventilator, which augments the patients breathing. This increases oxygen and reduces carbon dioxide levels. A range of ventilators can be used, such as the BIPAP (Respironics), Nippy (Thomas Respiratory Systems), DP90 (Taema and Brompton Pac (Pneupac). Many of these are portable and all are easy to operate.

In most individuals, ventilation is initially needed only at night. If respirator muscle weakness progresses, then use during the day may be needed. Most people are able to quickly acclimatise to nasal ventilation and find their sleep quality improves.

One study (2) showed that people using Bipap survived for significantly longer than people who could not or chose not to use it, but that there was a need to assess quality of life.

The need for non-invasive ventilation should be determined by a recognised sleep studies unit.

CPAP (*continuous positive air pressure*)

Continuous positive airway pressure" (CPAP) is a mask and compressor system that resembles nasal ventilation but delivers a constant pressure rather than breathing support. This treatment is helpful in obstructive sleep apnoea as the pressure acts to hold the upper airway open.

There is a lot that can be done now to control respiratory problems in MND. Although a decline in respiratory capacity is inevitable, symptom control produced by treatment such

as nasal ventilation has been shown to improve the quality of life.

Ventilation with a tracheostomy

It is generally accepted that home ventilation using a tracheostomy can prolong life significantly but that there are major personal, emotional and financial costs involved.

Ventilation is more likely to be successful in certain conditions. These are:

- The person is highly motivated and engaged in life
- MND is progressing slowly
- The person can communicate and has some independence
- Everyone involved understands the options
- The family are able and want to be involved
- Resources are available
- A team of professionals experienced in MND is involved (4)

PLANNING FOR THE USE OF VENTILATION

Making a decision about the use of ventilation can happen several ways:

- Some people actively choose no ventilation
- Some die without making a choice
- Many are forced into making a decision by a medical emergency
- Some people plan ahead and make decisions without the pressure of an emergency.

Planning ahead can be frightening, as most people are never in a situation of making decisions about their own death.

The nature of MND makes it is possible to make these decisions and exert some control over life.

Planning issues are:

- Evaluation at a sleep studies unit
- Decision making needs to be on the basis of reliable information about options
- The reality of respiratory failure effects everyone, so decisions should be shared
- Because the burden of care is mainly on the family, they need to be able to decide

for themselves that they are willing to take on the commitment

- Planning for the resources needed (equipment, experienced health professionals, support for the carer, assistance from family and friends)
- If a decision is made to use ventilation, it is important to define the limits beyond which it is unacceptable, such as the inability to communicate in any way
- Decisions should be documented and it is important that they are reviewed and can be changed at any time
- There is a need to plan for emergencies and the person's wishes need to be known in advance

ISSUES OF VENTILATION USE

Psychological adjustment

Living on a ventilator can seem to dominate the whole of life for everyone concerned and the reality may only become apparent after a period of adjustment.

People with MND and their carers who have activities and interests outside the home seem to adjust better.

Quality of life

Most people who are living on a ventilator report that their quality of life is better than might be expected. Some people even feel that their quality of life is better than that of their carer.

One overseas study of people on ventilation (3) reported that 89% of people using a ventilator would choose to do so again. 80% of carers would also make the same choice.

The effect on the carer(s)

Family members can feel trapped and resentful of demands made on them but given the choice they would make the same decision.

Carers who cope best are those who are able to take care of their own needs without guilt, can share the burden and who have a strong support system. (1)

Cost

Because most people on ventilators have very limited speech and movement, there is a physical burden of care. This includes:

- Extra time taken in communication
- Tracheostomy care (suction, hygiene)
- Personal care (washing, turning, feeding)
- Infection control

Financial costs of ventilation can include

- Equipment (ventilator and backup)
- Running costs
- Caregivers and respite
- Feeds
- Car modifications
- Electronic communication

The decision to use or not to use ventilation is a complex one and needs to be taken in consultation with all involved.

References

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