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# MOTOR NEURONE DISEASE

## FACT SHEET No 13

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### Living on a Ventilator

The person with Motor Neurone Disease (MND) and their family face many difficult adjustments and decisions as they cope with the effects of this disease. The issue of mechanical support to assist breathing when it is no longer possible to do so naturally is of **critical importance**. For those who decide to live at home with mechanical ventilation via a tracheostomy, there are many changes involved and issues to be faced.

#### CARE OF THE PERSON ON THE VENTILATOR

It is an oversimplification to state merely that life changes on a ventilator. For a person with MND who chooses to continue life on a ventilator, several things must occur.

First, the person is admitted to hospital where a surgical procedure called a **TRACHEOTOMY** is performed. This is the placement of a permanent breathing tube, called a **TRACHE-OSTOMY**, directly into the trachea (windpipe).

The person is then placed on a ventilator in the intensive care unit of the hospital for several days while the proper settings on the ventilator are adjusted.

The person will remain in hospital for some time so that their family and other caregivers can be properly trained to care for the ventilator and the person who is being ventilated.

#### CARE ACTIVITIES INCLUDE

- ♦ Suctioning which is vacuuming the phlegm and mucous from the throat

through the tracheostomy (breathing tube).

- ♦ Care of the tracheostomy, which includes cleaning and changing the tubing and ties that hold the tube in place.
- ♦ Care and understanding of the ventilator, which requires the carer to be familiar with the dials, buttons and switches on the equipment.
- ♦ Alarms need to be understood to ensure a proper response to any emergency sounds from the ventilator.
- ♦ Emergency care is necessary in the event that the ventilator stops working.
- ♦ Communication methods need to be established as often people placed on ventilators lose their ability to use their voices. They and their families will need to learn alternative methods of communication.

Arrangements will be made during hospitalisation for care following discharge. Proper equipment such as respiratory supplies, wheelchair and hospital bed must be ordered.

The nursing needs of the person will be assessed. The assistance for non-insured patients for home nursing is limited, but there is some assistance for home nursing through private health insurance for people who have top private hospital cover. All people with MND should be eligible for community-based services, such as Domiciliary Care and Options Coordination, who can assist in the provision of equipment and some services.

Five to six designated family members and friends should also be trained to care for the ventilator dependent person, who is to be cared for at home.

It is very important to realise that care of the ventilator is a '24 hour a day' responsibility. For example, a ventilation dependent person may require suctioning in the middle of the night as well as during waking hours. In addition, the alarms on the equipment may sound at any time letting the caregiver know that there may be a malfunction.

The ventilator dependent person can **NEVER** be left alone. There should always be a trained caregiver within earshot in case of mechanical problems or breathing difficulty.

## **THE EFFECT ON QUALITY OF LIFE**

Life on a ventilator is not easy. Families must remember that MND is still a very obvious part of the person's life and that, even while on a ventilator, the disease will continue to progress and the body will continue to weaken.

Some quality of life concerns are:

**Lack of privacy:** This is a concern for both the individual and the family. For the ventilator dependent person there will never be prolonged privacy again. A caregiver must be in close proximity at all times in case of emergency.

For the family of the ventilator dependent person, there may be nurses, respiratory therapists, attendant carers, and friends in the house for many hours each day, providing care or helping out. This changes the structure and dynamics of the household.

**Physical environment:** Once a ventilator dependent person is sent home, there will be medical equipment, supplies and hospital-like machinery in the home. This may be intimidating or bothersome to some families.

**Planning outings:** For a person with MND on a ventilator, to leave the home usually requires careful planning. Families must remember to bring with them

emergency equipment such as a portable suction machine, back up medical supplies and a communication device. Most MND ventilator dependent people need to use wheel chairs that can store a portable ventilator unit.

Typically, transportation is only possible in a vehicle with a wheelchair lift in it or access cabs. Though certainly not impossible, excursions away from home require extra thought, time and effort.

**Communication:** Because verbal communication is often not possible when on a ventilator, people with MND must consider how they will cope with having to communicate via computer, electronic communicator, written words (when hand function is strong enough), or alphabet board.

The loss of the ability to easily share thoughts, ideas, and needs through speech, can be a difficult thing to accept.

**Lifestyle:** Life on a ventilator may change the lifestyles of an entire family. Sleep patterns, living quarters, delegation of routine daily chores and responsibilities, and time for diversional activities will all be changed.

The need for the primary caregiver to stop working outside the home would need to be evaluated. The effect on young children of life with a parent who is ventilated should be considered carefully.

**Finances:** Availability of financial resources may drastically change once a family member is on a ventilator. Money once used for other things may now be needed to pay for nursing care, special van transportation and equipment.

Costs for care of the ventilator dependent person at home vary, depending on the number of hours of nursing or attendant care service that is required. Hours in excess of those provided by community based agencies and covered by health

insurance will need to be paid for by the family.

This needs to be explored carefully.

**Alternative care:** Families, with the assistance of their careworkers, need to determine if the care of the ventilator dependent person is physically, financially and practically viable. If the individual cannot be cared for at home but wants ventilation, placement must be discussed. Families must consider their ability to handle this drastic change in structure and quality of life.

## **DISCONTINUING MECHANICAL VENTILATION**

It is sometimes the case that a person on mechanical ventilation decides to discontinue it.

Often the person no longer wants a lifestyle that is dependent on ventilation and is ready to die. Financial constraints can also play a part in this decision.

Many ventilator dependent people determine that, when they are no longer able to communicate by any means, in writing, by computer, or with their eyes, it is time to stop artificial breathing support.

People who are unable to communicate in any fashion are identified as “locked in”; that is, they are of sound mind, but completely unable to communicate their

thoughts and needs. It is important that an advanced directive is made whilst the person is still able to communicate, to ensure their wishes are documented prior to reaching this stage.

Once the ventilator dependent person and their family decide ventilation is to be stopped, a medical evaluation will be made to ensure that the decision to stop ventilation is well thought out.

The person will receive sedation to offer relaxation and comfort and the ventilator will be turned off. In a matter of several minutes to hours, the person will stop breathing and will die.

## **SUMMARY**

**In summary, life with MND is difficult and challenging.**

**One’s decision to sustain life with MND on a ventilator must be carefully thought out. Both practical and emotional factors must be considered.**

**Discussion with family and health care providers is necessary to come to a sound decision.**

This information is reprinted with permission and adapted for Australia from an article by Janis Sacks, RN, MS., Clinical Coordinator of the Lois Insolia ALS Centre at Northwestern University Medical School. Chicago, IL,

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