

## ***When breathing problem occur....***

Some of the Motor Neurone Disease patients will have weakness involving the breathing muscles. Their breathing become shallow and carbon dioxide can build up. When this happened, they need the help of machine/ventilator to help them to breathe. This shallow breathing is exaggerated when they go to sleep. Some of the MND patient only use NIV when they go to sleep (Nocturnal NIV). In some patient, they became breathless at all time that they need the support of NIV throughout day and night.

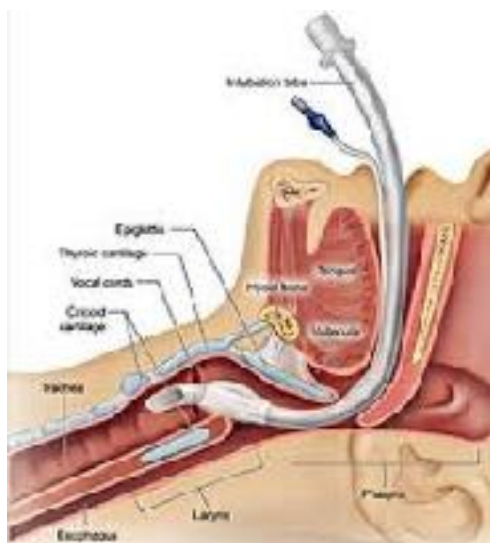
### **Symptoms suggestive of breathing problems in MND patients:**

- unable to lie flat
- breathless when talking or exert themselves
- unable to sleep well at night
- feeling sleepy at daytime
- difficulty clearing their secretions
- feeling tired all the time
- loss of appetite
- feeling depressed
- difficulty in concentrating and sometimes with poor memory
- headache in the morning
- frequently wake up at night for urination (more than 2 times)

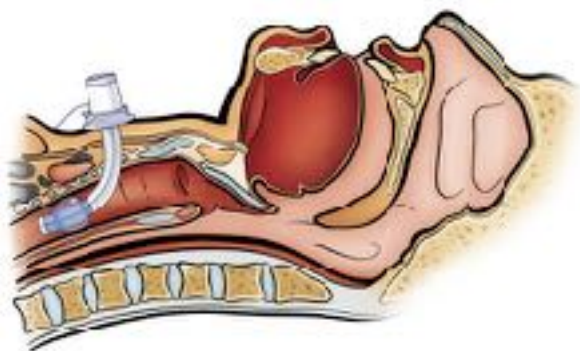
NIV (Non-invasive Ventilation) does not involve poking or inserting of any tube on your body. The ventilation (the assistance of breathing) is delivered through the mask or interface. There is variety of interface available and the patient need to choose according to their suitability. For example, if you are a mouth breather (you tend to breathe through your mouth), we advise the use of oronasal mask. If you still can eat or need to expel your saliva/secretion through your mouth, we advise you to use nasal mask.

With the help of your doctor from the palliative team, they can assist you in decision making if you choose to use the machine/ventilator to help you to survive longer. Research has shown that NIV can prolong survival, improve quality of life and improve symptoms. Every patient has their right to choose and we respect and support your decision. This is an incurable disease, some patient don't want to prolong their suffering in battling with this disease. It is always good to discuss with your palliative doctor and think about your decision in advance (we call this Advance Care Planning). Situation of emergency may arise when the patient with increasing breathlessness (usually in the case of the diaphragm muscle weakness), the doctor in the emergency department will put in a tube to your airway (intubation) and

connect to the ventilator to help you to breath. This is the protocol if you do not have advance decision or will stated. This is a form of invasive ventilation.



We know that the chances of taking off the tube and the patient can breath on his/her own without the machine is very slim and almost zero. For long term mechanical ventilation, the doctor will operate and put in tracheal tube at your neck to connect to the ventilator for tracheal ventilation. This is also a form of invasive ventilation.



The care of a tracheal ventilated MND patient involved increase burden of care to the caretaker. They require frequent suction and feeding through nasogastric tube or PEG tube. Some patients ended up in a “lock-in syndrome” in which state they are conscious but unable to move and hooked on to the machine for the remaining days or years of his/her life.

The progress of the disease of each patient is hard to predict. Some patient deteriorated fast and some slowly. We want to journey along with the patients and prepare for the worst right from the diagnosis of Motor Neurone Disease.

We perform sleep study on MND patient. This is to detect breathing problems or changes that occur during sleep. We also do respiratory function test and arterial blood gas as part of the respiratory assessment.



MND Malaysia is a NGO that offer support to MND patient and family. Through the public donation and fund-raised, we loan ventilator to the patient who cannot afford the machine. We also share resources of equipments and information and to raise awareness about this rare disease.

Visit MND website: [www.mnd.org.my](http://www.mnd.org.my)

# Types of ventilation in MND

NIV( Non-Invasive Ventilation) through various mask/interface

Types of mask/interface to choose from:



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NIV via oronasal mask:



NIV via nasal mask:



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Mouthpiece ventilation:

