

## **BREATHING SPACE KIT – info for health care professionals**

Patients with Motor Neurone Disease usually die of respiratory failure, due to ventilatory failure, occasionally after a respiratory infection.

As the diaphragm and intercostal muscles lose function, increasing use of accessory (neck) muscles for ventilation is seen. If a panic attack occurs at this stage lorazepam 1-2mg SL stat is given, and repeated as necessary.

Even this movement steadily diminishes, and then stops at the end. Central cyanosis may be noticed at this stage.

When patients die, they feel severely dyspnoeic, experienced as suffocation.

Since sensation and mentation is intact at the same time as patients are unable to communicate, their distress can only be imagined. We need to alleviate this suffering.

This is done with a combination of drugs. We use Lorazepam (Ativan) 1 mg stat (into a moist mouth), with Morphine (10-15 mg) + midazolam (Dormicum) 10-15 mg stat imi together.

We then set up a syringe driver, which delivers SC, over 24 hours:

Midazolam 30-60 mg (decreases anxiety, may induce sleep)  
Morphine 15-30 mg (relieves dyspnoea, fear and anxiety, and pain)  
Atropine 0.5 mg (reduces saliva & lung secretions, relaxes smooth muscle)

Oxygen, if available, can be used palliatively in the terminal phase.

A separate information sheet is given to the patient's family to use until medical help arrives.

They are instructed to give lorazepam 1 mg SL stat; and midazolam 15 mg crushed, plus morphine solution 20 mg, both with water, into the PEG if the patient has one.

If the patient does not have a PEG, the carer can give the midazolam and morphine intrabuccally or rectally.

Atropine eye drops can be given intra buccally if secretions are a problem.

If all these drugs have been given, and have taken effect, the syringe driver can be commenced as above.