

BREATHING SPACE (for families of patients with Motor Neurone Disease)

We all know that we will die one day. In spite of this, it's normal to postpone thinking about the reality of that until we absolutely have to. Having someone in the family with a terminal illness like cancer, AIDS, or Motor Neurone Disease confronts us with the reality of this fact.

Many of us have fears about death and dying. They seem particularly prominent when we are caring for someone with a terminal illness whose health is deteriorating. If we can address these fears, it may help reassure us, and enable us to care for our loved one more effectively.

While many of us believe we are not afraid of death, most of us have fears around the actual process of dying. While no-one knows exactly what will happen, when it will happen, or how it will happen, staff of Hospice have had enough experience to give our patients help, to minimise suffering so that they will die a peaceful comfortable death.

Apart from the family's natural fears about losing a loved one, and all the implications of that, some of the fears that people with Motor Neurone Disease have expressed about the process of dying are suffering from pain, losing their mind, becoming incontinent, choking, and struggling to breathe. We can reassure them that pain can be effectively controlled, that people with MND retain their mental faculties, do not become incontinent, and very rarely choke. While they do often struggle to breathe, that is something we can help them with.

When people die, naturally their breathing stops. This usually happens gradually, and the person gradually loses consciousness as it happens, so is not aware of any distressing feelings. People with Motor Neurone Disease also die when their breathing stops. However, when this happens, it is usually because the muscles they need to use for breathing don't work any more. Their heart and brain work fine right until they run out of air, so the person may feel distressed when it happens.

Family members may notice that the person with MND gradually becomes increasingly short of breath as their diaphragm and chest muscles weaken. After a while, their neck muscles start working hard to get air into their lungs. Eventually, even these muscles will become too weak to work effectively, and the patient will die. When this happens, family members may notice that the patient is struggling hard for breath, and may even appear blue.

It is important to relieve the distress that the person may feel at this stage. Fortunately, that is easily possible. Knowing what to do, and having the means to relieve any suffering their loved one may experience makes family members feel less fearful of the end.

Keeping a box ready, with these instructions, and the medicines you need, will help you to be confident of managing until you have help.

The medicines you need to keep available are:

Ativan (lorazepam) 1mg tablets X 20
Dormicum (midazolam) 15 mg tablets X 4
Morphine syrup (10 mg in 1 ml) X 100 ml
Atropine eye drops X 1 bottle

Family members should call their Hospice home care Sister as soon as they think the person with MND is struggling for breath. She will remind you what to do, and be ready to come and help. Do not wait for her to arrive before you start to help the patient.

The first thing is to give the patient an Ativan tablet – put it under the person's tongue, with a few drops of water to make sure that it can be absorbed. You can give another one if the first one doesn't seem to have relaxed the person after a few minutes.

Two other medicines that can be given now are morphine and Dormicum. If the patient has a PEG, they can be given, with water, into the PEG. They are quickly absorbed and will work soon.

If the patient does not have a PEG, the Dormicum (1-2 tablets) can be given by putting the dissolved tablet into the space between the lower gums and the cheeks. The carer can put 10-20mg (1-2 ml) concentrated morphine syrup in the space between the lower gums and the cheeks on the other side.

If the patients seems to have too much phlegm or mucus in their throat, Atropine eye drops can also be given in the mouth.

When she arrives, the Hospice Sister will check what has been done, and if necessary, she will give an injection, and then medicines through a syringe driver, which makes sure the medicines are continuously absorbed and the person stays comfortable and peaceful.