

## THE BREATHING SPACE PROGRAMME

The breathing space programme was introduced by the Motor Neurone Disease Association (MND Association) in 1991 and in June 03 was comprehensively revised and updated. The programme aims to address sudden change in the person with MND – in particular choking, breathlessness or related panic, which may occur during the course of the illness, and the fear of dying. The programme comprises information, and a series of practical measures to help those affected by motor neurone disease (MND), their carers and health and social care professionals.



It is often very difficult to talk over fears and concerns as the disease progresses. This reluctance can often serve to increase anxiety, much of which may be unfounded. Breathlessness, choking or related panic may occur from time to time, during the progression of the disease, but the final stages of MND are usually peaceful and dignified.

### The Kit: practical help, easily to hand

To help everyone talk more openly, two leaflets have been produced. The first (Death and Dying) is for doctors, nurses and health and social care professionals. It explains the problems that may be encountered and how to talk about them with those concerned. A shorter leaflet (How will I die) has been written which can be read by the person with MND and their carer and discussed with the professionals involved in their care. Both leaflets will automatically be sent with the Breathing Space Kit (BSK). They can also be ordered separately through the Care Information Service (contact details at the end of this sheet).

An important part of The Breathing Space Programme is the Breathing Space Kit. The ready availability of the kit in the home is appropriate once the symptoms outlined become evident. The Kit is a small box supplied on a named patient basis to the general practitioner (GP) free of charge. The box is divided into two sections for use as follows:

**Carer:** The lid of the box contains a leaflet for the carer explaining the purpose of the kit and an explanation of the medication that may be enclosed. Should an emergency occur the carer can offer immediate relief by giving the patient appropriate medication. Advice and instructions will be given locally when the kit is supplied.

**Doctor/Nurse:** The lid of the box contains an information leaflet for the use of the doctor and/or nurse. Suggested medication including midazolam, glycopyrronium bromide, and diamorphine, will be supplied by the GP when the kit is received by the family. Should breathlessness, choking or related panic occur the doctor or nurse called to the home can take immediate and appropriate action.

Although most people will never need to use a Breathing Space Kit, its presence in the house will bring confidence and reassurance to many people with MND and their carers – practical help, readily at hand, just in case.

The MND Association has introduced the kit working closely with GP's, community nurses and other health care professionals. The use and value of the kit is regularly monitored and evaluated so that recommended improvements in management can be made to the benefit of people with MND and their carers.

*The MND Association would like to thank members of the Ken Hopkins Working Party and Dr David Oliver, Medical Director of the Wisdom Hospice for their help in devising the Breathing Space Programme.*

#### **HOW TO OBTAIN A BREATHING SPACE KIT**

1. Supply of Kit agreed by the person with motor neurone disease (MND) carer and general practitioner (GP)
2. The GP requests a Kit on a named patient basis from MND Association.
3. MND Association despatches the Kit to the GP, free of charge.
4. The GP provides a prescription to equip Kit with medication (appropriate to individual need) and supplies direct to the patient.
5. It is recommended that the GP:
  - Discusses the purpose, and the provision of a kit, with the community nurse involved in the care of the person with MND.
  - Involves the community nurse in advising/training the carer in how to give the medication contained within the carers section of the Kit.

*For further information contact:*  
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