Death and dying

A patient and carer centred approach for health and social care professionals
**Introduction**

Although all of us are going to die, it is often very difficult to discuss the issues and feelings that can occur around the subject of death.

If we are to care effectively for people with motor neurone disease (MND), we do need to be able to face the facts of the finality of death. For health care professionals, different cultural and ethnic approaches to death and dying can also present particular challenges, not only to our own attitudes, but also to the services we represent.

The challenge is being sensitive to the diverse and varied ways that people express their concerns, then having the confidence to address death and dying honestly and openly.

The aim of this booklet is to encourage professionals to discuss death and the process of dying, as and when people with MND wish to deal with this subject. We have to be aware of all the needs of people with MND. To provide effective care, we may need to help them and their carers to prepare for death.

**Glossary**

- Additional publications available – see publications list order form
- Further information available in other sections of the *Personal Guide*
Fears

People with MND may have many fears about the process of dying or death itself. However, these fears may not be expressed openly and time may be needed for that person to feel comfortable enough to talk about their worries. Building a relationship where trust can develop is very much a part of the holistic care that people with MND need. It is important to put aside some appropriate time to allow people to express their fears and concerns and answer them openly. More time will be needed for people who have communication difficulties.

Choking and breathlessness

A great many people with MND fear choking, as this is often quoted in the popular press as the mode of death in MND. Many people do not experience ‘choking’ at all. For those that do, the careful control of dyspnoea (difficult or laboured breathing) and dysphagia (difficulty in swallowing), with medication such as diamorphine and anticholinergics to control excess salivation, can reduce this symptom to a minimum.

The experience of breathlessness can lead to anxiety, which can increase the panic of breathlessness. The panic can spiral out of control when people fear that they may die fighting for breath or suffocating. Talking about fears and concerns with the person and family is an important aspect of minimising anxiety.

Often the mode of death for a person with a low respiratory reserve is respiratory failure. This is usually a sudden deterioration over a short period of time with little distress as the diaphragm and intercostal muscles fail and anoxia (absence of oxygen) quickly follows. Severe breathlessness can be controlled with small doses of diamorphine and midazolam. The advice of a Specialist Palliative Care Team will be important in easing the symptoms and also to provide support to the person with MND.

People with MND who are anxious about severe breathlessness, or inability to clear saliva or secretions, are often reassured by having an MND Just in Case Kit (JIC Kit) nearby. The JIC Kit was introduced by the MND Association in 1991 (previously called the Breathing Space Kit). The JIC Kit is part of a programme that aims to address sudden changes in the person with MND – in particular choking, breathlessness and related panic. These symptoms can occur at any point during the course of the illness, but particularly near the end of life.

see MND Just in Case (JIC) Kit and request Information Sheet P4A

The JIC Kit is a box for storing medication and information in the patient’s home. It must be requested by the GP on a named patient basis. This ensures GP agreement to provide an appropriate prescription to fill the box that 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. (The purpose of the medications and how to use it must be provided by the GP or district nurse.) Should an emergency occur the carer can offer immediate relief by giving the patient the appropriate medication.

- **Doctor/nurse**: The lid of the box contains an information leaflet for the use of the GP and/or district nurse. This provides useful information about the disease and the medication in the box and is especially useful to an out of hours GP who has never met the patient or encountered MND before.
Although many people will never need to use the JIC Kit, immense confidence and reassurance can be gained by having medication on hand in case of an emergency.

Pain

People with MND rarely die a painful death, although some people with MND do have pain from musculoskeletal causes, muscle spasm or from skin pressure due to immobility. These pains can usually be controlled by appropriate analgesics. Physiotherapy can ease the pain from immobile joints and pressure prevention should be high on the whole team’s agenda. Opioid analgesics may be necessary, especially for pressure pain and should not be withheld if required. With careful titration excessive drowsiness and respiratory depression can be avoided.

Regular analgesics should usually be continued until death, even if oral medication is no longer possible because of dysphagia (difficulty swallowing). Alternatives, such as suppositories or parenteral routes (intramuscular or intravenous injection) should be considered. Parenteral medication may be more conveniently given as a continuous subcutaneous infusion using a syringe driver (directly under the skin using portable battery-driven infusion pump).

Note: Before putting any medication through the PEG check with the pharmacist that it won’t harden and clog the tube.

Cognitive changes

People with MND may fear a loss of intellectual powers. Many people with MND don’t have major cognitive changes, although some will experience varying levels of cognitive or behavioural changes. A small minority develop frontal lobe dementia. People with MND and their families may want to talk about this and may want to be involved in advance care planning (see later heading Advance Care Planning).

Incontinence

The sphincters are not affected in MND. If incontinence does occur, it is usually due to restricted mobility or an inability to get to a toilet. Weakness in the abdominal muscles can contribute to constipation and ‘overflow’. A poor diet due to swallowing difficulties can lead to other complications with elimination.

Loss of sexual power

Any disabled person fears a loss of the ability to perform bodily functions, and this is likely to include loss of sexual performance. With MND there is rarely a loss of erectile ability or sexual drives, although there is obviously a need to reassess the capability for intercourse as disability increases. With guidance and imagination, most people are able to meet their sexual needs through changes of position and/or consideration of mutual masturbation. The importance of this will vary from person to person, but it is worth remembering that other ways of expressing intimacy and closeness can be just as important.

Social/family fears

Family reactions to death and dying can be as diverse as the many cultures we live amongst in modern society. We have a responsibility towards people from cultural and ethnic communities to acknowledge and respect these differences. There are numerous publications available that will guide and help health and social care professionals to maintain sensitivity. Hospice libraries are often a good resource for these. We cannot assume Western medical values that believe in the right of an individual
to know even the worst news about their condition will be culturally relevant or ethically appropriate. Careful exploration is advised.

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see Information Sheet 22 – Benefits

The person’s consultant neurologist should have dealt with concerns about heredity. Although in a small percentage of people with MND there is evidence of a genetic component, this is rare, and most families can be reassured on this point.

Important needs

People with MND need to be able to exercise choice and self-determination just like anyone else. This should be done while they are able to communicate and make the most of the time available.

the following issues are covered more fully in the booklet End of life decisions in the patient information Personal Guide

Choosing where to die

The death of a person with MND can sometimes be foreseen, even when it follows a lengthy period of severe disability. The most common clinical picture is a rapid deterioration over a few days, often following an upper respiratory tract infection.

Many people with MND wish to remain at home and choose to die within the security of familiar surroundings, close to family and the usual carers. Death at home can be a peaceful experience, which is helpful to those who are left. However, people with advanced MND may need high levels of care, increasing the demands on the carers as they feel the need to provide extra help. This help may involve the carer in moving, handling and/or using complex medical equipment.

Carers often take on the full responsibility and burden of caring for someone with MND, and their need to be involved must be balanced with their need for respite. This is especially important where sleep is lost through caring. A night sitting service may be available and can be arranged via district nurses or the GP. The MND Association can sometimes offer limited funding towards respite care.

Carers are sometimes in touch with the MND Association through contact with Association visitors or the local branch or group. These contacts can provide additional social and emotional support.

The cooperation and support of the GP and the primary health care team is essential.

Hospital is often not the preferred place to die, as medical or neurology wards may seem too busy or impersonal. Some people with MND may however wish to return to a ward where they are known and feel safe and comfortable.

Some people may choose a care home or nursing home, but not all will have the necessary training and facilities to support someone with MND at the end of their life. Many hospices welcome people with MND, but may not always be able to offer inpatient care for more than one or two weeks. Many hospices also have a community palliative care team who may accept referrals (usually via the GP) to look at symptom control. Alternatively, the local palliative care team may be based elsewhere in the district (eg attached to the local hospital) or as a separate community team.

Early introduction to a local hospice and its services such as home care or day care is always helpful. Hospices may also provide out patients appointments for the Specialist Palliative Care Team, Macmillan nurses and other services such as physiotherapy.
Wills

Many of us try to ignore the fact of our mortality by refusing to make a will. For the sake of those left behind, plans should be clearly defined in a will, especially if there are problems within a family or where partners are not married. If there are concerns regarding guardianship of children, these will need to be clearly expressed in a separate legal document to a will.

Mental Capacity Act

Health and Social Care providers must be aware of the Mental Capacity Act, which empowers people to make decisions for them where possible and protects people that lack capacity to make specific decisions. Wherever possible, people with MND must be supported to make their own decisions.

Advance care planning

Advance care plans are statements of values, wishes, priorities or preferences, including medical choices about what is to be done, should a person lose capacity at some point in the future. Health professionals should take these into account as part of an overall best interests judgement, but they are not legally binding.

Advance Decision to Refuse Treatment (ADRT)

An ADRT requires the person to identify specific treatments to be refused and the specific circumstances in which this applies. The health care professional may offer support and advice about how to make an ADRT. The decisions written down are legally binding as long as the document is dated and witnessed, and is applicable to the situation. It can only be used if the individual lacks capacity to make that particular decision.

Lasting Power of Attorney

People with MND may want to consider completing a Lasting Power of Attorney (LPA). This is a legal document lodged with the office of the Public Guardian, which allows a trusted friend or relative (the Attorney), to make decisions on their behalf if they are unable to communicate their wishes or if they lack capacity to make decisions. The Attorney can be appointed to make decisions regarding financial or care related matters (or both).

Family preparation

When someone is near the end of life, families often need to share what is happening. The person who is dying needs to feel able to discuss their concerns and fears, which may or may not be shared with the family. Many families will cope very well with this new and unfamiliar issue, while others may need the specialist support of a family support worker, perhaps from the local hospice. Some couples may need encouragement to talk things through sooner rather than later, especially if the person with MND appears to be deteriorating rapidly.

Children also need time to prepare themselves and may have things they want to do or fears they need to express. Equally important, they may need time to themselves. Be ready to identify the need for specialist support for children.

see When someone close has MND an interactive workbook designed to promote coping strategies for children aged four to ten years. Also So what is MND anyway? a booklet designed to introduce MND to young people, including a section on being a young carer.

see Advance Decision to Refuse Treatment Information Pack which includes a pro forma and Information Sheet 19 – Advance Decision to Refuse Treatment (ADRT) explained.
Tissue donation

Any arrangements should be made well in advance, ensuring the family and health care team are aware of the person’s wishes.

If you are interested in finding out more about tissue donation see Information Sheet L – Helping MND research through Tissue Donation

For further information

If you have any questions about the information on this sheet, please contact the MND Connect team.

MND Connect offers advice, practical and emotional support and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and MND Association staff and volunteers who directly support people with MND.

Downloads of all our information sheets and most of our publications are available from our website. You can also order our publications direct from the MND Connect team, who will also be able to advise on individual needs:

MND Connect
MND Association, PO Box 246, Northampton
NN1 2PR

Telephone: 08457 626262 (people living with MND, their families and carers)

Telephone: 01604 611870 (health and social care professionals)

Fax: (01604) 638289
Email: mndconnect@mndassociation.org
Website: www.mndassociation.org
We welcome your views

The MND Association encourages feedback about any aspect of the information we produce.

Your feedback is really important to us, as it helps us to develop our information. Your input enables us to produce even more useful information for the benefit of people living with MND and those who care for them.

Want to know more?

There are a variety of ways you can get involved. To find out more about how you can help shape our information development in the future, please contact us by email: infofeedback@mndassociation.org
Alternatively, write to us at:
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