MND Factsheet 8
Care Planning and End-of-Life Issues

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End-of-life issues such as the kind of care you want and organising financial and legal affairs are things all of us need to address no matter what the status of our health is today. However, unless we are knowingly in our last phase of life, most of us would prefer not to talk about it, much less plan for it.

How we deal with death can be deeply affected by our cultural and religious values. Some cultures view death as a welcomed spiritual transition. Others believe that death and rebirth are a continual process. During our lives, the cells in our bodies die at an ever-increasing rate, while at the same time our learning, intelligence and spiritual awareness can continue to grow.

For many, the final stage of life can be a time of tremendous personal growth previously not experienced at any other time. Accepting that time is limited can motivate people to really make a difference in their lives and those around them. This time of life can be a very special gift. Approaching the end-of-life phase in a positive, well-thought out way, can make for a good death, which can help provide comfort to surviving friends and family members.

The information in this factsheet encompasses end-of-life concepts, advance care planning, and ideas for telling one's life story

Why It's Important to Talk About It

As MND progresses, there are numerous practical issues to deal with and arrangements to be made. Poor communication and planning of these practical concerns could force family members or health care professionals to make decisions without knowing your wishes.

Approaching the Concept of End-of-Life

In personal terms, end-of-life may begin at diagnosis for some and not until the final days for others. Regardless of when you believe the end-of-life stage is, making decisions about the kind of care you want at the end-of-life and the provisions you want to make for your surviving family members should take place much earlier.

Contemplating the End-of-Life Phase

Acceptance/Denial

Accepting that life is coming to a physical end may be less difficult when the illness has been lived with for some time. With MND and the functional and role changes associated with it, lifestyles often slow down in pace, perhaps giving you more time to reflect. When diagnosed with MND, a future fraught with changes and losses is faced, and thus an ongoing grief process can be experienced. Acceptance is one of the stages of grief one passes through along the journey. Sometimes we accept things, then go back to denial, or anger, and eventually, work our way back to acceptance. For many people

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with MND there is time for this process to unfold, therefore allowing time to contemplate what lies ahead.

Instead of thinking of yourself as dying, it may be easier to accept being in the final stages of life; so placing the emphasis on living. Once someone accepts that the natural progression of their illness is a shortened life, their acceptance can help prepare and comfort those around them. A sense of peace about death may open up opportunities for deep and meaningful communication and planning for what is to come.

Expectations of the Dying Process

An area that may be frightening to people who are facing death, and those around them, is what actually happens to them during the last days and hours of the dying process.

To minimise fear, it is best to ask your doctor or MND Care Team Specialist what you might expect to experience during the dying process.

A DVD that may also be of help, **"Conversations to Remember"** is available to borrow from the MND Scotland library. Contact info@mndscotland.org.uk by e-mail or telephone 0141 945 1077 and ask for the information officer.

Advance planning

Advance planning can avert potentially difficult situations for family members and limiting the number and type of decisions others have to make on one's behalf can substantially reduce their stress and tension levels.
However, once plans have been made, decisions should be revisited every so often to make sure the plan is still desirable and to make changes if necessary.

You can take control in advance.

- Making peace with family and friends if needed.
- Discussing future care and medical treatments.
- Exploring spirituality and faith.
- Completing a welfare power of attorney and sharing its contents with family, doctor, and clergy.
- Communicating openly with loved ones about the desired environment for the last days or hours of life. Advance planning can avert potentially difficult situations for family members.

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Advance planning can be started as soon as you are ready, and may include choices no different from before you had MND. Regularly reviewing your advance directives to reflect your current outlook allows you, your proxy decision maker and the healthcare team to become comfortable with your choices.

Care Choices

Explicit instructions in a living will, sometimes also referred to as an advance healthcare directive should help to ensure a dying person is treated according to their wishes and will have a dignified death as defined by themselves.

This can be done in Scotland by making an advance directive and appointing a substitute decision maker ("proxy”) in a legal document, called a "Welfare Power of Attorney." These documents only become effective in the event that you are unable, or too sick, to communicate your wishes for care. Wishes expressed in a Welfare Power of Attorney can be as specific as the individual wants them to be. When preparing how you want to be cared for in your final phase of life consider not only what medical care measures you want, but also where you want to die and who and what you want to have around you. This is your life and death, and you are entitled to be in control of your dignity. Conversely, the “Advance Directive” should only contain information regarding those possible treatments our condition might require that you do not wish to experience. More detail and references to these issues are included in our factsheets 38, *Financial and Legal Issues*, 19, Advance Directives and 24, *Powers of Attorney.*

In a nutshell, there are four steps to advance care planning:

1. **Gather** information so you know what is possible.
2. **Talk** about your preferences and decisions in advance so everyone knows your wishes,.
3. **Prepare,** sign and REGISTER a “Power of Attorney”.
4. **Inform** appropriate others and provide them with copies of the above document.

Medical Care Choices
The type of medical care that you want during the course of your disease as well as in your final days is up to you and no one else. Just as it is you who needs to make the decision about tube feeding or ventilation at given stages of your MND, it is you who will decide when to suspend these treatments. Decisions about medical interventions geared to maximise quality of life are very personal and should be based on medical information, carer support and resources, and your perceived quality of life.

When you prepare a Welfare Power of Attorney remember to:

1. Register it with the Office of the Public Guardian in Scotland.
2. Discuss your decisions with your loved ones and doctor.
3. Keep a copy in a safe, easily accessible place at home that your carers know about.
4. Give copies to your doctor for your medical records and your appointed decision-maker(s).
5. Carry a wallet sized card with you that names your appointed proxies and their contact information, in the event of a medical emergency outside the home.
6. Revisit your decisions every few months and re-evaluate. Communicate any changes you want to make.

It is critical to periodically review your advance care plans. While quality of life means something different to every single person, it can also change meaning within an individual over time. For instance, a person with MND may indicate at one point that in the event of respiratory failure they do not wish to use assisted ventilation. However, that same person may change their mind when they hear there is a new grandchild on the way.

On the contrary, it is perfectly acceptable for someone with a feeding tube and/or breathing support to decide they no longer want to live with those interventions if a given situation were to arise.

Three major intervention issues that ought to be addressed in a directive are:

Resuscitation: Ask yourself if you do or do not want to be resuscitated in the event of respiratory failure. Ask your doctor about how you go about getting a Do Not Resuscitate (DNR) order, if that is what you prefer.

Interventions such as feeding tubes and assisted ventilation: Feeding tubes are normally inserted through the abdomen directly into the stomach and are normally covered by clothing so are not seen except when in use. The operation to insert a feeding tube is carried out under sedation. As you will be lying down during the procedure it should be undertaken while your breathing is relatively unaffected by lying down. For more information see factsheet 6, “Feeding Tubes”.

Many people confuse the issue of assisted ventilation with that of a tracheostomy. Assisted ventilation does NOT necessarily mean a tracheostomy (a tube inserted into the front of your throat.) More often than not satisfactory ventilation can be achieved by the use of non-invasive methods in which a clear plastic mask is strapped tightly over both the mouth and nose or, sometimes, only the nose. If you have concerns about either of these possible interventions you should discuss these issues fully with your GP or MND Care Team Specialist.

Pain management: Stating your desire to have pain appropriately monitored and treated is very important. This should be the goal of care.

In discussing the content of the Welfare Power of Attorney with your healthcare team, it is vital you discuss the medical management and strategy of care of symptoms when a particular intervention is not desired (e.g. invasive ventilation). In particular, when you choose not to have breathing support, you need to have explicit strategies for managing feelings of breathlessness, and for the rare instance of acute breathing distress.

Faced with the dilemma of acute breathing distress and yet a directive indicating no invasive ventilation, it may be reasonable to accept temporary breathing support to control symptoms.

You can ask for artificial ventilation to be withdrawn at any time, and the medical team can ensure that this is done comfortably. It is legally and morally acceptable in Scotland to ask to have life-sustaining therapies including assisted ventilation withdrawn. However, this should be discussed specifically with your spiritual advisor, as there are some cultures where withdrawal of assisted ventilation is not acceptable.

Choices About Where to Die

Many people with MND prefer to die in the peace of their own home. Others may prefer to be in a hospice or care setting of some kind. Whichever is your wish, you must discuss this with your family while you are still able to do so.

If you choose to die at home, you may consider some specifics such as:

- Which room do you want to be in?
- Is there a favourite view you want

to be positioned toward?
- Who and What You Want Around You?

There are many decisions you can choose to make. Give as much thought as you can and involve others to help you sort through it all. There are some excellent resource books and videos available to support you. Many are listed in the "Recommended Reading" factsheet (35). An excellent and very comprehensive resource guide which includes numerous references to web sites, books, and videos can be found on-line at http://www.healthtalkonline.org.

Bereavement Planning

Another type of advance planning is bereavement planning. It is very beneficial for family members and close friends of a dying person to identify resources that may help them cope with the overriding sense of loss and grief they will experience afterwards.

Anticipatory grief is experienced before death by both the person who is going to die and their loved ones. This type of grief is unique to those affected by long-term illnesses. During the course of the illness there is grieving around losses of function, roles, and hope.

Psychosocial support during the grieving process can help individuals process and express their feelings in healthy ways that will eventually help bring about healing. Sources of support in the community include hospice organisations, members of the clergy, and mental health practitioners such as therapists who specialise in grief counselling. Another great source is peer support from others who have gone through the same experience. MND Scotland is able to match bereaved carers with counsellors who have been trained in both grief counselling and MND.

Being Remembered

Have you ever thought about how you want to be remembered, or what you want to leave behind to help comfort your loved ones? Telling one's life story and documenting memories on paper, video, or audio tape can be an excellent way to help transition to the final stage of life and leave one's mark on the world. The process can be very therapeutic in terms of searching for the meaning of one's life and identifying core values and beliefs. Sharing it will pass on valuable lessons to others.

Looking back and sharing special memories can be both a fun and enriching experience for yourself as wells as loved ones engaged in the process. Family and friends will probably be able to trigger memories of things you may have forgotten and vice versa.

If you choose to tell your story there are many formats you can use. If you can type or use computerised communication software, documenting a written story may be your preference. If your speech is good, you may prefer to have a friend or family member document or videotape your stories as you tell them. It's up to you. An excellent resource for getting started and guiding you through the process is, *A Guide to Recalling and Telling Your Life Story*, published and available through the Hospice Foundation of America can be bought on-line at (http://www.hospicefoundation.org/teleconference/books/guide.asp). This is a work book that suggests topics such as "Family Life," "Growing Older," and "Reflections" - and suggested questions to use to elicit stories and experiences from you and your loved ones. While you may need to spend a couple of pounds to buy the Guide plus some documentation materials, what you end up with is a rich personal legacy which is priceless.

Further Information

Factsheet 6	Feeding Tubes
Factsheet 30	Communication Strategies
Factsheet 34	Adapting to Swallowing Problems
Factsheet 35	Breathing Matters
Factsheet 36	Oral Health
Factsheet 38	Financial and Legal Issues
Factsheet 40	Ventilation in MND

Other Resources

www.build-uk.net	This is a UK site for people affected by MND, built by people affected by MND. Primarily it is intended as a site where people can discuss in open forum issues related to MND.
www.patientslikeme.com	PatientsLikeMe is a privately funded company dedicated to making a difference in the lives of patients diagnosed with life-changing diseases by sharing information.
www.healthtalkonline.org.	This site used to be known as “Dipex” and has recently rebranded itself. It contains links to many useful resources and also gives people a chance to tell their story.