

Planning Ahead



If you know you have an illness from which you are not going to get better, or if you know you are going to die, you are naturally concerned for those you love. There will be things you feel you need to do; care for children, deciding about organising money, benefits, housing, nursing home, making a will or deciding on funeral arrangements.

You may also be exploring some of your own spiritual beliefs and have practical questions about the physical process of dying: “What is likely to happen to me” and “How will I die?” are frequently asked questions.

We put a lot of time and effort in preparing for a family birth; in a similar way some people have the opportunity to prepare for their dying, with the unexpected result that the capacity for living becomes richer and fuller than ever before.

Let your loved ones know what you want while you are able to communicate your preferences. Continue to have regular discussions about your views, as they may change over time. Plan ahead by drawing up a ‘Living Will’. Here you can leave written instructions about your medical care. Alternatively, you can nominate someone you trust to make healthcare decisions on your behalf if there is ever a time that you are unable to do so yourself.

The following information is to help signpost you through some of these issues.

Not everyone will want to read the section “How will I die?” This information has been left to the end of this section and you don’t have to read it.

The topics covered in this section are:

- Making choices
 - o At home
 - o In hospital
 - o In a nursing home
 - o Hospices and what they can offer
- Making a will
- Making a ‘Living Will’
- Family and children
- How will I die?
- What to do when someone dies
- Funerals
- Bereavement
- Tissue donation

Making choices

“We agreed to be frank and honest with each other and to talk everything out together – all the heartaches, all the fears, all the problems.”

Making choices and end-of-life decisions are important steps in preparing ourselves for the future. It is really important that everyone – the person with MND and their family – is involved.

One of the key decisions to be made is likely to be where someone would prefer to be at the end of their life – and whether this choice is supported by their family and those professionals involved in their care.

There are three main places where someone with MND may want to be at the end:

At home: Many people want to stay at home. The security of familiar surroundings, close family and usual carers can make death a peaceful experience, something that can be a real comfort to those who are left. It's worth remembering, though, that there will be increasing demands on the carers. They will need a high level of help from the GP and primary health care team, which may not always be available as quickly or as often as necessary.

In hospital: Modern hospitals are generally too busy and rarely set up to meet the needs of the terminally ill who need longer stays on the ward. Having said that, some people with MND do want to return to a ward where they have been nursed before, or simply feel 'safer' in hospital.

In a nursing home: Many nursing homes today are very different to those of the past, offering personalised accommodation and services, social activities and personalised care tailored to your needs. However it is worth noting that Irish nursing home services generally cater to long term care and elderly care.

For nursing home listings, consult your local Health Service Executive (HSE) health office or your GP. Alternatively check the phone directory for your national area or the golden pages directory. If you or your family prefer to use the internet, consult an online directory at www.nursinghomesireland.ie There are both public and private nursing homes available.

To find out about funding towards the cost of nursing homes, you should contact your local HSE health office. Funding might be available to you. Since 2007, the HSE has provided funding to people needing nursing home care through the 'Nursing Home Subvention Scheme'. The current scheme relies upon a medical assessment and a means test to ascertain the type of nursing home and funding available to each individual. Many funding arrangements allow you to choose where you want to go and the HSE will advise you even if you decide to pay your own way.

A new scheme to replace nursing home subvention has been proposed by Government, called "A Fair Deal – The Nursing Home Support Scheme". Legislation to provide for this scheme was published in October 2008 and is due to be enacted during 2009.

If you do decide on a nursing home, take a little time to visit a few before choosing.

Any queries with regard to nursing home services, subvention funding or other information, please call the HSE national infoline available from Monday to Saturday, 8am to 8pm on 1850 24 1850 for any queries on this scheme.

Useful links relating to nursing home services

www.hse.ie click to [Find a Health Service](#) then click on [Older People Services](#) then click on [Benefits and Entitlements](#). These sections of the HSE website contain useful information on where your local HSE health office is located, the contact details and information on funding available for nursing home services – both the 'Nursing Home Subvention Scheme' and the 'Fair Deal' scheme.

www.irishhealth.com This site contains useful case studies detailing how the 'Fair Deal' scheme will work when in operation.

www.nhi.ie This site represents voluntary and private nursing homes in Ireland and contains information on best practice standards and the regulation of nursing services in Ireland.

In a Hospice: Most hospices welcome people with MND, but some hospices may only be able to offer care for a limited time. Check with the hospice in question. It is important to note that hospice care is not only provided to the person with MND at end of life stage but also throughout the duration of their experience with the disease.

→ See the 'How to get more information from the IMNDA and Other Organisations' section for hospice services in your area.

Hospices and what they can offer

Referral forms for hospice services may be obtained through the admissions office at the hospice or through the palliative care services in hospital.

The application should be completed by either the patient or family member and the medical section should be completed by either the patient's GP or hospital doctor – depending on whether the patient is at home or in hospital at the time.

Once the application is received it will be assessed by the admission team and prioritised according to need. The admission office will liaise with the family or referring agency and every effort will be made to accommodate the patient when necessary.

The relevant home care nurse will liaise with the admissions office on behalf of patients being attended by the home care team who require admission.

The focus of hospices is caring rather than curing and hospice care allows those with a terminal illness to achieve the best quality of life by helping to control symptoms and providing support. As such, they offer a very homely environment where your medical, emotional and spiritual needs can be met, tailored to you and your family's needs and wishes.

Some hospices offer their services to people who are not terminally ill but would benefit from **Palliative Care**. Palliative Care treatment aims at making you as symptom-free and comfortable as possible. Palliative Care Nurses work closely with other health care professionals to ensure that your care is continuous wherever you are.

It often helps to allay any anxieties if early contact is made with your local hospice through respite or day care.

Useful links relating to hospice services

www.hospice-foundation.ie This website contains useful information on what hospice care is, where it is practiced, where the national hospices are located and how to gain admission to hospice services.

Making a will

Everyone should make a will regardless of whether they are sick or healthy. It makes a huge difference to the speed and efficiency of what happens to our possessions and family when we die. This is particularly true if there may be any dispute over our estate or if our loved ones are not legally related to us. In addition, if there are any concerns over future guardianship of children, these will need to be clearly expressed in a separate legal document.

If you die without having made a will – ‘intestate’ – your estate will be used to pay off any liabilities or debts and then divided among members of your family. Who gets what is decided according to strict rules laid down by the Succession Act 1965.

Making a will is very straightforward. Anyone over the age of 18 can make a will. They do not have to be drawn up by a solicitor – you may prefer to buy a pre-printed form from your post office or local stationers. It is wise to check, though, that these ‘ready-made’ forms are appropriate to your circumstances.

Useful links relating to wills

www.flac.ie This website contains useful information on how to get free legal advice when making decisions around the creation of a will.

www.citizensinformation.ie

The Citizens Information Centre may know of local schemes that help people to make a will.

Making a ‘Living Will’

Also known as ‘advance directives’, ‘Living Wills’, allow people to give instructions about any possible medical treatment should there ever come a time when they are unable to communicate decisions for themselves to others. In essence a ‘Living Will’ allows you to state, in advance, the medical treatment you would, or would not, like to receive in the event that you are no longer able to communicate this.

The provision of these instructions should never be associated with voluntary euthanasia and should not be confused with the debate about assisted dying. A ‘Living Will’ is asking for the withholding or withdrawal of life-sustaining treatment, and should never be considered suicide.

While there is no law that governs the use of ‘Living Wills’ in Ireland, a clear written or verbal decision to refuse treatment in advance should take into account the following:

- You are mentally able, not suffering from mental distress and over 18 when you make the will
- You are fully informed about the nature and consequences of your ‘Living Will’ when you make it
- You understand that the ‘Living Will’ should apply to all situations or circumstances that arise
- You are not pressurised or influenced by anyone else
- The ‘Living Will’ is your most recent expression of your wishes
- You then become incapable of making any decision because you are either unconscious or otherwise unfit.



Advantages and disadvantages

You should discuss your ‘Living Will’ with a relative, and ideally with your GP too. A living will is not legal in Ireland, but the Law Reform Commission has drawn up a consultation paper as part of its 2008-2014 Programme for Law Reform.

When a medical team is faced with a difficult decision about what treatment or care to provide for a patient who is not in a position to communicate a decision, having a ‘Living Will’ means that they know what that patient would have wanted. It allows you to take responsibility for your own health and care right up to the end of your life.

Having said that, not every situation can be planned for and any ‘Living Will’ needs to be interpreted to ensure that it does still apply. What a Living Will does do, though, is give the patient control over their treatment and, in planning one, the opportunity to discuss difficult issues with close family and friends.

Useful links relating to Living Wills

www.rip.ie Use the search engine provided on the website to find information on ‘Living Wills’.

Family and children

“At first I wanted to be completely independent. I wanted to spare him the humiliation that I imagined would arise out of being cared for by others. I also thought I could protect the rest of the family from the awful truth...I began to see that they needed to give help as much as I needed to receive it – they too had to feel they were making a contribution. By excluding them and insisting on doing everything myself, I would have actually make it harder for them to cope, not easier.”

When someone is near the end of life, families often need to share what is happening. The person who is dying needs to feel that they are able to discuss their concerns and fears, many of which will be shared by their family. It is important that, whatever the worries are, they are talked through.

Talking these issues through effectively needs time – something that may become very precious if the person who is ill suddenly deteriorates. So try not to leave such important discussions too late. Take the time earlier on, so that communication is not difficult and everyone can talk, share and cry more easily.

This time of preparation within a family can be positive. The person with MND and their family can look back at their lives together, plan to achieve things that are important to them and tie up loose ends. Family and friends can be seen again, important things can be said and preparations can be made – not only for death but for what can be done while living.

Involving children

“She was exposed to traumas that many adults never face in a lifetime. She also witnessed love, kindness, honesty, humour and courage that I hope she will never forget.”

Many people fear that children will become too upset if they know someone they love is dying. Yet, if they are not involved they will sense a strangeness and tension in the home and may actually feel more insecure. They may feel that somehow they are to blame and become more fearful. Children also need time to prepare themselves and may have things they want to do or fears they need to express. Equally important, they will also need time to themselves.

→ See the ‘Talking With Young People About MND’ section, for more information on including or discussing your life with MND with your children or grandchildren.

Further reading

The IMNDA has a library where you can loan books which you may find useful:

- **When someone special has motor neurone disease:** aimed at 6-12 year-olds, this is an illustrated booklet about the disease and its impact on the family. It is written for children to read on their own or with an adult
- **When your parent has motor neurone disease:** aimed at teenagers and young people, this is written by young people themselves. It describes their feelings and experiences when a parent has MND
- There are a number of publications available that help parents talk to their children about death and dying. These can be found in your local library, bookshop, hospice or enquire at the IMNDA.

How will I die?

“I was certain that I could do anything for him in those last precious moments of intimacy. He died in my arms. I cuddled him for a long time...I sat with him, talking to him and, some two hours later when I felt ready, I called the doctor. He died exactly as he had wanted – at home. It was peaceful and painless.”

For many of us there is a greater fear of the process of dying than of death itself.

With MND such fears may be greater as there is often a fear of choking and breathlessness. Unfortunately, much has been written about 'choking' to death and 'suffocation', both in the newspapers and in other articles about MND. If care has been taken to reduce your various symptoms as the disease has progressed, choking and breathlessness are rare and, for most people, there is no such dramatic event at the time of death but, rather, a peaceful ending.

The MND Nurse Specialist or your medical and nursing team (Occupational Therapist, Physiotherapist, Public Health Nurse, GP) are available to help and reassure you and to take the necessary steps to ensure a peaceful and dignified ending. Though nobody can say with certainty what dying is like, you will probably find it helpful to talk to someone about your fears and concerns. In this way, many of the fears can be reduced.

Fear of choking is sometimes only one of the anxieties people with MND and their carers have:

- You may be worried about pain; although MND does not act directly on sensory nerves, immobility and muscle weakness can produce severe discomfort. Pain control has advanced to a stage where no one need suffer without relief
- Many people fear the indignity of bladder or bowel incontinence; this is also not a feature of MND.

The terminal stages of MND will usually involve a gradual weakening and increasing sleepiness. Death usually follows the weakening of the respiratory system, either because of an infection or the deterioration of the muscles that make breathing possible. Breathing may become weaker, but with the help of medication, this is not distressing. Consciousness reduces as the body becomes weaker and the moment of death comes peacefully as the breathing slowly reduces and, finally, ceases. On occasions, the breathing may change shortly before death, with the depth of breathing varying from deeper breaths to much shallower ones. (Source: Dr. David Oliver, 'Motor Neurone Disease – A family affair')

In short, if proper steps are taken, dying with MND can be peaceful and dignified, with opportunity for farewell.

Spiritual fears

Although many people today do not actively practice a religion, the majority of Irish people believe in God or the concept of a 'God' or an 'ultimate being'. This can bring a great deal of comfort. Some people, though, may have negative experiences or attitudes that could make the concept of death itself frightening. They may fear, for example, the concept of 'hell' or the 'unknown'.

If you feel the need to talk through any fears or concerns you may have about any of these things, try to think of someone you would feel comfortable to talk to. This could be a minister from your religion, even if you do not attend church or someone from your care team. Talking worries over can help with peace of mind.

What to do when someone dies

If you have never had to cope with the 'official' tasks that need to be done when a loved one dies, it can be a cause of concern.

If someone dies in a hospital, hospice or care home: The staff will contact the person named as next of kin and will be on hand to guide you through the next steps.

If someone dies expectedly at home: While the GP or Palliative Care Nurse, Public Health Nurse or MND Nurse Specialist will usually be aware that death is imminent, they may not be immediately on hand to attend. If death comes in the night or out of hours, you may prefer to wait until morning when your own GP can be contacted to issue a death certificate.

If someone dies unexpectedly at home: If the death was unexpected or the person was not seen by a GP for up to twenty eight days before death, you will need to inform the GP practice as soon as possible.

Registering the death: The death should be registered as soon as possible but no longer than 3 months from the date of death. The death can be registered with any registrar. Contact information for registrars of Births, Marriages and Deaths throughout Ireland is available from your local Health Service Executive office

In order to register the death you will need the Death Notification Form. You can get this from the doctor who attended the deceased during his/her last illness. You will need several copies of the Death Certificate and it is cheaper to purchase these at the time of registering rather than later.

Who you need to inform:

There are several people you will need to inform when someone dies:

- **Benefits:** If the deceased was in receipt of any benefits, contact the relevant government department or agency
- **Banks and Building Societies:** If the money in the bank or building society is solely in the deceased's name then family members usually cannot get access until probate is taken out. If the amount of money in the bank is small, the bank may release it provided the personal representatives or the next of kin sign an indemnity form. Direct debits and standing orders from the deceased's account must be cancelled
- **Mortgage Provider:** If the deceased held a mortgage you must get in touch with the financial institution where the deeds/mortgage is held to notify them of the death
- **If the deceased lived in rented accommodation,** the landlord/local authority needs to be notified so names can be changed on tenancy agreements
- **Creditors:** You will need to inform anyone to whom money is owed – such as gas, electricity, credit cards and phone
- **Insurance policies:** If the deceased held any insurance policies (including car or household insurance) it is important to notify all insurance providers
- GP
- Employer

At the same time, you will need to ensure that the following documents are returned:

- Passport
- Driving licence
- Season tickets or club membership cards
- Library books
- Medical card

Funerals

Some people may have already discussed the type of funeral arrangements they wish to have made, or they may be guided by particular religious affiliation. The important thing is to make arrangements that are 'right' for the person that has died and that you can afford.

Payment

The person who has died may have taken out a Pre-Paid Funeral Plan. If so, check what services it covers.

Funeral costs can vary widely depending on what you opt for and depending on whether it is a city or country funeral (rural funeral costs are generally less expensive). If you have difficulty paying for the funeral, your Community Welfare Officer may be able to help.

Funeral directors

The best way to choose a funeral director is through recommendation. The Irish Association of Funeral Directors can be contacted on ph: 1800 927111 to help you to find local members.

Alternative funerals

For imaginative ideas, including biodegradable coffins, woodland funerals and non-religious ceremonies, ask your funeral director to get you more information.

Bereavement

The loss of someone you love may well be the most stressful experience you will ever face. The grief of bereavement is a life crisis that will affect you in ways you cannot predict and may bring to the surface deep and intense emotions that you may not know how to handle. Support at times like this is invaluable. You may feel able and willing to talk to a trusted friend or family member. Alternatively, you could consider:

- Contacting the IMNDA to enquire as to whether you are eligible for financial assistance toward counselling. The IMNDA offers financial assistance toward a portion of counselling to one significant other as well as the person who has had MND
- Contacting your local hospice. They can guide you to bereavement support services that are available whether you have had previous contact with them or not
- Contacting one of the national organisations, that provides counselling, advice and information

→ See how to get more information from the IMNDA and other organisations 'Bereavement Services' section, for more information on who may be able to help during this difficult time

Benefits

New bereavement benefits are now in place, some of which are subject to conditions such as the age of the claimant and PRSI contributions.

For more information, contact the Citizens Information Phone Service on lo-call: 1890 777 121.

Useful links

www.citizensinformation.ie

