

Treatment and Care Decisions in Advanced Multiple Sclerosis (MS) - Briefing Document and Position Paper

Multiple sclerosis is not a fatal condition. Average life expectancy for people with MS is only very slightly lower than that of the general population. Furthermore, advances in treatments in recent years mean that it is now possible to manage symptoms and delay disability progression so that people can live well with MS for many years. However, for a small proportion of the population of people with MS, the effect of debilitating symptoms and progressing disability can have a substantial negative impact on their quality of life.

This paper provides some information on palliative care and some of the complex and controversial issues that may arise when people in advanced stages of MS consider their treatment and care options, including Advanced Healthcare Directives, assisted suicide and euthanasia. MS Ireland recognises the complex and highly emotive nature of the issues discussed in this paper. Contacts for appropriate support services are included at the end of the document.

Background information

Palliative care

Palliative care aims to provide the best quality of life possible for people with terminal illnesses and incurable progressive conditions such as multiple sclerosis, including keeping the person free from pain as far as is possible. It responds to physical, psychological, social and spiritual needs and extends to support for families in bereavement. The Health Service Executive (HSE) has responsibility for providing palliative care services.

For a person with MS, palliative care might include pain relief, the management of swallowing difficulties, or prevention of pressure sores. It could also involve supporting the person to plan ahead and make the most of their life, finding ways to participate and get fulfilment from activities of interest and maintain relationships. Health care professionals are increasingly recognising the importance of adopting a palliative approach to care of people with MS, and also availing of the advice and support of the specialist palliative care team for symptoms that are complex.

Palliative care can be utilised as a complement to MS comprehensive care; ideally both can be provided in an integrated way to enhance the care that each can offer the person with complex or challenging symptoms and help them plan for their future.

Palliative care can be provided in a hospice, in an acute or community hospital or in the person's home. Access to palliative care is decided by the HSE on the basis of need. There is some variation in the availability of palliative care throughout the country.

Palliative care is provided in a number of ways by specialist palliative care in-patient units (hospices). These units form the hub around which other services are developed. Currently there are nine hospice units; three in the Dublin area and one each in counties Kildare, Limerick, Cork, Galway, Sligo and Donegal.

Hospice or palliative care is provided:

- In people's own homes, by home-care nurses working in cooperation with the family doctor and/or specialist palliative care team
- In hospices (dedicated specialist palliative care in-patient units)
- In general hospitals, by the hospital's specialist palliative care team
- In community hospitals and nursing homes, by home-care nurses working in cooperation with the family doctor and/or specialist palliative care teams

Palliative care is provided by the HSE in partnership with voluntary service providers. Both public and private patients can use the in-patient units and other services.

A referral for palliative care services can be made in a number of ways; through a GP or through a hospital doctor in consultation with the GP, or through the hospital's specialist palliative care team in consultation with the GP. Enquiries can also be made to HSE Local Health Offices and the Irish Hospice Foundation – contact details for the Foundation are at the end of this document.

Refusing medical interventions and Advanced Healthcare Directives

A person in Ireland who is judged to have the mental capacity to make decisions regarding their own healthcare can refuse medical interventions, including life-sustaining treatments. The Assisted Decision-Making (Capacity) Act 2015, which was passed by the Oireachtas on 17th December 2015, provides a legal framework for someone to make an Advanced Healthcare Directive about their future healthcare, should they lose capacity to make decisions at some point in the future. The Irish Hospice Foundation and the Forum for End of Life Care in Ireland have produced a briefing paper on Advanced Healthcare Directives which provides the following 12 key information points:

- Advance Healthcare Directives have been recognised in common law for some time but the new Act provides for a legislative framework
- Under the new provision, a person aged 18 and over who has capacity can prepare an Advance Healthcare Directive
- They must put their decisions on future medical treatment in writing and their Advance Healthcare Directive must be witnessed
- A person can revoke an Advance Healthcare Directive **at any time** in writing providing the person still has capacity to do so
- No-one can be forced to create an Advance Healthcare Directive
- Having witnesses to the Advance Healthcare Directive is designed to prevent people being forced to make certain decisions
- Individuals can nominate people who will be legally recognised as acting on their behalf at a time when they lose capacity and can ensure their Advance Healthcare Directive is enforced
- An Advance Healthcare Directive only comes into force when someone has lost capacity and cannot make a decision
- Having an Advance Healthcare Directive helps healthcare professionals in caring for people in the way they want
- Having an Advance Healthcare Directive helps families as it removes doubt about what care their loved one wanted
- If there is any doubt about an Advance Healthcare Directive, a person can go to the courts
- This is not euthanasia or assisted suicide. These acts are illegal in Ireland.

Assisted suicide V's. euthanasia

There are important distinctions between assisted suicide and euthanasia. Euthanasia is the act of deliberately ending a person's life to relieve suffering, such as a doctor giving a person who is terminally ill an overdose. Assisted suicide is the act of deliberately assisting or encouraging another person to kill themselves. An example might be purchasing drugs for someone who you knew intended to use them for the purpose of suicide.

Assisted suicide and euthanasia in Ireland

Ireland has some of the strictest laws on assisted suicide and euthanasia in Europe. Both are currently illegal. Depending on the circumstances, euthanasia would be classified as either murder or manslaughter with a maximum sentence of life imprisonment. Assisted suicide carries a maximum penalty of 14 years in prison. As things stand, this includes assisting someone to travel to a country such as Switzerland, where assisted suicide is legal. To date, there have been no successful prosecutions for assisted suicide in Ireland

Relevant Irish cases

A number of high-profile cases of people living with multiple sclerosis seeking the right to die have hit the Irish media in recent years. In 2013, Marie Flemming took her case for the right to die as far as the Supreme Court. The Court found that there is no constitutional right to die in Ireland. However, the panel of judges on the case said that there was nothing in the judgment that prevented the State from introducing legislation to deal with similar cases in the future.

In 2014, Gail O'Rorke was arrested and charged in relation to attempting to assist the suicide of her friend, Bernadette Forde after a travel agent alerted Gardai that they suspected Gail O'Rorke had booked flights to Switzerland so Bernadette Forde could attend the Dignitas clinic there. Gail O'Rorke was also accused of helping Bernadette Forde to obtain barbiturates for the purpose of taking an overdose. In April 2015, Gail O'Rorke was found not guilty of these charges.

MS Ireland's position on palliative care and treatment decisions in advanced MS

MS Ireland respects the autonomy and ability of persons with MS and their families to make their own choices regarding their own lives, within the boundaries of the law.

MS Ireland believes that:

- People with MS should be empowered and equipped to make fully informed decisions about their treatment and care at all stages of the disease
- People with MS have the right to be treated with dignity and respect, as per human rights legislation. For some, this may require the provision of appropriate palliative care that encompasses a range of personal care and pain management services. The aim of such care

should always be to minimize suffering and maximize independence and quality of life for the individual, for as long as possible

- Continued and targeted investment is needed in palliative care services in Ireland, to ensure that no person with MS has to experience unnecessary suffering if they are faced with the progression of their condition to an advanced stage. At present, regional discrepancies exist in the provision of palliative care services and this issue must be addressed by the HSE and the Department of Health

MS Ireland is often asked by the media to comment on particular cases where an individual is seeking the right to die. MS Ireland is unable to comment on such individual cases.

Contacts for support organizations

MS Information Line - 1850 233 233

A list of MS Ireland's regional offices, where you can make contact with our Regional Community Workers, can be found here: www.ms-society.ie/pages/what-we-do/contact-us

The Irish Hospice Foundation provides information on palliative care services. Their website is www.hospicefoundation.ie. Their phone number is 01 679 3188. There is also further information on palliative care for advancing neurological conditions at www.hospicefoundation.ie/healthcare-programmes/palliative-care/palliative-care-for-all/advancing-neurological-illness/

References

www.hse.ie/eng/health/az/E/Euthanasia-and-assisted-suicide/

www.nhs.uk/conditions/euthanasiaandassistedsuicide/pages/introduction.aspx

www.thejournal.ie/explainer-assisted-suicide-2045083-Apr2015/

www.irishtimes.com/news/ireland/irish-news/john-halligan-moves-bill-allowing-assisted-end-to-life-1.2467713

Information about palliative care services was taken from:

www.citizensinformation.ie/en/health/health_services/cancer_services/palliative_care.html

www.ms-society.ie/pages/living-with-ms/carers-/palliative-care

Information regarding refusing medical interventions and the Assisted Decision-Making (Capacity) Act was taken from "A Briefing Paper on Advanced Healthcare Directives" prepared by the Forum on



End of Life in Ireland and the Irish Hospice Foundation. This document can be accessed at www.thinkahead.ie/wp-content/uploads/2016/01/Advance-Healthcare-Directives-Briefing-Paper-January-2016.pdf

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