

The Palliative Care Needs of People with Advancing Neurological Disease in Ireland

Key Messages

Introduction

Many advancing neurological diseases are progressive, chronic conditions, that impact on the physical, intellectual, emotional, social and economic life of the person and their family. This document outlines key findings from an Irish Hospice Foundation (IHF) & Neurological Alliance of Ireland (NAI) study which sought to explore and identify the palliative care needs of people with advancing neurological disease from of 7 NAI member organisations (See list overleaf).

Project Aim

The aims of this study were to:

- Investigate NAI member organisations understanding of palliative care.
- Investigate how NAI member organisations identify and respond to the palliative care needs of their members.
- Provide a greater understanding of the palliative care needs of people with advancing neurological conditions.
- Give direction to the supports, resources and developments required to respond to needs identified.

- 1.** Ambiguity exists around the terminology of palliative care. Palliative care is primarily associated with specialist palliative care services.
- 2.** The following issues arise when palliative care is discussed -
 - Sensitivity of the topic
 - Difficulty accessing specialist palliative care services
 - The need for Planning Ahead
 - The increased requirement for training
 - Uncertainty when palliative care should begin
- 3.** The following themes were identified by the study participants as a means of enhancing palliative care available to people with advancing neurological disease:
 - Greater understanding of the symptoms and unpredictable and progressive nature of those with advancing neurological disease – with additional focus on need for nutritional advice, support with anxiety and depression, access specialist equipment and identifying the dying phase.
 - Emphasis on interventions that support quality of life and planning ahead
 - Availability of palliative care approach earlier in the disease trajectory
 - Enhanced multi-disciplinary and psycho-social care
 - More timely referral to specialist palliative care
 - That Specialist Palliative Care Services are available to people with advanced neurological disease on an equitable basis
 - More training available to support all staff in identifying and responding to the palliative care needs of people with advanced neurological disease

Project Partners

The project was funded by the IHF in collaboration with the NAI. The Neurological Alliance of Ireland member organisations that participated in this research are:

Brain Tumour Ireland
Cheshire Ireland
Huntington Disease Association of Ireland
Multiple Sclerosis Ireland
Motor Neurone Disease Association of Ireland
Parkinson's Association of Ireland
Progressive Supranuclear Palsy Association Ireland

Recommendations

Recommendations are set out in the following four areas:

1. Awareness and Planning Ahead

Those with advancing neurological illness have distinctive palliative care needs. Palliative care needs to be introduced early in neurological care with the concept of planning ahead and quality of life. Advanced care planning guidance is required

2. Multidisciplinary Approach

Multidisciplinary approach should be adopted as the 'norm' within neurological care. Palliative care is integrated in this approach and consequently the routine care of people.

3. Specialist Palliative Care Services

Protocols are required to promote equity of access to specialist palliative care services for **ALL** neurological conditions. Greater clarity is required from palliative care services regarding the services they provide.

4. Training, Resources & Research

More information on palliative care training available to be provided to NAI member organisations. NAI member organisations need to support their staff to access training and education. Funding is required to resource the research & work of clinicians with expertise in neurological conditions to support the development of palliative care for people with advancing neurological illnesses.

Next Steps

IHF and NAI will seek ways to work in collaboration with other relevant stakeholders to take the following steps forward in addressing the palliative care needs of people with advancing neurological illnesses:

1. Awareness and Planning Ahead

-The unique palliative care needs of people with advancing neurological illnesses will be an integral part of both organisations awareness raising campaigns.
-IHF and NAI encourage others to engage in Advanced Care planning.

2. Multidisciplinary Approach

-IHF and NAI encourage others to work in a multidisciplinary manner.
-IHF and NAI encourage others to Introduce the concept of palliative care early in neurological illness.

3. Specialist Palliative Care Services

-Both organisations will continue to advocate and seek ways to promote equity in accessing specialist palliative care services throughout Ireland.
-Specialist Palliative care services are encouraged to provide information regarding services available.

4. Training, Resources and Research

-IHF will seek ways to engage with family carers of those with neurological illnesses to address their palliative care needs.
-IHF and NAI encourage others to engage in training and education

4. Work with relevant stakeholders

-IHF and NAI will work with relevant stakeholders to support the development of palliative care for people with advancing neurological conditions through all stages of the disease

The report is available for download from the Irish Hospice Foundation website:
<http://hospicefoundation.ie/what-we-do/palliative-care-for-all/advancing-neurological-illness/>

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