Foreword:

I welcome this briefing paper that outlines some of the work that is occurring in Ireland in relation to identifying the palliative care needs of people with neurological illnesses. It is important to remember that palliative care is for people living (as opposed to dying) with chronic and progressive illnesses. The entire construct is about the preservation of quality of life, and the importance of understanding the person in the context of their entire life, and not merely in the context of their illness. It is in this context that this report serves as a means to understanding the holistic needs of the 700,000 people who are living with neurological illnesses in Ireland. The report seeks to provide direction to health planners, providers and voluntary organisations to more adequately address the palliative needs of people with advancing neurological illnesses throughout the country.

It is well recognised that most chronic neurological illnesses are incurable, and that the focus of care necessarily relies on good symptom management. The palliative care approach is increasingly being recognised throughout neurological care since the publication of “The Palliative Care For All Integrating Palliative Care into Disease Management Frameworks” report in 2008. However, it remains the case that neurological illnesses continue to be inadequately managed in Ireland.

In 2014 the Neurological Alliance of Ireland and the Irish Hospice Foundation commissioned a piece of work to outline the palliative care needs of people with advancing neurological disease from the perspective of Neurological Alliance of Ireland member organisations. This work signalled the start of a conversation about palliative care and neurological conditions in Ireland. Specifically outlined is the requirement of increased training and education about both neurological and palliative care and the requirement of a more integrated multidisciplinary approach. The report of this work, “The Palliative Care Needs of People with Advancing Neurological Disease in Ireland” was published and launched at a meeting in November 2014.

The launch of that report in the Irish Hospice Foundation in late 2014 brought together a range of healthcare professionals, academics and researchers with an interest in addressing the palliative care needs of people with neurological illnesses. The launch and meeting served as an important forum to share current work and discuss the role of palliative care in caring for people with neurological illnesses. The meeting also served as a means to identify how best to embed the conceptual framework inherent in the palliative approach toward clinical management within the larger domain of neurological care.

This briefing paper outlines the structure and content of November’s meeting. Six pieces of current Irish research addressing the palliative care needs of people with advancing neurological disease in Ireland are discussed and the next steps are outlined. Over twenty key opinion leaders participated in the November meeting, signalling the growing interest and role of palliative care as an essential part of neurological care. I am proud to be involved in this work and look forward to our continued participation in building services that address the palliative care needs of those with progressive neurological illness.

Prof. Orla Hardiman
Head of Academic Neurology Trinity College
Dublin & Consultant Neurologist, Beaumont Hospital, Dublin.

Prof. Orla Hardiman BSc, MD, FRCPI.

Irish Hospice Foundation, Morrison Chambers, 32 Nassau Street, Dublin 2.
Aim:

This meeting sought to strategically address the palliative care needs of people with advancing neurological conditions in Ireland and provide a platform to:

- Share current work and developments addressing the palliative care needs of people with advancing neurological conditions
- Encourage future synergy in service development, research and education provision
- Inform current models of care that are under development within the Neurology, Palliative Care and Gerontology Clinical Care Programmes.

The meeting comprised of two sessions. The first session was chaired by Professor Orla Hardiman and consisted of seven ten minute presentations about Irish projects that have/are addressing palliative care for people with advancing neurological illness. During this session the joint Neurological Alliance of Ireland (NAI) and Irish Hospice Foundation (IHF) report "The Palliative Care Needs of People with Advancing Neurological Disease in Ireland" was launched. This report is available online on the IHF and NAI websites or by clicking [here]. The second session was a discussion among those present about palliative care for people with neurological illnesses in Ireland. This session identified service and research gaps and also provided direction for the future of palliative care for people with advancing neurological illnesses in Ireland. This session was chaired by Sharon Foley, CEO, IHF.

Attendees:
The meeting was attended by twenty people with representation from Neurology voluntary organisations, researchers, academics, the Neurology National Clinical Care Programme, healthcare workers to include a Neurology consultant, Palliative Care consultants, nurses, psychologists and physiotherapists.

The Meeting:

Professor Orla Hardiman opened the meeting giving a personal reflection of her experience of caring for people with a neurological illness and spoke about how previously palliative care was not discussed within neurological care. Professor Hardiman spoke of the importance as a medic of addressing palliative care for people with neurological illnesses before introducing the presenters below. (These presentations are available on the IHF website click [here]).

Mags Rogers, Development Manager, Neurological Alliance of Ireland.
Palliative care needs of people with advancing neurological disease & report launch
(Completed and available online [here]).

Mags is leading the implementation of the report findings.

Contact: Mags Rogers, Development Manager, Neurological Alliance of Ireland, Coleraine House, Coleraine St, Dublin 7. Ph: 01-8724120
Email: naiireland@eircom.net

Siobhan Fox, Research Support Officer, University College Cork.
Palliative care needs in Parkinsons disease
(Due to be completed October 2015).

David Hegarty, Physiotherapist, St Francis hospice
Physiotherapy led exercise programme for Parkinsons disease patients
(Completed, awaiting publication).

Geraldine O’Callaghan, Physiotherapist.
Physiotherapy management of Motor Neurone Disease
(Completed and available online [here]).

Mary Rabbitte, Our Ladys Hospice & Care Services & Dublin City University.
Psychological and psychotherapeutic approaches for Motor Neurone disease patients
(Project completed, awaiting report).

Amanda Callan, Head of Clinical Support Services, Cheshire Ireland.
Dying with dignity in disability services in Ireland
(Project completed, awaiting report).

Marie Lynch, Head of Healthcare Programmes, Irish Hospice Foundation.
Overview of Irish hospice Foundation dementia and palliative care projects
(Due to be completed September 2016).
The second session consisted of questions and answers to presenters which was followed by discussion about the opportunities and challenges of addressing palliative care within neurological care. There appeared to be a hunger among those present to drive the issue of palliative care for people with advancing neurological illnesses forward. The issues that arose in the discussion centred on the following issues:

1. EDUCATION:
It was pointed out that many healthcare professionals involved in the care of people with advancing neurological illness do not receive adequate education in palliative care and advanced communication skills to support assessment and identification of palliative care needs. The education needs of carers was also highlighted.

2. SERVICES:
Discussion was generated around the place of care delivery with many agreeing that community care was most appropriate for people with advancing neurological illness. The specific challenges with this were raised and included the inability of consultants to refer people to specialist palliative care services in the community. Access to community palliative care services was highlighted as being variable and location dependant and some services were reported as being effective but working in isolation.

3. AWARENESS:
There was consensus that more awareness is required as to how palliative care benefits people with advancing neurological illness and their carers, particularly with regard to improvements in quality of life. It was also agreed that there needs to be more clarity as to how palliative care can be integrated into the routine care of the neurological team, as well as triggers for referral to specialist palliative care.

4. MULTIDISCIPLINARY TEAM INVOLVEMENT:
Collaboration among all healthcare professionals was strongly advocated and noted as being of crucial importance when providing care to people with advancing neurological illnesses, and this approach underpins the philosophy of palliative care. In particular effective communication among team members was noted to be of importance, particularly linking community based staff with specialists teams, and the value of palliative rehabilitation.

5. ADVOCACY, RESEARCH AND DISSEMINATION:
There was agreement among those present that the palliative care needs of people with advancing neurological illnesses requires more attention and research. Messages sent about this should be unified in nature, linked to emerging evidence from research and policy positions, and addressed at European and international levels as well as relevant national fora. Particular reference was made to the forthcoming consensus paper from Oliver et al addressing palliative care for patients with progressive neurological disease which is due for general circulation in 2015, as well as the work of the Joint Programme – Neurodegenerative Disease.

Next Steps:

Based on the findings from the Joint report “The Palliative Care Needs of People with advancing neurological disease in Ireland” the key messages from the presentations at the roundtable and the ensuing presentations, IHF and NAI will seek ways to work in collaboration with other relevant stakeholders so that the palliative care needs of people with Advancing neurological disease are routinely considered. The actions to support this work are listed below.

1. AWARENESS OF PALLIATIVE CARE
   a) IHF will seek ways to raise awareness of the need for and benefit of palliative care for people with advancing neurological disease with relevant groups including the Irish Association of Palliative Care, the Irish Palliative Medical Consultants Association, the All Ireland Institute of Hospice and Palliative Care, the Irish Neurological Association and NAI. This will include Power Point with summary information on the findings of the Joint Report.
   b) IHF and NAI will raise awareness to Health Care Professionals of the benefit of engaging in discussions about preferences for future care and advanced care planning as part of routine care planning with people with advancing neurological disease.
   c) IHF will seek ways to provide practical support to family carers as they care for their family member with advancing neurological disease, including the development of an information leaflet, to assist them in understanding palliative care and the benefits of planning ahead.
   d) In collaboration with the NAI and other interested parties, IHF will seek to arrange a seminar addressing the palliative care needs of people with advancing neurological illnesses in 2016
   e) Commitment was also made by IHF and NAI to provide this summary of the roundtable meeting to be available for general circulation.

2. MULTIDISCIPLINARY APPROACH
   • IHF and NAI encourage all HCP to work in a multidisciplinary manner.
   • IHF and NAI will encourage all members of the multi-disciplinary team to integrate a palliative care approach early in the disease trajectory of those with advancing neurological illness.
   • IHF and NAI will present issues raised via research and discussion to relevant National Clinical Care Programmes (Neurology and Palliative Care) and seek to link this work with the Integrated Care Pathway currently under development by the HSE.
3. SPECIALIST SERVICES

• Both organisations will continue to advocate and seek ways to promote equity in accessing specialist palliative care services and services of neurology teams throughout Ireland.

• It is recommended that Specialist Palliative care services will provide information regarding how their services support people with advancing neurological disease.

4. TRAINING, RESOURCES AND RESEARCH

• IHF and NAI will continue to highlight the research gaps that exist for people with advancing neurological illnesses.

• IHF and NAI encourage all health care staff (particularly medical and nursing staff), to engage in palliative care training and education, with reference to the recently published palliative care competence framework.

• IHF will offer adapted end of life communication training (based on ‘What Matters To Me’) to NAI member groups that participated in the IHF & NAI research.

• Both the IHF and NAI Websites will have links to this subject area, which will be regularly updated.

This work was carried out as part of the IHF Palliative Care for All Programme that is continuing to seek ways to ensure that all people with a life limiting illness access the care and support that they need.

Resources:

All Ireland Institute of Hospice and Palliative Care. Available at: http://www.aiihpc.org/ [Accessed: 15 January 2015]

European Association of Palliative Care (2014) EAPC taskforce on the development of guidelines and a core curriculum for the palliative care for people with neurological disease Available at: http://www.eapcnet.eu/Themes/SpecificGroups/PeopleWithNeurologicalDisease/GuidelinesCurriculumTaskforce.aspx [Accessed: 18 November 2014]


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