

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

A Report Prepared for the Neurological Alliance of Ireland and the Irish Hospice Foundation

By **Dr. John A. Weafer**

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PREFACE

Neurological Alliance of Ireland

There is increasing recognition of the need to adopt a palliative care approach in relation to people with progressive neurological conditions. Understanding the specific nature of these conditions and the experiences of individuals and their families is vital to inform a response to these needs. Life-limiting progressive neurological conditions present a particular set of challenges and experiences to people with neurological conditions and their families. There can be considerable variation in the time period involved, but in all these conditions, there is a realisation associated with the condition, which requires all those involved to engage in supportive planning for the later stages of the condition. The requirement to develop services and responses to the palliative care needs of people with progressive neurological conditions has been recognised in the UK and the development of a framework in that jurisdiction has provided a useful starting point to examine the situation here in Ireland.

The Irish Hospice Foundation and the Neurological Alliance of Ireland are engaged in a collaborative relationship to open a conversation about palliative care and neurological conditions in Ireland. We recognise that this engagement must include all those involved, from those living with neurological conditions and their families, to services and organisations that work to support them throughout their illness.

The current research aims to begin a dialogue around the experience of people with progressive neurological conditions and their families from the perspective of voluntary organisations. These organisations are often engaged in a unique relationship with the individual and family, in many cases lasting throughout the duration of the person's life and often providing a source of support for family members after bereavement. Some of those involved in these organisations have themselves been affected by neurological illness in a family member and bring their perspective to supporting others affected by the condition.

The Alzheimer Society of Ireland have pioneered discussions about palliative care and dementia, providing an important impetus for people working with individuals and families with this neurological condition to explore the often difficult and challenging issues involved and develop a way forward to support their needs. With the support of the Irish Hospice Foundation, the Alzheimer Society of Ireland have led the way in providing a framework for examining and understanding palliative care and dementia from the perspective of all those affected. The Alzheimer Society had an advisory role in this research study.

The findings of this study point to the key role of those working with people with neurological conditions and their families in initiating and supporting discussions about palliative care. They highlight the importance of training and guidelines for staff and volunteers in order that information and appropriate guidance is provided at key points and in a supportive dialogue with the individual and family. There are important recommendations for engaging in a palliative care approach throughout the care pathway, not just at the late stages of the condition. We recognise that the findings of this research must be shared, and a discussion opened with all those involved before we and our partners in the Irish Hospice Foundation can arrive at an understanding and a way forward in relation to the palliative care needs of Irish people with neurological conditions.

Mags Rogers

Development Manager

Neurological Alliance of Ireland

IRISH HOSPICE FOUNDATION

The Irish Hospice Foundation aims to achieve dignity, comfort and choice for all people facing the end of life, and one of our key programmes (Palliative Care for All) seeks to ensure that people with diseases other than cancer receive appropriate access to palliative care. So we were delighted to work in partnership with the Neurological Alliance of Ireland to investigate how their member organisations integrate and consider the palliative approach to care as part of their role. The Irish Hospice Foundation are indebted to those individuals who agreed to participate in this research, and are also grateful to John Weafer who conducted the research so deftly.

The findings from this research, which was funded by the Irish Hospice Foundation, support the rationale for addressing the palliative care needs of those with advancing life limiting disease; however, its conclusions also highlight the sensitivities and inhibitors that prevent the timely introduction of the palliative approach to care in all care settings. The report also notes the individual journey that people with advancing neurological disease and their families need to take as they address the decline associated with their disease. These findings, whilst not surprising, are salient and deliver key messages to service providers and policy makers.

The Irish Hospice Foundation looks forward to working with the Neurological Alliance of Ireland and its member organisations in implementing the recommendations. We also welcome opportunities to disseminate the findings to health service providers and planners, so that the palliative care needs of people with advancing neurological diseases in Ireland can be recognised and responded to appropriately.

Marie Lynch

Programme Manager

Irish Hospice Foundation



ACKNOWLEDGEMENTS

I would like to thank the organisations that commissioned this research – the Neurological Alliance of Ireland (NAI) and the Irish Hospice Foundation (IHF). The project was funded by the IHF. I would also like to thank the members of the Working Group who guided and supported the project (Appendix C). I would like to thank the representatives from the following organisations who participated in the study.

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 (PSPA) Ireland

EXECUTIVE SUMMARY

The main aim of this study is to explore the palliative care needs of people with advancing neurological conditions from the perspective of Neurological Alliance of Ireland (NAI) member organisations. The study was carried out by an independent researcher, Dr John A. Weafer, with guidance and oversight from the Project Working Group (See Appendix C). In January 2014, a schedule of interviews was arranged with 14 representatives from seven NAI member organisations (see appendix C). The main findings from the research are as follows:

1. Palliative Care Terminology

Most the research participants spontaneously associate palliative care with the specialist palliative care services provided to people who are in the final stages of life. Many of them reported that they are uncomfortable discussing palliative care in case it upsets people. However, their understanding of palliative care is evolving from its traditional focus on death and specialist palliative care to one that is increasingly holistic, relatively long-term, and with an emphasis on quality of life and enabling people with life limiting disease to live well. It is a slow process and a number of respondents believe that attitudinal and behavioural change to shift this focus will require time and continued education for individuals with neurological conditions and everyone concerned with their care.

2. Issues Surround Palliative Care

The respondents identified a number of issues that arise when palliative care is discussed in NAI member organisations.

Sensitivity of Topic

The topic of palliative care is considered very sensitive and challenging in most organisations and accordingly, little or no discussion takes place on palliative care unless the individual or their carers/family members initiate the conversation. Organisations are also reluctant to distribute information on palliative care to their members or to include the topic in meetings in case it upsets people. This creates a situation where individuals and carers can be left without information they could find helpful. However, the situation is changing, albeit slowly, and organisations will give out information or refer the individual to a medical specialist if they are requested.

Accessing Palliative Care Services

Some people with advanced neurological conditions reported difficulty accessing palliative care services due to a perception that the condition is too chronic and complicated, and therefore not suitable to specialist palliative care services. A number of respondents also noted a reluctance on the part of some health professionals to refer individuals to specialist palliative care.

Quality of Services Available

Most respondents are critical of the range and quality of services that are available for their members. The neurology and palliative care services are generally perceived to be fragmented, lacking coordination, concentrated in a few specialist centres, lacking sufficient specialist staff with expertise and experience in palliative and neurological care, and under-resourced. Overall, respondents indicated that the needs of people with advanced neurological conditions are not being met by existing services.

Uncertainty when Palliative Care Should Begin

The respondents are uncertain regarding the most appropriate time to initiate 'the conversation' on palliative care and when palliative care should begin. The literature states that conversations on palliative care should commence when the individual is ready, and that staff need to open the discussion at key transition points in the person's journey. All agreed on the important role of the neurologist in adopting a palliative care approach and in referring to specialist palliative care.

Planning Ahead

Most respondents felt that individuals and their carers should be encouraged and assisted to plan ahead for their condition. This is particularly important when cognitive deterioration is one of the disease's symptoms.

Training

A number of respondents highlighted the need for training in palliative care for all those who accompany the person on their journey.

3. Addressing the palliative care needs of people with advancing neurological conditions

In order to meet the palliative care needs of people with advancing neurological conditions, there needs to be improvements in: multi-disciplinary clinical and psycho-social care; nutritional advice; specialist equipment, availability of palliative approach to care earlier in the disease trajectory and a more timely referral of individuals to palliative care services. There also needs to be a greater awareness of potential anxiety and, depression associated with living with advancing life limiting neurological disease, the triggers for the end of life/dying phase; the unpredictable and progressive nature of these conditions, and the value of advance care planning. Providing a greater understanding (through training, education and awareness) of the palliative care needs of people with advancing neurological conditions by medical and nursing staff, will support equity in the provision of all levels of palliative care for the full range of neurological conditions.

4. Role of Voluntary Organisations

The primary role of the NAI member organisations that participated in this study is to resource and support individuals with a life-limiting neurological condition and their families/carers, which would include information on palliative care. They are also concerned with raising awareness of the condition they support. For the most part, as they do not employ staff with medical expertise, they usually refer medical queries to the appropriate specialists. While they don't have protocols in place to identify when someone is entering the final phase of life, or when to prompt conversations on palliative care, some of the organisations have staff who will know from experience when significant change is happening. They will not usually initiate a conversation on palliative care or end-of-life, but they will respond with information or a referral if they are approached by an individual or carer. Recognition was given to advocacy organisations as regards to their role in raising awareness and supporting education developments in this area.



RECOMMENDATIONS

Awareness and planning ahead

1. The literature suggests that individuals with advancing neurological conditions benefit from early and ongoing palliative care intervention, appropriately timed, throughout the life of their disease to support them living well with their condition. The evidence from the present study supports this position. However, many people are fearful of discussing matters relating to palliative care, and as a result some people do not benefit from palliative care at appropriate times.

a) It is recommended that IHF and NAI disseminate the findings from this study to health care professions, in an effort to highlight the distinctive palliative care needs of people with advancing neurological conditions and the key messages from this study.

b) To support the early introduction of the palliative approach to care it is recommended that GPs, neurologists, members of the neurology multidisciplinary team, and other health care professionals should introduce the concept of future planning and focus on quality of life measures as part of their overall treatment goals. It is recommended that the IHF and the NAI continue with its programme of education and awareness-raising on the nature and benefits of palliative care for those with advancing neurological diseases to the wider population.

2. Planning ahead is considered to be a critical aspect of palliative care, and this can be very challenging when an individual's cognitive function deteriorates.

c) It is recommended that all organisations are made aware of the IHF Think Ahead programme, and other advance care planning tools and that protocols are agreed to provide guidance on salient planning issues, such as how to start these conversations and communicate these discussions and decisions with other key health care professionals.

Multidisciplinary Approach

3. The literature also suggests that a multidisciplinary approach, (comprising neurologists, specialist palliative care teams, nursing teams, primary care teams, psychologists and allied health professionals with experience and expertise in providing care to people with advancing neurological disease), is required to address the complex palliative needs of these individuals and their families.

d) It is recommended that a multi-disciplinary approach is the norm in all parts of the country.

e) That palliative care is integrated into the multidisciplinary approach, and therefore into the routine care and treatment of people with advancing neurological conditions.

Palliative Care Services

4. The present study suggests that some neurological conditions have more difficulty accessing specialist palliative care services than other life limiting conditions and that NAI member organisations are unsure of the extent of service available from specialist palliative care.

f) It is recommended that protocols are put in place which would promote equality of access to palliative care services for all neurological conditions.

g) It is recommended that palliative care services provide greater clarity with regard to the services they provide to people with advancing neurological disease.

Training, Resources and Research

5. A number of organisations stated that they would like training and resources to help them respond more effectively to the palliative care needs of their members.

h) It is recommended that more information on the range of palliative care training available is provided to relevant member organisations of the NAI.

i) It is recommended that NAI member organisations support their staff to access palliative care education and training, with assistance from the IHF and Specialist Palliative Care education providers.

6. The input of clinical expertise is critical to the development of care pathways for individuals with advancing neurological conditions and the control of and management of pain and other symptoms needing palliative care.

j) It is recommended that funding is sought to resource the research and work of clinicians with expertise in neurological conditions to support the development of palliative care for people with advancing neurological conditions through all stages of the disease.



CHAPTER 1

INTRODUCTION AND BACKGROUND

The care of people with long-term neurological conditions is often complex and varied due to the symptoms they face and the rate of progression of the disease. This will vary from case to case but most people will deteriorate, dying as a result of their condition (National End of Life Care Programme, 2010, p.3).

1.1 Introduction

Ireland has a long and credible tradition in caring for people with advanced and life limiting illness. In some cases, the care is provided by specialist palliative care services, while in many other cases, palliative interventions and support are being delivered by primary care teams, health professionals in disease-specific services, and family members. The focus of the present study is on the understanding and provision of palliative care for people living with advanced neurological conditions in Ireland. Approximately, 700,000 people in Ireland live with a neurological condition, representing approximately 17 per cent of the total population of Ireland (Neurological Alliance of Ireland, 2010). There are various types of neurological conditions, including Acquired Brain Injury, Cerebral Palsy, Dementia, Epilepsy, Huntington's Disease, Multiple Sclerosis, Motor Neurone Disease, Stroke, and Parkinson's Disease, all of which adversely affect the brain or spinal cord. While each of these groups share some similar palliative care needs, they also have distinctive needs, and research suggests that some groups have a greater need for palliative care support than others (Kristjanson et al., 2005).

It is increasingly acknowledged that people with advanced neurological conditions face 'complex problems and needs that are often unrecognised and undertreated' (Hussain et al., 2013, p.162). Many of these diseases are progressive, chronic conditions, which impact on the physical, intellectual, emotional, social and economic life of the person and their family. Indeed, many people die as a result of their neurological condition. For example, it is estimated that in Ireland one person dies with Motor Neurone Disease every five days (O'Toole, 2014). However, while neurological conditions share some characteristics in common, they are also quite different to each other, with implications for palliative care. For example, while a person with Motor Neurone Disease may experience a rapid progression of their condition, the progress for a person with Parkinson's Disease is often much slower, although there can be considerable variation and uncertainty concerning every individual's disease trajectory.

During the past twenty years or so, tangible progress has taken place in the provision and awareness of palliative care in Ireland. Specialist palliative care services have been developed, the importance of palliative care has been acknowledged in Irish health policy (Appendix A), and independent organisations such as the Irish Hospice Foundation (IHF) have been to the forefront in identifying and promoting equal access to quality end-of-life and palliative care, regardless of age, diagnosis, or geographical location (Appendix A). The

provision of appropriate and timely palliative care is also a concern for most of the stakeholders in this study (Huntington's Disease Association of Ireland, 2013). The IHF has also commissioned a number of research projects to identify and understand the public's attitudes towards dying, death and bereavement (McCarthy et al., 2009, McCarthy et al., 2010, Weafer, 2004, Weafer et al., 2009, Weafer, 2014 (forthcoming)), and a number of policy-related documents (Irish Hospice Foundation, 2006a, Irish Hospice Foundation, 2006b, Irish Hospice Foundation, 2009, Irish Hospice Foundation, 2010b). Other organisations, such as the Alzheimer Society of Ireland and the Neurological Alliance of Ireland have also published salient research on this topic (The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012, The Alzheimer Society of Ireland, 2013, Neurological Alliance of Ireland, 2010). In brief, palliative care is an area of growing prominence for organizations concerned with long-term neurological conditions.

Neurological disorders represent one of the greatest threats to public health (World Health Organization, 2006). In 2006, the World Health Organization estimated that the cost associated with neurological conditions in Europe was €139 billion, a figure that exceeded the total costs associated with the treatment of respiratory diseases in Europe (€102 billion). However, in spite of the significant amount of funding spent in treating people with neurological conditions, individuals often experience difficulties gaining access to specialist neurological or rehabilitative services during key stages of their illness (McClinton and Byrne, 2009, Neurological Alliance of Ireland, 2010). A joint report by the IHF and the Health Service Executive in 2008, *Palliative Care for All*, reported that not all groups receive equal access to the palliative care they need, including people living with non-malignant diseases, such as dementia, heart failure and chronic obstructive pulmonary disease (COPD) (Irish Hospice Foundation and Health Service Executive, 2008). Two years later, a report by the Neurological Alliance of Ireland (NAI), *The Future of neurological Conditions in Ireland*, wrote of the 'historical underdevelopment of specialised services at every stage of the care pathway' (Winslow, 2010, p.96). Similar observations have been made by health professionals in the UK, where research indicates that in spite of policy changes to improve access to high-quality care for all individuals approaching end of life irrespective of their diagnosis, 'only a small proportion of individuals with non-malignant disease, including neurological conditions, access specialist care services' (Hussain et al., 2014, p.30). Research and anecdotal evidence suggests that many people living with long-term neurological conditions in Ireland and the UK do not receive the palliative care they need due to a number of factors including: a 'serious shortage' of specialists and the concentration of specialist in-patient services at national level (Neurological Alliance of Ireland, 2010, p.43); the 'fragmentation of services' located in the community (Department of Health, 2011, p.7); and healthcare professionals do not have sufficient 'knowledge and skills' on how 'to provide coordinated, integrated, neurological care' (McClinton and Byrne, 2009, p.160). In Australia, some commentators believe that there is a 'reticence' to accept referrals for people with long-term neurological conditions, from both patient and family perspectives, as well as health professionals' experiences (O'Connor et al., 2011).

Providing appropriate care in the last stages of life can be 'ethically, practically and clinically challenging' (McClinton, 2010, p.108). For example, knowing when a person with an advancing neurological condition is approaching end of life and what their wishes are can be very problematic to determine. Unlike most people living with cancer who can 'communicate well into the disease process what their wishes are and what they would like to happen', many people living with long-term neurological conditions 'have not been able to communicate verbally for years' (McClinton, 2010, p.108). It is also increasingly accepted that cognitive impairment in advanced neurological conditions is 'more

prevalent and occurs at earlier stages of the disease trajectory than was previously recognised' (Hussain et al., 2013, p.162). Thus, in spite of the acknowledged value of advance care planning, the reality is that 'end-of-life issues are rarely discussed with patients with an advanced neurological conditions' (Hussain et al., 2013, p.162). Furthermore, 'many will have an unsatisfactory experience in the last year or so of their life' (Hussain et al., 2013, p.162).

Historically, palliative care is generally perceived as a specialist medical discipline that provides treatment and support to people dying from cancer and individuals who are in the final stages of life. In 2005, for example, the vast majority (95%) of patients receiving palliative care in Ireland had a cancer diagnosis (Carlos Centeno et al., 2007). A similar focus on dying from cancer is also found in many other countries, such as the UK (McClinton and Byrne, 2009). Consequently, it is argued that the palliative needs of people with advanced neurological conditions have not been adequately recognised or addressed (Neurological Alliance of Ireland, 2010, McClinton and Byrne, 2009). However, this situation is changing in Ireland and the UK, where there is currently 'much interest regarding the needs of people affected by non-malignant disease and whether or not these are being met by palliative care services' (Travers et al., 2007, p.125).

1.2 Rationale for the Study

The present study has been commissioned for a number of reasons. First, the IHF and the NAI believe that the provision of a range of palliative care supports would improve the quality of life for people with advancing neurological conditions. Second, the stakeholders in this research have become increasingly concerned that the palliative care needs of people with advancing neurological conditions are not adequately understood or addressed in Ireland. Third, there is a shortage of information in Ireland on the palliative care needs of people living with advancing neurological conditions.

1.3 Aims and Objectives of the Study

The main aim of this study was to address the palliative care needs of people with advancing neurological conditions from the perspective of Neurological Alliance of Ireland (NAI) member organisations.

The study was guided by five objectives:

- To investigate the NAI member organisation's understanding of palliative care.
- To investigate how NAI member organisations identify and respond to the palliative care needs of their members.
- To determine what issues arise when palliative care needs are discussed in NAI member organisations.
- To provide a greater understanding of the palliative care needs of people with advancing neurological conditions.
- To give direction to the NAI, the IHF, and diverse statutory and voluntary service providers regarding further supports, resources and developments that is required to respond to the palliative care needs of people with advancing neurological disease.

1.4 Methodology

Further to the terms of reference for the study, the research was divided into two inter-related parts, a literature review and a series of qualitative interviews with NAI member organisation representatives. The primary aim of the literature review was to provide context to the study and to identify the challenges and issues that could be expected to arise if a palliative care approach were introduced in Ireland. In the first instance, a literature review was conducted of relevant policy documents in Ireland and the UK, which addressed the topic of palliative care for people with advancing neurological disease. This was followed by a general search of the EBESCO database, and a more focused search of three journals, the British Medical Journal, the International Journal of Palliative Nursing, and the British Journal of Neuroscience Nursing. This is a relatively new field of study and consequently the number of published empirical studies is quite limited. However, this trend is changing and a number of studies have been published and a number of important studies on long-term neurological conditions are ongoing in Ireland.

Following a meeting with the Working Group in January 2014, a schedule of interviews was arranged with 14 representatives from seven NAI member organisations: Cheshire Ireland, Brain Tumour Ireland, Huntington's disease Association of Ireland, Irish Motor Neurone Disease Association, Multiple Sclerosis Society of Ireland, Parkinson's Association of Ireland, and the Progressive Supranuclear Palsy Association (PSPA) Ireland. These organisations were asked to participate because their clients were most likely to have advancing neurological diseases. The interviews were conducted in the three-month period, January to March 2014, with a range of staff, volunteers and carers identified by each of the organisations.

A qualitative research approach was deemed most appropriate for the study because of the exploratory nature of the research and the relatively narrow focus of the study. Exponents of qualitative research believe that this approach makes it possible for the researcher to 'explore a wide array of dimensions of the social world, including the texture and weave of everyday life, the understandings, experiences and imaginings of our research participants, the ways that social processes, institutions, discourses or relationships work, and the significance of the meanings that they generate' (Mason, 2002, p.1). Thus, the primary focus of qualitative research is on understanding rather than statistical measurement.

1.4.1 Limitations

No research method is perfect and qualitative research, like its quantitative counterpart, is perceived to have limitations and potential biases. One issue is that the findings of qualitative studies cannot be taken as statistically representative of any larger group because they typically use relatively small samples. This contrasts with the 'primary goal' of quantitative research in sampling, which is to get a representative sample 'such that the researcher can study the smaller group and produce accurate generalisations about the larger group' (Neuman, 2003, p.210). However, this was never the focus of the present study. Rather, like other comparable social research, its primary goal was to produce data from a relatively 'small collection of cases' that would 'illuminate social life' (Neuman, 2003, p.211).

Finally, it should be noted that the views expressed by the research participants are their personal views based on their experience of working with, and on behalf of, people with advancing neurological conditions. Accordingly, unless otherwise stated, the research findings should be regarded as indicative but not necessarily representative of the policy of the seven organisations that participated in the study. There is clearly a need to build on the findings of this project by engaging in a much wider consultation, involving all the stakeholders, including people with neurological conditions and their families in order to more thoroughly explore the experiences of this group and to determine a way forward based on the evidence from both the qualitative and quantitative research studies.

1.5 The Structure of the Report

Following this introductory chapter, the terminology of palliative care is briefly discussed in chapter two, followed by a review of literature on issues surrounding the palliative care of people with advancing neurological conditions in chapter three. The main findings from the research are summarised in chapter four. A summary of the findings and the recommendations are outlined in the Executive Summary section of the report. An overview of the policy context of palliative care in contemporary Ireland and a brief profile of the key stakeholders are appended.

CHAPTER 2

THE EVOLVING TERMINOLOGY AND UNDERSTANDING OF PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation)¹

2.1 Introduction

The terminology of palliative care has evolved during the past fifty years, suggesting a changing mindset and understanding of palliative care. Up to the 1970s, care of the dying was usually referred to as 'terminal care' and most of the treatment occurred in hospital settings (Fallon and Smyth, 2008). During the 1980s the concept and philosophy of 'palliative care' gained more widespread acceptance amongst statutory agencies, medical specialists, and independent organisations working in this field². More recently, the terminology has begun to evolve once again to reflect the emerging viewpoint that palliative care is more of a continuum than can extend over a relatively lengthy period of time, and that it comprises different levels of care³. The traditional view of palliative care implies a relatively tight time-line, where death is imminent and the disease trajectory is relatively certain. The New Zealand Palliative Care Strategy, for example, suggests that palliative care should 'generally be available to people whose death from progressive illness is likely within 12 months' (New Zealand Ministry of Health, 2001, p.3). Similarly, most of the integrated care pathways, such as the Liverpool Care Pathway and the Manchester Care Pathway, are used to cater for the palliative care needs of patients in the final days of life. Even when the timeframe is extended to include patients that are not perceived to be actively dying or suffering from cancer, such as the (Birmingham) Supportive Care Pathway's focus on older people, the timeframe is considerably shorter than that experienced by many individuals with advancing neurological disease.

¹ www.who.int/cancer/palliative/definition/en/

According to the World Health Organization (WHO), palliative care provides relief from pain and other distressing symptoms it affirms life and regards dying as a normal process; it intends neither to hasten or postpone death; it integrates the psychological and spiritual aspects of patient care; it offers a support system to help patients live as actively as possible until death; it offers a support system to help the family cope during the patients illness and in their own bereavement; it uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; it will enhance quality of life, and may also positively influence the course of illness; and it is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

² A number of key organisations working in the area of palliative care were formed in the 1980s and the early 1990s. The Irish Hospice Foundation (IHF) was founded in 1986; the Irish Association for Palliative Care (IAPC) was established in the early 1990s; and in 1995 the Irish Medical Council approved palliative medicine as a medical speciality.

³ <http://hospicefoundation.ie/what-we-do/palliative-care-for-all/advancing-neurological-illness/13398-2/when-is-palliative-care-appropriate>

In recent years, some groups have begun to use 'end-of-life' care instead of, or in addition to palliative care to take account of disease trajectories that are less certain and spread over a longer period of time. The concept of end-of-life care is increasingly being used as 'a generic term in preference to palliative care when considering the needs of people with conditions other than cancer, particularly in community settings and long-stay care settings' (O'Shea et al., 2008, p.25). The Irish Hospice Foundation (IHF), for example, uses end-of-life to refer to all aspects of the care provided to a person with a life-limiting illness, from the time of diagnosis through the last months of life, up to and including the final hours. A number of national strategies have also adopted end-of-life as an appropriate concept for their work, such as the UK's End of Life Care Strategy (Department of Health, 2008). However, not everyone accepts this understanding or use of the term 'end-of-life', while others use the concepts of palliative care and end-of-life care interchangeably. In many countries, the distinction between end-of-life care and palliative care has become 'increasingly blurred' through the 'diversification and expansion of palliative care within all facets of medicine, not just oncology, and its expansion into different care settings (O'Shea et al., 2008, p.26).

A number of countries, such as Northern Ireland and Canada, have used both palliative care and end-of-life care virtually interchangeably (Department of Health, 2009, Health Canada, 2007). ⁴The Northern Ireland document, for example, perceives end of life care to be 'an integral part of palliative care' which 'helps all those with advanced progressive and incurable conditions to live as well as possible until they die' (Department of Health, 2009, p.23). The World Health Organization also suggest that palliative care need not be confined to the last days or hours of life when it advocates that palliative care is 'applicable early in the course of the illness' (WHO, 2002). The IHF also use both concepts, although its understanding of palliative care includes a concern with quality of life and not just the traditional focus on the active dying phase. While acknowledging the inconsistency and variability in the terminology used to describe palliative care (Fallon and Smyth, 2008), both concepts are used interchangeably in this study unless otherwise stated.

2.2 The Continuum of Palliative Care

Palliative care is increasingly concerned with an individual's quality of life and not just about the final stages of their lives. Thus, while the provision of specialist palliative care in dedicated palliative care facilities is a central part of palliative care, it is increasingly accepted that palliative care includes both a specialist service and an over-arching approach to end-of-life care. It is 'both a philosophy of care and an organised highly structured system for planning and delivering care' (Department of Health, 2009, p.14). It is a philosophy that affirms person-centred and holistic care, and an approach to care that promotes comfort through relieving pain and other symptoms. The IHF believes that there are three levels to palliative care (Irish Hospice Foundation and Health Service Executive, 2008):

Level One: Palliative Care Approach

Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. This level refers to the practice of palliative care principles by all health care professionals. Its aim is to promote both physical and psychosocial well-being.

⁴ The document states that palliative and end of life care 'is both a philosophy of care and an organised, highly structured system for planning and delivering care' (Department of Health, 2009, p.14).

Level Two: General Palliative Care

This is an intermediate level of care, which is provided by health care professionals with some training and experience.

Level Three: Specialist Palliative Care

Specialist palliative care services are those services with palliative care as their core speciality. The services are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine. Specialist palliative care services are available within primary care settings, acute general hospital settings and specialist inpatient units i.e., hospices.

The value of providing different levels of palliative care for individuals with neurological conditions is gaining momentum amongst Irish and UK policy makers and support groups (The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012, Irish Hospice Foundation and Health Service Executive, 2008, National End of Life Care Programme, 2010, Neurological Alliance of Ireland, 2009). In 2010, for example, the UK National Council for Palliative Care, in association with the Neurological Alliance UK, and the NHS National End of Life Care Programme published a document on End of life care in long term neurological conditions (National End of Life Care Programme, 2010). The authors of this report suggest that since palliative care for people living with advancing neurological conditions is often required over an extended period of time, due to the progressive nature and variability of disease-specific issues, this care will necessarily require more than specialist care at different points in the disease trajectory. The model they propose is one where palliative care specialists share their expertise and experience with others concerned with quality of life of the patient e.g., neurologists, elderly care physicians, rehabilitation consultants, psychiatrists, nurse specialists, physiotherapists, occupational therapists, dieticians, speech and language therapists, psychologists and social workers, nursing homes and community hospitals. They believe that this will ensure that the 'the person's wishes are central to care plans and that each member of the team is clear about their roles and responsibilities' (National End of Life Care Programme, 2010, p.10).

While the practical application of palliative care principles for individuals with long term, neurological and non-malignant illnesses has been difficult to achieve (O'Connor et al., 2011), the results of a small but increasing number of empirical studies endorse the benefits of palliative care. In her qualitative study of dementia, for example, MacConville argues that palliative care has a value and that it should be provided from the time of diagnosis (MacConville, 2011); O'Toole observes that palliative care could have alleviated suffering in her study of people with Motor Neurone Disease (O'Toole, 2014); and in the UK, Embrey's study of patients with Multiple Sclerosis noted the holistic benefits of palliative day-care therapies on physical, psychological and social aspects of life with MS (Embrey, 2009).

2.3 Concluding Comment

In summary, the concept of palliative care is complex and changeable, comprising different levels of care that is provided by a range of specialist medical staff and other health professionals. It is a concept that has evolved to reflect the increasingly held view that palliative care operates along a continuum of care, from the early stages of the person's illness to the final phase when they are actively dying. This viewpoint is particularly relevant to people with advancing neurological conditions, who traditionally would not have received palliative care until the final stages of their lives, if at all. Medical opinion and the views of various organisations, including the NAI and the IHF believe that a palliative care approach would improve the quality of life for persons with a neurological condition and that it should be integrated within their routine care and treatment. This is a view that is supported by a small but growing body of empirical research (MacConville, 2011, The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012). However, this process is not straightforward and the literature suggests that some challenges and obstacles will have to be overcome. The nature of these challenges is explored in chapter three.

CHAPTER 3

THE PALLIATIVE CARE NEEDS OF PEOPLE WITH ADVANCING NEUROLOGICAL DISEASE

Bringing about change within health care provision is particularly challenging because of the complex relationships that exist between a wide variety of organisations, professional groups, patients and carers and the HSE. Seeking to extend palliative care to people with non-malignant diseases is no exception (Irish Hospice Foundation and Health Service Executive, 2008, p.49)

3.1 Introduction

At one level, the palliative care needs of people living with advancing neurological conditions are similar to anyone else in the final stage of their lives. Some individuals in this situation require access to and support from specialist palliative care services in the final hours and days of life. In some countries recognised tools are in place that can identify and address their palliative care needs e.g., the Gold Standards Framework.⁵ However, at another level, the situation is more complex for people living with long-term neurological disease, particularly when the disease trajectory is uncertain and prolonged. Research and anecdotal evidence suggest that neurological conditions often have a progressive and terminal trajectory, with a requirement for extended care and access to different levels of palliative service that is not usually required by patients with other malignant diseases, such as cancer (Irish Hospice Foundation and Health Service Executive, 2008, National End of Life Care Programme, 2010, Department of Health, 2005). Thus, while people in the advanced stages of long-term neurological conditions may need specialised care services, it is increasingly acknowledged by some observers that they may also need a longer and ‘a less intensive engagement with palliative care services than people with cancer’ because of the prolonged nature of some neurological conditions (Department of Health, 2005, p.52). A greater awareness and understanding of the specific care needs of individuals with long-term neurological conditions could, according to some commentators, be fostered by the development of disease-specific care pathways that would identify the services and care that is required by individuals throughout the lifetime of their disease trajectory (Brown and Sutton, 2009, Byrne and Beety, 2007, Huntington’s Disease Association of Ireland, 2013, Murray et al., 2008, Sutton, 2008).

Some commentators believe that extending palliative care beyond cancer has been ‘hampered’ by a combination of factors in the UK and possibly also in Ireland, including ‘prognostic uncertainty, funding difficulties, a lack of palliative care clinicians with expertise in non-malignant diseases, and a hitherto relatively weak evidence base in relation to appropriate models of care’ (Murray et al., 2008, p.958). Other potential barriers to the expansion of the notion and practice of palliative care include, the widely accepted traditional view of palliative care as a relatively short-term intervention that is provided by specialists, and the increasing demands being made of the health services. However, this situation is changing, albeit relatively slowly, and seminal documents and policy statements

have been published in the UK and Ireland, amongst other countries, identifying the benefits and challenges of providing non-specialist palliative care for people with advanced neurological conditions (Department of Health, 2005, Irish Hospice Foundation and Health Service Executive, 2008, National End of Life Care Programme, 2010).

3.2 The Palliative Care Needs of People with Advancing Neurological Conditions

The UK National Service Framework for Long-term Conditions framework published in 2005, for example, includes a quality requirement for palliative care, which says that 'People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care' (Department of Health, 2005, p.51). Progress was slow, however, and five years later, a report that focused on end of life care in long term neurological conditions was published by the NHS National End of Life Care Programme, in conjunction with the Neurological Alliance and the National Council for Palliative Care (National End of Life Care Programme, 2010). The authors of this influential report, End of life care in long term neurological conditions, stated that palliative care 'can improve quality of life throughout the disease progression' (National End of Life Care Programme, 2010, p.3). However, they also acknowledged that this task would entail a number of challenges, including the following:

- The long duration of the disease
- Recognition of the end-of-life phase
- Potential for sudden death e.g., Motor Neurone Disease
- Lack of predictable course, or fluctuating course e.g., Parkinson's disease
- Complex multidisciplinary care e.g., Multiple Sclerosis, Huntington's Disease
- Specialist treatments e.g., deep brain stimulation in Parkinson's disease
- Neuro-psychiatric problems e.g., behavioural and cognitive changes
- Rapidly advancing diseases may need palliative care early on
- Many people die with but not from their neurological condition
- Neurological conditions are widely variable, making planning end-of-life care challenging
 - Many people with neurological disease face cognitive change, making it necessary for the person and their carers to discuss end-of-life at a relatively early stage

Some people may require complex and often invasive interventions that may be complicated by ethical issues, such as withdrawal of treatments. The authors of this report believe that services providing care for people with advancing neurological conditions should be 'co-ordinated, personalised, effective and integrated – and treat individuals with dignity and respect' (National End of Life Care Programme, 2010, p.32). One of their key recommendations concerns the importance of communicating with people who have neurological conditions, so that they can understand as much as they want to know about their disease, be aware of what may happen as their disease progresses, feel empowered to make informed choices over their future care, and feel that their views and

preferences have been heard and understood. Hence, they believe that Advance Care Planning is very important for people with neurological disease and that changes in neurological disease progression are recognised in all care settings 'as triggers for the introduction and subsequent involvement of palliative care' (National End of Life Care Programme, 2010, p.5). A subsequent study of the seven 'triggers' recommended by the National End of Life Care Programme (2010), found that four symptoms explained most of the variance: rapid physical decline; significant complex symptoms, including pain; infection in combination with cognitive impairment; and risk of aspiration (Hussain et al., 2014). The study suggests that these triggers can identify the terminal phase of the disease in most cases, thereby facilitating the provision of appropriate and timely access to palliative care for individuals with advanced neurological conditions. A number of other studies have also noted the complexities and challenges that face people with advanced neurological conditions, including a number of unmet needs (Hussain et al., 2013).

Another UK study found that many people with end-stage Huntington's disease were accommodated in environments unsuited to their needs, in nursing homes, mental health units, or community hospitals. This same study identified a number of unmet needs including, housing, social services contact, financial advice, carer support and input from professionals, such as physiotherapy and speech therapy (Skirton and Glendinning, 1997). A relatively large quantitative Australian study found that individuals with long-term neurological conditions, and especially Motor Neurone Disease and Huntington's Disease, experienced anxiety and depression, and low quality of life (Kristjanson et al., 2005). A UK study found that patients with Parkinson's Disease were not usually referred to specialist palliative care services but suggested that they would benefit from a referral (Saleem et al., 2012).

A number of Irish studies have also explored the palliative care needs of people with advanced neurological conditions, such as Dementia and Motor Neurone Disease. One important study, 'Opening Conversations' commissioned by the Alzheimer Society of Ireland, for example, equates palliative care with 'a good death', in which there is 'a level of acceptance and peace on the part of the dying person and also of their families'. In order for this to happen, the study suggests that 'attention needs to be paid to the multi-dimensional needs – physical, emotional, social and spiritual – of the dying person and their families'. However, 'these needs call for considerable preparation by way of integrated interventions prior to the actively dying phase' (p.38). O'Toole's research found an uneven pattern in the care of people with Motor Neurone Disease in the Irish health system, and she concluded that the suffering of some people with Motor Neurone Disease could have been alleviated by palliative care. A study on Parkinson's disease funded by the IHF is ongoing through UCC (Timmons, 2015 (forthcoming)).

3.3 Concluding Comment

In summary, the literature review suggests that palliative care is beneficial for people with advancing neurological conditions, and that the care should ideally be provided from early on in the course of the disease. However, due to the unpredictable, progressive, and prolonged nature of neurological conditions, it is likely that palliative care would be provided for longer but less intensively in the early phases of the illness. The long duration of the disease is just one of the challenges facing individuals with advancing neurological conditions. Other challenges that impinge on the quality of life and death of people living

with long-term neurological conditions include a variable and rapid progression of the disease, symptoms that are distressing for patients and their carers/families, a reticence by the patient and his/her carers to use palliative care services because they associate palliative care with dying, a reluctance by GPs and other health professionals to refer patients, the fragmentation and inadequate resourcing of appropriate specialist palliative care services, the impact of cognitive difficulties on the capacity of patients to plan ahead and the complex nature of their condition which often entails multiple symptoms. The perceived needs of Irish people with advancing neurological conditions are discussed in chapter four.

CHAPTER FOUR

THE RESEARCH FINDINGS

4.1 Introduction

In this final chapter, the main findings from the research are summarised under the following headings:

- How do NAI member organisations understand palliative care?
- What issues arise when palliative care needs are discussed in NAI member organisations?
- What are the palliative care needs of people with advancing neurological conditions?
- How do NAI member organisations identify and respond to the palliative care needs of their members?
- What direction would the member organisations like to give the NAI, the IHF and others regarding further supports, resources and development that are required to respond to the palliative care needs of people with advancing neurological conditions?

4.2 How do NAI member organisations understand palliative care?

The Terminology of Palliative Care

The terminology of palliative care and other associated concepts, such as end-of-life care, is considered to be confusing and frightening for many people. Most of the research participants believe that people are generally frightened by the notion of palliative care because it is typically associated with cancer, hospice care, and imminent death. It is 'fearful' and 'shocking' and 'no one wants to talk about it'. Many individuals and their carers are fearful that the person will 'drop dead at any minute' if they discuss palliative care, so best to avoid it entirely until 'it happens'. Some verbatim comments⁶ illustrate their views on this point.

Most people think of cancer and death when they hear palliative care.

Most people will take it that it is absolutely end of life; there is no hope for a cure or any medical care that can improve their life. Their condition has reached the advanced, terminal stage and there is nothing that can be done for them.

⁶ Some words have been changed or omitted from the verbatim quotations in order to protect the confidentiality of the respondents. References to specific neurological conditions have also been removed.

There is confusion in understanding in the community. A lot of our clients would feel frightened by talk of end of life management. They think of the neighbour down the road who died, particularly the older generation, and there are a lot of comparisons made. When they hear hospice, the word is very frightening.

There is no cure for this disease and it is a very frightening space for people, especially those recently diagnosed.

Most people associate palliative care as the end, and end of life as the very last stages of this process. Palliative care is holistic but end of life is just 'that's it'. Fear is huge and you don't want to upset the person because when you do, their whole day is upset.

Conversely, some respondents said that they and other members who have experienced palliative care in their own families found it to be 'wonderful' and that it gave them a new lease of life. One woman said 'it made her feel like herself again because she received so much care and they explained to her and her husband how to care for different issues'. Unfortunately, for too many people it is closely associated with death and dying, and not with improvement of quality of life or relief of complex symptoms, with the result that people who could benefit from palliative care are too afraid to access services that would improve their quality of life.

The use of an alternative terminology, such as end-of-life care, is perceived to be even more frightening and upsetting than palliative care because it reinforces the final stages of life.

End of life care is too stark and it does not capture the full meaning of palliative care.

It is just so frightening for the person and it can be very subjective. Palliative care is a better term to use when saying that it extends life and quality of life, not the end of life.

The end of anything is never good. Nobody wants anything to end if there is any sort of quality of life there. Thinking Ahead or Going Forward would be better. People prefer to think they are on a journey or going through a process. I don't like the word 'end' in that context.

When asked if they could suggest a terminology that would capture the essence of palliative care and lessen the fear factor, most respondents were unable to suggest any terminology that would be more appropriate. One person suggested 'support for life-limiting conditions' instead of palliative care 'which can be a scary word'. Conversely, others said that the way the service is delivered is more important than how it is described, while another felt that the use of terminology such as 'comfort care' for general palliative care could ultimately be counterproductive as 'it just feeds into the idea that palliative care is only for people who are dying'. They suggested that a 'better' course would be for people to be educated on the true meaning of palliative care, which whilst addressing symptom management focuses on quality of life and holistic care.

NAI Member Organisations' Understanding of Palliative Care⁷

The NAI member organisations' understanding of palliative care is currently 'under review', with most respondents spontaneously associating palliative care with the final stages of a person's life. However, their view of palliative care is changing and a number of respondents said they increasingly understand palliative care to be an approach that is broader than the specialist services provided by palliative care teams to people who are actively dying. In their view, palliative care has as much, if not more, to do with symptom management and quality of life, as dying. Furthermore, they can see that palliative care is different for their members because of the prolonged nature of the illness.

Conversely, since many of their members are fearful of palliative care, most organisations are reluctant to discuss or to provide information on palliative care to their members. One respondent, for example, believes that there is 'a huge lack of understanding of palliative care' in her organisation and that once people hear palliative care, 'there is no conversation'.

The whole terminology makes people uncomfortable. When they hear palliative care they think of cancer and people dying; they think of morphine pumps and the horrible noises people make when they are dying. It is just fear and some people believe we should be promoting well-being and not talking about dying.

This situation is changing however and most of the research participants indicated that they and their organisations are 'slowly moving towards' a more balanced and positive understanding of palliative care, which associates palliative care with the long-term management of a life-limiting illness. Increasingly, they see palliative care as a holistic process that looks after the individual and the carer.

We tell our clients that we use palliative care services to manage their condition on a day-to-day basis and that it is not about end of life. Rather, it is just another tool in the community to assist them with their care.

I see palliative care as part of the process of Thinking Ahead and focusing on the trajectory of the person's condition. Now that I am more familiar with palliative care and the different levels, I am not so frightened but others are still frightened.

From my experience, palliative care is a pain-free, comfortable, end of life experience with multi-disciplinary teams around you to tend to your needs, which can be many and varied.

End of life is about preparing for the very end; palliative care is about the approach that is taken to get there and make end of life more comfortable. There is no cure for the condition but the symptoms can be managed and their quality of life improved. Palliative is about making the most of what you have and being able to do what you can for as long as you can do it, to give people more dignity. When speech begins to go, there is a lot of excess saliva, and this can be very embarrassing but there are medications that can help reduce this and alleviate the condition without curing it. Physiotherapy can stop cramps and spasms. All this is palliative.

When you hear palliative, you just think that's it, even though I have grown to understand that palliative can be for life-limiting conditions and a person might live for 10 years with a life-limiting condition or longer.

For me and many of my colleagues, it is around something that is not end of life. We would see palliative care as a combination of general and specific, and that people are providing a general palliative care service to people who are transitioning through various stages of their lives with the disease and they need more intensive care and clinical support towards the end. I would see palliative care as providing physical, emotional and spiritual support to people along the course of their disease journey/trajectory.

For me palliative is the relief of pain; I am going to keep you comfortable and make sure you have no pain. For me, it has an end of life connotation because you are not going to get better. This could be a good length of time but it definitely includes an end point. What you have is not going away.

Palliative care is about managing symptoms associated with a non-curable condition. Ideally, you see palliative care is a continuum that begins when a person's life begins to change following diagnosis and which changes as a person transitions through various stages of their lives. It is about maintaining quality of life, pain management and symptom control. In practice, however, palliative care has an end of life connotation because people are not going to get any better from their illness, and everyone knows that people with a life-limiting disease will require more intensive care and clinical support towards the end of their lives. Palliative care is about 'providing physical, emotional and spiritual support towards the end of their lives'.

Palliative care is an approach but it has a service dimension also. It is the way you work with people and the support you provide.

I know there are different levels of palliative care and I believe that all professionals should have some understanding of palliative care. That is the kind of support people need when they get a life-limiting diagnosis. That initial support should be there to talk through the problems they will face and know they will be supported on this journey. To know that there are points they will need more support but that the support will be there.

Their evolving understanding of palliative care has been influenced by a number of factors, including the personal experiences of staff and volunteers in caring for somebody close to them, attendance at conferences where the topic was discussed, the publication of policy reports and empirical studies concerning the palliative care needs of people with advanced neurological conditions, information provided by the NAI, and especially through the ongoing work of the IHF. Two respondents said that they had changed their views of palliative care during the course of this research. Both of them have come to understand that palliative care is an approach that can respond to a person's needs in a non-specialist way, and include diverse therapies

I would have said before the meeting in the Irish Hospice Foundation that we didn't provide palliative care and that we are not a palliative care organisation, but now I believe we provide palliative care informally. We wouldn't refer to what we do as palliative care but yet we say that people with this disease should be treated as

palliative from the day of diagnosis to make their symptoms easier to manage and a better quality of life. It is a palliative approach but the term is not used. We will continue to do what we do no matter what we call it but it is eye opening to see what we do as part of the longer-term palliative care picture.

In summary, most the research participants spontaneously associated palliative care with the specialist palliative care services provided to people who are in the final stages of life. Many of them, like most of their clients and their carers, are uncomfortable discussing palliative care in case it upsets people. Accordingly, most organisations have been reluctant to provide information on palliative care to their members or to discuss it in public meetings with their members. However, the situation is changing, albeit slowly, and they will give out information or refer the individual to a medical specialist if they are requested. Their understanding of palliative care is increasingly one that is holistic, relatively long-term, with a focus on quality of life and living well rather than exclusively death, and is inclusive of non-specialist care. The broader interpretation of palliative care is perceived to be consistent with their ethos and practice of care. However, it is a slow process and a number of respondents believe that change will require time and continued education for individuals with neurological conditions and everyone concerned with their care.

4.3 What issues arise when palliative care needs are discussed in NAI member organisations?

The respondents identified a number of challenges that arise when palliative care needs are discussed in their organisations. First, as previously discussed, the topic of palliative care is considered very sensitive and accordingly, little or no discussion takes place on palliative care unless the client or their carers/family members initiate the conversation. Organisations are also reluctant to distribute information on palliative care to their members in case it upsets people. They feel they have to be careful in what they say at meetings because most individuals and carers are struggling to deal with the disease on a day-to-day basis and are not ready to hear certain things. Very often, individuals attending meetings are at different stages of diagnosis and they may have very little knowledge if any of what lies ahead for them with this disease. Their main tasks are providing information and raising awareness of the condition and advocating for the needs of their members. This is especially the case with rare conditions where most people, including medical staff, are perceived to have little knowledge of the condition.

Fear is the big thing.

Unfortunately for many people it does mean the very end of life and for most people it is associated with cancer. Many people are fearful and in denial when it comes to palliative care, and they would prefer to avoid any mention of palliative care even when it is clearly needed.

When I hear palliative care, I think of death. Having gone through it with my own dad. I probably have a very negative view of palliative care but that is what other people feel too.

The 'fear factor' is also perceived to be a significant reason as to why some people with advanced neurological conditions do not access palliative care services.

There is very little uptake of palliative services by our clients and this probably leads to more discomfort. Their deaths could be made easier and less harrowing for family members if they were not in so much pain. We have to educate people to realise that palliative care is not just about dying.

Second, some respondents noted that people with advanced neurological conditions report difficulty in accessing specialist palliative care services due to a perception by some that the condition is too chronic and complicated and therefore not suited to specialist palliative care services. On occasion, GPs and other health professionals are reluctant to refer a patient to palliative care services 'before their time', thereby making the person's life less comfortable than it could be. Others may not refer the person at all because the disease has no cure.

A lot of the time, palliative care is not accessible for our members because their condition is too complicated. The medics are slow to mention palliative care when a patient is first diagnosed or even to tell them much about the condition. People are left to wonder why their loved one is choking. A lot of time is lost before a person gets a diagnosis

If you ring a GP to request palliative care, a lot of them will ask if that is ok when the person doesn't have cancer. A lot of people think palliative care is just for cancer care. I knew one GP who told me he had three patients with our condition on his books but he had never referred to a neurologist because they know they have it and there is nothing that can be done.

Some respondents also gave examples of instances where individual health professionals showed a lack of understanding and compassion for individuals with advanced neurological conditions.

I had a very negative experience with a nurse, when I requested an air mattress for my mother to prevent bedsores because she spent all day in bed. She was entitled to it but the nurse thought it was a waste if she got one because she was palliative and didn't have long left. To me, this showed a complete lack of compassion and understanding and respect for someone in palliative care.

Third, most respondents are critical of the range and quality of services that are available for their members. Neurology and Palliative care services are perceived to be fragmented, lacking coordination, concentrated in a few specialist centres situated in cities, lacking sufficient specialist staff with expertise and experience in palliative and neurological medicine, and are under-resourced. Consequently, there is a perceived requirement for resources that would permit more clinical input, respite care, specialist equipment, and more research. A number of respondents felt that people with advanced neurological conditions should not be cared for in a nursing home because of their need for specialist long-term facilities that are not readily available in a nursing home e.g., specialist nurses, physiotherapist, occupational therapists, dietician, speech and language therapist etc. A number of respondents were also very critical of the lack of information given to patients by medical staff when they are diagnosed.

In general, the services are terrible and there is little support for people with this condition. You are told nothing, apart maybe that there is no cure or that the prognosis doesn't look good. I had no idea what to expect when my mother was released home.

The doctors don't tell you that neurological conditions are not like cancers, that a person's brain and personality will be affected, that they may not be able to drive or plan their lives. Most of the people who contact us are overwhelmingly negative about the service they receive.

You have to go to Dublin or Cork to see a (neurology) specialist. There is huge inequality around Ireland regarding the availability of palliative care. It very much depends on where you live. Some counties are very poorly served while others have a hospice, which offers excellent palliative care service. In some parts of the country, there is no palliative care for people who don't have cancer. The palliative care teams don't have the resources to deal with this type of protracted death.

It is a very poorly managed service, with very long waiting lists when you have been diagnosed. A big problem is the poor knowledge of neurological conditions because of poor neurology services, especially for conditions that are relatively rare.

Conversely, other respondents are quite satisfied with the care given to their members. Most satisfaction was expressed by the longer-established organisations, where a clinical specialist supported their condition and where the condition has traditionally been supported by palliative care services.

We would like to continue as we are. Our clients get a very good deal from palliative care services and we know we are a lot luckier than other groups. We have good access to frontline staff and they support us very well. It would be good, perhaps, if there were more services for people who need longer term care but who don't need a specialist care setting but there is nowhere else for them to go.

Fourth, the respondents are uncertain regarding the most appropriate time to initiate 'the conversation' on palliative care. In an ideal world, most of the research participants believe that palliative care should be provided from the start of the illness when a person has to come to terms with their diagnosis of an incurable disease. Ideally, palliative care should be introduced gradually as just another part of the care process.

The sooner people get palliative care the better.

Palliative care is needed early on for people with this condition because people have issues with mobility, eye-sight, speech and swallow, choking chest infections, apathy and depression. A huge issue is that many doctors are unfamiliar with the condition, it is difficult to diagnose and frequently misdiagnosed so it can take a number of visits to different doctors before the condition is finally diagnosed. Many doctors are unable to tell people much about the condition, so it is often up to the person to look it up themselves. This means that time is lost in providing appropriate care in these progressive conditions and patients are unaware of the services available.

Conversely, others believe that palliative care should start some years into the condition when the carer cannot cope anymore or when the symptoms of the disease indicate that the individual requires additional specialist attention. The latter situation is perceived to be more realistic given the shortage of resources in the health system. All agreed that a neurologist, supported by appropriate medical staff, should provide the diagnosis and follow-up medical care. The role of their organisations is to support the person and to provide them with the information they need to understand the system, so that they don't feel isolated or abandoned.

Palliative care is needed from the start when change starts to happen. The first change is that people have to accommodate the news. In an ideal world, palliative care should start from diagnosis because it is a life-limiting disease but there are insufficient resources, which make this impossible. If we refer people too soon, we may overload the system and it would not be available for people who need it in the final months of life. It is better to introduce palliative care when the individual needs it most.

One or two years seems like a long time to be receiving palliative care, especially if the person is able to move around and to take part in activities. You just don't know when a person's health is going to take a turn for the worst but palliative care is needed most closer to the end.

This should happen two to three years into their condition when a person has more frequent falls, more difficulties eating and swallowing, depression and apathy. Palliative care caters for pain control and discomfort and a referral to the palliative care team is needed once the person is in pain.

Palliative care should start at home when the carer begins to struggle. It can be done gradually. If you bring in someone from palliative care, they can be just another person offering care. The care becomes part of the multidisciplinary team.

Fifth, most respondents felt that patients and their carers should be encouraged and assisted to plan ahead for their condition, this is particularly important when cognitive deterioration is one of the disease's symptoms. However, they are aware that this will require a sensitive approach. While most of the respondents were unaware of the **Think Ahead** initiative by the IHF, most agreed that it could be very useful for their members. Sixth, a number of respondents highlighted the need for training of all persons who accompany the patient on their journey.

In summary, this section has identified some of the issues that arise when palliative care is discussed, or rather often not discussed, in NAI member organisations.

1. The topic of palliative care is considered very sensitive and challenging in most organisations and accordingly, little or no discussion takes place on palliative care unless the client or their carers/family members initiate the conversation. Organisations are also reluctant to distribute information on palliative care to their members in case it upsets people. This creates a situation where patients and carers can be left without information they could find helpful.
2. Some people with advanced neurological conditions can experience difficulty accessing specialist palliative care services due to a perception by some that the condition is too chronic and complicated, and a reluctance on the part of some health professionals to refer patients to specialist care.
3. Most of the organisations are critical of the range and quality of services that are available for their members. The services are perceived to be fragmented, lacking coordination, concentrated in a few specialist centres, lacking sufficient specialist staff with expertise and experience in palliative and neurological care, and are under-resourced.

4. The respondents are uncertain regarding the most appropriate time to initiate ‘the conversation’ on palliative care and when palliative care should begin. All agreed that a neurologist, supported by appropriate medical staff, should provide the diagnosis and follow-up medical care.

5. Most respondents felt that patients and their carers should be encouraged and assisted to plan ahead for their condition. This is particularly important when cognitive deterioration is one of the disease’s symptoms.

6. A number of respondents highlighted the need for training in palliative care for all persons who accompany the patient on their journey.

4.4 What are the palliative care needs of people with advancing neurological conditions?

The main palliative care needs of people with advancing neurological conditions identified by the respondents are as follows (Table 4.1)

Table 4.1 Palliative care needs of people with advancing neurological conditions

Palliative Care Needs	Description
1. Clinical input from neurologists and specialist staff.	Pain and symptom management; multi-disciplinary care of complex needs; clinical staff and research.
2. Psycho-social care of individuals and their carers (before and after the person dies).	More concern with the person living rather than the disease. Multi-disciplinary care and holistic approach to the different non-physical needs of individuals and their carers e.g., emotional, social and spiritual. Awareness of possible anxiety and depression amongst patients and their carers.
3. Availability of palliative care earlier in the disease trajectory.	Acknowledgement of the relatively long duration and unpredictability of the disease, and the benefits that can result from the provision of different levels of palliative care at different stages of the disease. More timely referral of individuals to palliative services, especially with rapidly advancing conditions.
4. Improve range and quality of palliative care services.	Less fragmented and more coordinated services; more services nationwide; more resources for respite care, night nursing, nutritional advice, speech and language, equipment to help people communicate etc. Some individuals find access to services more difficult than others. Palliative care should be accessible for people with different conditions and people who do not live in the geographic area served by a palliative care team.

5. Recognition of end-of-life phase.	Research to establish more accurate triggers of the end-of-life phase.
6. Acknowledge unpredictability of diseases.	Awareness of the potential for sudden and unexpected progression of the disease, and death.
7. Awareness and understanding of different neurological conditions	Some medical staff are perceived to know little about rarer conditions. Some diseases require specialist treatments.
8. Planning Ahead	Cognitive and behaviour change can make planning ahead challenging, especially if left too late in the process. Individuals should be given every opportunity to make informed choices about their future care. IHF Think Ahead document or similar.
9. Staff informed, confident and sensitive in anticipating people's needs	Training is required for carers and health professionals on understanding and responding to the needs of people with advancing neurological conditions.
10. Increasing focus on quality of life	Provide individuals with interventions and activities that impact positively on their quality of life.
11. Staff adopt approach that acknowledges respect and dignity of the person	Some health care professionals, carers and individuals lack an understanding of the condition e.g., cognitive and behavioural change, an awareness that resources are not 'wasted' on people who are dying of an incurable condition.
12. General information and support.	Knowing where to get help and information Being present to the person, responding to questions.

The primary palliative care need for people with advancing neurological conditions is for a multi-disciplinary team that caters for their needs from diagnosis to death. Their needs are often complex and multi-dimensional, and the team composition needs to reflect this reality e.g., neurologist, specialist nurses, physiotherapy, occupational therapist, dietician, psychologist, public health nurse, GP, and a range of non-specialist carers. The clinicians would be primarily responsible for pain and symptom management, while psycho-social care would be provided by the allied professionals and carers. Both 'treatments' are increasingly regarded as essential for the provision of the holistic care that would benefit individuals with advancing neurological care.

I think there is a need for more non-specialist care to improve quality of life. It would appear that palliative care is the preserve of professionals as opposed to people who are accompanying the patient towards their end. If a person is being cared for at home or in a nursing home, his/her care is palliative and his/her carers should be trained, supported and acknowledge for what they do. As the disease progresses, the focus goes on a client's symptoms as distinct from their lives e.g., how is your bladder, legs – grand, see you in six months. Not enough space or time given to other changes e.g., loss of employment, fear of falling, incontinence etc. Palliative care is more than hospice care and we should challenge palliative care teams to make them realise they don't have ownership of palliative care services.

The greatest need is for a specialist clinic for our condition where they could develop care pathways and have an outreach service for other parts of Ireland. There is also a need for specialist nurses who can talk to each other as professionals, and non-specialists, like psychologists who could operate at level one of palliative care.

Most of the research participants also felt that the earlier availability of palliative care would have tangible benefits for their members and improve their quality of life. Many people with a neurological disease face significant cognitive and behavioural change, making planning of end-of-life care potentially very challenging if not addressed at a relatively early stage. The variability and unpredictable nature of some diseases makes this process even more challenging. Initially, the palliative care may correspond with levels one and two, as defined by the HSE, and eventually progress to level three specialist palliative care as the person enters the final stages of their lives. Some members expressed concern that their members sometimes found it difficult to access palliative services due to the perceived complexity of their condition and a lack of understanding shown by some health professionals to individuals and their carers.

Most respondents felt that the range and quality of palliative services could be improved by, for example, providing a more uniform service throughout the country, better coordination between primary health care and other health care services, and by ensuring that all neurological conditions are treated equally.

GPs and public health nurses need to be trained to cope with the needs of a person with an incurable condition, to show compassion and understanding of their needs and those of their carers.

Others stressed the need for palliative services to treat individuals with advancing neurological conditions with dignity and respect. This could be achieved in a variety of ways, such as giving the patient sufficient and timely information so that they are aware of what is happening to them and allowing them to make informed decisions over their future care.

In some instances, 'the person will know the end is in sight and they just need a road map to know what to expect', while in other cases, the patient will have lost much of their cognitive capacity. One respondent believes it is important that their members have access to activities that 'make them feel alive' and which promote a good quality of life.

In summary, the palliative care needs of people with advancing neurological conditions are complex and varied. The main improvement needs identified in this research project include, multi-disciplinary clinical and psycho-social care, availability of palliative care earlier in the disease trajectory, timelier referral of patients to palliative care services. There also needs to be a greater awareness of potential anxiety and depression that can be linked to living with an advancing neurological disease. Improvement in the range, quality, availability and co-ordination of palliative care services would be welcomed. Greater availability of nutritional advice and specialist equipment would support the care available. Whilst acknowledging that the nature of advancing neurological disease is unpredictable greater understanding of these conditions by medical staff is required, along with the triggers for the end of life phase, and benefit of planning ahead.

4.5 How do NAI member organisations identify and respond to the palliative care needs of their members?

A primary role of the NAI member organisations that took part in this study is to provide information and support to individuals with a life-limiting advanced neurological condition, and their families/carers. They are also concerned with raising awareness of the condition they support.

We are trying to create awareness of the disease and to promote access for people with the condition when they need it, and access to information for carers. We also target GPs and other people who work with our clients to raise awareness of the disease.

For the most part, they do not employ staff with medical expertise and accordingly, they do not give medical advice or information. Neither do they have official protocols in place to identify when one of their clients requires palliative care or how they should respond to individuals who have palliative care needs. In many situations, their staff 'will know from experience' that significant change is happening, or the patient or their carer will 'notice changes in a person's breathing or swallowing' and this is known to be an indicator or trigger of significant physical deterioration. Conversely, most respondents believe that protocols would be useful and help to raise awareness of their work.

We know when a person is dying. The person knows themselves; their symptoms are changing. Sometimes you have to tell the GP what we and the person knows, they are dying and ready for palliative care.

We don't have any protocols for referral to palliative care services. It is so individualised and best left to the GP and the neurologist. I believe that protocols would be very important in situations where medical support is not always available.

However, while they are increasingly aware of the palliative care needs of their clients, it is just one of many needs their clients have to deal with on a daily basis.

Palliative care is a particular interest of ours but it is not in the plan for this year because we don't have the resources to do everything we would like and it is still a very sensitive subject for many people. It will probably be in next year's plan. For the moment we are focusing on broader support issues e.g., access to medical cards, transport, access to nursing staff, organising speech and language, helping people to meet up because the disease is very isolating.

Any medical issues are referred to medical staff. We are just volunteers with no training.

We try and provide information and support to people. Sometimes people will not know where to go because no one will tell them. We try to connect people with services they need e.g., disability nurse, respite bed, speech and language therapy. Recently I had to make more than twenty phone calls on a Friday evening to get a respite bed for a woman. She needed a bed and the GP was of no help, the Public Health nurse wasn't answering her phone because it was after 5.30pm, and I couldn't contact the social workers or anyone else.

As previously discussed, they will not usually initiate a conversation on palliative care because of the sensitivity of the issue. When a person asks for information or support, their usual response is to refer the individual to the appropriate medical experts, such as a neurologist, the liaison nurses in hospitals, or their GP. They are also very sensitive to the fears of people who may look for information on their website or by phone.

People are fearful and you don't want to scare people off when they come to your website. If there is too much information, they might think that everyone will need it. On the other hand, you don't want to leave people with no information. It is a difficult thing to find the right balance.

Every now and then we mention something around palliative care but we don't have much on our website because sometimes are fearful and in denial. This can be difficult when you know a person would benefit from palliative care but you can't push them too much.

We will answer any questions people bring up but you can't force them to talk about it. Eventually, a time will come when a person's condition deteriorates and breathing problems start and you have to try and have an end-of-life conversation.

I would never introduce palliative care until the person does. We refer people on to palliative services towards the end of their lives. We are involved with a lot of people who are making end of life decisions around their future care needs and they are very conscious themselves that they are on a downward trend, and that there will be no recovery. We don't refer to what we do as palliative care, even though it probably is. We don't want to frighten people and a lot of our work is to support people to live the best lives they can, without focusing on the end game and just making the best of what they have now.

Our response and model is not clinical; it is a psycho-social model. We refer people to specialist services.

Our role is to initiate the process, to get in touch with the GP and inform them that the person should be referred to palliative care. The GP will usually, but not always, refer the person to a neurologist.

We are planning to include information on palliative care as part of something bigger and to put the information out there. This is better and less scary than asking people if they have thought of palliative care when they contact us. Everyone knows what is going to happen but you can't scare them when they ring up. People are afraid. I have never spoken to anyone who wants to talk about death but they might say he/she is having difficulty breathing. We can't send out information on palliative care in case the person with the condition may open the pack and wonder if they are dying.

Their GP is best placed to make any decision.

We have to be careful about giving out information and raising awareness because our meetings are a mix of patients and carers. But people need to know what to expect and health professionals need to understand the condition.

On occasion, some hospitals and health professionals will contact them regarding the most appropriate form of dealing with their condition.

In summary, the primary role of NAI member organisations that took part in this study is to provide information and support to individuals with a life-limiting neurological condition and their families/carers which includes information on palliative care. They are also concerned with raising awareness of the condition they support. For the most part, they do not employ staff with medical expertise. They usually refer medical queries to the appropriate specialists. While they don't have protocols in place to identify when someone is entering the final phase of life or to prompt conversations regarding palliative care, some of them have staff who will know from experience when significant change is happening. They will not usually initiate a conversation on palliative care or end-of-life, but they will respond with information or a referral if they are approached by an individual or carer.

4.6 What direction would the member organisations like to give the NAI, the IHF and others regarding further supports, resources and development that are required to respond to the palliative care needs of people with advancing neurological conditions?

The seven stakeholder organisations identified a number of issues they would like the NAI and the IHF to consider when responding to the palliative care needs of people with advancing neurological conditions. First, a number of respondents stressed the importance and tangible benefits of training and education for their own staff, carers and allied health professionals. This would increase the capacity of NAI member organisations to respond more effectively to the palliative care needs of their members and 'create a space for good things to happen'. It would also enhance the understanding of palliative care and what

it entails for the different groups of carers. One respondent felt that health professionals would benefit from hearing the carer's experience during their training and vice versa. Another person felt that training would ensure that palliative care was more widely available outside specialist centres. A number of respondents felt that the IHF would be ideally suited to train them how to approach palliative care, and to understand the different levels of palliative care.

I can see the benefit of having trained staff providing palliative care to people with life-limiting conditions.

Training would be great and make sure everyone is singing from the same hymn sheet. The terminology of palliative care is associated with death, so any training and information that would help to balance this message would be very useful, just to put it out there for people who want to know about it.

Second, one respondent said that the fear should be taken out of palliative care by educating people that palliative care is about quality of life and not just about dying or pain. Health professionals should be encouraged to refer patients to palliative care sooner than they do at present. The creation of multi-disciplinary teams, which included neurological specialists, GPs, carers, family members, and allied health professionals, would also help to educate people that palliative care need not always be associated with death. A number of respondents felt that the current joint project by the NAI and the IHF was a positive initiative that may help to reduce the stigma of palliative care and neurological diseases.

This project is a very good initiative and it has helped us to see that the care we provide is palliative care.

Palliative care is much more than cancer. It needs to be extended and seen to be associated with a range of illnesses and conditions. Not everyone with a neurological condition will experience the same journey as others with that condition. We can take away some of the fear if we focus on quality of life and explore what can be done to enhance quality of life.

Third, the NAI and the IHF should continue to promote greater awareness and understanding of the different neurological diseases, including those that are less well known to the public. This would help to counteract the negative stereotypes and stigma of palliative and neurological diseases, especially if presented within the context of palliative care. Just as palliative care does not necessarily mean the final stages of life, neither should a neurological condition. A greater understanding of neurological diseases may also help to improve the empathy of some health professionals when caring for people with advancing neurological conditions.

Combining palliative care with multi-disciplinary care through the course of the disease will help the patient and their family make a successful transition through increasing levels of disability while maintaining independence and dignity.

We must deal with all symptoms of palliative care, including psychological. People will talk of the day they were diagnosed, so it is obviously a huge deal for them but we don't provide counselling services to help them through it.

There is a stigma attached to our condition and so much secrecy as well. It is easier to say that there is a project promoting palliative care among people with neurological conditions rather than it being something that is only needed by our condition. This project is great because it makes us feel part of a wider group.

Fourth, a number of respondents believe that the IHF 'Think Ahead' programme or something similar should receive more attention generally and that advance planning should be promoted amongst NAI member organisations. A number of the respondents were not aware of the Think Ahead programme but most felt that planning ahead was a positive thing to do, provided it was handled in a sensitive way.

I am not aware of it but I like the idea. It should be readily available so that a patient and their family can see what needs to be done, especially those who don't have family support.

The Think Ahead folder is great when people need them. It is something to give people when they contact us and to show family members.

You would need guidelines when to introduce the programme. You couldn't have the conversation with someone in their thirties.

The idea is brilliant but it would be difficult to get people to fill it out because no one wants to think about dying. It needs to be part of something else, like a newsletter or a campaign on planning ahead.

Fifth, most respondents identified a number of areas where they would like better and more integrated health services that understood neurological conditions. At one level, a number of respondents said that additional resources are required to support the development of care pathways that would manage the symptoms of the different neurological conditions. Ideally, there would be a specialist clinic for each neurological condition, staffed by a specialist clinician and specialist nurses. Others felt that individuals should have support to live in their own homes as long as possible, and possibly attend a day service where they could avail of various therapies, such as massage, aromatherapy and therapy.

Ideally, people should be able to live and die as near to home as possible and in a community they know, with appropriate supports.

Conversely, others said they were very satisfied with the current level of service provision.

Finally, individual respondents made a number of other suggestions they would like the NAI and IHF to consider, including the following:

- Introduce palliative care approach gradually into the care of the individual so that they can become used to it and minimise any of their fears, respecting individual choices, and in a manner that they can access this approach when they are ready. Balance honesty with sensitivity, and focus on quality of life and supportive care.
- A mechanism of early introduction to palliative care with strategic intervention when required by patient and carer, followed by progression to end of life care, with the aim of a palliative care system that is fit for purpose.
-

- Advocate for an integrated co-ordinated multidisciplinary service with key contact person identified and contactable, and develop an information booklet identifying services throughout Ireland.
- Introduce standards of care for neurological conditions that are equal to that of cardiac and cancer patients, that support timely access to service
- Provide resources to smaller organisations so that they can do their work better.
- Maintain a register of persons with rare neurological conditions which will include information on those that access palliative services.



APPENDIX A

THE POLICY CONTEXT OF PALLIATIVE CARE IN IRELAND

The Irish Government's commitment to palliative care was first reflected in the National Health Strategy in 1994, where the important role of palliative care services in improving quality of life was acknowledged. This commitment was reiterated in the subsequent National Health Strategy in 2001 (Department of Health and Children, 2001a), and the publication of *The Report of the National Advisory Committee on Palliative Care* in 2001 (Department of Health and Children, 2001b). The Government also published a National Cancer Strategy in 2006 (Department of Health, 1996). *The Report of the National Advisory Committee on Palliative Care* recommended that palliative care should be available in all care settings. However, the report also alluded to the practicalities on pursuing this policy when it observed that the need for palliative care services in Ireland would increase, and that 'the inclusion of non-cancer patients within the scope of specialist palliative care services would at least double the need for specialist services' (Department of Health and Children, 2001b, p.11).

However, progress was slow and in 2008, a combined report by the IHF and the Health Service Executive, *Palliative Care for All*, noted that services for people with life-limiting diseases, including COPD, dementia and heart failure were 'underdeveloped and fragmented in Ireland' and that there was 'no mention of the need for palliative care for people living with life-limiting chronic diseases in the few disease-specific reports and documents available' (Irish Hospice Foundation and Health Service Executive, 2008, p.2). This situation reflected what was happening in the UK, with policy documents and administrative changes relatively slow to emerge. However, the dialogue on end of life care in long term neurological conditions received a significant boost in the UK with the publication of an important document in 2010 by the UK National Council for Palliative Care, in association with the Neurological Alliance UK, and the NHS National End of Life Care Programme published a document on End of life care in long term neurological conditions (National End of Life Care Programme, 2010).

Since the publication of the *Palliative Care for All* report (Irish Hospice Foundation and Health Service Executive, 2008), the Irish Hospice Foundation has been committed to exploring and promoting end of life care in long term neurological conditions. Their work was strengthened by the publication of a number of studies that explored the relevance of palliative care for people with Dementia and Motor Neurone Disease. In 2011, the Alzheimer Society of Ireland published a qualitative study, *Opening Conversations*, that was 'aimed at developing a model of best-practice palliative care interventions for people with dementia' and to deepen an 'understanding of what palliative care means within the context of dementia care' (MacConville, 2011, p.4). The research proposes a model of dementia palliative care based on the understanding that 'the provision of good-quality end-of-life care for people with dementia and their families begins at the time of diagnosis and is not confined to the end stage of the illness or to the period in which the person with dementia is actively dying' (MacConville, 2011, p.4). The feasibility of providing palliative

care for people with dementia was explored in a joint study by the IHF and the Alzheimer Society of Ireland in 2012 (The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012). Another study on initiating end of life discussions with people who have dementia was funded by the IHF and the HSE in 2013 (The Irish Hospice Foundation and The Health Service Executive, 2013). The dialogue is also being informed by other sources, such as diverse submissions of organisations to the Forum on the End of Life (Neurological Alliance of Ireland, 2009).

The present study represents another important strand in this ongoing dialogue. As previously mentioned, a key proposition underpinning these studies, and the considered opinion of the IHF and the NAI, is that the palliative care needs of people living with life-limiting neurological diseases should be considered within a broad understanding of palliative care i.e., palliative care is a multi-faceted approach which comprises different levels of care, which are appropriate at different stages of the patient's disease trajectory. It is an issue that continues to develop. In summary, some of the key milestones in the Irish palliative care landscape are as follows.

1994: Publication of the Department of Health's strategy, *Shaping a Healthier Future – a Strategy for Effective Healthcare in the 1990s* (Department of Health, 1994), which acknowledged the important role of palliative care services in improving quality of life. The current policy on palliative care can be traced back to this document where the Department of Health gave a commitment to the continued development of these services.

1995: Ireland recognises palliative medicine as a distinct medical speciality (Carlos Centeno et al., 2007).

1996: Publication of the Department of Health's National Cancer Strategy that recommended the promotion of appropriate models of palliative care for patients and their families (Department of Health, 1996). The first National Cancer Forum was held this year and palliative medicine was represented.

1999: The Minister for Health and Children establishes the National Advisory Committee on Palliative Care.

2001: Publication of the Report of the National Advisory Committee on Palliative Care. This key document provided a framework for the development of a specialist palliative care service in Ireland. It recommended that a national policy on palliative care should be formulated, and that guidelines be put in place to ensure a national consistency of standards for all specialist palliative care centres (Department of Health and Children, 2001b).

The Government also published a new National Health Strategy in 2001, *Quality and Fairness. A Health System for You*, which, amongst other things, reiterated its commitment to the development of a national palliative care service, and research on the specialist palliative care service requirements of non-cancer patients (Department of Health and Children, 2001a).

2003: Publication of the Council of Europe Report on the organisation of palliative care.

2005: The Government establishes the National Council for Specialist Palliative Care.

2006: Publication of the National Cancer Control Strategy in Ireland (National Cancer Forum, 2006). This report recommended the development of four managed cancer control networks with two cancer centres and a comprehensive specialist palliative care service in each.

2006: Publication of the IHF Baseline study on the provision of hospice/ specialist palliative care services in Ireland (Irish Hospice Foundation, 2006a). The rationale for this study was to ascertain to what extent the model for palliative care proposed in the Report of the National Advisory Committee on Palliative Care (2001) had been implemented in the state and to ensure that all stakeholders in the field of palliative care should have access to reliable, relevant and up-to-date information on the degree of service development and on service capacity requirements for the future. This review found that there were 'wide regional variances in the provision of hospice/ specialist palliative care in all care environments' and that there were 'wide regional disparities in current government spending on palliative care services in all care settings' (Irish Hospice Foundation, 2006a, p.15). It also reported that there were 'major deficits in staff and bed numbers in all the health board areas' (Irish Hospice Foundation, 2006a, p.15).

2008: Publication of the joint HSE and IHF report, Palliative Care for All. Integrating Palliative Care into Disease Management Frameworks (Health Service Executive and Irish Hospice Foundation, 2008). This report explored to what extent the palliative care needs of people with non-malignant diseases, specifically COPD, Dementia, and Heart Failure was included in palliative care policy. A key message from the report is that palliative care should be embedded within the disease management framework, and that palliative care should be included in the care pathway for people with dementia. The report concluded that while progress was beginning to happen in this area, the implementation of such policy would be a challenge for the health services.

The report recommendations included the need for further education, the development of service models and research so that people with life-limiting conditions other than cancer could receive appropriate palliative care interventions.

Publication of a joint study by the National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation's HfH, End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland (O'Shea et al., 2008). This led to the IHF hosting an inaugural Forum on End of Life in Ireland in 2009 and each subsequent year (Irish Hospice Foundation, 2009).

2009: Publication of the Department of Health and Children's report Palliative Care for Children with Life-Limiting Conditions in Ireland (Department of Health and Children, 2009). This year also marked the publication of the HIQA report, National Quality Standards for Residential Care Settings for Older people in Ireland (Health Information and Quality Authority, 2009) and the HSE document, Palliative care services – Five-Year-Medium-Term Development Framework (Health Service Executive, 2009).

2010: The launch of the All Ireland Institute of Hospice and Palliative Care (AIHPC), which was set up to drive strategic developments in education, research and policy. For example, the AIHPC have awarded a clinical research fellowship to support a study, Physiotherapy-led palliative exercise programme for Parkinson's disease (PEP-PD) patients in an out-patient setting: a feasibility study.

2011: Publication of an ethical framework on end-of-life decision-making in healthcare settings, End-Of-Life Care Ethics and Law by UCC (McCarthy et al., 2011).

Publication of a study commissioned by the Alzheimer Society of Ireland, 'Opening Conversations' that explored best-practice palliative care interventions for people with dementia and their carers.

2012: Publication of a joint report by the Alzheimer Society of Ireland and the IHF, Building Consensus for the Future, which advocated the need to further develop palliative care services for people with dementia (The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012).

2013: Publication of additional reports exploring the needs of people with dementia, (The Alzheimer Society of Ireland, 2013, The Irish Hospice Foundation and The Health Service Executive, 2013).

2014: Publication of current study on the palliative care needs of people with advancing neurological disease.

Palliative care policy has progressed considerably in Ireland since the publication of the Report of the National Advisory Committee on Palliative Care in 2001. Significant progress has also been made in the funding and development of palliative care services (Irish Hospice Foundation and Health Service Executive, 2008, p.vi). There is now a greater understanding and commitment to the value of palliative care in Irish society. However, while the need to develop services for people with non-malignant life-limiting conditions, such as dementia, heart failure and chronic obstructive airway disease (COPD) was acknowledged in the joint HSE and IHF report Palliative Care for All (2008), much more needs to be done to meet the complex needs of people living with a neurological disease (The Irish Hospice Foundation and The Health Service Executive, 2013).

APPENDIX B

WORKING GROUP MEMBERS

Alison Cashell	<i>Parkinson's Association of Ireland</i>
Tracey Hutchin	<i>Irish Motor Neurone Disease Association</i>
Aidan Larkin	<i>Multiple Sclerosis Ireland</i>
Marie Lynch	<i>Irish Hospice Foundation</i>
Mags Rogers	<i>Neurological Alliance of Ireland</i>
Gráinne McGettrick	<i>Alzheimer Society of Ireland</i>
Deirdre Shanagher	<i>Irish Hospice Foundation</i>
Patricia Towey	<i>Huntington Disease Association of Ireland</i>

APPENDIX C

PROFILE OF STAKEHOLDERS

This study was commissioned by the Neurological Alliance of Ireland (NAI) and the Irish Hospice Foundation (IHF), and funded by the IHF. These two organisations were part of the Working Group that guided and supported the project. Other members of the Working Group included representatives from the Alzheimer Society of Ireland, Huntington Disease Association of Ireland, Motor Neurone Disease Association of Ireland, Multiple Sclerosis Ireland, and Parkinson's Association of Ireland. Seven members of the NAI took part in the research process and their views are summarised in this report. A brief profile of these organisations is presented below, together with a summary of the symptoms of the main neurological conditions supported by these organisations.

The **Neurological Alliance of Ireland (NAI)** is the umbrella organisation representing non-statutory organisations working with people with neurological conditions in Ireland. The aim of the NAI is to promote the development of services and supports for people with neurological conditions, their families and carers. The NAI works to highlight the needs of people with neurological conditions throughout Ireland by contributing to policy development, participation in consultation, holding seminars and conferences on key issues in relation to neurological care and organising an annual programme of events for National Brain Awareness Week. They have published a number of key discussion documents, including one on the future of neurological conditions in Ireland in 2010, and a submission to the Forum on End-of-Life in 2009 (Neurological Alliance of Ireland, 2009, Neurological Alliance of Ireland, 2010).

The **Irish Hospice Foundation (IHF)** is a non-profit organisation that promotes the hospice philosophy and supports the development of palliative care in Ireland. The IHF aim to facilitate the practice of hospice care by working with the statutory, voluntary and professional bodies concerned with hospice and palliative care in Ireland. Their vision is that no one should have to face death or bereavement without appropriate care and support. Four of their core strategic objectives are, to advocate for quality services for care at end-of-life for all, including bereavement care; to continue, through partnership, to build capacity to meet the end-of-life and bereavement care needs of patients and their families in all care settings, irrespective of age or diagnosis; to develop innovative responses to specific end-of-life care challenges in the areas of service equity, patient choice and the physical environment; and to inform, educate and empower about key issues at end-of-life, including bereavement. They have published many studies and documents on diverse aspects of palliative care and end-of-life (Hospice friendly Hospitals Programme, 2008, Irish Hospice Foundation, 2006a, Irish Hospice Foundation, 2006b, Irish Hospice Foundation, 2009, Irish Hospice Foundation, 2010b, Irish Hospice Foundation, 2010a, McCarthy et al., 2011, McKeown et al., 2010, Weafer et al., 2009). The present project emanates from the Palliative Care of All programme (Irish Hospice Foundation and Health Service Executive, 2008).

The **Alzheimer Society of Ireland**⁸ is the leading dementia specific service provider in Ireland. It is a national voluntary organisation with an extensive national network of offices and services that aims to provide people with dementia, their families and carers with the necessary support to maximise their quality of life. Their mission is to help people meet the needs of people with Alzheimer's or dementia and their carers. Their vision is an Ireland where no one goes through dementia alone, where policies and services respond appropriately to the person with dementia, and their carers, at the times they need support. Alzheimer's disease is the most common type of dementia. Dementia is a progressive neurological disease that describes a range of conditions, which cause damage to our brains. The symptoms of dementia can vary from person to person, and each type of dementia can have particular symptoms associated with it. Some general symptoms include: memory loss, difficulties in thinking and speaking, changes in mood and behaviour, becoming confused in familiar surroundings or situations, difficulty in following conversations, difficulty in performing everyday tasks or solving problems, and repeating a story or question several times without realising it. Not every person will experience all the signs and symptoms of their type of dementia, but it is possible to identify three stages that are associated with Alzheimer's disease. On average people live eight to ten years from the time the first symptoms emerge, but this can be affected by a range of factors, including other illnesses a person may have. In the early stages of dementia changes are relatively slight, with an individual experiencing some signs of confusion and forgetfulness. In the middle stage, changes are more significant and a person will need more support to cope with day-to-day living. During the late stage of dementia, a person becomes dependent on others for their care. They may have difficulty recognising people, experience a gradual loss of speech, have difficulty eating and sometimes swallowing, experience incontinence, and appear listless and vacant. Since 2008, the Alzheimer Society of Ireland and the IHF have published a number of salient documents aimed at increasing understanding of palliative care needs in relation to people with dementia and their families (The Irish Hospice Foundation and The Alzheimer Society of Ireland, 2012, MacConville, 2011, The Alzheimer Society of Ireland, 2013)

Brain Tumour Ireland⁹ was founded in 2012 by a small group of people caring for a family member who was lost to a brain tumour in early 2012. As a national voluntary organization, their aim is to continue to fight the battle against the disease in her honour. Through the Ronnie Fehily Foundation they hope to create a place where people can come for information, guidance and comfort; a place to learn what to expect and a community to provide support. Their goals are to raise awareness of and promote education about brain tumours; to provide information and support to brain tumour patients and their families/friends' and to promote and fund medical research on the topic of brain tumours in Ireland and abroad.

⁸ The information on The Alzheimer Society of Ireland and dementia has been mainly taken from www.alzheimer.ie.

⁹ This information was taken from www.braintumoureireland.com.

Cheshire Ireland¹⁰ provides a range of support services to people with both physical and neurological conditions in their homes, in residential centres, in supported accommodation and in stand-alone respite facilities. Cheshire Ireland provide services to almost three hundred people in 21 centres in Dublin, Cork, Galway, Wicklow, Limerick, Donegal, Kerry, Carlow, Waterford, Sligo and Mayo. Their aim is to provide quality, person-centred services, which facilitate people with disabilities to live a life of their own choosing. Cheshire Ireland has been established in Ireland for nearly 50 years, and they are currently the biggest provider of supported accommodation in the country.

Huntington's Disease Association of Ireland is a national voluntary organisation that provides consultation, information, advocacy and individualised support to those with Huntington's disease (HD), those at risk, their families and carers. Huntington's disease is a genetic neurological condition that causes brain cell degeneration leading to progressive deterioration of the physical, cognitive and emotional self. Symptoms can vary and may include involuntary movements, speech impairment, difficulties planning and organising tasks, changes in perception, motivation and behaviour. Symptoms usually appear between the ages of 30 and 45, although they may appear earlier or later. Each child of a parent with HD has a 50% chance of inheriting or not inheriting HD. Some individuals develop HD without ever knowing they were at risk, because they have no known family members with the condition. Others represent "new mutations," caused by rare expansions of parental genes. Clinical assessment of motor, cognitive, emotional and mental health symptoms should determine services required. Rehabilitative therapy including: physiotherapy, occupational therapy, speech and language therapy and diet and nutrition expertise can help maintain function. Support and information, psychological, neuropsychological and psychiatric services can help with cognitive and neuropsychiatric changes. Physiotherapy, speech and language therapy, occupational therapy and support from a dietician etc is necessary to manage the physical symptoms associated with Huntington's disease. Maintaining a healthy body weight is essential because people who are underweight lose muscle mass and therefore feel weaker, become more apathetic or depressed and are more prone to catching infections.

The Irish Motor Neurone Disease Association (IMNDA)¹¹ is the primary support organisation in Ireland providing care for people with Motor Neurone Disease, their families and carers. Their key services include home visitation by an MND dedicated nurse, financial assistance towards home care help, and the provision of specialist medical equipment and appliances on loan, free of charge, to their clients. Their mission is threefold: first, to encourage and promote the best methods of care, education, research and treatment for people with MND throughout the Republic of Ireland, and to contribute to worldwide efforts in research and the development of treatment; second, to establish and promote models of good practice in the delivery of specialised services to their patients, their families and carers, setting standards of excellence; and third, to communicate widely knowledge of MND and related disorders in order to raise awareness in the wider community. Motor Neurone Disease (MND) is an incurable neurological condition that can leave people unable to do the everyday things in life that most people take for granted. It selectively affects the motor neurones, the cells that control voluntary muscle activity. Activities such as walking, talking and swallowing may become virtually impossible, while cognitive abilities and the senses remain intact in the majority of cases. It is a degenerative, life-limiting disease, with the rate of progression varying greatly from one person to another.

¹⁰ This information was taken from www.cheshire.ie

¹¹ The information on the IMNDA and Motor Neurone Disease has been mainly taken from www.imnda.ie.

The average life expectancy for a person with MND is three to five years following diagnosis, depending on the activity of the disease and the particular muscle groups affected. The disease strikes people from teens to old age but the majority are in the middle to older age groups. The cause of Motor Neurone Disease is unknown, although various theories have been proposed – viral infection, environmental poisons, metabolic disturbance and genetic defects. There are approximately 300 people living with MND in Ireland at any one time. The role of palliative care has long been recognised from the perspective of those with MND, resulting in research on the value of advance care planning and patients' perspective on the progression of this disease (www.iapc.ie).

The Multiple Sclerosis Society of Ireland¹² is the only national organisation providing information, support and advocacy services to the MS community in Ireland. They work with people with MS, their families and carers, health professionals, students and others interested in, or concerned about, multiple sclerosis. MS Ireland is chiefly a services-driven organisation, focusing on providing timely, person-centred services that create independence and choice for persons with MS and their families. Their mission is 'to enable and empower people affected by Multiple Sclerosis to live the life of their choice to their fullest potential'. Multiple Sclerosis (MS) is a disease of the brain and spinal cord, where messages from the brain are distorted or blocked by a faulty central nervous system. The presence, severity and duration of all MS symptoms are unpredictable and can vary considerably from person to person. Some symptoms include reduced mobility, fatigue, changes in sensation, memory and concentration problems, balance problems, bladder and bowel problems, muscle problems, vision loss, speech and swallowing, and tremors. The symptoms can be managed by a combination of factors including, drug treatments, a healthy lifestyle, a balanced diet, and complementary therapies. For most people, MS progresses over time, resulting in progressive disability for the person.

The aim of the **Parkinson's Association of Ireland**¹³ is to assist people with Parkinson's, their families and carers, health professionals and interested others, by offering support and information on any aspect of living with Parkinson's. They also initiate and fund research into Parkinson's disease, its causes and effects. Parkinson's Disease is a progressive neurological disorder, which results from a shortage of dopamine, a chemical that helps instructions from the brain to cross from one nerve cell to the next. While everyone loses some of this chemical as we get older, it is only when we lose around 80% of our dopamine that the symptoms of Parkinson's disease appear. Parkinson's disease has no cure but it can be controlled and managed for many years with dopamine replacement therapy. The most common signs of Parkinson's disease are tremors (involuntary shaking), usually seen in one hand or foot, a slowness in movement and increase in rigidity (stiffness). During 2013, the UCC Department of Gerontology, in collaboration with neurologist and palliative care specialists, commenced a two-year project to examine the palliative care needs among a group of people with Parkinson's disease. They aim to provide national guidelines and a local pathway for the assessment and management of palliative care needs in Parkinson's disease. The project is funded through the IHF Development Grants scheme. PSPA Ireland was set up in 2012 and is dedicated to helping people with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) both degenerative brain diseases with causes unknown and for which there are currently no cures. PSPA Ireland seek to make a positive difference to the lives of people with these conditions.

¹² The information on Multiple Sclerosis Ireland and multiple sclerosis has been mainly taken from www.ms-society.ie.

¹³ The information on the Parkinson's Association of Ireland and Parkinson's disease has been mainly taken from www.parkinsons.ie.

The voluntary organisation runs support groups, provides information, and advice to families and healthcare professionals by telephone or email. They raise awareness of PSP and CBD on a local and national level and work in partnership with the relevant bodies and umbrella organisations in Ireland, Northern Ireland and in the United Kingdom. PSPA Ireland supports research to better understand the possible causes of PSP and CBD, to find ways to achieve earlier and better diagnosis and to develop treatments that could potentially slow down, or even halt, the progression of these diseases. Working for a world free of PSP: All of those involved with PSPA Ireland are committed to supporting, providing and developing services for people with PSP and CBD. PSP is caused by the progressive death of nerve cells in the brain, leading to difficulty with balance, movement, vision, speech and swallowing. It is so called because it is Progressive (it gets steadily worse over time), Supranuclear (it damages parts of the brain above the pea-sized 'nuclei' that control eye movements) and Palsy (it causes weakness). Early symptoms may include loss of balance and unexpected falls (usually backwards), stiffness and eye problems. Some people can experience behavioural and cognitive changes - depression, apathy, clumsiness, or tiny, cramped handwriting. Cortico Basal Degeneration (CBD) is a degenerative brain disease, affecting people from the age of 40 onwards. Although there are biological similarities to PSP, with similar nerve cell damage and buildup of tau protein in the brain, the classical clinical picture is quite distinct. It comprises Cortico (affecting the brain cortex), Basal (also affecting other parts of the brain such as the basal ganglia), and Degeneration (death of nerve cells in the brain).



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