

**Submission to Joint Committee on Health and Children
House of the Oireachtas
Leinster House
Dublin 2**

End of Life Care in Ireland

Primary Care / Community Focus

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"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

— Dame Cicely Saunders, nurse, physician and writer, and founder of hospice movement (1918 - 2005).

I work as The Professional Development Co-ordinator for Practice Nursing (PDC/PN) in the Dublin North East Area, of the HSE. I am responsible for the continued professional development and the strategic development of Practice Nursing in my area and nationally with my six PDC/PN colleagues. I also have an interest in Palliative care and am a member of **The Primary Palliative Care Phase 2, Steering Group (Irish Hospice Foundation)** representing Practice Nursing. Practice Nurses are generally trained Nurses who are registered on the Nursing and Midwifery Bord of Ireland live register and work with a General Practitioner in the Primary Care setting.

Presently there is a major focus nationally on the management of chronic illness. It is anticipated that much of this management will be delivered in the Primary Care setting by appropriately trained Practice Nurses working along side their General Practitioner colleagues. Therefore I suggest it is imperative that Practice Nurses, GPs and other members of the Primary Care Team (PCT) are involved and appropriately trained in Palliative care for both patients and their families especially regarding "The End of Live" care.

Nursing experience would indicate that approximately 80% of people who are at this end stage of their disease would express a wish to die at home. In order to achieve this for our patients an appropriately resourced service is desired and required. It is also important to acknowledge that much of the care of the last year of a person's life is provided by GPs, together with Practice Nurses and other members of the Primary Care team.

For a long time Palliative care has been associated with Cancer care. However, now it is acknowledged that palliative care is also required and supported for those with non malignant disease and other chronic/life limiting conditions.

The Clinical Care Programmes (HSE, 2012) are developing and improving processes whereby patients are better managed across all the health care sectors. This will be achieved by the utilisation of more efficient ways of working, communicating and co-ordinating care. Specific educational programmes have been developed for the care of individuals with specific health needs to care appropriately for individuals in their community. As we are aware, some individuals who have a chronic disease will experience disease progression and may require Palliative care. It is important we care for such patients in the "end of life" as we do when they were born.

Palliative care is an approach that gives health professionals the expertise to improve the quality of life of individuals and their families who are experiencing life threatening disease. It is acknowledged internationally that palliative care is administered at three levels;

Level, 1 - Palliative care approach

Level, 2 - , General Palliative care

Level 3 – Specialist Palliative care

Level 1 and 2 are two areas when a Practice Nurse could be both helpful and supportive to individuals and their families. At Level 3 stage they may have reduced patient contact as the patient enters the end phase of terminal illness. This is when the patient may not be able to attend the surgery but family members may do so and require support. The practice nurse can be of support both to them and the specialist palliative care services (Charlton, 2002). The Practice Nurse and GP are ideally placed to ensure support for the bereaved family when their loved ones life cycle is complete and to support families to cope with their emotions and their loss

To this end it is appropriate that Practice Nurses receive education in the nursing management of “end of life care” both for patients and their families. They may require time to assist family members deal with their experience. Practice Nurses also require knowledge -

- To know how to approach the issue of palliative care with the patient,
- To have the skills to discuss what terminal disease is and what it means for the Individual,
- To achieve a safe environment for patients and their families to discuss their illness and any wishes they may have,
- To learn and develop good listening skills and communication skills,
- To have the knowledge of support structures that are availability within their community.

Nurses supporting GPs in the Out of Hours Service especially those dealing with triage calls would also benefit from support and education regarding how to manage end of life calls to their service. They need to be aware of patients in the community who may be approaching “the end of life” in order to deal appropriately with telephone callers and inform the GP doing house call visits from their service. Another requirement would be to improve communications between GPs and the GP Out of Hours and services in general to ensure a dignified and patient centred approach, both for the individual themselves and their families.

Some of these issues are already being progressed due to the identification and now the implementation of findings in the report *Primary Palliative Care in Ireland Identifying improvements in Primary care to support the Care of those in their last year of life* (Irish Hospice Foundation, ICGP, 2011).

As reflected in many new developments within the Health service the issues of improved co-ordinated care and improved sector communications are necessary. For example co ordination is required in areas such as:-

Health care professionals with related health care professionals
I.T. Links across all sectors
Involving cross-disciplinary integration of care.

This co ordination provides the best opportunities to achieve optimal quality of life for patients in later stages of life.

If we are to achieve better end of life care for our citizens it is essential that patients are supported in their needs and given the care in the most appropriate and cost effective setting to fulfil their needs. This in turn will require the resources and education to be available for health care professionals to achieve this in the primary care setting. This should also provide locally based support for both patient and families during a difficult time. Finally it would be more cost effective to care for such patients in primary care and thereby reduce the possibility of inappropriate admissions to the acute hospitals. This is especially relevant due to the projected increased numbers of elderly in our communities in the future. This service should be available for all groups and age groups in the community.

The National clinical Programme for Palliative care states -

“To ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.

The programme work plan has four objectives; each objective has a number of work streams. The suggestions below address what is required for Practice Nurses

Objective 1: Improved planning for palliative care services to ensure optimal resource utilisation.

Suggestion

This requires resources and education at Primary care level especially for Practice nurses who may develop relationships with families attending the Practice where they work.

Objective 2: Strengthened specialist palliative care services to improve access and quality of care.

Suggestion

To give patients access to services but develop services to enable them to remain at home for their care if they wish.

To ensure the “end of Life care for an individual is in a place that fulfils his/her needs. For many this would be in their own home

Objective 3: Strengthened generalist palliative care services in order to strengthen access and quality of care.

Suggestion

To improve resources available in Primary care to address patient needs and requests.

To ensure Practice Nurses are appropriately educated and have the necessary skills to be involved in a patients palliative care process and needs.

To have protected time to give support to family members especially when attending the surgery.

To improve communication skills.

Objective 4: Improved partnerships in care to improve continuity and quality of care.

Suggestion

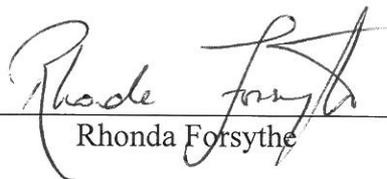
Improved co-ordination of care.

Better communication between all health care professionals and all sectors

Improved listening skills.

In conclusion, if it is a wish of a patient to be cared for and die at home, the health service should try and achieve this. Now is the time to commence what is required in order to achieve what is the best or most appropriate care for individual at this very important time “the end of Life”. We owe it to those who have gone before and our future patients to achieve appropriate palliative care at the “End of Life stage” with dignity and to allow patients leave this world in a way and a place chosen by them. Resources should be managed and made available to achieve these goals and ensure patient centred care is being achieved.

Signed:


Rhonda Forsythe

Date: 19th November 2013

**The Oireachtas Joint Committee on Health
and Children Consultation on the End of Life
Care in Ireland**

Submission

by the

Irish Nutrition & Dietetic Institute

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1. Executive Summary

Malnutrition (under-nutrition) is not inevitable in patients with life limiting illnesses. Many patients will require nutritional support to maintain their nutritional status (allowing them to live as normal a life as possible and to allow them have the best possible quality of life until the very end stage of disease), yet the failure to provide even basic nutrition support to patients with life-limiting disease is unfortunately all too common, often done in the mistaken belief that nutrition will merely prolong their suffering.

Issue 1: There is a startling lack of access to nutritional care for our palliative patients

INDI Recommendation: Address lack of Dietetic services available to palliative patients at SPC level by increasing services to recommended level of 0.2 WTE Senior Dietitian per 6.7 beds, whether in acute-care setting or in free standing palliative care unit / hospice and 0.2 WTE Senior Dietitian per 125 hospital beds for acute-care hospital consultative service.

Issue 2: Lack of access to Dietetic services for palliative patients at community level

INDI Recommendation: Address lack of Dietetic services available to palliative patients at community level by increasing services to 0.2 WTE Senior Dietitian per 100,000 population served.

Issue 3: Lack of nutrition screening for patients nation-wide

INDI Recommendation: Introduction of systematic nutrition screening in all level 4 acute hospitals by end of 2014 extended to all other acute hospitals level 1 to 3 by 2017 under pinned by sufficient resources and personnel to ensure appropriate assessment and follow up of patients such as those requiring palliative care services.

Issue 4: Undergraduate palliative care training for doctors, nurses and other health professionals is evolving but the area of nutrition remains largely neglected.

INDI Recommendation: Palliative Training regarding nutritional issues for Dietitians and other Health Care Professionals working in the Acute Sector

2. Introduction

Malnutrition (under-nutrition) is not inevitable in patients with life limiting illnesses. Many patients will require nutritional support to maintain their nutritional status (allowing them to live as normal a life as possible and to allow them have the best possible quality of life until the very end stage of disease), yet the failure to provide even basic nutrition support to patients with life-limiting disease is unfortunately all too common, often done in the mistaken belief that nutrition will merely prolong their suffering. In fact, this is rarely the case. The use of nutrition support, whether oral or enteral/peg feeding, can help ensure that the patient is in the best possible condition to enjoy their life through their final months or weeks without suffering avoidable complications, such as wound breakdown, fistula and infections. Involvement of a Dietitian as a member of the healthcare team is essential, as they can best assess the needs of the patient as they change through the course of their disease.

Patients report finding the lack of appetite, dramatic weight loss and inability to eat normal amounts of food distressing both emotionally and physically, causing weakness and debilitation that prevents them from enjoying the time they have left. Allowing patients to suffer the de-humanising effect of dramatic weight loss can have a devastating impact on terminally ill patients, cutting short their remaining time with their families and friends and giving rise to avoidable complications and hospitalisations. Conversely at the penultimate end of life, food can be a struggle as patients and family battle to let go.

Nutritional issues such as weight loss and anorexia are a great source of concern for both patients and carers of people with life limiting illnesses (Hopkins, 2004). These issues combined with various ethical issues increase the complexity of the nutritional needs of this patient group. The reality however is that many patients with life limiting illnesses do not receive the appropriate level of nutritional care in this country.

Malnutrition (under nutrition) should not be an inevitable part of illness and/or ageing.

‘Every patient deserves good nutritional care’ and it is everyone’s responsibility to demand

that malnutrition is recognised through screening and that action is taken to make sure the right nutritional care is given at the right time.

Case Study

Vincent's background

Vincent is a 58 year old gentleman. He works in construction and lives on his own in Dublin. Vincent has a diagnosis of lung cancer and has just finished a course of radiotherapy. Vincent lost about 16kg (29% weight) over 18 months. Most of his weight loss occurred over 3-6 months, preceding admission to a large Dublin Acute Teaching Hospital. Vincent was seen in a Rapid Access Lung Cancer Clinic within 2 weeks of referral by the GP and was admitted a week after this. Vincent was 38kg on admission, giving a Body Mass Index (BMI) of 14.3kg/m². This means Vincent was severely malnourished.

Impact of malnutrition on Vincent

Vincent's biggest issue at home having lost so much weight was fatigue. He could not walk for very long and had to take a taxi for any appointments. Otherwise he was almost housebound. Shopping was nearly impossible. He could not climb the stairs at home and had no energy to do any of his usual day-to-day activities.

Vincent's nutritional care

His multidisciplinary team identified Vincent as being malnourished and took steps to improve his nutritional status. Vincent was started on overnight enteral tube feeding and was advised by a Dietitian on a high protein high energy diet. He also started oral nutritional supplements during the day. Vincent's appetite and weight have improved greatly and he has since stopped the tube feeding. He is now 44.3kg which is a 16.5% increase in weight, and is holding his weight on a high protein high energy diet and oral nutritional supplements. His nutritional status continues to be monitored regularly.

Case Study Reference: 'Every patient deserves good nutritional care' Call to Action, The Irish Society for Clinical Nutrition and Metabolism (IrSPEN), in association with the Irish Nutrition & Dietetic Institute (INDI) and the European Nutrition for Health Alliance (ENHA). See attached Call to Action Document.

3. Background

Palliative care is described by the World Health Organisation (WHO) as 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 (WHO, 2004).

Palliative care begins when a patient is diagnosed with a terminal disease and its philosophy advocates that when the quantity of life can no longer be increased, the quality of life must be maximised (Gallagher-Allred, 1989 as cited in Hill and Hart, 2001). The goal of palliative care is to promote the best possible quality of life for patients and their families (Hopkins, 2004).

4. Role of Nutrition in Palliative Care

Eating and drinking are an important part of our daily lives (Van der Riet et al, 2008). The provision (or non- provision) of food and fluid has profound emotional and social meanings for patients and families (Van der Riet et al, 2008). Nutrition is not solely concerned with refuelling the body with appropriate nutrients: it also has an important psychological, social, spiritual and cultural role (Eberhardie, 2002). It can be a pleasurable experience, which helps to promote psychological comfort, communication and social interaction (Eberhardie, 2002). Eating might also help patients to maintain a sense of autonomy and normality within their lives (Eberhardie, 2002).

Nutrition related problems namely anorexia; the loss of appetite associated with chronic illness (Yavuzsen et al, 2005) and weight loss are frequently reported as distressing symptoms in the palliative care setting (Fairtlough, 1996; Hill and Hart, 2001; Poole and Froggatt, 2002; Holder, 2003). For the patient appetite loss may be a persistent reminder of the disease; it may affect the mealtime experience negatively several times every day and diminish the patient's desire or ability to be sociable (Thoresen and De Soysa, 2006). In addition being unable to eat can cause feelings of guilt, letting loved ones down, fear, pain (Hill and Hart,

2001), social isolation and conflict (Holder, 2003). For carers' the consumption of food may act as a barometer of a patient's condition where reduction in intake is indicative of deterioration (Poole and Froggatt, 2002). This can cause heightened anxiety, conflict and distress for the patient and carers (Watson et al, 2005).

Excessive weight loss can cause additional anxiety for patients and carers. Ongoing weight loss can adversely affect the patient's quality of life due to weakness, lethargy, inability to tolerate treatment, impaired wound healing and increased susceptibility to pressure ulcers and infection (Hill and Hart, 2001). Early identification, assessment and implementation of a care plan for anorexia, weight loss and other nutrition related issues are critical to effective management. Because nutrition issues for palliative patients and their families are myriad, it is necessary to have a health care professional who understands these issues, who intervenes when appropriate and who advocates for the patient's and family's wishes (Gallagher-Allred and O'Rawe Amenta, 1993).

It is a qualified Dietitian who is most uniquely qualified through education and experience to supervise the assessment and development of the nutrition care plan and to render counselling services in both basic and more complex situations (Gallagher-Allred and O'Rawe Amenta, 1993). The role of Dietetic Therapy in palliative care is to enhance quality of life (Watson et al, 2005).

Through extensive nutritional knowledge Dietitians are able to translate scientific theory into practical advice for patients, carers and other health professionals depending on the patient's needs (Watson et al, 2005). Although basic nutrition assessment and some nutrition counselling is often effectively performed by palliative nursing staff, palliative nurses frequently express a need for more in depth knowledge of the nutritional aspects of care (Gallagher-Allred and O'Rawe Amenta, 1993). A Dietitian helps meet this need through education programs, individual consultation, and participation in patient related meetings (Gallagher-Allred and O'Rawe Amenta, 1993). Early referral to the Dietetic service allows the

Dietitian to monitor the patient's disease progression, helps to identify nutritional issues in a timely and appropriate manner and offer nutritional counselling and ongoing support regarding nutritional options to the patient, carers and professional team caring for the patient.

5. Nutritional Therapy in Palliative Care

Nutritional management in palliative care should always be supportive and goals should be set with patients and carers, ensuring that they are individually tailored and realistic (Hill and Hart, 2001). The aims of nutritional care will change as the patient's condition progresses (Holder, 2003). Dietitians involved in the patient care are in a position to continually monitor the patient's condition and adapt the patients nutritional care plan in accordance with the patients changing condition.

In the early stages of the disease during active treatment the aim is to restore or maintain nutritional and functional status (Eberhardie, 2002). During this stage every effort should be made to ensure that the patient maintains their nutritional status.

Initially management may focus on the relief of symptoms in combination with dietary counselling and support for patients and carers.

Many patients experience adverse symptoms such as pain, early satiety, anorexia, taste changes, sore mouth, dry mouth, oral infection and nausea which significantly impact on the patient's ability to eat (Hill and Hart, 2001; Power, 1999). Patients, staff and carers should be educated and supported regarding the management of the nutrition related problems experienced by the patient.

Nutrition-related problems such as anorexia and weight loss are frequently reported as distressing symptoms in people with advancing cancer, and are also often a feature in end stage disease of other aetiologies such as cardiac, respiratory, renal, hepatic and neurological disorders. Anorexia contributes to poor function and high levels of distress for patients and

carers. Weight loss and consequent malnutrition are associated with poorer outcomes and poorer quality of life. These symptoms negatively impact on quality of life, physical and psychosocial function (Breura E, 1997, Shragge et al, 2006, Garcia – Peris et al, 2007, Raykher et al, 2007, Hopkinson et al, 2008, Reid et al, 2008, Bozetti, 2009, Radbruch et al, 2010, Katzberg & Benatar, 2011). However research has indicated that these symptoms are not always identified, assessed and managed in patients with advancing progressive disease (Findley et al, 2004, Andrew et al, 2008, Radbruch et al, 2010).

6. Nutritional Therapy in End of Life Care

Towards the end of life, the goals of care shift and thus the emphasis of care should be on quality of life rather than aggressive nutritional therapies (Hill and Hart, 2001).

As patients enter into the terminal stages of their palliative journey the patient's appetite for food and drink diminishes. It is natural for patients who are dying to gradually reduce the amount that they eat and drink. As death approaches, the body and organ systems begin to slow down (Pitorak, 2003; Cinocco, 2007). Metabolic functions slow down and patients begin to lose interest in food (Cinocco, 2007). Difficulty swallowing may also occur (Cinocco, 2007).

As patients progress to the last stage of their life carers may instinctively feel the need to help the patient to maintain nourishment (Cinocco, 2007). Although it may seem logical at first, it is now known that hydration and nutrition at the end of life may provide little or no benefit and may actually make the period of dying more uncomfortable (Cinocco, 2007).

During the terminal phase of the patient's palliative journey family members and carers can often become particularly anxious about the patient's nutritional needs. At this time ongoing support, reassurance and education is necessary. This is most frequently provided by the nursing and medical staff caring for the patient however the counselling and negotiation skills of the Dietitian may be warranted particularly when ethical issues surrounding feeding arise.

Dietetic management should focus on the relief of symptoms, education of the patient and family in relation to any nutritional problems or ethical dilemmas that may arise and the provision of comfort and support for the patient and family.

7. Role of Dietitian in Specialist Palliative Care (SPC)

The unique professional role and responsibility of the qualified Dietitian working in palliative care is to provide expert consultation to patient, family and staff on the creative variety of feasible options that might meet each individual patient's evolving nutrient needs while catering to the patient's food preferences and tolerances (O' Sullivan Maillet and King, 1993).

The Dietitians role in providing ongoing advice, support and education is paramount.

Nutritional supplements should be considered in patients failing to maintain their nutritional status. Patients should be given a choice of supplements to trial and individual goals for supplement usage should be agreed. Enteral or parenteral nutritional support should be considered in patients who are unable to eat, swallow or absorb nutrients, before weight loss becomes significant i.e. >10% over period of 6 months (British Dietetic Association, 2004).

Expert and individualised dietetic assessment and intervention is essential at all stages in the patient's journey to ensure all nutritional needs are met.

In addition the Dietitian supports other members of the palliative team through education regarding nutritional care, communication of patient's specific needs, involvement in ethical decision making and involvement in strategic planning and policy development.

8. Nutritional Issues in Palliative care

Issue 1: There is a startling lack of access to nutritional care for our palliative patients

Access to Clinical Nutrition and Dietetic services in all SPU's was recommended in the report of the National Advisory Committee on Palliative Care report (2001) as "an important factor in improving quality of life". However, the reality 12 years on is that access for palliative patients to dietetic services remains severely limited in Ireland. Patients in the earlier stages of palliative care undergoing continued review in acute hospitals may have access to clinical Dietitians specialising in a number of areas including Oncology, Haematology, Dietetics, Neurology, Cardiology, ENT and Surgery. However, when care in the acute sector is completed and patients transfer back to the community services or hospice care there may be no further access to dedicated palliative Dietetic services.

In 2010, the INDI recommended the following minimum Dietetic workforce recommendations in SPC as adapted from Palliative Care Australia, 2003:

	Community based services	Acute-care hospital consultative service	Designated palliative care beds
Dietitian	0.2 WTE Senior Dietitian per 100,000 population served	0.2 WTE Senior Dietitian per 125 hospital beds	0.2 WTE Senior Dietitian per 6.7 beds, whether in acute-care setting or in free standing palliative care unit / hospice

The reality is that strained resources in the acute sector cannot maintain the services to these patients and the lack of Dietetic posts attached to SPC services is resulting in minimal services to this patient group. At present there are **only 2.2 W.T.E posts in of Ireland for SPC** – 1 full time post based in Milford Hospice in Limerick and 1 post based in the Health Service Executive Dublin North East Region SPC Service.

The area of Paediatric Palliative Care in Ireland is a speciality which is slowly evolving as services become available. Dietetic emphasis in this field focuses on two main areas:

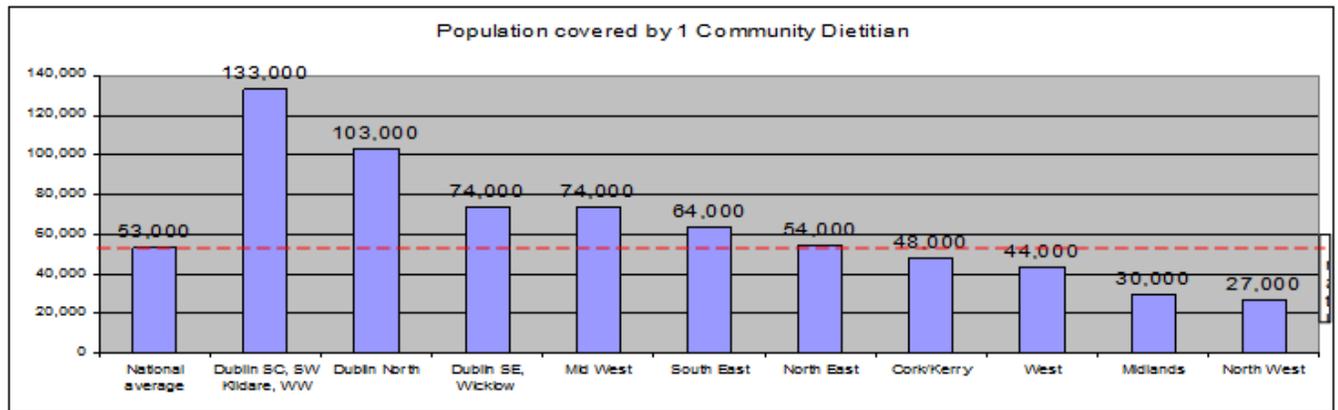
1. Palliative care for the child with a life-limiting condition The Dietitian provides nutritional expertise to the child and family, often for many years, on a vast range of conditions. Problems are wide and varied and include:
 - a. Unsafe swallow
 - b. Inability to maintain weight and optimal nutritional status; gastro-oesophageal reflux gut dysfunction, prolonged tube feeding and associated problems
 - c. Optimise growth – this is unique in paediatric palliative care where often there may be an early diagnosis (in early infancy), so the child may be palliative for months/years but during that initial and perhaps extended phase, growth needs to be optimised to optimise quality of life, whereas with latter stages in palliative care, less emphasis may be placed on growth whilst with other dietetic input becomes more important.
2. Nutrition and Hydration at End of Life. Family support, comfort and empowerment are crucial services delivered by the Dietician when the child is nearing the end of life. Ethical issues must be teased out and symptoms controlled in a pain-free environment.

This staffing level for Dietetic services reflects the lack of importance placed on the highly contentious issue of food and feeding at the end of life. This inequality of Dietetic care provision must be highlighted at the highest level to ensure that equal and adequate Dietetic service levels are available to all palliative care patients requiring Dietetic intervention independent of geographical location.

INDI recommendation: Address lack of Dietetic services available to palliative patients at SPC level by increasing services to recommended level of 0.2 WTE Senior Dietitian per 6.7 beds, whether in acute-care setting or in free standing palliative care unit / hospice and 0.2 WTE Senior Dietitian per 125 hospital beds for acute-care hospital consultative service.

Issue 2: Lack of access to Dietetic services for palliative patients at community level

The current level of access to nutrition services in general is inequitable in Ireland, particularly in some of the most deprived areas of the country:



Anticipating the nutritional needs for palliative care can assist in preventing inappropriate emergency admissions to expensive care settings such as acute hospitals, and can facilitate discharge and the provision of care closer to home, in line with patient preferences.

INDI Recommendation: Address lack of Dietetic services available to palliative patients at community level by increasing services to 0.2 WTE Senior Dietitian per 100,000 population served.

Issue 3: Lack of nutrition screening for patients nation-wide

Studies have shown that patients experienced concern when advanced cancer became visible through weight loss, as it is seen as a symbol of proximity to death, loss of control and both physical and emotional weakness. Weight loss and eating-related concerns are commonly experienced by people with end stage diseases receiving palliative home care. In spite of this, weight loss is often not routinely assessed. Research has shown that weight loss was not routinely assessed by palliative care nurse specialists in the belief that little could be done to help people live with the symptom and that healthcare professionals may be reluctant to

address cancer cachexia when it presents in clinical practice and use an ad hoc reactive approach to care (Hopkinson et al, 2006). Patients want their profound weight loss acknowledged, information provided on why it is happening and what can be done about it (Reid et al, 2009).

“The human cost of malnutrition is very considerable both for the person affected and those that care for them. Everyone knows someone who has experienced the problems of patients not receiving the help they need to eat – food and water left out of reach or supplements left on the locker in the heat of a hospital ward. There needs to be far greater focus on looking after the most vulnerable – good nutritional care must be recognised as a basic human right”.
Mary Nally CEO ThirdAge

INDI Recommendation: Introduction of systematic nutrition screening in all level 4 acute hospitals by end of 2014 and extended to all other acute hospitals level 1 to 3 by 2017 and under pinned by sufficient resources and personnel to ensure appropriate assessment and follow up of patients such as those requiring palliative care services. This will ensure that nutrition support is targeted effectively and at an early enough stage to reduce complications for palliative patients and reduce subsequent hospital admission and re-admission and longer length of hospital stay.

Issue 4: Undergraduate palliative care training for doctors, nurses and other health professionals is evolving but the area of nutrition remains largely neglected.

Palliative care poses a number of challenges for Dietitians and other Health Care Professionals working in the acute sector. Nutritional goals in palliative care continuously shift. In the acute sector the goals of care are to cure the patient and to help the patient achieve maximum potential. Accordingly the goal of dietetic care is to maximise the patient’s nutritional status. These goals vary greatly from the goals of the patient with advanced progressive disease, particularly the patient group entering the terminal stage of their disease trajectory where the

goals are to optimise patient comfort and symptom management. This can present a number of problems for those caring for the nutritional needs of the patient if the individual does not have adequate training and experience in the area of palliative care. Numerous ethical issues can arise if goals of care are not appropriately adapted. The unrealistic goal of maximising nutritional status may lead to the inappropriate commencement of artificial nutritional support in the palliative patient. In the patient whom is already receiving nutritional support either enterally or parenterally ethical dilemmas can arise regarding the decision to reduce or discontinue these therapies when considered burdensome to the patient.

In addition if Health Care Professionals do not feel confident in this area family members and carers of patients can invoke undue pressure on the team caring for the patient. Insistence by family members to continue futile therapies despite increasing discomfort and visible deterioration in the patient's condition can result in quandaries for those with limited palliative care experience.

At present there is limited undergraduate training in palliative care for Dietitians.

Undergraduate palliative care training for doctors, nurses and other health professionals is evolving but the area of nutrition remains largely neglected. Postgraduate training in the area of nutrition and palliative care is evolving however deficits also exist in this area. The importance of education in this area is imperative to ensure optimum care for patients.

The need for SPC input into the Dietetic curriculum both at under and post graduate level is essential to achieve excellence in dietetic care provision at all stages of the patient's life, from conception to conclusion. Further emphasis needs to be placed on the development of nutritional care modules for Doctors, Nurses, Care Assistants, Catering staff and other health Professionals caring for palliative patients.

INDI Recommendation: Palliative Training regarding nutritional issues for Dietitians and other Health Care Professionals working in the Acute Sector

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Submission of the
Irish Society of Chartered Physiotherapists
to
The Joint Oireachtas Committee on Health and Children
On
End of Life Care

November 2013

Introduction

The Irish Society of Chartered Physiotherapists as the sole health professional body for Chartered Physiotherapists in Ireland welcomes the fact that the Joint Oireachtas Committee for Health and Children is considering End of Life Care.

The Society would also welcome the opportunity to make a presentation to the committee. This submission will outline the role of physiotherapy in the treatment of adults and children in specific conditions, in different locations and will include the evidence for such treatment

As a core member of the multidisciplinary team, physiotherapists have a key role in the treatment and management of people in the End of Life stage and physiotherapy must be an integral part of a national approach to End of Life Care.

Chartered Physiotherapists working in this specialised area operate in all three levels within the speciality, as outlined in NCACP (2001). (See below and separate attachment). Continuous Professional Development is obligatory. This is mostly provided through the Society's Clinical Interest Group in Oncology and Palliative Care. As well as clinical care, chartered physiotherapists are involved in research, poster presentations and publications as noted in this submission. They also lecture on undergraduate and post graduate physiotherapy courses and on the Higher Diploma for Nurses course in TCD. The latest textbook about Physiotherapy and palliative care "Potential and Possibility: Rehabilitation at End of Life" <http://www.palliative-physio.eu/> has been recently published.

Background

In the care of patients with cancer, formalised physiotherapy dates back to the 1960s to before the commencement of the modern hospice movement. In relation to Dietz's (1969) four-part framework for cancer rehabilitation: prevention, restoration, support and palliation, physiotherapy was initially limited to the restorative stage and extended in the 1970s to include the support stage. Zislis (1970) reported the usefulness of physiotherapy to maintain range of motion post-operatively, and Mayer (1975) noted that physiotherapists could implement a graduated exercise programme to assist in maintaining mobility. The role in all aspects of rehabilitation was fully established by the late 1970's.

Since then physiotherapy in the End of Life care has developed far beyond cancer to include a diverse range of cardiorespiratory and neuromuscular conditions, in both children and adults. Treatment is delivered in a variety of settings including hospital, home, hospice and residential care. The wishes and goals of the patient are paramount and where a person is an inpatient and wishes to go home, the physiotherapist as part of the multidisciplinary team, assists in co-ordinating a smooth transition to home and liaising with community physiotherapists to ensure continuity of care and follow on treatment.

The general aims of physiotherapy in End of Life care are to achieve patient and family goals and to maintain comfort, independence and safety in the chosen venue. As with all physiotherapy; assessment treatment planning, implementation and evaluation are fundamental to the approach. In End of Life care, ongoing evaluation is critical to the effectiveness of physiotherapy symptom management when a patient is deteriorating. In a recent paper (Cobbe and Kennedy, 2013) profiling physiotherapy activity in an Irish hospice, the rate of referral to physiotherapy was high and physiotherapists treated patients to within a day of dying.

Physiotherapy approach

End of Life communication is an integral facet of the physiotherapy approach as physiotherapists, particularly in the community setting, are often a contact person for patients, their carers and family. Physiotherapists working in End of Life care in all settings need to be comfortable in dealing with issues that patients may wish to talk about (such as death) or decisions that they may wish to make about their care. Physiotherapists fully support the concept of patient involvement in decision-making and that patients can meaningfully participate in a range of complex decisions. Appropriate goal setting is the key to meaningful end of life care; physiotherapists support the patient to identify, adapt and realise their goals which must be achievable and realistic and may change constantly. Physiotherapists embrace an honest, positive, optimistic problem-solving approach with the aim of maximising potential at the end-of-life.

Symptom management

In End of Life care, the emphasis is on symptom management and the scope of physiotherapy includes pain management, discharge planning in general and to facilitate people who want to die at home, assistive device/equipment, functional mobility and transfer training and advice, patient/carer education and training, breathlessness management, secretion management, energy conservation, positioning advice, assistance with physical impairment, limited mobility and

independence and generally working as a MDT member addressing the needs of the patient independently of their diagnosis.

Physiotherapy management of physical impairment and immobility

During the end stage of life, there are multiple causes of physical impairment; the existing disability, deteriorating disability secondary to malignancy/progressive condition deconditioning, disuse atrophy, steroid induced myopathy, pain, respiratory compromise and fatigue.

The advantages of exercise are that they are non-pharmaceutical, patient controlled, easy to administer, low cost and have a placebo effect. (Refer to section on exercise therapy for further information).

Physiotherapy management of respiratory conditions and symptoms

Physiotherapy has a significant role in the management of patients with End of Life respiratory conditions or respiratory symptoms secondary to other conditions. These include Cystic Fibrosis and Chronic Lung conditions such as COPD and Sickle Cell. The role is in assisting the relief of primary symptoms such as cardiac, metastases, breathlessness, swallow impairment/aspiration.

Secondary symptoms where physiotherapy can contribute to relief include anxiety, anaemia, hypoxia, infection, effusions, cardiac failure, pulmonary oedema and muscle weakness.

Following assessment and the out ruling of any symptoms that would be contraindicated, physiotherapy interventions can include positioning for respiratory comfort, relaxation/breathing control, oxygen management, manual and mechanical applications to relieve the work of breathing, induce relaxation of the respiratory musculature and secretion management

Treatment may comprise, positioning, rehabilitation, exercises, stretching exercises, massage, Mobility Aids, education and advice on movement and handling for patient and carers. (See Section on breathlessness for further information and evidence for treatment).

Physiotherapy as part of the Multidisciplinary Team (MDT)

The Department of Health and Children (2001) stated that *it is a fundamental principle of palliative care that no one individual or discipline possesses the range of skills necessary to comprehensively meet and address the varied needs of patients and their families. A good palliative care team should be composed of members of multiple disciplines representing a variety of areas of expertise.*

The Palliative Care Needs Assessment (NHS, 2010) identifies optimising access to physiotherapy (and other health professionals) to support people who wish to be cared for and to die at home where possible.

The National Advisory Committee on Palliative Care (NACPC) report of 2001 recommended staffing levels for palliative care services in Ireland. The physiotherapy, and other Allied Health Professional, levels have yet to be met as highlighted in both the Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland (The Irish Hospice Foundation, 2005), Staffing levels and bed numbers in Specialist Palliative Care in Ireland, (Irish Hospice Foundation 2007) and Palliative Care Service Five Year/Medium Term Development Framework (Health Service Executive, July 2009).

The National Advisory Committee on Palliative Care, (2001) also outlines the three levels of palliative care provision. Level 1 is a 'palliative care approach' adopted by all clinicians at hospital and community level, e.g. primary care physiotherapists; Level-2 care is provided by clinicians with additional palliative care training; and Level-3 services are provided by specialists in palliative care, including specialised palliative care physiotherapists (NACPC, 2001).

Specialised palliative care physiotherapy results in superior gains in function, pain relief, and fatigue recovery compared with regular physiotherapy (Laakso et al, 2003). Specialists in palliative care have in-depth knowledge and experience of life-limiting illnesses and of working with dying patients and families, as well as the ability to respond quickly to rapidly changing situations (Watson and Payne, 2008). Palliative care physiotherapy for community-dwelling patients is a relatively new development internationally. To date there is one published study on this topic: Mueller and Decker (2011) found that physical therapy in an American community hospice, including home treatments, resulted in benefits to mobility, physical tasks such as standing and transfers, breathlessness, and oedema.

The aim of physiotherapy in palliative patients is 'to minimise some of the effects which the disease or its treatment has on them' (ACPOPC 1993). The theoretical framework and principles of treatment for physiotherapists working with cancer (CSP 2003; Bancroft 2003; Fulton 1994) and palliative care (Cobbe and Kennedy 2009; Pizzi and Briggs 2004; Joliffe and Bury 2002; Fulton and Else 1997) have been outlined. It is possible to improve quality of life (QOL), regardless of prognosis, by maximising functional ability and relieving distressing symptoms (ACPOPC 1993).

Physiotherapy is now regarded as a valuable addition to the multidisciplinary palliative team and is included in national standards for service provision in palliative care in Britain and Ireland (NICE 2004; NACPC 2001; NCPC 2000). A multi-disciplinary team approach, including physiotherapy, has been recommended in several international guidelines (Anderson et al, 2007; Anderson et al, 2005; Miller et al, 2009b; National Institute for Health and Clinical Excellence, 2010) in the management of patients with MND / ALS.

Evidence

The section on evidence will look mostly at physiotherapy in symptom management at end of life rather than at specific end of life conditions. While much of the research focuses on patients with cancer, the physiotherapy management of symptoms in neuromuscular and cardiorespiratory conditions will in principle be similar in a holistic approach employed by physiotherapists.

There is growing evidence that physiotherapy benefits palliative patients. Specialised palliative physiotherapy (staff expertise, timely intervention, superior community follow up, and better availability of time) was compared with routine physiotherapy in hospital-based palliative patients and resulted in better functional gains on follow-up, reduced pain and fatigue, and better satisfaction with the service (Laakso et al. 2003). This study, part of a review of physiotherapy services in Australia, indicated that the provision of an adequately resourced physiotherapy service incorporating early intervention and community follow-up can contribute significantly to the maintenance of functional independence and quality of life among patients receiving palliative care. Physiotherapy contributed to significantly higher functional levels on mid-survival follow up; improved maintenance of functional independence, patient satisfaction and quality of life; and reduced demand for costly formal inpatient care as patients were significantly more likely to be discharged to, and prefer to die at, home. In turn, this may result in decreased demand for formal inpatient care and subsequent cost savings. A physiotherapist to inpatient ratio of 1:12 is recommended in order to produce such results.

Patients have themselves reported benefits from physiotherapy: it promoted improved function and independence, provided relief from symptoms, and offered psychological support (Dahlin and Hewe 2009; Martlew 1996). Yoshioko (1994) and Montagnini et al. (2003) found that terminally ill patients make functional improvements with physiotherapy. In these two studies, the Barthel Index and Minimal Data Set were used respectively to measure function however neither has been validated for use on palliative patients.

Physiotherapy for relief of pain

Cancer pain is a mosaic composed of acute pain, chronic pain, tumour-specific pain and treatment-related pain cemented together by ongoing psychological responses of distress and suffering (Carr et al. 2004). Physiotherapists may be able to influence pain of bony, neural and musculoskeletal origin, as well as pain from lymphoedema and non-cancer pain (Rashleigh 1996). Non-pharmacological treatments for pain include positioning, massage, application of hot/cold, Transcutaneous Electrical Neuromuscular Stimulation (TENS), exercise and splinting (William and McLeod 2008; Chang 2007; Robinson 2000; Joliffe and Bury 2003; Gray 1989; Fulton and Else 1997; Rashleigh 1996). Evidence for TENS in the treatment of cancer pain is inconclusive due to poor quality research (Robb et al. 2008) and the effectiveness of the other interventions has not yet been investigated.

Exercise physiotherapy

Research into exercise therapy in palliative cancer patients is in its infancy. Trials have been conducted on mainly well-functioning patients, however results are promising. Lowe et al (2009) found that the majority of participants were able to tolerate exercise, noting improvements in quality of life (QOL), fatigue, physical functioning, or in some cases a lower rate of decline. In individuals with metastatic cancer, exercise resulted in improved QOL, muscle strength, endurance and fitness (Beaton, 2009). Patients with advanced lung cancer can tolerate exercise (Jones and Warner 2009) and show a reduction in symptoms or a slower rate of decline in QOL and other markers (Temel et al. 2009). In addition, group exercise has social and psychological benefits for palliative patients (Palthiel et al. 2009).

Physiotherapy for Breathlessness

About 70% of cancer patients will suffer breathlessness in the last few weeks of life (Reddy et al 2009). A Cochrane review (Bausewein et al 2009) supported the use of neuromuscular electrical stimulation, chest wall vibration, provision of walking aids and breathing retraining in the treatment of breathlessness in advanced malignant and non-malignant diseases. Breathlessness programmes in palliative patients resulted in improvements in breathlessness, QOL, functional capacity and better coping mechanisms (Connors et al 2007; Syrett and Taylor 2003; Hatley et al. 2003, Bredin et al 1999, Corner et al 1996). The best improvements were seen in patients with slightly longer prognoses i.e. not in the last few weeks of life (Hatley et al. 2003, Connors et al. 2007).

Physiotherapy for Lymphoedema

Secondary lymphoedema is chronic swelling caused by blockage or failure of the lymphatic system, the main cause being cancer or its treatments (Todd 2009a). In advanced disease, lymphoedema can occur in the limbs, genitals and trunk, and may lead to reduced physical and social functioning, skin and tissue changes, lymphorrhoea and increased risk of infection (Honnor 2009). Lymphoedema has profound emotional and social consequences for patients (Frid et al 2006). In earlier papers, pneumatic intermittent compression of limbs was described (Yoshioko 1994; Fulton and Else 1997) but this has been replaced by complex decongestive physiotherapy (CDP). CDP can significantly benefit patients with advanced disease, improving function and enhancing psychological well-being (ILF, 2010). The four cornerstones of care are compression (including bandaging or garments), massage, skin care and exercise and these can to be modified for palliative patients to provide relief and prevent complications (Todd 2009b; Honnor 2009; Williams 2004).

Fatigue

There has been substantially research into cancer related fatigue over the past number of years and physical exercise has been proven to be beneficial in its treatment (Cochrane Collaboration, 2010, Luctar-Flude et al. 2009). Research is also being undertaken in the management of fatigue in non malignant diagnosis (Anderson et al, 2007; Anderson et al, 2005; O'Connell et al, 2007: ACPOPC 2003) which also supports to use of exercise in the treatment of fatigue.

Psychological support and education

In general practice, physiotherapists routinely use education as part of their treatments (Rindflesch 2009; Gahimer and Domholdt 1996; Chase et al 1993). Caregiver education was the most common physiotherapy intervention and patient education the fourth most common in primary care units (PCUs) in Michigan (Drouin et al. 2009). Furthermore, education from a specialist palliative physiotherapist results in better patient satisfaction compared with regular physiotherapy advice/instruction (Laakso et al. 2003).

Psychological support was identified by palliative patients as a benefit of physiotherapy (Dahlin and Hewe 2009; Martlew 1996) and palliative rehabilitation (Belchamber et al. 2004). Patients need help adapting to their altered and altering status which requires sensitivity, skill and appropriate goal-setting (Eva et al. 2009; Sheinlick et al. 2008; Pizzi and Briggs 2004; Robinson 2000; Hockley 1993). Specific research into this aspect of palliative physiotherapy is, however, lacking.

Palliative rehabilitation

There is a growing body of evidence to support the rehabilitative role of physiotherapy in hospices. Terminal or palliative rehabilitation has been described with growing frequency in the last decade (Santiago-Palma and Payne 2001; Cheville 2001; Hopkins and Tookman 2000; NCPC 2000; Frank et al. 1998). Rehabilitation is now being investigated for populations with advanced malignant disease. Trials have shown the effectiveness of rehabilitation for elderly cancer patients with advanced asthenia (Scialla et al. 2000), metastatic spinal cord compression (Tang et al. 2007; Ruff et al. 2007; Eriks et al. 2004; Parsch et al. 2003) and for primary and secondary brain tumours at all stages of the disease (Tang et al. 2008; Giordiana and Clara 2006; Marciniak et al. 2001; Huang et al. 2001). It has also been described for a ventilated patient with lung metastases (Kendig et al. 2008), and for patients with bone metastases (Bunting and Shea 2001). As a result, palliative rehabilitation is a growing feature of hospice care, reflected in the substantial rate of discharge home from British hospices (Eve and Higginson 2000).

Physical function is an important marker in palliative care, and is closely associated with life expectancy (Maltoni et al. 2005). Poor function/mobility is a frequent symptom on admission to PCUs: Yoshioko (1994) and Stromgren et al. (2006) found it was the third most common complaint on admission and White et al. (2009) found it was the fourth most common. In terminally ill patients, QOL and personal identity are closely linked with physical ability (Lowe et al 2009, Dahele et al. 2007; Mackey and Sparling 2000, Martlew 1996); therefore the importance of rehabilitation in improving QOL is apparent. Rehabilitation should start once symptoms are controlled and can be continued until close to death (Yoshioko, 1994).

Briggs (2000) described levels of rehabilitation in palliative medicine from high intensity rehabilitation to slow stream and finally to rehabilitation-in-reverse. Two studies specifically examined PCU-based rehabilitation programmes. Yoshioko (1994) found that nearly all physiotherapy patients acquired relief from symptoms, average functional improvement on the Barthel Index was 27%, and satisfaction rates were high (78%). Montagnini et al. (2003) found that 56% of physiotherapy patients made at least temporary functional improvements on the Minimal Data Set, and 33% had sustained improvements (lasting over 2 weeks). A study measuring changes in patient function with a valid palliative scale is warranted.

Conclusion

There is much recent evidence to support the role of physiotherapy in end of life care and as well as the benefits for patients/families. Early involvement is essential. Physiotherapists place the patient and family at the centre of the therapeutic relationship in a goal centred approach which is flexible to meet the patient's needs and has an emphasis on open communications, independence, comfort and treatment in the patient's preferred location.

Acknowledgements

The submission was based on a previous document by Shirley Real entitled "The Value and Contribution of Physiotherapists in Palliative Care" which itself was part of a larger document by members of the Allied Health Professions.

The Society acknowledges the contribution of many of its members involved in End of Life Care to this submission:

Melissa Chavira

Niall Geoghan

Mary Hickey

Marian Johnson

Jo McGuickin

Diarmuid O'Riain

Liz O'Sullivan

Shirley Real

On behalf of Chartered Physiotherapists in Management and Community Care Employment Groups and Oncology and Palliative Care, Paediatrics, Intellectual Disability and Respiratory Care Interest Groups.

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Diarmuid O'Riain

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Introduction

This is the case of an 18 year old male with a diagnosis of relapsed Medulloblastoma. The original diagnosis was at age 10 and treatment included surgical resection of the tumour, chemotherapy and radiation therapy (RT). At age 17 he was diagnosed with a relapse of the same tumour. He underwent surgical resection to de-bulk the tumour and commenced on a relapsed Medulloblastoma chemotherapy protocol. This treatment was due to last for a year and was to include further RT.

Case History

9 months into treatment he presented with an Ascending Polyneuropathy similar to Guillain-Barré Syndrome. He was transferred to ICU with progressive quadriplegia and respiratory distress. He received ventilatory support and a tracheostomy was performed. On examination he had no LL power, was unable to move in bed and was fully dependent. He could shrug his shoulders and had head movements although had no anti-gravity movements. Physiotherapy (PT) was involved in initial assessment and progression of weakness as well as with supportive treatment measures including chest physiotherapy (CPT), passive movement stretches (PMS) and splinting. A Multidisciplinary team (MDT) meeting was held involving his parents and it was decided that further chemotherapy would not be appropriate and that a supportive palliative care route should be taken. All supportive measures were to be maintained and goals were put in place including weaning ventilation and possible discharge to home to be investigated in the long term. Regular fortnightly MDT meetings were planned to discuss his ongoing condition and care.

After 5 weeks his symptoms continued to deteriorate. He was receiving full ventilatory support with no breath initiation, he had no UL movement, minimal head movement and some cranial nerves were impaired. Supportive PT continued including PMS, sitting with maximal assist of 4/5 therapists and sitting out in a wheelchair. During an MDT meeting held with his parents, the situation was felt to be quite grave. Not for Resuscitation (NFR) order was discussed and agreed. A request was made by his family to investigate the possibility of a visit to home. 4 weeks later a home visit took place with support provided by an ambulance team, ICU nurse, Clinical engineer, PT and 2 Anaesthetic Consultants. The visit lasted 2 hours and was appreciated greatly by the large group of family and friends who were able to see him in the family home. 3 months after admission the deterioration in his condition had reached a plateau. He was fully dependent on the ventilator, had minimal head movements, and could mouth and blink to communicate. PMS had to be minimised due to increased pain, and withdrawal of all non-CPT was considered and discussed with the family.

4 months into admission several improvements were noted on examination. Some spontaneous breaths were triggered on the ventilator. The cranial nerve palsy had improved, head and neck movements had become stronger and flickers were noted in the trapezius muscle while protesting during PMS. At the MDT meetings it was agreed to wean his ventilation and to recommence active rehabilitation. Twice daily PT included CPT, active assisted and PMS. His ventilation weaning was at a rate of decreasing 1 mandatory breath every 2 days down to pressure support/BIPAP only.

He was transferred to the Transitional Care Unit (TCU) after a month. The intensity of rehabilitation was increased and involved PT, OT, SALT and Psychology. PT included CPT, active assisted and PMS, bed mobility exercises, tilt table, sitting balance with assist of 4/5 and sitting out in wheelchair. Members of the family were present daily and supported by helping with a daily exercise programme. BIPAP continued to be weaned to self ventilating for short periods. MDT meetings were weekly in TCU and decisions for this patient were the

continuation of rehabilitation, weaning BIPAP and removal of tracheostomy, referral to a rehabilitation hospital (RH) and plan a home visit at Christmas time as requested by the family.

6 months into admission, he was managing 2 x 2 hours self ventilating a day, and was sitting out in a wheelchair for $\frac{1}{2}$ an hour per day. Recovery in UL power was proximal to distal with active movement in all groups. The RH could only accept admission when patients were self ventilating without a tracheostomy. The weaning and rehabilitation continued through the next 2 months with a few setbacks due to recurrent chest infections and poor exercise tolerance but overall his condition was improving.

After 8 months he was self ventilating for 12 of 24 hours, sitting in wheelchair for 2 x 2 hours a day, started with oral intake and rehabilitation sessions started in the PT gym. A home visit was made during Christmas week with assistance from ambulance team, nurse, PT and anaesthetic consultant.

Rehabilitation was intensified in the New Year with night weaning of BIPAP which was completed in 3 weeks and the tracheostomy was revised. PT sessions took place in the gym and involved UL and LL stretches, core exercises, rolling, tilt table and sitting balance work. Recovery of LL power was evident, stronger proximal to distal. At the MDT meeting, the decision was made for transfer to a medical ward, plan for transfer to the RH and as requested by himself and his father the possibility of attending an international rugby match.

Ten months after admission he was attending PT twice a day. He could stand with assistance of 3 therapists and could sit out for an entire day. His family and he managed to get home for hours without assistance. He attended the national rugby team training session and both home rugby matches of that season. 11 $\frac{1}{2}$ months after admission he was transferred RH for ongoing rehabilitation.

2 months later he became unwell and was diagnosed with Myelodysplasia. It was decided that all medical treatment would be withdrawn apart from blood product support was to be provided. He was unable to continue with his rehabilitation at the RH. He was discharged to home independent with care, transfers and wheelchair mobility. 15 months after admission with GBS the patient died at home with his family.

Conclusion

A WHO statement describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems 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." 1.

This case was selected because of the unusual nature of the presentation. When active medical treatment is withdrawn from a patient, rehabilitation is often not considered an option. The family and the patient had a very strong bond and close ties to the family home and local area, and to discharge home was their main goal. This case shows that the input of rehabilitation services provided an improved quality of life for the patient and became a very positive experience for the patient, family and professionals involved even though the eventual passing of the patient was expected. Factors that contributed to this positive experience included full MDT communication with regular meetings involving the family, cooperation with the patient and family wishes, commitment and patience demonstrated by the professionals and family, and support from extended family and friends. The case also highlighted the need to produce guidelines to provide direction for the indepth planning and decision making required for patients with complex needs.

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Every patient deserves good nutritional care:
A CALL TO ACTION



The Irish Society for Clinical Nutrition and Metabolism (IrSPEN),
in association with the Irish Nutrition & Dietetic Institute (INDI)
and the European Nutrition for Health Alliance (ENHA)

Foreword

In Ireland, an estimated 140,000 community and hospital patients are malnourished, or likely to become malnourished, without adequate nutritional care or nutrition support¹. Unfortunately, some will fail to have their needs identified or properly addressed due to low awareness of the problem amongst the public and health professionals alike.

The condition, correctly termed 'disease-related malnutrition', is common in those with cancer, Crohn's disease, COPD, cystic fibrosis, multiple sclerosis and conditions that make eating or utilising food difficult. Older people are at the highest risk, particularly those living alone and coping in poor social circumstances, where their difficulties are more likely to go unnoticed.

Cost burden to patients, the health service and society

Although the problem attracts relatively little attention, the annual healthcare costs associated with malnutrition are enormous, estimated at over €1.4billion in Ireland² and €170billion across Europe³, exceeding that of obesity. This is because inadequately nourished patients suffer more complications, have poorer outcomes and are less able to withstand the effects of medical treatment or surgery. Consequently, they spend longer in hospital and are more likely to need long term care than normally nourished patients.

No excuse

Far from being inevitable, most malnutrition is preventable and nearly all manageable – treatment of malnutrition is simple and relatively inexpensive, especially when detected early. Yet every day in Ireland, many older and chronically ill patients are put at avoidable risk by the low priority given to ensuring good nutritional care for all patients, whether living at home, in hospital or in long-term care. **This urgently needs to change.**

Time to act is now

In 2009, under the Czech Republic European Presidency, a declaration to stop disease related malnutrition (known as 'the Prague Declaration'³) committed signatories, including the Irish Government, to tackling the problem of malnutrition. Since then, many member states - including The Netherlands, UK, Poland, Greece and Belgium - have taken important steps to implement its recommendations. **It is now Ireland's turn, as current holders of the EU presidency, to take decisive action to address what is a largely preventable or manageable problem - and to urge others to do the same.**

Alliance against malnutrition

This 'call to action', supported by European and Irish expert bodies and patient organisations, urges immediate Government action to address the current gaps in our systems, our education of health professionals and our practices that permit patients to become malnourished within our healthcare system. This will not only bring benefits for the many patients whose recovery and health are jeopardised by inadequate or delayed nutritional care, but can be predicted to deliver significant net savings.



Chairman IrSPEN

supported by:



The Case for Action

Scale of the problem

- At any time, more than 140,000 adults in Ireland are malnourished or at risk of malnutrition, half are over 65 years of age¹
- The vast majority of malnourished patients are living in the community⁴
- 1 in 3 patients admitted to Irish hospitals were found to be at risk of malnutrition, over 75% were at high risk⁵

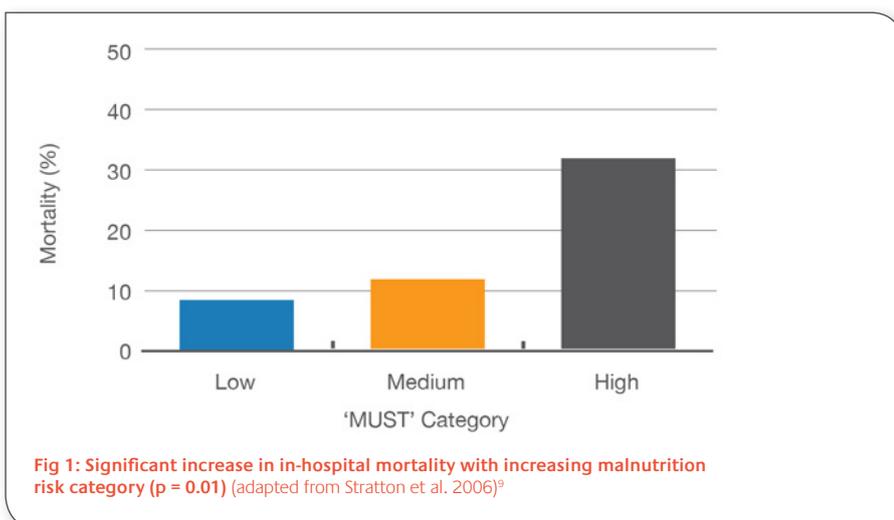
Awareness of the problem is low, so malnutrition is often overlooked

- Most health professionals are poorly informed about malnutrition, as nutrition is not a compulsory part of undergraduate training.
- Many patients with malnutrition are not ‘thin’ and are overlooked, making it imperative to use a validated screening tool to identify those at risk⁵.
- Few Irish hospitals routinely screen patients, contrary to 2009 Department of Health guidance⁶.

Consequences of malnutrition

Compared with normally nourished patients, malnourished patients have:

- Threefold greater risk of infection⁷
- Between two and threefold greater mortality risk, according to age^{8,9} (see fig 1)
- 85% higher risk of hospital admission and re-admission (over 65)⁴
- 30% longer length of hospital stay, on average⁴.



Financial impact of malnutrition

- Total healthcare costs of malnutrition in Ireland estimated at €1.4 billion per annum¹,
- It is estimated that the number of inpatient bed days, arising from longer length of stay due to malnutrition, exceed 250,000 per year*
- Malnourished patients have been shown to incur, on average, **double** the healthcare costs of non-malnourished patients in the year following diagnosis¹⁰.

*Calculated by applying malnutrition prevalence findings to Irish hospital activity data for 2010.



EXPERT VIEW

“Evidence consistently shows that poorly nourished patients fare badly when compared with normally nourished patients, especially if they are older. Conversely, nutrition support has been found to be highly effective in improving health outcomes and reducing costs. On that basis alone, good nutritional care must be recognised as a critical component of good medical care, and a fundamental right for all patients”.

Dr Declan Byrne
Consultant Geriatrician

THE FINANCIAL CASE FOR ACTION

Systematic reviews and meta-analyses consistently show that the appropriate use of nutrition support improves outcome – reduces health utilisation in both community and hospital patients, thereby reducing costs⁴.

In the UK, it has been estimated by NICE that the implementation of screening programmes and improved nutritional care standards will produce net savings of over €54.1 million per year to the NHS, even after the costs of investment in additional staffing, training and resources¹¹.

In Ireland, the estimated savings are proportionately greater, due to higher potential savings in the acute care setting and more effective targeting of nutritional supplements.

Case Study

Malnutrition should not be an inevitable part of illness and ageing. It is everyone's responsibility to demand that malnutrition is recognised through screening and that action is taken to make sure the right nutritional care is given at the right time.

Here is Vincent's story – an example of a personal care plan to aid a patient's recovery.

Vincent's background

Vincent is a 58 year old gentleman. He works in construction and lives on his own in Dublin. Vincent has a diagnosis of lung cancer and has just finished a course of radiotherapy. Vincent lost about 16kg (29% weight) over 18 months. Most of his weight loss occurred over 3-6 months, preceding admission to a large Dublin Acute Teaching Hospital. Vincent was seen in a Rapid Access Lung Cancer Clinic within 2 weeks of referral by the GP and was admitted a week after this. Vincent was 38kg on admission, giving a Body Mass Index (BMI) of 14.3kg/m². This means Vincent was severely malnourished.

Impact of malnutrition on Vincent

Vincent's biggest issue at home having lost so much weight was fatigue. He could not walk for very long and had to take a taxi for any appointments. Otherwise he was almost housebound. Shopping was nearly impossible. He could not climb the stairs at home and had no energy to do any of his usual day-to-day activities.

Vincent's nutritional care

His multidisciplinary team identified Vincent *as being malnourished* and took steps to improve his nutritional status. Vincent was started on overnight enteral tube feeding and was advised by a dietitian on a high protein high energy diet. He also started oral nutritional supplements during the day. Vincent's appetite and weight have improved greatly and he has since stopped the tube feeding. He is now 44.3kg which is a 16.5% increase in weight, and is holding his weight on a high protein high energy diet and oral nutritional supplements. His nutritional status continues to be monitored regularly.



“The human cost of malnutrition is very considerable, both for the person affected and those that care for them. Everyone knows someone who has experienced the problems of patients not receiving the help they need to eat – food and water left out of reach, or supplements left on the locker in the heat of a hospital ward. There needs to be far greater focus on looking after the most vulnerable – good nutritional care must be recognised as a basic human right”.

Mary Nally
CEO ThirdAge

Key Actions

A key recommendation of the 2009 Prague Declaration on Malnutrition was the need for successive EU Presidency holders to make malnutrition and its prevention a key priority. Reiterating many of the actions already committed to by previous EU Presidency holders, the following represent the key actions needed to make progress, both in Ireland, and in countries that have not yet implemented such measures:

1. Public awareness and education

Awareness of malnutrition is low and has not been a public health priority to date. Effective educational campaigns need to make the public aware of malnutrition and its risks, targeting older people, those with chronic illness, their families and carers.

2. Mandatory nutrition screening

Nutrition risk screening is now mandatory in nursing homes in Ireland but not conducted widely elsewhere.

Nutrition risk screening must become mandatory in all hospitals and long stay care facilities, underpinned by protocols and adequate resources for follow up assessment and appropriate management of those identified as 'at risk'. A national screening policy should be immediately developed for primary care services targeting high risk groups. This will ensure that nutrition support is targeted effectively and at an early enough stage to prevent serious and costly complications.

3. Nutrition training of health professionals

There is currently no requirement for health professionals, other than dietitians, to receive education and training in nutritional care.

Nutrition education should be a requirement on the curriculum of medical, nursing professions (including primary care), pharmacists and other healthcare workers. All healthcare professionals should receive, as a minimum, training on how to identify the signs of malnutrition and the components of good nutritional care.

4. Quality standards for nutritional care

Although all patients have the right to safe, effective care, there are no explicit quality standards for the delivery of good nutritional care in Ireland.

National Quality Standards should be immediately established for healthcare providers, outlining their obligations in ensuring that patients are offered the best nutrition and nutritional care possible, including hydration, and that any specialised needs identified through screening are addressed at the earliest opportunity.

5. Equitable access to safe, effective home nutrition support

Deficits exist in the current funding arrangements and clinical support services provided for patients requiring or receiving nutrition support in the community in Ireland.

No patient should have to remain in hospital or care home solely to receive nutrition support. Adequate resources must be provided at community level so that all patients have equal access to required nutrition support at home, irrespective of location or ability to pay. All patients on home artificial nutrition support must have regular access to community-based dietitian to ensure safe, effective care. In this way, patients who require artificial nutrition support have the best opportunity to live independent, fulfilling lives.

“Every day, many patients are admitted to Irish hospitals in a pitiful nutritional state due to lack of community services and resources aimed at prevention of malnutrition. This really must be addressed, as no modern health service can justify continued inaction in the face of such a prevalent and entirely avoidable public health issue”.

Richelle Flanagan
President, INDI



“Malnutrition is not an inevitable consequence of old age or disease – it is a potentially life-threatening condition that can be predicted to develop in many older and chronically ill patients if the systems are not in place to ensure its early detection and treatment”.

Professor John V Reynolds
Chairman, IrSPEN

Every patient deserves good nutritional care: A CALL TO ACTION

KEY ACTIONS

1

Public awareness and education

2

Mandatory nutrition screening

3

Nutrition training of health professionals

4

Quality standards for nutritional care

5

Equitable access to home nutrition support

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Presentation to the Joint Oireachtas Committee on Health and Children

Public Hearings on End of Life Care

November 7th 2013

Julie Ling, Head of Strategic Development, LauraLynn Ireland's Children's Hospice

Introduction:

Lauralynn is a voluntary organisation dedicated to the development of a comprehensive service for children with life-limiting conditions and their families who require palliative care. Built on the site of the Children's Sunshine Home, Lauralynn House is Ireland's only purpose built hospice for children. Lauralynn House opened in September 2011 and is an eight-bedded unit providing respite, transitional, crisis and end of life care to children with life-limiting conditions. Whilst the majority of children using our services are from Dublin and the surrounding counties we have recently seen an increase in the number of children from across Ireland who avail of our services.

Palliative and End-of-life care for children:

When considering the question of what needs to happen in order for children to die well in Ireland, it is important to remember that uncertainty is an integral part of children's palliative care and that in childhood conditions in particular, dying is not a linear process.

End of life care is an integral part of palliative care for children however rather than focussing on end of life, the focus in children's palliative care is on enabling children to live well until they die. Children's¹ palliative care is a small, highly specialised area of healthcare that has become increasingly of interest to healthcare professionals. It has been defined as an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on enhancement of the quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement (*ACT 2009*). **A life-limiting condition is defined as any illness for which there is no reasonable hope of cure** and from which the child is unlikely to survive beyond early adulthood (*DOHC 2010*)².

¹ The term children encompasses infants, children, adolescents and young adults

² In this paper the term "life-limiting" refers to life-limiting, life-threatening and life-shortening conditions.

A recent study from the USA found that children who received palliative care were less likely to undergo invasive procedures prior to death and were less likely to die in Intensive Care. The authors also found that diagnosis was a factor in the receipt of palliative care with children with neurological disabilities the most likely recipients (*Keele et al 2013*). Technological advances mean that many children who would have previously died are living longer.

Children’s palliative care differs significantly from adult palliative care and therefore professionals and care-givers supporting children require specific training and expertise to deal with their unique needs. There is a notable overlap between the needs of children requiring palliative care and those with disabilities and other complex care needs. Children continue to develop physically, emotionally and cognitively throughout their illness thus their care needs and palliative care needs change over time.

(LauraLynn & Irish Hospice Foundation 2013).

Currently, the provision of services to children with life-limiting condition depends on diagnosis and the geographical location of the family home. As a result of limited primary care services in Ireland parents often struggle to access the care that their child requires. Comparisons with children’s palliative care services in the UK are often drawn however; it is noteworthy that in the UK there are paediatric nurses working as part of the community team. Parents require support to enable them to provide care for their sick child whilst often also caring for their other children. In particular, services such as respite (in-home and out-of the home) are valued by parents and **respite is viewed as a key component of children’s palliative care.**

Identifying the children who need palliative care:

As **the range of conditions that are potentially life-limiting in children is vast**, identifying which children may need palliative care services can be challenging. Internationally, four groups of conditions have been identified as encompassing those who are most likely to require palliative care services, however, many but not all children with these conditions will require palliative care (Table 1) (ACT 2009). Some life-limiting conditions are inherited and as a result of this some parents may have to face dealing with a life-limiting condition in more than one of their children.

Table 1 - ACT groups of life-limiting conditions (ACT 2009)	
I.	Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included. Examples: <i>cancer, irreversible organ failures of heart, liver, kidney.</i>

II.	Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. Example: <i>cystic fibrosis</i> .
III.	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: <i>Battens Disease, muscular dystrophy, mucopolysaccharodosis</i> .
IV.	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Examples: <i>severe cerebral palsy; multiple disabilities, such as follow brain or spinal cord injury</i> .

Children’s palliative care is marked by uncertainty. In particular it is difficult to predict how long a child will survive with a life-limiting condition. **Depending on diagnosis many children experience several episodes where it appears that they are at end of life therefore planning for care is challenging with each episode requiring the same level of support whether the child dies or not** (Figure 1).

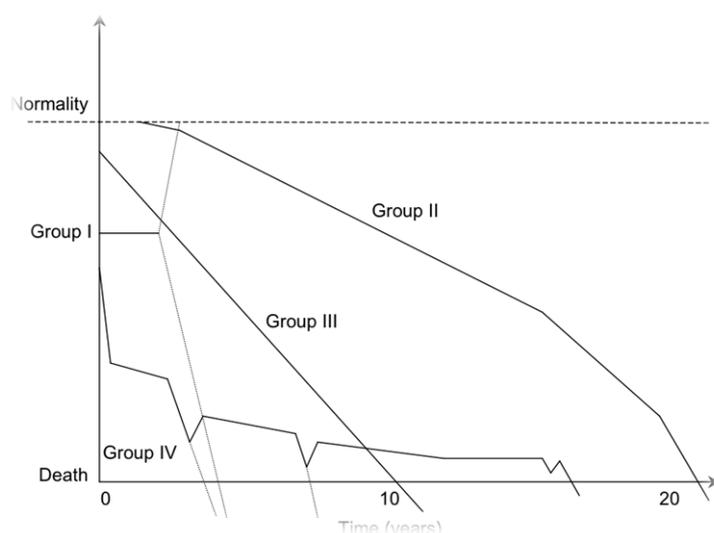


Figure 1 – The trajectory of life-limiting conditions in children by group

The course of a life-limiting condition in a child is often unpredictable. Some children require palliative care for a few days or months while others may live into adulthood and require palliative care (including respite care) over several or sometimes many years. Many children with life-limiting conditions have long periods when they are relatively stable and do not need specialist palliative care but still require other palliative support such as respite.

Childhood deaths in Ireland:

In Ireland the most recent figures available show that approximately 423 children die each year and of these approximately 322 are from life-limiting conditions (Table 2). The **majority**

of deaths occur in the first year of life. Of all childhood deaths in Ireland, 57% occur in infant (<1 year age) and 32% in the first week of life. Congenital anomalies are a leading cause of death in this age group. These children all have palliative care needs.

Table 2 -Mortality data for children under 18 years in Ireland 2002-2010 (CSO 2012)		
Year	Number of deaths	Number of deaths from life-limiting conditions
2005	417	292
2006	421	321
2007	413	306
2008	462	347
2009	403	316
2010	423	348
TOTAL	2,539	1,930
Average annual number of childhood deaths	423	322

As children with life-limiting conditions may be close to death many times and this presents a **compelling argument why childhood deaths are a poor indicator of the need for end of life and palliative care.** Determining the number of children living with a life-limiting condition is difficult. In 2005 it was estimated (based on Irish and international data), that there are approximately 1400 children living with a life-limiting condition in Ireland (*DOHC 2005*). This figure forms the basis for all calculations of children’s palliative care service requirements including respite (figure 2).

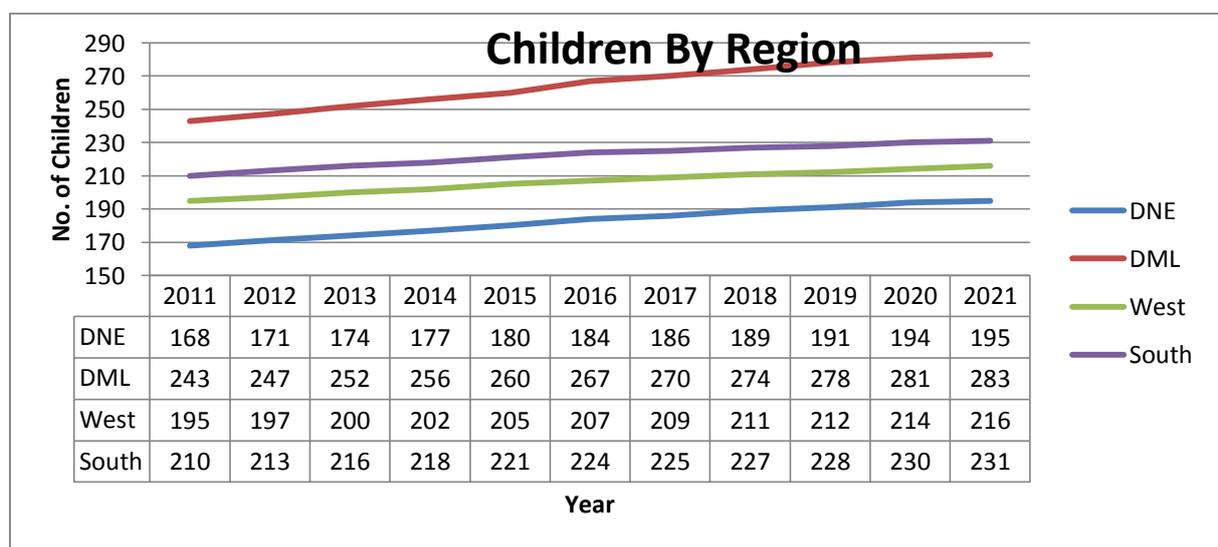


Figure 2. Projected no. children with active palliative care requirement in all HSE areas

An important consideration is the findings of recent research from the UK however, indicates that these figures are likely to be severely underestimated with true figures likely to be at least three times higher at 32 per 10,000 children resulting in a **revised estimate of approximately 4,000 children living in Ireland with a life-limiting condition** (Fraser et al 2012). It is important to plan for services based on the number of children living with a potentially life threatening condition rather than basing calculations on the number of children who die.

Collaborative working in children’s palliative care:

In order to provide comprehensive palliative care services for children and their families collaborative working between the whole healthcare system is required and should include voluntary and statutory providers of care. There are currently a number of key stakeholders providing support to children and their families (Figure 3). Evidence suggests that children may spend up to 5 times longer under the care of a palliative care teams than adults (Hain 2013). This has consequences for all stakeholders and ideally requires a collaborative approach to providing care that meets the needs of the child and family.



Figure 3. Key stakeholders in children’s palliative care in Ireland

Providing palliative care services for children:

All health care professionals working with children and their families should be familiar with the principles of a palliative care approach and be able to recognise their palliative care needs (level 1). All physicians and nurses involved in caring for children should be trained in basic approaches to symptom management and in clear compassionate communication with children and families (level 2). There should be recognition of when referral to a specialist children's palliative care service is necessary (level 3). It is noteworthy that not all children with life-limiting conditions will need referral to a specialist service and many can be managed by their primary team. However, all three levels of children's palliative care should be available to all children with a life-limiting condition in all care settings as necessary.

Policy underpinning children's palliative care:

There have been several key documents published in Ireland in recent years relating to palliative care for children. The **National Advisory Committee Report (2001)** focused on the provision of palliative care for adults, however the Committee specifically highlighted that children's palliative care was different to adult palliative care and recommended that local needs assessments were undertaken on the development of children's palliative care. This recommendation was the catalyst for the **Palliative Care Needs Assessment for Children (2005)**. This was a national needs assessment which identified issues which needed to be addressed in order to provide appropriate palliative care services for children in Ireland. Findings of this research indicated a need for:

- Equity in service provision
- Better coordination of and access to services
- Homecare and community services to be developed
- Accurate data collection on prevalence and mortality
- A "key worker" for each family to improve coordination and access to services
- Education and training of health care professionals
- Ready access to locally based respite
- Improved hospital facilities particularly for dying children and their families
- Planning of the development of services
- Specific needs of adolescents to be recognized and considered
- A broader range of bereavement supports to be available

A national policy was developed by the Department of Health and Children, **Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (2010)**. Published with the aim of addressing the issues raised in the needs assessment this policy now provides a blueprint for the development of children's palliative care services. Several of the key recommendations have been implemented including: the establishment of the National Development Committee on Children's Palliative Care; the appointment of the first Consultant Paediatrician with a Special Interest in Palliative Care and eight regional outreach

nurses. These achievements have relied heavily on the voluntary sector for funding. Several key recommendations that remain outstanding include:

- **The development of a range of respite services (including in-patient hospice beds, community)**
- **The development of Hospice-at-home teams**
 - To include Multidisciplinary team access
 - End-of-life care
- **The development of bereavement support**
- The collection of accurate data
- **Education and training of healthcare staff**
- **Collaborative working between statutory and voluntary agencies**

Government policy is clear on the development of services for children with life-limiting conditions and their families and by all stakeholders adhering to this policy it is possible to develop comprehensive and cohesive children's palliative care services in Ireland.

Current situation at LauraLynn House

There is clear evidence to support the role of children's hospices in the provision of palliative and end of life care. Evidence from the United Kingdom and Canada suggests that not only do children with life-limiting conditions benefit from hospice care but their parents and siblings also find admission to a children's hospice to be beneficial (Eaton 2008; Davies et al. 2004).

LauraLynn Children's Hospice aims to provide holistic care to children with life-limiting conditions and their families through the provision of comprehensive palliative care services. Our primary aim is to allow children to live well until they die. The philosophy of the hospice is to promote the best possible quality of life and care for every child with a life-limiting condition and their family. Giving families real choice has been key to this approach; a choice of place of care; a choice of place of death; a choice of emotional and bereavement support; and putting the child and family at the centre of decision making, to produce a care plan that is right for them. Our vision is that high quality palliative care will be available to all who may need it, in all care settings and in line with national policy and best practice.

In the two years since opening (September 2011 until August 2013) we have provided care to 198 children and their families. The majority of these children remain under our care where we provide support such as respite; during this time we have cared for 35 children at the end of life. The majority of the children under our care are from Dublin and the surrounding counties. We accept referrals nationwide and have had admissions from all over Ireland including Kerry and Donegal.

At LauraLynn we recognise the essential role of education and research in progressing our small but highly specialized field of healthcare. In 2012 we established a **Clinical Education and Research department** dedicated specifically to the provision of responsive programmes, seminars and workshops for professionals, carers and parents involved in the care of children with life –limiting conditions. This new department is underpinned by the strategic objectives of LauraLynn Ireland’s Children’s Hospice to care for children with life-limiting conditions and palliative care needs. The department aims to educate, train and empower professional colleagues who deliver care to meet the very unique needs of children with life-limiting and terminal conditions. These include colleagues in tertiary care, primary care and adult palliative care services.

As children’s palliative care is such a new and evolving specialty it is essential that services can provide evidence of what they are providing and how or if this has made a difference to children with life-limiting conditions and their families. Internationally, there is very limited evidence to either support or refute the role of children’s palliative care in improving support and care to families. Evidence is required to demonstrate the value and the need to show how hospice is able to make a difference

Funding:

Unlike adult voluntary hospices who receive 69% of their revenue funding and 19% of their capital funding from the state, 100% funding for LauraLynn Children’s Hospice has been achieved through fundraising activities including the capital costs of €5.5 million and annual revenue costs of €2.4 million.

Conclusions:

1. LauraLynn is Ireland’s only children’s hospice. Providing care to children with life-limiting conditions and their families and supporting them in caring for their child in their location of choice be that home or as an in-patient. LauraLynn receives no state funding.
2. End of life care is only one part of palliative care. The focus of care is to help children live well until they die rather than focussing on the last hours and days of life. Depending on diagnosis children may use palliative care for many months and years.
3. Children’s palliative care is different to palliative care for adults.
4. All plans for the future development of LauraLynn Services are in line with national policy and include the development of LauraLynn at home.
5. Collaboration between all stakeholders involved in caring for children with life-limiting conditions will provide families with the best quality of care.
6. Formal links between the Consultant Paediatrician with a special Interest in Children’s Palliative Care and LauraLynn are required.

7. A major challenge nationally in children's palliative care is a lack of suitably trained and qualified staff to provide care to children and their families at the end of life.

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Submission on 'End of Life Care in Ireland' from the Mental Health Nursing Discipline, Trinity College Dublin.

Introduction:

This submission focuses exclusively on people with existing mental health difficulties who may require palliative care. Members of the submission group consist of academics who contribute to the teaching of undergraduate and postgraduate mental health nurses. Our experience and expertise lies primarily within the realm of mental health nursing with an additional input from psychology, sociology and biological science.

Executive summary:

People living with enduring mental health problems have a higher level of morbidity and mortality than the general population. To date however the palliative care needs of this population have been poorly met. This submission briefly considers three main points with regards to end of life care for those with existing mental health difficulties. These are: 1; location of palliative care, 2; training of both palliative care staff and mental health staff and 3; issues concerning end-of-life decision making and capacity to consent (or not) to treatment.

Recommendations:

- People with enduring mental illness and palliative care needs should have access to the same palliative care services in their home as the rest of the population. For many people with enduring mental health problems, this home might be a residential group home in a community setting. Those living in these settings should not be transferred to nursing homes or hospitals solely as a direct consequence of living in a group home. Those living in supported accommodation should have the same expectation to die in their home as anybody else.
- There is a requirement for increased training for palliative care staff about mental health issues.
- There is a requirement for increased training for mental health staff about end of life issues.

- There is a requirement for consideration of the issue of decision making for end of life care by people with enduring mental illness.

Main body:

Despite advances in service delivery following mental health policy initiatives such as *'Planning for the Future'* (1984) and *'Vision for Change'* (2006) there continues to be a cohort of long stay patients with mental health problems who remain in the long term care of the HSE primarily within hostel type or group home settings within the community. These group homes and hostels are essentially home for these individuals, some of who have been in continuous care for most of their adult life, while living with severe and enduring mental illness (SEMI). Severe and Enduring Mental Illness includes the diagnoses of schizophrenia and bi-polar disorder and many people living with SEMI experience a substantial disability as a result of their mental health problems. For example, they may be unable to care for themselves independently, sustain relationships or work, and are either currently displaying obvious and severe symptoms, or have remitting / relapsing conditions (Barker and Barker 2012).

Individuals with SEMI are vulnerable to physical health problems, with multiple co-morbidities and higher than average morbidity and mortality rates (Woods et al 2008). For example, there is evidence that people diagnosed with schizophrenia are twice as likely to develop cardio-vascular disease when compared to the general adult population (Ellison 2008). There are many factors which may explain this trend including a less healthy lifestyle with increased smoking, alcohol use and decreased exercise, poor uptake of screening and health checks, adverse effects of prescribed medications and a tendency for staff to focus on the mental health problem and not assess for a physical health problem.

To date however, those with both physical and mental health problems remain poorly served in relation to assessment, diagnosis and treatment. Indeed, a delay in the diagnosis and subsequent treatment of physical health problems has meant that in many cases palliative care is the first line of treatment for these individuals and the literature suggests that terminal illness among those with enduring mental health problems is high (Ellison 2008). In a synthesis of the current research evidence, Woods et al (2008) identified that there was a need for inclusiveness to address the palliative care needs of this specific cohort of individuals in service design, development and delivery so that their palliative care needs are met.

One of the first issues requiring consideration is the location of palliative care for people with an existing mental health problem. People with severe and enduring mental health problems who require palliative care should have access to the same quality of treatment as the rest of the population (Ellison 2008). Consequently, they should have the same right and expectation to die in their home as everybody else and should not be excluded from preferred services including homecare or hospice care. For many of those with severe and enduring mental illness, their home is a group home or supported accommodation. Traditionally, there was a tendency to move individuals with palliative care needs from their home in supported accommodation to nursing homes or hospitals for their end of life care needs. However, it is critical that this is re-assessed in order to provide an equal standard and quality of end of life care to those with mental health needs that is provided to the rest of the population.

Another area requiring consideration is that of training. One of the standards of the Mental Health Commission identified in their Quality Framework (2007:43) acknowledges that "...training is a key element in the delivery of a quality mental health service". No one team has all of the skills necessary to meet the often complex needs of those with severe and enduring mental illness and palliative care needs. There is therefore a need for good communication and effective partnership between the palliative care services and the mental health services, so that individuals can receive the care that they require in the most appropriate place of care, supported by specialist palliative care services. To meet the multifaceted challenges of caring for individuals with SEMI requiring palliative care, education and training is required both for palliative care staff and for staff working in mental health settings. In order to be able to deliver treatment, care and a comprehensive service, staff need to continually update their knowledge and skills (Cooper 2012). For those working in the palliative care services, education is required in the area of mental health so that they can have a greater understanding of the mental health needs of the person they are caring for and how it might impact, or not, on the decisions they make regarding end of life care. Similarly, those working in the mental health services require a greater understanding of the principles of palliative care and in particular how to access end of life services for the people they work with. Creating optimal partnerships with specialist palliative care services, in terms of guidance on symptom assessment and management, communication issues and psychosocial care will attempt to address the deficit in care that currently exists in relation to the provision of palliative care for people with SEMI. Cross training of mental health care professionals and palliative care providers is needed, so as to optimise the care that those individuals receive. Such developments would contribute to positive inter-professional

modelling and would support the integration of educational initiatives at all levels of professional development.

The final issue addressed in this brief submission is that of end-of-life decision making for those with severe and enduring mental illness. Discussions regarding end of life care often “bypass” individuals with SEMI. This is, in part, possibly due to the presumption of their incapacity to comprehend the situation and a fear that such discussions may be emotionally and cognitively destabilising (Foti 2003). While people with SEMI may have more difficulty in understanding and reasoning about end of life care when compared to the general population, it cannot and should not be assumed that decisions made about end-of-life care are clouded by a person’s mental health difficulties. In some instances, there is anecdotal evidence from the services of the use of mental health legislation, the threat of forced hospitalisation and compulsory treatment, for those with diagnosed with enduring mental health problems who refuse treatment. An important consideration in this regard is the right to consent to treatment. This concerns the role of capacity and consent. The mere presence of an enduring mental illness should not automatically preclude someone from having the capacity to be able to give a valid consent or the right to refuse treatment (Re C [1994]) and in these instances the perceived coercive nature of these actions can of themselves worsen the person’s experiences.



Submission to the Department of Health and Children on End of Life Care

By: Aidan Larkin,

National Services Development Manager

19th November 2013.

End of Life Care

Submission from the Multiple Sclerosis Society of Ireland

The Multiple Sclerosis Society of Ireland welcomes the opportunity to make a submission on End of Life Care to the Department of Health and Children. We Welcome this focus on end of life and what ever emanates from this process the Multiple Sclerosis Society of Ireland would like to ensure that the strategy is placed in the context of the well established current policies for meeting supportive and palliative care needs that arise throughout the person's journey with MS. That will mean ensuring that the new strategy takes account of, and complies with National and International guidelines.

The Multiple Sclerosis Society of Ireland was established in 1961. In the 48 years since its foundation, the mission of MS Ireland has evolved to support people with multiple sclerosis (**PwMS**) in a rapidly changing therapeutic, social, political and economic environment. With a membership of over 6,000 individuals and an organisation spanning ten regions with professionally staffed offices, 41 member-run branches, a respite Care Centre and a help line, MS Ireland works to build the capacity to enable people affected by MS to live the life of their choice to their fullest potential. In the current context, the society has prioritised the area of end of life care and palliative care as a deficit in service provision for PwMS and as a priority area for both policy and service planning for the immediate. MS Ireland is cognisant of the challenges facing the demands of the health services but acutely aware of the needs of PwMS especially in the area of end of life care.

As a condition-specific organisation and the only national body working solely on behalf of PwMS, MS Ireland collaborates with a variety of service providers, recognising that support for the development of services for PwMS can only progress in a collaborative and partnership style fashion.

This is demonstrated in the good working relationship MS Ireland has with the range of statutory and non statutory organisations delivering services to people with MS and disabilities in general. MS Ireland currently collaborate in service delivery in the following ways:

- ◆ **Case worker role:** Through its professional staff a very comprehensive case work service which supports PwMS and their families throughout their life's journey following on from their MS diagnosis in problem solving. This service focuses on the emotional and social needs of PwMS and their families. Given the MS population age profile, e.g. people in their teens and into old age, situations can be very complex with a myriad of emotional, social, financial and vocational issues that can arise. The case worker works closely with the all of the allied health care professional within community and hospital settings and with the HSE disability teams
- ◆ **Support programmes:** MS Ireland's professional staff design and deliver specific programmes to meet the needs of PwMS and their families through a variety of innovative programmes such as newly diagnosed programmes, symptom

management programmes, fatigue management programmes, carer education and support. We also provide education programmes to health care professionals addressing the changing world of multiple sclerosis and its treatment and management

- ◆ **Counselling Service:** A bank of trained counsellors is available to PwMS and is resourced by MS Ireland. This is a vital service which offers PwMS an opportunity to explore the issues arising out of their diagnosis and out of the changes that they face as the disease progresses.
- ◆ **The Branch network.** MS Ireland, through its 41 voluntary Branches support many initiatives throughout the country such as physiotherapy, equipment purchase, welfare and also provide a social network for people with MS and their families
- ◆ **The MS Care Centre.** This is the only MS dedicated respite service in the country providing not only respite but also comprehensive assessments for PwMS and work within a well thought out referral process connecting the user group with key services within their own communities and dedicated neurology departments following on from the respite break
- ◆ **Research:** MS Ireland is very committed to research and not only contributes financially to research projects and design (e.g. *Getting the Balance Right A Nationwide exercise-based, health promotion and research programme for PwMS* in collaboration with the University of Limerick) but also participates with many of the universities and teaching hospitals.
- ◆ **Information line:** Our confidential information line provides immediate information and support to those affected by MS. The Information Line is open from Monday to Friday 10am – 2pm.

Historically, palliative care focused largely on the management of symptoms of people who were living with cancer. During the past decade continued research has proven that palliative care can also play a crucial part in helping people with non-cancer conditions, such as multiple sclerosis (MS).

The World Health Organization's definition of palliative care states the following:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.

"Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life...and includes those investigations needed to better understand and manage distressing clinical complications." ¹

MS and palliative care

Most people who are diagnosed with MS will be in their 20s and 30s and, like anyone else in the general population, will live for decades. But for some people, MS can cause serious disability over time and some symptoms can be life threatening. Palliative care can help people with MS to manage their symptoms and should be made available whenever it is needed.

What we know now

Most common neurological disease of young adults
Mean age at diagnosis 30
Issues resulting -
Chronic disease of the CNS
Inflammation
Demyelination, Axonal degeneration

Palliative care in the past has often been associated with death and not the journey to the end of life. Many aspects of palliative care are applicable earlier on, not just towards the end of life, in conjunction with other treatments, such as physiotherapy, psychological support or complementary therapies. Palliative care for people affected by MS must respond to the fact that MS is a highly unpredictable condition; the end of life trajectory is therefore extremely difficult to identify. The term end of life often describes the period immediately before and during death. High quality, person-centred palliative care should be made available to people with MS whenever it is needed rather than being confined to the last stages of life.

Do people with MS have palliative care needs?

There is increasing evidence to suggest that people with advanced MS and other long-term progressive neurological conditions have unmet health and social care needs in the last years of their lives. It is known that those with advanced MS represent a 'silent minority' who have often fallen out of acute care follow up and may benefit from specialised palliative care services. These services promote physical, psychological and spiritual wellbeing, and emphasise quality of life and good symptom control. Research has shown that palliative care is effective in improving symptom management and quality of life care in cancer, and that similar approaches are effective in the long-term management of neurological conditions. There is evidence of the effectiveness of interventions to control pain, spasticity and breathlessness. Unfortunately the progression of the disease for people with non-relapsing progressive forms of MS is not amenable to disease-modifying treatments. It is therefore all the more important that appropriate palliation of attendant symptoms and psychological distress is given.

Approximately 8,000 PwMS in Ireland
Women: Men 2:1
No known cause
No known cure
Diagnostic categories
<i>Benign</i>
<i>Relapsing remitting</i>
<i>Secondary progressive</i>
<i>Primary progressive</i>

For many, palliative care has been synonymous with end of life and cancer care. People with advanced disease such as MS are often described as having reached a palliative stage of their disease. **What do we understand palliative care to mean for the individual with a life-limiting disease?** Active holistic care with a life-limiting disease regardless of their diagnosis. Expert management of pain and other distressing symptoms. Provision of psychological, social and spiritual support is paramount. However, it is widely recognised that a palliative care approach has an

important role **throughout the course of a non-curative disease, and can be delivered in conjunction with active disease modifying treatments**. A key principle in the guidance on the commissioning of palliative care services for adults is that 'it is the right of every person with a life-threatening illness to receive appropriate palliative care services wherever they are. The key message is that specialist palliative care should be available on the basis of need and not diagnosis.

The Journey with MS

The MS journey may be difficult to plan due to the uncertainty of the disease trajectory and the unpredictability of symptom presentation
- it must be led by individual need rather than diagnosis.

For some pwMS it may start very early in their illness and continue right through to end of life, for others they may need support at different stages and will use the service as needed. For people with life limiting non-malignant diseases, palliative care support may be needed alongside disease modifying interventions. This may be carried out by professionals within each specialist care area.

Cognition and Capacity

Cognition

Up to 65% of people with MS have some cognitive impairment and 5% to 10% suffer global cognitive impairment. Contrary to previous belief, a recent longitudinal study by Amato in 2001 has found a significant relationship between severity of cognitive impairment and duration of MS. Cognitive impairment places an enormous strain on carers, most usually the spouse, who has to adapt to new roles and sometimes also to profound personality changes in their partner. A similar situation may be in place for a parent care giver. The implication of these findings is that choices need to be discussed much earlier in the disease trajectory so that there can be no challenge to a person's capacity in making these choices and everyone is clear about their wishes. The incidence of depression is also greater in advanced MS. This can be due to organic brain changes that are part of the disease itself as well as reactive depression, caused by the challenges and demands of disability.

Capacity

Capacity is a legal term and part of the three-point test for consent. Any health care intervention requires consent and this can be given as implied or explicit consent. A patient visiting their GP who proffers their arm to have their blood pressure checked is giving implied consent. Consent for surgery tends to be in a formal written and explicit format. For consent to be valid, an individual must:

- have mental capacity
- be informed
- be free from coercion

Mental capacity

Unless there are concerns or evidence to the contrary, the law assumes that a person

has mental capacity. There are three stages in determining whether someone has it:

- Can they comprehend and retain the necessary information? This is obviously important in any disease that causes memory impairment or intermittent competence such as Alzheimer's disease.
- Can they believe in it (within their own belief structure)?
- Can they weigh up the information, balancing the risks and arrive at a choice? This last stage requires cognitive abilities to make a decision on the basis of the information presented. **(The Mental Capacity Bill needs further debate to ensure that these nuances are reflected in its interpretation.)**

Palliative care in MS requires a clear pathway that would recognise potential trigger points

Access to timely care – some vignettes

Symptom control – to promote comfort, provide emotional support, prevent complications and improve QoL

Cognition and Capacity – some vignettes

Advance planning

End of life issues Die with or of MS?

Sadovnick, Eisen, Ebers and Paty found that in about 50% of patients with advanced MS, cause of death is related to complications of chronic disease, usually sepsis and fatigue caused by overwhelming infection. Overall, causes of death are similar to the rest of the population: heart attacks (11%), tumours (16%) and stroke (5%).

Symptoms in the last few days of life are common to many disease areas, and derive from similar underlying physiology, namely breathlessness, nausea, confusion, insomnia, pain and overwhelming fatigue. This means that robust expertise can be applied across the board to provide comfort in the last few days of life. The area of spirituality can be important throughout life but its importance can be heightened at this time. Spirituality is difficult to define, precisely because it encompasses the immeasurable and often unspoken aspects of humanity. Spiritual needs are not necessarily the same as religious needs, and people who would not define themselves as religious may still have spiritual needs. Health professionals should not assume that spiritual care is the province of religious leaders. While this can be true for some, it might ignore the needs of others with no religious affiliation. Identifying and meeting all of an individual's needs are at the core of providing spiritual care. Including spiritual care in every aspect of care, providing opportunities for talking and listening, and identifying other routes such as music that are meaningful and helpful to the individual, are all potential aspects of good spiritual

care. There is some preliminary evidence that religious and spiritual belief can affect the way patients and their relatives cope with bereavement.

A 'GOOD DEATH'

According to the National Council of Palliative Care, 56% of the population would prefer to die at home but only 20% manage to achieve this. In contrast, only 11% of the population would choose to die in hospital, as opposed to 54% who actually do. There is evidence to suggest that palliative care for people with neurodegenerative conditions can be provided effectively in a home environment if a co-ordinated team approach is adopted. Current information suggests that the numbers of people able to die at home is low and decreasing. Communication difficulties can be a barrier to people being able to express their choice in this matter. The concept of a 'good death' has developed as an important feature of modern palliative care, although what constitutes a good death and whether it is possible or desirable is still open to debate.

There appears to be consensus related to pain control, dignity, privacy, choice of the location of death, and support for spiritual and emotional needs, but the extent to which people should be able to control their death and dying introduces wider ethical questions.

End of life care helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both the individual and their family to be identified and met throughout the last phase of life and into bereavement.

Who provides palliative care?

All professionals involved in the day-to-day care and support of people with advanced MS may provide a palliative care approach. However, some people with complex needs may benefit from referral to specialist palliative care teams for one-off assessment or continued support. MS Ireland recommends that: that those health care professionals providing day-to-day care should be able to:

- a) Assess the care needs of each person and their families across physical, psychological, social, spiritual and information needs
- b) Meet those needs within the limits of their knowledge, skills and competence in palliative care
- c) Know when to seek advice from, or refer to, specialist palliative care services

Specialist palliative care services may be able to provide:

- a) Assessment, advice and care for patients and families in all care settings, including hospitals and care homes
- b) Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams to meet

complex needs

c) Intensive co-ordinated home support for patients with complex needs who wish to stay at home. This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home

d) Many teams also provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home

e) Day care facilities that offer a range of opportunities for assessment and review of each patient's needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies, advice and support to all the people involved in a patient's care, bereavement support services that support the people involved in a patient's care following the patient's death, education and training in palliative care

Palliative care in practice should provide:
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- | |
|--|
| <ul style="list-style-type: none">• Expert control of pain & symptoms.• Communication & decisions about goals of care with the individual & family.• Coordinated care across fragmented healthcare system.• Practical support for the individual with MS, their family & professional caregivers. |
|--|

Every area of the Republic of Ireland should have access to both inpatient (hospital) and community (home) palliative care teams based on identified need. Specialist palliative care teams can include consultants in palliative care medicine, clinical nurse specialists and social workers, together with a range of expertise offered by physiotherapists, occupational therapists, dieticians, pharmacists and those offering spiritual support. Many areas also liaise with an extended team, including rehabilitation teams, pain specialists, anaesthetists, psychologists and counsellors.

MS and palliative care

The NICE guidance for supportive and palliative care for adults with cancer (2004) sets out the benchmark for palliative care services. While this guidance is oriented towards cancer, many of its principles and recommendations apply to MS.

Many of the symptoms experienced in the advanced stages of MS can be similar to cancer, e.g. pain, nausea and breathlessness. But some are specific to MS and require understanding of the disease itself, for example:

1. The unpredictability and variability of the disease makes prognosticating on an individual basis extremely difficult.

2. MS is the most common cause of chronic disability in young adults causing long-term challenges. The situation may be particularly difficult for young adults with extremely aggressive disease who are nearing the end of their lives managing pain arising from spasticity or neuropathic pain needs a different approach from managing cancer pain.

3. Cognitive and communication problems can limit the ability to express choice and take part fully in counselling or other supportive interventions

4. There may be issues around mental capacity and consent and the need for advance directives

Demand for palliative care: What PwMS & Families want:

- | |
|--|
| <ul style="list-style-type: none">• Pain & symptom control• To avoid inappropriate prolongation of the dying• Process• To achieve a sense of control• To relieve burdens on family• To strengthen relationships with loved ones |
|--|

The NICE guidance on palliative care emphasises the importance of co-ordinated planning and care across all agencies to provide continuity of appropriate care. This guideline is reiterated in the NSF for long-term conditions which states:

Professionals working within neurology, rehabilitation and palliative care need to work closely with primary care staff and care providers, combining their expertise to support people in the advanced stages of long-term neurological conditions.

The way forward:

- Promote equitable access to palliative care based on individual need. Needs based approach when allocating resources to ensure equitable share for all.
- Develop partnerships – Good interdisciplinary communications between relevant agencies (HSE & Voluntary Agencies with specific expertise)
- Client centered communication file, Studies have shown that the implementation of personally held records leads to improved service. This also empowers people to demand better service, all parties are directly accountable to the person who has central control in the interdisciplinary network which should leave less room for error.
- Educate staff – Hospice & Disabilities services need to share training and experience in liaison with all other healthcare disciplines working with the person with a life limiting disease, with emphasis on standards development and disease specific indicators for care pathways.

- Formal and informal carers need constant support and education. It is important to recognise that palliative care is a demanding area of healthcare, and formal and informal carers need a high level of support.
- Multi cultural needs must be considered in all education and provision for its inclusion into all planning stages of care pathways to ensure that we foster cultural sensitivity in non mainstream palliative care.
- Assure provision of care
- Access to resources to facilitate choice as to where care should happen, e.g. home/hospital or other facilities
- Provide ethical guidelines for all in particular relation to capacity and consent, advanced directives and living wills.
- Evaluate and measure outcomes continuously – to further develop & improve services.

“It is important to know the person who has the disease as to know the disease” William Osler

Only then do we have a ‘who’ as well as a ‘what’

Submission to the Committee on Health and Children Public Hearings on End of Life Care

24 October 2013

**By: Patricia Rickard Clarke, on behalf of the National Council of the
Forum on End of Life in Ireland.**

Patricia is a member of the National Council of the Forum on End of Life in Ireland, as well as a solicitor and former Law Reform Commissioner



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Introduction

The National Council of the Forum on End in Ireland welcomes the initiative of the Joint Oireachtas Committee on Health and Children to hold hearings into how people are being cared for in Ireland at the end of their lives and how that care can be improved.

We congratulate all of the Deputies and Senators on the committee, led by Chairman Jerry Buttimer, who have decided to consider what is perhaps the last taboo in Irish society.

With up to 29,000 people dying in Ireland every year and as many as 290,000 people newly bereaved annually, it is appropriate that our national parliament should consider the many issues that patients, their loved ones and professionals face in ensuring that people have a dignified final journey.

This submission gives a brief overview of the work of the National Council of the Forum on End of Life in Ireland and will focus on a number of areas which we believe will help citizens to secure a positive end-of-life experience in line with their preferences and for their families to start their bereavement journey with a positive first step.

The reforms proposed involve:

1. Promote openness to change policy and practice
2. End-of-life proofing our buildings
3. Regulation of the funeral services industry
4. The need for a national end of life and bereavement strategy.
5. Advance care planning

Most of this submission will be concerned with the importance of actively promoting advance care planning which is the single biggest measure that the National Council of the Forum on End of Life in Ireland promotes in order to secure a good death for Irish citizens.

The work programme undertaken by the National Council and particularly our work in promoting advance planning is rooted in the public consultation process that we engaged in over the course of a year from 2009.

A. National Council of the Forum on End of Life in Ireland

The National Council of the Forum on End of Life in Ireland - Chaired by former Supreme Court Judge, Mrs Justice Catherine McGuiness - was formed in July 2010 following an extensive year-long public consultation (2009-2010) by the Forum (outlined below which identified what end-of-life issues mattered most to people.

The National Council was established with a view to broadening the advocacy base of end of life beyond health care. It considers all issues relating to end of life, including legal, economic, administrative and social aspects.

The National Council of the Forum on End of Life in Ireland is an initiative of the Irish Hospice Foundation (IHF) and meets at least four times a year. Membership of the National Council reflects a wide range of stakeholders and the diversity of end of life issues in Irish society.

Forum on End of Life in Ireland public consultation 2009-2010

The Forum conducted a year-long public consultation which asked the Irish public about the issues that mattered most to them around dying, death and bereavement.

The Forum received 167 written submissions from organisations and members of the public. It ran 23 workshops at which 108 presentations were given. People also attended nine public meetings nationwide.

Following its examination of submissions and presentations made to the Forum, the Forum has focused on a number of areas:

A baseline report of the proceedings which outlines the main themes, messages and issues raised by contributors to the Forum, *Perspectives on End of Life in Ireland: Report of the Forum on End of Life*, was published in 2009. It formed the basis for an initial Action Plan¹ based around 10 key action areas.

1. Availability and Access to services
2. Carers
3. Information and Communication
4. Spiritual and Psychological Support
5. Financial, Legal and Administrative Issues

¹ Available on the Irish Hospice Foundation website, www.hospicefoundation.ie

6. Ethical Engagement
7. Physical Environment
8. Standards and Regulation
9. Planning and Co-ordination
10. Public Engagement

National Council membership:

- Mrs. Justice Catherine McGuinness, Chairperson
- Catriona Crowe, Head of Special Projects, National Archives of Ireland
- Dr. Brian Farrell, Dublin City Coroner, Barrister-at-Law
- Dr. Ciaran Browne, Head of Acute and Palliative Care Services, Health Service Executive
- Dr. Ita Harnett, Consultant in Palliative Medicine, Galway
- Dr. Geoff King, Director, Pre-Hospital Emergency Care Council
- Dr. Deirdre Madden, Senior Lecturer, UCC Law Department
- Ita Mangan, Barrister/Murphy Commission Member
- Úna Marren, Convenor of the Network of Hospice Friendly Hospitals
- Sharon Foley, CEO, Irish Hospice Foundation
- Mr. Gus Nichols, Irish Association of Funeral Directors
- Seán Ó Laoire, Past President, Royal Institute of the Architects of Ireland
- Professor David Smith, Associate Professor Health Care Ethics, RCSI
- Dr. Max Watson, Consultant in Palliative Medicine at Northern Ireland Hospice
- Patricia Rickard Clarke, former Law Commissioner and solicitor
- Mervyn Taylor, consultant with expertise in end of life issues
- Senan Turnbull, retired senior civil servant and Chair of the Think Ahead Project Team

Principles underlying the work of the Forum

Based on the Forum's findings there are a number of inclusive principles which must underpin the Action Plan:

- **Death is a part of the life-cycle:** In this country we have adopted a life-cycle approach in national policy and planning. Death is a significant part of the life-cycle. End of life, death and bereavement must be integrated in planning initiatives for all age groups. There should be a provision to monitor the development and implementation of national social policy in Ireland on dying, death, and bereavement.
- **End of Life is everybody's business:** Contributions to the Forum identified a wide range of financial, legal, environmental, administrative, cultural and educational measures, which might be taken to improve the quality of life of those at end of life and of bereaved persons.

Separate action plans should be drafted for the attention of particular groups of people working in different sectors.

- **End of Life is a public health matter:** The responsibility for articulating and responding to end of life questions, including questions about end-of-life care, should not be left only to those who provide hospice and palliative care services. We must see and treat dying, death and loss as public health matters; they must be anticipated, and any harm that they cause the individual must be minimised by building our capacity to show solidarity with the dying and the bereaved. Community development, education, legislation and policy changes should be adopted using a public health approach to end-of-life.
- **High quality palliative care should be available to all:** High quality, person-centred palliative care should be available to all, regardless of age or circumstances, including psychological and spiritual care. Families and carers should also be supported.
- **Everyone is entitled to die with dignity:** The National Council is committed to ensuring that conditions of privacy and respect prevail in end-of-life care, including improving availability of private rooms for those that want them.

Activities of the Forum 2013-2015

Changing policy and practice - Recommendation to extend authority to pronounce death to nurses and paramedics

It is essential that our health services and the professionals who deliver care are open to both review and change practices which are no longer effective or hamper the delivery of the best possible care.

The Forum produced a position paper in 2012 recommending that authority to pronounce death be extended to nurses and paramedics.

This was raised as an important issue during the year-long public consultation that was conducted by the Forum in 2009-2010. Submissions from medical professionals and from bereaved families spoke of the inefficiencies inherent in processes of pronouncement as they currently stand.

The fact that doctors have sole responsibility in the pronouncement of deaths, while nurses or ambulance staff are amply qualified, means that doctors are frequently called away from more senior medical duties, causing delays and impacting on the quality of care provided.

Extending this responsibility to other healthcare personnel would address this problem and would make for faster and more efficient services.

Similarly, reducing the time it takes to register and certify death will enhance service provision to grieving families.

The Forum prepared a discussion paper outlining this proposal which outlines the rationale for extending authority to senior nurses and advanced paramedics. This document summarises the legal context and outlines the scenarios in which death would be pronounced by senior nurses and advanced paramedics.

It is important to note that Irish law does not preclude against extending authority to pronounce death. The basis for doctors pronouncing death is found in common law rather than statute and legislation would not be required to extend this responsibility.

While the law does not require a doctor to confirm that a death has occurred; to view the body of a deceased person; or to report the fact that a death has occurred, it does require the doctor who attended the deceased during the last illness to issue a certificate detailing the cause of death. For this reason we are limiting our proposal to pronouncement and not certification of death.

This paper is currently being reviewed by the HSE with a view to drafting a policy to extend this authority to nurses. The recommendation has also been approved by the Medical Committee of the Pre-Hospital Emergency Care Council, the regulatory body for paramedics in Ireland, who are progressing it.

Physical environment

Dignity is about respect for the individual and the quality of the physical environment has the power to enhance or detract from the dignity of patients, families and staff.² The physical environment is a prime example of the an end of life issue that goes beyond the domain of health and one that would need to be addressed as part of an End of Life Strategy.

Research has shown that better and more appropriate design can promote good care and organisational culture and can enhance the experience of people at end of life. Good design can also play a significant role in lower costs of care. Privacy is of paramount importance for individuals and their loved ones at end of life. Research shows that single occupancy rooms reduce costs of care by reducing the risk of infection, reducing medication errors, lowering length of stay and the number of falls (Ulrich, 2003).

In 2007, a report on the quality of the physical environment of hospitals in Ireland was commissioned by the IHF.³

The results included:

- The lack of facilities for private consultations and conversations in situations where confidentiality is critical
- The under-provision of single room accommodation
- The extent to which already very limited single-room accommodation is denied to the dying and their families because of the emerging priority given to infection control and isolation
- The lack of facilities for families
- The inadequate working conditions of staff
- The numbers of patients sharing a ward/ward section and the lack of adjacent sanitary Facilities
- The poor condition of mortuaries and associated family rooms
- The use of clinical and family areas for administrative and office use
- The lack of provision for different religious traditions and beliefs
- The lack of attention to external and natural surroundings

The IHF's Hospice Friendly Hospital Programme's Design and Dignity Guidelines were developed in 2008 to address these concerns. The Design and Dignity projects fund "exemplar" projects in public hospitals to transform the way hospital spaces are designed for people at the end of life and their families. The 11 hospital projects are located in Dublin, Sligo, Cork, Limerick, Meath, Tipperary, Mayo and Kilkenny. The project is co-funded by the IHF and the HSE.

The Forum is committed to building on this work. The Forum hosted a workshop in September 2012 with key stakeholders. The Forum is currently developing a work plan to address end of life issues relating to the physical environment. This may include advocating for local authorities to ensure that

² Hospice Friendly Hospitals, Design and Dignity Guidelines, June 2008

³ Design and Dignity Baseline Review, Tribal UK, 2007

their local development plans are “end-of-life proofed” to facilitate people to be cared for and to die in their own homes.

Regulation of the funeral services industry

The Forum believes that the funeral services industry should be regulated and supports the development of best practice guidelines for funeral service providers.

There are currently no barriers to entry and no licensing in an industry responsible for the burial or cremation of the 30,000 people who die in Ireland every year. There are no regulations or standards in the area of embalming which is often carried out by untrained personnel in inadequate hospital premises. Cremation, which is becoming an increasingly popular option, is not governed by any law.

The Forum is currently working with the Irish Association of Funeral Directors to develop best practice guidelines for funeral service providers in Ireland.

Advance care planning

Over the past two years the Forum has been advocating for the introduction of legislative provision for advance directives. There has been a commitment by Government that this will be added to the Assisted Decision Making (Capacity) Bill at committee stage.

Think Ahead is the flagship project of the Forum and was launched by An Taoiseach Enda Kenny in 2011. Think Ahead guides members of the public in expressing their preferences around end of life and seeks to initiate dialogue about these issues.

While the Think Ahead form includes health care preferences, it also encompasses legal and financial affairs, as well as funeral preferences and wishes regarding organ donation and post-mortems.

There have been several studies on Think Ahead conducted with health professionals and their patients and also with members of the public which have had very positive results.

Dr Brendan O’Shea, GP and Associate Professor on the TCD GP Training Scheme, has coordinated two pilots involving 100 patients and several GP practices in Dublin. The findings from these have been written up and accepted by the Irish Medical Journal. They are due to be published soon.

Dr Brendan O’Shea is working on another study with KDoc in Kildare from August 2013-March 2014 to look at the introduction of Think Ahead with patients across health care settings, including GP practices, Naas Hospital, nursing homes, palliative care teams and emergency services.

Think Ahead aims to bring about a culture change in Ireland to encourage people to THINK, TALK, TELL: **think** about their preferences around end of life, **talk** about their wishes with professionals and **tell** their loved ones about their decisions and ensure they understand these wishes. A national public campaign is currently being planned.

Public meetings

The Forum holds public meetings on issues of public interest relating to end of life. Two of these meetings were held in June 2012 on organ donation and Do Not Attempt Resuscitation Orders.

The Forum has developed a work plan for 2013-2015 which is appended to this submission.

B. Advance care planning

1. Ethical rationale for advance care planning

1.1 Context

Advances in medical technology present challenges to patients' understanding, choices and well-being. Very ill people at end of life can now be kept alive in ways that were not previously possible, such as with the support of artificial ventilation and PEG feeding. This can bring new ethical dilemmas. The moral weight that is **given to patient autonomy derives from:**

- Past abuse in medical research and medical paternalism
- Recognition of the rational reflective nature of human beings who choose values and want to live by them (McCarthy, 2012)
- Emerging evidence that advance care planning improves the quality of patient care

1.2 Advance care planning: origins, definitions and rationale

Advance care planning is the process of care planning that generally occurs in an end of life context. The Quality Standards for End of Life Care in Hospitals that was developed by the Hospice Friendly Hospitals programme of the IHF defines advance care planning as the process of discussion between a person and their carer, and often those close to them, about future care. Advanced care planning usually takes place in the context of an anticipated deterioration in the person's condition in the future, with increasing loss of capacity to make decisions and/or ability to communicate their wishes. However, this is not necessarily always the case. Issues which may be discussed are the service user's concerns, his/her values or personal goals for care, his/her understanding of their illness or prognosis, in addition to particular preferences for types of care or treatment and preferred place of care in the future.⁴

Current thinking advocates a holistic approach that recognises the values of the process and outcomes of care planning in general across the health sector, a process that constitutes advance care planning when carried out in the context of end of life care. Advance care planning also serves to assist health care professionals to provide appropriate care and facilitate decisions that take into

⁴ Hospice Friendly Hospitals (2010): Quality Standards for End-of-Life Care in Hospitals, Irish Hospice Foundation, Dublin: 142

account what is known in relation to the person's wishes, feelings, beliefs and values (Randal, 2009).⁵

Advance care planning is based on three core principles in healthcare ethics:

1. Obligation to avoid or minimize harm
2. Provide maximum benefit
3. Respect patient autonomy.

It has developed in response to the recognition that planning options for care with patients leads to:

- Reduction of the effects of complicated grief, stress, anxiety and depression in surviving family members.⁶
- More appropriate management of care (Davison & Torgunard, 2007)
- Higher quality end of life care that is better tailored to the needs and preferences of patients (Hirshman et al, 2007)⁷
- Supported decision making (Sulmasy et al, 2007)
- Improved family satisfaction and supported bereavement experience

1.3 The case for advance care planning: improved patient care

There is an emerging evidence base regarding the role that advance care planning can play in improving the quality of care that can be delivered by health professionals.

The Association for Palliative Medicine (APM) has issued a position statement on advance care planning in which it welcomes national and local initiatives that enable patients to fulfil their wishes for care at the end of their life. The statement says that:

Advance care planning is becoming an increasingly popular approach within end of life strategy and policy documents. It enables patients to express their preferences about their wishes for future care should they lose capacity. The APM supports the more widespread use of advance care planning and advance decisions to refuse treatment. Advance care planning requires sensitive, timely and honest discussion with the patient and those they choose, which may or may not be supported by tools to facilitate and document this. Advance care

⁵ Randall, 2009: The Mental Capacity Act: Implications for Palliative care, EAPC 11th Congress, Vienna, Austria

⁶ Detering et al, 'The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial', *British Medical Journal*, 2010, 340: c1345

⁷ Research has shown that a lack of openness surrounding the fact that a patient is going to die and a lack of planning for their death may act as barriers to achieving high standards of care. In this way, a lack of communication prevents patients and their carers from being able to plan their care (Ellershaw & Ward, 2003)

*planning may be helpful in clarifying decisions to withhold or withdraw treatments...it may also help to achieve a better death for that person.*⁸

The UK End of Life Care Strategy emphasised the importance of advance care planning for better end of life care outcomes.⁹ The first step on the end of life care pathway set out in this strategy is 'discussion as the end of life approaches', involving 'open and honest communication' and 'identifying triggers for discussion'. The NHS tool 'Preferred Priorities for Care' records advance care planning discussions and decisions relating to end of life care.

In Australia, recent research based on older patients in Australia by Detering and Silvester has found that advance care planning 'improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives'.¹⁰

The NHS defines advance care planning as: a *process* of discussion and review enabling patients to express and, if they wish, to record views, values and specific treatment choices to inform their future care. It is important to note that it is the discussion and expression of preferences that is key, even if someone does not go so far as to make an advance care directive. In this way, if Think Ahead serves to stimulate discussions about end of life, this will be a gain in itself and will contribute to a change in the culture of 'death denial' in Ireland and a move towards a more open treatment of these issues.

A 2008 report to the US Congress by the Department of Health and Human Services on the subject of advance directives and advance care planning found that advance care planning discussions contributed to increased patient satisfaction without evidence of negative psychological effects.¹¹ When advance care planning is embedded in approaches to care, it has been proven to enable access to palliative care, reduce hospital admissions, and interventionist treatment that may lessen people's quality of life.¹² Similarly, an absence of advance care planning has shown to lead to

⁸ Association for Palliative Medicine (APM) position statement on advance care planning (2008), <http://www.apmonline.org/documents/128499910432102.pdf>

⁹ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

¹⁰ Detering, K, The impact of advance care planning on end of life care in elderly patients: randomised controlled trial: *BMJ*2010;340:c1345; Silvester W et al, Advance care planning (ACP), and its impact in the renal unit, *BMJ Support Palliat Care*2012;2:191-192 doi:10.1136

¹¹ [U.S. Department of Health and Human Services, Advance Directives and Advance Care Planning: Report to Congress, Office of the Assistant Secretary for Planning and Evaluation: August 2008](#)

<http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>; Song MK. Effects of end-of-life discussions on patients' affective outcomes. *Nurs Outlook*. May-Jun 2004;52(3):118-125; Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news. 2: What evidence is available to guide clinicians? *Behav Med*. Summer 1998;24(2):61-72

¹² Seal, M, Patient advocacy and advance care planning in the acute hospital setting, *Aust J Adv Nurs*. 2007 Jun-Aug;24(4):29-36; Seymour et al, Implementing advance care planning: a qualitative study of community nurses' views and experiences, *BMC Palliative Care*, 2010, 9:4

poorer outcomes in quality of life and lower levels of satisfaction.¹³ There is also evidence that advance care planning improves satisfaction among patients and families in relation to decision-making.¹⁴

While there is as yet relatively limited research in this area,¹⁵ there is an emerging research focus on this topic. One example is ACEP, the International Society of Advance Care Planning and End of Life Care, that is committed to building this evidence base for advance care planning.¹⁶

1.4 Consent and capacity

Informed consent occurs when a competent and informed person, understanding the risks and benefits at stake, voluntarily and intentionally either gives permission to a health care professional or refuses a health care professional permission to treat them for their condition. The requirement of informed consent to treatment and care:

- Minimizes harm, e.g. deception, manipulation, assault. The Non-fatal Offences Against the Person Act (1997) asserts that treating someone that has opted to refuse that treatment constitutes a criminal assault of the person
- Maximizes benefit (e.g. adherence, better outcomes)
- Respects autonomy (e.g. choices, priorities, privacy)

Informed consent presupposes voluntariness, information, and **capacity**, (McCarthy, J., M. Donnelly, et al. (2011); O'Shea, E., K. Murphy, et al. (2007).

Measuring capacity is complex, difficult and uncertain. Irish law upholds a presumption of capacity but it is important to note that capacity can fluctuate.

The **functional approach** to assessing capacity focuses on the individual's ability to perform the task of understanding and deliberating on the particular health-care decision being made. The **functional test** determines that the individual is:

- Free (uncoerced)
- Able to understand a therapeutic procedure
- Able to deliberate on its benefits and risks in light of their own values and desires
- Able to communicate (through talking, sign language etc.) their wishes.

¹³ Lynn, J et al, *End of Life Care and Outcomes. Evidence Report/Technology Assessment No. 110* (Southern California Evidence-based Practice Centre), AHRQ Publication No. 05-E004-2 Rockville MD: Agency for Healthcare Research and Quality, 2004

¹⁴ Caplan, GA et al, Advance care planning and hospital in the nursing home, *Age and Ageing* 2006, 35: 581-585

¹⁵ U.S. Department of Health and Human Services, *Advance Directives and Advance Care Planning: Report to Congress, Office of the Assistant Secretary for Planning and Evaluation: August 2008*

¹⁶ This paper has been informed by results of controlled searches on CINAHL/Medline, Psychology and Behavioural Science Collection databases and PubMed, as well as open keyword searches on Scirus search engine and Google scholar

The functional approach is applied in the Mental Capacity Act 2005 England and Wales and is also referred to in the Irish Mental Health Act 2001 Supreme Court judgment *In re a Ward of Court [1996] 2 IR 79; Re C Adult: Refusal of Medical Treatment [1994] 1 WLR 290*.¹⁷

In the case that a person has lost capacity, health professionals have ethical responsibility for deciding on the best clinical approach to their care.

They should do this on the basis of:

- **Any existing advance directive/Power of Attorney:** An advance directive was defined by the Irish Council of Bioethics as a ‘statement made by a competent adult relating to the type and extent of medical treatments she or he would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time’ (2007). An enduring power of attorney is a document drawn up by a competent adult empowering another to make certain decisions on their behalf if capacity is lost. This is currently limited to property and personal care decisions, which does not include health or treatment decisions. The Assisted Decision-Making (Capacity) Bill 2013 now makes provision for the extension of Enduring Powers of Attorney to include healthcare decisions.
- **Substituted judgement standard:** A decision that would be consistent with what the patient would decide if they were competent. This decision would be based on information drawn from people who know the patient and understand their values e.g. carers, family members to whom the patient has expressed their views (McCarthy et al, 2010)¹⁸
- **Best interests standard:** A decision made based on the well-being of the person according to their wishes and taking into account the harms and benefits of using different treatments compared with the harms and benefits in withholding treatments. Treatment is not started, or it is stopped if it is ineffective or futile and excessively burdensome (Mental Health Act 2001; *In re a Ward of Court [1996] 2 IR 79*; Irish Medical Council 2009).

McCarthy (2011) suggests that professional responsibilities regarding the informed consent process include to:

- Assess capacity in a way that is fair and free from prejudices
- Facilitate people with borderline capacity
- Address broader issues of communication
 - Listen and speak; information is a two-way process
 - Understand emotional and social context
 - Provide honest advice
- Consider consent (and refusal) as a process of repeated engagement; it is not a once-off event.

¹⁷ The Scheme of Mental Capacity Bill of 2008, which was drafted as a result of the recommendations made by the Law Reform Commission, also provided for the functional approach

¹⁸ McCarthy et al, ‘Irish Views on Death and Dying: A National Survey’, *Journal of Medical Ethics*, 2010; 36; 454-458

2. Advance care planning and health professionals

2.1 Understanding and attitudes of health professionals

A major challenge with regard to applying the principles of advance care planning, as well as the implementation of advance care directives, is a lack of understanding and knowledge among health care professionals regarding their role and responsibilities in this area.

Research carried out in Ireland in 2006 found that 27% of consultant physicians had experience of caring for a patient with an advance care directive.¹⁹ It is hoped that the guidelines that are expected to follow the National Consent Policy (outlined below in Section 3.2.1) will work to counter this lack of understanding.²⁰

With regard to attitudes, while the majority of research on the attitudes of health professionals to advance care planning finds largely positive responses to the concept, concerns have been reported by some health professionals in relation to their perceived capacity to have these conversations with patients and the communication skills involved.²¹

US research has found that the attitude of health professionals will often determine the nature of the end of life care that is provided, as well whether or not related discussions and decision-making processes are undertaken.²²

In terms of employee well-being and job satisfaction among health care professionals, research has found that increased job satisfaction is an associated gain with increased quality end of life assurance that is provided by advance care planning process.²³

More research is required on the levels of confidence and competence that health professionals have in having these conversations as well as the skills required to both initiate and respond to discussions.

2.2 Professional ethical standards

There is growing acknowledgment among medical professionals and their regulatory bodies of the importance of patient autonomy and the obligation of medical professionals to respect and implement their patients' wishes. This is within the parameters of the law: while people have the legal right to refuse treatment, they cannot demand treatment.

A person's autonomy relates to the way they have lived their life and the things that are most important to them: '[A] person's autonomy is found also in how they express their sense of self, in

¹⁹ Butler et al, 'Dissatisfaction with Do Not Attempt Resuscitation Orders: A nationwide study of consultant physicians practices', *Irish Medical Journal*, 2006

²⁰ At the time of writing, this policy remains in draft form as it has not yet been approved by the HSE Board

²¹ Seymour et al, Advance care planning for patients with inoperable lung cancer, *International Journal of Palliative Nursing* 2006, 12: 172-179

²² Bach JR. Threats to "informed" advance directives for the severely physically challenged? *Arch Phys Med Rehabil*. 2003;84(4 Suppl 2):S23-28

²³ Seal, M, Patient advocacy and advance care planning in the acute hospital setting, *Aust J Adv Nurs*. 2007 Jun-Aug;24(4):29-36

their relationships with those important to them, and in their values and preferences' (Nuffield 2009: 74).

The **Irish Medical Council's Guide to Professional Conduct and Ethics (7th ed, 2009)** acknowledges the role of the doctor in assisting people to deal with the reality of death and the importance of effective and sensitive communication with patients so that they have a clear understanding of what can and cannot be achieved in relation to their own care. The Irish Medical Council's Guide also advises doctors that a patient's advance treatment plan should be respected if it represents an informed choice by the patient at a time when they had capacity, it covers the relevant situation which has now arisen and there is no evidence that the patient has changed their mind.

The Irish Medical Council holds that an advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected on condition that:

- The decision was an informed choice
- The decision covers the situation that has arisen, and
- The patient has not changed their mind.

If there is doubt about the existence of an advance treatment plan, the patient's capacity at the time of making the treatment plan or whether it still applies in the present circumstances, the treating doctor should make treatment decisions based on the patient's best interests. In making these decisions the Medical Council calls for doctors to consult with any person with legal authority to make decisions on behalf of the patient and the patient's family if possible.

An Board Altranais is currently in the process of reviewing its code of conduct and this will likely include issues of care planning and nurses' role in initiating and facilitating patients' care plans.

Momentum for Change

3.1 International policy context

3.1.1 International rights instruments

The **European Convention on Human Rights** has enshrined the right to self-determination.

In December 2009, the **Council of Europe** issued a recommendation which noted that where legal systems provide for advance care directives, increasing numbers of people avail of them.²⁴ The statement recommended that Member States promote self-determination for adults in the event of their future incapacity by means of powers of attorney and advance directives.

The **2006 UN Convention on the Rights of Persons with Disabilities** also calls for states to facilitate people with disabilities to exercise their right to make choices and express preferences in relation to their care.

²⁴ *CM/Rec(2009)11*

3.1.2 Other legal jurisdictions

Advance care directives enjoy legal status in **other jurisdictions** such as:

COUNTRY	LEGAL SITUATION
US	The US has led the trend regarding policy development to enhance patient autonomy in this area. ²⁵ The Patient Self Determination Act was passed in 1990. Medical professionals in the US have a legal obligation to ask all patients in their care, regardless of age, if they have made an advance directive or appointed a power of attorney. Similarly, nursing homes in the US are required by statute to offer the facility to make an advance care directive to all people that are admitted.
England and Wales	Advance directives are legal. The Mental Capacity Act was passed in 2005, allowing people to make an advance directive or appoint a proxy to make decisions on their behalf. The British Government has upheld the right of every adult with mental capacity to consent to or refuse medical treatment.
Scotland	Advance care directives do not currently enjoy a statutory footing in Scotland but are considered to be legally binding in Scotland under common law. Under the <i>Adults with Incapacity (Scotland) Act 2000</i> any medical treatment administered to an adult with incapacity must take into account his or her 'past wishes and feelings', including advance directives.
Germany	In 2009, Germany passed a law on advanced directives based on the principle of the right to self-determination, applicable since 1 September 2009. Such law, based on the principle of the right of self-determination, provides for the assistance of a fiduciary and of the physician.
Netherlands	Netherlands passed the Medical Treatment Contracts Act (WGBO) in 1994 which provides for advance directives to be made by patients aged 16 or over. The Act calls for care providers to comply with patients' expressed preferences. The Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 contains provisions on advance directives relating to euthanasia.
New Zealand	Patients have a legal right to make advance directives in New Zealand under Right 7(5) of the Code of Health and Disability Services Consumers' Rights. The Health and Disability Commissioner (HDC) has produced an Advance Directive which allows people with mental illness to specify what treatment they agree to, and what treatment they do not consent to receive, if they become unwell in the future. ²⁶
Canada	The Health Care Directives and Substitute Health Care Decision Makers Act was passed in 1997. In addition, 11 out of 13 states have federal legislation providing for advance care directives and/or proxies. Advance directives are recognised by

²⁵ Ulrich, LP. *The Patient Self-Determination Act: Meeting the Challenges in Patient Care* (Washington: Georgetown University Press, 2001)

²⁶ Wareham P et al, *Advance directives: the New Zealand context* (Nurs Ethics. 2005 Jul;12(4):349-59

	the Canadian Medical Association
Australia	Advance care directives are legally binding in Australia, however there is significant variability in the terminology used and in the format and forms of advance care directives across territories and states which makes it difficult for one jurisdiction to recognise an advance care directive from elsewhere. To remedy this, a National framework for Advance Directives was prepared in 2011 by a Working Group of the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. The framework sought to harmonise advance directives across jurisdictions in terms of terminology and formats used.

3.1.3 International advance care planning initiatives

In addition to international examples of the legal recognition of advance care directives, as mentioned above, there has also been recognition internationally that the effective storage of personal information regarding patients' preferences is vital in the delivery of quality care. In this context, there is significant international momentum behind developing systems to record people's health preferences and other information.

COUNTRY	ADVANCE CARE PLANNING INITIATIVE
US	<p>The U.S. Living Will Registry has been storing advance directives since 1996. The Registry electronically stores the documents and makes them available to hospitals and health care providers.</p> <p>Medicare in the US has also developed end of life orders called POLST (physician order life sustaining treatment). There are state-specific versions of the POLST form.</p> <p>The Conversation Project, launched in 2010, is an initiative dedicated to helping people talk about their wishes for end-of-life care.²⁷</p> <p>Honoring Choices is a programme developed in Minnesota providing professionally facilitated advance care planning conversations for members of the public, as well as training for health care staff.²⁸</p>
UK	<p>The NHS National End of Life Care programme has developed a guide for health and social care staff in the importance of assessing a person's capacity to make particular decisions about their care and treatment and of acting in the best interests of those who are assessed as lacking capacity to make these decisions.²⁹</p>

²⁷ <http://theconversationproject.org/>

²⁸ www.HonoringChoices.org

²⁹ <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

	<p>Dying Matters³⁰ was set up in 2009 by the National Council for Palliative Care (NCPC). It is a broad based and inclusive national coalition of 28,000 members, which aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement and to encourage conversations about these issues. Its members include organisations from across the NHS, voluntary and independent health and care sectors (including hospices, care homes, charities supporting old people, children and bereavement); social care and housing sectors; a wide range of faith organisations; community organisations; schools and colleges; academic bodies; trade unions; the legal profession and the funeral sector.</p>
Northern Ireland	<p>The Northern Irish Public Health Agency is engaged in a regional initiative called Living Matters and Dying Matters. The aim of the initiative is to develop a regional approach to promoting open discussion about palliative and end of life care, aimed at all members of the public and the health and social care sector. A Regional Implementation Board, representative of key stakeholders, has been established with a remit to ensure the recommendations contained within the 'Living Matters, Dying Matters' Strategy and Priorities for Action 2009/10, are developed and embedded into practice. The Regional Implementation Board has three work streams: Education; System and Process; and Raising Awareness - the raising awareness subgroup, comprises PHA, all five Health and Social Care Trusts, Patient and Client Council, voluntary, charity and community sector will engage across public and professional communities, working with and through already established groups.</p> <p>The Royal College of General Practice established an end of life care group in 2011. The group is in the process of developing a patient passport which was included as an objective in the End of Life care strategy. Dr Aine Abbott was appointed as a Clinical lead GP in January 2011 and has been funded part-time for 2 years to develop the patient passport. There is not yet a fully evolved tool but a basic blueprint has been produced which is going to be piloted and modified over the next six months. The hope is that a group of clinicians will pilot each version: dementia; neurodegenerative conditions which don't immediately impact on mental capacity; cancer; children with life limiting illness; and long-term co-morbidities. The version for dementia is to be piloted first.</p>
Scotland	<p>Anticipatory care planning is one of the five priorities of <i>Living and Dying Well: Building on Progress</i> and patients are officially encouraged to create anticipatory care plans.³¹ The electronic sharing of these plans among clinicians is currently under development.³² The Government has also developed an ACP toolkit which includes a conceptual framework, triggers for creating anticipatory care plans, and practical guidance in this regard, including core components and a sample plan.³³</p>

³⁰ <http://www.dyingmatters.org/>

³¹ *Living and Dying Well: Building on Progress* was published in 2011 following the 2008 national action plan for palliative and end of life care, *Living and Dying Well*

³² <http://www.scotland.gov.uk/Publications/2010/04/13104128/1>

³³ These resources are available at: www.scotland.gov.uk/livinganddyingwell

Canada	Speak up is a Canadian initiative aimed at helping health professionals and governments to better understand how advance care planning practices can improve care and address the many issues the health system faces in delivering services to an aging population. ³⁴
Australia	Respecting Patient Choices comes from the Australian <i>National Palliative Care Program</i> and is supported by the Australian Government Department of Health and Ageing . It was introduced in 2002 to provide guidelines and training on having advance care planning discussions. It includes advance care planning resources both for members of the public and also for training for health care professionals ³⁵
New Zealand	In 2009 the Ministry of Health published a consultation document, <i>Advance Care Planning: An Overview</i> , which was intended to for the basis of standardised information and formalised guidelines for health professionals in the area of advance care planning. ³⁶ Another document, <i>Advance Care Planning for Adults: Planning for your future care</i> , was published by the Ministry to inform and guide patients and their families in relation to these issues.

3.2 Irish policy context

3.2.1 Policy commitments

There have been several **policy statements** supporting the concept of advance care planning.

i) HSE:

While there is no national policy and guidelines in this area, care planning is nonetheless an activity carried out within the health services, albeit with significant variation. Some hospitals have adopted the Liverpool Care Pathway, although feedback on its application has been very varied. Acute and community hospitals are also looking at care pathways more generally.

In terms of **documentation**, hospitals use **health care records** for every patient and these can perform a care planning function. Health care records are not available to community staff but discharge letters and test results are sent to GPs. Health care records include information related to health matters and relevant treatment plans.

A goal of the **HSE Strategic Plan for 2008-13** is ‘to develop the role of the “expert patient”, especially those with long-term illnesses, in developing their own care plan and in looking after their own condition’ (p.14). Two of the related actions to achieve this goal are:

- a) The promotion of patients as ‘partners with health professionals’ and;
- b) The education of staff on the ‘importance of patient involvement in their care’ (*National Strategy for Service User Involvement in the Irish Health Service 2008-13: 14*).

³⁴ <http://www.advancecareplanning.ca/>

³⁵ These resources are available at: <http://www.respectingpatientchoices.org.au/>

³⁶ <http://www.moh.govt.nz/moh.nsf/indexmh/advance-care-planning-consultation>

The HSE's Quality and Clinical Care Directorate has developed a wide range of National Clinical programmes and one of these is the **Palliative Care Programme**. A key work stream of the Palliative Care Programme is advance care planning. Initially this will focus on older people with life-limiting illnesses and the plan is to develop a universal documentation form for all settings. One of the programme's objectives for 2012 was the 'development of a national advance care planning programme which empowers patients and their families to express their wishes about treatment choices and care provision towards the end of life'.³⁷

ii) Department of Health: The Department of Health **Future Health: A Strategic Framework for Reform of the Health Service 2012 – 2015** commits to a:

- Focus on the rights and dignity of the person concerned, with care guided by the person's own views and wishes
- A strengths-based approach to needs assessment, i.e. a focus on supporting and enhancing ability to enable active community living;
- Individual care plans with a focus on personal goals and outcomes;

iii) National Consent Policy

The National Consent Advisory Group (NCAG), was convened in June 2011 under the auspices of the HSE's Quality & Patient Safety Directorate. The aim of the NCAG was to develop one overarching policy for consent in health and social care. The draft policy was published in 2012 and was approved by the HSE Board in April 2013.

The policy acknowledges the fact that the overall survival rate after CPR is relatively low at 13-20%; the associated risks of long-term brain damage and disability, as well as traumatic side adverse effects including bone fractures and organ rupture.³⁸ These considerations have prompted extensive national and international debate regarding the appropriate use of this procedure. Existing local and regional guidelines in Ireland relating to CPR and do not attempt resuscitation (DNAR) orders show a lack of consistency in how resuscitation decisions are made and documented and a lack of clarity about roles and responsibilities.

The national policy aims to: 'provide a decision-making framework that will facilitate the advance discussion of service users' preferences regarding CPR and DNAR orders and to ensure that decisions relating to CPR and DNAR orders are made consistently, transparently and in line with best practice. It is also stated that this policy should be read in conjunction with the Medical Council's 2009 document, Guide to Professional Conduct and Ethics for Registered Medical Practitioners.

³⁷ <http://www.hse.ie/eng/about/Who/clinical/natclinprog/pallcareprog.html>

³⁸ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR)
http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Patient_Safety/National_Consent_Advisory_Group/ncag4.pdf

In the context of advance care planning, the policy states that the views of the individual are very important and that: ‘In particular, service users are the best judges of their own quality of life’.³⁹

The policy calls for healthcare professionals involved in the decision-making process to have the requisite experience, training, knowledge and communication skills to coordinate this process, stating that decision-making responsibility rests with the most senior member of the person’s team. In the hospital setting this would be a consultant or registrar or the person’s GP in other settings. The policy suggests that standardised DNAR forms should be developed in the future to ensure appropriate documentation of these decisions and facilitate them being communicated across settings.⁴⁰

Where a person might be considered to be approaching death, this policy states that:

‘Cardiorespiratory arrest may represent the terminal event in their illness and the provision of CPR would not be clinically indicated. Attempting CPR when it is not clinically indicated may cause harm to the service user, increase his/her suffering and/or result in a traumatic and undignified death. In most cases, a sensitive but open discussion of end-of-life care will be possible in which service users should be helped to understand the severity of their condition...care provided should follow a palliative approach and focus on easing that service user’s suffering and making him/her as comfortable as possible’.⁴¹

Finally, the policy sets out principles to be applied in reaching a decision about CPR. One of these is that if a person with capacity refuses CPR, or a person lacking capacity has a valid and applicable advance healthcare directive refusing CPR, this should be respected.⁴²

iv) HIQA

HIQA Standard 16 calls for nursing homes to engage with residents in relation to planning their end of life care and preferences.⁴³ It is important to note that there is no specific guidance in the standards for residential care settings for timing of discussions and any consequent documentation regarding residents’ wishes and choices regarding end of life care. This is leading to the development of inconsistent approaches.

³⁹ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 9

⁴⁰ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 19

⁴¹ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 12

⁴² National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 14

⁴³ HIQA Standard 16: The resident’s wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident. This includes his/her preferred religious, spiritual and cultural practices and the extent to which his/her family are involved in the decision making process. Where the resident can no longer make decisions on such matters, due to an absence of capacity, his/her representative is consulted

3.2.2 Political support

There has been political recognition of a movement in Ireland for more patient autonomy with increased awareness among members of the public of their rights in relation to treatment and care.

There was strong political support expressed at the launch of Think Ahead at the Forum on End of Life in October 2011 by An Taoiseach Enda Kenny who said that:

'The Think Ahead initiative helps prevent shock, helps avoid confusion...by encouraging us to think, talk and tell. Think Ahead takes the attention, the intention and desire of the way we live and applies them equally and exquisitely to our death and dying, so we have some control, choice, peace, dignity at the end.'

The Taoiseach went on to say that:

'Putting the patients' choices and concerns at the centre of health services is a key aim of and driver for Government's reform programme for our health services. The end of life is no less precious than any other stage. In fact in many ways it is even more so. Which is why when we're at that stage we are entitled to dignity and respect, to have our wishes and concerns taken on board. The new 'Think Ahead' form is a key part of this new approach.'

Government deputies and senators have also been extremely supportive of Think Ahead during the pilots in Limerick and Louth from September to November 2012.

There have been several statements made by politicians in the Dail in relation to advance care directives. In June 2012, Deputy Liam Twomey's Advance Healthcare Decisions Bill came before the Dail in the form of a private member's bill. While there was widespread support for the objectives of the bill, it was withdrawn by Deputy Twomey following an undertaking by the Minister for Health James Reilly that provision for advance care directives would be included in the Assisted Decision-Making (Capacity) Bill.

During the debate of Deputy Twomey's bill the Minister said:

'There is increasing recognition that advance health care directives can empower patients by giving them greater control over their treatment and care decisions. They are also regarded as an important instrument in fostering a patient centred health care model and strengthening partnerships between individuals and their health care providers. In this respect, I recently attended an informal meeting of European Ministers for Health in Denmark at which the issue of patient empowerment was the main focus of discussion'.⁴⁴

1.1 Legal framework

While there is currently no Irish legislation governing advance care directives, they are legally binding in Ireland according to Irish law and to international law to which Ireland is bound. The decision of the Irish Supreme Court in *Re a Ward of Court (No 2)* [1996] 2 IR 79 says that advance

⁴⁴ Minister for Health's response speech to Advance Health Decisions Bill at Second Stage in the Dáil, Friday 18 June 2012

care directives are recognised by Irish law, provided that the author was competent and that the directive was specific to the patient's current situation.

Think Ahead is a tool designed to ensure that people have an understanding of their legal rights to refuse care and to express preferences.

3.3.1 Law Reform Commission Report

The Think Ahead project comes in the context of the **Law Reform Commission's Report, Bioethics: Advance Care Directives**, published in September 2009.

The report made 42 specific recommendations:

- It called for legislation to provide for advance care directives in the wider context of advance care planning, stressing that advance care directives are not limited to wishes made in a healthcare setting but rather encompass wider care settings as well
- It suggested a draft Mental Capacity (Advance Care Directives) Bill 2009, intended to implement the recommendations
- It called for a system for the registration of care preferences and advance care directives, citing the Irish Hospice Foundation as one possible organisation which might support such a system.

3.3.2 Assisted Decision Making (Capacity) Bill

In March 2013, a commitment was made by Government that provision for advance directives would be included in the **Assisted Decision Making (Capacity) Bill** at Committee Stage. The enactment of this legislation and its inclusion of provision for advance care directives would go toward fulfilling Ireland's obligations under the **2006 UN Convention on the Rights of Persons with Disabilities** and the Council of Europe's Recommendation on Advance Directives.

The Law Reform Commission's draft Bill on Advance Care Directives (2009) was set in the context of the proposed Assisted Decision-Making (Capacity) Bill which provides for a functional approach to the assessment of capacity, sets out principles that must be followed for those who lack capacity and provides an overarching modern framework for the protection of people who lack capacity. It would be important that any decisions that are being made (to include health care decisions) for a person whose capacity is at issue are being made with the benefit of this overarching framework. In addition, an important aspect of the right of self-determination in the context of advance care directives is the right of a person to nominate a person to make decisions for them – a health care proxy.

3.3.3 Health Information Bill

The potential storage of advance directives, and their accessibility by relevant authorities, will be influenced by the forthcoming Health Information Bill. At the time of writing it is not known when this Bill will be published.

Submission to the Committee on Health and Children Public Hearings on End of Life Care

The Forum on End of Life in Ireland

19 November 2013

The Forum on End of Life in Ireland would like to make the following recommendations to the Committee following the six hearings on end of life care:

1. End of Life and Bereavement Strategy

The Forum calls for a cross-departmental End of Life and Bereavement Strategy to address all end of life issues, including health, financial, administrative, legal and economic, as well as to address bereavement needs and endorsing pathways for people – from assessment to treatment

2. Regulation of the funeral industry

The Forum calls for the regulation of the funeral industry in Ireland

3. Extension of authority to pronounce death to some nurses and paramedics

The Forum recommends that authority to pronounce death be extended to some nurses and paramedics

4. Physical environment

The Forum calls for the importance of the physical environment in providing dignity and privacy to people at end of life and their families to be respected by policymakers. The Forum also calls for building regulations to bear in mind the wish of the majority of Irish people to die in their own homes in the community and to help facilitate this

5. Inclusion of advance directives in the Assisted Decision Making (Capacity) Bill 2013

The Forum calls for the inclusion of advance directives in the Assisted Decision Making (Capacity) Bill 2013 at Committee Stage as agreed by Cabinet in March 2013

6. End of life care - definition

The Forum recommends that the term end of life care be used to refer to all aspects of care relating to dying, death and bereavement which a person receives towards the end of life. In this context, 'end of life' can be from the time of diagnosis, the months before death or even the last hours of a person's life – it is a continuum, rather than a point in time. Care at end of life includes care for:



- People living with advanced life-limiting conditions (for whom death within a period of 1-2 years is likely)
- People in the terminal phase of illness
- Parents and families where there has been a death in the womb or in infancy
- The bodily remains of the deceased person
- Those affected by sudden death
- Families and friends of the person nearing the end of life, and also the staff who care for them
- The bereaved

The Forum endorses the following recommendations that were made by other speakers:

Needs of minorities:

- Ensure that any standards introduced to monitor health care delivery, including palliative care are capable of recognizing the needs of minorities, not just the majority culture.

End of life care and bereavement as public health issues:

- Policy reform to ensure that end-of-life care and bereavement are recognised as important public health issues; separate to palliative care but inclusive of many of its key elements.

Ethics:

- Ethics support should be a standard part of healthcare organisations
- A National End-of-Life Healthcare Ethics Observatory should be established which would be the joint initiative of third level educators in ethics, law and related disciplines drawn from relevant institutes and universities in partnership with hospital education centres and professional bodies in Ireland
- Hospital ethics committees should be linked at local, regional and national levels in the form of a National Network

Older people:

- Greater consultation with older people in order to establish expressed needs and preferences with respect to end-of-life care

Advance care directives

- The Think Ahead form developed by the Forum on the End of Life, an initiative of the Irish Hospice Foundation, should be promoted. Relevant health professionals should have access to people's preferences, as articulated in the Think Ahead form, on a 24/7 basis, ideally in a central on-line register, to ensure that appropriate levels of care and comfort can be provided, consistent with the wishes of the patient and their current clinical status. Ideally, every competent person entering a nursing home for long-term, end-of -life care, should be provided with encouragement and support to fill in this form.

- This central on-line register could be created as part of the Assisted Decision Making (Capacity) Bill 2013

Do Not Resuscitate Orders (DNARs)

- While the National Consent Policy provides clarity around the issues pertaining to CPR and DNAR orders in the context of consent, it does not provide guidance for technical and practical considerations relating to resuscitation procedures and this needs to be provided in the form of national guidelines.

Staff development:

- The health service should take responsibility for delivering end-of-life care training and development
- Adoption of the National Clinical Care Programme for Palliative Care clinical competencies, which include the importance of recognising cultural differences, communication skills, and ethics.
- Ensure staff release is facilitated for continuing professional development and access to training in communication, end of life and bereavement care
- Education in palliative care should be part of the under-graduate core curriculum of all health care professionals
- Statutory support for further palliative education for GPs, Primary care teams and out of hours GP services
- Managers should be encouraged to acknowledge the challenges inherent in end-of-life care, and to value 'emotional labour' and to coach and support staff in their provision of end of life care.
- Non-statutory stakeholders must have access to appropriate education. GPs should be facilitated to engage in end-of-life care training, especially end-of-life care training that is focused on initiating discussions with people about their end-of-life care preferences or breaking bad news to people with compassion and care
- Registered Nurse Prescribers to all be issued with a prescription pad and enabled to prescribe. Other healthcare professionals should also be educated on this role of nurses so that they can work to facilitate this.

Bereavement:

- Support strategically-driven training initiatives in end of life and bereavement care – e.g. address undergraduate education gaps around bereavement and loss, not only for our health professionals but for teachers, educators, solicitors and others.
- Ensure quality information and resource provision is incorporated into a national strategic approach for bereavement and loss.
- Support grief at work initiatives in the health service

Children:

- Sustainable funding and implementation of the National Policy on Children’s Palliative Care should be planned for
- High quality specialist palliative care services for children across a multidisciplinary team should be available to all children with life limiting illness, with access to a high level of expertise when necessary
- Fund the Consultant in post and outreach nurse programme and further expansion of consultant posts is essential.

Palliative care in the community:

- Enhance community nursing to support those dying at home
- Increase access to home support including access to 24/7 nursing care and specialist palliative care on call support in the community
- A formal framework should be developed to provide guidance, support and resourcing for GPs and primary care teams caring for patients who are dying at home, as part of a national integrated care plan linking primary care, hospice care and hospital care.
- A formal mechanism for GPs to communicate with out-of-hours services should be implemented without delay
- Palliative care patients waiting to access fair deal beds should be prioritised
- Funding from the ‘Fair Deal’ scheme could be accessed to fund care packages to allow people to stay in their own homes
- Fast-tracked medical cards given to people with a terminal diagnosis should be capable of being renewed on the basis of a covering letter from GP or consultant without means test should this be required
- The HSE publish the findings of the QPSA (2013) audit on Primary Care Team Services and outlines the actions taken to address the deficits in service provision.

Acute care:

- Each of the new hospital groups being developed by the HSE should have an end-of-life care plan
- Investment should be made to provide separate areas within emergency departments that can be used to support the patient and their family, during the process of dying, and after death
- Palliative care expertise should be available to Emergency Department staff
- Emergency Department staff should appropriately refer patients to spiritual support from pastoral professionals

Paramedic services:

- More ambulances should be made available to ensure effective transfer of patients and appropriate location of care

Specialist palliative care services:

- Specialist Palliative Care services should be integrated with other healthcare services in each region, so that the service can be brought to where the patient is, and patients and families can access the element of care most appropriate at any given time
- A dedicated budget for palliative care nationally and a single entity responsible for palliative care services country-wide
- The specialist palliative care budget should not be allowed to fall below current (2013) levels
- More practical funding methods should be explored for specialist palliative care; the 44 existing (but unopened) additional beds should be brought into commission as soon as possible; and the HSE should move to pre-planning stage for those areas of the country which currently have no in-patient unit
- National Service Plans to ensure equity of access
- Palliative care should be part of all health and social care policies for non-communicable diseases, including care delivery, education for the community and clinical staff, optimising models of service delivery, and research
- The Government would maintain an ongoing awareness campaign informing the public of the health benefits of 'specialist palliative care' to people of all ages with life limiting illness.

Research:

- Infrastructure support to ensure the basic research network architecture is sustainable, continues to develop and achieves impact

Dementia:

- Have dementia recognised as a life limiting condition
- Ensure specific palliative interventions are provided for the whole dementia 'journey' - from diagnosis to end of life
- Give dementia palliative care full policy recognition in the National Dementia Strategy to be published this year. The Strategy should also recognise that skilled expertise in this area is needed and that palliative care is relevant throughout the illness trajectory.

Human Tissue Bill:

The Human Tissue Bill should be published and enacted. The enactment of this Bill would ensure clarity and consistency of standards in relation to obtaining consent or authorisation for post mortem examinations and organ retention.

Submission on the Needs of People with Neurological Conditions for Palliative Care and End of Life Supports

Introduction

The Neurological Alliance of Ireland is the umbrella group representing over thirty charities working with people with neurological conditions and their families. Over 700,000 people are living with a neurological condition in Ireland.¹ The issue of end of life care is of huge relevance for this population. Many neurological conditions are progressive and life limiting, with many individuals experiencing greater levels of disability and symptomatology as the condition progresses. In addition, there are issues in relation to capacity and the ability to make decisions about their care.

The Neurological Alliance made a detailed submission on end of life issues for people with neurological conditions to the End of Life Forum organised by the Irish Hospice Foundation in 2009. A number of NAI member groups also made submissions in relation to end of life issues for people with multiple sclerosis, Huntington's disease and dementia. The Irish Hospice Foundation is a member of the Neurological Alliance of Ireland and the two organisations are currently engaged in a research study to examine the palliative care needs and experiences of people with neurological conditions from the perspective of these individuals and their families and of a number of NAI member organisations working with them.

There is increasing recognition of the needs of people with neurological conditions and their families for palliative care and end of life supports. The Neurological Alliance of Ireland is committed to exploring and highlighting this issue with the aim of ensuring that these individuals receive the understanding and support required.

Executive Summary

People with neurological conditions have significant needs for physical and psychological support towards the end stages of their condition. There are specific challenges presented to palliative care services by people with neurological conditions due to their need for specialist interventions and treatment, the challenge of co-ordinating palliative care approaches over a range of services and providers and unique features of neurological disease such as the need for palliation to commence at earlier stages and the fluctuation in the progression associated with certain neurological conditions.

¹ The Future for Neurological Conditions in Ireland: A challenge for healthcare; an opportunity for change. Neurological Alliance of Ireland 2010.

There is a dearth of reports on the experience of people with neurological conditions in Ireland in terms of their needs and experiences in relation to palliative care and end of life support. However, extrapolating from research into specific conditions and reports from patient organisations indicates the need for a range of measures that need to be put in place.

This submission outlines a series of recommendations in relation to:

1. The need to promote and support research into palliative care and neurological conditions in Ireland, including the needs of this population, current patterns of service use and interaction with services, mapping of existing supports and research into initiatives that are effective in working with people with neurological conditions and their families.
2. The need to develop a policy framework to address the palliative care needs of people with neurological conditions and integrate this into existing services. The clinical programmes provide an opportunity to support the development of the important interface of neurology, rehabilitation and palliative care by developing pathways and guidelines for the management of palliative care and end of life needs of people with neurological conditions.
3. The need to develop a range of specialist services including addressing capacity issues in neurology and neurorehabilitation services which are vital in the delivery of palliative care and interfacing with palliative care services. There is also a need to address awareness, understanding and training among service providers around palliative care and end of life issues for people with neurological conditions and their families. Family carers provide the substantial majority of care to people with progressive neurological conditions. Training for carers in appropriate skills such as lifting, administration of treatments, feeding etc is needed.
4. The need to address the requirements of people with neurological conditions and their families for information and support around the legal, financial, emotional, future planning, bereavement and aftercare aspects of their condition and to recognise and support the vital role of patient organisations in this regard.

Main Submission

Neurological Conditions in Ireland

Over 700,000 people are affected by neurological conditions, affecting the brain and spinal cord, in Ireland. Many of these are long term chronic conditions, some resulting in progressive disability over time and the loss of physical and intellectual function as well as changes in behaviour and personality. The Neurological Alliance in the UK estimates that 2% of the population are disabled as a result of their neurological condition while 33% of people living in residential care have a neurological condition.

A number of neurological conditions require consideration of end of life issues and the need for palliative care:

- Rapidly progressing fatal neurological conditions such as CNS tumours or motor neurone disease
- Life shortening, progressive neurological diseases in the advanced stages, e.g. multiple sclerosis, Parkinson's disease –
- Acute neurological illness with poor prognosis

-Palliative care needs among people with long term progressive neurological conditions may be present from diagnosis but people with multiple sclerosis, Parkinson's disease and Huntington's disease may live for as many as 15 to 25 years after diagnosis. In contrast, people with motor neurone disease may live for only a few months, with very rapid deterioration.

What is Palliative Care?

What is Palliative Care? The World Health Organization describes palliative care as an approach that improves the quality of life of individuals and their families facing the problems 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. Palliative care is defined as care that:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- 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.

Palliative Care and End of Life Care for People with Neurological Conditions

There are a number of characteristics of neurological conditions which require specific consideration:

1. The long duration of the disease in some neurological conditions
2. Sudden death in relation to certain conditions
3. Lack of a predictable or fluctuating course in some conditions
4. Complex multidisciplinary care in the management of neurological conditions, requiring co-ordination a number of professionals and agencies in relation to identifying and meeting needs for palliative care and end of life support
5. Specialist treatments (such as deep brain stimulation) can address disabling symptoms for people with advancing neurological disease
6. Neuropsychiatric problems: Issues of cognitive and behavioural effects of the condition require understanding and specialist support from people involved in their care
7. Rapidly progressing neurological conditions may need palliative care early on

8. Many people die but not directly as a result of their neurological condition
9. Neurological conditions are widely variable in their progression, even in the same condition, making planning for End of Life Care challenging².

Specific Issues in relation to Palliative Care and End of Life Support for People with Neurological Conditions

1. Cognitive Difficulties/Dementia

The advanced stages of progressive neurological illness can in some cases lead to impairment of cognitive functioning, ranging from memory loss to difficulty in comprehending information and decision making. There is a need for sensitive communication in recognition of these deficits. A range of techniques such as frequent repetition, concrete rather than abstract information and avoiding complex or long explanations can be used.

2. Behavioural Difficulties

Some neurological conditions can alter brain functioning to produce changes in personality and behaviour. These can range from depression to increased passivity and neglect of personal care to anxiety and distress and emotional lability. Depression can be caused by organic changes to the brain as well as the reaction to their disability. Understanding and learning to manage these behaviours is very important both for family members and staff involved in the care of these individuals. Cognitive and personality changes in a person with a neurological condition place significant burden on families which has been shown to have a cumulative effect over time. Support and training for carers in the management of these changes is critical.

3. Communication Problems

Neurological conditions can result in communication problems such as dysphasia, dysarthria and cognitive speech disorders which can affect the ability of these people to communicate. Understanding of their needs and use of assistive devices for communication are required

4. Competency and Mental Capacity

Cognitive impairment or changes in the mental health of people with neurological conditions may make health professionals and others in charge of the care of people with neurological conditions concerned about the person's ability to make sound decisions. In all cases, every effort must be made to ensure that the person with a neurological condition is involved as much as possible in decisions about their care. This may require supportive decision making, where alternatives are outlined in a way that the person can clearly comprehend, weigh up the information and make an informed choice. Information should be given in an appropriate medium and language and take account of any communication or comprehension difficulties.

² End of Life Care in Long Term Neurological Conditions: A framework for implementation. The National Council of Palliative Care and Neurological Alliance UK 2008

The Assisted Decision Making (Capacity) Bill is to replace the wards of court system in Ireland, with a modern framework governing decision-making on behalf of persons who lack capacity. Under the proposals: (a) It will be presumed that a person has capacity; (b) No intervention is to take place unless it is necessary, having regard to the needs and individual circumstances of the person, including whether the person is likely to increase or regain capacity; (c) A person will not be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success; (d) A person is not to be treated as unable to make a decision merely because he makes an unwise decision; (e) Any act done or decision made under this Bill must be done or made in the way which is least restrictive of the person's rights and freedom of action; (f) Due regard must be given to the need to respect the right of a person to his dignity, bodily integrity, privacy and autonomy; (g) Account must be taken of a person's past and present wishes, where ascertainable; (h) Account must be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made known; (i) Any act which is done or any decision made under this Bill for or on behalf of a person who lacks capacity must be done or made in his best interests.

The Bill also provides that a person is entitled to supportive decision-making. The person must, so far as is reasonably practicable, be permitted to participate, or to improve their ability to participate, as fully as possible in any act done for them and any decision affecting them. The NAI is concerned that proper support needs to be given to enable supportive decision making by people with neurological conditions and the use of substitutive decision making only where necessary. Clear guidelines must be available to those working with people with neurological conditions around determining capacity to consent. The provision of appropriate advocacy supports in this area is very important.

The Bill also provides that a medical practitioner who performs any act in connection with the personal care, health care or treatment of another person whose decision making capacity is in doubt, must take reasonable steps to establish whether the person lacks capacity in relation to the matter in question and when carrying out the treatment, reasonably believe that the person lacks capacity in this manner and that the intervention is in their best interest.

Where a person has been found to lack capacity, a personal guardian can be appointed by the High Court or the Circuit Court to make decisions concerning his personal welfare or property and affairs. The Bill will also establish an independent Office of Public Guardian to supervise persons appointed by the courts to perform guardianship or other decision making functions on behalf of people deemed to lack capacity.

This legislation is of substantial relevance to the welfare of people with neurological conditions where cognitive changes as a result of the condition impact on their ability to make decisions about their care. The Bill has the potential to ensure that these individuals are facilitated as far as possible in making decisions and where this is not possible, those in charge on their behalf are ensured to be doing so in their best interest and under due supervision. The NAI is concerned that supportive decision making is facilitated as far as possible by practitioners with an appropriate understanding of the effects of neurological conditions and that those making decisions on behalf of people with neurological conditions are sufficiently informed to make such decisions.

5. Physical Symptoms relating specifically to the neurological disease

Neurological conditions can result in a range of physical symptoms depending on the type of neurological condition, the stage of progression and the area of the brain affected. These symptoms can include:

- pain
- breathing or swallowing problems
- spasticity and involuntary movement
- side effects of medications
- muscle weakness and loss of muscle tone
- seizure control
- bladder and bowel control

Many of these symptoms will require ongoing management by health professionals and care staff to prevent complications and reduce discomfort as much as possible. For example, lack of accessible dieticians or nutritionists can have a significant impact on patients with swallowing difficulties, when not addressed properly this may result in malnutrition or pneumonia. There is great diversity of needs among people with people with neurological conditions. For example, symptoms related to different conditions and within conditions vary greatly, and in terms of those experienced by each person over time. Patients often suffer several recurring symptoms, which arise and then disappear partially or completely, only to be replaced by a different symptom or group of symptoms.

A person with a Long Term Neurological Condition should be referred to specialist palliative care services if they have:

- a limited lifespan – usually 6–12 months, and/or distressing symptoms – especially pain, nausea and vomiting, breathlessness, which fall within the remit of the palliative physician, and/or a need or desire for end-of-life planning, with or without competence issues.

A person who is dying from an LTNC should have timely and ongoing access to specialist palliative care services which include: symptom control, planning and support to the end of their life, aftercare and bereavement support for their families³.

6. Meeting the needs of the Individual with Slower Progression of the Condition

In some neurological conditions, the slow progression of the disease can present unique challenges for the individual and their family. People may receive a diagnosis while in good health and realise that they have little control or knowledge of when their condition will deteriorate. For families, there may be a much extended period of time when they need to provide increasing levels of care and reliance on health services. Most studies on carers of people with disabling neurological disease show a cumulative impact on the carer over time, with those caring for longer periods at increased risk of health problems and reporting greater levels of burden and distress.

7. Planning and Support to End of Life

Many of the issues in relation to planning for end of life will be similar for any illness with a negative prognosis. People with neurological conditions face unique challenges in that they may receive their diagnosis while they are in a position to be aware of the possible loss of mental capacity and

³ (Long Term Neurological Conditions and management at the interface between neurology, rehabilitation and palliative care. National guidelines issued by the Royal College of Physicians, National Council for Palliative Care and the British Society of Rehabilitation Medicine, March 2008)

functioning at a later stage. Supportive counselling needs to incorporate aspects of bereavement such as grief and loss of possible life choices, changes in family roles and managing painful and disabling symptoms as well as advice on financial management, information on entitlements and legal issues.

8. Aftercare and Bereavement Support to Families

Families of people with neurological conditions may have had to adjust to a long period of gradual loss of functioning over time, with greater physical disability, loss of cognitive functioning and changes in personality and behaviour. There is a need for constant readjustment in family roles and responsibilities as well as an increase in the demands of caregiving tasks over time. Research studies with families of people with neurodegenerative conditions point to stages of grief in family members, where different aspects of loss are mourned as the person loses key abilities. Families require ongoing support and counselling throughout this period, not just at the end of life. However, it is recognised that there will be a particular need for support at this stage. Families can experience complex reactions of guilt, relief for the person as well as a final sense of loss and bereavement. There may be particular issues around the manner of a person's death, particularly if there is the perception that it would not have been as they wished. In the case of neurological conditions with a hereditary component, there will be need for specialist genetic counselling available to these families. In some neurological conditions such as Huntington's disease, genetic transmission means that carers may face a double burden, someone caring for a parent may need to start caring for a sibling or a spouse/partner caring for their partner may need to start caring for their child.

Advanced Planning and Neurological Conditions

Everyone should have the right to make choices about their care at the end of life. Those involved in the care of people with neurological conditions need to be able to facilitate or support decisions about future management of the condition with the individual and their family.

Advanced Directives

An advanced directive (or living will) is where a person sets out their views in writing regarding future medical care to cover a situation where they were to become mentally incapable or unable to make decisions themselves. A living will can only relate to lawful treatments (such as withdrawal of medical treatment). There is no legislation in Ireland governing living wills and it remains uncertain whether a Living Will has any definitive legal standing in Ireland. In jurisdictions where they are recognised: -The individual must be over 18 and have mental capacity at the time they express their advance refusal -They need to be informed and should understand the nature and consequences of the treatment/intervention they are refusing -They need to be free from coercion.

While there is no legislation at present to underpin advance directives, either formal or informal, they are a means of ensuring wishes are respected following the onset of incapacity and not just at end of life. Advanced care planning can be facilitated through a discussion between an individual and the staff involved in their care. It may include family members and friends. There is a role for an independent advocate in assisting the person to make a decision about their care and treatment. This discussion be documented, regularly reviewed and communicated to key persons involved in their care.

The Irish Council for Bioethics has noted that⁴:

In Ireland, there is no specific legislation in relation to advance directives. The lack of legislation makes the status of advance directives unclear and, as a result, their implementation may or may not be enforced. Nonetheless, it has been suggested by the Law Reform Commission of Ireland (LRC) that it should be possible for an individual to make a legally binding advance directive, provided the decisions within the directive are themselves legal. However, in its final report on the issue of healthcare decision-making for vulnerable adults, the LRC concentrated on “the limited context of certain healthcare decisions which might be conferred using an enduring power of attorney”, as opposed to dealing with the issue of advance directives directly. It should also be noted that the discussion of the issues surrounding advance directives and end-of-life care has been a relatively recent development in Ireland. The lack of clarity surrounding the validity and applicability of advance directives in Ireland is, no doubt, a result of the fact that there have been very few decisions of the courts that have touched on the issue of a patient’s previous wishes regarding treatment.

The NAI welcomes the fact that the Department of Health has recently agreed to address the issue of advanced care directives, as part of the development of legislation in relation to Assisted Decision Making.

Disease-specific Issues in relation to Palliative and End of Life Care in Neurological Conditions

Multiple Sclerosis

Most people with MS initially have relapsing and remitting progress, with attacks affecting different parts of the central nervous system and with complete or partial recovery between attacks. Whether the disease begins with a relapsing or progressive course, in most cases the disease progression will result in progressive disability. The disease may be highly variable, the majority of people will experience progression and for some, this can occur shortly after diagnosis.

Parkinson’s disease

This is a progressive condition and with modern dopamine replacement therapy it can be controlled for several years. However, most people will suffer a progressive decline before the end of life due to motor and nonmotor fluctuations, neuropsychiatric problems and problems with muscle control.

This makes careful and timely care planning and provision essential. Palliative care should be involved at an early stage to assist with symptom management. Individuals should be encouraged to undertake advanced care planning but they, their careers and clinicians need to be aware that people can deteriorate dramatically and appear close to death due to treatment problems, and/or intercurrent infections, only to recover swiftly with appropriate intervention and resume their previous way of life.

Huntington’s Disease

The development of a standard care pathway is critical to the management of HD in order to identify the services and care required by people with HD from initial onset/diagnosis to rehabilitative treatment and on to end of life care.

⁴ Is it time for Advanced Care Directives. The Irish Council for Bioethics 2007

Conveying a HD diagnosis requires sensitivity and support from the clinician involved. A Neuropsychological assessment following diagnosis is necessary to establish decision making capacity and facilitate advanced care plans and legal and financial decision making. Neuropsychological services are required for people with HD and their families throughout the disease trajectory. Health and social care professionals working with people impacted by HD should be aware of the genetic impact of HD and the myriad of physical, cognitive and psychiatric symptoms in order to effectively assist in supporting the patient and family. Combining palliative care with multi- disciplinary care throughout the course of HD will help the patient and family make a successful transition through increasing levels of disability while maintaining independence and dignity. Care facilities and healthcare teams should recognise the carer's knowledge of the condition and of their loved one's preferences. Family carers should be included and consulted at each stage of the person's care⁵.

Parkinsonian syndromes - multiple system atrophy (MSA) and progressive supranuclear palsy (PSP)

These conditions may be initially be mistaken for PD, but most are usually less responsive to medication and the progression of symptoms is generally more rapid. In MSA there is a combination of Parkinsonism with brain and nervous system dysfunction whereas in PSP there is limited eye movement, cognitive change and physical instability (leading to falls and fractures). The prognosis is usually two to four years from diagnosis - people develop considerable disability and require careful assessment and care.

Motor Neurone Disease

Whilst for many the course of MND is predictable and palliative care can be planned in a similar way to that of individuals with a cancer diagnosis, others can die suddenly from respiratory collapse. Around 10 percent have a slowly progressive form of MND that can last 10 to 20 years.

Other conditions

Muscular dystrophy, progressive nerve and brain disorders each pose their challenges. These include both inherited and degenerative conditions. Diseases of the central nervous system such as Huntington's disease, prion diseases and cerebellar degenerations may have the additional complexity of cognitive loss. The nervous system can also be affected by a variety of cancerous conditions and the individual may have other diseases. Specialist management, a multidisciplinary team and close liaison with palliative care should all be considered.

Dementia

The Alzheimer Society of Ireland has produced a series of excellent reports in relation to palliative care and end of life issues in dementia and their recommendations will be supported and addressed in the course of this submission. It is important to understand that dementia is a feature, not just of Alzheimer's disease but a range of other neurological conditions including Huntington's disease and a proportion of those with Stroke, Parkinson's disease and other movement disorders and Multiple Sclerosis with a proportion of people with these conditions developing symptoms of dementia.

⁵ From the Huntington's Disease Association of Ireland submission to the Hearings on End of Life Care. 2013

*Building Consensus*⁶, provides an excellent insight and understanding in relation to the palliative care and end of life support needs of people with dementia.

The recommendations of this report will be discussed in the next and subsequent sections of this submission.

Irish Reports, Papers and Some Current Research on Palliative Care Needs and Palliative Care Services for People with Neurological Conditions

Palliative Care Service Use and Service Need among People with Neurological Conditions

A 2008 report on end of life care for older people in acute and long stay care settings in Ireland⁷ provides a summary of the main difficulties in relation to the provision of palliative care facilities in Ireland, many of which are also relevant for people with neurological conditions. These include:

- Few designated palliative care beds
- Low levels of access to consultant-led palliative care teams
- Lack of training for health professionals in palliative care
- Routine visiting/service provision in long term care settings for a variety of health professionals is very low
- Low provision of formal bereavement support services
- Existence of written policies on advanced directives is low, particularly in public long stay facilities

There has been no research to date in relation to the needs and experiences of people with neurological conditions as a group in relation to end of life support and palliative care and there is a critical dearth of information about the overall pattern of service use and service need for this population.

However we can extrapolate an understanding of the issues and challenges facing this population through consideration of the information that is available in Ireland at present.

This section will highlight

- (1) Findings and Recommendations of the Feasibility Study on Palliative Care needs among people with dementia
- (2) Findings from NAI consultation with members organisations working with people with neurological conditions
- (3) Other reports and papers in relation to palliative care and neurological conditions in Ireland

1. Findings of the *Building Consensus* Report

⁶ Building Consensus for the Future: Report on the Feasibility Study on Palliative Care for People with Dementia. Alzheimer Society of Ireland and the Irish Hospice Foundation 2012

⁷ End of Life Care for Older People in Acute and Long Stay Care Settings in Ireland. Department of Health and Children 2008

Building Consensus for the Future includes a number of insights into the needs of service users and their families and number of recommendations which are also applicable to the wider population of people with neurological conditions, as well as those experiencing dementia.

Many of the key features of current service provision identified in the report also apply across a range of neurological conditions in terms of the need for targeted information and support services, “transitional” points in the care journey and lack of capacity in a number of areas of service provision which impacts on service users and their families.

Need for Services

Building Consensus outlines that there are a wide range of sectors, service domains and service providers involved in the care of the person with dementia. The report points to the particular challenges facing the family in terms of “navigating” these services. Primary care, and specifically the GP, play a critical role throughout the disease trajectory. There is a real need to engage with the person with dementia and the family in a meaningful way and to also support and inform them about the range of services available. The report identified ‘transitions’ to services including acute care, residential care, respite care, community care, as key milestones in the progression of the condition. Families and healthcare professionals have identified that more supports and help are needed to make the transitions successful and as seamless as possible. Using integrated care pathways models to support the delivery of dementia care in general and dementia palliative care in particular are needed. The report outlines a series of specific recommendations in relation to service provision, including:

- case studies of selected sites with existing good dementia palliative care practices to be disseminated as good practice
- Developing and resourcing dementia palliative care interventions in residential settings through engagement with the residential care sector
- Supporting primary care and acute hospitals in the introduction of interventions to support palliative care in dementia, including the Irish Hospice Friendly Hospital Programme.
- Engagement with the Special Delivery Unit to provide fast track protocols to prevent people with dementia being admitted to hospitals and if admission is needed, to reduce the number of days the person is in hospital and reduce distress.
- Producing a suite of information products to meet the information needs of people with dementia and their families, as well as guidance materials for staff to include a focus on palliative care.

Need for Education and Training

Building Consensus identified a limited knowledge and skills base across the services in relation to dementia palliative care. The report outlined a series of recommendations to address the need for education and training including:

- evaluation of existing training and educational materials in order to strengthen and develop dementia palliative care awareness and expertise among healthcare professionals
- development of a dementia palliative care web based training and education site

-establishment of a peer to peer learning network to bring together dementia experts and palliative care experts

Need for Research

The feasibility study found a dearth of research in the area of dementia palliative care. It pointed out that there is a need for more research across a range of areas in relation to palliative care and dementia in Ireland including:

- research to understand the policy, services, education and training required
- mapping what is currently happening in Ireland and developing initiatives as needed.

Specific recommendations include:

- formulating a research agenda that spans the policy, services, education and training needs to promote dementia palliative care
- carrying out a prevalence study of people with dementia in one of the major acute hospitals in order to ultimately move towards the design of a Dementia Friendly Hospital.
- Research and develop a range of guidance documents/good practice guidelines/decision making trees for healthcare professionals dealing with the specific aspects of end of life care for example PEG feeding, nutrition and hydration and communication etc.
- Research the palliative care needs of the person with dementia, their carer and family including anticipatory grief and bereavement counselling.
- Building on existing tools and frameworks, research ethical dilemmas that present at end of life care for people with dementia and build a framework for informing ethical decision- making.
- Dissemination of these research findings across a range of stakeholder groups.

Need for Advocacy

The report outlines a series of recommendations in relation to providing an overall strategic approach to the management of dementia which includes palliative care. Specific recommendations include:

- The forthcoming national Dementia Strategy in 2013 gives full policy recognition to dementia palliative care as an area that requires skilled expertise and that dementia palliative care interventions have relevance right throughout the illness trajectory.
- The various professional groupings are informed and influenced to include dementia palliative care in their education and training initiatives, especially the GP, the primary care teams and legal professions.
- The Department of Health's Special Delivery Unit is urged to consider protocols and specific policy measures that direct acutely ill people with dementia away to the most appropriate setting.

-The HSE clinical care programmes that specifically relate to dementia palliative care (care of the elderly, primary care and palliative care) promote and support the development of appropriate policy leading to interventions across the clinical care programmes.

- There is an assessment of the forthcoming mental capacity legislation conducted using a palliative care lens and its implications for advanced care planning, living wills and Enduring Power of Attorney/Advocacy

2. Report Compiled by the Neurological Alliance of Ireland for the End of Life Forum

In preparing its submission to the End of Life Forum in 2009, the NAI compiled the concerns of its member organisations specifically in relation to current service provision for people with neurological conditions around end of life issues and palliative care. These can be summarised as follows:

1. The NAI acknowledge the excellent service provided by palliative care services, including Hospice home care teams and Hospice respite care. However, people with neurological conditions have difficulty in some parts of the country accessing palliative care services as the limited service is under pressure to provide care to a range of patients, predominantly cancer patients.

2. From reports of NAI member organisations, there appears to be little co-ordinated specialist support available to enable people with neurodegenerative conditions to be cared for in their own homes.

3. Most non-specialist care providers such as GPs, District Nurses and staff in care homes are likely to have little experience of the type of care patients and their families may need.

4. A lack of specialist in-patient facilities places a significant burden of responsibility of community based staff to deliver the complex care required at home for long periods. Organisations report that community services do not have the capacity or expertise to meet the level of need

5. Overall lack of capacity in the provision of acute neurology services in Ireland and the lack of a community based neurology service leads to delays and difficulties in the ongoing medical management of neurological conditions which particularly impacts those with significant care needs. The ability of acute neurology services to support and liaise with the work of palliative care services is necessarily dependent on their own resources. A number of reports on neurology and neurosurgery have pointed to the low numbers of neurospecialists in Ireland relative to recommended levels.

6. There is lack of suitable palliative care facilities to provide appropriate accommodation for people at the end stages of neurological disease. This is particularly the case for younger people

7. Availability of specialist information, training and counselling for people with neurological conditions and their families around symptom management, end of life planning and bereavement is very limited in Ireland.

8. The lack of integrated care planning for neurological conditions means that there is inadequate preparation for end stage needs and services fail to respond quickly and adequately leading to significant anxiety and distress for families and the individual themselves.

9. There is a significant lack of neuropsychological input to assess and manage cognitive and behavioural changes as a result of neurological conditions. This impacts on all stages of the care

pathway, from helping people to deal with their initial diagnosis to providing appropriate advice on later stage care and capacity to consent. 10. Individuals and health professionals need access to services which can provide information and guidance on issues such as legal capacity, consent and power of attorney to allow informed decision making about their options.

Consultation with NAI member groups resulted in a series of recommendations in relation to addressing the needs of people with neurological conditions for services and support in relation to end of life and palliative care.

1. Need for multidisciplinary neurospecialist input around symptom management and medication at all stages of neurological conditions but most particularly at the later stages of the disease. The important role played by clinical nurse specialists was stressed in this regard.

2. Need for ongoing training and information for carers on symptom management, lifting and moving the person and advice on medication

3. Where it is suitable and desired that a person be cared for in the home, the provision of appropriate medical and care support, adaptation and equipment and respite to enable this to take place

4. Appropriate accommodation facilities for end stage care of neurological conditions including the availability of staff trained in both the management of these conditions and in palliative care

5. A number of specialist interventions can be used to control spasticity in neurological conditions. These include botulinum toxin injections, intrathecal baclofen pumps and phenol blocks. Administration and monitoring of these interventions by a neurospecialist is required. In addition, physiotherapy support and other follow up is needed. Pressure on acute neurology services and the lack of community based services impacts on the availability of these services and proper follow up for patients.

6. There is a need for counselling and support for individuals and family members around legal issues, advanced care planning and end of life issues. Communication of a neurological diagnosis by health professionals requires sensitivity in understanding and dealing with individuals and family members as follows:

- Invite the person to bring someone with them when getting test results
- Convey the diagnosis sensitively giving the person time and undivided attention
- Allow time for the information to sink in checking that the person understands what is being said.
- Provide information on specific and general support
- Arrange a follow up appointment in the near future
- Discuss referrals to neuropsychology, rehabilitative therapies etc

7. Facilitated choice over preferred place of care for individuals and their families

8. Guidelines for the management of neurological conditions to ensure that staff who come into contact with these patients have an understanding of their needs at the later stages of their condition (including the specific needs of people with neurological conditions:1-6 outlined earlier

9. Palliative care needs to be a central aspect of the management of neurological conditions with protocols developed for communicating bad news, discussing options and facilitating access to support from voluntary organisations. Research in this area indicates that people need a staged approach to the discussion of end of life issues, with the facility to take in some information, then come back later with questions rather than being given a lot of information all at once. Patients also report the need for open and honest communication from professionals about future consequences of their condition and the opportunity to discuss these.

3. Other research/reports including forthcoming research on palliative care and neurological conditions

A number of research studies are ongoing in relation to understanding and meeting the palliative care needs of people with neurological conditions in Ireland. When completed, the findings of this research will be vital in informing the development of initiatives to address the needs of this population

- (i) Study on Palliative Care in Parkinson's disease involving University College Cork and specialists in geriatric and neurological care, Cork University Hospital.

This study is an initiative to raise cultural awareness, educate healthcare workers and provide cohesive support to patients and their carers/families. This project aims to develop National guidelines, a National HCW education package, and National patient/ carer information, as well as a local pathway for palliative care in PD.

- (ii) National MND Clinic Beaumont Hospital and Irish Motor Neuron Disease Research Foundation (RMN). Project to improve the quality of psychological care for Motor Neurone Disease (MND) patients and their carers through development and delivery of an accessible training program for the multidisciplinary team in collaboration with the Irish Motor Neurone Disease Association (IMNDA). This development project proposes to design, deliver and evaluate a training program for the multidisciplinary team to improve the competence of palliative care staff to deliver psychological services to patients with life-limiting neurological disorders, specifically MND. The project will include the development of eLearning course(s) for ease of access by regional centres, a workshop at Irish Hospice premises and knowledge base of support material. This project will leverage off research being undertaken by Our Lady's Hospice care services to examine the different psychological approaches used by therapists in Ireland, UK and Italy for MND patients. This development project will be in collaboration with the Irish Motor Neuron Disease Association (IMNDA) and Professor Orla Hardiman and her team at Beaumont Hospital.

- (iii) The Neurological Alliance of Ireland and the Irish Hospice Foundation are commencing a feasibility study to examine the needs of people with neurological conditions in relation to palliative care and end of life support from the perspective of these individuals and their families and the staff and volunteers of the not for profit organisations working with them. The following groups have agreed to be part of this research: the MS Society of Ireland, Huntington's disease Association of Ireland, Irish Motor Neurone Disease Association,

Progressive Supranuclear Palsy Association, Brain Tumour Ireland and the Parkinson's Association of Ireland.

(Note: This just a sample of current research into the area of palliative care for specific neurological conditions)

- (iv) Dr Tim Counihan, a Consultant Neurologist based in University College Hospital Galway has written a paper on Palliation in Movement Disorders⁸ including Huntington's disease and Parkinson's disease. The paper notes that palliation in these conditions aims to enhance the quality of life of both patients suffering from these progressive illnesses and their families. The report outlines the need for a multidisciplinary therapeutic strategy in relation to the management of these conditions encompassing neuropsychology, speech and language therapy, occupational therapy, nutrition and dietetics, physiotherapy, social work, respiratory care, specialist nurses, orthotic and wheelchair services, geneticist and neurologists.

The paper addresses a number of critical issues in relation to the palliation of Huntington's disease and Parkinson's disease including:

- Quality of Life and Invasive Procedures in Advanced Stage Parkinson's disease
- Pain Progression and Pain Management
- Dementia concerns
- Care options including hospice care
- Bereavement care

(v) The Alzheimer Society of Ireland continue to work with a range of other stakeholders towards the implementation of the findings of the Building Consensus Report. The NAI is fully supportive of the work of ASI in this area in developing appropriate responses to dementia which is a feature of a range of neurological conditions.

Summary of Current Issues in Relation to End of Life Support and Palliative Care for People with Neurological Conditions in Ireland

The following section is an attempt to summarise the considerable range of points made in the preceding pages and outline a set of recommendations to be considered.

Research/Understanding in relation to palliative Care issues

There is a critical need for more research into palliative care issues and end of life support for people with neurological conditions in Ireland. Research is needed to understand the current experiences of this group, their needs for information, support and services, current patterns of service use including mapping of existing supports and engagement with health professionals and other service

⁸ Palliation in Movement Disorders. Dr Tim Counihan, Consultant Neurologist, University College Hospital Galway. Published in "Modern Medicine" paper available on request.

providers. Research is needed to outline the understanding, awareness and skills base among health professionals in relation to the palliative care needs of this group. There is also a need for research on interventions and initiatives to support people with neurological conditions and their families in relation to a wide range of aspects of coping with the onset and progression of neurological conditions.

Policy Framework and Integration into Existing Services

Palliative care principles are relevant and applicable to anyone with any life limiting illness, through their disease trajectory, although they have traditionally been associated with the treatment of cancer in the last days of their life. There has been increasing recognition that the need for palliative care should be extended to include people with other conditions. However, to date, there has been an overall lack of direction when it comes to providing palliative care within existing disease management frameworks. The NAI is currently working with the Irish Hospice Foundation to work towards promoting the integration of palliative care principles in the provision of services to people with neurological conditions.

Neurological conditions require the input of a wide range of service providers and health professionals due to the complexity of these conditions and their resulting sequelae. There is a need for palliative care to be understood and addressed at each stage of the care pathway. The development of models of care through the clinical programmes in neurology and rehabilitation medicine, provide an important opportunity to ensure that palliative care is included and that guidelines are developed for specific neurological conditions which include addressing palliative care and end of life needs. The NAI would encourage a link between the palliative care programme and the neurology and rehabilitation medicine programmes in developing guidelines and pathways around palliative care needs and end of life support.

Specialist Services and Supports

Recommendations for services in this area include:

1. the availability of medical management interventions and treatments to provide palliation at all stages of neurological disease and the necessary facilities to provide these treatments
2. the availability of specialist staff to deliver and monitor these treatments, interventions and ongoing symptom management

The interface between neurology, neurorehabilitation and palliative care is vital in ensuring a co-ordinated response to addressing the need for palliative care supports at each stage in the progression of a neurological condition. It is important to understand that many aspects of palliative care start at the early stages, managing symptoms, planning for the future and making decisions about further care. The current lack of capacity in neurology and neurorehabilitation services continues to have a critical impact on the ability of these services to provide the multidisciplinary input required for the long term management and palliation of neurological conditions. The ability of neurology and rehabilitation medicine services to support and liaise with the work of palliative care services is necessarily dependent on their own resources.

3. the need for specialist inpatient facilities for end of life care for people with advancing neurological conditions.
4. Where it is suitable and desired that a person be cared for in the home, the provision of appropriate medical and care support, adaptation and equipment and respite to enable this to take place.
5. There is a crucial need to promote awareness and understanding and develop the skills base of health professionals and other service providers in meeting the palliative care needs of people with neurological conditions through the provision of guidelines and training. Healthcare professionals and other service providers require training and guidance in identifying and meeting the palliative care needs of people with neurological conditions and their families. Guidance in this area should address a range of areas in addition to the medical management of the condition, including:
 - sensitive and appropriate communication of the diagnosis and of information in relation to the condition
 - support and information with future planning
 - linking families to appropriate supports in relation to the financial, legal and personal/emotional aspects of progressive neurological conditions
6. Family carers provide the substantial majority of care to people with progressive neurological conditions. Training for carers in appropriate skills such as lifting, administration of treatments, feeding etc is needed.

Information, Support and Advocacy

It is vital to understand that palliative care and end of life support for neurological conditions is not just about the medical management of the condition. There is the need for consideration, awareness and expertise among service providers of the legal, emotional, financial and future planning issues, bereavement and aftercare in relation to advancing neurological disease. Patient organisations have stepped in to play a vital role in supporting people in addressing these aspects of palliative care. There is a crucial need to recognise and support this aspect of service provision as a vital aspect of palliative care and end of life support for people with neurological conditions and their families.

For Further Information on this Submission please contact

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Member Organisations of the Neurological Alliance of Ireland

Acquired Brain Injury Ireland

Alzheimer Society of Ireland

Aware

Brainwave: The Irish Epilepsy Association

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Headway

Huntington's disease Association of Ireland

Irish Heart Foundation

Irish Motor Neurone Disease Association

Meningitis Research Foundation

Migraine Association of Ireland

Move 4 Parkinson's

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

Neurofibromatosis Association of Ireland

North West MS therapy centre

Parkinson's Association of Ireland

Post Polio Support Group

Syringomyelia Support Group of Ireland

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Irish Hospice Foundation

The Rehab Group

Volunteer Stroke Scheme

Associate Members

Irish Society of Physicians in Geriatric Medicine

Myasthenia Gravis Association of Ireland

Irish Association of Speech and Language Therapists

Irish Institute of Clinical Neurosciences

Appendix 1. : Models and Tools to Support Service Provision for Palliative Care in Neurological Conditions

A number of initiatives developed in the UK in relation to palliative care for cancer have been incorporated in the design of specialist palliative care programmes for people with neurological conditions and their families in the later stages of their illness. These models include:

Gold Standards Framework

The aim of the Gold Standards Framework is to:

-identify patients in need of palliative/supportive care towards the end of life -assess their needs, symptoms, preferences and any issues important to them -Plan care around patient's needs and preferences and enable these to be fulfilled, in particular allow patients to live and die where they choose

The 5 goals of the Gold Standards Framework are to ensure that

1. Patients are as symptom controlled as possible
2. Place of care: patients are enabled to live well and die well in their preferred place of choice
3. Security and support-better advanced care planning, information, less fear, fewer crises/admission to hospital
4. Carers are supported, informed, enabled and empowered
5. Staff confidence, communication and co-working are improved.

7 key tasks or standards to aim for in the Gold Standards Framework:

- (a) Communication (between health care staff and patient and family as well as with each other)
- (b) Co-ordination
- (c) Control of symptoms
- (d) Continuity of care including out of hours provision
- (e) Continued learning
- (f) Carer support
- (g) Care in the dying phase

The Liverpool Care Pathway

The Liverpool Care Pathway for the Dying Patient was developed for cancer patients by the Marie Curie Palliative Care Institute, Liverpool

The Liverpool Care Pathway for the Dying Patient aims: -to improve the knowledge related to the process of dying -to improve quality of care in the last hours/days of life

Key sections include initial assessment, ongoing assessment and care after death. The pathway incorporates key domains of care to make sure that all these areas are addressed: -Physical - Psychological -Social -Spiritual

Preferred Place of Care

The preferred place of care is a patient-held record that will follow the patient through their path of care into the variety of different health and social care settings. The document records: -a family profile and carers needs -The patients thoughts about their care, their choices and preferences -The services that are available in a locality and being currently accessed by the patient -recording changing care needs

At any time, the PCC can be changed based on decisions about treatments, medication or the preferred place of care itself.

End of Life Framework for Long Term Neurological Conditions

The UK Neurological Alliance the UK National Association for Palliative care published a framework in 2008 for end of life care in neurological conditions.

This document sets out an End Of Life Care framework for implementation that specifically meets the needs of those with neurological conditions and can apply to professionals in all care settings.

Step 1: Discussion as end of life approaches

Step 2: Assessment, care planning and review

Step 3: Co-ordination of care

Step4: Delivery of high quality services in different settings

Step 5: Care in last few days of life

Step 6: Care after death

The framework provides information and guidance on a range of aspects of palliative care for people with neurological conditions, including:

1. Management of physical symptoms
2. Holistic care: psychosocial and spiritual aspects
3. Care at end of Life
4. Supporting carers of people with neurological conditions and the issues facing them
5. Education and training for health professionals and other service providers

Appendix 2

Night Nursing Neurological Statistics 2011-2012 Irish Hospice Foundation

Referrals:

Illness:	2010	%	2011	%	2012	%
MND:	23	9.96	37	12.01	47	11.08
Neurological:	17	7.36	23	7.47	22	5.19
Dementia inc Alzheimers	14	6.06	25	8.12	50	11.79

Number of people in receipt of service:

Illness:	2010	%	2011	%	2012	%
MND:	18	11.92	24	11.54	32	11.85
Neurological:	9	5.96	16	7.69	15	5.56
Dementia inc Alzheimers	8	5.30	17	8.17	31	11.48

Number of nights delivered:

Illness:	2010	%	2011	%	2012	%
MND:	97	15.86	73	10.03	150	15.79
Neurological:	45.25	7.40	76	10.44	84	8.84
Dementia inc Alzheimers	33	5.40	66	9.07	98	10.32