Strategic Plan for Palliative Care in the Mid West 2013 - 2017

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Milford Care Centre

July 2013

Strategic Plan for Palliative Care in the Mid West 2013 - 2017

Health Services Executive (HSE) West

and

Milford Care Centre

Report prepared by

Anna de Siún, MHSc

Health Services Research Consultant

2013

Table of Contents

Foreword

"I know they are busy but you feel like they have all the time in the world to listen to you"

"I'm being spoiled; they are so in tune with what you need"

The above are just two comments from research carried out to evaluate patients' and carers' experience of care received in the Specialist Palliative Care Inpatient Unit at Milford Care Centre.

The expansion of this Unit was just one of 34 recommendations included in the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011.

That Strategy was reflective of a period of unprecedented economic growth in this country and was very expansionist in nature. A comprehensive Review of the implementation of the Recommendations of that Strategy in 2010/2011 found that the large majority of the 34 recommendations had been achieved with 2 partially met and 4 outstanding.

A visit to the Milford Care Centre campus or contact with the many community based palliative care services is testament to the excellent progress achieved over the lifetime of that Strategy and indeed palliative care services in the Mid West Region are seen to be to the forefront of service provision across the country.

Indeed, it is worth noting that down through the years a very strong statutory / voluntary partnership has been formed between the now HSE and Milford Care Centre and this approach has contributed very significantly to the scale of strategic service developments which has occurred in the Mid West since the early 1990's.

However, in contrast to the 7 year period of the last Strategy, our country is now experiencing the most challenging economic time in its history and it should come as no surprise that this Strategic Plan for Palliative Care in the Mid West 2013 - 2017 is reflective of these changed times.

The Steering Committee has produced this Strategy conscious of the need to "consolidate and maintain existing services while providing a positive vision and definite framework for the future". The recommendations concentrate on the need for review and evaluation of existing services and the need to establish their effectiveness and efficiency.

The Committee acknowledges the critical part “access” plays in the provision of care and makes recommendations to improve access at a time when the Central Statistics Office and the National Cancer Registry of Ireland are predicting more and more demands on palliative care services due to demographic changes and expected increases in the prevalence and incidence of cancers.

The promotion of equity of access for people with non-malignant conditions is also highlighted.

High standards of patient safety will continue to be a cornerstone of patient care in the Palliative Care services. Indeed Milford Care Centre actively supports the development of quality standards of care at national level and there is a strong commitment to local implementation of these national standards.

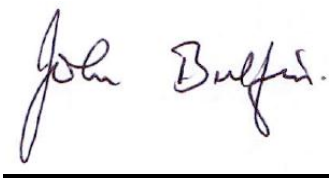
The Strategy includes a number of recommendations outlining an ongoing commitment to quality and research and acknowledges the very important role education will continue to play going forward.

I want to take the opportunity to express my gratitude to the members of the Steering Committee for their commitment and enthusiasm throughout this process. They are an exceptional team; dedicated to the people they provide care for each day.

A special thank you to Ms Pauline Campbell, who was always available with her advice and help while providing administrative support to the Committee.

Finally, a particular word of appreciation to Ms Anna de Siún, Researcher and Report Author, for patiently and professionally producing this report, taking on board the many and varied views of the Committee members.

As well as being a Strategy for Palliative Care for the next 5 years for the Mid West the completed report is a very useful reference document for anybody requiring information on Palliative Care Services in the Mid West Region.



John Bulfin
Chairman, Steering Committee
31st July 2013

Section 1: Introduction and Context

Since the establishment of the first hospice beds at Milford in 1977, services have been continually improved and expanded, in line with national and international best practice, to better meet the emerging and existing palliative care needs of people living in the Mid West region. Since 1991 it is stated Health Board (now Health Service Executive, HSE) policy that all palliative care services in the Mid West should be developed in conjunction with Milford Care Centre (MCC). Today MCC is the designated specialist palliative care provider for Clare, Limerick and North Tipperary, serving a population of approximately 379,000.

During the period 2004 - 2011 services were developed in a planned and co-ordinated manner based on the recommendations of the *Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region*, which was the most recent collaborative project between the former Mid Western Health Board (now subsumed into the HSE) and Milford Care Centre. This strategic plan was guided by the publication of the *Report of the National Advisory Committee on Palliative Care* (DoHC) in 2001 and the *Specialist Palliative Care Needs Assessment* in the Mid West which was published in 2004.

The *Report of the National Advisory Committee on Palliative Care* (DoHC, 2001) outlined a vision for the development of palliative care services in Ireland. In order to ensure a comprehensive palliative care service, three levels of ascending specialisation were detailed:

- Level one: Palliative Care Approach – practised by all health care professionals
- Level two: General Palliative Care – provided by those with some additional training in palliative care
- Level three: Specialist Palliative Care – delivered by those whose core activity is limited to palliative care.

The report also recommended that a specialist palliative care inpatient unit should act as the hub for all other levels of palliative care service delivery in each of the former Health Board Regions. In line with the recommendations of this report, the former MWHB carried out a needs assessment in its area over the period 2002 to 2004. Through widespread consultation with interested parties, including the Regional Consultative and Development Committees on Palliative Care, the report identified levels of service provision available and the gaps which needed to be addressed.

The *Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011* detailed thirty four recommendations for the development of specialist palliative care services in the Mid West. The thrust of the recommendations was very much patient centred and sought to enhance the delivery of palliative care in all settings. A key aim of the strategic plan was to ensure that services would deliver the highest quality of care and would be accessible to everyone who would require them. A comprehensive review of the implementation of these recommendations was carried out in 2010/2011. The review found that the large majority of recommendations had been achieved. Currently just two recommendations remain partially met, with four outstanding.

The service developments achieved through the implementation of these recommendations include:

- A 50% increase in the number of available specialist inpatient beds from 20 to 30 beds
- The establishment of a fully multidisciplinary Hospice at Home team across all of the Mid West
- The appointment of two additional Consultants in Palliative Medicine
- The establishment of a Clinical Nurse Specialist (CNS) service in Ennis General Hospital, Nenagh General Hospital and St. John’s Hospital, Limerick

- The establishment of a regional Lymphoedema service
- Palliative care outpatient clinics in both Mid Western Regional Hospital (MWRH) Limerick and MCC
- Expanded Palliative Day Care services
- More comprehensive education and research facilities
- Network of Support Beds expanded
- Directory of Day Care Centres for Palliative Care patients published
- Compassionate Communities project established
- Accreditation awarded by Irish Health Services Accreditation Board (IHSAB) in 2007
- Quality & Safety Committee established in MCC
- Linkages formed with University of Limerick (UL) and All Ireland Institute of Hospice and Palliative Care (AIIHPC).

Another pertinent development in the Mid West during the strategy timeframe was the rollout in early 2011 of the Hospice Friendly Hospitals Programme in all acute and continuing care hospitals across the region. The overall purpose of the Programme, initiated and funded by the Irish Hospice Foundation, is to ensure that end-of-life care is central to the mission and everyday business of healthcare sites. This project is being further supported by Milford Care Centre in efforts to improve palliative care service delivery in all care settings outlined above.

The implementation of the Strategy's recommendations was a joint initiative between HSE and Milford Care Centre, who enlisted a number of additional supporters along the way. These service developments have allowed the main elements of palliative care to be provided to an acceptable level in all care settings across the Mid West as per national policy. This is highlighted by results from research carried out to evaluate carers' experience of care received in the Specialist Palliative Care Inpatient Unit (O'Reilly, M). Results show that:

- 97% of carers were very satisfied / satisfied with the management of physical symptoms and comfort

- 81.5% were very satisfied / satisfied with the provision of information
- 85% were very satisfied / satisfied with the level of family support
- 93% were very satisfied / satisfied with patient psychological care.

One carer commented *"I know they are busy but you feel like they have all the time in the world to listen to you".* In addition, this research shows that patients' needs are being met to a high standard. Hospice patients were asked to rate how clear, on admission, the information given to them about what to expect regarding their condition was. The majority of patients rated the information as very clear. In the same study, the majority of patients felt that the care they were receiving fitted their goals. One patient commented *"I'm being spoiled; they are so in tune with what you need".*

In the evaluation of the Hospice at Home service, carried out by UL in 2011, interviews with patients and carers found:

- High satisfaction levels regarding the provision of care and support
- Responsiveness of the service to changing circumstances
- Excellent communication and interpersonal skills from Hospice at Home staff members
- Efficient and timely monitoring of symptoms and medications.

Patients' choice on location of care is also being substantially met. Recent data for the Mid West Region illustrated that on average patients spend 143 days in home care, compared to 13.5 in an inpatient unit. Of those in the Mid West Region who died from cancer, 60% died at home or in a hospice compared with 30% in the twelve counties in Ireland without a hospice inpatient unit. In 2011 just 7% of cancer deaths in the Mid West were in an acute hospital, compared to a national average of 41%. The importance for such outcomes means that not only are more patients being cared for at home but that there is reduced demand on acute beds.

In this way Specialist Palliative Care in the Mid West is operating fully in accordance with the *Report of the National Advisory Committee on Palliative Care* (DoHC, 2001) and constitutes a model of best practice. Furthermore, across the region, referrals to palliative care over the period 2004 to 2012 have increased by 40% and there has also been a noticeable increase in the number of patients with non-malignant conditions being referred.

While a great deal has been achieved in improving and expanding services, the *Review of the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011* also outlined some issues to be considered in the future planning of services and identified a number of reports, strategies, policy documents and plans, published since 2004, which have implications for the development of palliative care services both nationally and in the Mid West region. These reports highlight the changing needs of palliative care patients and the changing social, economic and health service environment in Ireland today.

Projections from the Central Statistics Office (CSO) and the National Cancer Registry of Ireland (NCRI) indicate that there will be increased demand on palliative care services over the coming years due to demographic changes and expected increases in the prevalence and incidence of cancers. Between 2010 and 2030, the number aged over 65 is expected to increase by 90% for females and 112% for males (CSO, 2008). Between 2005 and 2035, the overall number of invasive cancers is projected to increase by 17,063 (165%, 6% annually) for females and by 24,809 (213%, 7% annually) for males (NCR, 2008). While the impact of demographic changes on cancer projections is startling, it is not confined to just one condition. The burden of many diseases is expected to increase dramatically in the next 20 years (NCR, 2008).

This expected increase in demand for palliative care services is combined with the challenging reality of resource constraints and budgetary cuts due to the current economic recession. In addition, the health services sector is currently

undergoing a comprehensive reform of both the structure and delivery of services, as outlined in *Future Health: A Strategic Framework for Reform of the Health Service 2012 - 2015* (DoHC, 2012). The Report identifies the four pillars on which this reform is to be built and provides a number of actions which comprise the major building blocks for the transition to a reformed health system based on Universal Health Insurance. These changes will need to be made in a step by step manner, based on research evidence and best practice. Therefore it is envisaged that a number of detailed actions will be necessary as the reform process proceeds. A White Paper on Universal Health Insurance, due to be published in 2013 will provide the basis for many of these actions. A Programme Management Office (PMO) is to be established in the Department of Health to act as a central, overarching, coordination function for the health reform.

The impact this reform process will have on palliative care is not yet clear. Due to the fact that palliative care is delivered across a range of healthcare settings, the HSE is currently working on a prospective funding model which will assist in integrating and accounting for palliative care across all funding streams and delivery models.

The HSE recognises that this fourth successive joint statement of strategic intent between HSE and Milford Care Centre builds on the work done to date. The driving force of that work for the Mid West has been the agreed strategic development of services provided by Milford Care Centre with the Health Service Executive increasingly being a commissioner of such services. As we progress into this new phase to 2017 the HSE recognises that MCC is the leader of provision and direction for all elements of Palliative Care service delivery across the three Counties of Clare, Limerick and North Tipperary and this strategy aims to consolidate that position.

Section 2: Overview of Strategic Planning Process

It is clear that a new strategic plan for the development of palliative care services in the Mid West is necessary in order to sustain the focus and commitment to the development of high quality palliative care services in the region and to reflect the unique social, political and economic environment in Ireland today. In order to begin this process a steering committee was formed in September 2012. Membership of the committee included representation from Levels 1, 2 and 3 providers of palliative care services, as defined by the *Report of the National Advisory Committee on Palliative Care* (DoHC, 2001), and service user representation. Membership and terms of reference of the steering group are listed in Appendix A. In addition a number of health care providers from a broad range of HSE and specialist palliative care services were invited to sit on a larger consultation group.

The steering committee first reviewed the recommendations of the *Review of the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011* and ten additional reports relevant to the future development of palliative care services which had been published since 2004. An overview of each of these reports is available in Appendix B. As the majority of these reports are based on comprehensive needs analyses which have included widespread consultation with key stakeholders, it was determined that no additional research or service user consultation was required at this time. It was agreed that the Strategic Plan would be developed based on recommendations from these pertinent reports, a review of current services and new palliative care initiatives established, or in the process of being established, in the Mid West region, consideration of the policies determined by the HSE's Clinical Care Programme for Palliative Care and the expertise and feedback of the wider consultation group.

Drawing on the expertise available through the steering committee membership, a service mapping exercise was carried out to identify current palliative care services available in the Mid West, the strengths and weaknesses of current service provision and how services might be developed in the future to best meet the palliative care needs of people living in the Mid West region. This exercise also allowed the committee to evaluate the progress to date in extending access to palliative care for patients with non-malignant conditions, and provided potential actions to optimise delivery of quality palliative care services in all settings, both inpatient and community based.

Through this exercise a large number of potential areas for development were identified. The steering committee then discussed and reviewed all suggestions, leading to four overarching themes emerging:

- Sustainability of Existing Services
- Access & Integration
- Quality
- Education

In line with the terms of reference of the steering committee, a consultation workshop was then held with the larger group of key stakeholders. Membership of the consultation workshop can be found in Appendix C. The findings from the work of the steering committee were briefly presented under the four themes outlined above, following which an open discussion was facilitated. All topics raised were explored in full and all attendees were encouraged to share any developments/concerns/issues in their service areas. The forum provided an opportunity to ensure that all stakeholders had input into the development of the strategy, and allowed professionals from different areas to discuss how services might optimally work together.

Themes emerging from the consultation workshop included:

- Sustainability, Quality and Efficiency

- Necessity of Service Provision
- Service Development
- Managing Demand
- Education
- Integration
- Equality of Access.

It was agreed that meeting patients' needs must remain one of the highest priorities for the future. Discussion also focused on the impact the current economic climate will have on service provision and the critical importance of maintaining current services. Many people agreed that education had a key role to play in continuing to build capacity and ensure optimum collaboration between specialist and generalist palliative care services. Finally it was suggested that while the focus on sustainability is important, it is essential that the palliative care strategy continues to drive improvements and provide a positive vision for the future.

The findings from the consultation workshop were then integrated with the findings from the service mapping exercise, the recommendations from the *Review of the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011* and recommendations from national and regional reports. A number of recommendations were developed and grouped under the themes of:

- Sustainability of Current Services
- Access
- Integration
- Quality and Research
- Education

Section 3 outlines all the specialist palliative care services currently being provided in the Mid West, highlighting the breadth and comprehensiveness of

current service provision. Statistics are provided up to 2011 to tie in with the original timeframe of the *Seven Year Strategic Plan.* Section 4 outlines the vision for the future development of services through this process. Section 5 outlines the recommendations and key steps for the maintenance and development of specialist palliative care services in the Mid West over the next five years.

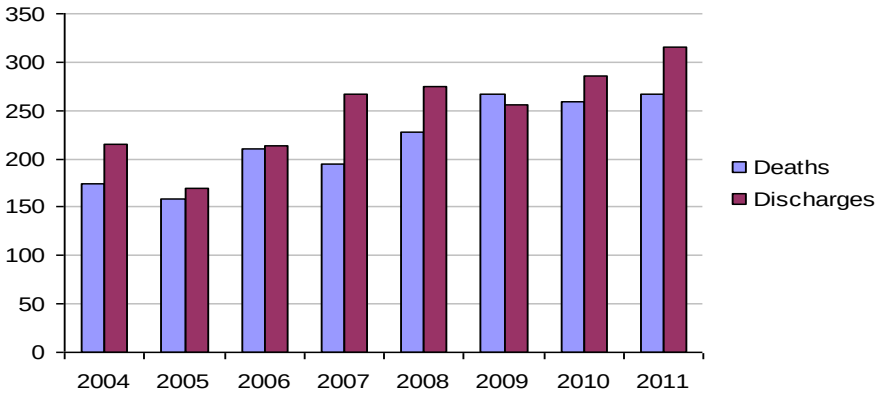
Section 3: Overview of Current Services

Inpatient Unit

Milford Care Centre is currently operating a purpose built 30 bedded inpatient unit, opened in 1999, which provides specialist multidisciplinary inpatient care focused on the medical, nursing, psychosocial and spiritual care of patients and their families. Though the unit has the potential to operate as a 30 bed unit current funding resources dictate that only 28 beds are in use. Patients are accommodated in either single or four bed rooms and there is an additional single room available to facilitate the transfer of a patient from the shared rooms as deemed clinically appropriate. Quiet rooms, sitting rooms and overnight facilities are provided for visiting families and friends. There is an Oratory within the Inpatient Unit, Mass is said every morning in the Chapel and every effort is made to meet the varying spiritual needs of patients on an ongoing basis.

Services are provided based on need, irrespective of diagnosis and referrals are taken from the Hospice at Home team, GPs and hospital consultants. Referrals are discussed each morning at an admissions meeting and admission requests are considered in line with the unit's admissions and referral criteria. The average length of stay in the unit is 13 days, while on average 50% of patients are discharged home, as illustrated in Figure 1 below.

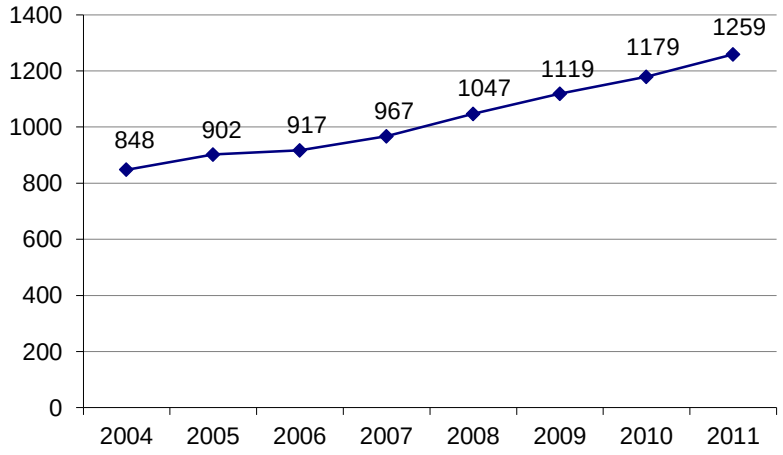
Figure 1: Deaths and Discharges from the IPU



The facility closely links with the hospital palliative care teams, specialist palliative care Hospice at Home and Day Care teams. It also works closely with other teams in the hospitals, and GPs / Primary Care Teams (PCTs) in the community. A full range of clinical and supportive services are available to all patients including Medical, Nursing, Dietetics, Art Therapy, Music Therapy, Pharmacy Services, Complementary Therapy, Occupational Therapy, Physiotherapy, Pastoral Care, Social Work, Horticulture and Speech and Language Therapy.

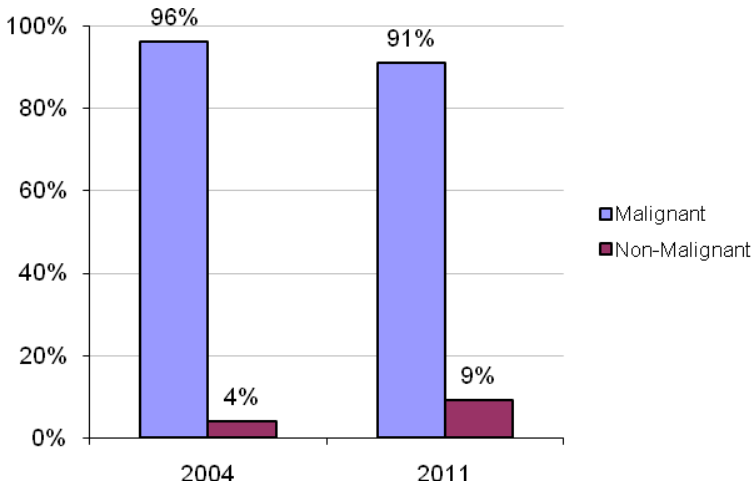
The expansion of inpatient services over the course of the 2004 - 2011 strategic plan is one of the service developments that has allowed Milford to continue to meet the growing demand for palliative care services in the Mid West region, as illustrated by the growth in activity levels outlined in Figure 2.

Figure 2: Patients Treated



Furthermore, access to palliative care has been extended to include more patients with non-malignant disease as can be seen from Figure 3.

Figure 3: Extending Access



Outpatient Services

Palliative Medicine Outpatient Clinic services in the Mid West are available to patients with any advanced, progressive, life-limiting condition who have a specialist palliative care need. Their key function is to support colleagues in primary care and the Milford Hospice at Home team to maintain the care of patients with specialist palliative care needs and their families at home, if that is what they wish for. Referrals are accepted from Consultants, GPs and Palliative Care Clinical Nurse Specialists.

The weekly Consultant-led Palliative Medicine outpatient clinic service is well established at the Mid Western Regional Hospital Limerick (MWRHL). This clinic provides for the review of patients with specialist symptom control and palliative care needs referred by colleagues in Oncology, Haematology, Medical and Surgical specialties, GPs and the Hospice at Home team. In 2012, 145 patients, of whom 97 were new referrals, attended the Palliative Medicine Outpatient Clinic at the MWRHL.

A new development in 2012 was the establishment of twice weekly Palliative Medicine Outpatient clinics held at Milford Care Centre. These clinics facilitate the review of patients in the community referred by General Practitioners or the

Hospice at Home team and facilitate follow up of patients discharged from the inpatient unit. In 2012 fifty nine patients attended Palliative Medicine Outpatient Clinics in Milford Care Centre, of whom forty two were new patients. It is envisaged that this service will expand in the years ahead to incorporate multidisciplinary input.

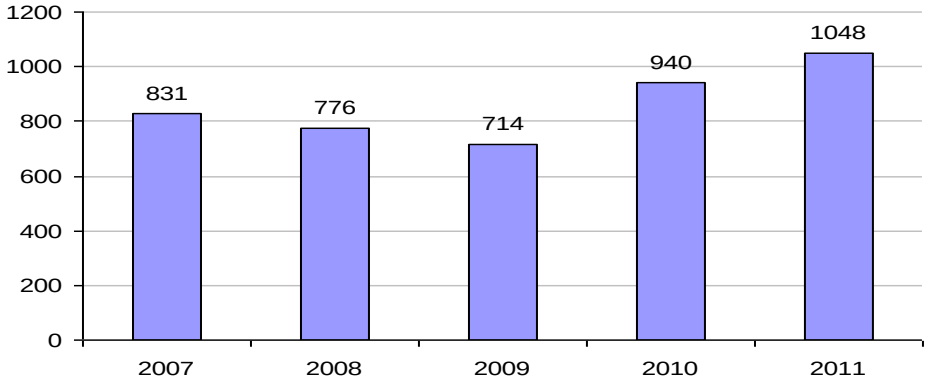
Since late 2011, MCCs commitment to St. John's Hospital includes a Palliative Medicine Outpatient clinic and a joint Palliative Medicine/Pain Clinic. In addition to providing a service to the patients of St John's Hospital this service affords appropriate patients across MCC's services access to a joint specialist assessment and to interventional pain procedures as required.

Day Care Services

Milford Care Centre provides both Older Persons and Specialist Palliative Care Day Care services.

Specialist Palliative Day Care is provided to patients with a specialist palliative care need irrespective of diagnosis. Up to 12 patients a day can attend. In 2011 the availability of the service was increased from 2 days per week to 3 days per week, which is reflected in Day Care attendance figures illustrated in Figure 4 below.

Figure 4: Day Care Attendances



From February 2013 the service is available either two days or three days a week, depending on demand, and is delivered in pulsed 8 week cycles of focussed and energetic care during which patients' progress is tracked and reviewed. Each patient's needs are assessed with them by members of the multidisciplinary team and an agreed plan of care and intervention developed. Most elements of the multidisciplinary team available in the Inpatient Unit are also available to patients attending Specialist Palliative Day Care. Daily Mass, baths, Jacuzzis and shower facilities, hairdressing, social activities, refreshments and lunch are available within the Centre. In addition to contact with team members, the service complements the care provided in the community by the Hospice at Home team, GPs, and Public Health Nurses / PCTs and also provides an important opportunity for people to meet and socialise with others in similar situations.

Hospice at Home Service

The Hospice at Home service is a multidisciplinary specialist palliative care service available in the Mid West region. The service provides direct patient care to adults and children with advanced progressive life-limiting illness in their own home, including residents of nursing homes. Staff also provide support to family members, including bereavement support, and have a significant education remit with other service providers.

Teams are based in Limerick City, Newcastle West, Ennis and Nenagh with a satellite office in Thurles. The Service is clinically led through Consultant input and the teams comprise Nurses (CNSs and RGNs), Care Assistants, Social Workers, Physiotherapists, Occupational Therapists and some Pastoral Care in-put; administrative support is centrally based. The nursing service is available seven days a week while Physiotherapy, Occupational Therapy, Social Work and Pastoral Care are available Monday to Friday 8.30am – 5pm. Elements of the Social Work and bereavement services are provided outside of these hours as the need arises and as resources allow. The Irish Cancer Society's Night Nursing

Service is available from 5pm to 9am following assessment of patient need and as resources allow. This service is provided as a partnership between MCC and the Irish Cancer Society. In addition a Night Nursing service is provided for patients with non-malignant conditions with support from the Irish Hospice Foundation. Also a telephone advisory service is available each day from 5pm – 9am and is managed by the Senior Nursing Team at MCC.

The service works closely with the acute hospitals through the Palliative Care Consultants and with primary care providers - the patient's GP and Primary Care Teams (PCTs), the Doctor on Call Services, the Community Intervention Team and Nursing Homes throughout the region. Staff are in regular contact with GPs/PCTs regarding patient care issues and co-ordinate visits to patients where possible and appropriate.

Referrals are accepted directly from GPs and medical teams in acute and other hospital settings. Referrals are also accepted from other health care providers and discipline specific professionals with the consent of the patient's GP. All patients newly referred to the service are reviewed and discussed at a weekly care-planning meeting and ongoing reviews take place at monthly base meetings. Referral & discharge protocols and education sessions have been provided to clarify the roles of the specialist and generic providers. Referrals to individual disciplines in the Hospice at Home service will be accepted where deemed appropriate. A rapid response to identified clinical need, and depending on the degree of urgency, is usually available within 48 hours.

In line with national policy, a key focus of the 2004 – 2011 Strategy was to enable more patients to be cared for and to die in community settings, which ultimately is their preferred choice. Through the combined inputs of the Inpatient Unit in Milford and the expanded Hospice at Home service, this goal has been broadly achieved as can be seen from Figure 5 and Table A.

Figure 5: Visits by Hospice at Home Team 2004 - 2012

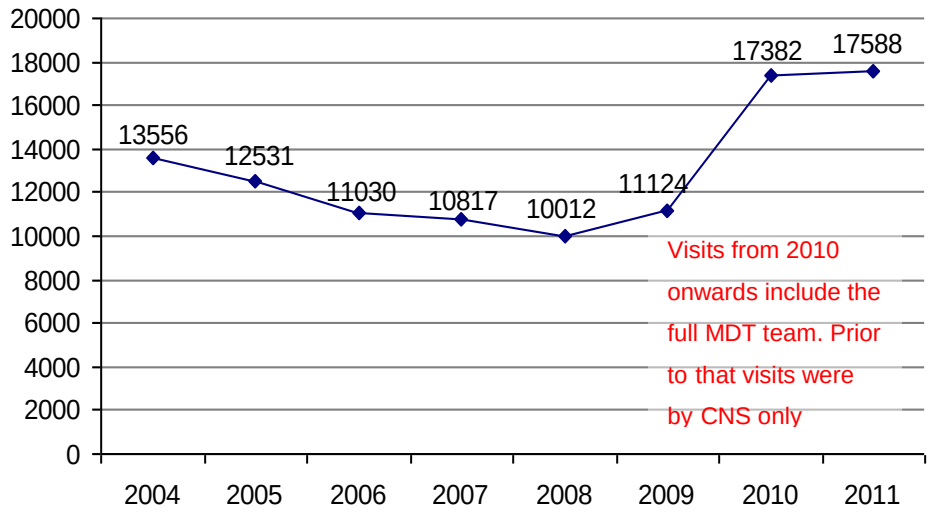


Table A: Location of Cancer Deaths

	National 2004	MCC 2004	National 2009	MCC 2009	MCC 2011
Hospice	**14%**	**31%**	**17%**	**36%**	**33%**
Acute Hospital	**42%**	**15%**	**41%**	**10%**	**7%**
Community Settings	**44%**	**53%**	**42%**	**54%**	**60%**

Lymphoedema Service

Milford Care Centre provides a palliative Lymphoedema service to patients in the Mid West. Assessment and intervention are offered in a variety of settings to best meet the patient's needs i.e. outpatients, home visits, day care and inpatient unit. Referrals are accepted from all of these services as well as Hospice at Home staff.

The management of Lymphoedema/Oedema in palliative care is multifactorial. The service is currently organised through the physiotherapy department, thus allowing for the integration of Lymphoedema treatments and functional issues that arise due to the complications of Lymphoedema. Patients with Lymphoedema and advanced disease often experience rapidly changing functional challenges throughout their disease trajectory. Integrating the Lymphoedema service into the physiotherapy team allows for the coordinated treatment of co-existing symptoms. Treatments incorporate the four cornerstones of best practice: multilayer bandaging, compression, skin care and education.

Early identification and intervention significantly improve treatment outcomes – the physiotherapy team provide education to colleagues in the community setting and formally in both under- and post-graduate courses in the University of Limerick. This raises awareness of this condition, its management and the necessity for early intervention. It is anticipated that, based on current trends, in excess of 100 patients will receive Lymphoedema treatment in 2013.

Recognising the need for continued quality improvement the team plan to complete 2 studies in this field in 2013:

- Provide a profile of the Lymphoedema service
- Evaluate outcomes of treatments, utilising a case series process.

Compassionate Communities Project

The Compassionate Communities Project is a pilot project being undertaken by Milford Care Centre that adopts a Health Promoting Palliative Care (HPPC) approach to working in partnership with people, individuals and groups to enhance the social, emotional and practical support available to those living with a serious life-threatening illness, facing loss and experiencing bereavement. An underlying theme for the Project is that death, dying and loss affect everybody and are not just the responsibility of health and social care professionals and services. Most people who are living with advanced life-limiting illnesses spend their time at home

and in their communities and neighbourhoods, with families, relatives, friends and work colleagues (IHF, HSE & ICGP, 2011). The majority of people affected by advanced illness want to be cared for, and to die, at home (IHF, 2004).

In focusing on the experiences of death, dying, loss and care in whatever circumstances they occur, HPPC aims to:

- Provide information about death, dying, loss and care
- Explore and develop a range of personal and community supports.

HPPC seeks to build on a community's ability to provide supportive care as neighbours, family and friends, recognising that services are not enough on their own and cannot provide all that people need.

The Compassionate Communities Pilot project, as a HPPC initiative, seeks to answer the question '*How do we use the experience and knowledge of the Specialist Palliative Care Service to support communities, groups and individuals to enhance the social, emotional and practical support available to those living with a life-threatening illness, those facing loss and those experiencing bereavement?'* by combining the accumulated knowledge of Specialist Palliative Care with a health promotion and community development approach. In taking a 'whole population' approach and by working with community organisations, groups and individuals the aim is to increase and enhance the capacity within communities to cope with and provide support to others in dealing with issues of death, dying, loss and care.

The Project is guided by an Oversight Committee and delivered on the ground by a part-time project worker(s). Phase 1 of the Pilot Project, which ran from January to December 2011, focused on an area of North-West Limerick city, was delivered by a 0.5 WTE Project Coordinator. In this period the Project engaged in a wide range of initiatives and partnerships.

Phase 2, which runs from June 2012 to May 2013, has extended the scope of the project to all of Limerick City and the town of Newcastle West. It is delivered by two 0.5 WTE Project Workers. This phase of the Project is working to a plan that is 'targeting' 3 related strands:

- Strand 1: A Whole Population Approach
- Strand 2: Community Engagement
- Strand 3: Community Good Neighbour programme / A Social Model of Care.

Education

The Education Service at Milford Care Centre is a major national provider of Education and Learning opportunities for all those involved, both at professional and family carer level in all aspects of Palliative Care and Care of the Older Person. The service promotes a multi-professional approach to all education programmes and encourages the development and delivery of flexible, affordable learning options for all.

Milford Care Centre's Education service is currently managed under the Head of Human Resources who is supported by two nurse tutors, a librarian, a training officer and administrative support staff. The service seeks to empower and facilitate MCC professionals and the community they serve. Partnership and collaboration are also strong underpinning values directing how the service functions.

Many members of the organisation contribute to parts of the education programme as members of a wider education team. The Education Service also has strong partnership and collaborative relationships with a wide range of individuals and organisations, both within and outside of Milford Care Centre.

The scope of the service includes ongoing professional education programmes for Doctors, Nurses, Volunteers, Health Care Assistants, Allied Health and Social

Care Professionals, Pharmacists, family carers and members of the public. Education is provided both on-site in the purpose-built lecture rooms in Milford Care Centre or off-site at various venues upon request. Education programmes are delivered by classroom training and supported with web–based information on www.e-life.ie (using Moodle as the platform) coordinated by the Librarian.

The Service includes a Library and Information Service which provides a range of professional help. In response to a number of requests, the Education Service provides some compassion-fatigue countermeasures such as Techniques of Yoga, Meditation and Mindfulness.

2011 was an exceptionally busy year for the Education team with over 1,060 places filled on a wide range of courses. Approximately 70% of these places were filled by non-Milford Care Centre participants. Off-site Palliative Care, Gerontology and associated Clinical Skills education occurred upon request in various places such as Acute Hospitals, Day Care Centres, and Residential Care Centres throughout the Mid West and its border areas. This seems to be a growing trend in an environment where study leave is increasingly difficult to obtain due to the embargo on the replacement of staff and scarce funding.

Quality and Safety Systems

Milford Care Centre strives to continuously develop and improve the care it provides to the people of the Mid West, through implementation of an audit and quality assurance programme across all aspects of the service, both clinical and non-clinical. The Quality and Safety Committee established in 2006, which oversaw the organisation's accreditation award from the Irish Health Services Accreditation Board in 2007, has been reviewed and restructured. The committee membership in 2013 has being considerably reduced, from 22 to 7, and it shall act as a steering committee, to oversee patient safety and quality assurance throughout Milford Care Centre's services.

A number of quality and safety sub groups are being formed under specific service related headings, including clinical quality assurance and patient safety, human resources / learning and development group, environment and hygiene group, information governance group and finance group. These groups will be responsible, on behalf of Milford Care Centre, for the quality assurance framework of the organisation. Their work will ensure a culture of continuous quality improvement is present within the organisation for both clinical and non-clinical activities.

Each group will have a group lead who will coordinate the activities of the group. Meetings of these groups will be coordinated by the quality and research coordinator in collaboration with the group lead. An annual audit programme has been devised for key processes. The work programme for each group has been derived from a gap analysis against the Health Information and Quality Authority's National Standards for Safer Better Healthcare (June, 2012). Implementation of this work programme shall be monitored through an information management system suite which has been developed by the Quality and Research Coordinator.

Research

A new Research and Systems Group chaired by a Consultant in Palliative Medicine has been established in Milford Care Centre. This group will function as the governance and coordinating group for research projects in Milford and will be reviewed for effectiveness after 12 months. The group aims to promote, develop and integrate research activities as part of the provision of care throughout the organisation. The Research and Systems Group will be supported on an ongoing basis by the Quality and Research Coordinator.

A five year strategy (2013 - 2018) has been drafted following a scoping exercise, which involved requesting departments to identify research priorities and ideas.

As a result of the scoping exercise, four primary areas of particular focus and their sub-themes have been identified as follows:

- Quality
  - Systems analysis
  - Performance assessment
  - Service user experience
  - Outcome measurement
  - Performance indicators
  - Clinical effectiveness
  - Service evaluation
- Public Health and Palliative Care
  - Compassionate Communities
  - Attitudes toward death, dying, loss and care
  - Death education
- Education Delivery/Models
  - Advanced Communication Skills
  - European Certificate in Essential Palliative Care (ECEPC)
  - Course evaluations – Pre and Post and Follow Up
  - E-Learning
- Interventional studies
  - Measuring the effectiveness of certain palliative care interventions as performed by the multidisciplinary team.

These overall primary research areas were derived from the grouping of similar sub-themes identified through the scoping process. Further development of these proposed research ideas, proposals and initiatives is underway. In conjunction with University of Limerick and the All Ireland Institute of Hospice and Palliative Care, the primary researchers will assess how the current initiatives align with

national projects. Thereafter, more formal methodologies and timelines will be finalised and decisions regarding submission to ethics and funding bodies made for the most appropriate projects.

Additionally, a register of past and current research in Milford Care Centre has been created. This register seeks to acknowledge past work and to provide a repository of research questions, methodologies, findings and recommendations for future research proposals. It is anticipated that such a repository will inspire future research activity and encourage clinicians to network and collaborate with colleagues.

In recent years, Milford Care Centre has been working very closely with the University of Limerick to jointly foster and develop research programmes in palliative care, all under the scope of a joint Steering Group named SLI. It is equally recognised that the Health Service Executive has an active involvement in supporting research initiatives and the possibilities of HSE participating on the SLI Committee will be explored further as part of this strategy.

Bereavement Support Services

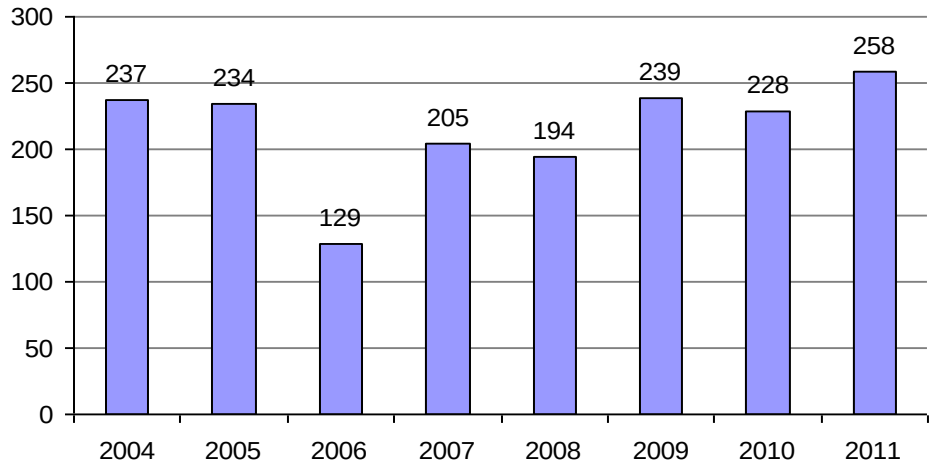
Bereavement support is a fundamental part of palliative care. Milford Care Centre's bereavement support service was established as an integral part of the Social Work Department in 1991. Today Milford Care Centre, through its Social Work Department, offers an extensive and wide ranging Bereavement Support and Counselling Service The service encompasses direct provision of bereavement support and counselling to individuals and families, group support to adults and children, the recruitment, training and supervision of volunteer bereavement facilitators, the support of parish and community based bereavement support groups and the delivery of a wide range of educational inputs across a spectrum of organisations and services.

The service is guided by three fundamental principles:

- Grief is a normal part of life and most people do not need bereavement counselling
- The service is open to all whether or not there had been prior contact with the palliative services
- Grief and loss are everybody's 'business'; as a specialist provider MCC has a role in supporting and assisting others to provide bereavement support.

The number of individuals accessing the service for bereavement support and counselling in recent years is shown in Figure 6.

Figure 6: Referrals to Bereavement and Counselling Services*



* Figures do not include those attending the 'open' information evenings

On average, year on year, over half (54%) of all referrals to the service are in respect of those for whom their deceased family member/friend had not been cared for by the palliative services. All individual assessments and the focused time-limited counselling are provided by members of the Social Work team. In addition, however, a broad range of group supports and public/community education have been developed, including:

- Adult Bereavement Support Groups for
  - Bereaved Partners
  - Bereaved Parents
  - Bereaved Adult Children
- A monthly ‘drop-in’ bereavement meeting
- Children and Young Persons Bereavement Support Programme
- Bereavement Support Programmes for the parents of school-aged and pre-school children
- Bereavement Information Open Evenings
- Bereavement Support Education Programme
- Bereavement Volunteer training
- Parish/Community Bereavement Group support and training
- Professional education and training

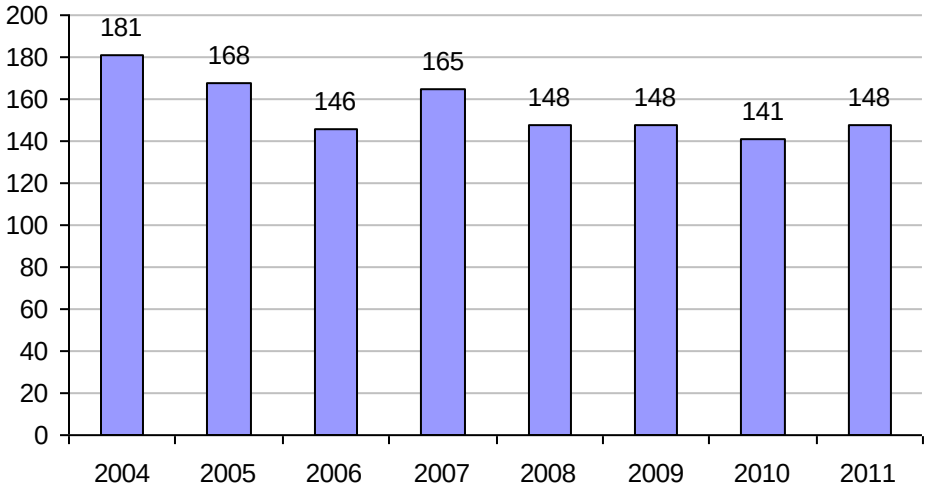
Support Bed Network

MCC supports HSE and non-statutory services that have Level 2 (Intermediate Care) beds. These beds provide locally based respite and end-of-life care for patients with non-complex needs.

There are 17 beds in 8 units (2 each in Kilrush, Raheen, Thurles, Roscrea and Nenagh, 1 bed in both Ennistymon and Milford Care Centre and 5 in Cahercalla). These units are self-contained within the Community Hospital/Nursing Unit/Nursing Home (CH/CNU/NH) and have facilities for relatives to stay overnight if desired.

Admissions are on the basis of referral to the Unit’s Director of Nursing, outside of the Placement Panel. Admission of patients under 65 is accepted and there is no charge for the stay and patients remain under the care of their GP. Figure 7 illustrates the numbers of admissions to the network from 2004 - 2011.

Figure 7: Support Bed Network Admissions



The Hospice at Home team offers support to the patient in residence and the staff of the unit – this includes an education component delivered locally and/or on MCC's campus. Both the Unit staff and the Hospice at Home team liaise with the patient's GP and other members of the Primary Care team. Consultants in Palliative Medicine and the medical team are available to advise, primarily by phone, if required.

Links with Acute Services

The Specialist Palliative Care service in the Acute Hospitals is led by three Consultants in Palliative Medicine, based at Milford Care Centre, working alongside Clinical Nurse Specialists in the Mid Western Regional Hospital and St. John's Hospital in Limerick. In addition, the Mid Western Regional Hospital has the input of a Registrar in Palliative Medicine. The teams provide specialist advice on a consultation basis to teams working with patients with advanced and progressive illness in the hospitals. The service facilitates timely discharges and transfers, for example, where appropriate the palliative care teams arrange transfer to Milford Hospice when more specialist treatment is needed and arrange for Hospice at Home involvement for patients when community palliative care is necessary. The service also operates a number of outpatient clinics both

in the hospitals and in Milford Care Centre. Close links have been established between Palliative Medicine and both Oncology and Pain services.

Ennis and Nenagh hospitals have Clinical Nurse Specialist led palliative care services. The service is provided on a full-time basis in Ennis and a part-time basis in Nenagh. The service works alongside the medical teams offering advice on pain, symptom control and psycho-social issues, offering support to palliative care patients and relatives finding difficulties with grief situations, liaising with existing Hospice at Home teams, GPs and PHNs to ensure a seamless transfer/discharge of patients. In addition the CNS provides education and training to staff, both structured and impromptu, on palliative care issues. The service is supported by Consultants in Palliative Medicine through regular education sessions and telephone advice. Patients remain under the care of the referring consultant in the hospital.

Links with Community Services

Primary care provides continuing, accessible, personal, holistic care delivered in the community setting. Primary care is often delivered by healthcare professionals working within designated Primary Care Teams (PCTs) or Health and Social Care Networks (HSCNs). Patients with palliative care needs living in the community will remain under the care of their GP at all times. GP care is delivered either in the surgery or in the patient's home.

The Public Health Nursing Service in the Mid West is comprised of Public Health Nurses (PHNs), Community Registered General Nurses (RGNs) and Assistant Directors of Public Health Nursing working within PCTs or HSCNs. PHNs have a role in a wide range of areas, including antenatal/postnatal care to mothers, child health screening and child welfare, family support services, in home nursing to individuals with clinical nursing needs, education and health promotion. It is estimated that palliative care constitutes approximately 3% of total active caseload. Services are delivered Monday – Friday with planned essential nursing

services provided at weekends/bank holidays. The service is provided to all care groups with priority given to clients with medical card eligibility.

Where patients living in the community have specialist palliative care needs, care is provided in cooperation with GPs, PHNs, Home Helps, Care Assistants, and members of the Hospice at Home teams. Hospice at Home staff are in regular contact with GPs/PCTs regarding patient care issues and co-ordinate visits to patients where possible and appropriate.

Links with Children's Palliative Care

There are an estimated 1,400 children living with life-limiting conditions in Ireland. Approximately 350 children die each year, the majority in the first year of life due to congenital abnormalities, with 11% of children dying at home. The majority of these children do not have a malignancy but have a Category 4 condition, defined as a progressive condition without curative treatment options where treatment is exclusively palliative and may commonly extend over many years. Internationally, malignancies constitute approximately 22% of referrals to paediatric palliative care. The national policy document 'Palliative Care for Children with Life-Limiting Conditions (2009) provides a foundation for the development of children's palliative care services in Ireland.

Children's Palliative Care in the HSE Mid West is an "add on" service for children with life-limiting malignant and non-malignant conditions. The service is delivered via a "Hospice at Home" model with each child having a named Consultant Paediatrician, input from the Children's Outreach Nurse (CON), Public Health Nurse, GP, Disability, School and Respite services as appropriate. Children under 4 years of age with neurological conditions also receive home nursing support from The Jack & Jill Children's Foundation. Children may be admitted to the acute paediatric service for current illness or symptom control if necessary, but most contacts with the hospital are done via the Caterpillar Day Ward during working hours, which avoids having to present at the Emergency Department.

The child may be reviewed by the Paediatrician, CON or dietician on the Day Ward.

Specialist Palliative Care services provide a consultative/advisory service on specialist palliative care aspects of care. At the MWRH Limerick, patients with both malignant and non-malignant conditions are reviewed on the paediatric inpatient and day wards at the request of the responsible Consultant Paediatrician. Occasionally children are referred by Temple Street Children's Hospital or Our Lady's Children's Hospital, Crumlin directly. The child's paediatrician remains in charge at all times and all medical decisions are made by them. Children are not seen in palliative care outpatient clinics and, as a matter of policy, are not generally admitted as inpatients in Milford Care Centre.

The Hospice at Home team often remain involved in the care of children with appropriate needs. This is also a consultative role, working with all the other services contributing to the care of children with palliative care needs. Currently the General/Community Paediatrician and two Consultants in Palliative Medicine link semi-formally on a quarterly basis.

Achieving Full Integration across all Areas of Service Provision

While considerable progress has been made in recent times to achieve integration amongst all service providers it is recognised that much work still remains to be done in this area. The importance of this is fully recognised from the outset and achieving optimum integration amongst all service providers is a key objective of the strategy. Accordingly, MCC and HSE will re-establish the Consultation Forum for Palliative Care, which will include representatives from all palliative care service providers and will address the ongoing matter of ensuring optimum integration across all of the service providers, in line with national policy.

Section 4: Vision for the Future

Section 2 clearly outlines the well-developed services which are currently available and highlights the substantial work achieved during the period of the 2004 - 2011 Strategic Plan. The recommendations outlined in Section 5 reflect the two main concerns which arose during the strategic planning process; the need to consolidate and maintain the services currently in place, and the need to provide a positive vision and definite framework for the future development of palliative care services in the region.

In the current economic climate where resource constraints continue to be a challenging reality it is imperative that the effectiveness and efficiency of these services is highlighted, thereby giving essential support to the need for services to be maintained. In order to facilitate this many actions associated with the Recommendation 1 below focus on reviewing these services. In order to ensure that the findings of these reviews are given due consideration and implemented where appropriate, it has been agreed that an interim review will be necessary in 2015. This interim review will bring together the findings from each individual review and re-evaluate service delivery and sustainability. In addition, there has been agreement between MCC and the HSE to appoint a joint implementation team at senior level to oversee the recommendations of the strategy.

As mentioned previously, this strategic plan has been developed during a time of considerable reform and change in the structure and delivery of health services in Ireland. Therefore, while the recommendations and actions outlined in Section 5 represent the best course of action at this time, it is vital that the strategic plan maintains a level of flexibility to reflect any major national developments that take place during its lifespan.

The timeframe assigned to all actions below refers to year end of the identified year. The following abbreviations are used under the Lead Responsibility Section:

CEO:	Chief Executive Officer
CLC:	Clinical Leadership Committee
CNS:	Clinical Nurse Specialist
CON:	Children's Outreach Nurse
DON:	Director of Nursing
DPHN:	Director of Public Health Nursing
HSE:	Health Service Executive
ICS:	Irish Cancer Society
IHF:	Irish Hospice Foundation
MCC:	Milford Care Centre
MWRHL:	Mid Western Regional Hospital, Limerick
PCTs:	Primary Care Teams
QASC:	Quality Assurance and Safety Committee
RSG:	Research and Systems Group
SPC:	Specialist Palliative Care
TSCS:	Therapy & Social Care Services
UL:	University of Limerick

Section 5: Recommendations, Key Steps and Actions

Recommendation	Key Steps	Actions	Time Frame*	Lead Responsibility
Sustainability of Current Services				
1. Service developments made to date must be reviewed and consolidated to ensure current service provision is maintained.	***Inpatient Unit*** 1.1 Optimise existing Specialist Palliative Care bed usage to meet current demands.	1.1.1 Carry out ongoing reviews of bed usage / patterns.	2013	Clinical Leadership Committee (CLC), MCC
		1.1.2 Strengthen linkages with existing referral sources.	Ongoing	
		1.1.3 Create a greater awareness of palliative care amongst potential new referral sources.	Ongoing	CLC, MCC
	1.2 Identify optimum bed capacity in respect of emerging future demands in order to ensure that ready access to inpatient care is available to all patients.	1.2.1 Carry out a review of future service demands arising from expected significant increases in cancer rates.	2013	CLC, MCC
		1.2.2 Continue to extend access to people with non-malignant conditions.	Ongoing	CLC, MCC
	1.3 Ensure all structures and processes are in compliance with HIQA standards.	1.3.1 Initiate a review of current shared ward configuration and facilities within Milford Hospice to ensure that it meets current standards and best practice.	2014	Chief Executive / Mgt Team, MCC
		1.3.2 Review the current Quality and Safety structures within palliative care across all settings so as to ensure that they meet current standards and best practice.	2013	Quality Assurance and Safety Committee (QASC), MCC

	Outpatient Services 1.4 Review the operation and provision of Outpatient services to ensure services meet current and emerging demands with a particular focus on MDT service provision.	1.4.1 Review services provided in MCC, St John's and MWRH with a particular focus on the development of MDT service provision and optimising referrals of patients with non-malignant conditions. 1.4.2 Carry out an evaluation of patients' experience of OP services.	2014 2015	CLC, MCC QASC, MCC
	Day Care Services 1.5 Review the role/remit and operation of the Specialist Palliative Day Care Service to ensure maximum benefit to the greatest number of patients.	1.5.1 Finalise the change process involved in moving from a general service to a more specialised service. 1.5.2 Initiate a targeted awareness campaign amongst potential referral sources to specialist day care services. 1.5.3 Carry out an interim evaluation of service provision.	2013 2013 2014	CLC, MCC CLC, MCC CLC, MCC
	Lymphoedema Service 1.6 Review service to ensure efficient and effective use of available resources to facilitate ready access to service is available to all palliative care patients who might benefit.	1.6.1 Review service profile and activity levels. 1.6.2 Evaluate outcomes of treatments, utilising case series process. 1.6.3 Strengthen links between the Lymphoedema services in MCC, MWRH & Community.	2013 2015 2014	Therapy & Social Care Services (TSCS), MCC Physio Manager MCC/Lymph Nurse MWRHL

	Hospice at Home			
	1.7 Review the efficiency and effectiveness of the Hospice at Home service.	1.7.1 Develop service delivery goals for the Hospice at Home service.	2014	CLC, MCC
		1.7.2 Review the regional distribution and usage of service resources.	2013	CLC, MCC
		1.7.3 Review data collection systems to ensure that the full MDT nature of the service is being captured.	2013	Head of Non-Clinical Support Services, MCC
	1.8 Review and implement within available resources outstanding recommendations identified in the Evaluation Report of the Hospice at Home Service, carried out by UL.	1.8.1 Establish a working group to finalise the implementation of all outstanding recommendations from the UL report.	2013	CLC, MCC
	Education			
	1.9 Review educational programmes to ensure that they meet current and future needs of specialist and generic palliative care providers with particular reference to the National Competency Framework Model.	1.9.1 Establish a working group to review educational programmes with particular reference to maintaining core skills and best practice within specialist palliative care.	2014	Education Dept., MCC
		1.9.2 Identify specific training programmes for staff working in non-specialist palliative care service provision, including services caring for non-malignant patients.	2014	Education Dept., MCC
		1.9.3 Review existing programmes for family carers and develop new programmes as deemed appropriate.	Ongoing	Education Dept., MCC
		1.9.4 Proactively seek to protect continued funding for the Higher Diploma in Palliative Care under the Free Fees initiative.	Ongoing	Chief Executive/ Mgt Team, MCC

	1.10 Promote study leave policies in all relevant organisations which recognise the importance of education in palliative care.	1.10.1 Create and maintain awareness amongst decision makers on the cost benefits of palliative care education. 1.10.2 Consult actively with service providers to ensure that the range of education programmes on offer / being developed are relevant and user friendly.	Ongoing Ongoing	MCC/HSE Education Dept., MCC
	Bereavement Support 1.11 Review the operation of Bereavement Services and its co-ordinated development to ensure the services are meeting the needs of those who might benefit from same.	1.11.1 Agree standards against which to benchmark the Bereavement Service offered by MCC and audit the service against the agreed standards 1.11.2 Review bereavement supports in acute hospital care services in consultation with the End of Life Care Standing Committee. 1.11.3 Explore strategies to develop capacity and linkages between MCC and other bereavement supports across the Mid West. 1.11.4 Initiate awareness programmes for the general public to optimise the potential usage of bereavement support services.	2015 2014 2016 Ongoing	TSCS, MCC End of Life Care Standing Committee, MCC/HSE TSCS, MCC/HSE TSCS, MCC
	Support Bed Network 1.12 Review the existing Support Bed Network, including resource allocation, having due regard to the recommendations of the HSE's Review of Palliative Care Support	1.12.1 Review current usage patterns and potential future usage of bed network. 1.12.2 Review staffing issues in each unit that are impacting on admissions/	2013 2013	Chief Executive/ Mgt Team, MCC & Senior Operations Manager, HSE

	Beds.	opening of beds 1.12.3 Reconvene the Consultation Forum in the Mid West and review its role.	2013	Chief Executive, MCC
	Compassionate Communities 1.13 Complete the implementation of Phase 2 of the Compassionate Communities pilot project	1.13.1 Carry out an evaluation of Phase 2 of the existing project. 1.13.2 Assess the merits of extending the project across the Mid West area.	2013 2013	Comp. Communities Project Steering Group
	<u>Linkages</u> ***Links with Acute Services*** 1.14 Continue roll-out of Hospice Friendly Hospitals project.	1.14.1 Maintain the support and input of the established End of Life Care Standing Committee to identify ongoing needs.	Ongoing	HSE, MCC & IHF
	1.15 Continue developing networks with other specialities.	1.15.1 Maintain the synergistic relationship between Oncology, Haematology, Pain Management and Specialist Palliative Care MDT in all acute hospital settings. 1.15.2 Continue to develop professional working relationships with colleagues in specialties including Cardiology, Respiratory Medicine, Nephrology, and Medicine for the Elderly and Neurology.	Ongoing 2014	Palliative Medicine, Hospital CNSs & Clinical Director of Medicine, HSE Palliative Medicine, Hospital CNSs & Clinical Director of Medicine, HSE
	1.16 Formalise existing ad hoc arrangements between SPC and Anaesthetic Services.	1.16.1 Action plan to be agreed between all key stakeholders in order to progress this matter. 1.16.2 Review existing pain	2014 2014	Chief Executive, MCC & Hospital CEO, MWRHL CLC, MCC &

		management model between St John's and MCC and assess its potential for other service areas.		Clinical Director of Medicine, HSE
	Links with Community Services 1.17 Review and strengthen linkages between SPC, Primary Care, ICS and CITs across the Mid West Region.	1.17.1 Establish pilot projects between HSE and MCC aimed at optimising the use of all existing resources for palliative care patients in the community and evaluate same. 1.17.2 Promote CNS Palliative Care attendance at Primary Care Team Meetings. 1.17.3 Continue to proactively educate primary care team members in the palliative care approach.	Ongoing Ongoing Ongoing	DON/Director PHN, MCC and Primary Care Teams (PCTs), HSE DON/Director PHN, MCC and PCTs, HSE Education Department, MCC
	Links with Children's Palliative Care 1.18 Review and implement within available resources recommendations of the report Palliative Care for Children with Life-Limiting Conditions in Ireland.	1.18.1 Establish links with the Palliative Care Children's Programme National Network. 1.18.2 Engage with key stakeholders to ensure continuation of funding for the Children's Outreach Nurse.	2013 2015	'Champion' Consultant for Paediatric Palliative Care and Children's Outreach Nurse (CON), HSE Clinical Director for Maternal and Child Health
	Links with Mental Health 1.19 Formalise existing ad hoc arrangements between specialist palliative care and adult psychiatry.	1.19.1 Post doc student to progress this with the psychiatric liaison service.	2013	CLC, MCC and UL

Access					
2. Improve access for patients to Specialist Palliative Care services.	2.1 Explore appropriate patient cohorts specialist palliative care services wish to create/strengthen links with.	2.1.1	Carry out an analysis of the profile of people with non-malignant conditions accessing palliative care services.	2014	Head of Non-Clinical Support Services
	2.2 Provide information and increase awareness of the role and definition of specialist palliative care and the services available.	2.2.1	Increase awareness of the role of multidisciplinary specialist palliative care earlier in the course of the patient's illness to promote earlier referral to the team in all care settings.	Ongoing	CLC, MCC and Clinical Care Programme, HSE
	2.3 Ensure patients benefit from optimum use of services through timely and appropriate referrals.	2.3.1	Introduce/implement standardised admission and discharge criteria to facilitate referral to and discharge from specialist palliative care services to and from other service providers where appropriate.	2013	CLC, MCC
	2.4 Continue to promote equity of access for people with non-malignant conditions.	2.4.1	Examine the resource implications of continuing to extend access to people with non-malignant conditions.	2014	Chief Executive/ Mgt Team, MCC
	2.5 Progress the appointment of a fourth Consultant in Palliative Medicine with the shared academic role of Chair in Palliative Medicine and with a direct clinical role aimed at addressing unmet need across the Mid West Hospital Group.	2.5.1	Establish a working group to progress this matter.	2014	UL, MCC, HSE
	2.6 Promote access to services for children.	2.6.1	Establish a working group to develop an appropriate paediatric palliative care service, including in their remit further development of PC services for teenagers and	2014	'Champion' Consultant for Paediatric Palliative Care and CLC, MCC

		integration with adult services where appropriate and consideration of the recommendations of the Respite Services for Children with Life-Limiting Conditions and their Families in Ireland – A Needs Assessment Report.		
	2.7 Promote access to services for people from multicultural communities, people with disabilities and people from all geographical locations in the region.	2.7.1 Explore opportunities to identify groups where a focus on the development of equitable access may be appropriate with a view to developing appropriate supports as resources allow.	Ongoing	MCC, HSE and 3rd Level Institutes
	2.8 Support the expected re-establishment by HSE of the Local Area Consultative and Area Development Palliative Care Committees.	2.8.1 Support the work and activities of the two committees as required.	Ongoing	HSE,MCC
Integration				
3. Continue to integrate all services involved in the delivery of palliative care.	3.1 Ensure integration of all disciplines within Specialist Palliative Care.	3.1.1 Further integration of OPD with other multidisciplinary team personnel to allow patients to have their full review in one visit.	2014	CLC, MCC
		3.1.2 Further internal and external integration and co-ordination of the Hospice at Home multidisciplinary team to ensure comprehensive assessment, care planning, appropriate discharge and follow up.	Ongoing	CLC, MCC
		3.1.3 Integrating and expanding IT service between the acute	Ongoing	Head of Non Clinical Support

		services, Hospice at Home teams and MCC Inpatient Unit to maximise sharing of information between and within services to improve the efficiency of services and the quality of care for the patient.		Services
	3.2 Develop a communication strategy / forum aimed at optimising integration of all palliative care providers.	3.2.1 Re-establishing Consultation Forum for Palliative Care in the Mid West, representative of all key service providers.	2013	Chief Executive, MCC and Senior Operations Manager, HSE
		3.2.2 Consider strengthening linkages/ communication streams between specialist and non-specialist palliative care providers.	2015	Chief Executive, MCC and Senior Operations Manager, HSE
		3.2.3 Develop a plan to promote health promoting palliative care to be an integral part of palliative care thinking, planning and delivery through the Compassionate Communities' project.	2014	Comp. Communities Project Steering Group
Quality and Research				
4. Specialist palliative care services to promote and participate in the development of quality indicators and outcome measures of services on a national basis.	4.1 Continue to develop quality and patient safety as part of core business.	4.1.1 The quality group in MCC to be restructured to contain both a quality assurance group and a research, quality and patient safety committee.	2013	QASC
		4.1.2 Ensure participation in the development of the HSE National Performance Management System and the subsequent roll-out of agreed KPIs for the sector.	Ongoing	HSE, MCC
		4.1.3 Assess all aspects of service to		QASC

		ensure adherence to HIQAs quality and performance framework.	2013	
		4.1.4 Explore options for optimising service user feedback.	Ongoing	QASC
	4.2 Continue to develop research as part of core business.	4.2.1 Progress the implementation of MCC's Research Strategy in partnership with UL and the AIIHPC.	Ongoing	Research and Systems Group (RSG)
		4.2.2 Explore the strengthening of the current MCC / UL Steering Group to include ongoing representation from HSE.	2013	Chief Executive, MCC / Senior Operations Manager, HSE and Dean of Education / Health Sciences, UL
		4.2.3 Work with UL and the HSE to develop research themes which they may be able to assist with.	Ongoing	HSE, RSG and SLI
		4.2.4 Develop and enhance existing research capability through the AIIHPC.	Ongoing	RSG and SLI
		4.2.5 Clinical/tutor positions developed in MCC for Masters and PhD students, funded by the HRB.	Ongoing	HSE, MCC and UL

Education				
5. To continue to develop a flexible range of information and education programmes to meet the needs of a wide and varied audience and support the delivery of palliative care services.	5.1 The Education, Learning and Development Service will be further strengthened in its position as a valuable regional and national resource.	5.1.1 Develop the Education, Learning and Development service through: • Providing ongoing formal and informal education to MCC staff, palliative care users and health care providers working in the community, acute, paediatric and older person care settings. • Developing education programmes to increase the capacity and resilience of the public in dealing with issues of death, dying, loss and bereavement, which are in compliance with the National Core Competency Framework. • Optimising the use of e-learning methods and off site training provision across the region. 5.1.2 Appoint a Medical Clinical Tutor/Research Facilitator. 5.1.3 Implement a robust annual cycle of education, learning and development in MCC. 5.1.4 Continue to develop links with the All Ireland Institute of Hospice and Palliative Care. 5.1.5 Progress the accreditation process for the advanced palliative care training programme developed for health care assistants.	Ongoing July 2013 Ongoing Ongoing	Education Department Consultants in Palliative Medicine Education Department Chief Executive/ Mgt Team, MCC and UL

Appendix A

Membership of the Steering Committee

- Mr John Bulfin – Chairperson
- Dr Feargal Twomey, Consultant in Palliative Medicine, MCC / HSE and Clinical Lead for Palliative Care (HSE West)
- Dr Michael Lucey, Consultant in Palliative Medicine, MCC / HSE
- Ms Marian Moriarty, Director of Nursing, MCC
- Ms Ann Doherty, CEO, Mid Western Hospitals Group (pending the appointment of the Chief Operating Officer)
- Professor Rajnish Gupta, Consultant Medical Oncologist, MWRH
- Dr C. J. Cronin, Consultant General Physician, St. Johns Hospital
- Ms Catherine Hand, Chairperson, End of Life Care Standing Committee, Mid West Acute Hospitals
- Dr Siobhan Gallagher, Consultant in Community Paediatrics – Mid Western Regional Hospital
- Mr Jim Rhatigan, Head of Therapy and Social Care Services, MCC
- Ms Carol Murray, Head of Non Clinical Support Services, MCC,
- Mr Pat Quinlan, Chief Executive, Milford Care Centre
- Ms Nora Murphy, Service User Representative
- Ms Jackie Gibson, A/Director of Public Health Nursing, HSE
- Ms Mairead Greene, A/Director of Nursing, Community Hospital of the Assumption, Thurles
- Dr John Loughnane, General Practitioner, Boherbue, Newcastle West, Co. Limerick
- Ms Anna de Siún, Researcher/Report Author
- Ms Pauline Campbell, MCC, acted as Secretary to the Steering Committee

Terms of Reference

- Review the findings and recommendations of the *Review of Seven Year Plan for the Development of Specialist Palliative Care Services in the Mid West Region: Seven Year Plan 2004 - 2011*
- Review relevant and more recent reports on palliative care and assess their implications for current and future service provision in the Mid West
- Undertake a SWOT analysis of current service provision in the Mid West in the context of the above reports and findings; including the evaluation of progress to date in extending access to palliative care for patients with non-malignant conditions and in seeking to optimize delivery of quality palliative care services in all settings both inpatient and community based
- Consider the further development of palliative care services in conjunction with policies determined by HSE's Clinical Care Programme for Palliative Care
- Consider quality standards for palliative care in all care settings in the context of the recent launch of HIQA's *National Standards for Safer Better Healthcare (2012)*
- Identify any gaps in palliative care service provision across all care settings and make recommendations for addressing such service need areas on a priority basis over the duration of the Strategy timeframe
- Develop costing proposals for any revised or new service development areas identified.

Appendix B

Overview of Pertinent Reports Published Since 2004

Review of the Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011 (HSE & MCC, 2012)

The report reviewed all 34 recommendations of the 2004 - 2011 strategic plan and outlined service developments made to date. At the time of the report twenty four recommendations had been achieved, six had commenced with four requiring further attention. The service developments achieved during the period 2004 - 2011 include:

- Services have been developed in a planned and co-ordinated manner
- Capital project completed in MCC in 2009. Final elements brought into operation end of 2010 through a five year funding agreement between HSE and MCC
- Establishment and evaluation of the Hospice at Home Service
- Increase in the availability of inpatient beds
- Continued development of integrated inpatient and community services
- Excellent emphasis on review, evaluation of services and the provision of outcome measures
- The public/voluntary partnership between MCC and the HSE has evolved in a progressive and innovative manner
- Continually developing links with other services to ensure the delivery of an integrated palliative care service
- Enhancement of multi-disciplinary team working arrangements
- Appointment of two additional Consultants in Palliative Care
- Working in partnership with MWRH and IHF on the HFHP to improve palliative care service in acute hospitals
- Continuing to develop dedicated palliative day care services in the region
- The Education, Research and Professional Development Service has become a leading provider of palliative and clinical skills education
- Links with the All Ireland Institute for Hospice and Palliative Care
- Development of the Health Promoting Palliative Care Project.

The report also identified a number of areas where further attention was required. These included:

- Continue to develop a dedicated bank of equipment in each community care area
- Further development of a regional Lymphoedema management service
- Need for an evaluation of the community support bed network
- Formalise existing arrangements between anaesthesia and adult psychiatry
- Appointment of a fourth Consultant in Palliative Medicine
- Creation of a Chair of Palliative Medicine.

Issues identified for the future included:

- Projections for increases in the incidents of cancers over the period 2005 – 2035 (The National Cancer Registry)
- Opportunities to maximise collaboration with the All Ireland Institute of Hospice and Palliative Care
- Economic analysis report being compiled by TCD
- Ongoing reconfiguration of HSE services
- Maintaining current standards and ensuring sustainability.

An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre (UL 2012)

In 2006 Milford Care Centre expanded its existing community based services to include a specialist 'Hospice at Home' service. An evaluation was carried out between February 2009 and June 2011 by UL. Two core themes were examined:

- The quality of the service and its impact on quality of life for carers and patients
- The management and co-ordination of the service at both intra-agency and inter-agency levels.

It was found that the service exceeded expectations of carers and provided a high level of care and support. It enabled patients to be cared for at home in

accordance with their wishes and their symptoms were managed to an acceptable level. The report also highlighted that the organisation, co-ordination and management structure needs to be reviewed to meet the demands of an evolving service. In addition primary care teams need greater awareness of the range of services and clearer communication to maximize the benefits for patients and carers.

A number of recommendations for the further development of this service were made under six headings:

- Co-ordination of Teams
- Provision of Information to Carers and Patients
- Communication
- Bereavement Support
- Information Management
- Quality Assurance

National Standards for Safer Better Healthcare (HIQA 2012)

In 2012, the Health Information and Quality Authority developed National Standards to complement the work of other healthcare regulators to protect service users and to drive improvements in the quality and safety of services provided to them. The standards provide a basis for a common understanding of quality and safety in all healthcare settings. In total 44 standards are outlined under four dimensions of quality and four key areas where service providers need capability and capacity.

<u>Dimensions of Quality</u>

- Person-centred care and support
- Effective care and support
- Safe care and support
- Better health and wellbeing

Key Areas

- Leadership, governance and management
- Workforce
- Use of resources
- Use of information

Primary Palliative Care in Ireland: identifying improvements in primary care to support the care of those in their last year of life (IHF, HSE, ICGP, 2011)

Healthcare professionals working in primary care recognise the role they have to play in providing palliative care for people with life-limiting conditions living in the community. The Report on Primary Palliative Care in Ireland identifies a number of supports and services that are in place in the community to facilitate the delivery of high quality palliative care. It also identifies significant gaps in service provision and presents a number of prioritised and long term recommendations.

Gaps in Service Provision

- Flexible out of hours nursing for patients nearing end of life
- Standardised communication systems between primary, secondary and tertiary care providers to assist in timely information regarding patients palliative care needs
- Psychological support for patients and families
- Timely access to specialised equipment and retrieval collection of equipment following death
- Formal palliative approach to care within private health sector.

Recommendations

- The need to formalise links between primary care teams and SPC teams to ensure consistency and equity in the delivery of palliative care services
- Despite a number of educational programmes offered by MCC, the report also identified the need for further education in the area of palliative care
- Finally there is a need to clarify the extent and means of access to 24-hour specialist palliative care advice and information.

Quality Standards for End-of-Life Care in Hospitals in Ireland (IHF 2010)

In 2008/2009 a national audit was carried out to assess the quality of care provided by Irish hospitals in the last week of life. The results of the audit influenced the development of the Quality Standards for End-of-Life Care in Hospitals. Thirty standards were published under four headings:

- The Hospital: This section outlines 13 standards, including A Culture of Compassionate End-of-Life Care, General Governance Policies and Guidelines and Effective Communication with Patients and their Families

- The Staff: This section contains five standards, including Staff Induction, Staff Education and Development Needs and Staff Support

- The Patient: This section outlines six standards, including Communicating a Diagnosis of the Possibility of a Need for End-of-Life Care, Clear and Accurate Information and Patient Preferences

- The Family: This section also outlines six standards, including Communication with Family Members - Where death may be anticipated, Communication with Family Members - Sudden/unexpected death or sudden irreversible decline in health leading to death and Patient Discharge

Palliative Care for All: Integrating Palliative Care into Disease Management Framework (HSE 2009)

This report highlights the need for a structured approach to palliative care for people with life-limiting diseases, including COPD, heart failure and dementia.

It recommends that palliative care services should be integrated within existing disease management frameworks. Specialist palliative care services need only be introduced where a person’s needs become complex and extraordinary.

The report highlights that the projected 80% increase in demand should services be made available to people with both malignant and non-malignant conditions has not been backed up by research. It goes on to recommend the introduction of eligibility and discharge criteria as a means of introducing an equitable and consistent approach to access to specialist palliative care services. Finally a number of barriers and challenges to implementing change are identified, including lack of eligibility and lack of resources, and these are addressed from the perspective of service model, policy, education and research.

Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy (DoHC 2010)

The report outlines the need for a responsive palliative care service for children and their families which needs to function within a co-operative model with close liaison between general practitioners, paediatricians, nursing services, therapists and the voluntary sector. It highlights that the needs of children with life-limiting conditions differ significantly from those of adults and that not all children with palliative care needs will require SPC input. A service model led by a Consultant Paediatrician with a special interest in palliative care is outlined.

A number of recommendations are made including:

- The development of a hospice at home service for children in need of palliative care
- The establishment of outreach nurses who would have a particular role in facilitating integration of service delivery and would act as the link between the primary care teams and the hospital network system
- The need for the HSE and voluntary agencies to develop closer relationships as they provide services for children with life-limiting conditions.

Forum on End of Life: Draft Action Plan (IHF, 2010)

The Irish Hospice Foundation (IHF) inaugurated a Forum on End of Life in Ireland at the beginning of 2009 to identify what matters most to the public regarding end of life from a wide range of perspectives: social, health, economic, legislative,

administrative, educational, cultural and religious. From the findings of this process, sixteen themes were identified, three of which refer to the breadth of the work and the inclusive principles which must underpin it, while thirteen detail a range of potential actions.

The three overarching themes identified were:

- Death is part of the life cycle: with a focus on an integrated approach across policy areas, ensuring no population group is overlooked and ensuring the citizen rather than the provider is at the heart of public services and planning
- End of life is everybody's business: highlighting that end of life is not just the business of the caring professions. 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
- End of life is a public health matter: an international work group on death, dying and bereavement proposed a 'charter for the normalization of dying, death and loss'. This would require community development, education, participatory health care approaches, legislative and policy change.

Palliative Care Services – A Five Year/Medium Term Development Framework (HSE 2009)

This report aims to develop palliative care services nationally using a holistic system-wide approach to addressing needs identified in earlier assessment of needs studies. Forty one national priorities are listed, grouped under four headings:

- Home Care Deficits
- Specialist Inpatient Bed Deficits
- Capital Developments
- Acute Hospital Support

Palliative Care Services – Strategic Plan for Specialist Palliative Care HSE West 2009 – 2013 (HSE 2008)

The overall aim for palliative care in HSE West is to provide an adequately resourced, safe, high quality palliative care service, available in all care settings, that is patient centred, accessible, responsive and equitable, operating in line with evidence-based practice. The objectives outlined to achieve this aim are to:

- Improve access to palliative care services
- Enhance partnerships at all levels to maximize the development and scope of available palliative care services
- Integrate the palliative approach into all clinical practice
- Improve psychosocial palliative care provided to service users, their families and staff
- Increase levels of palliative care knowledge
- Manage risk and continuously improve quality
- Ensure accountability and financial stability.

Appendix C

Membership of the Consultation Workshop Group

Ms Maria Bridgeman, Senior Operations Manager, PCCC, Limerick/Nth Tipperary

Mr John Bulfin, Chairperson

Dr Marian Conroy, Consultant in Palliative Medicine, MCC/HSE

Ms Mary Cooney, Palliative Care Clinical Nurse Manager, MWRH Limerick

Mr Michael Corcoran, Hospice at Home Co-ordinator, MCC

Dr. Cornelius Cronin, Clinical Director of Medicine, MWRH Limerick/Consultant Physician, St John's Hospital

Ms Anna de Siún, Health Services Researcher

Ms Ann Doherty, CEO, Mid Western Hospitals Group

Sr Brigid Finucane, Mission Development Co-ordinator, MCC

Mr Bernard Gloster, Area Manager, PCCC, HSE Mid West

Dr Ann Hogan, Principal Medical Officer, HSE Mid West

Ms Jacqueline Holmes, Deputy Director of Nursing, MCC

Dr Michael Lucey, Consultant in Palliative Medicine, MCC/HSE

Ms Carmel McLoughlin, Disability Manager, HSE Mid West

Ms Catherine McNamara Hannan, Cardiac Failure CNS, MWRH, Limerick

Ms Ethna McTeague, Older Persons Manager, HSE Mid West

Ms Marian Moriarty, Director of Nursing, MCC

Ms Nora Murphy, Service User Representative

Ms Carol Murray, Head of Non-Clinical Support Services, MCC

Ms. Ursula Paine, Clinical Nurse Specialist 2, HSE Mid West

Mr Pat Quinlan, Chief Executive, MCC

Ms Cathy Sheehan, Head of Finance, MCC

Mr Jim Rhatigan, Head of Therapy and Social Care Services, MCC

Dr. Feargal Twomey, Consultant in Palliative Medicine, MCC/HSE

References

A Nationwide Survey of Public Attitudes and Experiences Regarding Death and Dying. The Irish Hospice Foundation (2004)

An Evaluation of the Hospice at Home Service Delivered by Milford Care Centre. University of Limerick (2011)

Cancer projections 2005 - 2035: A Summary. National Cancer Registry, Cork (2008)

Central Statistics Office (2008). www.eurohealth.ie/cancom/defs.htm

Future Health: A Strategic Framework for Reform of the Health Service 2012 – 2015. Department of Health and Children (2012)

O'Reilly, M. *The Development and Validation of a Palliative Care Admission Assessment Tool.* Unpublished PhD

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, Health Service Executive, Irish College of General Practitioners (2011)

Report of the National Advisory Committee on Palliative Care. Department of Health and Children (2001)

Review of Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011. HSE and Milford Care Centre (2011)

Seven Year Strategic Plan for the Development of Specialist Palliative Care Services in the Mid West Region 2004 - 2011. Mid Western Health Board (2004b)

Specialist Palliative Care Services Needs Assessment in the Mid West. Mid Western Health Board (2004a).