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Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

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A Palliative and End of Life Care Strategy for Adults in Northern Ireland

March 2010

Living Matters Dying Matters

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Living Matters Dying Matters

Foreword

By the Minister for Health, Social Services and Public Safety

Most of us now live longer than ever before. However, increasingly more of us, as we age, will live with the consequences of chronic conditions that can have a debilitating effect on our health and general well-being. Good quality palliative and end of life care will be important to us all.

The vision of this Strategy is that any person with an advanced non-curative condition, lives well and dies well irrespective of their condition or care setting. This requires a philosophy of palliative and end of life care that is person-centred and which takes a holistic approach to planning, co-ordinating and delivering high quality reliable care, enabling patients to retain control, dignity and crucially, choice in how and where their care is delivered to the end of their life.



Over the 5 year time span of this Strategy we will continue to make high quality palliative and end of life care a priority within health and social care services and, as a result, offer people real choice in how and where their care is delivered.

To make this vision a reality requires that:

- both the public and health and social care professionals understand what palliative and end of life care is and how it can ensure that people with progressive conditions have a good quality of life and, when they reach the end phase of their life, compassion, dignity and comfort in death;
- all those responsible for planning and delivering palliative and end of life care have the knowledge, skills and competence, informed by evidence-based research, to confidently and sensitively undertake their roles in caring for people who are dying and their families and carers;

Foreword

- the palliative and end of life care needs of patients, families and carers are identified, addressed and regularly reviewed as a matter of course, including the need for physical, spiritual, psychological, financial and social support;
- all palliative and end of life care is planned around the assessed needs of the individual, their family and carers and is responsive to their expressed preferences;
- all care is delivered in a way that is structured, planned, integrated and co-ordinated irrespective of when that care is needed and where it is provided.

To achieve this requires a cultural and behavioural shift both in how palliative and end of life care is perceived and in how it is delivered. It means being sensitive to the personal beliefs, cultures and practices of individuals and their families and carers and recognising the contribution that good palliative and end of life care can make to the quality of their lives. It means that where the person's preference is to receive care, and where possible to die at home, that the infrastructure and opportunities are in place to make such a choice real and viable.

I believe this is possible as I reflect on the care and compassion I have seen displayed by all those who provide palliative and end of life care. I refer not only to the tireless commitment demonstrated through our hospices, but also by staff within care homes, hospitals and throughout the community. I am also mindful that families, carers and volunteers continue to be the crucial cornerstone of this care.

I am committed to ensuring that the people of Northern Ireland have access to high quality health and social care at all stages of their lives. This Strategy will ensure that palliative and end of life care for adults in Northern Ireland, irrespective of their condition or where they live, will help achieve this.



Michael McGimpsey
Minister for Health, Social Services and Public Safety

Executive Summary

Palliative and end of life care is the active, holistic care of patients with advanced progressive illness. This Strategy identifies palliative and end of life care as a continuum of care that can evolve as a person's condition progresses. This is an integral part of the care delivered by all health and social care professionals, and indeed by families and carers, to those living with, and dying from any advanced, progressive and incurable conditions. Palliative and end of life care focuses on the person rather than the disease and aims to ensure quality of life for those living with an advanced non-curative condition. This 5 year Strategy provides a vision and direction for service planning and delivery. It has been developed and should be implemented within the existing legal framework.

The Strategy builds on current and predicted demographics, intelligence and consultation which have informed the implementation of other Departmental policy areas, Service Frameworks, and Priorities for Action Targets and takes into account policy context from the other United Kingdom (UK) countries and the Republic of Ireland (RoI).

The Strategy sets out a vision for palliative and end of life care across all conditions and care settings, based on what people value most and expect from such care. This vision emphasises the importance of:

- Understanding palliative and end of life care;
- Best and appropriate care supported by responsive and competent staff;
- Recognising and talking about what matters;
- Timely information and choice;
- Co-ordinated care, support and continuity.

Driving the service improvement expectation of this vision requires ownership and leadership from across all commissioners and providers. The roles of public, independent, community, and voluntary sector organisations, and the collaborative arrangements that exist between them, are essential to quality palliative and end of life care. The Strategy reinforces the need to continue to strengthen these creative partnerships through local and regional infrastructure and strategic plans. An Implementation Board representative of key stakeholders will be established with a remit to ensure that the

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recommendations contained within the Strategy are developed and embedded into practice.

Greater public and professional understanding of palliative and end of life care will ensure that patients, carers, families, communities, and staff will have the right knowledge and skills available at the right time and in the right place to deliver compassionate, appropriate and effective generalist and specialist palliative and end of life care.

The Strategy considers the delivery of quality palliative and end of life care and recommends the concept of a Model for Palliative and End of Life Care as a vehicle for delivering high quality care. This Model reflects the components of the existing regional community facing model for palliative and end of life care and enables the discussion and identification of patient, family and carer needs through continuous holistic assessment. This in turn informs the planning, co-ordination and delivery of person-centred care across care settings, particularly throughout the last years, months and days of life, and identifies bereavement care as a key part of palliative and end of life care.

The Model recognises how patient choice needs to be supported by appropriate infrastructures and services, including access to 24 hour essential services. Crucial to the implementation of the Model will be the role of the end of life key worker with responsibility for co-ordinating services and facilitating effective communication of information between patients, families, carers and health and social care providers.

A number of specific tools and frameworks to direct service planners and providers to key areas of service improvement have been included within the Strategy. In addition a number of exemplars also feature to illustrate good practice already happening in Northern Ireland or elsewhere.

The 25 recommendations emanating from this Strategy have been built into an Action Plan to enable the planning and delivery of quality palliative and end of life care over the next 5 years.

Note: • Throughout this Strategy the use of the word “patient” should also be taken to mean “client”
• “Family” is best defined by the patient themselves and may include dependants, step-family, family by marriage or civil partnership or family by choice

Recommendations

Section 3 – Developing Quality Palliative and End of Life Care

1. Open discussion about palliative and end of life care should be promoted and encouraged through media, education and awareness programmes aimed at the public and the health and social care sector.
2. The core principles of palliative and end of life care should be a generic component in all pre-registration training programmes in health and social care and in staff induction programmes across all care settings.
3. Mechanisms to identify the education, development and support needs of staff, patients, families, carers and volunteers should be in place to allow person-centred programmes to be developed which promote optimal health and well-being through information, counselling and support skills for people with palliative and end of life care needs.
4. A range of inter-professional education and development programmes should be available to enhance the knowledge, skills and competence of all staff who come into contact with patients who have palliative and end of life care needs.
5. Arrangements should be in place which provide families and carers with appropriate, relevant and accessible information and training to enable them to carry out their caring responsibilities.
6. A collaborative and collegiate approach to research and development should be established and promoted to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care.

Section 4 – Commissioning Quality Palliative and End of Life Care

7. A lead commissioner should be identified for palliative and end of life care at regional level and within all Local Commissioning Groups.
8. Systems should be in place which capture qualitative and quantitative population needs relating to palliative and end of life care.

Recommendations

Section 5 – Delivering Quality Palliative and End of Life Care

9. Each patient identified as having end of life care needs should have a key worker.
10. Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services with no loss of needed service experienced as a result of the transfer.
11. The potential for a Managed Clinical Network should be explored to ensure leadership, integration and governance of palliative and end of life care across all conditions and care settings.

Section 6 – A Model for Quality Palliative and End of Life Care

12. Arrangements should be put in place which allow for the most appropriate person (be that clinical staff, carers, spiritual care providers or family members) to communicate with, and provide support for, an individual receiving significant information.
13. Appropriate tools and triggers should be implemented to identify people with palliative and end of life care needs and their preferences for care.
14. A locality based register should be in place to ensure (with the permission of the individual) that appropriate information about patient, family and carer needs and preferences is available and accessible both within organisations and across care settings to ensure co-ordination and continuity of quality care.
15. Condition specific care pathways should have appropriate trigger points for holistic assessment of patients' needs.
16. Timely holistic assessments by a multi-disciplinary care team should be undertaken with people who have palliative and end of life care needs to ensure that changing needs and complexity are identified, recorded, addressed and reviewed.

Recommendations

17. Timely holistic assessments by a multi-disciplinary care team should be undertaken with the family and carers of people who have palliative and end of life care needs to ensure that their needs are identified, recorded, addressed and reviewed.
18. Respite care should be available to people with palliative and end of life care needs in settings appropriate to their need.
19. Patients, their families and carers should have access to appropriate and relevant information.
20. Palliative and end of life care services should be planned and developed with meaningful patient, family and carer involvement, facilitated and supported as appropriate and provided in a flexible manner to meet individual and changing needs.
21. Services should be prioritised for the provision of equipment, transport and adaptations, for all patients who have rapidly changing needs.
22. Policies should be in place in respect of advance care planning for patients with palliative and end of life care needs.
23. Tools to enable the delivery of good palliative and end of life care, for example, the Gold Standards Framework, Preferred Priorities for Care, Macmillan Out-of-Hours Toolkit or the Liverpool Care Pathway, should be embedded into practice across all care settings with ongoing facilitation.
24. All out-of-hours teams should be competent to provide responsive generalist palliative and end of life care and advice to patients, carers, families and staff across all community based care settings.
25. Access to specialist palliative care advice and support should be available across all care settings 24/7.

Vision for Quality Palliative and End of Life Care

The *Palliative and End of Life Care Strategy* has been developed in response to what people expect and value most from palliative and end of life care, recognising that living matters and dying matters to all. The Strategy's vision is that any person with an advanced non-curative condition, lives well and dies well irrespective of their condition or care setting. This requires a philosophy of care that is person-centred and which takes a holistic approach to planning, co-ordinating and delivering high quality, equitable and reliable care that enables people to retain control, dignity and, crucially, choice in how and where their care is delivered to the end of their life¹.

Making this vision a reality requires an understanding of the complexity of palliative and end of life care across all conditions, as well as ownership and leadership at all levels of policy, planning, commissioning, education and delivery of care. This will involve commitment to change culture and practice in the following 5 key areas:

Understanding palliative and end of life care

- Palliative and end of life care should be applicable across all conditions and all care settings.
- Palliative and end of life care should enhance quality of life, improve function and ensure comfort.
- Palliative and end of life care should present people with options for choice in by whom, how and where their care can be delivered.

Developing skills and knowledge

- Those responsible for the planning and delivery of palliative and end of life care will have an appropriate level of knowledge, skills and competence to provide sensitive and compassionate support and care.
- Those responsible for the planning and delivery of palliative and end of life care will have access to guidelines providing clear information on the best standards of practice.

Vision for Quality Palliative and End of Life Care

Identifying needs and talking about what matters

- The effects of illness on the person, family, carers and staff will be acknowledged.
- Individuals will have a holistic assessment that identifies the social, spiritual, financial, physical and psychological needs they face as a result of their illness.
- Every effort will be made to address patients' symptoms e.g. pain, nausea, shortness of breath, agitation, psychological and spiritual distress.

Planning care - timely information and choice

- Individuals' priorities, options and choices will be at the centre of all palliative and end of life care planning.
- Individuals, their families, carers and staff will feel informed and know what to expect as the condition progresses.
- A recorded plan of care will be made so that personal priorities are known to all care service providers and are accessible at all times.
- As far as possible, people will be supported to die at home if that preference is expressed.
- Patients will have access to specialist palliative care services based on assessed need.
- The concerns and needs of caregivers (including respite) will be assessed, addressed and recorded.

Delivering and co-ordinating care, support and continuity

- Patients, families, carers and staff can count on having access to appropriate professionals to rely upon at all times.
- Movement between services, settings, and personnel should only happen when necessary and to improve quality of care and life for the individual, their family and carers.
- Proactive planning and effective communication must underpin the smooth delivery of care on a 24 hour basis.

Adapted from NICE, 2004, Regional Model 2008, & Improving Care for the End of Life. Joanne Lynn, Janice Lynch Schuster and Anne Wilkinson, Lin Noyes Simon (2008) Improving Care for the End of Life. A Source for Health Care Managers and Clinicians (2nd Ed) Oxford University Press

SECTION 1 Introduction

- 1.1 Health and Social Care (HSC) services for people with palliative and end of life care needs have improved considerably over recent years. The work of the hospice movement has provided an important impetus for this as has the development of creative partnerships between public, independent, community and voluntary sector organisations, working together to design, develop and deliver services. As people live longer, and with the increasing prevalence of chronic conditions, it is essential that the HSC and its care partners collaborate further to meet the challenge of planning and delivering high quality palliative and end of life care for increasing numbers of patients and clients across Northern Ireland living with one or more chronic condition or physical and/or cognitive frailty.
- 1.2 Palliative and end of life care is both a philosophy of care and an organised, highly structured system for planning and delivering care². The philosophy affirms person-centred, holistic care and values patient and family lives, beliefs and preferences. The effective planning and delivery of palliative and end of life care improves the quality of care in three primary areas:
- Enhanced patient/carer/clinician communication and decision-making;
 - Better management of pain and other symptoms, including spiritual and psychological needs of patients, their families and carers;
 - Improved co-ordination of care across multiple health and social care settings.
- 1.3 The development of this Strategy has been informed by a range of national and international strategies and developments in palliative and end of life care undertaken by a number of national and international bodies. These include:
- The World Health Organisation (WHO)³ and the Council of Europe⁴;
 - Department of Health (DoH) England⁵;
 - Welsh Assembly Government⁶;
 - Scottish Government⁷;

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- Irish Hospice Association and Health Service Executive (consultation framework)⁸.

1.4 The Strategy also builds upon a considerable amount of work that has already been undertaken in Northern Ireland. For example, the Northern Ireland Cancer Network (NICaN), through the auspices of its Supportive and Palliative Care Network Group, has developed generic standards for palliative care as well as regional guidelines for best practice care.

Terms of Reference and Aim of the Palliative and End of Life Care Strategy

1.5 The terms of reference were to develop a Strategy that identifies palliative and end of life care as a continuum that is applicable across all conditions and care settings. The overall aim of the Strategy is to improve the quality of palliative and end of life care for adults in Northern Ireland, irrespective of condition or care setting by:

- Providing a policy framework which enables public, independent, community and voluntary care providers to deliver high quality palliative and end of life care to the people of Northern Ireland;
- Ensuring that palliative and end of life care is focused on the person rather than the disease and that the principles and practices of high quality care are applied, without exception, to all those with palliative and end of life care needs.

Outcomes of the Strategy

1.6 The Strategy provides a framework which will support commissioners and providers in achieving the following outcomes:

- A raised awareness and understanding of palliative and end of life care;
- Increased knowledge and skills of health care professionals in respect of palliative and end of life care;
- Health and social care professionals enabled to identify individuals who could benefit from palliative or end of life care;

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- Holistic assessment of the needs of individuals requiring palliative and end of life care, their families and carers;
- A raised awareness of the need for appropriate support arrangements for carers, families and staff;
- Increased opportunities for choice for individuals in respect of where they receive palliative and end of life care and ultimately where they die;
- Timely, effective and efficient deployment of resources, targeting care towards need;
- The provision of best practice guidelines and standards for the delivery of palliative and end of life care which will meet patient, family and carer needs;
- An integrated and co-ordinated whole systems approach to palliative and end of life care through the development of care pathways that are responsive to patient needs, irrespective of their condition or care setting;
- A *Palliative and End of Life Care Strategy* which links with other Departmental policies and strategies, in particular the Department's policy of providing services closer to, or in, patients' and service users' homes.

Scope of the Strategy

- 1.7 The Strategy, which has been developed within the existing legal framework, recognises that people must be considered and cared for as individuals with reasonable adjustments made accordingly. It acknowledges that all palliative and end of life care should be provided with an equitable, person-centred approach respecting the diversity of patients, their families and carers. It endorses an integrated and holistic approach to the assessment and management of symptoms and treatment, moving beyond a purely clinical response to include recognition of emotional, spiritual, social, and psychological circumstances. This requires responsive care and support that is designed to meet their specific needs co-ordinated across all care settings.
- 1.8 The Strategy recognises that palliative and end of life care forms a continuum of care that may apply from diagnosis of a life-limiting

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condition, right through to death and bereavement. Within this context, the Strategy provides a framework for high quality palliative and end of life care, emphasising the significance of early identification of an individual's need for palliative care, the interplay between palliative care and chronic condition management and the importance of ensuring that the skills are in place to anticipate and deliver quality end of life care.

- 1.9 In addition, the Strategy recognises the significant contribution within communities which families and carers make in providing informal care for their loved ones. It promotes their role in the inter-disciplinary and inter-agency teamwork that is central to good quality palliative and end of life care.
- 1.10 Palliative and end of life care for children and young people is not within the scope of this Strategy given their very specialised needs in this area. However, where a young person moves into adult care it is important that their transitional care needs are considered. Transitional care is the purposeful, planned process that addresses the medical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions from a child-centred to adult-orientated health care system⁹. The Strategy references existing best practice guidance on the transitional care of young people into adulthood.

SECTION 2 Background

The Need for Palliative and End of Life Care

- 2.1 Palliative and end of life care is increasingly recognised as a public health issue that encompasses the health and wellbeing of the population as a whole. Approximately 15,000 people die in Northern Ireland each year (see Figure 1). The main causes of death are circulatory diseases (35% of deaths); cancer related deaths (26%) and respiratory diseases (14%). Changing demographics mean that people are living longer and often with one or more chronic conditions. As a result, over time increasing numbers of people will require more complex care for longer.
- 2.2 By 2017, projections for the regional population (based on the 2006 mid-year population estimates) suggest that 310,000 people in Northern Ireland will be aged 65 and over - this represents 16% of the total population. It is within this section of the population that the highest incidence and mortality from cancer and other chronic conditions exists. Given that the prevalence of chronic conditions and dementia increases with age, demand for palliative and end of life care services is likely to increase as the population ages and more people live with the consequences of physical and/or cognitive frailty.
- 2.3 The House of Commons, Health Committee Palliative Care, 4th Report of Session 2003-2004¹⁰; recognised the inequity of access to palliative care for non-cancer patients. The Committee also accepted that many of the care practices for cancer are transferable in nature and could be used across other conditions. The symptom burden for people with chronic conditions, including chronic obstructive pulmonary disease (COPD), dementia, heart failure, and all other neurological and degenerative diseases, equals that of people with cancer and may often be of longer duration.
- 2.4 Studies by the National Council for Palliative Care highlight that approximately two thirds (9,570) of people dying in Northern Ireland every year would benefit from a level of palliative care during the last year of life but for reasons of diagnosis are excluded¹¹.

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Figure 1: Deaths in Northern Ireland 2006 – 2008 by Place of Death

Place of Death	Registration Year					
	2006		2007		2008	
All Hospitals	7,706	53.0%	7,520	51.3%	7,515	50.4%
Nursing Homes	2,102	14.5%	2,249	15.4%	2,421	16.2%
Hospices	490	3.4%	523	3.6%	550	3.7%
Other Places ¹	4,234	29.1%	4,357	29.7%	4,421	29.7%
All Deaths ²	14,532	100.0%	14,649	100.0%	14,907	100.0%

Note

¹ Includes deaths at home.

² These figures represent all deaths in Northern Ireland as a result of illness and all other causes.

Source: General Registrar's Office¹²

2.5 In meeting the anticipated higher demand for palliative and end of life care, it will also be necessary to address people's expectations of options and choice in how and where care is delivered. Studies show that the majority of people with a terminal illness would prefer to die at home¹³, however approximately 50% of all deaths in Northern Ireland still occur in hospitals (see Figure 1). As far as possible the aim should be to provide care in the environment of the individual's choice.

Policy Context

2.6 This Strategy builds upon a number of existing policies and guidelines which have directly and indirectly contributed to the development of palliative and end of life care services in Northern Ireland.

"A Healthier Future" Regional Strategy (DHSSPS, 2004) and *"Caring for People Beyond Tomorrow"* Primary Care Strategic Framework (DHSSPS, 2005) set out the Department's overarching commitment to the development of responsive and integrated health and social care services which aim to reduce dependence on hospitals and instead provide care to patients and clients in their own communities.

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- 2.7 The following policies and guidelines have also contributed to the development of palliative and end of life care services in Northern Ireland:

The Campbell Report “Cancer Services - Investing for the Future” (DHSSPS, 1996) made a number of recommendations including the need for a Regional Review of Palliative Care Services;

“Partnerships in Caring – Standards for Service” (DHSSPS, 2000) was developed in conjunction with key public and voluntary organisations and made a number of wide ranging recommendations for the development of palliative care services. This report was instrumental in promoting improvements in cancer and palliative care services, including highlighting the need for partnership between patients, families, carers and those providing health and social care services;

“Best Practice Best Care” (DHSSPS, 2001) described how the quality of services could improve and recommended that everyone involved in health and social care should recognise the need to deliver high quality services;

“Valuing Carers” (DHSSPS, 2002), and *“Caring for Carers”* (DHSSPS, 2006) provided strategic direction for the provision of support services for carers;

“A Strategic Framework for Respiratory Conditions” (DHSSPS, 2006) highlighted the importance of adopting a whole systems approach to the prevention and treatment of respiratory disease and made a series of recommendations as to how services for respiratory patients might be developed;

“Improving the Patient and Client Experience” (DHSSPS, 2008) set out five standards, developed by the Department’s Chief Nursing Officer in collaboration with the Royal College of Nursing (RCN) and the Northern Ireland Practice and Education Council (NIPEC), which stipulate what the public should expect from staff in the health service in relation to respect, attitude, behaviour, communication and privacy and dignity;

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An *“Integrated Care Pathway for Children with Complex Physical Health Care Needs”* (DHSSPS, 2009) provided guidance in meeting the needs of children and young people up to 18 years of age who have complex physical health and social care needs. It also recognised the needs of their families and carers;

“The Northern Ireland Health and Social Care Services Strategy for Bereavement Care” (DHSSPS, 2009) aimed to promote an integrated, consistent approach to all aspects of care across public health and social care services in support of people who have been bereaved. It provided valuable information and guidance aimed at improving the knowledge and competence of health and social care providers in caring for those who have been bereaved.

- 2.8 In addition, the National Institute for Health and Clinical Excellence (NICE) has published a series of guidance documents on palliative care and chronic conditions. These include:

“Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care” (NICE 2003);

“Guidance on Improving Supportive and Palliative Care for Adults with Cancer” (NICE 2004);

“Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care” (NICE 2004);

“Parkinson’s Disease; Diagnosis and Management in Primary and Secondary Care” (NICE 2006);

“Dementia; NICE-SCIE Guideline on Supporting People with Dementia and their Carers in Health and Social Care” (NICE 2007).

- 2.9 Each of these guidance documents made a number of recommendations which included an emphasis on the personal involvement of those who experience care to enable the planning, delivery and evaluation

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of their services. Access to information, the role of a key worker and the co-ordination of proactive and responsive care, including access to specialist palliative care services, were all highlighted within these guidance documents.

In 2004 the NHS Modernisation Agency published the *“Supportive and Palliative Care for Advanced Heart Failure, Coronary Heart Disease Collaborative”* to complement the 2003 NICE guidance on the management of chronic heart failure.

- 2.10 Work is ongoing on the development of a series of Service Frameworks for Health and Well-being in Northern Ireland. Each of these frameworks will contain explicit standards reflecting the care and support which patients, clients, their carers and families should expect to receive and will promote particular areas of performance improvement for health and social care organisations¹⁴. Standards for palliative care, which aim to promote equity of care, have been developed for inclusion in the frameworks.

Defining Palliative and End of Life Care

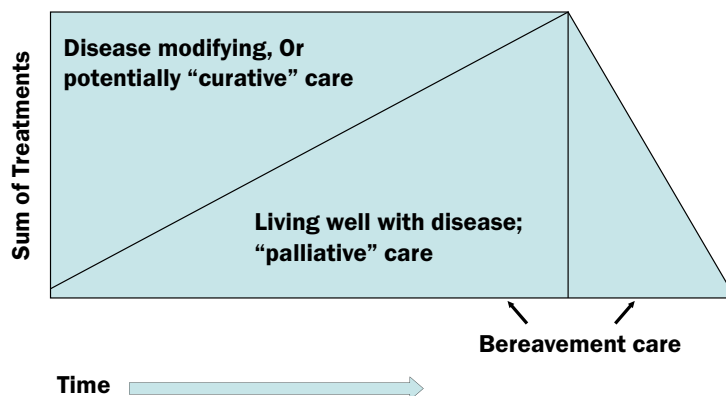
Palliative Care

- 2.11 Palliative care is defined as: “the active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments”¹⁵. More latterly the importance of “early identification and impeccable assessment” has been added to this definition as it is thought that problems at the end of life can have their origins at an earlier time in the progression of the illness and should therefore be recognised and dealt with sooner¹⁶.
- 2.12 Palliative care can in some cases mean a shift from a curative focus towards an approach which seeks to alleviate and prevent the escalation

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of symptoms (See Figure 2). The transition between curative and palliative care is often blurred, which emphasises the importance of communication between the individual and the health care professional with regards to the intention of treatment. Identifying this transition informs thoughtful decision-making about the appropriateness of proposed treatment options and explores the provision of further social and spiritual support to address emotional, psychological and practical needs, invaluable to the individual, their family and carers in managing the condition.

Figure 2: Shifting Focus to Palliative Care



Adapted from Murray, S A et al (2005) & Lynn, J & Adamson D (2003)

Principles of Quality Palliative Care

2.13 Good palliative care, which may be applicable from diagnosis:

- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological, emotional and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

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- offers a support system to help the family cope during the patient's illness and into bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- will enhance quality of life, and may also positively influence the course of illness¹⁷.

End of Life Care

2.14 End of life care is an integral part of the wider concept of palliative care and consequently many of the same principles will apply. Recently the emphasis on end of life care has focussed on helping all those with advanced progressive and incurable conditions to live as well as possible until they die. It enables the palliative care needs of both patient and family to be identified and met throughout the last phases of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support¹⁸. For the purposes of this Strategy, end of life will be described as the period of time during which an individual's condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months, however a specific timescale cannot always be applied.

2.15 This point will be different for each individual and will often depend on an assessment of their condition by health and social care professionals, carers and/or the patient themselves. Identifying the point at which illness becomes advanced or reaches the end of life phase allows health and social care providers to plan best care for their patients in order to meet their needs and those of their families and carers throughout the last phase of life and the experience of bereavement. As with palliative care, end of life care also includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support¹⁹.

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Figure 3 below summarises the elements of care within the continuum of palliative and end of life care.

Figure 3

Palliative Care	End of Life Care a component of palliative care
Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life limiting illness	End of Life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die
Prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual	Includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support
	It enables the palliative care needs of both patient and family to be identified and met throughout the last phase of life and the experience of bereavement

Clinical Prognostic Indicators for End of Life Care

2.16 Recognising when a person enters the end of life care phase can be difficult but is essential to good quality care. Clinical Prognostic Indicators are tools which can help provide a guide to estimating when a person with an advanced disease or condition is in the last year or

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so of life. When the indicators are interpreted as part of the holistic assessment for an individual, they can help to alert health and social care professionals to identify when a patient may begin to require end of life care.

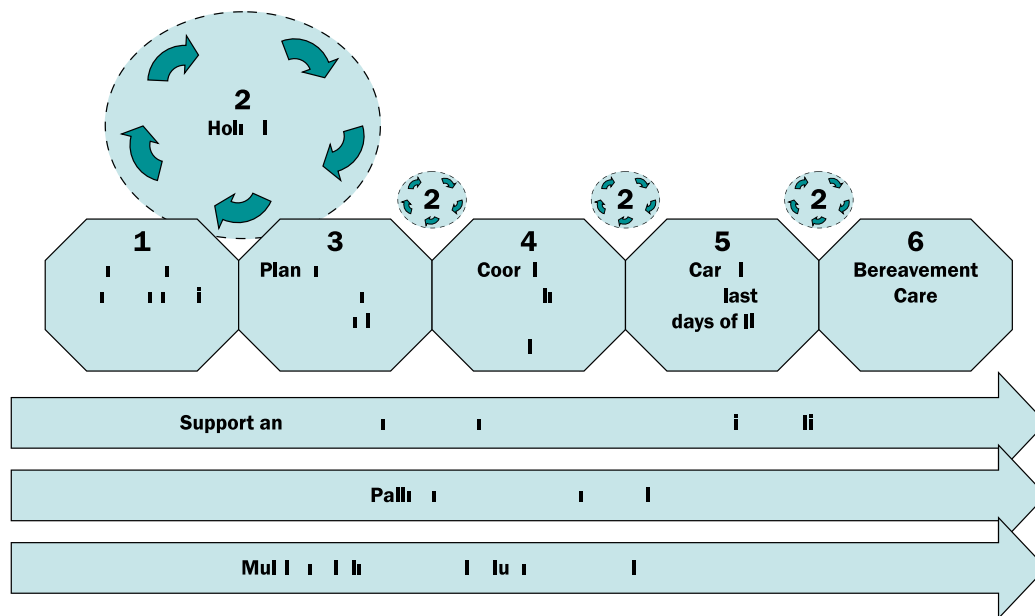
- 2.17 Clinical Prognostic Indicators are advocated within the Gold Standards Framework (<http://www.goldstandardsframework.nhs.uk>) and are also included within the generic standards for palliative care. Integration of Clinical Prognostic Indicators within agreed protocols and clinical pathways will ensure that people living with chronic progressive illness will have timely identification of palliative and end of life care needs.

A Model for Palliative and End of Life Care

- 2.18 Palliative and end of life care is a continuum of care that may apply from diagnosis of a life-limiting condition right through to the end phase of life when death is expected. This can include pre and post bereavement support. Figure 4 represents this care continuum within an overarching Model for Palliative and End of Life Care. Continuous holistic assessment of palliative and end of life care need is crucial throughout to ensure an individual's care is assessed, planned for and delivered according to their need and in line with the vision presented in this Strategy.
- 2.19 The Model for Palliative and End of Life Care is considered in more detail in Section 6.

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Figure 4: A Model for Palliative & End of Life Care



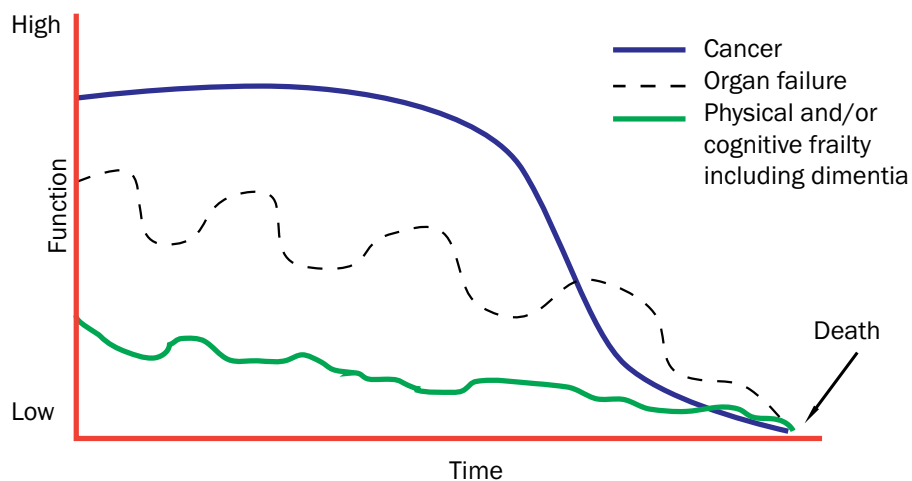
Disease Trajectories

- 2.20 Individuals can access palliative care from different routes. For some, palliative care may be necessary as a result of a condition inherent from birth and therefore the need for care might extend over a lifetime. For others the need for this care may be as a result of a deterioration of an existing chronic condition that will require a re-adjustment of ongoing case management arrangements to focus specifically on palliative and end of life care needs. In other instances palliative and end of life care may be the outcome of a newly diagnosed condition where prognosis may be short or longer term.
- 2.21 As palliative care is relevant to people with a wide range of conditions, attempts have been made to determine how functional decline differs between different types of conditions. Understanding disease trajectories (how a condition progresses) can help predict how both population-level and individual health and social care needs may develop

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over time. Figure 5 represents an adaptation from work by Lynn et al²⁰, showing trajectories over the last year of life.

Figure 5: The Three Main Trajectories Reflecting Decline at the End of Life



Adapted from Murray, S A et al. & Lynn, J & Adamson D (2003)

- 2.22 The diagram illustrates how health and well-being can gradually decline as chronic conditions such as heart or lung failure, advanced dementia or cancer progress. While the time span of trajectory for any individual is particularly difficult to quantify, the experience of living with a chronic condition will be interspersed with episodes of sudden exacerbation, which may be physical or psychological in nature. At these times, indicated by the abrupt or sometimes subtle dips on the lines of trajectory, the patient and their family and carers will have changing needs.
- 2.23 Understanding the difference in disease trajectories supports better planning, enabling care to be stepped up or stepped down in response to identified triggers or critical points and reflecting the circumstances of the patient and their families and carers at any particular time, including when illness becomes advanced and reaches the end of life phase.

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A Whole Systems Approach to Palliative and End of Life Care

2.24 The development, commissioning and delivery of high quality palliative and end of life care services require a whole systems approach. Such an approach considers care systems in their entirety and in relation to each other so that health and social care is planned, designed and delivered across care settings to meet the needs of patients, families and carers. The following Sections 3 - 6 explain how the whole systems approach can be applied.

SECTION 3

Developing Quality Palliative and End of Life Care

- 3.1 Fundamental to the development of high quality care is increasing public and professional awareness and understanding about what palliative and end of life care is and ensuring that those responsible for its delivery have the knowledge, skills and competences necessary to deliver care effectively. Individuals receiving palliative and subsequently end of life care should feel confident in the skills and knowledge of their health and social care professionals and know that their individual expertise is enhanced through good teamwork and the accessibility of 24-hour support.

Raising Awareness and Understanding of Palliative and End of Life Care

- 3.2 One of the main challenges to raising the quality of palliative and end of life care is to increase the understanding of the public, health and social care planners and service providers that palliative and end of life care is an integral part of the wider health and social care system which can support individual choice and improve quality of life for those with life-limiting conditions.
- 3.3 The perception that palliative and end of life care is set apart from other aspects of health and well-being - perhaps seen as a sign of “treatment failure” by clinicians - emphasises how lack of awareness can lead to a negative impression of the potential and value of such care.
- 3.4 Improved public health, medical advances and the successful management of disease have significantly prolonged life expectancy, with the result that increasingly over recent decades we have distanced ourselves from death and dying. Subsequently people are less open or comfortable with discussing death, dying or bereavement with the effect that these are often seen as the last taboos of our society. Increasing the level of public and professional awareness and stimulating discussion around options and preferences for palliative and end of life care will require a cultural and behavioural shift in how palliative and end of life care is perceived and accepted.

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Developing Quality Palliative and End of Life Care

Exemplar 1: Marie Curie Stories: A DVD focusing on how patients and families cope with life-changing events

This offers a valuable observation of real life care encompassing rich narratives from patients and carers. The resource was designed to be used to support training and education for people working in any setting where patients with life-limiting or life threatening conditions are being cared for. It aims to:

- Deepen learners' understanding of the impact of serious illness on the lives of patients and families;
- Detect and understand the communication and information needs of patients and families;
- Increase their knowledge of palliative care and hospice services.

Source: Marie Curie Hospice, Belfast

3.5 For those receiving palliative and end of life care, increased awareness and understanding of the purpose and benefits of such care can provide patients, families and carers with the knowledge and confidence they need to take an active role in decisions about their care. This can include the identification of appropriate services and management of the physical, psychological and spiritual demands of living with a progressive illness. Public awareness of palliative and end of life care should therefore be promoted to increase understanding and counter the negativity that can be associated with it.

Education, Training and Development

3.6 Service improvement within palliative and end of life care is dependent on having a compassionate, skilled, knowledgeable and competent workforce. The importance of flexible and accessible education and training in palliative and end of life care has been repeatedly emphasised at both national and regional level^{21, 22}.

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Developing Quality Palliative and End of Life Care

3.7 Quality assured education and training should be in place to ensure the appropriate knowledge, skills and competences are available within the workforce to enable high quality palliative and end of life care to be planned, delivered and evaluated across all care settings and to inform personal appraisal. Education and training should recognise the diversity of people receiving palliative and end of life care and acknowledge that individuals will have different needs and expectations of care that may be influenced by their background, culture, beliefs and personal circumstances.

3.8 Collaboration between palliative and end of life care service providers and palliative care educators is essential to design effective education and training programmes that meet identified workforce need and promote a culture of continuous professional development. Four areas have been identified as essential for workforce development in palliative and end of life care. These are:

- Communication;
- Assessment of needs and preferences;
- Advance care planning;
- Symptom management of the most common symptoms²³.

Common symptoms can include: pain, nausea & vomiting, agitation, anorexia/cachexia syndrome (ACS), fatigue, and breathlessness.

3.9 To ensure that the associated generic skills are in place to provide quality palliative and end of life care across all care settings, palliative and end of life care should become a core element of all pre-registration, post-registration and clinical education programmes for all health and social care students.

3.10 The White Paper *“Trust, Assurance and Safety – the Regulation of Health Professionals in the 21st Century”* (2004)²⁴, proposes a system for renewal of registration. Communication skills are likely to be an important component of this process. Regulators of all professions will wish to ensure that the skills required for effective and sensitive care are sustained and kept up to date throughout careers.

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Developing Quality Palliative and End of Life Care

Provision of Education and Training

3.11 Education and training in palliative and end of life care can be provided through a variety of media. Professionals who specialise in palliative care for example, are a key resource for providing formal and informal learning to non-specialist colleagues.

3.12 The Hospice movement has also contributed to the advancement of professional development through research and a structured education programme in palliative and end of life care - for example, through the provision of education and training such as the Princess Alice Hospice Certificate in Essential Palliative Care.

Exemplar 2: The Princess Alice Hospice Certificate in Essential Palliative Care available through the Northern Ireland Hospice

This eight week distance learning programme only requires attendance at the introductory session and the final assessment day and currently runs twice each year.

This programme of study and associated assessments aims to:

- Provide participants with an opportunity to demonstrate their ability to develop clinical practice by integrating this with up-to-date and relevant theoretical palliative care knowledge. Particular attention is paid to the holistic patient and family centred nature of palliative care, including grief and bereavement;
- Provide opportunities to participate in supervised, personal and professional reflection about the management of a patient with palliative care needs;
- Develop the ability to change clinical practice in the light of increased theoretical knowledge and personal reflection.

Source: Northern Ireland Hospice

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Developing Quality Palliative and End of Life Care

3.13 Multi-disciplinary and multi-professional learning opportunities should also be developed which build on the inter-disciplinary ethos of palliative and end of life care. This is particularly significant when implementing palliative and end of life care tools such as the Gold Standards Framework²⁵ or the Liverpool Care Pathway²⁶ which are dependent on effective multi-disciplinary teamwork and require robust training, induction and mentorship. In addition, the professional training and accreditation of chaplains, social workers and care home support staff in palliative and end of life care knowledge and skills should also be developed.

Exemplar 3: The Northern Ireland Cancer Network (NICaN) Multi-disciplinary Competency Framework for Adult Palliative and End of Life Care

A Multi-disciplinary Competency Framework for Adult Palliative and End of Life Care has been developed by the Education Work Strand of the NICaN Supportive and Palliative Care Network²⁷. The Framework identifies the competencies required by all health and social care providers and can be interpreted and applied to all disciplines, across public, independent, community and voluntary sectors.

The competencies to be achieved within the Framework are appropriate to all adult populations requiring palliative and end of life care regardless of diagnosis, culture or need. The Framework focuses on delivering two levels of palliative care, generalist and specialist, providing guidance to commissioners, academic institutions, service providers and health and social care professionals with regard to principles of good practice and equitable standards of education and training across Northern Ireland. It provides a robust tool to establish educational standards for generalist and specialist providers of palliative and end of life care. Implementation of this Framework will enable audits of workforce needs with regard to palliative and end of life care education and training.

Source: www.cancerni.net/publications/educationframeworkforgeneralistspecialistpalliativecare

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Developing Quality Palliative and End of Life Care

Exemplar 4: Demonstrating development of multi-professional training

The South Eastern HSC Trust Specialist Palliative Care Team recognised a need for all staff to have an awareness of palliative care. A multi-professional audit of Trust wide palliative care training needs initiated the development of a multi-professional programme of training.

The content included:

- What is palliative care?
- Access to specialist palliative care services;
- Communication;
- User involvement;
- Symptom management;
- Emergencies in palliative care;
- End of life care and bereavement.

This multi-professional training programme has been well attended and evaluated and has become recognised as a core topic for all health care professionals working in the Trust. Each member of the Specialist Palliative Care Team contributes to the delivery of this programme.

Source: South Eastern HSC Trust

Exemplar 5: Palliative Care Link Nurse Programmes

Palliative care link nurses are identified as those with a special interest in the provision of palliative care. A number of link nurse programmes have been established in Trusts across Northern Ireland.

Within Western HSC Trust approximately 40 nursing staff across community, acute, chronic disease managers, rapid response teams and site specific nurses meet every 4 months to share evidence of good practice, to explore issues arising and enhance partnership working for palliative care patients and to enhance knowledge and skills spanning across all care settings. The programme is changing and developing practice e.g. through the production of work relating to care pathways for non-malignant diseases.

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A further link nurse programme targets representation from each of the private nursing homes in the southern sector of the Western Trust. Similar programmes have been developed for social workers and allied health professionals (AHPs). The programmes examine the basic principles of palliative care, the care of the dying pathway, the role of voluntary organisations, social considerations, communication and loss, grief and bereavement.

Source: Western HSC Trust

Specialist Palliative and End of Life Care Education and Training

3.14 Access to advanced education and training is essential to ensure the continuous acquisition of the specialist learning and skills required to support the development of multi-disciplinary specialist palliative care teams. Whilst specialist education is available to doctors and nurses, this will need to be extended where appropriate to incorporate other team specialists e.g. allied health care professionals, social workers, pharmacists, psychologists and chaplains.

Education and Training for Carers, Families and Communities

3.15 It is important to recognise the unique contribution of carers, families and communities which provide valuable services that complement the care provided by paid palliative care professionals. Community based volunteers for example can provide transport, help with cooking, washing and ironing and provide respite to carers as well as companionship and bereavement support.

3.16 As more palliative and end of life care is provided in the community; families, carers and local communities, including volunteers, are essential partners in caring and it is crucial that they have the confidence and competence to take on these roles and responsibilities.

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- 3.17 The level of competence required by families, carers and volunteers will be different in each situation and should be determined by ongoing assessment to identify individual needs and capabilities. Education and support should be available to families, carers and volunteers on an individual and ongoing basis as their needs evolve and in a format and setting that is best suited to them. Programmes are also available which have been developed with life-long learning principles and these should be offered where it is considered beneficial to do so.

Research and Development

- 3.18 Research and development plays a key role in improving palliative and end of life care. Academic researchers, service providers and clinicians should establish partnerships to develop a co-ordinated approach which builds on the existing body of knowledge. The proposed All Ireland Institute for Hospice and Palliative Care is an example of how a collaborative and collegiate partnership might work. Research and development will inform future policy, planning and delivery, drive up quality and improve outcomes in palliative and end of life care. Mechanisms should be in place to ensure research findings are translated into timely and standardised improvements for patients.
- 3.19 A branch of research focusing on transition for young people with palliative care needs moving from children's to adult services should be identified within the overall research programme. There has been a number of studies of disabled young people and those with complex health needs, including several condition specific studies, which have produced findings which have some relevance for young people with palliative care needs²⁸ which could be further developed.

Recommendations

1. Open discussion about palliative and end of life care should be promoted and encouraged through media, education and awareness programmes aimed at the public and the health and social care sector.

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Developing Quality Palliative and End of Life Care

2. The core principles of palliative and end of life care should be a generic component in all pre-registration training programmes in health and social care and in staff induction programmes across all care settings.
3. Mechanisms to identify the education, development and support needs of staff, patients, families, carers and volunteers should be in place to allow person-centred programmes to be developed which promote optimal health and well-being through information, counselling and support skills for people with palliative and end of life care needs.
4. A range of inter-professional education and development programmes should be available to enhance the knowledge, skills and competence of all staff who come into contact with patients who have palliative and end of life care needs.
5. Arrangements should be in place which provide families and carers with appropriate, relevant and accessible information and training to enable them to carry out their caring responsibilities.
6. A collaborative and collegiate approach to research and development should be established and promoted to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care.

SECTION 4

Commissioning Quality Palliative and End of Life Care

- 4.1 High quality palliative and end of life care depends on effective commissioning arrangements which support the development of palliative and end of life care services within the wider public health agenda. These should also build on the creative partnerships and collaborations which already exist between public, independent and community and voluntary service providers both regionally and in local communities.
- 4.2 The role of commissioning is to secure the best possible health and social care within available resources. Driving up the quality and availability of palliative and end of life care so that it is responsive to patient needs and preferences is a key aspect of the health and social care commissioner's role.
- 4.3 Effective commissioning of quality palliative and end of life care will depend on the development of robust service specifications which identify the short and long term objectives of the service to be delivered, define performance and quality standards and specify how they will be measured.
- 4.4 A number of elements make for good quality commissioning of palliative and end of life care including:
 - Effective information systems;
 - Increased personal and public involvement;
 - The development and adoption of care pathways across conditions;
 - Common guidelines for the management of symptoms and situations;
 - Generic palliative care standards within the Service Frameworks for Northern Ireland that set out the standards which will be expected of high quality palliative and end of life care;
 - The adoption of the community-facing integrated service model as described within the regional model for palliative and end of life care²⁹;
 - Performance objectives, including Priorities for Action targets, which set out common methods of measuring quality to ensure services meet what is required;

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- A robust infrastructure to bring patients, families and carers alongside public, independent, community and voluntary sectors and in so doing enable all organisations to work collaboratively to design, deliver and improve palliative and end of life care services.

4.5 These elements are discussed in more detail in the following paragraphs.

Effective Information Systems

4.6 A lack of comprehensive information about the palliative and end of life care needs of non-cancer patients has meant that in the past, care has predominately been planned and responsive to those living with cancer. Improving palliative and end of life care services across all conditions requires that commissioners are informed by, and respond to, individual, community and regional needs, monitored over time by continuous assessment. Information systems should be able to support the collection of qualitative and quantitative data that will inform the evidence base for future commissioning, planning and delivery of services.

Personal and Public Involvement

4.7 Personal and public involvement is based on the principle that effective service user and public involvement is central to the development and delivery of safe, high quality services. Guidance is already in place to support HSC organisations in strengthening and improving service user and public involvement in the planning, commissioning, delivery and evaluation of services as part of their clinical and social care governance arrangements³⁰.

Exemplar 6: Palliative Care Focus Group

The Southern HSC Trust is developing a process of reform and modernisation for palliative and end of life care in response to Priorities for Action targets. As part of this process a focus group was arranged so that the Trust could hear service user stories about their experiences of current palliative care services and use the learning to shape the future services.

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Commissioning Quality Palliative and End of Life Care

Key staff working in palliative care services were asked to recruit service users to participate in the focus group. Eight Service Users and Carers were recruited and the focus group arranged at a time and venue that suited the service users and carers. A flexible approach was used combining patient stories and structured topics.

The following topics were discussed:

- Introduction including: service user and carer involvement, quality and standards, learning to shape services, learning from experience;
- Experience of services in general – positive/negative;
- View of staff roles;
- Expectations prior to discharge (if relevant);
- Empowerment/Self Management;
- Access to services;
- Information/Communication;
- Equipment.

Openness and honesty were encouraged throughout the process.

The findings from the focus group have been collated and a summary report produced to disseminate to all participants which will include key actions to be taken as a result of the information provided by the service users and carers.

Source: Southern HSC Trust

The Development of Integrated Care Pathways

- 4.8 Integrated Care Pathways set out the steps in the care of a patient with a specific condition and describe the expected progress of the patient as their condition progresses. Care pathways aim to support the integration of clinical guidelines into clinical practice whilst also promoting better communication with the patient by giving them information about how their care will be planned and progressed over time.

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4.9 Over recent years the management of chronic conditions has been improved by the development of integrated care pathways across a wide range of conditions; however there is a need to recognise the continuum of palliative and end of life care as a unique and ultimate period within a person's pathway of care. Palliative and end of life care should be integrated within the patient's care pathway so that their care is planned and seamless. The adoption of the Model for Palliative and End of Life Care (outlined in paragraph 2.18) across all conditions can support health and social care planners and providers to identify best expected outcomes for patients, families and carers. The implementation of this Model is considered in more detail in Section 6.

Common Clinical Guidelines for the Management of Symptoms

4.10 Clinical guidelines reflect the evidence base for best practice in palliative and end of life care. They help ensure that consistent and high standards of patient care and experience are in place by providing an expectation of standardisation within particular areas of clinical activity. A regional approach to guideline development is advocated to reduce the duplication of effort and enhance continuity and equity in the commissioning and delivery of care. Clinical guidelines should be multi-disciplinary in their approach and include patient involvement in their development and audit.

Exemplars 7+8: Demonstrating development of regional guidelines

Regional syringe driver prescription chart template for Northern Ireland

A NICaN multi-disciplinary steering group was set up to produce a regional syringe driver prescription chart. As a result of a scoping exercise and two extensive consultations throughout Northern Ireland, three chart templates were produced:

- a regional template for syringe driver prescription and administration chart;
- a continuation chart for primary care;
- a prescription and subcutaneous administration of medicines for breakthrough symptoms for primary care.

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These templates were endorsed by the NICaN Board in February 2009 and were commended by the DHSSPS in June 2009. The templates are offered to primary and secondary care organisations for local approval and implementation.

Implementation of these templates will:

- facilitate safer prescribing and administration through standardisation (healthcare professionals frequently rotate through or work in different locations in primary and secondary care. Patients often move between care settings and localities); and
- facilitate training of appropriate healthcare professionals across Health and Social Care organisations.

Source: NICaN

Regional symptom control guidelines for patients with end-stage chronic heart failure in Northern Ireland

Developed by a regional multi-disciplinary sub-group, the guidelines include criteria by which a professional can decide if the patient's management should include a palliative perspective. Important issues such as advanced planning, bereavement care and the vital role of carers are included. The guidelines aim to promote a seamless service for chronic heart failure patients along the palliative pathway and a more co-ordinated approach with good clear working relationships between health care professionals involved.

Source: Northern Ireland Cardiac Services Network

Generic Palliative Care Standards

- 4.11 The generic standards for palliative and end of life care, developed for disease specific Service Frameworks (set out in Figure 6), focus on identification and assessment of care needs, access to integrated and responsive services, open communication, the management of symptoms and the availability of choice in care provision as essential

SECTION 4

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elements of quality care. Commissioning health and social care against the service standards will drive up the quality of care across all settings by ensuring that the standards become embedded within commissioning service specifications as well as supporting audit systems to monitor quality improvement.

Figure 6: Generic Standards for Palliative & End of Life Care (DHSSPS)

Standard 1	Standard 2	Standard 3
<i>Health and Social Care professionals, in consultation with the patient, will identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver(s) and family.</i>	<i>Patients, carers and families have access to responsive, integrated services which are co-ordinated by an identified team member according to an agreed plan of care, based on their needs.</i>	<i>People with advanced progressive conditions, their caregivers and families, will be informed about the choices available to them by an identified team member, and have their dignity protected through the management of symptoms and provision of comfort in end of life care.</i>

Regional Community-Facing Palliative Care Model

4.12 The generic palliative care standards have informed the development of a regional community-facing model for the delivery of palliative care³¹. This model of care, which was developed under the auspices of NICaN's Supportive and Palliative Care Network, is part of a wider programme of work to reform and modernise palliative and end of life care in Northern Ireland.

4.13 The regional community facing model provides a framework for the commissioning and delivery of care that is centred on the patient, their

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family and carers. The model focuses on the provision of palliative and end of life care within the community underpinned by supportive hospital and specialist provision. The model's core values including equity, respect, empowerment and choice, reflect the principles of the generic palliative care standards as well as the standards set out in "Improving the Patient and Client Experience"³². Six core components form the basis of the model. These are listed below and are incorporated throughout this Strategy:

- Professional and Public Awareness;
- Identification of Palliative Care;
- Holistic Assessment;
- Integration of Services;
- Co-ordination of Care;
- End of Life Care and Bereavement Care.

Priorities for Action Target

4.14 The Priorities for Action (PfA) target for 2009-2011 provides a key vehicle to guide commissioners in the planning of palliative and end of life care services and service providers in how these services should be designed and implemented. The PfA target states that "by March 2011, Trusts should establish multi-disciplinary palliative care teams, and supporting service improvement programmes, to provide appropriate palliative care in the community to adult patients requiring such services". To support the achievement of this target a Regional Service Improvement Manager for palliative and end of life care has been appointed to liaise with the HSC Board and Trusts. All Trusts will be monitored to assess their progress towards and achievement of this PfA target.

Recommendations

7. A lead commissioner should be identified for palliative and end of life care at regional level and within all Local Commissioning Groups.
8. Systems should be in place which capture qualitative and quantitative population needs relating to palliative and end of life care.

SECTION 5

Delivering Quality Palliative and End of Life Care

5.1 Delivering high quality palliative and end of life care requires a mixed economy of care provision with public, independent, community and voluntary sector organisations working together in partnership to provide integrated services such as those set out in Figure 7. Palliative and end of life care services can be delivered either by generalist staff or by staff who specialise in palliative and end of life care.

Figure 7: Examples of care services which deliver palliative and end of life care

- Primary care
- Access to information
- Access to equipment
- District nursing
- Occupational Therapy (OT)
- Personal social care
- Physiotherapy
- Psychological support
- Carer support
- Spiritual and chaplaincy support
- Respite care
- Complementary therapies
- Specialist clinical interventions
- Day care
- Acute medical care
- Pharmacy
- Specialist palliative care
- Financial advice
- Out-of-hours care
- Dietetics
- Ambulance/transport
- Independent sector
- Community and voluntary services
- Speech and language therapy

Often a combination of these services will be delivered through a multi-disciplinary team approach which is drawn around the patient and their carers as individual needs dictate.

Delivering General and Specialist Palliative and End of Life Care

General Palliative Care

5.2 General palliative and end of life care is delivered by multi-disciplinary teams in primary and community care settings, hospital units and wards. This is the level of care required by most people and is provided by non palliative and end of life care specialists including General Practitioners, District Nurses, Allied Health Professionals (AHPs) and Social Workers.

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- 5.3 General palliative and end of life care is also provided by health and social care professionals who have expertise in particular health and social care fields, such as respiratory disease, heart failure, renal disease, neurological conditions and dementia. Experts within these conditions are pivotal in recognising when palliative and end of life care is needed.
- 5.4 Generalist staff should have access to palliative and end of life care education and training that will allow them to understand and apply the principles of high quality care. They should also have access to specialist palliative care advice and services, for example, if a patient's condition exacerbates. Often a collaborative approach, such as multi-disciplinary team meetings or informal discussions, will enable mutual learning and a sharing of knowledge and experience between professionals and specialties.

Exemplar 9: Demonstrating shared learning across speciality areas to meet the needs and priorities of an individual

Traditionally, the approach applied to people with a learning disability who had palliative care needs was ad hoc, with crisis intervention being the 'norm'. Palliative care was usually applied only to those who had aggressive cancers, the majority of whom were nursed and died elsewhere despite institutions like Muckamore Abbey Hospital being their long term place of residence.

In the recent past, an individual was transferred to the local acute sector hospital for investigations and a diagnosis of cancer was made. The family requested that she be nursed in her own ward in Muckamore Abbey Hospital where she had resided for many years. Relationships were quickly established with the Belfast HSC Trust, Oncology and Palliative Care Team, who provided clinical support and training around end of life issues including management of pain and syringe drivers. This approach enabled staff from Muckamore Abbey Hospital to provide high quality patient-centred care which led to the patient's dignified death in the place most familiar to her and with people she recognised and trusted.

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Learning gained as a result of this patient episode across the learning disability and palliative interface has served as a catalyst for a number of service development projects. These initiatives are aimed at highlighting the palliative care needs of this very vulnerable population and enhancing the education of the multi-professional teams across specialties. Encouraging and supporting a collaborative approach which embraces the knowledge and skills of each specialty involved ensures patients with learning disability receive the highest standard of palliative / end of life care possible.

Source: Belfast HSC Trust

Specialist Palliative Care

- 5.5 Specialist palliative and end of life care is the management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. This is provided by specialist personnel with expert knowledge, skills and competences³³. It is delivered by specialist multi-disciplinary teams dedicated to palliative and end of life care. The responsibilities of specialist palliative care professionals will include the physical management of pain and other symptoms and the provision of psychological, social and spiritual support to individuals and their families.
- 5.6 Membership of specialist palliative care teams should include doctors, nurses, pharmacists, allied health professionals as well as non-clinical members such as social work staff, chaplains, counsellors and volunteers. This will enable patients to achieve their optimum quality of life through holistic support and rehabilitation. Sharing knowledge and expertise across conditions with other specialist and generalist colleagues, including training and development opportunities, should be a central element to their role.

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Delivering Quality Palliative and End of Life Care

5.7 Specialist palliative care is provided in four main ways:

- Inpatient hospice and specialist palliative care units (Northern Ireland has 4 adult hospices);
- Hospital – based services, where multi-disciplinary palliative care teams work with patients in wards and clinics;
- Community teams, which provide specialist advice and work alongside a patient's own GP practice teams enabling specialist care to be provided in the patient's home or care home;
- Day care, which enables patients to continue living at home while having access to day facilities provided by a multi-disciplinary health and social care team.

Palliative and End of Life Care – The Adoption of a Case Management Approach

5.8 Designing a system for the delivery of proactive care for people with palliative and end of life care needs is challenging. One response to this is the adoption of a case management approach. Case management provides a more intensive level of symptom management and clinical support to the most vulnerable patients with chronic conditions, helping people to be cared for in their own homes and enabling them to experience a better quality of life. Increasingly people with chronic conditions receive palliative care as an integral part of their case management arrangements.

5.9 Patients with chronic conditions may need care to be sustained over many years and across organisational and professional boundaries. It is important from the perspective of the individual, their family and carers that care is co-ordinated and does not become fragmented, confusing and overwhelming, with different people responsible for different parts of care. The development of the case manager role has sought to address this and shapes and informs the role of the key worker in end of life care.

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The Role of a Key Worker in End of Life Care

- 5.10 As complexity and/or decline become apparent, the need for care to be planned, organised and delivered, often across care settings, will require significant co-ordination. The role of a key worker is therefore crucial.
- 5.11 The key worker is an identified individual with responsibility for planning and co-ordinating patient care across interfaces, (including within and between care teams), promoting continuity of care and ensuring that the patient and health and social care staff know how to access information and advice. The role of the key worker will be to:
- Provide practical and emotional support to the patient and family;
 - Provide a point of contact to the patient;
 - Act as a patient advocate up to and including the end of life as appropriate;
 - Co-ordinate the end of life care journey and, where appropriate, ensure interventions take place in a timely fashion;
 - Provide information, where appropriate, and ensure that it is timely and tailored to the individual's needs and understanding.
- 5.12 The key worker is likely to be identified from the existing team e.g. General Practitioner, Community Nurse, Specialist Nurse (palliative or condition specific), Social Worker, AHP or other appropriate person. The key worker may change over time depending on the nature and complexity of the condition and the disease/decline trajectory. It is important that patients, carers and families are engaged in the decision when key workers are identified.
- 5.13 Key workers should have role-specific training to help them perform this co-ordinating role. Although the identified key worker may change over the course of the individual's illness, it is important that where there is a change in personnel this is managed sensitively involving the patient, their family and carers.

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A Care Pathway Approach for Transitional Care for Young People

- 5.14 The concept of a care pathway approach to care is a feature of how quality care can be provided to children and young people with life limiting conditions.
- 5.15 The Association for Children's Palliative Care (ACT) *"Transition Care Pathway"* (2007), *"NICE Improving the Outcomes for Children & Young People with Cancer"* (2005) and DoH *"Better Care, Better Lives"* (February 2008) offer frameworks through which services can be organised and integrated to provide a seamless transition from Children's to Adult services for young people with life-limiting or life-threatening conditions. It is critical that Children's and Adult services are proactive and engaged as early as possible in the young person's journey. ACT has appointed a Transitions Co-ordinator for Northern Ireland whose responsibility it is to drive forward the implementation of the Transition Care Pathway, ensuring that providers and commissioners from both children's and adult services are supported and actively engaged. The Northern Ireland Co-ordinator works closely with the Regional Inter-agency Implementation Group on Children with Complex Health Needs.
- 5.16 A report *"Developing Services to Children and Young People with Complex Physical Healthcare Needs"* was launched by the Minister for Health, Social Services and Public Safety in 2009. The report also launched the *"Integrated Care Pathway for Children and Young People with Complex Physical Health Care Needs"* which includes end of life care. In Northern Ireland the Community Children's Nursing Service has responsibility for the co-ordination and implementation of the Integrated Care Pathway on a multi-disciplinary basis within Health and Social Care Trust areas. A copy of the report can be found on the Department's website at: www.dhsspsni.gov.uk/complex_needs_report.pdf.

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Case Study 1: Transitional Palliative Care

Simon, a teenager with Spinal Muscular Atrophy (SMA) acknowledged that he didn't want to remain in children's services but felt daunted by the move to the unknown; he stressed; "I'm not a child, neither am I an adult, as far as health services are concerned I'm in 'Limbo'". Simon has a tracheostomy, severe scoliosis, uses nocturnal non-invasive ventilation, is unable to walk and has very poor dexterity due to muscle wasting, he has a portacath for iv antibiotic therapy (as required) is emaciated and has poor appetite and complains of acute and chronic pain and severe fatigue. He is dependent for all areas of care, is studying for his 'A' Levels and enjoys a social life. His nominated key worker was the Children's Hospice Nurse Specialist (CHNS), Simon and his parents as well as professionals from children's and adult services were involved from the outset in the transition process. Starting early meant that the professionals from the adult services had an opportunity to meet Simon, understand the support he required, develop relationships with him and his parents and learn more about his condition. Simon's parents needed to understand that he was starting to make the decisions about his care. The children's service professionals needed to support the family and their adult colleagues through and beyond the transition process.

Today Simon is almost 19, his entire home care package is provided through adult services and the Independent Living Fund, he and his parents are very happy with the support they receive and although they still fear hospital admissions; 2 recent life-threatening episodes were managed at home.

Source: NI Hospice, Belfast

Managed Clinical Networks (MCNs)

- 5.17 MCNs seek to bring together multi-professional, multi-disciplinary and cross-boundary staff (including doctors, pharmacists, nurses, health visitors, physiotherapists and occupational therapists), organisations from primary, secondary, voluntary and independent care, as well as patients, families and carers, to ensure the development of high quality effective and equitable services.

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- 5.18 At a time when increasing numbers of people are living and dying with chronic disease, identified ownership and leadership of palliative and end of life care has never been more important. As a Managed Clinical Network, the NICaN Supportive and Palliative Care Network has already been a key driver in progressing the quality of palliative and end of life care in Northern Ireland by bringing together the expertise of a range of health and social care planners and providers to identify improvements in how palliative and end of life care can be delivered. The Supportive and Palliative Care Network currently sits within the NI Cancer Network, however it has sought to engage and encompass interest and membership from across a range of chronic conditions.
- 5.19 Palliative and end of life care has been recognised as particularly suitable for a managed clinical network approach because it is delivered in a broad range of care settings by a wide spectrum of healthcare professionals, and requires good communication and co-operation. A network approach offers economies of scale, value for money and a more robust approach to governance and allows key tasks to be undertaken at network level rather than Trusts working independently to produce the same outputs.
- 5.20 The successful delivery of, among other outcomes, the service framework standards and the PfA target will require continued effective regional co-ordination that will bring together expertise across a broad range of supporting work strands, which include workforce and education, research and development, service planning, service improvement, governance and audit. To deliver on any of these strands in isolation will not be sufficient and the breadth of work required can best be delivered through a network approach.

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Recommendations

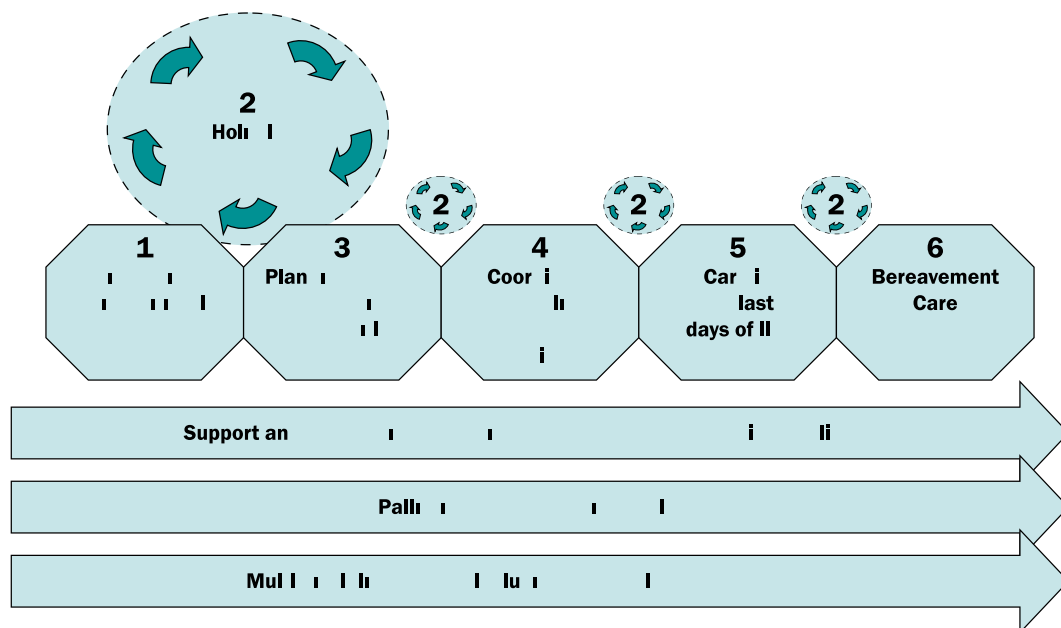
9. Each patient identified as having end of life care needs should have a key worker.
10. Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services with no loss of needed service experienced as a result of the transfer.
11. The potential for a Managed Clinical Network should be explored to ensure leadership, integration and governance of palliative and end of life care across all conditions and care settings.

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6.1 Section 2 introduced a *Model for Palliative and End of Life Care*. The care model illustrated in Figure 8, is an overarching system of care which has been informed by the regional community-facing model (outlined in para 4.12 and 4.13) and defines a number of key steps which, when implemented effectively, support the delivery of quality palliative and end of life care. This concept of a continuum of care allows for the alignment of integrated clinical pathways, evidence based practice tools, triggers and standards.

Figure 8: A Model for Palliative & End of Life Care



6.2 The recognition that treatment intent is shifting from curative to palliative focuses treatment and care on the needs of the individual and their family and carers and the best management of disease or symptoms. Whilst there may be variation in individual experiences of illness and disease trajectory, the key steps within this Palliative and End of Life Care Model support the provision of high quality care across a wide range of conditions. Steps 1 to 4 are applicable to all patients with early identified palliative care needs. Steps 1 to 6, spanning the whole model, encompass the complete palliative and end of life care journey.

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- 6.3 The Palliative and End of Life Care Model as a vehicle for delivering quality care is considered in more detail below.

1

Discussion and Identification of Palliative and End of Life Care

- 6.4 Recognising and talking about what matters is important for most people and there is increasing evidence of partnership working between individuals and health and social care professionals in discussing palliative and end of life care needs and how to respond to these. This includes recognition of the impact of the condition on the individual and their family and carers. In shared decision-making, professionals communicate the evidence of what is known about a condition whilst recognising the expertise of the patient in experiencing it and in bringing to the discussion information about what is most important and practical to them in their situation. Importantly some patients may choose not to enter into such conversations and where this is the case this should be respected, although it should not compromise the offer of services which best respond to apparent needs.
- 6.5 All health and social care staff who may need to initiate discussions about the need for palliative and end of life care should have the necessary knowledge, skills and competency to do so sensitively. Training in communication skills, such as Breaking Bad News³⁴ or advanced communication skills training, is fundamental to this.

Case Study 2: A Patient's Story

Emma was a 37 year old lady, married with a two year old daughter. She had advanced colorectal cancer which had spread to her liver with associated complications. Emma had not appreciated the extent of her illness and the specialist palliative care team was asked to review her symptoms. The next morning her symptoms had improved enough for her to talk about her illness and piece together “where she was with her illness” like a jigsaw. She had always wanted to be at home to die when the time came, but had not appreciated that she was so ill. The specialist palliative care team had further

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discussions with her husband, the General Practitioner, the ward staff, and the district nurse and she was discharged home the next day with community care support. She died at home comfortably two days later.

Source: A patient's story

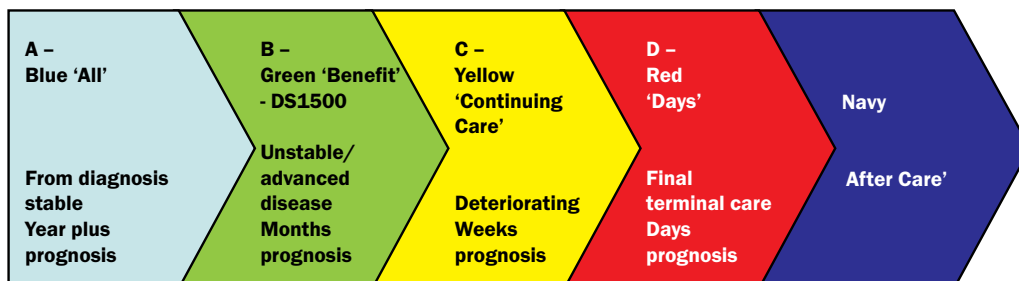
- 6.6 When a person has been identified as requiring palliative and subsequently end of life care, this information should be shared (with the permission of the patient) with those immediately involved in the ongoing care and support of the patient, family and carers to ensure that all those concerned have a shared understanding and consistency in their approach. This requires protocols for communication across care providers and care settings.
- 6.7 Communication flow across care settings is crucial for high quality palliative and end of life care services but is an area that requires considerable development. Palliative care registers, which list identified patients, draw attention to individuals, families and carers who may require additional support and prioritisation. Such systems are already in place within most primary care practices and should be extended to include patients with non-cancer palliative care needs. Primary care Information Communication Technology (ICT) systems however are not always compatible with Trust and other ICT systems. Where this is the case however, the information held on a palliative care register should still be accessible to care providers and should also be available to all out-of-hours and ambulance services to improve communication outside normal hours.
- 6.8 Needs coding provides a mechanism to enable a whole systems approach to enhancing palliative care registers. Colour coding charts and/or records can help highlight the potential and actual needs of individuals. This can enable care providers to plan for care needs in the short and longer term, based on an assessment of the condition of the patient at any given time. Figure 9 shows an example of such a coding system based on considering if the clinicians would not be surprised if the patient were to die within the next 12 months. It prompts the

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clinician to think about appropriate access to benefits or increasing levels of care needs as the patient's condition deteriorates and recognises the importance of bereavement support.

Figure 9: Needs based coding – using the ‘surprise question’ to predict main areas of need and support required



For further information - <http://www.goldstandardsframework.nhs.uk>

2 Holistic Assessment

6.9 A key feature of the Model for Palliative and End of Life Care is an ongoing holistic approach to needs assessment. A holistic assessment of need goes beyond the physical needs of the individual. It will include the social, mental health and emotional and spiritual well-being of the patient, their family and carers, as well as recognising other issues that might impinge on wellbeing, such as financial and legal concerns. Following the diagnosis of a life-limiting condition, recurrent holistic assessment of need can determine the level of palliative or end of life care required, including the need for onward referral which may be necessary during the course of the individual's condition e.g clinical psychology, occupational therapy.

Assessment of Patient Needs

6.10 The holistic assessment of a patient's needs can be supported through the use of assessment tools such as the Northern Ireland Single Assessment Tool (NISAT)³⁵ and the NICaN Holistic Palliative Care Assessment Tool³⁶ (currently being piloted). Whatever methodology is

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used for needs assessment, staff should be appropriately trained in the use of such assessments and be competent to complete them with sensitivity. In undertaking holistic needs assessments, staff should take account of any particular circumstances such as special needs, culture or language.

- 6.11 The Michael Report, (2008)³⁷ reminds generalist and specialist palliative care services of their statutory obligations under the *Disability Discrimination Act (1995)*³⁸ to make ‘reasonable adjustments’ to ensure that equitable care and treatment are being delivered. This may mean making adjustments in relation to communication of information to and from people at all stages of the care process, in particular during assessment of need and adjustments in relation to the process of obtaining and recording consent to treatment and care.
- 6.12 When completed, the holistic assessment will form the basis of an individualised patient-centred care plan, agreed with the patient and aimed at planning and delivering care that best meets their capacity/ circumstances and requirements.
- 6.13 Regular review and consistent recording of needs are imperative, especially when the patient’s, their family’s or carers’ wishes or circumstances change. A number of triggers can prompt the initial identification, assessment and recording of palliative and end of life care needs and indicate how these should be addressed and reviewed. These may include:
- Diagnosis of a progressive or life-limiting condition;
 - Critical events or significant deterioration during the disease trajectory indicating the need for a “change of gear” in clinical management;
 - Significant changes in patient or carer ability to “cope” indicating the need for additional support;
 - Prognostic indicators;
 - The surprise question (clinicians would not be surprised if the patient were to die within the next 12 months);
 - Recognition of the last days of life when death is expected³⁹.

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Exemplar 10: SAGE & THYME: A model for training health and social care professionals in patient-focused support

Developed by a multi-professional group, the model consists of 9 steps to enable staff of all grades and roles to facilitate patients to describe their concerns and emotions if they wish to do so, to hold and respect those concerns, identify the patient's support structures, and explore the patient's own ideas and solutions before offering advice or information.

Source: Patient Education and Counselling (July 2009), NHS Improvements

Assessment of Family and Carer Needs

- 6.14 Family and friends have traditionally been crucial to the provision of palliative and end of life care. The unpaid care they provide includes help with dressing and bathing, domestic tasks like shopping and cleaning, emotional support, transport and help with medications.
- 6.15 Families and carers will often have their own needs. Use of the holistic NISAT carers assessment tool will help ensure that their needs are identified, recorded, addressed and reviewed. This may include sign-posting families and carers to information and advisory services, for example, Citizens Advice Bureau. Where respite care is identified as a need for family or carers this should be accessible through a variety of ways including within the patient's home or care home, in a community hospital or within hospices. Respite care should be flexible in its accessibility, age appropriate to the patient and available irrespective of condition. It offers carers valuable and necessary independent time and patients the opportunity to experience a change of environment and stimulus.
- 6.16 The *Carers and Direct Payments Act (Northern Ireland) (2002)*⁴⁰ imposes a legal requirement upon the Health and Social Care Services to advise carers of their statutory right to an assessment of their needs. In response to an assessment, HSC bodies are empowered, within local priorities and available resources, to provide a range of services directly to carers to help them in their caring role. The legislation also brought

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carers within the scope of Direct Payments, which can be made in lieu of service provision to meet assessed care needs.

Exemplar 11: Northern Ireland Hospice Carers' Service

This service for carers provides practical information and advice and offers companionship and support to reduce exhaustion and loneliness. It also offers complementary therapies which can reduce stress and anxiety.

The Hospice run a 6 week support programme providing the opportunity for carers of palliative patients to come together for one evening per week on 6 consecutive weeks. The programme is tailored to the needs of each specific group. It generally covers the following themes:

- Finances and benefits evening with general overview and one to one time with a financial advisor;
- Symptom management, what to look out for, what services are in place to help people manage if they are caring for someone at home, what medications are usually used, etc;
- Pamper evening with complementary therapists and information to help carers look after themselves;
- Coping strategies, how and when to have those difficult conversations around death and dying, or funeral arrangements, spirituality, communication.

The programme provides an opportunity to socialise and cement supportive relationships.

Source: NI Hospice

Spiritual Needs and Care

6.17 Identifying and addressing the spiritual needs of individuals, families and carers is an integral part of holistic care. At the end of life stage however, religious and spiritual needs may have a heightened significance and every opportunity should be made to respect and facilitate these

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individual needs. Chaplains and spiritual care providers will often have a key role to play within the palliative care team at end of life stage and it is important that they are sensitive to and competent in the skills necessary for providing spiritual care to individuals, their families and carers as well as to staff who may be in need of support.

Exemplar 12: NHS Fife Spiritual and Pastoral Care

NHS Fife has a dedicated hospital chaplaincy service which can follow up patients after discharge from hospital into the community if needed. Although not specialised in palliative care, the chaplains are an integral part of the specialist palliative care team, have flexible role boundaries and view their service as providing pastoral, emotional, psychological and spiritual support as needed by patients and families. They are on call via pager 24-hours a day. The chaplains provide support for staff on a one-to-one or group basis as needed, for example, if ward staff have faced a series of deaths or a particularly difficult death. They also provide training courses for staff on topics such as breaking bad news and bereavement support.

Source: Audit Scotland

3

Planning Palliative and End of Life Care across Care Settings and Conditions

- 6.18 Care planning can help people exercise choice by working in partnership with health and social care professionals to improve the effectiveness of their care through a planned and structured system. This partnership in planning should seek to balance recognised preferences and requirements for care, with a respect for safety, effectiveness and achievability.
- 6.19 Accessible information is essential to support meaningful patient and carer involvement in developing an individualised plan of care which considers available options and reflects and records preferences in light of these. Patients, their families and carers should therefore have access to timely, accurate and consistent information provided in a way

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that helps them understand the nature of their care, reduces anxiety and allows participation in planning how their care will be delivered. Information sources should also provide the vital signposting to services and options, including financial and other assistance, that can help meet the needs of the individual, their family and carers. Further consideration should be given to how a whole systems approach can be maximised to support better communication and information transfer.

Exemplars 13 + 14: Showing information and signposting systems

Information pathway for people with advanced disease

The NICaN Patient Information Programme seeks to bring regional teams of health and social care professionals together with patient and public involvement representatives to identify the information resources currently used and the gaps which exist. An information pathway for advanced cancer has been developed and contains many references to palliative and end of life care.

Source: NICaN

www.pallcareni.net

This is a website dedicated to palliative and end of life care in Northern Ireland. It will be a resource for all patients with palliative care needs and those providing their care. Developing the content for the site has required engagement with a wide variety of providers across the province and clinical speciality areas.

Source: NICaN

Preferred Priorities for Care

6.20 The Preferred Priorities for Care⁴¹ (PPC, formerly Preferred Place of Care) is a patient held record that can support the planning of care delivery by identifying, recording and respecting an individual's preferences and choice regarding how and where their care is provided. Documenting and sharing information about preferences for care across care settings

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can help ensure that plans of care are implemented effectively and can prevent unnecessary crises, for example, in situations where a patient's condition deteriorates outside normal working hours. Effective and recorded planning for out-of-hours care, including anticipatory prescribing over weekends and bank holidays, ensures that the individual, their family and carers can have confidence in the continuity of the services that wrap around them.

6.21 Improving the pre-planning of care is one of the most important ways in which person-centred care can be achieved and communication and decision-making between clinicians and patients made more effective. The development of an individualised care plan may also include elements of advance care planning around issues such as resuscitation and organ donation. Consistent and clearly communicated Do Not Attempt Resuscitation (DNAR) policies across all care settings can support decision-making and improve care planning for clinicians, patients, families and carers.

6.22 A DNAR order applies only to Cardio-Pulmonary Resuscitation (CPR) and does not imply that other treatments will be stopped or withheld. Staff must make clear to patients, people close to the patient and members of the healthcare team that all other treatment and care which provide overall benefit for the patient will be continued.

Direct Payments Scheme

6.23 The Direct Payments Scheme can support a more flexible approach to planning and purchasing social care services. It facilitates the proactive involvement of the individual, their family and carers, and enables them to make their own decisions about how their care and support is shaped and delivered. The scheme allows cash payments to be made in lieu of social services provision to individuals who have been assessed as needing services. Commissioners and providers may wish to consider how direct payments can be better used.

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4

Co-ordinating and Delivering Palliative and End of Life Care Across Care Settings

6.24 It is not uncommon for a patient to move between services and care settings as their condition progresses, or indeed to be utilising services simultaneously from different care providers. The seamless delivery of appropriate palliative and end of life care at all stages, and in all settings, during the patient's illness requires an integrated and co-ordinated approach to care.

Exemplar 15: A nurse liaison project

As part of palliative care development within the South Eastern HSC Trust, the Trust set up a palliative care nurse liaison project to assist with complex palliative care discharges from hospital. The project currently focuses on patients within the Ulster Hospital and the North Down and Ards Community Hospital.

The purpose of the palliative care liaison nurse as outlined in the Cancer Service Strategic Plan 2008 – 2013 (South Eastern Health and Social Care Trust, 2008) is to:

- Ensure that the care of patients is co-ordinated and streamlined to provide timely discharge, facilitate preferred place of care and patient choice for end of life care and prevent unnecessary re-admission to hospital;
- Reduce the need for unnecessary outpatient follow up appointments in hospital;
- Facilitate liaison and linkage of all teams within primary care thus ensuring appropriate discussion and implementing efficient and effective discharge planning;
- Provide education to enhance generalist palliative care.

The liaison nurse meets the patient and their family or carer in the acute setting, ensures that the discharge plan is in place prior to discharge, establishes links with the primary care team and undertakes a follow up visit, if deemed necessary. Primary care teams can access the liaison nurse for

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clarification regarding follow up appointments and current treatment options in order to support primary care advanced care planning.

Source: South Eastern HSC Trust

- 6.25 One way of facilitating seamless delivery of care is through the use of a patient passport. A patient passport is the person's own document, designed to provide vital information about the individual which would instantly be of help to health and social care professionals and other agencies. Its purpose is not only to reduce the repetitive questioning over personal details, but also to highlight information with regard to medications or details about any open access to support and advice from services which the person is known to, including hospital, hospice or own GP.
- 6.26 Palliative and end of life care services should be effective in meeting the needs of patients, families and carers. This is dependent on developing integrated services that work together and are delivered in a seamless and consistent way. To achieve this requires a robust knowledge of the services themselves, good communication and the thoughtful planning of how services can best be delivered both within organisations themselves and in partnership with other providers. The role of a key worker is crucial in ensuring the co-ordination of care services across interfaces and between normal working hours and out-of-hours.
- 6.27 Co-ordinating the care of individuals at the end of life, and that of their families and carers, means ensuring that integrated services are provided in a timely and organised way. This is necessary at several levels (DOH, 2008):
- Co-ordination within an individual team, e.g. within the primary care team;
 - Co-ordination between teams working within a single environment, e.g. heart failure team and specialist palliative care team within a hospital setting;

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- Co-ordination across organisational boundaries e.g. when an individual moves between hospital and care home.

Exemplar 16: Integrated Services: Dedicated transport – Palliative Care Ambulance (Leeds)

These vehicles ensure that palliative care patients can be discharged quickly, safely and in comfort – without facing long delays and missing the opportunity to return home in accordance with their wishes.

Source: Marie Curie, Delivering Choice, Leeds

Co-ordinating 24/7 Palliative and End of Life Care

6.28 To enable people to be cared for and ultimately to die in their place of choice, essential medical and nursing services should be further developed and accessible in the community on a 24/7 basis for all who need them (NICE 2004). Essential services can include:

- Nursing services (e.g. visiting and rapid response services to the patient's home, including care home);
- Medical services;
- Social care services;
- Access to medication and pharmacy services;
- Access to equipment;
- Access to Ambulance services;
- Access to AHPs;
- Access to spiritual support
- Access to specialist palliative care teams.

6.29 These services should be available in a way that allows the patient to be assessed and their needs addressed out-of-hours as necessary. Co-ordination of care also requires timely information flow between interfaces. This is particularly significant when the patient's condition and needs may be actively changing, requiring out-of-hours support or discharge from one care setting to another.

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Exemplar 17: Marie Curie Cancer Care Delivering Choice Programme,
Lincolnshire - Rapid Response Team (RRT)

The unavailability of 24 hour planned cover for patients and carers was identified as a major barrier to the provision of home care. The RRT provides twilight and out-of-hours nursing care for patients with palliative care needs, their families and carers at home. Team members make planned and emergency visits as well as providing support and advice over the phone. The Team also liaises with other care providers, Out-of-Hours (OOH) Teams and the Palliative Care Co-ordination Centre to ensure provision of an integrated service, provide specialist night support where night care is unavailable, and maintain and transfer patient information as appropriate. The Team provides a service 7 days per week during the twilight and out-of-hours period.

“Having the Rapid Response Team come was like someone throwing a lifebelt”

Source: Marie Curie, Delivering Choice, Lincolnshire

Exemplars 18, 19 + 20: Demonstrating service improvements

Enhanced Palliative Care Service in the Northern HSC Trust

The enhanced palliative care service was implemented in December 2008 and is fully operational across the Trust. The service is composed of 18 whole time equivalent senior Health Care Assistants (HCA), providing cover from 8am - 11pm, 7 days per week. The service is delivered in partnership with Marie Curie, which employs and manages the HCAs. The HCAs are aligned with core district nursing services which co-ordinate and supervise workloads. The HCAs provide all aspects of care to patients and support families who are caring for palliative patients at home. This initiative enables greater patient choice for those who choose to die at home. The service has retained the flexibility to respond quickly to patients, families and carers and to be utilised in partnership with core district nursing and domiciliary care providers to ensure that the needs of the patient, their family and carers are met.

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The service has proved invaluable within a short period of time with feedback from users extremely positive.

Source: Northern HSC Trust

Palliative Care Beds in Statutory Residential Facilities within South Eastern HSC Trust

The South Eastern HSC Trust has introduced primary care led palliative care beds located in two residential facilities for older people. This new initiative has enabled the Trust to support patients with palliative care needs close to their own community. Advance care planning discussions, which have included the residents' views regarding their preferred place of care, have prevented unnecessary admission to hospital or hospice. Patients' care is provided by their own GP and district nursing services and supported by the community palliative specialists.

Training of staff in relation to palliative and end of life care has enhanced the service delivered to the palliative resident.

Source: South Eastern HSC Trust

Out-of-Hours Toolkit Macmillan <http://learnzone.macmillan.org.uk>

This is a resource for professionals bringing together numerous examples of good out-of-hours practice for palliative care patients. The education chapter of the toolkit is a useful resource for professionals interested in elevating the standards of Generalist Palliative Care in the out-of-hours setting.

Source: Macmillan

Gold Standards Framework (GSF)

6.30 Best practice guidelines, such as the Gold Standards Framework⁴², enable generalist care providers to deliver high quality and integrated palliative and end of life care to patients through improving anticipatory

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care, discharge planning, co-ordination and provision of palliative and end of life care. Originally designed to support the delivery of palliative and end of life care by primary care teams, the GSF has since been developed for use within care homes and hospices. Piloting of the framework within hospital and prison settings has demonstrated that the GSF clearly supports the integrated, whole systems approach which maximises cross-boundary working between home, hospitals, hospices and care homes and improves the co-ordination of care services.

6.31 Resulting research and audits of the use of the GSF have demonstrated:

- a greater awareness of patient need and a more proactive approach to care;
- better organisation, consistency and communication;
- reduced hospitalisation i.e. fewer crisis hospital admissions;
- increased occasions of death within the patient's preferred place of care.

6.32 The use of the GSF can assist the early identification of patients with palliative and end of life care needs, effective communication and teamwork, early symptom management and proactive/anticipatory health care planning.

6.33 Mechanisms should be put in place to enable best practice tools such as the GSF to be implemented; for example, nurses who play a central role within the co-ordination and delivery of generalist and specialist palliative care should take a lead in initiating and co-ordinating quality palliative and end of life care across care settings and disciplines.

Exemplar 21: Role of the community heart failure nurse in palliative and end of life care

The aim of the Community Heart Failure Specialist Nursing Service is to maintain patients at home by optimising their medications, controlling symptoms and thereby improving their quality of life.

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As the patient's condition deteriorates the main priority is to keep the patient as comfortable as possible by controlling their symptoms and providing support to the patient, their family and carers. The Heart Failure Specialist Nurses may involve others such as the multi-disciplinary palliative care team, district nursing and General Practitioner as necessary, for advice and support.

Source: Belfast HSC Trust

Case Study 3: The role of the respiratory nurse in palliative and end of life care

Mary is a 65 year old lady with severe COPD who lives alone in North Belfast. She has been known to the respiratory specialist team for the past 5 years, originally referred for pulmonary rehabilitation. She has had a few admissions to hospital over this time and has been case managed for the last 2 years. A year ago she was assessed and needed to be started on long-term oxygen therapy.

Following an admission earlier in the year which necessitated Mary receiving non-invasive ventilation due to the severity of her exacerbation, she has become increasingly more breathless which has resulted in her being less mobile and more anxious. Her daughter has also expressed concerns about her mother's deterioration.

The respiratory nurse specialist recognised the significance of this deterioration and after considering the Gold Standard Prognostic Indicators, felt that she needed to complete a holistic assessment of Mary's palliative care needs. This was discussed with both Mary and her daughter and Mary was given the opportunity to speak about her concerns which were clearly contributing to her terrible anxiety.

The respiratory nurse presented Mary's case at the multi-professional respiratory team meeting and other members, who also knew Mary,

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contributed to the assessment and the plan for her ongoing management. This included a review and optimisation of her medication for better symptom control. Referrals to social services and Occupational Therapy (OT) were made because she expressly wished to stay at home. A carers' assessment was offered to Mary's daughter and whilst she indicated that she didn't want any additional help at this stage, she would think about this in the future.

The respiratory nurse made contact with the GP and the Hospital Respiratory Team to ensure they were aware of the situation. She also asked if the GP would do a joint visit with her, to ensure continuity in the communication, information and treatment plan. The District Nursing Service was informed of Mary's condition. Mary will continue to be visited weekly by the Respiratory Team and has their contact details and those of the 24 hour team for out-of-hours support if required.

Source: Belfast HSC Trust

Quality and Outcomes Framework

6.34 Co-ordinating care within the primary sector has been further supported by the Quality and Outcomes Framework (QOF). The QOF, developed under the auspices of the new General Medical Services (GMS) contract, incorporates some components of the GSF and involves the establishment of a palliative care register within GP Practices and regular multi-disciplinary team meetings to discuss the planning and delivery of care for patients who are recorded on the register.

Medicines Management in Palliative Care

6.35 Good palliative care medicines management arrangements will provide safe, convenient and effective access to the right medication at the right time. A proactive approach should be taken whereby patient symptoms and needs are regularly reviewed and changes in treatment plans anticipated in advance, thereby providing the necessary assurance that treatment and advice are readily available when needed. Such an approach can reduce the potential for uncertainty and undue delay.

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6.36 Medication used in palliative and end of life care for all patients in the community should be accessible and available both in and out-of-hours and the role of the community pharmacist is key in this respect. Standards of good medicines governance should be in place, including records of clinical decisions and the delivery/collection of palliative care drugs as guided by the Fourth Report of the Shipman Inquiry⁴³.

Case Study 4: Community Pharmacist

Paula, a 53 year old lady was diagnosed with pancreatic cancer, she was understandably devastated by the diagnosis and had very little family or community support. She had attended one community pharmacy all of her life and had built up a good relationship with the pharmacist. The pharmacist knew her very well, in part of Paula's history of drug and alcohol addiction which meant they dispensed her medicines on a weekly basis. On discharge from hospital the first place Paula visited was her community pharmacy. She was completely confused and bewildered with the complex new medicine regime she had been given. The pharmacist spent two hours talking with Paula, explaining all her new medicines and contacted the hospital in an attempt to have the regime simplified. Eventually a final regime was agreed with Paula's hospital team, this simplified regime involved Paula taking 69 doses of medication every single day. The pharmacist offered to prepare the medicines for Paula in a pill box and she delivered the pill box weekly to Paula's home. During the pharmacist's visits as Paula's condition deteriorated, she checked that Paula seemed physically and mentally fit to manage the administration of her medicines. As her condition progressed the pharmacist contacted the nursing team to express her concerns and the team managed to organise a carer to help Paula with the administration of her medicines, the pharmacist counselled the carer on Paula's medicines to ensure she understood the regime. The pharmacist continued to visit Paula weekly providing advice and support as needed until sadly she passed away two months later.

Source: Pharmaceutical Contractors Committee (NI) Ltd

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5

Care In The Last Days of Life

- 6.37 When a patient has been identified as having entered the last days of life, it is vital that they continue to receive a high standard of care which is structured and focused on ensuring good symptom and comfort management and that appropriate support mechanisms are in place for their family and carers at this difficult time.
- 6.38 Unless death occurs suddenly or unexpectedly, the last days of life have recognisable features and require professionals to re-appraise the use of treatments in order to achieve symptom control.
- 6.39 Best practice guidelines for care in the last days of life, such as the Liverpool Care Pathway for the Dying Patient, can help ensure that individuals who have entered their final days and hours are cared for with sensitivity in a planned and structured way and with good communication between care providers themselves and with the patient, family and carers. It is appropriate at this stage that any decisions that were made about resuscitation are implemented in line with the patient's wishes.

Liverpool Care Pathway

- 6.40 The Liverpool Care Pathway (LCP)⁴⁴ is an integrated clinical pathway that has been recognised as a model of best practice for care in the last weeks or days of life and incorporated into the National End of Life Care Programme (2004-9)⁴⁵. The NICE guidance on supportive and palliative care for patients with cancer⁴⁶ also recommended the LCP as a mechanism for identifying and addressing the needs of dying patients. Originally designed for hospital use, the LCP has been adapted for use in hospices, care homes and patients' own homes and is appropriate for patients with malignant and non-malignant diagnoses.
- 6.41 As with any other best practice tool, the LCP is intended to support rather than replace, clinical experience and expertise and should only be initiated and used by clinicians who are trained and competent to do so. Continuous assessment of the patient's condition and the

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appropriateness of their remaining on the pathway are imperative and should be subject to ongoing review.

6

Bereavement Care

- 6.42 It is estimated that for every death, at least four relatives and friends experience the loss, with over 56,000 people in Northern Ireland being affected by bereavement in any one year.
- 6.43 Families and carers provide essential support for patients, but their own needs for emotional and practical support may go unrecognised, often because they put the needs of the patient first. While the effects of bereavement can have a significant impact on the physical and mental health of many individuals, to the extent that specialist support services may be required, the majority of people cope with the experience with the care and support of family and friends so that some degree of healing and recovery occurs. It is recognised that a compassionate and sensitive approach throughout end of life care can impact positively on the grieving process to facilitate such healing.
- 6.44 The *NI Health and Social Care Services Strategy for Bereavement Care*⁴⁷ aims to promote an integrated, consistent approach to supporting individuals, families and carers who have been bereaved, and those that support them, in a way that is appropriate to their individual needs and preferences. A number of standards for bereavement care have been developed around key themes and it is intended that these standards will inform regional guidelines and local policies and procedures where appropriate. Six principal standards have been identified:
1. **Raising awareness:** That Health and Social Care staff will be suitably trained to have an awareness and understanding of death, dying and bereavement. Staff should also acknowledge the fact that grief is a normal process following loss, and that needs vary according to an individual's background, community, beliefs and abilities.

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2. **Promoting safe and effective care:** That all Health and Social Care staff who have contact with people who are dying and/or those affected by bereavement will deliver high quality, safe, sensitive and effective care before, at the time of and after death. According to individuals' backgrounds, communities, beliefs and abilities.
3. **Communication, information and resources:** That people who are dying and those who are affected by bereavement will have access to up to date, timely, accurate and consistent information in a format and language which is appropriate and will be helpful to their particular circumstances consistent with their needs, abilities and preferences. Staff will remember that the availability of written or other information does not negate their personal support role.
4. **Creating a supportive experience:** That those who are dying and their families will be afforded time, privacy, dignity and respect and, wherever possible, given the opportunity to die in their preferred environment with access to practical, emotional and spiritual support based on their individual needs, abilities and preferences.
5. **Knowledge and skills:** That Health and Social Care organisations recognise the value of a skilled workforce by ensuring that those coming into contact with, or caring for people who are dying and those affected by bereavement are competent to deliver care through continuing professional development; and by having systems in place to support them.
6. **Working together:** That good communication and co-ordination will take place within and between individuals, organisations and sectors, to ensure that resources are targeted efficiently and effectively and that there is integration of care to meet the needs of people who are dying and their families, friends and carers.

This Strategy can be accessed at www.dhsspsni.gov.uk/nihsc-strategy-for-bereavement-care-june-2009.pdf.

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Recommendations

12. Arrangements should be put in place which allow for the most appropriate person (be that clinical staff, carers, spiritual care providers or family members) to communicate with, and provide support for, an individual receiving significant information.
13. Appropriate tools and triggers should be implemented to identify people with palliative and end of life care needs and their preferences for care.
14. A locality based register should be in place to ensure (with the permission of the individual) that appropriate information about patient, family and carer needs and preferences is available and accessible both within organisations and across care settings to ensure co-ordination and continuity of quality care.
15. Condition specific care pathways should have appropriate trigger points for holistic assessment of patients' needs.
16. Timely holistic assessments by a multi-disciplinary care team should be undertaken with people who have palliative and end of life care needs to ensure that changing needs and complexity are identified, recorded, addressed and reviewed
17. Timely holistic assessments by a multi-disciplinary care team should be undertaken with the family and carers of people who have palliative and end of life care needs to ensure that their needs are identified, recorded, addressed and reviewed.
18. Respite care should be available to people with palliative and end of life care needs in settings appropriate to their need.
19. Patients, their families and carers should have access to appropriate and relevant information.

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20. Palliative and end of life care services should be planned and developed with meaningful patient, family and carer involvement, facilitated and supported as appropriate and provided in a flexible manner to meet individual and changing needs.
21. Services should be prioritised for the provision of equipment, transport and adaptations, for all patients who have rapidly changing needs.
22. Policies should be in place in respect of advance care planning for patients with palliative and end of life care needs.
23. Tools to enable the delivery of good palliative and end of life care, for example, the Gold Standards Framework, Preferred Priorities for Care, Macmillan Out-of-hours Toolkit or the Liverpool Care Pathway, should be embedded into practice across all care settings with ongoing facilitation.
24. All out-of-hours teams should be competent to provide responsive generalist palliative and end of life care and advice to patients, carers, families and staff across all community based care settings.
25. Access to specialist palliative care advice and support should be available across all care settings 24/7.

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Action Plan for Quality Palliative and End of Life Care

- 7.1 This Action Plan details the recommendations which have been identified throughout the development of the Strategy.

It provides clear direction to support organisations to plan and deliver palliative and end of life care, which will achieve the quality outlined in the vision. Each high level recommendation is supported by identifying which organisations are responsible for planning and delivery, the expected timescale for implementation, the identified outcomes and how these should be measured.

The timescales have been defined as: Short (0-12 months), Medium (1-3 years) and Long (3-5 years)

LCGs – Local Commissioning Groups HEIs – Higher Education Institutions

Section 3 Developing Quality Palliative and End of Life Care

Recommendation	Responsibility	Timescale	Quality Outcome	Measure
1. Open discussion about palliative and end of life care should be promoted and encouraged through media, education and awareness programmes aimed at the public and the health and social care sector	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Patient & Client Council Community Sector Voluntary Sector Independent Sector HEIs Education Consortia	Medium	- All relevant organisations are aware of the views of the population with regard to delivery of palliative and end of life care - Strategies are in place for promoting public awareness of palliative and end of life care	- Reports, surveys, focus groups - Local strategic plans include actions to be taken to promote awareness

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
2. The core principles of palliative and end of life care should be a generic component in all pre-registration training programmes in health and social care and in staff induction programmes across all care settings	HSC Trusts Community Sector Voluntary Sector Independent Sector HEIs Education Consortia	Medium	The needs for education and training for all staff in all care settings have been assessed, prioritised and programmes initiated in palliative and end of life care and communication skills	- Local strategic plans encompass education and training requirements and priorities for staff who are not specialists in palliative and end of life care - Local strategic plans encompass communication skills training related to palliative and end of life care
3. Mechanisms to identify the education, development and support needs of staff, patients, families, carers and volunteers should be in place to allow person-centred programmes to be developed which promote optimal health and well-being through information, counselling and support skills for people with palliative and end of life care needs	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Patient & Client Council Community Sector Voluntary Sector Independent Sector	Medium	Person-centred programmes are available which promote optimal health and well-being, provide information, counselling and support skills in palliative and end of life care	- Local strategic plans identify the education and development needs of staff, patients, families, carers and volunteers - Written evidence is available to demonstrate local programmes have been developed in partnership with key education stakeholders and agreed with the Public Health Agency

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
4. A range of inter-professional education and development programmes should be available to enhance the knowledge, skills and competence of all staff who come into contact with patients with palliative and end of life care needs	Voluntary Sector HEIs Education Consortia	Medium	Flexible and accessible education programmes, based on the needs of health and social care workers, are available	• Written evidence of the availability, quality and uptake of inter-professional programmes
5. Arrangements should be in place which provide families and carers with appropriate, relevant and accessible information and training to enable them to carry out their caring responsibilities	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Patient & Client Council Community Sector Voluntary Sector Independent Sector	Medium	Individual family and carer information and training needs are identified and addressed	• Information and training needs assessed and agreed, and actions taken to address these are documented
6. A collaborative and collegiate approach to research and development should be established and promoted to inform planning and delivery, drive up quality and improve outcomes in palliative and end of life care	HSC Board Public Health Agency Patient & Client Council Voluntary Sector HEIs Research Consortia HSC R&D Office	Medium	Research findings are translated to timely and standardised improvements for the population	• Baseline assessment of research activity has been carried out • Written evidence that there is collaborative and collegiate planning for research programmes

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Action Plan for Quality Palliative and End of Life Care

Section 4 Commissioning Quality Palliative and End of Life Care

Recommendation	Responsibility	Timescale	Quality Outcome	Measure
7. A lead commissioner should be identified for palliative and end of life care at regional level and within all Local Commissioning Groups	HSC Board LCGs Public Health Agency	Short	Accountability and leadership for palliative and end of life care identified at regional and local levels	Written evidence demonstrates that regional and local plans are led by named commissioning leads
8. Systems should be in place which capture qualitative and quantitative population needs relating to palliative and end of life care	HSC Board LCGs HSC Trusts Primary Care Public Health Agency	Medium	Qualitative and quantitative population needs data are available relating to palliative and end of life care to inform policy, commissioning and planning	Evidence that robust data capture systems have been developed and implemented

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Section 5 Delivering Quality Palliative and End of Life Care

Recommendation	Responsibility	Timescale	Quality Outcome	Measure
9. Each patient identified as having end of life care needs should have a key worker	HSC Board LCGs HSC Trusts Public Health Agency Voluntary Sector	Short	Key workers are identified and available to all patients with end of life care needs	- Regional development of role specification of key worker - Local strategic plans will indicate actions to ensure the role of key worker is defined - Written evidence in work-force plans will demonstrate the development of key worker role
10. Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services with no loss of needed service experienced as a result of the transfer	HSC Board LCGs HSC Trusts Public Health Agency Community Sector Voluntary Sector Independent Sector	Medium	Every child with palliative and end of life care needs and their family, experience a seamless transition to adult services	Every child with palliative and end of life care needs, and their family, has an agreed transfer plan incorporating key standards for transitional care
11. The potential for a Managed Clinical Network should be explored to ensure leadership, integration and governance of palliative and end of life care across all conditions and care settings	DHSSPS HSC Board LCGs Primary Care Public Health Agency Community Sector Voluntary Sector Independent Sector Education Consortia	Intermediate	A decision has been made with regard to the feasibility and role of a Managed Clinical Network to improve delivery of palliative and end of life care	Evidence of decision-making process is documented

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Section 6 A Model for Quality Palliative and End of Life Care

Recommendation	Responsibility	Timescale	Quality Outcome	Measure
12. Arrangements should be put in place which allow for the most appropriate person (be that clinical staff, carers, spiritual care providers or family members) to communicate with, and provide support for, an individual receiving significant information	HSC Trusts Primary Care Community Sector Voluntary Sector Independent Sector	Short	Individuals have significant news discussed with them by the most appropriate person	• Protocols for communication are in place and audited
13. Appropriate tools and triggers should be implemented to identify people with palliative and end of life care needs and their preferences for care	LCGs Primary Care Community Sector Voluntary Sector Independent Sector	Medium	People with palliative and end of life care needs across all care settings are identified and their preferences for care known	• Written evidence that appropriate tools and triggers are being used to identify people with palliative and end of life care needs and their preference for care are recorded

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
14. A locality based register should be in place to ensure (with the permission of the individual) that appropriate information about patient, family and carer needs and preferences is available and accessible both within organisations and across care settings to ensure co-ordination and continuity of quality care	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Community Sector Voluntary Sector Independent Sector	Medium	A locality based register is in place and is accessible within organisations and across care settings	• A locality based register is in place and maintained for patients with palliative and end of life care needs • Written evidence demonstrates appropriate communication and information sharing has taken place
15. Condition specific care pathways should have appropriate trigger points for holistic assessment of patients' needs	HSC Board LCGs HSC Trusts Primary Care Public Health Agency	Medium	All patients with palliative and end of life care needs, regardless of condition, will have holistic assessments undertaken at appropriate points	• Written evidence that condition specific care pathways include anticipatory trigger points for holistic assessment
16. Timely holistic assessments by a multi-disciplinary care team should be undertaken with people who have palliative and end of life care needs to ensure that changing needs and complexity are identified, recorded, addressed and reviewed	LCGs HSC Trusts Primary Care Community Sector Voluntary Sector Independent Sector	Medium	Patient needs are identified and addressed by an appropriate member/s of a multi-disciplinary team	• Written evidence demonstrates timely assessment and review to identify, record, address and review changing needs and complexity

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
17. Timely holistic assessments by a multi-disciplinary care team should be undertaken with the family and carers of people who have palliative and end of life care needs to ensure that their needs are identified, recorded, addressed and reviewed	LCGs HSC Trusts Primary Care	Medium	Family and carer needs are identified and addressed by an appropriate member/s of a multi-disciplinary team	Written evidence demonstrates timely assessment and review to identify, record, address and review changing needs
18. Respite care should be available to people with palliative and end of life care needs in settings appropriate to their need	HSC Board LCGs Public Health Agency Community Sector Voluntary Sector Independent Sector	Long	Access to respite care is available and appropriate to patient, family and carer needs	Local strategic plans indicate how respite care will be delivered
19. Patients, their families and carers should have timely access to appropriate and relevant information	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Community Sector Voluntary Sector Independent Sector	Medium	Relevant and high quality information is accessible to individuals and conveyed in an appropriate manner	Written evidence demonstrates information pathways are in place, implemented and evaluated

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
20. Palliative and end of life care services should be planned and developed with meaningful patient, family and carer involvement, facilitated and supported as appropriate and provided in a flexible manner to meet individual and changing needs	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Patient & Client Council Community Sector Voluntary Sector Independent Sector	Short	Patients, families and carers are fully involved in planning palliative and end of life care services	• Focus groups and population surveys • Local strategic plans indicate how they will involve patients, families and carers in palliative and end of life care planning
21. Services should be prioritised for the provision of equipment, transport and adaptations, for all patients who have rapidly changing needs	HSC Board LCGs HSC Trusts Public Health Agency NI Ambulance Trust	Medium	• Each Trust to provide evidence of robust action and contingency plans • Patients with rapidly changing palliative and end of life care needs have access to services which are responsive to assessed need	• Protocols are in place to enable services to be prioritised in response to identified palliative and end of life care needs
22. Policies should be in place in respect of advance care planning for patients with palliative and end of life care needs	LCGs HSC Trusts Community Sector Voluntary Sector Independent Sector	Medium	Patients have the opportunity to discuss and record their preferences for care	• Policies for advanced care planning are in place, implemented and evaluated

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
23. Tools to enable the delivery of good palliative and end of life care, for example, the Gold Standard Framework, Preferred Priorities for Care, Macmillan Out-of-hours toolkit or the Liverpool Care Pathway, should be embedded into practice across all care settings with ongoing facilitation	LCGs HSC Trusts Primary Care Community Sector Voluntary Sector Independent Sector	Medium	The care of patients with palliative and end of life care needs is improved through implementation of best practice tools and guidelines	Written evidence to demonstrate best practice tools and guidelines are in use across all care settings and are audited for effectiveness across all care settings
24. All out-of-hours teams should be competent to provide responsive generalist palliative and end of life care and advice to patients, carers, families and staff across all community based care settings	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Voluntary Sector Independent Sector	Medium	Patients, families and carers have out-of-hours access to responsive generalist palliative and end of life care and advice, to sustain care in community based settings	Local strategic plans indicate actions to ensure that out-of-hours generalist palliative and end of life care and advice is available across all community based care settings

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Recommendation	Responsibility	Timescale	Quality Outcome	Measure
25. Access to specialist palliative care advice and support should be available across all care settings 24/7	HSC Board LCGs HSC Trusts Primary Care Public Health Agency Community Sector Voluntary Sector Independent Sector	Medium	Patients with identified complex need, their families and carers have access to specialist palliative care advice and support 24/7	Written evidence demonstrates that arrangements for accessing specialist palliative and end of life care support 24/7 are in place, implemented and audited for effectiveness

Conclusion

Palliative and end of life care is the active, holistic care of patients with advanced progressive illness. This Strategy identifies palliative and end of life care as a continuum that can evolve as a person's condition progresses. It is an integral part of the care delivered by health and social care professionals, as well as families and carers, to those living with, and dying from any advanced, progressive and incurable conditions. Compassionate caring is at the heart of good palliative and end of life care and focuses on the person and what matters to them rather than the disease, aiming to ensure quality of life for those living with an advanced, non-curable condition.

The Strategy recognises the history of outstanding care provided by the hospice movement in Northern Ireland, while the many local exemplars highlight the ongoing commitment to developing high quality and innovative care across the wider statutory, independent and voluntary sectors.

'Living Matters: Dying Matters' provides clear vision and direction for the planning and delivery of high quality care, and identifies an overarching Model for Palliative and End of Life Care as a vehicle for best practice. Turning this Strategy into a reality will require ownership, leadership, and engagement at all levels of policy, planning, commissioning, education and delivery. It calls for a commitment to change culture and ensure that the vision for palliative and end of life care is realised.

To meet this challenge, an Implementation Board representative of key stakeholders will be established with a remit to ensure that the recommendations contained within the Strategy are developed and embedded into practice. Key stakeholders will include public, independent, community, and voluntary sectors as well as the patients, families and carers who are at the very heart of the Strategy's vision.

The Implementation Board will support the reform and modernisation of palliative and end of life care in Northern Ireland, including prioritisation of commissioning arrangements for service delivery. Arrangements will also be developed to monitor and evaluate the Strategy.

Living Matters Dying Matters

Conclusion

'Living Matters: Dying Matters' presents a significant challenge over the next five years, however a foundation of care is already in place which will be built upon and developed so that the vision of quality palliative and end of life care for all who require it becomes a reality.

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

Dame Cicely Saunders, founder of the modern hospice movement.

APPENDIX 1 Membership of the Steering Group

Member	Position	Organisation
Martin Bradley (Chair)	Chief Nursing Officer	DHSSPS
Christine Jendoubi	Director of Primary Care	DHSSPS
Maeve Hully	Chief Executive	Patient and Client Council
Professor Judith Hill	Chief Executive	NI Hospice
Mary Hinds	Director of Nursing & AHP	Public Health Agency
Dr Ian Clarkson	Macmillan GP Facilitator	
Dr Frances Robinson	Consultant Palliative Care	WHSC
Fionnuala McAndrew	Director Social Care	HSC Board
Michael Bloomfield	Chair Reform and Modernisation Palliative Care Steering Group	HSC Board
Lorna Nevin	Supportive and Palliative Care Co-ordinator	Northern Ireland Cancer Network
Anne Mills	Nursing Officer	DHSSPS
Gillian Seeds	Head of Primary Care Development Unit	DHSSPS
Karen Dawson	Primary Care Development Unit	DHSSPS

APPENDIX 2 Abbreviations

ACT	Association for Children's Palliative Care
AHP	Allied Health Professional
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardio-Pulmonary Resuscitation
DDA	Disability Discrimination Act
DNAR	Do Not Attempt Resuscitation
DoH	Department of Health (England)
GMS	General Medical Services
GSF	Gold Standard Framework
HEI	Higher Education Institutions
HSC	Health and Social Care
ICT	Information and Communication Technology
LCG	Local Commissioning Group
LCP	Liverpool Care Pathway
MCN	Managed Clinical Network
NCPC	National Council for Palliative Care
NICE	National Institute for Health and Clinical Excellence
NICaN	Northern Ireland Cancer Network
NISAT	Northern Ireland Single Assessment Tool
OOH	Out-of-Hours
PfA	Priorities for Action
PPC	Preferred Place of Care
QOF	Quality and Outcomes Framework
R+D	Research and Development
WHO	World Health Organisation

APPENDIX 3 Glossary of terms

Acute Services

Health care and treatment provided mainly in hospitals.

Advance Care Planning

Advance care planning seeks to record a person's decisions for future care, to ensure that care is planned and delivered in response to the expressed needs and preferences of patients, families and carers. The process may take place in the context of an anticipated deterioration in the individual's condition in the future.

Allied Health Professionals

Groups of professionals working in the health and social care services including physiotherapists, occupational therapists, speech therapists, chiropodists/podiatrists, dieticians and orthoptists.

Care Home

A residential home which provides either short or long term accommodation with meals and personal care (e.g. help with washing and eating). Some care homes, known as nursing homes, also have registered nurses who provide nursing care for more complex health needs.

Care Plan

The outcome of a needs assessment. A description of what an individual needs and how these needs will be met. A care plan should reflect the choices made by a person about their care. In the case of people approaching the end of their life, this may set out how they wish to be cared for and where they would wish to die.

Carer

Carers are people who, without payment, provide help and support to a family member or friend who may not be able to manage at home without this help because of frailty, illness or disability. This can include caring for an individual who is approaching the end of their life.

Carer's Assessment

An assessment, carried out by a social worker or a member of social services, which enables an unpaid carer to discuss the help they need to care, to

APPENDIX 3 Glossary of terms

maintain their own health and to balance caring with their life, work and family commitments. The Carers and Direct Payments Act (NI) 2002 places a requirement on Trusts to inform carers of their right to a carer's assessment and gives Trusts the power to supply services directly to carers to help the carer in their caring role. Carers have a statutory right to a carer's assessment which allows for an assessment to be carried out even where the person cared for has refused an assessment or the provision of personal social services.

Chronic Condition

A long term disease lasting more than 6 months. They are non-communicable, involve some level of functional impairment or disability and are usually incurable. Chronic conditions can affect people physically, mentally and emotionally. Examples include: diabetes, asthma, epilepsy, cancer, heart disease; and arthritis.

Chronic Obstructive Pulmonary Disease (COPD)

A collection of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease, all of which can occur together and make breathing difficult. COPD is a progressive disease and one of the most common respiratory diseases in the UK. It usually affects people over the age of 40.

Commissioning

The process of identifying local health and social care needs, making agreements with service providers to deliver services to meet these needs, and monitoring outcomes. The process of commissioning seeks to improve quality of life and health outcomes for patients and carers.

Community health and care services

Services provided outside the hospital setting by health and social care professionals.

Dementia

A range of progressive, terminal organic brain diseases. Symptoms include gradual and progressive decline in memory, reasoning and communication skills, and ability to carry out daily activities, and loss of control of basic bodily functions caused by structural and chemical changes in the brain.

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Direct payments

Direct Payments have been available since 1996 and aim to promote independence by giving people flexibility, choice and control over the purchase and delivery of services that support them. Individuals can opt to purchase services tailored to suit them by means of a Direct Payment from the HSC Trust. From 19 April 2004 Direct Payments were extended to a wider range of service users under the Carers and Direct Payments Act (Northern Ireland) 2002 to include carers, parents of disabled children and disabled parents.

Disease Trajectory

The expected pattern by which a condition progresses over time. Different diseases have different patterns of trajectory. Main trajectories identified include cancer, organ failure and physical and/or cognitive frailty including dementia.

District/Community Nurse

District/Community nurses visit people in their own homes or in residential care homes, providing care for patients and supporting family members. They work with patients to enable them to care for themselves or with family members and carers supporting them in caring their responsibilities.

Do Not Attempt Resuscitation

A written order from a doctor that resuscitation should not be attempted in the event of a person suffering cardiac or respiratory arrest. Such an order may be considered appropriate in cases where successful restoration of the circulation is likely to be followed by a quality of life that would be unacceptable to the patient, or when cardiac or respiratory arrest is the end result of a disease process in which appropriate treatment options have been exhausted.

End of Life

A period of time during which a person's condition is actively deteriorating to the point where death is expected.

End of Life Care Services

End of life care is an integral part of the wider concept of palliative care and many of the same principles will apply. The emphasis on end of life care focuses on helping all those with advanced progressive and incurable

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conditions to live as well as possible until they die. It enables the palliative care needs of both patient and family to be identified and met throughout the last phases of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

General Palliative Care

Care that is delivered by multi-disciplinary teams in primary and community care settings, hospital units and wards. This is the level of care required by most people and is provided by non palliative and end of life care specialists.

Gold Standards Framework (GSF)

A systematic evidence based approach to optimising the care for patients nearing the end of life, delivered by generalist providers. It is concerned with helping people to live well until the end of life.

Health and Social Care (HSC)

Hospital services, family and community health services and personal social services.

Health and Social Care Providers

Organisations (including public, independent and voluntary/community) which provide health and/or social care services, for example Health and Social Care Trusts, hospices, voluntary and community organisations.

Holistic Care

Comprehensive care that addresses the social, psychological, emotional, physical and spiritual needs of the individual.

Hospice

Hospices provide care and support to people at the end of their life and their carers, through a range of services such as in-patient care, day care, community services, out-patient appointments, sitting services, respite care and bereavement counselling.

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Integrated Care Pathway

Integrated Care Pathways set out the steps in the care of a patient with a specific condition and describe the expected progress of the patient as their condition progresses.

Key Worker

A named member of a multi-disciplinary team with particular responsibility for co-ordinating both communication and the provision of care to the patient, their family and carers. The key worker undertakes a pivotal role in liaising between all parties involved in a patient's end of life care to ensure that this is planned and provided in a streamlined way.

Life-limiting Condition

Any illness where there is no reasonable hope of cure and from which the person will die.

Liverpool Care Pathway (LCP)

The Liverpool Care Pathway for the Dying Patient was originally developed to transfer the hospice model of care into other care settings. It is a multi-professional document which provides evidence-based guidelines for care in the last days and hours of life. The LCP provides criteria for diagnosing dying and guidance on various aspects of care, including symptom control, comfort measures and anticipatory prescribing. Psychological and spiritual care and family support is included.

Macmillan Out-of-Hours Toolkit

This toolkit aims to provide support, guidance and practical solutions to those responsible for the implementation of out-of-hours policies and procedure.

Managed Clinical Network (MCN)

A network of multi-professional, multi-disciplinary and cross-boundary staff (including doctors, pharmacists, nurses, health visitors, physiotherapists and occupational therapists) and organisations from primary, secondary, voluntary and independent health care working together to make sure that high quality effective services are provided equitably. MCNs will also involve patients with the experience of the particular illness.

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Multi-disciplinary Team

A group of people from different disciplines who work together to provide and/or improve care for patients with a particular condition. The composition of multi-disciplinary teams will include people from various disciplines (both healthcare and non-healthcare).

National Institute for Health and Clinical Excellence

An independent organisation covering England and Wales, responsible for providing guidance on the promotion of good health. NICE provides objective guidance on the clinical and cost effectiveness of drugs and treatments. The DHSSPS established a formal link with NICE on 1 July 2006 and reviews all guidance published by the Institute, from that date, for its applicability to Northern Ireland.

NI Cancer Network

The NI Cancer Network (NICaN) aims to work towards the continuous improvement in cancer care and cancer survival for the people of Northern Ireland. It does this by supporting groups of health professionals, patients and charities to work together in a co-ordinated way, ensuring good communication and sharing good practice.

NI Single Assessment Tool (NISAT)

A system designed to capture the information required for holistic, person-centred assessment of the health and social care needs of the older person. The tool has component parts which will be completed according to the level of health and social care needs experienced by the older person, from non-complex to complex. NISAT focuses on the person's abilities and strengths rather than their disabilities. Use of NISAT will standardise and streamline assessment and care planning processes.

Out-of-Hours

The out-of-hours period is usually 6.30pm to 8am on weekdays and all weekends and bank holidays. Under the new General Medical Services contract (2004), GPs can choose not to provide 24-hour care for their patients. During this time, local commissioners are responsible for the provision of GP services for local people.

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Palliative Care

The active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Preferred Priorities for Care

A process for identifying and recording an individual's personal preferences and choice about how their care is provided.

Primary Care

Family and community health services and major components of social care which are delivered outside the hospital setting and which an individual can access on his/her own behalf. Primary care will usually be a person's first point of contact with the HSC (e.g. GPs, dentists).

Priorities for Action (PfA)

Priorities for Action sets out the Minister's annual priorities and key challenges for the HSC. PfA provides the platform for monitoring the performance of the HSC in providing a continuously improving service.

Prognosis

The expected progression of a disease and its outcome for the individual.

Quality and Outcomes Framework

A component of the General Medical Services contract for GPs. The QOF sets targets for GPs against evidence-based criteria covering a range of general and condition-specific indicators. Payments to practices are calculated on the basis of the extent to which these targets are met.

Respite Care

Provided on a short term and time limited basis, from a few hours per week to a number of weeks, respite care can either be planned or provided in response to an emergency. It can be done in a variety of ways, either outside or inside of

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the cared for person's home, and should be tailored to the needs of individual families and carers.

Secondary Care

Care often provided in a hospital or particular specialised centre. Secondary care may be accessed by a patient directly but is usually as a result of referral from primary care.

Service Framework

Evidence based standards to improve health and social care outcomes, reduce inequalities in health and social well-being and improve service access and delivery. Service frameworks set out standards of care that patients, clients, families and carers can expect to receive.

Social Care

Care services for vulnerable people, including those with special needs because of old age or physical or mental disability, or children in need of care and protection. Social care services which support people in their day to day lives to help them play a full part in society. Social care is usually provided in response to a needs assessment and can include services provided in a care home, the provision of a home help facility, meals on wheels and the provision of equipment.

Specialist Palliative Care

The management of unresolved symptoms and more demanding care needs including complex psychosocial, end of life and bereavement issues. It is provided by specialist personnel with expert knowledge, skills and competences.

Symptom Management

Any intervention used to help relieve the individual's pain, discomfort or other negative experiences that arise as either a direct or indirect result of their medical condition or the aging process.

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Transitional Care

The purposeful, planned process that addresses the clinical, psychosocial and educational needs of adolescents and young adults with chronic physical and medical conditions from a child centred to adult oriented health care.

Whole Systems Approach

An approach to care that considers the needs of the whole person, their family and carers and how care can best be planned, delivered and co-ordinated irrespective of care setting.

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