

Partnerships in Caring

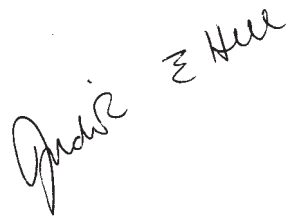
..... Standards for Service

Health and Social Services are undergoing significant change and challenge as we move into a new millennium. The review of Regional Palliative Care Services, '*Partnerships in Caring*' builds on the significant work already undertaken.

The review highlights in particular the need for partnership with patients and their families – between the variety of care providers and with service planners and commissioners, as it is only in working together, in a co-ordinated way that we can hope to provide consistently high quality services.

To help assess where organisations and teams need to develop we have commenced work on an accreditation tool that can be used for peer review or self-assessment or part of building the relationship with commissioners.

This review is only the beginning. I look forward to seeing the recommendations become a reality, with improved care and services the result.

A handwritten signature in black ink, appearing to read 'Judith E Hill', written in a cursive style.

Judith E Hill

Chief Nursing Officer

Partnerships in Caring

..... Standards for Service

A Review of Palliative Care

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1.0 Introduction

1.1 Following the publication of the Campbell Report, *Cancer Services – Investing for the Future*, each Health and Social Services Board conducted a review of cancer services within their area. These reports included a section on Palliative Care which had been considered in detail by separate subgroups at HSS Board level. As a recommendation of the Campbell Report, a Regional Review of Palliative Care Services was established. (Membership of the Regional Review group is set out in Appendix A.)

1.2 The remit of the Regional Review was:

To review the current provision of palliative care service, taking account of the recommendations of the report, "Cancer Services - Investing for the Future", and to make recommendations on the future provision of these services.

1.3 For the purposes of this report palliative care is defined as, ‘the care of patients with active, progressive, advanced disease with a limited prognosis and for whom the goal of care is the quality of life.’¹

This report recommends a way forward for palliative care services in Northern Ireland. As an integral part of this report accreditation criteria have been developed detailed in Appendix D.

1.4 The provision of palliative care is different from many other health and social services because there are multiple providers of care which is delivered in a variety of settings, including the home, hospital, nursing home and hospice. As a result, co-ordination of these services can be difficult, particularly as services need to be flexible to meet the often rapid change in patient need.

¹ Association of Palliative Medicine of Great Britain and Ireland

2.0 Identifying need

2.1 Health and Social Services (HSS) Boards adopted similar approaches to identifying local need, utilising the methodology developed by Professor Irene Higginson which is based on current research evidence, and national and local population and health services utilisation data.² Using a similar methodology, the total local palliative care needs were estimated and are illustrated below for cancer and non-cancer patients. Services for children are addressed in section 7.

Morbidity and mortality due to cancer

2.2 Each year there are on average 3580 deaths where cancer is the primary cause of death in the north of Ireland.³ Of these patients who die from cancer, statistically - over 84% (3007) will experience pain; - 70% (2506) will experience loss of appetite; - 50% (1790) sleeplessness, nausea and vomiting; - 47% (1682) will have trouble with breathlessness and - 37% (1324) will be affected by depression. Most patients will have a combination of these symptoms during the course of their illness⁴.

2.3 Studies suggest that over 2000 patients will need the skills of a specialist home care team and up to 900 will need the expertise of a specialist inpatient unit. Many patients will require both services and may need more than one admission.⁵

Morbidity and mortality due to non-malignant / non cancer disease

2.4 The prevalence of patients with progressive non-malignant / non cancer diseases who may require palliative care can be estimated at 11,040. Of these, statistically, - 65% (7286) will experience pain; - 48% (5409) will have trouble breathing, and - 27% (2980) will have nausea and vomiting. As with cancer conditions, many

² Higginson I (1997) Palliative and Terminal Care, in Health Care Needs Assessment. Ed. Stevens A. and Raftery J. (1997) Oxford. Radcliff Medical Press.

³ Source: NI Cancer Registry (1999) Cancer Incidence in Northern Ireland 1993-9. The Stationery Office Limited.

⁴ Higginson I (1997) Palliative and Terminal Care, in Health Care Needs Assessment. Ed. Stevens A. and Raftery J. (1997) Oxford. Radcliff Medical Press.

⁵ Addington - Hall JM (1993) Regional study of care of the dying. Feedback from district health authorities. Cancer deaths only. London: Department of Epidemiology and Public Health, University College London.

patients will experience more than one symptom. It is estimated that over 2000 of these patients will require the support of a specialist palliative care team and up to 1100 may require specialist inpatient palliative care.

2.5 If both groups are considered together, over 4000 patients will require the skills of a specialist palliative care team and up to 2000 may require access to inpatient specialist care service. If this is considered along with an ageing population and developments in clinical care which improve diagnosis and survival rates, it could be assumed that the magnitude of need is liable to increase.

2.6 The statistical analysis illustrates aspects of physical need only. In addition, all patients and carers will have significant psychological, spiritual and social needs, requiring good communication, co-ordinated domiciliary support and relief from the economic burden which caring often causes.^{6,7,8} **When developing palliative care services, commissioners need to be mindful of the total palliative care needs of patients with both cancer and non cancer conditions.**

⁶ Sykes N P, Pearson S E, Chell S (1992) Quality of care of the terminally ill: the carer's perspective. *Palliative Medicine*; 6: 227-236

⁷ Neale B (1991) *Informal Palliative Care: a Review of Research on Needs, Standards and Service Evaluation*. Occasional paper No. 3. Sheffield: Trent Palliative Care Centre.

⁸ Hunt M (1991) The identification and provision of care for the terminally ill at home by 'family' members. *Sociology of Health & Illness*; 13 (3) : 375-395

3.0 Provision of Palliative Care

3.1 While current provision of services is described in HSS Board reports, there was variation in the types of services described. When considered together, given the multiple agencies involved in providing care and the disparate nature of the services, it was not possible to obtain a complete analysis of the total current provision of palliative care services. The following overview however covers many of the main areas of service.

3.2 Palliative care services in Primary Care are provided through a range of professionals and from a variety of organisations. Continuity and co-ordination of care are vital to the delivery of high quality palliative care services. **The caring team, in partnership with the patient and their carers, should agree and clearly identify a key worker for each patient. The key worker should co-ordinate the efforts of the whole care team and ensure continuity of care. The key worker will often be the patient's general medical practitioner, but flexibility is important in order to reflect changing individual patient need.**

3.3 A range of services from both the independent, voluntary and statutory sector were identified in some HSS Board reports. These reports indicate a need for improvements in co-ordination and communication between the various health and social services providers. **HSS Boards should provide a directory detailing all available services, in collaboration with general medical and dental practitioners, HSS Trusts, independent, voluntary and community groups. This directory should be made accessible in a wide range of formats, to patients, families and professionals and provision made for annual updating.**

3.4 Current and ongoing changes in the provision of 24-hour care by general medical practitioners, through the development of new co-operative schemes could potentially lead to problems with continuity of primary medical care. Where there are potential problems or inconsistency in approach HSS Boards must discuss this with Local Medical Committees. **All HSS Boards should ensure that, in new schemes for out of hours medical care, arrangements are in place which will ensure continuity of care for patients with palliative care needs.**

3.5 The provision of specialist nursing services underpins the current developments in palliative care. As part of the primary care team community nurses, such as district nurses, provide much of the practical care for patients. These staff are supported by nurses with specialist skills and expertise such as those provided by Marie Curie Cancer Care, Cancer Relief Macmillan and Hospice nursing service teams. Nurses with the support of many of the voluntary organisations, have been developing a range new roles such as focusing on the care of patients with site specific tumours. When combined these nurses form a significant contribution to palliative care services.

3.6 Community pharmacists are essential to ensuring that patients and professionals providing care have access to the appropriate medication. A sound knowledge of those drugs used in palliative care is essential, as is the availability and continuity of supply of such medicines. The fact that there are some difficulties in obtaining medication out of hours and in confirming prescription changes emphasises the above need. **A local network of pharmacists who have received advanced training in palliative care should be established. These pharmacists would offer specialist advice, maintain appropriate levels of palliative care medicines for supply and provide out of hours dispensing services for such drugs. There should be established linkages between hospital and community pharmacies to ensure continuity of care between primary and secondary sectors.**

3.7 General dental practitioners have an important role in the provision of advice, care and treatment to this group of patients and their carers. **The patients key worker should ensure that all necessary professionals are aware of the appropriate contact point for dental services.**

3.8 To address some of the issues with regard to continuity of care, the development of a multi-professional 'patient held record' has been suggested. Work has already commenced in the area of cancer patients, through a Working Group, chaired by Miss Irene Duddy, Director of Nursing at Altnagelvin Hospital Trust. **All providers of services should adopt a common approach to patient held records.**

3.9 Primary care professionals, such as general medical practitioners, district nurses and social workers, who do not necessarily have specialist palliative care knowledge and skills, are often the main providers of 24-hour care. **Sufficient primary care, staff skilled in palliative care, should be available to ensure the provision of high quality care. Mechanisms should be put in place to ensure that specialist medical advice is available to general practitioners, other doctors who have examined the patient for whom the advice is required or other professionals.**

3.10 Palliative care can be provided in a variety of settings including nursing and residential care homes, hospice and hospital inpatient environments. There are indications that nursing homes have become increasingly the place of care and death, especially for the frail and elderly. **Standards for palliative care and treatment in nursing and residential care homes should be further developed, building on current good practice.**

3.11 It has been recommended that 12.5 specialist palliative care beds are required for a population of 250,000,⁹ based on the needs of cancer patients. For our population of 1.6 million, this equates to 80 beds. Current provision of inpatient specialist palliative care focuses on services provided through voluntary hospice organisations. There are 64 allocated specialist beds. However, this does not take account of beds in some smaller hospitals, which are currently allocated to palliative care. Services in these smaller hospitals do not have regular input from specialist consultants in palliative medicine. **Standards for the provision of specialist and general palliative care within hospice and hospital settings need to be further developed building on the accreditation manual in Appendix D. Palliative care services must have clear links or networks with specialist services and teams irrespective of the care environment. Staffing levels and accommodation must be adequate to ensure the delivery of high quality care.**

⁹Frankel S. (1990) Assessing the need for hospice beds. Hth Trnd 2:83-6

4.0 Model of Care

4.1 There is no 'correct' model for the provision of palliative care. It is reasonable to expect some variation in approach as a result of local demography and the current availability of specialist services. However, there are key building blocks to any model which need to be applied.

4.2 The palliative care approach should be practised by all health and social care professionals in all care settings.

4.3 Specialist palliative care services must be provided by an appropriately qualified and experienced multi-professional team, normally, led by a consultant in palliative medicine, linking in with the multi-professional team at the Cancer Centre and Cancer Units.

4.4 Mechanisms should be in place to ensure effective liaison between primary, community and secondary health and social care services. These mechanisms should help support collaborative working within and between the statutory and independent sectors.

4.5 All providers of current services should be involved in the implementation of HSS Board plans, as illustrated in the HSS Board Cancer Reports, to ensure a smooth transition from current arrangements to new models of care.

4.6 The views and opinions of patients, carers and their families must be central to the further development and implementation of HSS Board plans.

5.0 Quality

5.1 Maintaining and enhancing the quality of care is central to the provision of palliative care. **Patients, carers and their families should receive the same high standard of care irrespective of their location and source of service delivery.**

5.2 There are numerous models and frameworks in the literature for developing a quality palliative care service,^{10,11,12,13,14} and much good work has been achieved locally.

5.3 As with every other service, palliative care is undergoing change and development as a result of advances in clinical science, pharmacology, technology and, perhaps more importantly, as a result of increasing public expectations about what the service can and should provide. Palliative care settings will be subject to the same scrutiny and accountability as other service areas through new clinical and social care governance arrangements.

5.4 **As new arrangements for commissioning services are developed, it is important that services are underpinned by guidelines and standards based on robust evidence and subject to rigorous monitoring.**

Guidelines and Standards

5.5 This report concentrates on areas that require the development of regional guidelines from which local standards can be further derived. For the purposes of this report, guidelines are defined as;¹⁵ systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances', and standards as, 'a statement against which performance can be measured.' Standards must be specific, measurable, and achievable within realistic time-scales.¹⁶

¹⁰ Palliative Care Standards. (1998) A national view of work undertaken in the field of palliative care quality assurance. Anglia and Oxford.

¹¹ The Scottish Office NHS MEL (1997) 17 'Commissioning Cancer services in Scotland: Primary and Palliative Care Services' (1997) incorporating Palliative Care Guidelines. Scottish Partnership Agency for palliative and Cancer Care (1994)

¹² The Welsh Office (Cancer Co-ordinating Group) (1996) 'All Wales Minimum standards for Breast Cancer'

¹³ NHS Executive North Thames (1996) 'Criteria and Standards for Cancer Centres.

¹⁴ The Royal College of Nursing Standards for Palliative Care Nursing.

¹⁵ Field M and Lohr (Ed's) (1990) Clinical Practice Guidelines: Directions for a new Program. National Academy Press, Washington DC, pp.8,14.

¹⁶ Hurwitz, Brian. (1998.) Clinical Guidelines and the Law, Negligence, Discretion and Judgement. Radcliff Medical Press.

5.6 As indicated in 3.9, palliative care is provided in an increasing variety of care environments. **Accreditation criteria and standards have been developed for some palliative care services, including specialist and general palliative care services.** (Appendix D)

5.7 Key areas where guidelines and standards need to be developed include symptom control and communication. Recent research shows that pain and symptom control in patients receiving palliative care in different settings is still far from optimal, with many symptoms remaining unrelieved¹⁷ and current palliative care guidelines having yet to be implemented.^{18,19} **Regional guidelines for symptom control must be developed. A multi professional group linked to the overall quality strategy for the HPSS should take forward this work. A training strategy should be developed to support the dissemination of the guidelines to statutory and independent organisations. To ensure the implementation of good practice there should be continuous monitoring and evaluation by both providers and commissioners of services.**

5.8 Key to the development of guidelines is the work of the Health and Social Services Councils and work completed in the Western Health and Social Services Board Area (WHSSB) with members of the primary care team. The reports of the Eastern and Southern HSS Councils highlight some areas of common concern for service users, carers and families and provide a clear direction for the development of guidelines and standards.^{20,21} The WHSSB survey illustrated core problems in areas such as professional support and access to education and training²². Areas suggested for core regional guidelines have been illustrated in Appendix C.

¹⁷ Johnston G. (1995) The WHO objectives for Palliative care: to what extent are we achieving them ? *Palliative Med.* 9: 123-137

¹⁸ Doyle D. Domiciliary terminal care.(1980) *Practitioner* 224: 575 - 82

¹⁹ Doyle D. Domiciliary terminal care: demands on the statutory services. *JR Coll Gen Pract.*32:285-91

²⁰ Eastern Health and Social Services Council (1996) Survey of Views of Service Users of Palliative Care Services in the Eastern Board Area.

²¹ Southern Health and Social Services Council (1997) Carer's Perceptions and Experiences of Palliative Care Services.

²² WHSSB (1998) Unpublished Survey of Primary Care Professionals.

5.9 The development of any guidelines should:

- reflect guidelines produced by other bodies such as the National Institute for Clinical Excellence and the National Council for Hospice and Specialist Palliative Care Services;^{23, 24}
- be developed by a multi professional, multi agency group, and where possible, on a collaborative basis with patients, carers and family, or otherwise ensure that the patient and carer perspectives are considered;
- be applicable across care settings;
- be an integral part of any site specific cancer guidelines, and
- be rigorously monitored and updated.

Audit and Evaluation

5.10 The multi professional clinical network incorporating the Cancer Centre, Cancer Units and other providers of care should be utilised in developing a regional audit framework for palliative care.

5.11 The development of guidelines and standards will be of little value unless they are implemented and make a positive difference to the care of patients, their families and carers. Both providers and commissioners of service have a responsibility to ensure that high quality care is delivered through the implementation of these guidelines. **All providers of services should ensure that staff adhere to agreed standards and that there is effective monitoring through uni - and multi-professional audit.**

5.12 Health and Social Services Councils should be facilitated to review palliative care services on a regular basis, no longer than every three years.

²³ Department of Health (1998) A First Class Service. HMSO

²⁴ Making Palliative Care Better. (1997) National Council for Hospice Specialist Palliative Care services.

Research

5.13 Good quality research underpins the development of standards and guidelines and ensures that advances are made in the care and treatment of patients. **A research strategy for palliative care should be developed by a core palliative care group, linking in with the research framework and strategy of the Cancer Centre and the Research and Development Office.**

6.0 Workforce and Education

Workforce

6.1 The development of a specialist palliative care team has been proposed within each model of service developed by Boards. **To meet the patient's needs these teams should have as core members: a consultant in palliative medicine, a general medical practitioner with specialist training or interest in palliative medicine; palliative care nurses; social worker; pharmacist; professions allied to medicine; clinical psychologist and spiritual support. Additional members would link into the team, such as general dental practitioners, when patient need is identified.**

6.2 The workforce implications for the implementation of each HSS Board's plans have focused on the numbers of consultant medical staff required. The implications for other staff groups including nurses, physiotherapists, social workers, pharmacists, occupational therapists and other professions allied to medicine need to be more fully addressed. **HSS Boards should identify the total resource implications for the implementation of their plans for palliative care services. Accreditation criteria detailed in Appendix D will help HSS Boards benchmark current services.**

Staff Support

6.3 Caring for patients with palliative care needs can often be demanding and stressful for staff. **All providers of care should have mechanisms in place to ensure that staff have access to regular support to enable them to care for their patients, such as multi - professional case discussions, clinical supervision and a range of systems for personal support.**

Education

6.4 The level of palliative care training at undergraduate level for most professionals is limited. **Undergraduate training for all professionals should include training in the principles of palliative care, promoting a patient centred multi-professional approach. All developments in palliative care education should reflect the multi-professional, multi-agency system of care delivery.**

6.5 Specialist teams will support colleagues in primary and secondary care settings. For the majority of patients, particularly in the community setting, the majority of care is provide through the primary care team. **All staff providing care, including staff from the statutory and independent sectors, should have access to training in the palliative care approach.**

6.6 The level of training required will be dependent on the individual's role and the needs of patients. Three levels have been identified:

- Level One, which should be available to all staff with the objective of creating awareness of the principles of palliative care;
- Level 2, for health and social care professionals working in an environment where they have frequent and regular contact with patients and families requiring palliative care, and
- Level 3, in which professionals will have attained the recognised level of specialist practice, for example, registered on the General Medical Council's specialist register in palliative medicine, or comply with the UKCC's guidelines for specialist practice nursing.

6.7 Access to specialist training is not the same for all professional groups. **Where there is no local access to specialist training, mechanisms should be developed, for example through better use of information technology or distance learning packages, to improve opportunities for staff.**

6.8 **Each organisation and individual providing care should identify training and education needs and work in collaboration with the various providers of education to address these needs.**

6.9 **A multi-professional, multi-agency task force should be formed, to develop a strategy for palliative care education and training, which will make the best use of current resources, minimise duplication of effort and make the best of opportunities for shared learning.**

7.0 Services for Children

7.1 The Review has tried to identify the palliative care needs of children and suggest a way forward for local services, particularly for children with life threatening illness.

7.2 Palliative care for children and young people with life-threatening conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child with support for the family and includes the management of distressing symptoms, provision of respite services and care through the trauma of death and bereavement.²⁵

7.3 There have been significant improvements in the treatment and care of children in the past few decades. Children who previously would have had a poor life expectancy are now surviving longer, often with complex needs. Consequently the child and their family are faced with both the physical and psychological problems associated with chronic life threatening conditions²⁶ and, in addition, may have to deal with sibling adjustment, additional financial costs, other concurrent stresses and marital difficulties.²⁷

7.4 Defining a child can create some difficulties as providers of service use a range of different upper age limits. This can result in young people being inappropriately placed in adult facilities for their care and treatment. For the purposes of this report the group used the definition of the child as 'a person under the age of 18yrs'²⁸.

7.5 Four broad groups of children have been identified.

Group 1. Life-threatening conditions for which curative treatment may be feasible but can fail, such as cancer, irreversible organ failures of heart, liver, and kidney.

²⁵ Association of Children with Life threatening or terminal conditions and their families & Royal College of Paediatrics and Child Health, report of Joint Working Party. 'A guide to the development of Children's Palliative Care Services'. (1997)

²⁶ Koocher G. Psychological issues during the acute treatment of paediatric cancer. *Cancer* (1986.) 58, 468-472

²⁷ Odenven S, Childhood cancer: Helping the individual cope within the family. *Paediatric Nursing* Sept. (1997), Vol. 9, No. 7.

²⁸ The Children (NI) Order 1995 HMSO: Belfast.

- Group 2. Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but in which premature death is likely possible, including cystic fibrosis, muscular dystrophy.
- Group 3 Progressive conditions without curative treatment options, where treatment is exclusively palliative and may frequently extend over many years, such as Batten's disease, mucopolysaccharidosis.
- Group 4 Conditions with severe neurological disability which may cause weaknesses and susceptibility to health complications, and may deteriorate unpredictably, although they are not usually considered progressive, for example, severe muscular disabilities such as brain or spinal cord injuries including some children with severe cerebral palsy.²⁹

7.6 Many of the children in groups 2, 3 and 4 currently receive services through the children's services within a disability programme of care and/or specialist teams such as in cystic fibrosis. This report concentrates initially on children with life threatening conditions. As a separate initiative from the Review, an assessment of need for all children within the four groups is currently being completed by the Northern Ireland Hospice.

Projected Activity Profile

7.7 Current studies suggest that for every 50,000 children:

- five are likely to die in a year as a result of a progressive condition for which palliative care is appropriate, and
- 50 are likely to have a life limiting condition over half of who will have substantial palliative care needs.

²⁹ Association of Children with Life-threatening or Terminal Conditions and Their Families & the Royal College of Paediatrics and Child Health. (1997) A Guide to the development of a Children's Palliative Care Service.

It is estimated that there are 432,000 children under the age of 18 years. This means 43 children are likely to die of a life limiting condition and 430 who are likely to have a life limiting condition about half of whom will need active palliative care at any one time.^{30, 31}

7.8 More recent studies by Lenton suggest that non-malignant life-threatening illness is more prevalent than reported, with considerable morbidity experienced by the child and their family³². **When planning services HSS Boards need to consider the total palliative care needs of all children.**

Current Activity Profile

7.9 Assessment of current palliative care activity is limited by the information systems currently used. From 1993-95, on average, 52 childhood cancers were registered annually. Childhood cancer is rare and accounts for only 0.6% of all cancers³³. Information provided through the Royal Group Hospitals indicates that for 1997/98

- 31 children died as a result of cancer;
- 20 of these children died at home, and
- 11 died in hospital

Of the 20 children who died at home, all received care from a paediatric Macmillan nurse. Only two children accessed nursing care from community paediatric nurses³⁴, as this service is not yet fully developed.

Current Services

7.10 A range of individuals and organisations provide support and care for children with life-threatening illness. These include parents, family, statutory health and social care professionals and voluntary organisations.

³⁰ Botting Beverley (Ed) (1995) The health of our children. OPCS, Series DS no. 11 HMSO
London Stiller CA (1994) Population based survival rates for childhood cancer in Britain, 1980-91. British Medical Journal, 309, 1612-1616

³¹ Kilmurray A and Richardson V (1994) Focus on Children. Blue Print for Action.

³² Lenton SW, Stallard P, Lewis M, Mastroyannopoulou K (1999) Prevalence of non malignant life-threatening illness in Childhood Conference Presentation.

³³ NI Cancer Registry (1999) Cancer incidence in Northern Ireland. 1993-95. The Stationary Office.

³⁴ Source Royal Belfast Hospital for Sick Children (1998)

7.11 The current model of care relates mainly to children with cancer and is based on a paediatric 'outreach' service from the Regional Children's Cancer Centre at the Royal Belfast Hospital for Sick Children. (RBHSC) This service is co-ordinated and to a greater part provided through two specialist nursing staff. Initial funding for these posts has been provided through Macmillan Cancer Relief. Support for these nurses is provided through the professional nursing structures within the Royal Group Hospitals Trust and Macmillan Cancer Relief.

7.12 Medical support and advice is provided from the regional consultant paediatric haematologists and a clinical medical officer at the RBHSC and, on an occasional basis, from the consultant in paediatric palliative care, Great Ormond Street Hospital London. Advice is received from some consultant medical staff from local Hospice's although this arrangement is ad hoc and not acceptable as a long-term solution to the need for specialist paediatric palliative care advice. **Professionals require access to specialist advice and support from a consultant paediatric service, with expertise in palliative medicine.**

7.13 Parents, General Practitioners, district nurses and voluntary organisations generally provide the practical care required by these children. Children who do not have direct contact with the Children's Cancer Unit at RBHSC may be unable to avail of the limited specialist paediatric service, particularly children with brain tumours. **While referrals to the current palliative care service has been improving, further work is required to ensure that children and their families who do not have direct contact with the Children's Cancer centre have access to specialist palliative care services.**

7.14 There is a very limited and often non-existent children's community nursing service, which can support either the primary care team or the specialist paediatric Macmillan nursing service. The current model of nursing care cannot sustain a high quality service in the medium to long term. **Children's community nursing services should be enhanced to meet the standards recommended by the House of Commons Health Committee (1997) and the recent Department of Health and Social Services publications that is;**

- **All children requiring nursing interventions should have easy access to a Children's Community Nursing Service, staffed by qualified children's nurses and supplemented by those in training, in whatever setting in the community they are being nursed.**
- **The service should be available 24 hours a day, seven days a week.**
- **Every GP should have access to a named Community Children's Nurse.**
- **Information about the service should be easily available to all relevant health care professionals and voluntary organisations.**
- **Co-ordination between agencies and professionals should be regarded as an essential part of providing a good service.**^{35, 36, 37}

7.15 The Northern Ireland Hospice is currently developing a Children's Hospice. This service includes a children's community care team who will provide respite care in the home. It will be important that this team works in partnership with paediatric community nursing services and strategic plans for childrens services currently being developed by HSS Boards.

Future Service Model

7.16 The Review Group support the model of service contained in the report of, The Joint Working Party of the Association for Children with Life Threatening or Terminal Conditions and their families and the Royal College of Paediatrics and Child Health, '*A Guide to the Development of Children's Palliative Care Services*'. This includes:

- a locally based children's palliative care service which provides, nursing in the home, school or other location;
- access to professions allied to medicine service;

³⁵ Health Committee (1997) Health Services for Children and Young people in the Community: Home and School. HC 314 - 1, HMSO, London.

³⁶ Department of Health and Social Services. (1999) Nursing services for the Acutely Ill Child in Northern Ireland. Report of a Working Group. The Stationary Office. Belfast.

³⁷ Department of Health and Social Services (1999) Hospital Services for the Acutely Ill Child in Northern Ireland. Report of a Working Group. The Stationary Office, Belfast.

- involvement of psychology, mental health and social services;
- availability of specialist tertiary hospital services;
- access to respite care; and
- bereavement support.

7.17 There is sufficient evidence to indicate that a specialist paediatric palliative care team is required. The core membership of the team should include: a consultant paediatrician with specialist interest in palliative medicine; specialist paediatric nursing; specialist pharmacy; professions allied to medicine; social services staff and general practitioners with a special interest in paediatric palliative medicine. This team would develop a regional clinical network with strong links to the Cancer Centre and provide a resource of advice and practical help to the health and social care professionals who commission and provide care.

7.18 The provision of a local Paediatric Palliative Care Service should ensure that:

- the child, their family and the home are at the heart of all services;
- voluntary and statutory organisations work together to avoid unnecessary duplication of services;
- services are provided by a multi professional team of professionals and others who have the necessary skills and expertise to provide the highest quality of care possible;
- services are provided by paediatric trained staff;
- there is access to specialist services and advice when required, and
- services should be provided at home, or close to the home, whenever possible.

8.0 Summary

8.1 Many of the messages and recommendations in this review are not new. This review offers an opportunity to reassert the significance of palliative care services in the care and treatment of a wide range of individuals and their families. **Commissioners and providers must work in partnership to ensure that patient/carer needs are identified and resources made available to meet these needs.** The importance of implementing agreed guidelines and standards in the design, development and delivery of palliative care services cannot be under-estimated. The aim is to provide a high quality palliative care service which focuses on the needs of patients and their carers.

8.2 The review makes a number of recommendations. Key to the recommendations is an agreed time scale within which it is reasonable to expect action to have been taken. The table below illustrates the anticipated time-scale for action. The recommendations are illustrated under the following headings:

- General recommendations;
- Care Team;
- Patient , Carer involvement and views;
- Standards and Guidelines, and
- Education and Training.

General recommendations	Key Organisation responsible	Timescale
When developing palliative care services commissioners need to be mindful of the total palliative care needs of patients with both cancer and non cancer conditions. Paragraph 2.6.	Commissioners	<i>Immediate</i>
HSS Boards should identify the total resource implications for the implementation of plans for palliative care services. Paragraph 6.2.	HSS Boards	<i>Immediate</i>
All HSS Boards should ensure that, in new schemes for out of hours medical care, arrangements are in place which will ensure continuity of care for patients with palliative care needs. Paragraph 3.4.	HSS Boards	<i>Short Term</i>
Mechanisms should be in place to ensure effective liaison between primary community and secondary health and social care services. These mechanisms should help support collaborative working within and between the statutory and independent sectors. Paragraph 4.4.	HSS Boards	<i>Medium Term</i>

General recommendations	Key Organisation responsible	Timescale
Palliative Care Services must have clear links or networks with specialist services and teams irrespective of the care environment. Paragraph 3.10.	All Providers	<i>Short – Medium Term</i>
HSS Boards should provide a directory detailing all available services, in collaboration with general practitioners, HSS Trusts, independent, voluntary and community groups. This directory should be made accessible in a wide range of formats to patients, families and professionals and provision made to update annually. Paragraph 3.3.	HSS Boards	<i>Medium Term</i>
All providers of services should adopt a common approach to patient held records. Paragraph 3.8.	All care Providers	<i>Medium Term</i>
Patient, Carer Involvement & Views		
All providers of current services should be involved in the implementation of HSS Board plans, as illustrated in the Board Cancer Reports, to ensure a smooth transition from current arrangements to new models of care. Paragraph 4.5.	HSS Boards	<i>Immediate</i>
The views and opinions of patients, carers and their families must be central to the further development and implementation of Board plans. Paragraph 4.6	HSS Boards	<i>Immediate</i>
Health and Social Services Councils should be facilitated to review palliative care services on an regular basis, no longer than every three years. Paragraph 5.12.	HSS Councils	<i>Immediate</i>
Care Team		
The caring team, in partnership with the patient and their carers should agree and clearly identify a key worker for each patient. This key worker should co-ordinate the efforts of the whole care team and ensure continuity of care. This key worker will often be the patients general medical practitioner, but flexibility is important in order to reflect changing individual patient need. Paragraph 3.2.	HSS Trusts	<i>Immediate</i>
All providers of care should have mechanisms in place to ensure that staff have access to regular support to enable them to care for their patients, such as, multi professional case discussions, clinical supervision and a range of systems for personal support. Paragraph 6.3.	All care Providers	<i>Short – Medium Term</i>

General recommendations	Key Organisation responsible	Timescale
Care Team		
A local network of pharmacists who have received advanced training in palliative care should be established. These pharmacists would offer specialist advice, maintain appropriate levels of palliative care medicines for supply and provide out of hours dispensing services for such drugs. There should be established linkages between hospital and community pharmacies to ensure continuity of care between primary and secondary sectors. Paragraph 3.5.	HSS Boards	<i>Medium Term</i>
Specialist palliative care services must be provided by an appropriately qualified and experienced multi-professional team normally led by a consultant in palliative medicine, linking in with the multi-professional team at the Cancer Centre and Cancer Units. Paragraph 4.3.	HSS Boards	<i>Medium Term</i>
Staffing levels and accommodation must be adequate to ensure the delivery of high quality. Paragraph 3.10.	HSS Boards – All Providers	<i>Short – Medium Term</i>
Sufficient primary care staff, skilled in palliative care, should be available to ensure the provision of high quality care. Mechanisms should be put in place to ensure that specialist medical advice is available to general medical practitioners, other doctors who have examined the patient for whom the advice is required, or other professionals. Paragraph 3.8.	HSS Trusts and Boards	<i>Medium – Long Term</i>
Standards		
Patients, carers and their families should receive the same high standard of care irrespective of their location and source of service delivery. Paragraph 5.1.	All Providers HSS Boards	<i>Short Term</i>
Standards for palliative care and treatment in nursing and residential care homes should be further developed, building on current good practice. Paragraph 3.9/5.7.	Regional multi professional standards group HSS Boards	<i>Medium Term</i>
Accreditation criteria and standards should be developed for all palliative care services at including specialist and general palliative care services. Paragraph 5.6. Appendix C.	Regional multi professional standards group	<i>Short – Medium Term</i>
The multi professional clinical network incorporating the Cancer Centre, Cancer Units and other providers of care should be utilised in developing a regional audit framework for palliative care. Paragraph 5.10.	HSS Boards/ All Providers	<i>Medium Term</i>
All providers of services should ensure that staff adhere to agreed standards and that there is effective monitoring through uni and multi-professional audit. Paragraph 5.11.	All care Providers	<i>Medium Term</i>

General recommendations	Key Organisation responsible	Timescale
A research strategy for palliative care should be developed by a core palliative care group, linking in with the research framework and strategy of the Cancer Centre and the Research and Development Office. Paragraph 5.13.	Research and Development Office.	<i>Medium Term</i>
As new arrangements for commissioning services are developed it is important that services are underpinned by guidelines and standards based on robust evidence and subject to rigorous monitoring. Paragraph 5.4.	HSS Boards and other Service Commissioners	<i>Medium – Long Term</i>
All providers of services should ensure that staff adhere to agreed standards and that there is effective monitoring through uni and multi professional audit. Paragraph 5.11.	All care Providers	<i>Medium Term</i>
Education & Training		
Each organisation and individual providing care should identify training and education needs and work in collaboration with the various providers of education to address the identified need. Paragraph 6.8.	All care Providers	<i>Short Term</i>
Undergraduate training for all professionals should include training in the principles of palliative care, promoting a patient centred multi-professional approach. All developments in palliative care education should reflect the multi-professional, multi-agency system of care delivery. Paragraph 6.4.	Pre and post registration Education Providers	<i>Medium Term</i>
All staff providing care, including staff from the statutory and independent sectors should have access to training in the palliative approach. Paragraph 6.5.	All care providers	<i>Medium Term</i>
Where there is no local access to specialist post registration training, mechanisms should be developed, for example through better use of information technology or distance learning packages, to improve opportunities for staff. Paragraph 6.6.	Post Registration education providers	<i>Medium Term</i>
A multiprofessional, multi-agency task force should be formed, to develop a strategy for palliative care education and training which will make the best use of current resources, minimise duplication of effort and make the best of opportunities for shared learning. Paragraph 6.9.	Regional Review Group	<i>Established in the Short term with outputs in the Medium Term</i>
Services for Children		
While referrals to the current palliative care service has been improving, further work is required to ensure that children and their families who do not have direct contact with the Children's Cancer Centre have access to specialist palliative care services. Paragraph 7.13.	HSS Trusts	<i>Short – Medium Term</i>

General recommendations	Key Organisation responsible	Timescale
Specialist advice and support from a consultant paediatric service with expertise in palliative medicine is required. Paragraph 7.12.	HSS Boards	<i>Medium Term</i>
Children's community nursing service should be enhanced to meet the standards recommended by the House of Commons Health Committee (1997) and the recent DHSS reports. Paragraph 7.14.	HSS Trusts and Boards	<i>Medium Term</i>
There is sufficient evidence to indicate that a specialist paediatric palliative care team is required. The core membership of the team should include, consultant paediatrician with specialist interest in palliative medicine; specialist paediatric nursing; pharmacy; professions allied to medicine; social services staff and general medical practitioners with a special interest in paediatric palliative medicine. Paragraph 7.17.	HSS Boards	<i>Medium Term</i>
<p>The provision of a Paediatric Palliative Care Service for the north of Ireland should ensure that:</p> <ul style="list-style-type: none"> • The child, their family and the home are at the heart of all services; • Voluntary and statutory organisations work together to avoid unnecessary duplication of services; • Services are provided by a multi professional team of professionals and others who have the necessary skills and expertise to provide the highest quality of care possible; • Services are provided by paediatric trained staff; • There is access to specialist services and advice when required; and • Services should be provided at home, or close to the home, whenever possible. <p>Paragraph 7.18.</p>	HSS Boards All care Providers	

Immediate – < 6 months post publication of the review

Short Term – < 1 year

Medium Term – < 1-2years

Long Term – < 5 years

Appendix A

Membership

Miss Judith Hill (Chair)	Chief Nursing Officer, DHSS
Mr. St John Hattersley	Service Development Manager, Macmillan Cancer Relief
Ms Paula Mulally	Assistant Nurse Manager, Marie Curie Nursing Service Marie Curie Centre, Belfast
Ms Maeve Hully	Caring Services Manager Marie Curie Centre, Belfast
Dr Angela Garvey	Chair of Western Board Palliative Care Group
Dr Sheila Kelly	Consultant in Palliative Care Medicine, Belfast City Hospital
Dr John Galway	Consultant Anaesthetist, Craigavon Area Hospital (now retired)
Mrs Nuala Mc Ardle	PAMS Officer, DHSS
Ms Heather Robinson	Secondary Care Unit, HSSE until January 1999
Dr John Johnston	General Practitioner, Northern Health and Social Services Board Area
Ms Margaret Dodds	Social Worker, Northern Ireland Hospice (Northern Ireland Forum for Palliative Care Social Workers)
Mrs Hillary Herron	Children's & Palliative Care Services, Royal College of Nursing
Mr Noel Mc Cann	HSS Executive (from January 1999)

Mrs Jane Graham,	Chief Officer, Eastern Health & Social Services Council
Dr Aleen Jones	Consultant Geriatrician, South Tyrone Hospital
Dr Yvonne Duff	Medical Director, Northern Ireland Hospice
Dr Adrian Mairs	Senior Medical Officer, DHSS
Mr Eugene Fee	Director of Acute Services, Sperrin Lakeland Trust
Ms Anne Friel	Head of Pharmacy, Craigavon Area Hospital
Mrs Lynda Campbell	Primary Care Manager, Down Lisburn HSS Trust
Mrs Liz Atkinson	Nursing Director, NI Hospice

SECRETARIAT

Hilary Jennings	Secondary Care Unit HSSE
Mrs Mary Hinds	Nursing Officer, DHSS

Appendix B

Board Area	Currently designated specialist beds	Beds allocated to provide palliative care
Northern Health and Social Services Board		Robinson – 4 Braid Valley – 4 Moyle – 2
Southern Health and Social Services Board	Newry Hospice – 8	
Eastern Health and Social Services Board	Marie Currie Centre – 23 NI Hospice – 21	
Western Health and Social Services Board	Foyle Hospice – 12	

Appendix C

Areas for Development of Guidelines

Bereavement care

Assessment

Information

Communication

The role of the Key Worker

Teamwork

Care of the family

Breaking bad news

Record Keeping

Choice of care and care setting

Specialist Palliative Care

Partnerships in Caring

Standards for Service

A working guide to accreditation.

2000

Introduction

1.0 Palliative care is, ‘the care of patients with active, progressive, advanced disease with a limited prognosis and for whom the goal of care is the quality of life.’¹ Palliative care is delivered by a variety of individuals and organizations and in a range of settings including hospital, community and hospice. Not all palliative care services are the same. The difference between services is not always clear to patients, professionals or the general public causing confusion. Because of this variation in approach there is a need to agree a common language which will define services.

1.1 There has been a history of co-operation and partnership between the statutory and independent sectors in the development of current palliative care services. The publication of the ‘Campbell’ report, Cancer Services, Investing for the Future, and the subsequent Regional Review of Palliative Care services has created the opportunity and impetus to build on this good work and further develop local palliative care services. This manual is a continuation of this work.

1.2 This manual aims to provide clarity with regards to the definition and description of palliative care services. It is a tool which can be used by commissioners and providers of services to assess current service against a set of clearly defined standards for palliative care. This will help providers and commissioners of palliative care service;

- Categorize the current position of services;
- Identify areas where improvements could be made and
- Enable services to be developed to a consistently high standard.

1.3 Following initial assessment this tool should be used bi annually, allowing time for services to develop and continuously improve.

¹ Association of Palliative Medicine of Great Britain and Ireland.

2.0 Levels of Palliative Care Service

2.1 Three levels of palliative care service have been identified

- **Level One** – This level of palliative care is generally delivered by the Primary Care or Ward Team . This level is often referred to as the palliative care approach, informed by a knowledge of the principles of palliative care and a fundamental competence in the symptom control and emotional problems which can arise for patients with a life threatening or incurable illness. It embraces the palliative care approach in all aspects of health and social care.
- **Level Two** – Palliative care at this level is general palliative care delivered for example in the home, local, area or tertiary hospitals, nursing homes and some hospice settings by professionals with enhanced palliative care skills. It may require some specialist intervention.
- **Level Three** – This level is specialist palliative care where patients with the most complex needs require a high degree of specialist intervention, incorporating services provided by an accredited specialist multiprofessional team with advanced education, training and experience.

While all of these levels of care can be provided within any environment they each require a different concentration of specialist skills, expertise and resources. Services can only be developed in an incremental way, Level three being reached only after Levels one and two have been achieved.

1.5 The development of criteria to define the various levels of palliative care services concentrate on two key areas:

- Professionals
- Systems to support the delivery of services.

Definitions of Levels of Palliative Care

Level One – The Palliative Care Approach

The Palliative care approach aims to promote both physical and psychological wellbeing. It is an essential component of all good practice and is core to the primary care and ward teams. The key principles include:

- Focus on quality of life which includes good symptom control.
- Whole person approach taking into account the person's past life experience and current situation.
- Care which encompasses both the person with the life threatening disease and those important to that person.
- Respect for patient autonomy and choice.
- Emphasis on open and sensitive communications which extends to patients, informal carers and professional colleagues.³

Staff

Staff should be aware of the above principles and should be supported and encouraged in the application of these principles in their daily work.

Level Two – General Palliative Care

General Palliative care embraces the principles of the palliative care approach. General palliative care is the provision of long term or respite care for those with less complex problems or whose problems are responding to clinical management. This type of care can be provided by a variety of professionals and in a range of settings, such as in the home, local, area or tertiary hospitals and nursing homes. Some hospices may elect to provide general palliative care, where appropriate to local need, professional skills and support.

² Ward Team is defined as a team who work in an inpatient setting whether hospital, hospice or nursing home.

³ National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care (1998) Reaching Out: Specialist Palliative care for Adults with non malignant disease. Occasional paper 14.

Staff

Staff who are providing general palliative care must have extended skills and expertise in palliative care. They will have access to the specialist palliative care team for advice and support.

Level Three – Specialist Palliative Care

There are some patients whose physical symptoms and psychosocial needs are so complex or intractable that they require the care of a multi disciplinary specialist palliative care team. Specialist services must offer a full and comprehensive service, including 24-hour access to specialist medical advice.

Specialist Palliative Care Services will generally provide the following services:

- Specialist Assessment
- Inpatient
- Home Care
- Day Hospice Care
- Outpatient
- Domiciliary visits

Specialist palliative care must be organized in multi professional teams of specialist professionals. These teams have two key roles, they can provide direct care to patients and their families or provide advice to other care providers, such as local hospital staff or the primary care team. The team;

- provides specialist advice, care and treatment in the management of complex care issues such as symptom control;
- co-ordinates specialist care;
- provides emotional and bereavement support, and
- participates in specialist education and training programmes.⁶

Staff

All staff should have experience in the palliative care environment and have an accredited, recognized or specialist qualification, appropriate to their professional group, in palliative care/medicine.

Where nurses have been employed to care for cancer patients with site specific tumors, arrangements must be in place to supplement care if necessary to ensure that the palliative care needs of the patient are met.

Inpatient Units

Specialist units will admit and discharge many patients after short lengths of stay and perform some investigations and interventions traditionally associated with acute hospitals.⁴ The emphasis is on;

- symptom control and crisis intervention ;
- respite care, and rehabilitation generally limited to a maximum of 2 weeks, and
- terminal care, defined as the last phase of illness such as the last week of life.^{5,6}

Throughout inpatient admissions the patients needs are continually reassessed and where the need for Specialist Palliative Care no longer exists, in discussion with the patient and family the patient may be discharged to the most appropriate care setting.

This working guide to accreditation is a template on which other services areas can begin to set standards. Further work needs to be developed in areas such as childrens services. As a working document it will change to best meet patient, family and carer needs.

⁴ National Council for Hospice and Specialist Palliative Care Services. (1997) Dilemmas and Direction: The Future of Specialist Palliative Care. Occasional paper 11. National Council for Hospice and Specialist Palliative Care Services.

⁵ National Council for Hospice and Specialist Palliative Care Services. (1999) Palliative Care 2000, Commissioning through partnership.

⁶ Marie Curie Centre (NI) & NI Hospice (NI) (1999) Unpublished Paper. Specialist Palliative Care services in Belfast.

Level One – Palliative Care Approach

1 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<p>1. All staff should be aware of the palliative care approach and should be supported in the application of the palliative care approach to their daily work.</p>	<p>(a) Attendance records at palliative care awareness sessions for all staff who come in contact with the patient and their carers.</p> <p>(b) Evidence of continuing professional development in palliative care appropriate to professional groups. Examples include, CME, PREP PGEA, NICPPET)</p> <p>(c) Evidence of staff support mechanisms in place.</p>			
<p>2. Lead professionals should be identified within every HSS Trust / Provider to ensure that:</p> <ul style="list-style-type: none"> • Training needs assessments are completed; • Training and development opportunities are available and utilized by staff; 	<p>(a) A lead professional should be identified within each Trust / Provider.</p> <p>(b) Evidence of links with other Palliative Care Groups such as the Regional Group of the Northern Ireland for Hospice and Specialist Palliative Care Services.</p>			

1 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<ul style="list-style-type: none"> • Standards for the provision of services have been developed • Services are subject to regular audit and review, and • Staff have access to information on current and new developments in palliative care/medicine. 	<p>(c) Evidence of standards development, audit reports and action plans.</p> <p>(d) Dissemination protocols / communications strategy in place within each Provider.</p>			
1 Systems / Support Mechanisms				
<p>3. The environment facilitates the enhancement of the provision of palliative care and the quality of life of the patient and their family.</p>	<p>(a) Palliative care is provided within appropriate environments evidenced through views of patients/ carers.</p>			
<p>4. Systems must be in place to ensure that the continuity of care, particularly general medical care, is maintained outside normal working hours.</p>	<p>(a) Written protocols agreed with the key stakeholders regarding access to services after hours.</p>			

1 Systems / Support Mechanisms	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
	(b) Evidence of the provision of clear information to the patient and their family on access to services after hours. (c) Evidence of systems which ensure the smooth and timely exchange of clinical /care information between the health and social care professionals. (For example between hospital and primary care team or between primary care team and out of hours GP co-operatives)			
5. Services will be planned, provided and reviewed on a multi professional basis embracing the palliative care approach.	(a) Evidence of multi professional team meetings (b) Reviews of care plans. (c) Qualitative survey of staff providing care.			
6. Information will be provided in appropriate formats, to patients and their carers on the range and choice of palliative care and other support services.	(a) Evidence through leaflets made available to patients and their families/ carers.			

1 Systems / Support Mechanisms	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
7. A local directory of palliative care services will be available and regularly updated.	(a) Evidence of regular updated information provided by individual Trusts / providers of palliative care.			
8. Clear systems will be in place to support open and sensitive communication between patients, informal carers and professional colleagues.	(a) Evidence of processes developed and implemented within Trusts and providers of palliative care to support effective communication systems between patients, carers and professional colleagues.			
9. Systems, which facilitate the regular review of patients assessing their needs and the appropriateness of, level one care should be in place. Where level two care is required the transition to the appropriate care team should be facilitated.	(a) Evidence of case reviews and subsequent action			

Level Two – General Palliative Care

In addition to the criteria below all of the criteria in Level one must be met before Level Two can be achieved.

2 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<p>1. Providers should comply with the minimum requirement of palliative care training for at least one member of staff in each of the following professional groups.</p> <ul style="list-style-type: none"> • Medicine – Diploma in Palliative Medicine and /or experience in working in a palliative care environment and evidence of continuing professional development in palliative medicine. • Nursing – Post registration qualification in palliative care equivalent to one module and experience in working in a palliative care environment and evidence of continuing professional development in palliative care nursing. 	<p>(a) Evidence of staff qualifications and experience.</p> <p>(b) Evidence of continuing professional development.</p>			

2 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<ul style="list-style-type: none"> • PAMS – Post registration qualification or experience in the palliative care environment and evidence of continuing professional development in palliative care. • Pharmacy – Relevant post registration qualification or experience in the palliative care environment and evidence of continuing professional development in palliative care. • Social work – Relevant post registration qualification or experience in the palliative care environment and evidence of continuing professional development in palliative care. • Chaplains – Additional training and experience in working in the palliative care environment. 				
<p>2. All staff should have access to ongoing palliative care education and training opportunities, gaining experience in specialist units where appropriate.</p>	<p>(a) Records of attendance at educational and training opportunities. (Seminars / Courses)</p> <p>(b) Evidence of experience in specialist units.</p>			

2 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
3. Mechanisms should be in place to ensure GPs and other professionals have access to specialist palliative advice.	(a) Written protocols available for all professional groups to access specialist palliative care advice.			
4. There should be access to a 24 hour community nursing service through for example Voluntary organizations and HSS Trusts.	(a) Evidence of service level agreements between Trusts and Voluntary organizations.			
5. Patients and their families must have access to palliative care service outside normal working hours.	(a) Systems in place in each Trust / Provider to ensure patients and their families have access to the necessary information to enable them to access services outside normal working hours.			
6. All Providers must agree clinical and social care standards for palliative care. These local standards must reflect those developed by other bodies and be subject to regular audit and review. Information obtained from audit must be acted on and changes made if required.	(a) Standards available in each Trust / Provider organization. (b) Evidence of audit and review timescales. (c) Evidence of action taken as a result of audit.			

2 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
7. Communication systems must be developed between the primary care team, independent organizations and other services such as hospital or hospice services.	(a) Written documentation detailing roles and responsibilities which has been agreed and shared by all key stakeholders. (b) Mechanisms in place to assist communication, such as clear discharge policies or the development of care pathways.			
8. Arrangements must be in place to ensure ready access to specialist medication.	(a) Community pharmacist with advance training identified as part of a north of Ireland network.			

2 Systems	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<p>9. Assessment for aids and adaptations should be completed and speedy action taken as a result.</p> <p>10. Where patients have a poor prognosis there should be a 'fast track' assessment and delivery procedure.</p>	<p>(a) Written procedures for assessment of equipment needs which will ensure necessary equipment in place within one week of discharge or assessment.</p> <p>(b) Written agreements to ensure fast track provision of emergency equipment which will ensure that emergency equipment is in place within one week of assessment/ discharge.</p> <p>(c) Evidence of performance of the above systems.</p>			
<p>11. A common Patient held record will be utilized by all professionals involved in the care of the patient and family</p>	<p>(a) Review of records.</p> <p>(b) Evidence of multi professional sharing of information</p> <p>(c) Evidence of procedures to share information and effective communication.</p>			
<p>12. Services will be planned, provided and reviewed on a multi professional basis.</p>	<p>(a) Evidence of multi professional team meetings.</p>			

2 Systems	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
13. Written information will be provided to patients and their carers on the range and choice of palliative care and other support services.	(a) Evidence through patient information leaflets provided by each Trust/Provider.			
14. Systems should be available to ensure 24-hour access to specialist palliative care advice.	(a) Evidence of systems in place within each Trust / Provider.			
15. Systems, which facilitate the regular review of patients assessing their needs and the appropriateness of, level two care should be in place. Where level three care is required the transition to the appropriate care team should be facilitated.	(a) Evidence of case reviews and subsequent action			
16. Clear referral pathways to specialist palliative care services will be in place within each Trust /Provider.	(a) Referral pathways developed and audits of compliance with referral pathways identified.			

Level Three – Specialist Palliative Care

In addition to the criteria below all of the criteria in Level One and Two must be met before Level Three can be achieved.

3 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<p>1. All professionals involved in the planning, commissioning and delivery of care should have an appreciation and understanding of specialist palliative care services.</p>	<p>(a) Training records of attendance at palliative care educational and training opportunities. (Seminars / Courses)</p>			
<p>2. The Specialist Palliative Care Team shall have:</p> <ul style="list-style-type: none"> • Consultant in Palliative Medicine • Specialist palliative care nurses, social workers, pharmacists, professions allied to medicine, chaplains and clinical psychology. <p>Access to other professionals as required.</p>	<p>(a) Evidence of team membership and regular team meetings / case reviews.</p>			

3 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<p>3. Nurse staffing levels should aim to meet the guidelines outlined in the 'Care of People with terminal Illness' A Report by a joint Advisory Group: 1991 ISBN 0946832 81 1</p>	<p>(a) Evidence of nurse to patient ratios</p> <p>(b) Evidence of qualified to unqualified nursing staff ratios</p>			
<p>4. Providers should comply with the minimum requirement of palliative care training for each category of staff.</p> <ul style="list-style-type: none"> • Medicine – <ul style="list-style-type: none"> • Consultant in Palliative Medicine – CCST for Palliative Medicine or inclusion on the specialist register of palliative medicine. • Non Consultant Career Grade – Diploma in Palliative Medicine. 	<p>(a) Evidence of qualifications and continuing professional development</p>			

3 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<ul style="list-style-type: none"> • Nursing – <ul style="list-style-type: none"> • Clinical Nurse Specialist – Specialist Practice qualification in palliative care nursing to at least Degree Level and experience of working in a specialist palliative care environment. • General Nurse Staff – Specialist Palliative Care qualification to at least Diploma and /or experience of working in a palliative care environment. • PAMS – Post registration qualifications and/or experience of working in a specialist palliative care environment. • Pharmacy – Accredited specialist training in palliative care and experience of working in a specialist care environment. • Clinical Psychology – Relevant qualification in the area of palliative / terminal care. 				

3 Professionals	Examples of Evidence which should be available to illustrate the standard is met	Not Planned	In progress	In place
<ul style="list-style-type: none"> • Social work – Relevant post registration qualification or experience in a specialist palliative care environment and evidence of continuing professional development in palliative care. • Chaplains – Additional training and experience in working in the palliative care environment. 				
5. There will be 24 hour access to medical advice from a consultants in palliative medicine.	(a) Evidence of systems to access advice from Consultants in Palliative Medicine.			
3 Systems				
As in Levels one and two				