

Service Improvement Initiatives

Taken from

Living Matters: Dying Matters. A Palliative and End of Life Care Strategy for Adults in Northern Ireland. (DHSSPSNI, 2010)

Exemplar: 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

Exemplar: 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

Exemplar: 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 Networkⁱ. 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

Exemplar: Role of the community pharmacist in palliative and end of life care

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 she 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: Southern HSC Trust

Exemplar: Demonstrating development of multi-professional training

The South Eastern HSCT 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: 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

Exemplar: 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.

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.

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

Exemplar: 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

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 is now being 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

Case Study 2

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 hospital 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 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

Exemplar: 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.

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

Exemplar: Role of the community heart failure nurse and respiratory 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.

As the patient's condition deteriorates and end of life is imminent the role changes from active treatment to palliative care. At this stage 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

Exemplar: 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 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 by people she recognised and trusted.

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

Exemplar: 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

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 were included from the beginning, as were professionals from children's and adult services. 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 although they still fear hospital admissions; 2 recent life-threatening episodes were managed at home.

Source: NI Hospice, Belfast

Exemplar: Northern Ireland Hospice Carers' Service

This service for carers provides practical information and advice, 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

Exemplars: 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

Pallcareni

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. Pallcareni.net

Source: NICaN

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

Source: South Eastern HSC Trust

Exemplar: 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

Case Study 3

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, 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 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

Exemplar: 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: 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.

The service has proved invaluable within a short period of time, feedback from users of this service is 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