National Practice Development Programme

END OF LIFE CARE IN MAJOR ACUTE HOSPITALS IN IRELAND

2013
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Foreword on behalf of the Irish Hospice Foundation

On behalf of the Hospice Friendly Hospitals (HFH) Programme, Irish Hospice Foundation (IHF), I welcome this final report on The Implementation of a Model of Person-Centred Practice for End of Life Care in Major Band 1 Hospitals (2010-2012). The idea for a structured methodological focus on the culture of end of life care in Irish hospitals grew from discussions between the HSE Office of Nursing and Midwifery Services Director and the HFH Programme, following work with Professor Brendan McCormack from Ulster University. Subsequently it was agreed that a suitable person would be released from the HSE on a secondment basis for three years to take the lead in creating a practice development programme for hospitals wishing to engage in culture change. Lorna Peelo-Kilroe was appointed as National Practice Development Coordinator (End of Life Care) in May 2009.

Every year almost 30,000 people die in Ireland, with 75% of all deaths now occurring in hospitals and long term care settings. However end of life care is not seen as a core activity of hospitals, where the main focus is on curing. With this in mind, the IHF established the HFH Programme to improve the quality of end of life care in Irish hospitals. It provides a range of supports to hospitals, including end of life care coordinators, training and development courses, practical resources and specialised advice. Practice Development became an important element of the HFH Programme. Its emphasis on a person centred approach and the relevance of culture and context of care, resonates strongly with the aims and values of the HFH Programme.

Person-centredness is one of the cornerstones of good practice and something that is strongly endorsed throughout the HFH programme. Recognition of the individuality of each person be they service users, their families or staff has to be the foundation of care policy and practice. However the challenges to establishing person-centredness and person-centred workplaces cannot be underestimated in current times. The end of life care practice development programme, developed for major acute hospitals, facilitates staff to observe and question the detail of day-to-day work practices, so that they can change these to more person centred end of life care. The programme received considerable commitment from nursing leaders, senior nursing personnel, clinical nurses and health care assistants. We are delighted to be able to demonstrate in this report the impact and developments that have contributed to the establishment of a framework for person-centred end of life care for patients and residents. Crucially, the next steps will involve taking this initiative forward to become integrated as part of day-to-day work practice throughout the health system.

I would like to express my appreciation to all those who took part in the programme. It was the product of a unique, positive and beneficial collaboration between the IHF and the HSE. In particular, I would like to acknowledge Dr Siobhan O’Halloran and Dr Michael Shannon, HSE, for their partnership and support and Professor Brendan McCormack for his involvement in the planning and supervision of the programme. A word of thanks also to Mervyn Taylor and Mary Bowen for their leadership on behalf of the HFH Programme. Most especially, I would like to thank Lorna Peelo-Kilroe for her dedication, enthusiasm and professionalism throughout the course of this project.

Sharon Foley.
CEO
Irish Hospice Foundation
Foreword on behalf of the Office of Nursing and Midwifery Services
Director

This report is the culmination of twelve months of preparation, negotiating and planning and twenty months of implementation to support the targets of the Hospice Friendly Hospitals Programme. The aim of the programme was to develop infrastructures and capacity within major acute hospitals to provide effective person-centred end of life care to patients and their families using a facilitated practice development (PD) approach.

Our health service is facing increasing demands for better, safer health care in a climate that is seeking efficiency with effectiveness and value for money. Education and staff development needs to demonstrate its effectiveness by using existing and new knowledge, skills and innovation to deliver better outcomes for users of the health service. Cultures within organisations can impact significantly on the pace and progress of service redesign and by incorporating a focus on workplace culture development in tandem with strategic advancement will be a significant factor in practice improvement and innovation.

This report demonstrates a focus on person-centredness as a core principle of developing practices to increase effectiveness in end of life care. For the first time in acute hospitals, senior nurses and health care assistants worked together as part of a large national group as facilitators and developers of practice. By using this approach to PD programme participants have had the opportunity to use their experience, knowledge and skills to work together to bring about improvements in end of life care.

I wish to acknowledge all the staff, patients and their relatives who were directly and indirectly involved in this national programme in each hospital site. I would also like to acknowledge the significant role that the Directors of Nursing in particular played in supporting site facilitators and participants throughout the programme. Finally I would like to acknowledge the support of the Irish Hospice Foundation HFH Programme Management Team Mr Mervyn Taylor, Professor Brendan McCormack, Ms Mary Bowen and Ms Lorna Peelo-Kilroe.

Dr Michael Shannon.
HSE Nursing and Midwifery Services Director
Assistant National Director, Clinical Strategy and Programmes Directorate, HSE
Adjunct Professor UCD School of Nursing and Midwifery and Health Systems
Foreword on behalf of University of Ulster

The Hospice Friendly Hospitals (HfH) Programme of the Irish Hospice Foundation is a unique programme of work internationally. The focus on improving end-of-life care in hospital settings through the systematic development of standards, policies and frameworks as well as influencing national policy is inspirational. However like all major programmes, translating the knowledge developed through the programme elements into actual changes of practice is hard to achieve and requires considerable effort to make possible. A programme such as the HfH can develop as many products and processes as it likes, but if the culture of practice is not receptive to change then they land on barren ground! The need for culture change in clinical/care settings in order for the knowledge to be translated into practice is internationally recognised.

In this regard, the HfH programme leaders were insightful to recognise the need for a practice development programme to be embedded in the overall programme of work. Over a period of 3 years, practice development knowledge, skills and expertise was developed among the programme team with a particular focus on the development of facilitation knowledge and skills. The culmination of this approach was the launch of the National End-of-Life Care Practice Development Programme, to which Lorna Peelo-Kilroe was appointed as the National Facilitator. Lorna brought her knowledge and skills from the previous Older Persons National Practice Development Programme in which she was one of the Regional Facilitators working from the NMPDU Mid-West.

Anyone who engages in practice development work knows that it requires considerable and sustained effort, tenacity, resilience and systematic decision-making. Working with the internal facilitators in each of the hospitals involved in the programme, this report demonstrates how culture change was brought about and the outcomes arising. The report provides an honest and authentic account of the programme structures and processes, how these structures and processes were made work in practice, the challenges and successes involved and the outcomes achieved. The programme is no easy solution for fixing the many complex factors that shape a workplace culture. But it does show what is possible to achieve if we integrate emancipatory and transformational approaches to development and learning into practice and don’t shy away from the thorny problems that get in the way of practice excellence. If the report highlights nothing else, it shows the need to get away from traditional models of training that focus on skills but do little to change the contexts in which those skills need to be practiced. All organisations need to learn from this and think carefully about where and how it invests its professional development resources.

I am proud to have been part of this programme, to have worked alongside Lorna and to have supported her with her work. I have revelled in celebrating the small success with her, to have mopped up the spillages and to have invoked a sense of achievement when everything seemed overly-challenging. I am very grateful to Mervyn Taylor, HfH Programme Manager and Dr Michael Shannon, HSE Director of Nursing and Midwifery Service for their insightfulness to make this programme happen and for their financial and personal commitment to Lorna and the programme.

As the French philosopher Pierre Chardin says - “The more one sees the better one knows where to look ...” and this programme is a wonderful example of digging deep to see what is possible, maximising the potential of people and their passions and in the process identifying how to look forward to a better future for the care of people who die in Irish hospitals.

Professor Brendan McCormack.
Director, Institute of Nursing Research
and Head of the Person-centred Practice Research Centre
University of Ulster
ACKNOWLEDGEMENTS

I would like to acknowledge the following without whom this programme would not have taken place.

- The Hospice Friendly Hospitals Programme management for identifying the need for a practice development programme to compliment the other work strands of the HFH programme. In particular Mervyn Taylor, Mary Bowen, who also co-facilitated on programme days, Jackie Crinion, Grace O’Sullivan and all of my colleagues on the HFH programme and in the Irish Hospice Foundation who offered unconditional support.

- The HSE Office of the Director of Nursing Services, Dr Michael Shannon and the outgoing director Dr Siobhan O’Halloran for agreeing to support the Practice Development Coordinator Role and for making the secondment process possible. In particular I would like to thank Dr Michael Shannon for his leadership and support throughout the programme both to me, to participants and participating hospitals.

- To Professor Brendan McCormack from the University of Ulster who provided practice development and facilitation supervision throughout my secondment, for supportive challenge and creative nurturing all through the programme, and for enabling human flourishing to take place.

- The Directors of Nursing for agreeing to take part in the programme and for their continued support in particular for the facilitators and participants on the programme. Participants and facilitators expressed how valuable this support was to them and how they appreciated the time, interest and encouragement provided by directors for their work.

- The programme site facilitators who demonstrated a level of commitment to the work and to each other that carried the work forward over the 20 months of the programme in spite of considerable challenges along the way. Their growth and development on this programme, although considerable, cannot be adequately demonstrated in this report. Their committed belief in improving end of life care for their service users along with their trust and respect for participants in their working groups is evident in their reports within this document.

- The participants on the hospital PD programme who demonstrated significant courage and commitment to the work even when it became increasingly difficult to keep going. Many attended programme days in their own time and this can only be attributed to their commitment to their patients/residents and their vision for how end of life care could be improved.

- The staff on the wards/units involved in the programme for their patients and engagement in the work of the programme.

- To the specialist palliative care teams, the chaplaincy teams, the end of life care standing committees in particular who publically supported and championed the programme work.

- All the patients and their families who participated in the programme and contributed such valuable feedback.

Thank you everyone.
Lorna
PARTICIPANTS AND PARTICIPATING SITES

SITES INVOLVED

1. Adelaide and Meath National Children’s Hospital, Tallaght
2. Beaumont Hospital, Dublin
3. Connolly Hospital, Dublin
4. Cork University Hospital
5. Mater Hospital, Dublin with Beneavin Residential Home, Glasnevin, Dublin and Churchview Residential Home, Phibsborough, Dublin
6. Mid-Western Regional Hospitals, Dooradoyle, Limerick
7. St James’s Hospital, Dublin
8. University College Hospital Galway Group

DIRECTORS OF NURSING

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Sheila McGuinness, Beaumont Hospital and outgoing director Marie Keane.
Geraldine Shaw, Mid-Western Regional Hospitals, Dooradoyle, Limerick.
Mary Day, Mater Hospital, Fiona Bell (General Manager) Beneavin Nursing Home and Marie Neylon, Churchview Nursing Home.
Colette Cowan, University Hospitals Galway and Roscommon and outgoing director Mary McHugh (retired).
Mary Mills, Cork University Hospitals and outgoing director Dr Mary Boyd.
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EXECUTIVE SUMMARY

I. BACKGROUND AND PROGRAMME AIMS AND OBJECTIVES

A Hospice Friendly Hospitals Programme (HFH), as part of the work of the Irish Hospice Foundation and in partnership with the Health Service Executive (HSE) through the Office of Nursing and Midwifery Services Director, was developed in Ireland with a national focus on end of life care in acute hospitals and residential care settings. The HFH programme has several distinct strands of work with personnel to lead on developments in order to provide resources, direct support and education to address the four key elements of the programme: competency and compassion, the physical environment, planning and coordination, and an ethical approach.

One of these strands was a practice development (PD) programme which had five work streams: a national PD programme for major acute hospitals, a PD programme for acute and community settings in the North West, a PD programme for nurses working in intellectual disabilities services, PD workshops for end of life care, and a national practice development introductory summer school. This report is an evaluation of the major acute hospitals work stream.

The overall aim of this work stream, linked to the four key themes of the HFH programme, was to implement a framework for person-centred end of life care across multiple major Band 1 acute hospitals in the Irish Health Service using a collaborative facilitation model of emancipatory practice development.

II. Programme methodology

The programme was structured using a variety of related theories: co-operative enquiry, appreciative enquiry, emancipatory practice development and active learning (Dewing 2008, 2009; McCormack et al 2009). The work of the programme was guided by a framework developed by McCormack and McCance (2009) known as The Person-centred Practice Framework. In keeping with the principles of emancipatory PD methodology the emphasis of the work was on evaluation of care practices and of individual and team development.

III. Programme structure

The programme spanned 20 months and engaged senior nurse managers, clinical nurse managers, staff nurses, health care assistants and HFH Development Coordinators coming together to learn facilitation and practice development processes, skills and strategies to influence change in their practice areas. Eight national major acute hospitals and two nursing homes linked to one major hospital were involved.

IV. Programme evaluation

The programme incorporates continuous, systematic evaluation processes throughout as well as timed evaluation at specific points during the 20 months of the programme. All evaluation methods were implemented to determine the effectiveness of developments and changes implemented in care areas as well as developments and changes within individuals and teams. Specific site reports, incorporated in this overall evaluation report, use a Praxis evaluation framework to determine the changes and developments that took place in their hospitals during the PD programme. Process and outcome evaluation methods were used in keeping with the philosophical and methodological approaches used in emancipatory PD.

V. Summary of findings

Findings were summarised from data collected throughout the programme including participant and facilitator reflections, feedback from patients/residents and their families, feedback from colleagues in the workplace, programme day notes and discourse on programme days, a cultural evaluation tool, a context evaluation tool, and feedback from Directors of Nursing. Key themes were identified from the process and outcome evaluation analysis. The following summary outlines the common themes identified in the evaluation material:
a) Team Engagement
Collaboration, inclusion and participation (CIP) were the key principles guiding the facilitation approach used in this programme and participants were required to incorporate these principles when involving their colleagues in PD workplace activities. High importance was placed on the engagement by workplace colleagues in the programme work and the difficulty experienced when this didn’t happen. This particularly applied when the senior nursing team members did not engage fully. New understanding and appreciation of roles between nurses and health care assistants developed and greater understanding of the meaning of shared decision making as a team.

b) Growth and development
Evidence is provided in participant reflections of their own personal growth and development on the programme journey. Many referred to their increased confidence in discussing dying with patients/residents and families and being more able to offer support to colleagues when someone is actively dying. Some participants are now regarded as a resource when planning care at end of life and many colleagues defer to them on matters relating to end of life care. Several participants see themselves as role models for colleagues and are happy to share their knowledge and skills. Several participants have referred to their increased self-awareness and are now clear about their values and beliefs regarding the care they provide. There is an increased understanding of the meaning of person-centredness as applied to patients/residents/families and within their teams and skills to measure this in their practice areas.

c) Individuality of the patient/resident
The individuality of the patient/resident was unquestioned by all participants and concerns were raised about how that individuality can be overlooked in planning for care and in communication with and about patients/residents and their families. There are many examples of how these areas are now being addressed for example by ensuring that there is choice for patients/residents about the care they want to receive and that they are involved in decisions about their care. At the start of the programme most participants considered that they were person-centred both in their approaches to care practices and in communicating with patients/residents. However as the programme progressed and participants started to dig more deeply to look for evidence of person-centred practice with growing awareness of what it looks like in practice, many noted that there were moments and episodes of person-centred practice but that it was dependant on the many variables in their care contexts. They now want to have a more consistent approach to end of life care that reflected their values and beliefs and their vision statements.

d) Family/carer involvement
Many participants demonstrated a growing awareness of the needs of family. This included the need to be involved in care, the need to improve communication with family and the provision of quiet and private spaces for families in their ward/unit areas. Many expressed their reluctance to engage families in conversations that they perceived as sensitive prior to engaging in this work feeling either unskilled or that it wasn’t their role. As this changed and confidence grew participants acknowledged the importance to them of supporting both patients/residents and their families at end of life.

e) Care environments
During the programme there were many opportunities to evaluate care environments from the perspective of patients/residents and visitors. This was undertaken through discussions with patients/residents and visitors about noise levels, signage, how
welcoming staff were in order to create a more favourable and calmer environment; through direct observation of the area by staff and from international evidence, learning and discourse. There was growing realisation of how noisy and ‘hectic’ care environments are and questioning of how conducive this is for patients. Actions were initiated to address many of the environmental issues felt no longer acceptable such as reducing noise levels and the ‘hectic’ image, ensuring that visitors are greeted in a friendly manner, greater attention paid to the area when someone is actively dying to name but a few.

f) Communication
The impact of communication was identified by almost all participants as being of high importance to developing person-centred practices. Reference is made to the impact of language when promoting person-centred practice. The use of bed numbers or diagnosis to identify patients/residents was challenged. Language that can be demeaning used to and about patients/residents and their families particular where it can be perceived as demeaning albeit unintentionally such as referring to patients by their bed numbers or diagnosis. The appreciation of the need to recognise the individuality of the person in all communications about and with them became of high importance to reinforce person-centredness.

g) Dealing with challenge and conflict
The area where most participants had greatest apprehension was challenge. Although growing realisation that culture change will not happen without challenge, participants were reluctant to challenge many of their colleagues on points of agreed unacceptable practice. Many referred to their own experience of being challenged and of it being negative and painful. There was the fear of ‘falling out’ with colleagues if they challenge them and that some colleagues just couldn’t be challenged at all.

VII. LESSONS LEARNED

This programme addressed in part the four key elements of the HFH programme: competency and compassion, the physical environment, planning and coordination, and an ethical approach from an emancipatory practice development perspective. The work built on the experience and lessons learned in a previous similar national programming in Ireland.

- The engagement process was vitally important when planning the programme and the Programme Management Board and Directors of Nursing were vital to the success of this phase. From the outset the Directors of Nursing supported and motivated the site facilitators and participants to engage in and progress the work of the programme even when there were increasing challenges and competing priorities.

- A workshop was provided for Directors of Nursing to outline the focus of the programme work and the challenges that participants would face. This could be extended to other senior nurse managers to promote greater engagement and support structures for participants.

- Recognition is given to engaging and promoting the involvement of other disciplines in programmes such as this.

- The involvement of the senior clinical nurse manager on hospital PD working groups is vital to the success of the programme. Where CNM2’s were on the programme group in each hospital progress and buy-in was more consistent and changes and developments were facilitated more effectively.
• The involvement of health care assistants in culture work was seen as vital to the team and in influence culture change.

• Buy-in and support from other disciplines, in particular specialist palliative care and pastoral care.

• Buy-in from colleagues and peers with a commitment and an expectation to engage in the work of the programme and in exploring sustainability proposals developed by most PD groups.

• A commitment to further progress and utilise the facilitation and PD skill-sets of participants developed on the programme to influence and promote person-centred care practices and cultures within their organisations.

• An acceptance by organisations that culture change takes time and commitment and that it will not be effective if viewed in the short term rather than a long term approach to developing learning cultures and sustainable change.

• A number of action plans are as yet unfinished as work is on-going and will require support and evaluation to ensure plans are completed.
CHAPTER 1 INTRODUCTION

A twenty month practice development programme was undertaken in eight major band 1 hospitals and two residential homes in Ireland. This report will outline the methodology, programme structure, methods and processes that we used in this programme. Site facilitators will describe the work undertaken in their hospital PD Groups and clinical areas using PRAXIS Evaluation Framework. The structure used in this report is based on a previous similar report from the national practice development programme for older persons in Ireland (2009).

BACKGROUND

A Hospice Friendly Hospitals Programme (HFH), as part of the work of the Irish Hospice Foundation and in partnership with the Health Service Executive (HSE), was developed in Ireland with a national focus on end of life care in acute hospitals and residential care settings. Almost 30,000 people die in Ireland each year. While the majority of people would like to die at home, most people now die in a hospital, or similar setting, outside the home. At least half of all deaths occur in acute hospitals (48%) or hospice (4%); deaths at home still constitute a quarter of the total (25%), and a fifth die in long-stay facilities (20%; the remainder are deaths from suicide and traffic accidents (3%).

Despite the fact that so many people die in hospitals, end-of-life care has not always been seen as a core activity of hospitals, and until recently was not normally included in service plans. Neither is its importance adequately reflected in hospital cultures, systems and structures. The first ever National Audit of End-of-Life Care in Irish Hospitals, in the last week of life, suggests that end-of-life care in our hospitals compares favourably with that reported by hospitals elsewhere. Nevertheless, despite this relatively positive picture the audit gives rise to more unsettling insights. These relate to variances between nurses and doctors with regard to key aspects of care and symptom management, the quality and focus of communication with patients and relatives, and the degree to which care is documented and coordinated. The perspective of the bereaved relative in the audit rated the ‘acceptability of death’ lower than staff ratings.

The key focus of the HFH work is on mainstreaming end of life care more into overall hospital care structures, processes and practices. The principle aims of the HFH programme were:

1. To develop the capacity of acute & community hospitals to meet and where possible, to exceed the quality of standards for End-of-Life Care in Hospitals.
2. To change the overall culture in hospitals & residential facilities in relation to all aspects of dying, death and bereavement.

To achieve these aims the work of the programme is focused around four key themes: Competence & Compassion; Planning & Coordination; The Physical Environment; An Ethical Approach.

A suite of resources were developed as part of the HFH programme to support hospitals to address end of life care systems and practices. One of these resources is a national practice development programme developed to target workplace cultures and contexts where end of life care is provided. The PD programme consists of several strands designed to accommodate a variety of contexts and levels of participation, all with the same aim of developing cultures of person-centred care at end of life.
PROGRAMME AIMS AND OBJECTIVES

Overall Aims
The overall aim of the programme was to implement a framework for person-centred end of life care across multiple major Band 1 acute hospitals in the Irish Health Service using a collaborative facilitation model of practice development.

The definition of person-centredness used in this work was adapted from a previous similar national PD programme in 2007 for older persons’ residential settings:

“Person-centeredness is an approach to practice established through the fostering of therapeutic relationships between all care providers, patients/clients/residents and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approached to practice development”.

This programme aimed to provide participants with an understanding of how culture effects practice, how the quality of practice is affected by strong or weak team working structures, how shared decision making leads to better decision making, greater innovation, and ultimately better care outcomes. By focusing on appropriate facilitation skills and PD approaches and processes participants and their colleagues can transform their care that will effectively meet the needs of patients and their families, staff and the organisation.

Programme Objectives
- Provide participants with the opportunity to critically analyse a variety of facilitation processes and approaches that enable workplace cultural development
- Use practice development processes and activities to engage staff in clinical areas to critically reflect on their end-of-life care practices, identify practices that are in keeping with best practice norms and challenge unacceptable practices.
- Further strengthen the role between clinical and management staff in planning and implementing practice change working with shared principles, models, processes and methods.

PROGRAMME METHODOLOGY

The programme was structured using a variety of related theories: co-operative enquiry, appreciative enquiry, emancipatory practice development and active learning (Dewing 2008, 2009; McCormack et al 2009; Manley et al 2008, Reason and Bradbury, 2006). The work of the programme was guided by a framework developed by McCormack and McCance (2009) known as The Person-centred Practice Framework (Fig.1). In keeping with the principles of emancipatory PD methodology the emphasis of the work was on individual and team development and systematic evaluation.

Co-operative Enquiry
This approach focused on groups of participants exploring end of life care together through their own experience and reflecting together. A participative, person-centred inquiry explores with individuals rather than on or about them (Heron, 1996).

Appreciative Enquiry
“Appreciative Inquiry is the cooperative co-evolutionary search for the best in people, their organisations, and the world around them” (Cooperrider et al, 2008:3). For this programme appreciative enquiry focused on exploring collaboratively what is already
known to be good practice in existence and through questioning and exploration finding ways to improve further. It builds positively on the intuition and knowledge already in existence within care teams (Ludima et al, 2006).

**Emancipatory Practice Development**
The purpose of PD as defined by Garbett and McCormack (2004, pp34) is 'a continuous process of improvement towards increased effectiveness in person-centred care'. The additional added value of using emancipatory PD (ePD) is that it focuses on the development also of individuals and teams and the cultures and contexts in which they work to bring about continuous and sustained change (Manley et al, 2008). The focus of ePD is on changing cultures in the workplace and Drennan (in Dewing, 2008) defines workplace culture as ‘the way we do things around here’ influenced by a set of unwritten and unquestioned rules that shape attitudes and behaviours. The following definition of PD was used to describe the PD approach used in this programme:

"Practice development is a continuous process of developing person-centred cultures. It is enabled by facilitators who authentically engage with individuals and teams to blend personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformations of individual and team practices. This is sustained by embedding both processes and outcomes in corporate strategy".

(Manley et al 2008, p9)

**Active Learning**
An active learning approach was used in this programme in keeping with a co-operative enquiry method and workplace learning. Workplace learning takes place near or in the workplace environment so that learning can more easily be transferred into practice. This approach also recognises the existing knowledge and skills that participants already have and build on these as part of the evidence for change. Active learning focuses on using the multiple intelligences and senses of participants and adapting various learning styles suitable to adult learners through dialogue that engages self and others in the workplace (Dewing, 2008).

**The Person-centred Practice Framework**
The theoretical framework used to guide the focus of the person-centred work was one developed by McCormack and McCance (2009), the basis of which is derived from empirical research on person-centred practice and the experience of caring in nursing. The framework incorporates a focus on caring in everyday practice where caring has four distinct and related purposes: as a moral imperative to maintain the dignity and respect of the person (Morse et al 1991), as an interpersonal interaction between care giver and the patient, as an emotion that includes compassion and empathy, and as a therapeutic intervention.

The framework (see fig1) consists of four fundamental constructs starting with (1) **prerequisites** or attributes of the nurse, and moving to (2) **the care environment** and (3) **care processes** before moving into (4) **person-centred outcomes**. The movement through these four constructs is guided by core elements developed to operationalise the framework so that the work focused on the areas within the workplace requiring development. For example being professionally competent (an element of prerequisites) requires an understanding of what competencies are required to provide person-centred care in a person-centred workplace. In using this framework programme participants were able to target specific priority areas and use them as a means of measuring progress and developments.

Coincidently constructs in the framework have similarities with the key themes of the HFH programme particularly relating to competency and compassion, the physical environment and planning and coordination.
Emancipatory Facilitation
Facilitation in this programme focused on empowering individuals to engage in self-directed learning co-operatively with colleagues. In approaching learning in this way individuals and teams take responsibility for learning together (Heron, 1999). The emancipatory facilitative approach and guiding principles used in the programme encourage participants to work collaboratively using the knowledge and experience already within the team to question existing practices and explore possible alternatives. Known as collaboration, inclusion and participation or CIP principles, this style of facilitation guided the implementation of the Person-centred Practice Framework so that decisions about changing practice are made collectively in the workplace by the team rather than by the PD group.

PROGRAMME STRUCTURES AND PROCESSES

A consultation process was undertaken with Directors of Nursing from the national major band 1 hospitals. An initial introductory letter was sent with information on the programme followed up with a face-to-face meeting with the then Area Director of the Nursing and Midwifery Planning and Development Unit in Dublin Mid-Leinster and the Programme Coordinator to discuss the programme in more detail. Once agreement was reached to participate, Directors of Nursing identified site facilitator(s) to lead programme in hospitals and meetings were held with the facilitators and other key persons who could offer support before the programme started. A workshop was arranged to support Directors of Nursing committed to the programme before the start and communication, engagement and governance structures were agreed for the programme.

Engagement Structure
Eight major band 1 hospitals and two residential care homes were involved in the Practice Development Programme for Person-centred End of Life Care. The programme started in September 2010 with 13 site facilitators, all at senior level within their organisation, and two of which were End-of-Life Care Coordinators from the HFH Programme working in those hospitals. The 13 site facilitators were responsible for leading out the programme in their hospitals along with a group of nurses and health care assistants (HCA) from participating wards/units who formed a Hospital PD Working
Site facilitators met with the programme lead facilitators and formed a national group meeting six weekly for a formal programme and skills development day. The programme day was replicated in each site by the site facilitators who engaged with their PD Working Groups. The national group’s programme days were well attended in general although there were some changes to the composition of the original group with two facilitators leaving and four new facilitators joining. The level of engagement in hospital PD working groups varied with increasing pressure on ability to release staff for programme days. However most sites were able to continue with planned days and completed each programme day albeit in some cases condensing down to a half day basis.
Programme Structures
There were a number of activities that related to the developmental work of the programme. Agreement on commitment, feedback and communication structures were agreed to maximise engagement. These included:

- Sixteen eight hour programme days for site facilitators for planning and team development
- Sixteen four/eight hour programme days between site facilitators and hospital PD working groups
- Feedback sessions between the PD hospital working groups and Directors of Nursing
- Director of Nursing key stakeholder group
- National programme day for all PD hospital groups and programme facilitators
- Programme project board
- Site visits by lead facilitators
- Involvement of facilitators in the National Network of Hospice Friendly Hospitals
- Staged feedback on the work of the programme to the Irish Hospice Foundation Board and to the National Steering Committee for the Hospice Friendly Hospitals Programme.

Activities relating to practice
Foundation learning either as a once off overarching activity or as a frequent or continuous activity threaded throughout the programme included:

- Learning the principles and methodology of emancipatory PD and facilitation.
- Knowledge of the characteristics of a person-centred workplace and becoming accustomed to the Person-Centred Practice Framework
- Developing knowledge of workplace culture and approaches to change/development.
- Developing a shared vision for person-centred end of life care based on common values and beliefs of staff, and in some sites, patients and their relatives.
- Learning how to incorporate creative approaches and activities to support reflecting and planning change and to stimulate new ideas and innovations.

Examples of active learning activities in the workplace include:

- **Person-centred language**: Facilitators and the PD Groups engaged their colleagues in a person-centered language exercise at the start of the programme. There is ample evidence that the language we use conveys our beliefs, attitudes and conjectures (DOH UK EOLC Strategy and Programme; Manley et al, 2008; Aging Planning Bulletin, 2009; McCormack, 2001; Kitwood, 1997; The purpose of this exercise is to raise awareness of the effect language can have on staff attitudes towards individuals and their families, care practices and planning. With a broader scope than mere politically correctness, the language activity spotlights language that can be perceived as demeaning and impersonal by patients and families. This exercise was an on-going activity throughout the programme and required vigilance and challenge to bring about change. (More about language exercise can be found in individual site reports and in chapter 3).

- **Triad Task/Problem/Issue resolution**: An active learning activity that engages three people in sharing, facilitating and observing (referred to as presenting, facilitating and enabling) in a solution focused interaction that relates to a task, problem or issue. The activity is structured to maximise awareness and possible action in a supportive and trusting environment. All site facilitators and PD working group participants engaged together in the activity taking turns being the presenter, facilitator and enabler. The activity was greatly valued by participants who in general were not accustomed to having an opportunity to discuss an issue in this supportive environment and who were more used to
giving and receiving advice from colleagues – something that generally hinders empowerment.

**Environmental walkabouts (McCormack et al 2009):** Sites engaged in this activity, the purpose of which was for participants to look at how person-centred their workplace environments are. Participants had a facilitated walk through their care areas observing how the environment could impact on the patient and the family for example how welcoming staff are, how appropriate signage and information is, noise levels, lighting, heating, levels of privacy for patients and family, availability of quiet spaces for communication, availability of family rooms, the appropriateness of space used for storage that encroaches on patient/family space, clutter etc. For the majority of sites the activity was considered valuable and constructive and developed action plans following the activity.

**Observations of care:** This activity was incorporated in the evaluation of the workplace culture (WCCAT). The activity involves participants observing their care settings and practices with colleagues. Taking time out of everyday practice to undertake the observation provided an opportunity to see the area from the perspective of patients and visitors. A critical part of the activity is feeding back to colleagues on observations and where necessary challenging practices no longer acceptable.

**Structured reflection:** The approach to reflection used in the programme is sometimes referred to as critical reflection and based on what Alvesson and Willmott (1992:435) describe as ‘seeking to encourage the questioning of taken for granted assumptions’. The intention of critical reflection in PD is that individuals and teams will develop the skills to continuously evaluate what they are doing both in and on action thereby contributing to a learning culture. Reflection was an integral part of the programme activities and several reflective models were used over the course of the programme to stimulate questioning and learning.

**Facilitation skills:** Participants were offered opportunities throughout the programme to develop skills in emancipatory facilitation. The skills of facilitation encouraged questioning, high challenge with high support, giving and receiving feedback and approaches to developing safety and openness so that discourse about practices could take place in a structured and focused way.

**Practice development processes:** Coupled with a facilitative approach to learning was the knowledge to implement processes in practice that would meet with national and local standards on EOLC. This gave structure and direction to changing and developing practices that had a focus that was inclusive of all team members regardless of position or grade and adhered to the CIP principles of collaboration, inclusion and participation.

**Skills in evaluation:** For most participants evaluation of practice rarely strayed beyond formal audit processes and was not seen as a continuous process. In the PD programme participants learned how to collect and evaluate data from practice using a range of evaluation tools outlined in the evaluation section.

### Evaluation

The programme incorporates continuous evaluation processes throughout as well as timed evaluation at specific points during the 20 months. All evaluation methods were implemented to determine the effectiveness of developments and changes implemented in care areas as well as developments and changes within the PD groups and individuals. Evaluation approaches used both formal and informal methods and were both process and outcome focused in accordance with emancipatory practice development work. Evidence was collected from various sources including participant reflection; dialogue between participants and lead facilitators, site facilitators and participants and participants and colleagues; staff questionnaires; feedback from service users; cultural observations; observation of the care environment; and evidence from literature reviews.
The following tools were used to collect data because of their reputable validity and reliability in other similar emancipatory development work:

1. Workplace Culture Critical Analysis Tool (McCormack et al, 2009)
2. Context Assessment Index (McCormack et al, 2009)
3. Environmental Observation (McCormack et al, 2009)
4. Critical reflections by participants using an adapted form of Mezirow (1991) model in Reflective Critique and Learning and The Royal Hospitals Model of Reflection (McCormack, 2001)
5. Key stakeholder evaluation questionnaire

The Contest Assessment Index was collected at two points during the programme – at the beginning as a baseline and at the end. Analysis of the findings will be discussed later in the report. The Workplace Culture Critical Analysis Tool was undertaken at one point during the programme towards the end. Participant critical reflections were gathered throughout the 20 months of the programme. Key stakeholder analysis took place at three points of the programme: the beginning, after one year of the programme and when the programme finished.

**Praxis Evaluation Framework**

Traditional practice evidence relies on quantitative methods that, in the main, measure outcomes to interventions. Findings from a report *Review of Practice Development in Nursing and Midwifery in the Republic of Ireland and the Development of a Strategic Framework* (DoHC, 2010) identified a disconnect between outcome measurement and knowledge inputs, knowledge acquisition and outcomes for individuals, teams and organisations. The review also identified an over reliance on technical-rational approaches to bring about change in practice and culture. Over the last decade in the international arena evidence now encompasses a broader spectrum and includes hard and soft data as well as seeking to address questions that arise in practice, acknowledging clinical experience, and the diversity of those involved, including practitioners and patients (Bucknall et al, 2008).

A variety of frameworks have been designed to capture evidence from PD that embraces emancipatory approaches and programme designs. The evaluation framework chosen for this report is known as ‘praxis’ because it brings together prior knowledge, new understanding, developments based on critical reflection and creativity and demonstrates respect and engagement with others (Wilson et al, 2008). The components that form the basis of praxis evaluation are: purpose (programme aims and objectives), reflexivity (how participants critically reflect and engage), approaches (methods that address the questions raised), context (evidence from the care contexts involved and the local factors that influence them), intent (how active learning contributes to transforming individuals and workplaces), and stakeholders (the persons with a stake in the programme outcome and key to its success). In chapter 2 individual site reports used a Praxis Framework to evaluate the developments that took place in their hospitals during the PD programme.
CHAPTER 2 FINDINGS PART 1: INDIVIDUAL SITE REPORTS

MATER HOSPITAL, BENEAVIN NURSING HOME, & CHURCHVIEW NURSING HOME

REFLEXIVITY

Background

Site Facilitators

Assistant Director of Nursing, Emergency Department & End of Life Care Coordinator

Participants

Included Staff Nurses, Health Care Assistants, Clinical Nurse Managers from the following settings: Care for the Older Person Ward, Acute Medical Ward, one member of staff from the Day Oncology Ward and Staff from two Private Nursing Homes, both based within the catchment area of the north inner city of Dublin.

This was a unique programme that took facilitators and participants from their different areas of work and gave them time and skills to reflect on what it means to provide good end of life care. By taking structured time out in a focussed manner centring on the techniques values and principles of emancipatory practice development, participants were afforded the opportunity to re-evaluate how care is provided to patients and their families at the critical time in their lives. This programme also aimed to enhance their own facilitation skills so that this learning could be shared in their own ward / clinical environment with their work colleagues.

Reflection on Learning

"Each member of staff has to face different problems which has given me insight about different organisational structure which lead to having new experience”

"It helped to open my eyes to various aspects of care. It helped to gain knowledge regarding end of life care, various sources available to make end of life care better”

"The different tools enabled me to critically analyse the workplace culture, my own limitations, promoting learning new skills and realising areas of improvement needed”

"I have gained new insight in how to deal with patients and their relatives when it comes to end of life”

"It is only when I change then I can bring about change in my clinical area”

A number of actions plans were developed throughout the course of the programme, they identified actions, looked at resources required for implementation and identified those involved and responsible for completion. Most of those actions have already been achieved whilst some will necessitate on-going review and engagement by the participants.
<table>
<thead>
<tr>
<th>CULTURE PLAN / ACTIONS</th>
<th>RESOURCES REQUIRED</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staff involvement:</strong> all members of the team, creating open communication. Continuity/networking.</td>
<td>Handover meetings- PD is an agenda item. Vision statements – in place for on-going review by team members. Creativity with communication due to reduced staff numbers, prioritising work etc.</td>
</tr>
<tr>
<td><strong>Structural issues including environment and practical measures.</strong> Sympathy cards. Family rooms. Tea/coffee facilities. Deaths in single rooms.</td>
<td>Sympathy cards - well facilitated, CNM’S, CEO office. Tea/coffee facilities in progress. All staff trying to achieve this (Mater only)</td>
</tr>
<tr>
<td>Participation in Final Journeys training programme. Facilitation: discuss/reflect patient/residents journey with team. Get feedback from relatives.</td>
<td>Final Journeys should be mandatory. Also adapted for residential care. 4th yr. students – reflective day/? Final Journeys elder abuse awareness. Listening to relatives. Complaints &amp; discussions.</td>
</tr>
<tr>
<td><strong>How do we measure what we are achieving?</strong></td>
<td>Measure by talking to residents/families/staff. Informal discussion – asking family are we meeting their needs. Are they staying over/are facilities to their liking? Sensitive communication with resident/patient. Decision about using symbol. Formal questionnaire for staff (anonymously). Debrief away from nurse station. Facilitated e.g. what was good about this patients care? What didn’t work so well? What would we do differently? Sometimes we may get verbal feedback or through death notice. Follow-up remembrance service may be the opportunity. Get feedback from GP/Palliative Care team. WCAT Tool.</td>
</tr>
<tr>
<td>Unity of understanding of what good EOLC is (MDT)</td>
<td>Communication with staff &amp; education. Residents meeting. Formation of PD Group – so group can explore. Formed vision statement to help us identify. CAI questionnaire.</td>
</tr>
</tbody>
</table>

**APPROACHES**

There were several approaches used throughout the programme all of which were new to the participants. The choice of approaches used on individual programme days mirrored those which had been experienced on the national programme days. Each approach used, centred on a learning and reflective approach that was creative. Initially there was some reluctance to try out some of the new ideas, however as the programme progressed it became evident that participants could see the benefits of the approaches and how it elicited deeper and more meaningful reflective responses. Creative activities included the use of opening and closing exercises, role play, dramatisation, body
sculpture, a contemplative walk. Participants found each of these activities useful and described them as having a significant impact within their workplace settings. Each approach allowed participants to look at different elements of patient care and end of life care through different lenses. As one participant stated “Also to appreciate is the different tools like the CAI forms, Claims, Concerns and Issues, Role-play, Critical reflection which enable me to critically analyse the workplace culture, my own limitations promoting learning of new skills and realising areas of improvement needed.” We have illustrated below a number of examples of the creative approaches used and they included:

**Development of our Terms of Engagement**

The group devised terms of engagement in the early part of the programme and reviewed them on a regular basis (see fig 3). The terms were not only used by the group to reflect on their communication within the group but also in terms of their responsibilities to the group and their commitment to the programme. They formed the basis of all interaction and have proven to be the bedrock of good communication structures for the participants and facilitators.

**Figure 3**

**TERMS OF ENGAGEMENT**

- **Communication** – As it is important to bring back to the workplace what happens on the HiH National PD programme – we can learn from others’ ideas and take inspiration.
- **Peace** – To have peace between us all and with others. Shown by listening and respecting opinions, being accepting not judging.
- **Flexibility** – Be able to adapt to situations in different nursing environment. In group discussion to agree to see other view points.
- **Openness** – Feel free to tease out things. All together in it. Free to express and bring learning elsewhere. To challenge and be challenged within the group.
- **Honesty** - Hurts but it helps.
- **Willingness** - To go beyond something in order to change ourselves.
  To share with colleagues in MDT.
- **Light** - To open our minds.
- **Adventure** - Open up – ‘explore’ maybe take risk on condition.
- **Gratitude** - To be here and able to appreciate one another.

**Workplace Cultures and Person-centred Language**

One of the key elements of this programme was to look at the “culture of care” in the workplace. A number of the exercises undertaken by the participants and their colleagues assisted in this process in a very practical way. One such way was the use of the Person Centred Language exercise. This approach allowed participants discuss the impact that language has on us all e.g. what it feels like when someone calls us ‘pet’ or ‘dear’ and highlighted how we as people can be depersonalised. It was also interesting to note that the participants also identified how we as staff members can also use depersonalised language and language which infers hierarchy and example of this was when a manager says ‘my staff’ ‘my ward/unit’ ‘the girls’ etc. The discussion and use of person centred language was very familiar to staff working in the nursing home settings as both sites had completed a lot of work on person centred language through other training which centred on elder abuse.
This exercise challenged members to consider how they communicated to their colleagues about the people they looked after and how they communicated as a team in their work areas. The participants gave feedback to their team members which prompted further questions and engaged colleagues in meaningful discussion on the Collaboration, Inclusion and Participation principles and how this works in practice in their area of work. As one participant put it "What we are learning we are sharing" when giving the example of the language exercise.

Participants were asked to reflect on the language they used every day and how person centred it was. This not only applied to the spoken word to those they cared for and their colleagues but also language used in documentation. It is interesting to note that one team identified language that was non-person centred in their documentation and the language was changed from Feeding Sheet to Nutritional Sheet.

Participants developed posters to generate group discussion amongst their colleagues. The posters were displayed in the different areas, which prompted discussion about person-centred language and care. This also made it more acceptable for staff to challenge each other if language was not person-centred. Figure 4 below highlighted some examples of non-person-centred and person-centred language that the group identified with their own teams and work areas.

<table>
<thead>
<tr>
<th>Person Centred Language</th>
<th>Non / Less Person-Centred Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed rails</td>
<td>'Cot-sides'</td>
</tr>
<tr>
<td>Assisting with eating / drinking</td>
<td>'Feeding'</td>
</tr>
<tr>
<td>Meal time</td>
<td>'Feeding time'</td>
</tr>
<tr>
<td>Older person</td>
<td>'The elderly'</td>
</tr>
<tr>
<td>I'm going to make you comfortable</td>
<td>'I'm going to change your nappy/diaper'</td>
</tr>
<tr>
<td>Is it OK if I check your skin?</td>
<td></td>
</tr>
<tr>
<td>Going to individual person and quietly asking who needs assistance</td>
<td>Shouting aloud in ward &quot;who is for the toilet or commode?&quot;</td>
</tr>
<tr>
<td>Ask the person their preference of name e.g. first name or using their title such as Mr/Miss/Mrs</td>
<td>'Chicken ', 'Dear', 'Darling', 'Sweetie', 'Pet', 'Sweetheart', 'Mammy', 'Granny', 'oh Queen Mary', 'Angel', 'Little devil', 'The hip in bed 1', 'the lady with the stroke in bed 2'</td>
</tr>
<tr>
<td>Upset / Unsettled</td>
<td>Aggressive / Agitated</td>
</tr>
<tr>
<td>Unaware of capabilities</td>
<td>Helpless</td>
</tr>
<tr>
<td>A person with a disability, disabled person</td>
<td>'Handicapped', 'The disabled'</td>
</tr>
<tr>
<td>Wheelchair user or uses a wheelchair</td>
<td>'Crippled', 'Wheelchair bound'</td>
</tr>
<tr>
<td>Has own ideas</td>
<td>'Resistant'</td>
</tr>
<tr>
<td>Condition / illness</td>
<td>'Disease'</td>
</tr>
<tr>
<td>Derogatory terms that should not be used to describe people we provide care for.</td>
<td>'Bed Blocker', 'Delayed Discharge'</td>
</tr>
<tr>
<td>Assisting with personal care</td>
<td>'the washes', 'The changes'</td>
</tr>
<tr>
<td></td>
<td>'Geri chair'</td>
</tr>
<tr>
<td>Identifying team members</td>
<td>'The Girls', 'My Girls', 'My Staff'</td>
</tr>
<tr>
<td>Ensure you follow up if you make a commitment</td>
<td>'Back in one minute'</td>
</tr>
</tbody>
</table>

One group also facilitated drama centring on the language based exercise and reported that staff were enthusiastic about this type of engagement and the change it about in terms of their team members engagement.
Creative and new approaches to achieve programme objectives

The objectives of the programme were enhanced by the use of creativity and also the use of creative ways to review and reflect in how these could be addressed. The following activities were found to be particularly helpful to address issues that arose: claims, concerns and issues; feedback from WCCAT; discourse on what makes a good death.

Claims Concerns and Issues Exercise

Claims, concerns and issues was a process commonly used throughout the PD programme to:

- obtain feedback from the participants and evaluate progress
- highlight and celebrate some of the successes
- identify questions that needs addressing to progress issues or work further

This was a new and innovative approach to getting feedback and allowed both facilitators and participants focus on what needed to be completed without getting "stuck". We have outlined here an example of the Claims, Concerns and Issues (fig 5) that arose on one of the programme days by way of example. It highlights how it developed and subsequently focussed discussion with meaningful results to elicit more considered reflection on the issues that the group had identified. The following are direct quotes from one of the claims, concerns and issues exercises that the participants worked on one programme day:

Figure 5

<table>
<thead>
<tr>
<th>CLAIMS</th>
<th>CONCERNS</th>
<th>ISSUES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every Staff member is going to do Final Journeys training (St Johns ward).</td>
<td>Committing on paper ideas from vision statement (2 people).</td>
<td>How do we get colleagues to engage in PD?</td>
</tr>
<tr>
<td>Better communication in ward on EOLC.</td>
<td>Maintaining momentum we started with.</td>
<td>How to address/do it with the time issue?</td>
</tr>
<tr>
<td>Interest from Doctors on what we are doing on programme.</td>
<td>Time factor in sharing programme &amp; ideas.</td>
<td>How do we encourage colleagues to take the initiative in EOLC?</td>
</tr>
<tr>
<td>Programme days help me to put learning into practice.</td>
<td>Sense from colleagues that it doesn’t concern us/not relevant to practice.</td>
<td></td>
</tr>
<tr>
<td>Confidence in challenging colleagues on language.</td>
<td>? Evidence of momentum</td>
<td></td>
</tr>
<tr>
<td>Formed a PD group in Beneavin.</td>
<td>What happens when I’m not there?</td>
<td></td>
</tr>
<tr>
<td>Raised awareness in staff about key issues related to improving end of life care and linking to programme.</td>
<td>Strong personalities how they/we deal with them/get them on side?</td>
<td></td>
</tr>
<tr>
<td>Developed a vision statement with residents and staff.</td>
<td>Pressure in organisation can impact on meaningful engagement.</td>
<td></td>
</tr>
<tr>
<td>Developing self-awareness and transferring in practice.</td>
<td>How valid are questionnaire results.</td>
<td></td>
</tr>
</tbody>
</table>

Group worked together to explore how we could address our issues.

How do we encourage colleagues to engage in PD?

- Facilitate discussion with team e.g. when person has died
- Putting ourselves “out there”
- Helps to initiate and open conversation
- Explanation of being participant in programme/underlying that it gets conversation started
- End of Life Folder – letting staff know by making notes and placing in folder
- Scrap Book: Introduce to team and collect inspiring pictures, ask all to contribute to this.
• Allow group to be freed up – fun/stir up conversation to get people talking about the programme day
• Do we really understand what we are learning - having a good grasp of what we are trying to achieve, being comfortable
• Ward Report : reducing time and tailoring it to each ward area
• Ward report : Every day spending 2-3 minutes on EOLC
• Organise a meeting with participants and strategize together – could involve CNM not on programme.
• Staff meeting – having as item on agenda
• Suggestion box: using communication book
• Outlining achievements in EOL PD e.g. change in language
• Request team to suggest how we could improve EOL care here in this area/ unit – get their individual views
• Having informal/non structured conversations with all in team

Open Communication
• Open forum in team meetings – discussion on different aspects of patient care
• Delegation of task e.g. language in areas - ? mini teams to spread message
• Letting team members know of positive developments
• Role modelling – setting example
• Positive reinforcement – giving feedback when language is person centred
• Being open to encouragement - giving feedback
• Acknowledge existing practice, cultures and changes
• Suggest team members to complete critical reflections - getting person to think
• Ask team members if they would like to give email address for communication
• Explaining benefits of same in improving EOLC
• Exposing your own vulnerabilities (limitations) to encourage others to critically reflect through discussion e.g. asking ‘How are you about it today’?
• Time frame: Planning and placing a deadline
• Action planning: Sharing as opposed to delegating

Engaging a person who is described as having a strong personality/ person that challenges you in this work
• Concern that person is disempowering other members of the team
• Individual discussion with the person could be difficult
• Possible raise awareness with the individual (sensitively)

Get rest of the group on board – facilitate and focus energy and resources on those willing to participate
• Be consistent
• High Challenge – High support

Feedback from WCCAT Evaluation Tool
What was your learning?
• Realisation of what you/we were doing right/wrong
• Staff seeing what EOLC programme was
• Influence of facilitator attending ward
• Staff start to discuss EOLC programme
• 'Leaving emotions at door' taking role of observer
• Recognising good and bad practice
• A stranger sees some of the positive things differently
• Challenge for a member of staff to observe
• Can only say what you saw – not to rationalise
• Use of tool seen as a positive –CAI was tick box
• Earlier use of the tool would have informed understanding of PD work such as language exercise
• Utilised framework of KPI previously and therefore not as valuable
Was this useful?
- Yes – looking at different aspects of care
- Very similar to what HIQA would look for
- Allowed us not to assume
- Promotes good relationship between staff
- Outside influence of facilitator
- Depends on how tool is used – length of time - ? whole day observation
- To some extent parts of tool irrelevant, learning, library, health, safety
- So-so /introduction of tool earlier

An individual reflected that the WCCAT observation tool “helped me to identify things which I would never have noticed during my work time.”

3. What makes a good death?
Work was completed on what makes a good death in your hospital/nursing home. This simple question and the discussion it elicited left all participants thinking of their own role and their ability to influence the care and environment for patients and their families at end of life. The group identified the following:

<table>
<thead>
<tr>
<th>Physical Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowing family have personal mementos in the vicinity/single room/closer to nurse station/de-cluttering equipment.</td>
</tr>
<tr>
<td>Family room – space to provide psychological support / facilities to provide emotional support and practical support such as making tea etc.</td>
</tr>
<tr>
<td>Flexibility/open ended visiting hours.</td>
</tr>
<tr>
<td>EOL door sign/pictures/music/family handover bag.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom control/palliative care input/GP.</td>
</tr>
<tr>
<td>Free up staff member to provide psychological support – support your colleague who is caring for patient who is dying.</td>
</tr>
<tr>
<td>ADLS – Dignity of care, good nursing/care management of physical care needs.</td>
</tr>
<tr>
<td>Spiritual needs.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experienced/comfortable/confident in end of life care</td>
</tr>
<tr>
<td>Support from colleagues</td>
</tr>
<tr>
<td>Communication- verbal, written/good care planning, leads to clarity for the person &amp; family.</td>
</tr>
<tr>
<td>Medical intervention - importance of multidisciplinary team work.</td>
</tr>
<tr>
<td>Leaflets – Practical leaflets which helps families.</td>
</tr>
<tr>
<td>Education – staff participating in Final Journeys training</td>
</tr>
<tr>
<td>Follow-up support: sympathy cards being sent “left our ward and not our mind”</td>
</tr>
<tr>
<td>Supporting newly qualified colleagues – communicating privileged position that we as carers have looking after the person in the last moments of life,</td>
</tr>
<tr>
<td>Knowing the persons wishes and needs e.g. (open explicit conversations regarding advanced care planning and advance care discussions)</td>
</tr>
<tr>
<td>Reviewing care plan on an on-going basis to ensure we are meeting the needs and wishes of those who we are caring for.</td>
</tr>
<tr>
<td>Significant review when diagnosis of impending death e.g. charting of medication in advance, having a multidisciplinary team meeting etc.</td>
</tr>
</tbody>
</table>

To summarise, one participant reflected on the programme and the approaches used “I think this programme has succeeded thus promoting a person centred end of life care and analysing the workplace culture, and constantly challenging our practice and processes and guiding the areas that we need to change and improve”.

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A different participant stated “while it is not always easy the practice development skills I have observed and included into my clinical practice facilitates an easier approach with staff”.

Another participant reflected “this programme helped me to gain confidence in making positive challenges in the best interest of the patient”.

CONTEXT

The contexts of the care environments were very different for the participants. The environments ranged from private nursing homes, to the acute medical ward setting, day oncology to a medicine for older persons ward. Not only were the physical and care environments very different, the context in which care is delivered and organisational systems were also very different.

However, it was evident from the outset that participants were enthusiastic about reflecting and reviewing on ways to improve end of life care in each of their settings which was then brought to the ward/unit/home. There was recognition that to have an effective working relationship with your colleagues there needs to be room to challenge each other in practice. This was an area that was challenging in and of itself for both the facilitators and the participants. A number of participants have identified that their “Attendance and participation at Practice Development (programme) has increased my confidence to challenge colleagues. PD has actively encouraged me to challenge colleagues”. The idea of being challenged in a supportive way was difficult and midway through the programme group members indicated that they were “more comfortable and are feeling more challenged by the facilitators. Feeling more comfortable being challenged and the increased awareness of learning facilitation skills to challenge their colleagues”

Activities such as the one which looked at high support with high challenge and discussion centring on issues such as shared decision making facilitated participants to further reflect and challenge ‘the status quo’ within the group itself and in their areas of work. There are numerous examples from group participants where this has been brought into their area of work. Some examples given by the participants include:

• Staff Nurse highlighting to Clinical Nurse Manager and subsequently the medical team the need to get the Palliative Care team involved in a patients care.
• Health Care Assistant challenging a Clinical Nurse Manager (CNM) about commitment to engage in PD programme in their area of work.
- CNM negotiating release of all members of the team to attend Final Journeys training to enhance their skills in providing end-of-life care.
- CNM challenging medical team to review patient care and management to ensure patient had anticipatory drugs prescribed and minimise distress.
- Health Care Assistant challenging colleagues in use of non-person centred language.
- Staff member challenged colleagues about the way they treated a family when the patient was nearing end-of-life.

Shared learning and raising awareness
Participants have suggested that their participation in the PD programme has allowed them the time and space to talk and listen to colleagues and discuss issues pertinent to improving end of life care in each area of work. This was identified particularly following their work related to the CAI Questionnaires.
Other areas of personal growth and development identified by participants through participation on the programme include:
- It added to their repertoire of skills and ability to use time more creatively and efficiently e.g., using time already available in work to engage discussion centring on improving end of life care e.g., using handover time.
- Awareness raised and importance recognised of role each person can play in offering support. Discussed need to respect individual staff member responses and their right to prioritise time to give emotional support to patients and their family members at end of life. e.g., “feel able to challenge colleagues why I’m doing this follow-up support.” Awareness of practical resources and increased use of practical resources such as symbol and bed drape which emphasised ceremonial aspects and dignity. This has also included the use of sympathy cards/family rooms – increased use of them.
- There has been shared learning of good practices from colleagues in Nursing Home to colleagues in the acute setting e.g., nice tea pot and delph used for families when providing tea for families when a patient dies. It was also noted that the private nursing homes had always set a standard to have patients dying in single rooms – this was something that the wards in the acute setting have only more recently tried to achieve.
- Supporting newly qualified colleagues – “communicating privileged position that we as carers have looking after the person in the last moments of life”,
- Participants acknowledged that they now use report time to encourage and facilitate conversations centring on improving end of life care and discussions on verbal and non-verbal communication in relation to care.
- One participant indicated that due to their participation in the programme that they are now considering taking a different career path and undertaking further training working with patients nearing end of life within a palliative care context.

While the programme was initially aimed at the acute hospital setting the group comprised of staff from the acute setting and residential nursing homes. There was a range of staff from Health Care Assistants to a general manager and the working environments were a combination of consultant led and nurse led services. The participants were further challenged by the introduction to a new model of practice development (emancipatory) and a change of facilitators within a short time of the programme starting. This challenges the group:
“I felt panicked by all I have to do and swamped by work. I felt a little deflated by all of this”
“Too much discussions on hospital than general issues involving nursing homes”
“Don’t feel I have a good insight into the emancipatory model – need to look it up and apply to the programme”
“It was hard to engage the people I work with as time is not on their side, work is very busy and I feel this is forgotten about when we are asked to do certain pieces of work.”
As the group came together this was also expressed in the impact on the individuals, group and work environment.
Our PD journey in picture and words

The Group described their journey in words and demonstrated it visually in a poster shown in figure 6. The following account describes the group’s ‘PD journey’.
"We as the Beneavin & Churchview Residential Homes & Mater Hospital PD Group feel that when we started on this journey to learn about this stage of life it was like looking through a window and our curtains were opening. We were going to cross the bridge into end of life care – not sure whether we were going the right way (signpost on the bridge– which way) or if it would be happy or sad but we as a group were going together (steps going together). We were hesitant at first but we learned from each other about our areas of work and learned about areas such as Elder Abuse, we supported each other in developing our own vision statements and did our Final Journey workshop together.

We were bringing skills with us – hearing, looking, listening, observing, compassion but all the time aware of the quality of the listening ear/ the eye being the window to the soul. We came together as a group and started the uphill journey into person-centred end of life care. Some of areas covered were as in the person-centred framework with its prerequisites: clarity of beliefs and values (what we mean by quality end of life care); effective staff relationships (challenging ourselves and others); the physical environment (hospice bags, single rooms, hospice symbol); care processes: working with patients beliefs and values, having sympathetic presence; person-centred outcome: involvement with care, creating a therapeutic culture.

Of course we sometimes still question which is the right route to challenge and influence culture change (sign post). We were always aware that we are part of a national group and that the key to changing the culture around end of life care is facilitation. On a reflective walk some of our team put the essence of facilitation into words as seen on the right side of the poster. Now that the light of insight is shining in our window and the candle reminds us of spirituality (multicultural and multi religious) - as a group we now have our own frames and we no longer need the glass and our curtains are still open – no window frame or glass in final poster. We are committed to quality end of life care (signs across bottom of the poster). We have gained so much from each other and grown as a result of our different areas of expertise. And then there is the knowledge each of us brought with us and all we have learned through this process (tree of knowledge). And it is great to know that we are part of a national group (map of Ireland) with the same aims and beliefs – Hospice Friendly Hospitals”.

Reflections from Individual Participants

The Programme
"I’ve attended many courses but this programme was entirely a new experience”
“Have to be very honest when I say I did not fully understand what the programme entailed.” Following the visit of the National Programme Lead “I felt very angry and resentful towards her and our facilitators. On a more positive note this day brought clarity and renewed energy”
“His programme has given me time to reflect, tease out ideas, be creative in my thinking and practice and to prioritise what is most important during the EOL process”

End of Life Care
 “End of life care is a significant part of care which sometimes is not given the importance as the rest of the care needs”
“Proved that family is also a part of the care team. Their values and emotions need to be valued.”
“Having the opportunity to explore and discuss some ethical issues this allowed me to engage more confidently and competently as a member of the MDT in the end of audit of one of my patients R.I.P.”

Facilitation
“They facilitated the programme in a manner which promoted constantly challenging our practices and thoughts enabling us to understand and critically reflect our practice”
“It was unfortunate that the facilitators were only one step ahead of us. I felt the facilitators ‘floundered’ which for me resulted in a lack of understanding and clarity as to what was expected. ”
The facilitators acknowledge that at times their inexperience at facilitating this type of programme may have projected itself on the programme days.
There were number of elements to this programme that were not only new to the participants but also to the facilitators. One of the key issues related to the facilitation of the programme, this centred on the fact that as facilitators we did not have an overarching view of the programme and expected outcomes and therefore could not articulate this vision to the participants.

It is important to note that a number of programme participants identified the significant constraints on their time to facilitate activities related to the programme in their work areas. “For the facilitators of the programme, it is important to note the amount of time for programme work that cannot be facilitated during working hours. This needs to be stated clearly to future participants….. On the other hand I appreciate the opportunity it gave participants in skills of negotiating and facilitating...”

**Changing Practice**

“How easily non-person centred language can be in proactive and how I can bring the good practice”

“It helped me correct things and make changes to my practice”

“I realised that challenging the practice can lead to improving myself and the existing norms which can lead to better practice’

“The programme has provided me with the opportunity to challenge and be challenged on issues surrounding end of life care”

“I have challenged my colleagues at ward level and sometimes with great difficulty.”

**Different Care settings**

“A very positive and broad element was the participation of the …Nursing homes.”

“I realised that problems found by different health care professionals in their respective settings are different, which enabled me to understand their point of view.”

“This partnership allowed us to share our experiences at a broader level and has given us uniqueness”

“From a ‘distance’ having visited and being invited to ‘view’ the principles of EOL care in progress in … it gave me a glimpse into how best practice is achieved in a non-acute setting”

**INTENT**

The last two programme days focussed on sustainability of the work achieved to date and bringing it forward in the future. A number of participants reflected on the key challenges associated with this programme which included the duration of the programme, to quote one participant “Overall I enjoyed the programme, I am feeling tired towards the end, the programme needs to be shortened to ensure active participation”.

It is noteworthy to reflect that a number of participants changed roles during the course of this programme, one of the facilitators retired, one of the participants had a baby and returned to participate, one participant changed from a ward based clinical nurse manager two to a clinic nurse specialist role, one clinical nurse manager two changed role to become a site nurse manager and one member was promoted to a clinical nurse manager one role and as the programme came to a close, one of the participants moved from a general manager role to head of services within their health care group. In terms of sustainability and the intent of building on the achievements, it needs to be considered within the above context. There was widespread recognition that the knowledge and learning achieved by both participants and facilitators would be brought forward as part of their own personal and professional development.
Reflections from programme members on their final days

“Each element of the programme enabled me to understand how differently I can work in my work culture, like claims, concerns and issues enable me to discuss and resolve issues within the framework I am working with the available resources.”

“I know families have appreciated the changes to my ward from the thank-you card sent in.”

“The programme has allowed me to become more confident and competent in many aspects surrounding end of life care.”

“We brought different ideas together, every idea contributed, valued and it was helpful.”

“We developed our own ‘end of life group’ and with the enthusiastic participation from the group and resident we formed our vision statement”

“Before this programme I would have mainly engaged with families, however, now with staff members we plan and discuss care options and how best families can be facilitated.”

“Using the end of life sign and drape I was able to discuss the dignified end of life care with staff.”

“Overall the programme has huge significance as part of our daily hospital life.”

Sustainability
On the final programme day the group divided into two groups, comprising acute setting and the nursing home to explore these issues. Using the action learning process the groups explored the sustainability of PD work and the vital key stakeholder engagement process and their circles of influence (Fig 7 and 8). They presented this as:

Fig. 7: Hospital
Following a presentation from each group a general and active discussion took place and the group outlined the following issues:

**The future as:**
- PD Group – reflection on the programme when it is over
- Be selective on developing skills – role playing, influencing
- Can’t put awareness aside
- Rolling out the programme
- Networking
- Circle of influence
- ‘Lead by example’
- Support each other
- Utilise tools
- On-going support from facilitators
- Advocates for end-of-life-care

**STAKEHOLDER**

This programme would not have started here without the direct support of the Director of Nursing and members of the Nursing Executive who engaged wards under their management to participate. Likewise this programme’s success in the two private nursing homes not only centres on the commitment of the staff involved but also the support they received from their respective management teams.

An agreed communication structure was put in place with the Director of Nursing and the Standing Committee. One member of the team was identified on each practice development day to make an appointment with the Director of Nursing and provide feedback on the work completed. A similar process was initiated for feedback to the Standing Committee on death, dying and bereavement, however due to rostering this feedback occurred irregularly. In this case the feedback was provided by one of the facilitators both of whom are members of the Standing committee.

**Challenges**

As outlined in the interim report there were a number of challenges from the outset that made hindered this programme’s implementation and roll out. A number of other nurse led programmes coincided with the introduction of the PD programme in this site. Commitments had been made by the senior nursing management team for nursing staff...
to participate in these other programmes. The planned introduction and engagement with the National PD Programme here was therefore hindered by this. This was subsequently reflected in the numbers of wards engaged with the PD programme. There were two wards actively engaged in the PD programme and one person from the oncology day ward. This was considerably short of the expectation of the programme and posed challenges on how culture change could be influenced in such a large organisation without the suggested participation of the proposed six wards areas as indicated by the literature and the National Lead.

**Success**

Whilst we believe that this was an opportunity lost from the organisations perspective, we believe we have gained by the participation of the two private nursing homes. Their commitment, dedication and participation in the programme days has been unquestioning. Both private nursing homes dedicated the time, energy and commitment to introduce the programme. In one of the sites, the PD participants, with the support of the general manager replicated this model of the PD group in their health care campus to improve all aspects of end of life care. The development of a PD group in this Nursing Home has created the time and space for the staff members involved to develop their own facilitation skills whilst engaging colleagues and residents in discussion centring on improving end of life care for all. There is a strong sense of “Sharing the facilitation skills throughout the building” in this place of work.

They have successfully promoted the use of practical resources such as the end of life symbol and bed and trolley drape within other units to the point where all have now adopted them. These initiatives along with other key elements of the programme have been transferred to other nursing home sites that operate within this health care group.

The development of a shared vision statement was identified as being an important step on this journey and for some it was a milestone. A number of the participants indicated that work on getting their teams to create a shared vision statement of end-of-life care was difficult. Bearing this in mind it’s interesting to note that a number of participants subsequently suggested this was a turning point and led to their own teams becoming more involved and engaged in the PD programme. One group also involved residents in the creation of their vision statement. A group participant reflected on this as follow:

“Forming a vision statement was so helpful to our residents and staff as they were involved. This made most of our residents aware and accept the situation that there are in their end of life care. Some residents ended up making their own end of life care plans, through talking with them and reading a vision statement that we placed on each resident’s room.”

**OUR VISION STATEMENT FOR END OF LIFE CARE**

| Our vision is to provide a comfortable, peaceful, pain free end of life experience for you in our Nursing Home. We will respect your opinions and always treat you with dignity and empathy while providing for your privacy, cultural and spiritual needs. We will always maintain open lines of communication with you and your family and strive to fulfil your final wishes. |

**Final Journeys**

The group also took part in Final Journeys programme as one of their programme days. The participants themselves all scored the day highly in their evaluations and when asked in their evaluation of the day ‘what will you do differently in your own area of work’? A number of the participants spoke about the improving their communication skills as illustrated in the following quotes:

“I will take time to improve my communication skills”
"Try to utilize communication skills more effectively
"Being more aware of my own experiences and knowing what I can bring to communication for end of life care”.

**Conclusion**

Whilst initially we as facilitators were somewhat concerned of how this model and framework would work with two very diverse groups, it has been interesting to see the shared learning and change in workplace practices which has resulted. The interactive nature of the group was evidence that hierarchy was no longer seen as an issue. It has also been interesting to see how each area has challenged assumptions about each other’s work areas and work practices.

It is important to recognise the journey that facilitators and participants travelled together and also the journey participants and their colleagues in the clinical area travelled too. This could not have been achieved without the support of the two National Lead facilitators and the participants on the national facilitators programme.
THE ADELAIDE AND MEATH CHILDRENS HOSPITAL, TALLAGHT

**Participating wards:** There were six participants, this group comprised of a Staff Nurse, Health Care Assistants, Clinical Nurse Managers from three wards: Acute Renal/Medical Ward, Haematology/Oncology/Cardiac Ward and a ward for Oncology/Haematology which also admitted patients from every other speciality.

**Participants on Hospital PD Group**

The programme group front row seated: Mary Macdonald, Catherine Egan, Mairead Heery, Bernie Wall and Sile Dunne. Back row standing: Catriona Morrissey and Ann Hickey (Site Facilitator)

**REFLEXIVITY**

The genesis for Practice Development (PD) End of Life Care (EOLC) programme was the *National End of Life Care Audit & Quality Standards (2009/10).* Tallaght Hospital participated in this audit and the PD lifelong learning journey commenced in October 2010. The initial task was to develop terms of engagement which everyone could live with. They were reviewed at every programme day and added to as decreed by group consensus – with the only addition over the life of the programme being “Be open to challenge”.

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The three wards were chosen primarily because of their direct involvement in the National Audit, their specialities, and throughput. Participants were agreed, following recommendations from the Director of Nursing, discussions with the respective ADONS, CNM2 and the participants themselves.

Establishing terms of engagement was essential to really contribute to the development of the relationship within set boundaries – a safe and trusting environment.

Prior to the commencement of this programme the group knew each other on a superficial level but with a common goal “Even though we are from different wards we all want better end of life care for our patients.” I found that in getting to know the group, icebreakers proved very beneficial exercise to encourage individuals to interact in a safe environment. Our meeting room was the pastoral care room which is situated away from the main hospital noise/activity - a haven of tranquillity and for this we were most grateful to the Director of Pastoral Care.

It was the commitment to improve EOLC that initially connected this mixed group and team of individuals. This PD programme was unique in bringing together nurses and health care assistants at the micro level of healthcare where culture and context combine, on equal terms, to move them from their comfort zones to engage in the PD process, to flourish, to challenge the ward culture and each other in order to enhance EOLC. This was a bottom-up approach to changing the healthcare culture on the ward. Indeed, a participant suggested that “It’s a small step in a big world where things have always been done the old way. Some people find it hard to change habits of a lifetime but I’m sure in time we can”. Another participant asserted that “Our aim is to change the way people die in hospitals and I am really pleased to be part of this and hopefully change people’s views as the way this programme has changed my views”.

For the duration of the programme the participants were guided by the PD integral philosophy of:

- Collaboration
- Inclusive
- Participation
- Equality

**Terms of Engagement**

To come

To participate

Not be afraid to speak

Everyone has an experience to share / give

To listen to each other

Give each other time

Confidentiality

Trust

Be on time

Have room for joy and fun

Stay positive

Respect each others opinion

A later addition – Be open to challenges
Also, we adopted the theoretical PD framework for person centred nursing to focus attention on change, on individuals, the environment, person centred process and person centred outcomes. Within this PD framework there was an opportunity for all of us to engage in a variety of learning strategies that focus on critical reflection.

Emancipatory PD uses existing staff knowledge and skills to inform change and explore possibilities to build on existing person centred care by employing a process of supportive inquiry strengthened by current research in best practice. In addition, feedback from Patients and Families was also employed to change perspectives on care. On programme days, we used structured guided reflection to challenge current practice, to gain new understandings leading to actions. This was combined with listening to patients to elicit their wishes their hopes and fears.

It was a light bulb moment as participants reflected on their care experience and spoke of “Their lack of significant connection with patients due to the workings of the ward”. I posed the question “Is it possible to change this”? Doubt was the initial dominant response however the group did accept that changes could be made. The programme days afforded the participants protected time and space to think about the effectiveness of their care, how they work as a team, and it focused on the individual practitioner what they were learning and sharing with their colleagues. This was a new approach to learning and we all struggled initially to critically reflect.

**Participants’ reflections on the impact of the programme**

“I feel that the program is making me think a lot more about my own practice, and my interactions with patients and their relatives. It’s making me stop and think about what I am doing and saying before I do anything”.

“My learning so far can be summed up as having the knowledge and support to make a patient’s journey to death as comfortable and peaceful as possible”.

"It was important to get the HCA’s perspective – this will make the groups reflections richer”.

“I found working directly with staff had the most significant impact. This included nursing staff and care assistants. I felt if these group’s attitudes could be changed then it would have a knock on effect on members of the multidisciplinary team. However, the involvement of staff such as catering, portering and cleaning staff was not overlooked and they now appear more aware of the care environment”

“I feel my greatest learning is being more self-aware of my own values and beliefs therefore having a significant impact of my patients and their family’s values and beliefs”.

“I feel I have gained more insight into how each individual is very unique from the next and this should be our focus as front line staff to ensure each voice is heard and each wish is at least recognised”.

The participants appreciated the importance of reflecting on their care and in challenging their colleagues when they experienced non person centred care.
How can you promote more reflective sharing with your CNM and HCA colleagues?

- Discuss and examples
- Group discussions
- Putting all I have learned into practice
- Be more open talk about things
- Take time to allow for open reflection
- To improve myself to listen

PD programme developed a ripple effect in action learning where individual participants took responsibility for their learning. The following feedback reflects participants’ feelings in relation to their learning from the PD programme.

- I have become more aware of patients families and their need to be with their loved ones for privacy and peace.
- I have noticed the noise level on our ward and try to keep is as quiet and clutter free as possible
- I feel I have brought back to our staff the information that I get while doing this programme and am not afraid to answer any questions they have about the programme and feel more part of the team.
- I also think that our ward manager now treats me with more respect and is very supportive of me while I’m doing this programme. For me personally it is good to be back in education and the programme is making me a better person in my personal life.
- I am not afraid to talk about death or dying to any of my friends within work and to the wards that are not participating in this PD programme.
- I am confident that I can offer them information and support if they need it.

We developed action plans that prioritised areas we identified from practice evidence and evidence from what we were becoming aware of as the programme progressed. The following is a sample of actions implemented over the course of the programme.

1. All ward staff to take responsibility in ensuring pastoral care are involved and updated on a patient’s condition/deterioration throughout terminal illness and at End of Life.

2. Person centred communication at End of Life Care implemented including language used, and be quieter at critical times.

3. See can we achieve personal wishes of patients more. Ask what they are. Help to create a more therapeutic care environment.

**APPROACHES**

Here we will outline some of the PD and facilitation approaches and activities that we found had the greatest impact for us. The PD programme was developed in partnership between HFH and HSE to assist hospital to develop new approaches and practices in EOLC. The PD programme employed a variety of approaches and processes to achieve the required outcomes. A collection of different processes were introduced to empower the participants to develop skills in critical reflection and facilitation and thereby view EOLC in a new perspective. This enabled them to share their learning with their colleagues. The following were some of the approaches and activities used during the programme.
**Vision statement**
This activity involved the three wards participating in a values clarification exercise. This exercise determined the significant and important principles, values and beliefs the group held in relation to EOLC. There was holistic engagement, whole team involvement and participation on what really mattered to them during this exercise. The common themes were identified and consensus was employed to agree on the final wording of the shared vision statement. A great learning experience for the group as one participant noted

“To respect other people’s views and experience even if they are complete opposite to mine/ours”.

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**Vision Statement**
(Developed 18th February 2011)

We believe the ultimate purpose of person-centred end-of-life care is to ensure a dignified, peaceful, and comfortable pain free death. We acknowledge and respect all cultural and spiritual beliefs. We believe this can be achieved by striving to meet all personal wishes of the patient and their loved ones and to continuously develop effective and open communication.

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**Communication: Language exercise**

This profoundly important exercise was immensely practical action learning for the group and their colleagues. It started the conversation on how the group referred to each other and to their patients. It also focused their attention on the language used on the wards and to consider if it was person-centred or not. It challenged the group to identify substitute words which were more person centred and they agreed to challenge each other and their colleagues on non-appropriate language. One of the challenges was if the language used comprised personal respect. This is an on-going process – involving both the spoken and written language. The group acted out act scenarios to visually see the very powerful impact of language and how it can depersonalise patients and colleagues. They experienced the value of subtle change – to make language more person-centred. This activity helped re-focus attention on humanistic interactions. The activity really helped to raise awareness on the importance of language.
Feedback from the participants in relation to what changes are taking place on their wards:

"More awareness – environmental"
"Person centred language"
"Greeting people when they come in the ward"
"More aware of making eye contact",
"Communicate better with colleagues and the public"

**High challenge with high support**

High challenge is a process that we employed to raise the group’s awareness about what was happening on their wards and the role they play in this activity. More importantly it was used to foster a reflexive mode of inquiry. The approach used was that a challenge is always balanced with support to ensure the challenged colleague does not feel threatened or judged therefore reducing the reactive reflex to act on feelings. Guided reflection was used to challenge the group’s normative attitudes, assumptions and actions. These skills were employed on their wards with mixed success – it did raise awareness however initially the participants found “role play” uncomfortable and difficult. Following practice at programme days participants began learning the lifelong skill of asking the right questions within a safe environment of high challenge and high support. They started using this skill with their colleagues on the wards. They were not passive recipients of theory but enthusiastically used guided reflection on care to challenge colleagues.

An example of how the group viewed themselves using this skill is demonstrated below.

The group divided into two groups to role play two scenarios of their personal choice in relation to high challenge and high support. Following the role play, a discussion took place in relation to marking themselves on a grid from 1-10 as to where they perceived themselves to be in relation to supportive challenge. The group scored themselves 6.5 out of a possible 10. In the image below the arrow denotes the direction the group would like to go.

<table>
<thead>
<tr>
<th>High challenge/Low support</th>
<th>High challenge/High support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out on a limb</td>
<td>Teamwork</td>
</tr>
<tr>
<td>On own</td>
<td>Satisfaction</td>
</tr>
<tr>
<td>Frustrated</td>
<td>Can do attitude</td>
</tr>
<tr>
<td>Feeling let down</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Low challenge/Low support</th>
<th>Low challenge/High support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling de-motivated</td>
<td>Stagnant</td>
</tr>
<tr>
<td>No point</td>
<td></td>
</tr>
</tbody>
</table>

This exercise stretched the group beyond their perceived abilities, moved them out of their comfort zones. They told me that it felt scary, uncomfortable, but also exciting and very stimulating.

"We are learning to look at things differently and we accept that challenge is growth and we need to move out of our comfort zones to learn".

43
"We spent time reflecting on feeling empowered – our role models for same and how we can help each other and our teams”.

“We learned a lot from role play, our creative art work”

"Feel more focused on EOLC, more informed and I feel empowered now to challenge unacceptable practice"

**Reflective Nature Walk/ Creativity**

This learning process involved the profound use of silence. It involved participants initially walking in silence in nature then opening up conversations about their care environment using nature to stimulate conversation and creative thinking. The exercise also encouraged individuals to step back in order to reflect on their care environment from the perspective of a patients and relatives. This was a really powerful and effective exercise.

The walk took 20 minutes and when the group returned they were asked to capture their conversation in a poem, picture or HAIKU and share with the rest of the group. Discussion followed on how they can connect their learning to the care environment there was total engagement in this learning activity. The HAIKU below was developed by the group following the exercise.

<table>
<thead>
<tr>
<th>Group HAIKU</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joy to be alive</td>
</tr>
<tr>
<td>Help each other journey on</td>
</tr>
<tr>
<td>Nature is nurturing</td>
</tr>
<tr>
<td>When under pressure</td>
</tr>
<tr>
<td>Patient’s wishes can be heard</td>
</tr>
<tr>
<td>Our focus to change</td>
</tr>
<tr>
<td>What a great honour</td>
</tr>
<tr>
<td>In caring for all patients</td>
</tr>
<tr>
<td>When they are dying</td>
</tr>
<tr>
<td>I feel so privileged</td>
</tr>
<tr>
<td>I want it for all patients</td>
</tr>
<tr>
<td>I want it myself</td>
</tr>
</tbody>
</table>

**Introducing creativity to support innovation**

I facilitated creativity to problem solve, make decisions and thus develop the group. We used many different forms creativity such as poetry, art work, role play, sculpting exercise on evolving culture, scenarios, vision and mime to break down hierarchal barriers in order to help us gain new insights and unravel assumptions. This was very new for the group and for me as a facilitator. It was really about balancing our ‘critic selves’ with our ‘dreamer selves’ in order to make the change possible.

We used material to help us become creative such as Whack Cards. This was a very new way for us to learn. Here are some reflections from the group on their learning:

"Whack cards are good – make you think of other ways to look at things”
"What the message on the whack card meant and that we advocate for the patient”
"The cards were a great help in learning - Bring things together”
"Leaving personal worries outside door was a good practice picking cards that represented how we felt or what we would like to achieve that day drawing pictures, role play was good learning”. 
Claims, Concerns and Issues

This process was employed repeatedly throughout the programme to reflect everyone’s opinion on feedback of progress to date, what was working well, what were the perceived blocks/barriers and what issues required addressing. This key tool had a big impact on learning both for me as facilitator and the group. With practice there was greater engagement and it became the norm for each meeting.

This activity was based on appreciative enquiry: looking at what works and how to make it better. We started with positive statements about EOLC. Thereafter, participants could express their concerns. As facilitator, I tried to energise all to get involved and engage enthusiastically in the process. We used our terms of engagement to ensure that all contributions were taken on board and listened to and actions agreed to progress issues. The example below of the claims, concerns and issues exercise was taken from one of our programme days. The activity was to address the progress and challenges of the programme to date.
<table>
<thead>
<tr>
<th><strong>Claims (positive)</strong></th>
<th><strong>Concerns (negative)</strong></th>
<th><strong>Issues</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Much more confident</td>
<td>Not everyone on board - Consultants</td>
<td>1. How do we involve our Medical colleagues?</td>
</tr>
<tr>
<td>More understanding for Everybody:</td>
<td>Not fully actively participating</td>
<td>2. How do we maintain momentum?</td>
</tr>
<tr>
<td>Glad it has happened</td>
<td>Timing</td>
<td>3. How can we get the message across to the entire hospital?</td>
</tr>
<tr>
<td>Quietness</td>
<td>Time constraints(workloads)</td>
<td></td>
</tr>
<tr>
<td>More open communication</td>
<td>Resistance</td>
<td></td>
</tr>
<tr>
<td>HCA progressed</td>
<td>Staff issues – staff shortages</td>
<td></td>
</tr>
<tr>
<td>More involvement</td>
<td>Very challenging – finding the time to explain the programme on the ward</td>
<td></td>
</tr>
<tr>
<td>More team effort</td>
<td>Lack of understanding of what we are doing on the ward</td>
<td></td>
</tr>
<tr>
<td>Standard of care improved (overall)</td>
<td>Frustration</td>
<td></td>
</tr>
<tr>
<td>Pastoral care and all religions on board more than 2 yrs. ago</td>
<td>Not getting the full picture</td>
<td></td>
</tr>
<tr>
<td>More respect for HCA’s involvement</td>
<td>Opportunity for feedback limited</td>
<td></td>
</tr>
<tr>
<td>Involved in decision making</td>
<td>Would like more encouragement from -Ward managers - Senior Managers</td>
<td></td>
</tr>
<tr>
<td>Opinion taking on board</td>
<td>Resentment – not understanding</td>
<td></td>
</tr>
<tr>
<td>Work with different staff members strengths</td>
<td>Shorter time frame – perhaps too long</td>
<td></td>
</tr>
<tr>
<td>Confident in spreading the message to -Student nurses -Interns -Bank nursing staff</td>
<td>I hope I do not let down the programme</td>
<td></td>
</tr>
<tr>
<td>Gained an understanding of the programme</td>
<td>Attitudes – so hard to change and challenge</td>
<td></td>
</tr>
<tr>
<td>Interesting to see results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-developed very well – learned from each other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>We shared and enjoyed the experience</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Context Assessment Index (CAI)
This was part of the evaluation of the programme which we undertook at the beginning and end of the programme. This questionnaire enabled us to evaluate the culture of our workplace, the leadership style and what evaluation processes we use. The results of the CAI were discussed within the PD group in terms of numbers of respondents, questions that received very high scores and those that received very low scores and what the information is telling us. We also reviewed the findings in the context of espoused views without evidence in practice. This was our first experience in analysing data such as this and it gave us the opportunity to experience and understand the process.

Highest baseline scoring areas
Only the three wards participating in the PD programme were surveyed. In 2010, there was 66 responses from questionnaires distributed whereas in 2012, 42 completed questionnaires were returned. The baseline evaluation (2010) results that scores the highest related to patients’ privacy and dignity; Health Care Professionals (HCP) and Health Care Support Workers (HCSW) understanding their roles; high regard is given to patients psychological and spiritual wellbeing; care is based on comprehensive assessment and nurse leader acts as a model of good practice.

Lowest baseline scores
While the overall score for 2012 is lower in all three categories, this clearly demonstrates that individuals are starting to appreciate the questions more now and understand the significance of making improvements in some areas. This will become more obvious from the areas that they scored lower in 2012 than the baseline. It also proves that individuals are really thinking about their responses now and relating it to the care and services they provide from an informed knowledge base.

Highest scores in 2012
The areas that scores highest has some similarities with the baseline score with regard for the privacy and dignity of patients remaining high along with understanding of the roles of HCP and HCSW. The two new areas related to discussions planned between HCP and patient; and staff welcoming of cultural diversity.

Lowest scores in 2012
Four areas scored lowest and related to the high level of hierarchy within the organisation; the lack of reflective processes used to evaluate and develop practice e.g. action learning, clinical supervision or reflective diaries; the lack of review processes in place; and as with 2010 lack of appropriate equal authority for different disciplines in decision making about EOLC.

Summary of overall findings from CAI
Reflecting on the questions that received the lowest score in both surveys they apply to both culture and leadership. However, I must acknowledge as Kotter (1995) asserts that “Good leaders are those that always challenge the status quo”. The issue of equal authority in decision making on end of life care is highlighted in both surveys. Additionally, the opportunity for review and reflection on practice with goal setting is singled out as an area for potential improvement. During the life of the programme, there have been many organisational changes with the introduction of clinical directorates, a new CEO, and a new organisational structure and these cannot be dismissed as having some impact on the organisation. These multiple changes require time to bed-in and while they are in progress it may seem to some staff that we have a ‘command and control’ organisation until they see the ‘fit’. It is of interest in the 2012 response that staff gave a low score to reflective process to evaluate practice. Perhaps this might indicate that the participants have being sharing their experiences with their colleagues who it would appear would also like some time to
reflect on their practice. It also shows recognition that this is something that they should do. It is heartening to see that in both the baseline evaluation taken at the beginning of the programme and in the second evaluation carried out in 2012 indicate that individuals feel that there is a high regard for the privacy and dignity of patients. Additionally, Health Care Professionals (HCP) and Health Care Support Workers understand their roles and their unique contribution to the multidisciplinary team and the care provided on the wards. As a facilitator, I recognise that over the course of the programme the Health Care Assistants who were part of the group, engaged fully, gained insights and flourished. There seems to be a change in emphasis from the 2010 survey where high scores were given to a comprehensive assessment of patients. This was overtaken by planned discussions between HCP’s and patients. If you extrapolate this it would seem to imply that there is more engagement with patients about the care and service provided. Also noted is that staff welcome and accept culture diversity. The programme appears to be impacting on the culture in-situ on the three wards as is reflected in the two comments below:

“We were surprised that all the wards had similar issues from the questionnaires”.

“We all have the same issues and it is great to have time and space to discuss these issues in confidence”.

The level of understanding within the participating wards of what constitutes culture, leadership and evaluation has evolved over the duration of the programme and will help to implement and sustain a culture of person centred EOLC.

Workplace Culture Critical Analysis Tool (WCCAT):

This observational study was embraced by all wards with varied success. It was used to inform them of changes needed in their practice. This study was completed following an information session and it was conducted by a participant of the programme and the facilitator. This tool concentrates on the physical environment, communication, privacy and dignity, patient involvement, team effectiveness, learning culture, risk and safety and organisation of care, essentially all the elements required to have a person-centred workplace culture. It is a comprehensive observation tool, complete with observer prompts, space for observation notes and a space for questions arising from the tool. The ward can agree with the facilitator to use either the full observational toll or an abridged version which will concentrate on specific areas of improvement. The wards may continue to use this tool as they have become familiar with the methodology.

GENERAL THEMES FOLLOWING THE WCCAT OBSERVATIONS

- The nurses’ station were a hive of activity and patient areas have minimal staff
- Not enough seating for visitors
- Environment is everyone’s responsibility
- Lack of private space for sensitive communication to take place
- Report time too long and can be overheard – breakfasts can go cold
- Good rapport between staff
- Rushed and busy body language
- Awareness of how to appropriately meet and greet visitors to the ward,
- Vision statements in visible place
- Meaningful engagement with fleeting /task orientated communication,
- Respect for patients decisions
- Greater awareness of how to adapt the environment when a single room is not available
- Staff generated noise a problem – trying to get individuals to lower voices
- Challenging of poor practice is still a difficulty
- Praise for a job well done happens only sometimes
- More evidence of critical reflection required – questioning of some current practices
- Risk and safety generally at a good level
- Care could be more person-centred and patient-centred
- Individualised care plans in place
- Review of priority around assisting patients at mealtimes

Feedback on the observation experience

"The negative effect on patients of staff noise, environmental noise, lack of greeting, harsh lights, phones ringing, trolleys noise and position and finally poor signage”.

"The value of looking at our wards with the consideration of the patient not just as our place of work - This was highly valuable learning experience”.

"Patient stories, - Using a patient’s story to inform practice. Have to ask patients what they want – our care needs to be informed by them”

**CONTEXT**

In this section we reviewed how our contexts or care settings influence the care approaches and decisions we make and use and how that is starting to change. We looked at practices before the programme started and what has now changed or changing.

**Evaluation of the Care Context**

The overall context is an acute hospital operating on the medical model of care, HSE targets, where SDU qualitative results are required, cost savings including reduced staffing and reduced length of stay coupled with the requirement to discharge patients promptly to other care institutions. All these external drivers of decisions in care are not going to change for the foreseeable future however, notwithstanding that the HSE places a lot of emphasis on person centred care in its approaches and policies.

The newly launched HIQA standards also have a theme on person centred care as one of the eight themes in their standards. Taking cognisance of the organisational culture, we needed to progress slowly and build confidence in the participants so that they could engage fully with their colleagues back at ward level.

We acknowledge that there may never be a right or perfect time to introduce change into a hospital environment which by its very nature can be very stressful. We introduced this ambitious and complex PD programme into our hospital during a time of change and external review. Indeed as Manley (1999) asserted “the very first step is to break the cycle of busyness and create time to start the PD process”.

As highlighted above before the commencement of the PD programme conversations about EOLC seldom took place between staff themselves or between staff and patients and their relatives. Now, EOLC is embraced by the group and on all 3 wards. Participants identified notable culture changes on their wards since the beginning of the programme. From a reflection activity undertaken by the group the following changes were identified:

- Giving more time and respect
- Quieter at time of death
- More compassionate
- More time given to Patients and their Families
- Endeavouring to give family what they want
- More respect shown when symbol is on display
• More awareness of end of life – more peaceful – less noise
• More aware that every family’s need are different
• More aware of our co-workers emotions – real team work
• Patients have their own say
• The symbols have raised more awareness and greater respect
• More respect from all staff for EOLC
• More awareness on how patients are addressed i.e. by name rather than by bed number
• Before “task orientated” now more time given to patients and families
• Before elevated noise levels now more effort to create calmness

An example of actions taken to change practice
One of the things that was highlighted by the families in feedback to the ward staff was that they felt we provided their dying relative with great care, respect and dignity however when the death occurred they sensed an emotional withdrawal from staff. The comment passed was “you could not look us in the eye – you had already moved onto the next patient to be care for”. When the group discussed this and examined their practice they felt they were some truth in the observation. A HCA proposed that the staff member caring for the dying patient should accompany the family if they so wish with the remains to the mortuary. It was felt that this gave the family additional emotional support at this very difficult time. We went on a mortuary walk and engaged the staff about the possibility of introducing this new step. For some members of the group it was their first time in the mortuary. That in itself was educational for the group and led to a member of the portering staff invited to a programme day to discuss the implications for them of implementing this new process. Everyone agreed it was a good idea. We now accompany the remains with the family to the mortuary if they so wish.

"Facilitating this PD programme was a challenge it demanded a considerable amount of time and energy – far in excess to what I anticipated at the beginning of the programme. The programme introduced all of us to a new way and a different way of learning. The participants were focused on outcomes and the programme concentrated on the process. Many interesting conversations were had over the duration of the programme to get synergy of these two views”.

INTENT

This section will outline what is currently in place in the participating wards and what could be different along with our plan for the sustainability of the programme. The changes on that have taken place on our wards since we commenced participation in this programme are as follows:

• We developed a common vision for our care practices so that we can work towards developing consistency in our approach to care within the ward-based team. This vision is ours to own, developed by us using a systematic approach and with our priorities for the care we want to deliver outlined for all to see and for which we are proud of.
• We have engaged with our colleagues in our workplace in exploring traditional customs and practices and how we have traditionally prioritised our care. We challenged the way we interact together as a team, how we communicate with each other and our patients and their families.
• Over the course of the programme we identified terminology and language that we consider can be demeaning to patients, families and colleagues and are working on using more person-centred language that doesn’t belittle or cause offence.
• We have looked at our environment and how we can make it more suitable for persons at the end of their lives and for their families who are stressed and sad.
This has included reducing the noise levels that we as staff generate, thinking of more creative ways to provide quietness and privacy when a single room is not available for patients at the terminal stage of their lives or the patient wishes is to remain in a six bedded unit.

- We have developed knowledge and skills in care planning and practices for patients and their families at end of life. We have developed a deeper understanding of the need for care to be in accordance with what the patient wants rather than what we think they want.
- We have learned how to supportively challenge our colleagues when we observe practices that are not consistent with our vision for care and good practice.
- We have tried to engage other colleagues and other disciplines in our work with some success but we would like to have more success with this now that the programme is finished.
- We have developed a deeper appreciation and knowledge of each other’s roles within our ward based teams.
- We have learned how to be more inclusive in the decisions made about our workplace and our care.
- There is a resource folder on the three participating wards which is very comprehensive and very beneficial to all staff.
- We decided to put the EOLC road maps in our ward resource folders for all multidisciplinary team members to avail of.
- We have introduced flasks and crockery for tea/coffee making in wards in response to feedback from relatives.
- Peoples attitude towards their role in EOLC - everyone has a part to play.
- We now have two resource/link staff on each of the three wards and on all wards throughout the hospital.
- We have pastoral care lockers (or ward alters) on all wards.
- We have trialled the use of NorMor Chin collars and are now in the process of extending the provision of collars to all wards in the hospital.
- We have succeeded raising more awareness on EOLC.
- We have concentrated on using person centred language.
- There is more involvement for Health Care Assistants on all wards as a result of this programme.
- We all feel enabled empowerment of individually as a part of the multidisciplinary team. We all have a voice now and a powerful forum to be heard.
- We have seven camp beds in the hospital to assist families who wish to stay with their dying relative.

The following is an account of some reflections from the group on our learning:

"We got excellent learning from our role plays and our exercise on high challenge and high support. This is something we need to address continuously".

"We realised that from our expression through the medium of art pictures we are getting more comfortable drawing but also we are learning a lot about the different ways to express ourselves".

"We learned a lot from our reflection on what we have achieved in the last year. This was a very positive and bonding experience for all of us. It made us more determined to continue to improve EOLC for our patient’s".
SUSTAINABILITY OF THE PD PROGRAMME WORK FOR EOLC

We want to build on the knowledge and skills developed in our group and share this with other hospital staff to build an overall person-centred culture in our hospital. We believe that this will benefit our service users and our staff. It will improve the quality of the care we provide, reduce the number of complaints, to create greater satisfaction with care outcomes and more job satisfaction for staff providing care.

Now that the programme has finished we want to continue with our work in developing person-centred workplace cultures for patients and staff. Together we have decided that the following are the areas that we wish to focus on for sustainability.

1. We want to use the skills we have developed on this programme to ensure that this work does not come to an end.
2. Plans are being developed to have EOLC on nursing induction programme days.
3. We want to continue as a PD group to develop a learning culture. To do this we would like to develop a PD Forum Group to encompass other clinical colleagues such as Clinical Nurse Specialists in Palliative Care, PD Unit, Clinical Practice Coordinators, some other senior nursing managers, clinical managers and link nurses - staff interested in this work from other wards. This could be in the form of a meeting once a month where we get an opportunity to plan activities and share ideas and good practice.
4. We would like to be supported to run workshops to share our PD knowledge. These workshops would target different aspects of what we have learned such as:
   ▪ Vision Work - How to develop a vision statement in other wards/units.
   ▪ Language Exercise - How to develop awareness of language that can be demeaning.
   ▪ Environmental walk-about exercise – who to review the care environment through the eyes of a patient or visitor.
   ▪ High Challenge High Support Exercise – how to supportively challenge poor practice and how to acknowledge good practice.
   ▪ Person-centredness – how to recognise the elements of person-centred care and what is required.
   ▪ ‘A Wish’ (HFH resource DVD) – how to look at what is good about our practice and what we can do to make it better.
   ▪ Use of structured scenario learning to stimulate creative thinking in order to start challenging traditional practice not based on evidence.

We still need to promote EOLC throughout the hospital and with our sustainability plan our hope is for synergies to develop and grow between staff throughout the hospital who are passionate about person centred EOLC. With the enthusiasm and knowledge that the group gained in the programme we are confident of our success. "More focus on EOLC, patient’s having better experiences and families being better treated”

The challenge is now to engage staff throughout the organisation with our sustainability plan and not to lose momentum. "We have not reached a critical mass at Tallaght Hospital to date – there is still misunderstanding about the programme. A real concern that the “culture work” that we actioned to date will stop, unless we gain real momentum from all levels in the organisation”

Our learning from our final PD programme day
▪ To look at things differently, culture needs to be changed
▪ Claims concerns and issues pertaining to end of life – shared beliefs
▪ That I am going in the right direction and I am getting more confident
▪ We have a choice
▪ Environmental effects on patients for example hear, see and smell
▪ Challenge is growth
▪ Importance of challenge
• More self-aware more focused on the need for change in person centred care (culture)

**STAKEHOLDER**

Here we outline the support we received, the communication structure with our key stakeholders including the DoN, standing committee, peers, and colleagues in the workplace. We also discuss what we feel worked well and the challenges with gaining engagement and interest?

This programme would not have been possible without the direct support and encouragement from The Director of Nursing (DoN), coupled her strong acknowledgement of our work. All assistant directors of nursing were supportive of the programme. The Clinical Nurse Managers in all three wards facilitated programme day attendance with flexible rostering. This was fantastic and much appreciated. Following each programme day one participant who self-selected, and along with the site facilitator, agreed to give feedback to the DoN on the programme day. This feedback session updates the DoN on any developments and any help / support the group required. As the programme progressed, it proved more challenging to get a date that satisfied all work diaries. Meetings were rescheduled, cancelled and then feedback was combined from two sometimes three programme days.

The challenge in making changes was captured through the following comments captured on a programme day:

- Slow progress is being made but we are creating great change
- Very slow and time consuming to make small changes
- Challenging to create change in workplace
- Can be difficult but when change is made it is recognised and appreciated most times
- It takes time
- Can be challenging

Tallaght Hospital has a functioning Death, Dying and Bereavement Committee for a long time. It was renamed End of Life Committee in 2010. I was asked to become a member by the Director of Nursing in 2005. The committee decided that I should give the feedback from the programme days and not one of the participants. Again there was mixed success in giving the feedback as often agenda items ran over. One example of positive feedback from a member of the committee to the participants:

"The participants have engaged well and that there have been positive outcomes for the hospital and in particular certain wards. They are all champions for change in our hospital and for this I offer them 'buckets loads of support' and I encourage each member to carry on the work. The process of change and making people more aware of end of life care will continue".

The participants and I received tremendous support from lead facilitator and co-facilitator coupled with site visits. As site facilitator I also received great support from my fellow facilitating colleagues – ‘your friendship and encouragement was very much appreciated’. Additionally there was a national day attended by all eight participating hospitals – the participants found this day a source of great learning coupled with networking.

*Communication with patients and families*

Seeing patients and their families as key stakeholders was new for us. “Some of the group had previously never thought that maybe this family has previously never experienced the death of a close family member.”

Families frequently send “Thank you” to staff members following a death of a relative. One family's experience of EOLC was that the ward had "lived" their vision statement.
This was most hearting for the participants. "We realised that it is important to ask families what they are comfortable with in relation to EOLC and they may be more comfortable doing more for their loved one than we think – we are supported in thinking differently".

Colleagues as key stakeholders
After each programme day the participants had actions to complete before the next day. The actions all involve reaching out to other staff, getting engagement and buy-in. They were encouraged to be as creative as possible to communicate the message from the programme days. Unfortunately, Tallaght hospital did not have a development co-ordinator in post for a considerable length of time due to a serious illness. However, while in post she was a wonderful asset and a wonderful support to the group. A senior executive has currently taken responsibility for development of the co-ordinator role.

"Hospital Friendly Hospice group were an Aladdin’s cave of help, assistance and guidance when requested. I always felt that I had access to information and resources and a friendly voice at the other end of the phone. The invitation to network meetings was gratefully received and they proved to be a good source of up to-date knowledge and developments".

"We are making progress in small steps, keep going! Even if it makes a difference to one patient or family member it is worth it".

"Staff more aware of need to be more, person-centred on an individual basis with all patients not just at EOLC".

"Rewarding when you see change in persons behaviour".

"Differences have occurred in people’s attitude to EOLC - Staff more aware”.

“We are all making progress and I am improving as a Health Care Assistant”.

How we shared the work of the programme outside our work places
The site facilitator gave presentations to all ADONS at a meeting, this group included Paediatric DON and CNM3, the Librarian, staff from Patient Advocacy and Director of Nursing. We also gave regular updates to the ADON’s meetings to gain support and invite comment. I presented at the nurse managers monthly meetings, Doctors Grand Rounds. The CEO attended Grand Rounds to give her support to the programme which she articulated after the presentation. The group produced a newsletter to inform all staff of PD EOLC developments in the hospital and had a publication in the hospital newsletter. Work continues on developing a dedicated intranet site. We engaged with Housekeeping, the Art’s Officer, with the Mortuary staff (we were given a tour) Portering staff and the Health Services Supervisor to build alliances coupled with support. To date Tallaght hospital has had one Final journeys programme with the intention of training trainers to roll out the programme.

Conclusion
As demonstrated throughout this report, the participants fully engaged in this PD programme. The work of the programme targeted attitudes, customs and practices. We as participants are committed to improving care outcomes for patients and families, changing the workplace culture to enable the skills and knowledge and experience within the team can be fully utilised. We have observed as one participant described "More respect for patients and their families at EOLC and also an improvement in care at this time from staff since the inception of this programme”.

Our learning from our final PD programme day was captured in as part of our day evaluation and the following is a sample of how we felt about our journey:
- To look at things differently
- Culture needs to be changed
- Claims concerns and issues pertaining to end of life – shared beliefs
- That I am going in the right direction and I am getting more confident
- We have a choice
- Environmental effects on patients for example hear, see and smell
- Importance of challenge
- More self-aware more focused on the need for change in person centred care (culture)

"My greatest learning from the programme is to see people as individuals, all with different needs but with the same ending - death. We should give to patients at this time what we would like for ourselves or our love ones at end of life. I, myself as a carer have grown in my confidence, by encouragement from my facilitator and the group, to speak up for patients, their families and for my own concerns of care. I have really enjoyed the programme and learned so much”.

"I have been privileged to be afforded this opportunity, to witness human growth and flourishing, be challenged from my comfort zone to be an integral part of changes in care and culture in EOLC".
Galway University Hospital (GUH) is one hospital on two sites. Ten staff members make up the GUH Practice Development End of Life Care group, 2 Clinical Nurse Managers (CNM), 2 staff nurses, a clinical facilitator and 5 Health Care Assistants (HCA). The participating clinical sites are Emergency Department, ICU/High Dependency Unit, two medical wards and a care of the older persons unit on the Merlin Park University Hospital site. There are three ADON facilitators including the Nurse Practice Development Coordinator. This feedback is written using the Praxis framework to reflect 5 core components: reflexivity, approaches, context, intent, and stakeholder.

REFLEXIVITY

GUH staff involvement in Practice Development End of Life Care (PD, EOLC) programme has enabled 13 more healthcare professionals to have an opportunity to reflect on practice and their own individual response to supporting a patient and family at end of life. Learning in this group has included having a more open approach to talking about death. On reflection, group members considered the palpable anxiety at our first session and the overwhelming emotion present in the room when almost all individuals spoke about personal losses. “I think we were all very surprised at how it affected us” one group member recalls.

In another personal reflection the CNM wrote “I think that now I have gotten over fears about talking about death to patients; conversation/discussion with the patient and family has been easier. We are including the patient’s wishes in the care plans as much as is possible”.

Another participant wrote “The HFH project has given us permission to be more open about EOLC” Helen reported to the group “I am more comfortable talking about death ...it has helped by removing the “taboo” of talking about death”.

Personal reflection has been an uncomfortable and a challenging way of learning for some of us. At each programme day we schedule time to write a reflection. As facilitators we have encouraged the group to use this in their personal life also. Some members became more open to the concept of self-awareness and developed skills of reflecting and were able to drill down to explore feelings and concerns. While we may not always adhere to the more academic model of reflection e.g. Mezirow (1991) participants have remarked on being more confident in talking about feelings and emotions with ward staff.

When a patient dies the CNM will spend a few minutes talking about that death particularly when she is aware of how it has affected the team. Spending time talking about the death and encouraging the nurse to reflect critically on how she supported the dying process in the ward is recognised as a therapeutic aspect of team work and personal growth and development. We would also acknowledge that in order for some staff to cope they may choose not to talk about death.

“This programme has helped me to heighten my awareness of the needs of the family particularly in light of the results of the audit and I am also encouraging staff to be more observant for family needs“.
The group has revisited the principles of the programme by scheduling each person to speak about elements of person centred care, listening, giving and receiving feedback, language used, reflective practice, CIP principles, and high challenge high support. Our intention is to reinforce the main elements into our consciousness and ways of working. We acknowledge that changing culture in any organisation will require much time and commitment but we are working towards objectives of collaboration, inclusion and participation. When reflecting on ward based scenarios group members have become more active in challenging non person centered care and in considering how other non-nursing colleagues can assist and support a cultural change.

Professor Jan Dewing, facilitated a day with the national facilitator group where she shared her experiences of the pace and challenges of emancipatory practice development work. She described a constant struggle to engage with a wider group of healthcare workers and of the difficulty in measuring culture changes. As facilitators we took comfort and encouragement from her comments.

**APPROACHES**

In our PD group the language exercise has had great resonance. As a Health Care Assistant (HCA) participant says “it’s the way you say it”. “I am far more conscious of how I am speaking and I am thinking before I say something to a patient and the family because it might come out the wrong way”

The exercise brought up lengthy discussion on black humour and the sub text that maybe used as part of the routine in the ward area. Throughout the programme the comment most often raised is that there is an increased awareness of language used and this heightened awareness has been brought to the attention of work colleagues.
Involving the HCA in the HFH, PD group has given them a voice and in some areas they are now involved in contributing to and writing in care plans. This is helping to build confidence and acknowledging the significance and contribution of the HCA to the nursing team.

Helen, a HCA has taken a role in maintaining the diary which is used to record what went well and what could have been addressed differently in the care of the dying person. She also keeps thank you cards and comments made by family members to share with staff. "We don't know it all". "We can learn from families"

Another HCA shared an experience of challenging colleagues who continued to discuss a social event at the bedside. Martina asked the nurses to stop the conversation and she stressed the importance of having a much more person centered, inclusive focus on care.

Participants working together on a programme day

The use of a more creative ways of learning was, initially, viewed quizzically by our PD group. As participants in the national group, we sometimes found this approach unfamiliar, uncomfortable and it often took us out of our comfort zone. As we gained more confidence in taking on the role of facilitators we replicated this way of learning with the GUH group. For example the group drafted a poem about end of life care and presented it at the national group event day in Dublin:

We walked down the stairs – in pairs
Side by side – no leaders here, a nod to everybody, thirst – ladies first
Natures lead bowed, in grey, clouds shroud
Silence – peaceful difficulty – smiling looks
Seeking shelter in a covered nook
For those most in need
We can’t fix it all
But we can plant a seed
We may today walk an inch, tomorrow a yard
But our eyes are on the prize
Unconditional positive regard
Over the sessions we became conscious of using a range of approaches to engage, energise the group, involve participation from each person and tap into individual strengths. The latter became clearer as the group become more comfortable in sharing personal thoughts, talents and expertise. Strategies included art work, role play, mime, poetry, hand massage, physical exercises and a nature walk. Angel cards were used as a form of meditation. Members of the group might have considered this way of learning rather unorthodox but later acknowledged it as a powerful medium for engaging both right and left brain hemispheres. Participants have also been able to reflect on and evaluate their own learning.

"My priorities have changed, one time I’d be afraid that I didn’t know the decades of the rosary ... I was probably too concerned with the rituals.... my priority would be to make sure the person isn’t in pain... "

"Final Journeys programme day was really helpful; I think that all the staff should attend. It was a very practical programme”

"It was very personal when we were asked to think about how we wanted to die...it really brings it home to you”.

Carrying out the Workplace Culture Critical Analysis Tool (WCCAT) observations was identified as a very powerful exercise in facilitating participants to see their ward culture through a completely different lens. They were surprised by the interaction of members of the healthcare teams when viewed from the patient and family prospective. It highlighted issues which could be addressed in the ward action plans e.g. placing emphasis on a patient centred approach and ensuring privacy arrangements by using a space for family interactions. Feedback sessions to the ward teams provided an opportunity to raise awareness and it is only through reflecting on the current culture of care that we can challenge it and plan to deliver it differently.

Work-based activity

Since January this year we have adopted a bed-cohorting policy in the medical floors. We plan to repeat the WCCAT in the medical wards to check if this change in bed allocation and the reduction in the numbers of medical teams visiting the wards will have a positive effect on interdisciplinary interactions and ways of working.

We viewed the “A Wish” DVD and the reflections generated ideas for its use as a way of communicating what may be the patient’s experience of dying in hospital. It also presented some ideas for exploring the relevance of “being present” for the person and personalising the environment. It was considered a resource to use as an icebreaker to generate discussion of EOLC at ward level with the inclusion of the wider multidisciplinary team. We will also be using this as an education tools for the CNMII development programme, the ADON senior nurse managers meeting, nursing support staff meetings, ward clerk meetings and the EOLC steering committee meeting. There are staff from the Contract Services at this meeting and some patient representatives.
It will be useful to get their perspective and we hope to circulate copies to the Contract Service Managers and to have a facilitated discussion.

The national day provided an opportunity for EOLC group members from the 9 participating hospitals to meet. Before the meeting there was a sense of curiosity of what might be happening elsewhere and how the other sites were addressing concepts and exploring ways of changing culture. Our group came away from the day with renewed energy. “I think we feel a bit better; it seems to be the same in all the hospitals. We all seem to be at the same stage”

One family’s personal account of the care their father received made a great impression on us at the national group day. It was very powerful but uncomfortable to listen to a litany of very poor experiences for this family. Defensiveness could be felt in the undercurrent of the responses to the speaker. But it also provided an opportunity to apologise to this family for the shortcomings as they perceived them. That particular session further confirmed the group commitment to a plan to improve the experience of dying in hospital, so that there would be less of these very sad accounts.

**CONTEXT**

Where is right place to die?
A CNM participant says "Involvement in this group has made a huge impact, it has made me go further for the patient I will challenge the system in order to use a private room for a dying patient“

Participants in the group are very upset when they see, what they would perceive as inappropriate admission of a patient, who is actively dying. Through personal reflection and group discussion individuals have reported how they have challenged medical teams about the transfer of elderly people to the acute hospital when they may have a more peaceful death at home or in a nursing home. We see this as a major challenge for this group in changing the culture when in Ireland, 60% of people die in hospital. We have identified how we might address inappropriate hospital admission, at a higher level in the organisation, and in partnership with community services.

The group took on board a patient advocacy stance when we held a debate with a medical consultant to raise concern about the reluctance to designate and document the end of life care plan for patients. This consultant has declared his support for the group when we address the topic to the wider arena at a grand round forum.

The results of the most recent CAI demonstrated the lack of autonomy felt by healthcare teams around diagnosing end of life care. Failure of medical teams to acknowledge and recognise the dying phase and discuss end of life care with the patient and family leaves nursing teams in difficult situations. ICU nurses describe the efforts they are making to have open discussions inclusive of patient /families and the multidisciplinary (MDT), which, they believe, has generated a great improvement in the quality of the relationship with families and the MDT and has improved the outcome for patients.

All of our PD facilitators describe the ethical challenges faced by staff throughout the hospital when the DNR orders are unclear or not documented. This can result in unnecessary distress/confusion for patients/families and staff. This further highlights the importance of use of clear language when communicating what is meant by DNR. This group has identified this as an area of concern requiring further work at all levels of the hospital staff.
The use of the end of life symbol in the wards has caused much debate and it has been discussed numerous times in this group. Our group holds very strong feelings about the patient being labelled by use of the symbol.

“I think it is far more important that we tell all teams members that a patient is dying, communicating is far more important than the symbol”

Martina shared her experience of bringing in tea to a patient who had died: “I felt awful when I walked in, no one thought to tell me he had passed away” she said. It was agreed to display the symbol in conjunction with the vision statement see (fig 9) and to also use a discrete version on our new patient status white boards on each ward (these boards are accessible to medical, nursing, AHP, support staff and contract staff at ward level).

![Fig 9 Vision statement and EOLC symbol in use](image)

Within the clinical area the group has made available a resource folder, including articles relating to EOLC. Some of the practical resources for end of life care have also been purchased.

The bereavement officer took part in one of the PD sessions; this provided another occasion for participants to raise concerns about the challenges in providing person centred care particularly in an acute hospital setting. Participants have shared feelings of apathy and exhaustion and of not being adequately supported to deliver a high quality service. They have expressed frustration in not being able to provide person centered care e.g. making a private room available for end of life care.

One of the biggest cultural shifts we need to perpetuate is that there are other ways of making the environment person centered e.g. requesting family to bring in personal items, photographs, pillows, music. We ask staff to ensure that other patients and families know when a person is actively dying so that they can be involved in maintaining an environment as dignified and peaceful as possible. Staff will ask that people would move to another area leaving the environment free of noisy day time TV chatter.
Claims, concerns and issues (CCI) exercise has been used on a number of occasions to highlight progress. Identifying CCIs also allowed the group to check back with the vision statement to evaluate if we were appropriately addressing concerns like dignity and privacy. The use of role play during the group sessions empowered participants to challenge less patient centered care.

The triad exercises provided a new experience for the group. Bringing an issue of concern to light in a secure environment was seen as very useful and allowed the group to see the problem or issue from other viewpoints.

**INTENT**

When this programme commenced we spent time exploring concepts and meaning around end of life, reflective practice, emancipatory practice development. We experienced the different stages of group formation and as we were only getting together every 6 weeks we found ourselves often going back over topics. Group cohesion was challenging as we had changes in membership at different occasions, two HCAs left the programme, two CNMs resigned from work and we lost one participating ward due to reconfiguration. One CNM was moved to another ward and so the partnership with the HCA on her ward was severed and this resulted in more of a challenge for each of them to maintain a focus in their respective wards.

New members have joined the group at different stages and they have a sense of needing to catch up with previous learning and to devise an action plan to engage with ward teams. Changes in the group membership have resulted in difficulty in building momentum and this has been a challenge in maintaining focus and engagement. The introduction of new members has reinvigorated the programme. Happily, one of the HCAs leaves us to become an undergraduate nursing student and she can bring her knowledge and experience of being in the group to inform her practice in the future.

Stock taking feedback to the Director of Nursing included the significance of being facilitated by the organisation to be involved in the EOLC programme. At the commencement of the programme participants had to deal with the guilt they felt in leaving a busy clinical area to as they saw it; “sitting here in the classroom when we know they are so busy in the ward”. These feelings were explored and challenged and it seemed that the group was more focused as time went on. The opening and closing exercise were useful in setting boundaries and letting go of personal and professional concerns for the duration of the session.

Despite the many changes in personnel and challenges to group cohesion we have had good attendance at most sessions. Evaluation has included disappointment that some members have not attended. Two scheduled days had to be cancelled and so the overall plan lags behind somewhat. This has confirmed that the reality of work in a hospital environment is not clear cut and plans do need to be changed to address priorities for both patients and staff.

The intent will be to involve the wider MDT and this has already begun through involvement of more health care representatives in the end of life steering group. We expect the participation of consultants, catering, bereavement officer and one of the participants of this HFH PD group.

Creating the vision for the organisation facilitated a deeper understanding of what this group would work to achieve. There were at least three re writes to achieve a group consensus. The design of the vision statement and its subsequent display in the clinical areas has been taken on with pride and a sense of achievement. It has also encouraged discussion among colleagues when they review it again in the clinical area. Our challenge will be to keep the vision live and the principles embedded in the approach to the patient and family and the care given.
STAKEHOLDERS

Within this organisation there has been great change, reconfiguration of services and changes in the leadership structure which has impacted on roll out of this programme.

In the first 6 months of this year we have seen the appointment of an acting DON, a new CEO and hospital manager/chief operating officer. This brought radical changes in the governance structure and the commencement of the first Trust structure in an Irish hospital. The outcome has resulted in a sense of rapidly changing infrastructures and of a feeling of not knowing what’s coming next. This has impacted on our group in that the ADONs now work in partner hospitals and the unavailability of the lead facilitator was one of the reasons why a programme day was rescheduled. Redeployment of team members has also affected the programme when the leadership role changed.

From the onset participants challenged the absence of other members of the MDT involvement in this programme. The group had to acknowledge that for this part of the programme participants would be drawn from nursing and nursing support roles only. The group expressed very strongly that end of life care is shared by all members of the team and so they need to be participants in driving the philosophy of person centred care.

Inviting other members of the MDT to the sessions facilitated discussion and exploration of ideas for patient centered care, e.g. bereavement officer shared her experience of breaking bad news and she was able to give some practical advice to the group.

The EOLC steering group which includes service users provided feedback and support when we were working on the vision statement. The DON met, encouraged and provided support to the group and acknowledged contribution to the hospital. Updates on the work of this group are on the agenda for all the nurse management meetings and so there was very practical support and commitment assured.

Other stakeholders are involved in caring for patients and families. The Children’s Remembrance Day Committee is responsible for the Christmas tree lighting ceremony this is a special occasion for patients and staff and those who sponsored lights. Proceeds are used to fund activities of the committee including the annual Children’s Remembrance Day, the Golden Enrolment Mass for deceased staff and other projects within the hospital e.g. refurbishment of parent’s room in PBU.

An ecumenical memorial service for bereaved families takes place annually and this is supported by the multi denominational groups and individuals. Two of the participating wards/units Care of the Elderly, ICU/HDU organises an annual remembrance Mass.

Our next group meeting will address the very substantive issue of how we further develop and sustain our learning and the underlying principles of the EOLC programme. Planning will need to consider how to share information, address education needs and strengthen the group resolve to continue to challenge practice not conducive to person centred care.

The recurrent themes for consideration for this group have been: The need for an ethical discussion forum, the lack of a coherent policy on diagnosing death and planning for associated care, and the lack of engagement of medical teams to address this difficult issue. The competing demands for rooms that would help to provide privacy and dignity at end of life.
At the completion of this section of the programme participants feel that we have only taken “Baby Steps” and that our journey to support a better experience for patients, families and staff members is about to begin.

PD group members with some key stakeholder colleagues
PARTICIPANTS: Health Care Assistant & Clinical Nurse Manager from six wards:
Mary Mercers Ward
Hospital 5 Unit 2 (H5U2)
St. John’s
Walter Stevenson’s
Emergency Department
Intensive Care Unit

Care for the Older Person
Medical Ward
Surgical ward
Oncology Ward

SITE FACILITATORS: ADON & End of Life Care Facilitator
DURATION: October 2010 – May 2012

PURPOSE
The purpose of the programme was to implement a model of practice development based on a person-centered framework that targets workplace cultures and contexts.

REFLEXIVITY
The EOLC practice development (PD) initiative in our hospital was timely in that it began at the same time as the EOLC Standing Committee was convened and shortly before the appointment of the EOLC Coordinator. The programme was novel in a number of ways. It was the first time that clinical nurse managers (CNM) and health care attendants (HCA) were given to opportunity to step away from the coalface to think about and debate their practice together as equals. The emancipatory approach was new to all participants. It encouraged creativity in the way people thought about their work and ensured that any development was relevant and meaningful for the individual wards. The use of facilitators helped to guide the teams as they learned to dialogue and critically reflect on their way of working. Beginning with values clarification exercise that included input from patients, families and multidisciplinary team members was new and challenging for the group, but it meant that from the outset the programme was one that reached the hearts as well as the minds of the participating teams. It also ensured that the priority areas identified for change in the individual ward development plans were real in the context of each ward.

Reflection was a key tool used throughout to increase awareness, learning and resilience by both participants and facilitators. For some members, active reflection on work issues was new, so at each programme day dedicated time was allocated for personal and/or team reflection. Reflective models such as Johns, Gibbs and Mezirow were used. As the programme progressed, the level and depth of reflection deepened.

"Reflection on practice, and a chance to step away from the clinical area was a hugely beneficial aspect of this programme for me".
APPROACHES

Values clarification
For most of the group the values clarification exercise undertaken at the outset of the programme was something they had never done before despite having worked in the hospital/health care many years. Engaging with their ward teams, patients, families and visitors in this way from day one was a major challenge, but it gave the group permission to look into their hearts and identify and articulate what really matters to them in the context of End of Life Care. It stopped people doing what they were doing and allowed them to speak from the heart and focus on what really mattered for them in their work with patients. Knowing what really mattered to them gave them a sense of purpose not only on programme days but also back on the ward and sustained them through challenging situations.

The principles
The PD programme was underpinned by the principles of equality, collaboration, inclusivity and participation and the Framework for Person Centered Practice Development (McCormack & McCane, 2009). It focused on team approaches to care, stakeholder engagement, leadership skills, supportive challenge, positive attitude to change and lifelong learning. Throughout the programme, the group consistently returned to the underpinning principles and framework through reflective or challenging exercises.

Developing relationship
On Day 1, the group developed their terms of engagement (TOE), which was something that most of them never done before in their work. These TOE governed how people related to each other throughout the programme and beyond. They were revisited on each programme day and evolved naturally over time as the group developed. It was agreed that decisions would be made by “majority rule” plus the caveat ‘can I live with that?’ When reviewed again on day 15 of the programme the TOE had become more focused, supportive and succinct.

Group Terms of Engagement

Day 1: Terms of engagement (TOE)
- Talk openly  ✗ Be positive & open minded
- Don’t criticise ✗ Maintain confidentiality
- Actively participate ✗ Be motivated ✗ Commit to attend ✗

Day 10: TOE
- Be positive & open minded ✗ Focus ✗ Be motivated especially back on the wards ✗ Commit to attend ✗ Support each other ✗ Listen
Clearly articulated values, principles and TOE empowered the participants and gave them the confidence and support needed to change practice in relation to EOLC. Throughout the process the principles and values that governed the engagement of participants became a natural part of their relationships. Participants learned to speak up and to speak across status gradients in a way they had not before. The programme facilitated them to work with people from other wards, to listen to and respect the views and contributions of other. It also allowed them to actively seek each other’s perspective so they could learn from each other.

“I don’t make judgments or assumptions about anyone. I just like to value people for what they are.”

“I value the judgments of others…I also see that it is not safe to make assumptions about anyone or anything as it may not be correct.”

**Creativity:** Each programme day was structured using innovative & creative approaches that supported the group to meet the objectives of each day. Each day commenced with a warm up and an opening exercise. The former was fun and generated energy for the day. The latter helped to bring participants into the space to focus on EOLC work. Each day ended with a closing exercise that allowed closure to occur and enabled people to walk away from the day work with a sense of achievement and purpose.

The objectives of individual programme days determined the approaches and processes chosen by the facilitators. The aim was for people to think ‘outside the box’ by engaging in creative activities that would challenge them and speak to their hearts and not only their heads. While it took some time for people to allow themselves to try out new and novel ideas, the group enjoyed the creativity exercises because it allowed them to utilize skills & creativity that are usually not accessed in day-to-day business interactions in our hospital. Creative activities such as art, role play, human sculpture, theatrical improvisation, Angel & Whacky cards, an interactive museum visit, writing poetry and haiku and contemplative walks allowed people to reflect on their work, end-of-life and patient care issues with new eyes. By using these innovative approaches to reflect on issues of concern they discovered their work world anew, saw it from different perspectives and found solutions to problems they would not have found using traditional methods.

“I am learning about the methods for best practice, to use imaginative and creative ways to stimulate thinking around the subject of EOLC.

**Skills Development & Personal growth:** The facilitative approach provides structures for participants to develop skills such as: critical reflection, awareness of the Johari window, giving and receiving feedback, high challenge / high support, and mindfulness. Individuals were encouraged to speak up, to listen and practice appreciative inquiry. These techniques were practiced throughout the programme and contributed to the personal growth of many of the participants. The group also took part in Final Journeys and developed the content for a poster, presentations, the hospital Intranet site & education session for HCAs. Some group members further developed presentations skills in order to disseminate work through the poster and presentations at conferences and meetings. The resulting personal development of participants was significant. Their confidence, and sense of worth and value grew. One HCA became trained as a facilitator for the Final Journeys. For all, perhaps the most important learning was to become less defensive about their work and to develop the skill of critical thinking. Through the programme, participants spoke of how their sense of interest, commitment and satisfaction with their job was reawakened.
"I love my work again…"

"I feel my work has made me grow as a person. It has also made me look at life in a different way…"

"I have a new interest in my work because of my role in the PD group. I am more involved and more confident in my approach to patient care”.

Work based learning
This programme was essentially a work based one in which participants acquired knowledge and information on the programme days and brought these back to their own units. They saw themselves as enablers for the learning on their units:

"It is no good if I keep the knowledge that I have gained to myself - must share it with my colleagues.”

"They see me as a resource and facilitator for EOLC"

Participants very much appreciated the need to share their learning with their colleagues on the ward and did this through ward based action plans that were reviewed and progressed over time. While these action plans were initially very much task orientated and contained items such as EOLC resources (bereavement cards, ward altar, EOLC symbol etc.), they progressed toward activities that would change culture over time such as initiation of debriefing after a patient’s death, reflective sessions & improved communication.

Challenging the status quo
Early in the programme, participants started to challenge the status quo when they realized that the ‘way of doing this’ is no longer good enough. This realization energized them to look for better ways of ‘doing things’ and initiate culture change within their units.

"I perceive there to be many challenges within my area of work when introducing the idea of changing the way we do things or how we look at things, but I have decided if we are to move forward and improve things we must persevere and continue to challenge ourselves and the people we work with”.

"I am learning to be challenging with others and to be capable of being challenged and to give support and guidance to those who need it.”

These quotes also articulate participant’s realization that culture change does not happen overnight and that resilience and perseverance are required in order to make long term impact and change.
**CONTEXT**

**Culture**
Understanding the existing culture and developing a shared vision for the future state was an essential component for each of the six wards involved in the PD programme. The programme offered exercises (language, observation exercises) that enabled participants to look objectively at the practices on their wards.

"I put myself in a patient / relatives shoes"...and "looked at the unit with visitor’s eyes"

In time “emphasis in the department moved to EOLC, finding ways to help it, we can’t keep doing things the way we do them, we have to change”.

Much work was done on challenging language. Very early on participants started to value the concept of language and how it influenced thinking and culture on their wards. Non-person centered language started to become less and less acceptable as the group learned to challenge each other on inappropriate language used.

An part of learning about their role in the bigger picture, the group spend time at the beginning reacquainting themselves with the people, resources and services that were available to them to help them to do things better e.g. EOLC resources, a visit to the mortuary and inviting the palliative care team to talk about their input. This helped the group to realize they are part of a bigger organization and how important it was for their patients that they worked as part of the bigger system. It also helped them to be more open and to appreciate the contribution of others and how their work fits into the overall scheme of things.

**Making changes**
Clarified values and the development of a shared mental model were powerful in helping people to realize what the right thing to do was. It gave them the courage and confidence to begin a shift in perspective from the routine, ritualized, often task orientated work to individualized patient care and to transfer it in a way that would inspire their ward colleagues. Through collaboration with their team colleagues, each ward developed their own EOLC development plan that was right from them in the context of their ward. The exercises such as challenging non-person centered language, supportive challenge, appreciative inquiry and listening to and respecting the contribution of others provided the prerequisite tools that enabled the care environments and processes to become more person centered.

On one ward a change in the care environment occurred when a small bathroom was turned into a storeroom “so that the day room could be utilized as a quality area for patients and families”. Also, despite competing priorities for single rooms, participating wards began to prioritize side rooms for patients at end of life to accommodate their patients and families.

Changes in how ward staff approached their work and the care given to patients began to emerge.

"I spend more time with dying patients now. While I wouldn’t have avoided it before, I am now making a conscious effort to spend time, to talk to patients."

“The patient asked me about his prognosis “It’s not good is it?” I answered: “No its not, I am so sorry”. Felt huge relief being honest with him and he told me he had a lot of thinking to do."
"Now I am more relaxed, staff are more relaxed if I go with them”.

Improvements in holistic care that was more person-centred and respected the dignity and choice of patients began to emerge. For example, one HCA insisted on no longer using commodes at the bedside, instead wheeling patients to the bathroom. Initially this caused debate, but was soon adopted by all on that ward and others.

"I stuck to my guns and insisted on bringing the patient to the bathroom. The patient was not going to use the commode, this was her wish, I asked her what she wanted”.

Other examples of improvement in holistic care include:
- The discharge of a patient home from ICU so that they could die at home as was their wish. This is unusual from a large tertiary hospital and required a shift in mind-set and new learning for the ICU team.
- Colouring hair, putting on makeup for a patient when they could no longer do it for themselves.
- Letting a patient at end of life take sips or have an alcoholic drink when they want it.

Changes also occurred in the way that families were included in caring for their loved ones:

"The patient’s daughter was chief carer of her mum prior to admission. We always invited her to help nurse/HCA to attend the needs of her mum”

"Everybody is talking more to families”. “We offered to have family members lay out the body –positive feedback,

The following demonstrates an increase awareness and use of sympathetic presence.

"The medical team, nurses, HCAs felt such sympathy for the patient’s son who was effectively on his own. He appeared to struggle with females so we organized for a male palliative care nurse to come daily to see him even though his mom was non-symptomatic”

**Engendering a culture of high challenge / high support**

"I thought I challenged, but I don’t“.

"I need to challenge the correct people and address the right problem”

Learning to challenge others about how things are done was something that the new within the existing ward cultures. However, as staff skills and confidence in doing it in a supportive way developed, they began to have the courage to do it and as a result become better negotiators and advocates for person centered care.

"I challenged the doctors in their approach to the dying man (my challenge was to keep calm). I explained to the intern and fought for them to prescribe- which they did, and for palliative care to be brought in”.
Other examples include:

- A HCA challenged the CNM to allow the family of a patient who had died to stay for longer. It was something he had never done before, but offered to stay with the family and look after them. Within half an hour the family had left and all were satisfied.
- A CNM negotiated the use of EOLC symbol with a reluctant consultant and a HCA from a participating ward (not a member of the PD group) successfully negotiated when a reluctant senior nurse manager asked that the symbol be removed.
- A CNM challenged the medical team on the appropriateness of recommencing NG feeding at end of life.
- A HCA was able to challenge and support their fellow HCA about walking away from a patient at end of life who was crying.

Recognizing and addressing personal and team learning needs

Both within the PD wards and outside, the PD work has influenced staff awareness about their need to learn more. Evidence of this can be seen in the level of participation at Final Journey’s Communication training (250 staff have attended to date); the choice of EOLC as the subject of dissertations for both Masters and post-Graduate Students; the availing of HFH education bursaries for European Certificate in Essential Palliative Care.

Challenges

From the outset, participants were aware that changing the culture and practice of EOLC would not be easy. The challenges they faced were acknowledged through periodic exercises such as claims concerns and issues (summarised below).

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<thead>
<tr>
<th>Day 1: Concerns</th>
<th>Day 9: Concerns</th>
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<tbody>
<tr>
<td>Unavailability of resources: side rooms, time, tea at night for relatives, delays transporting bodies, viewing access in mortuary, no oratory, literature &amp; information, finances.</td>
<td>Things aren’t changing.</td>
</tr>
<tr>
<td>Choice for patients and how that is communicated, NFR management, Advanced Directives, Legal issues can take precedence, support for families, and breaking bad news in the corridor.</td>
<td>Some people are not listening / hearing.</td>
</tr>
<tr>
<td>We assume control, our habits, staff preparedness, knowing what to say.</td>
<td>Medical participation and buy-in.</td>
</tr>
<tr>
<td>No standardized routine and equipment at death.</td>
<td>Will people have the confidence to face the challenge?</td>
</tr>
<tr>
<td></td>
<td>How to keep momentum going.</td>
</tr>
<tr>
<td></td>
<td>Resources – access to relatives, social worker input.</td>
</tr>
</tbody>
</table>

Within our hospital the main challenge that emerged was the difficulty in getting others to buy-in to change and the group’s frustrations in trying to maintain those changes.

*Things aren’t changing...some people are not listening / hearing*"n

*"Staff keeps slipping back into old ways; it is a constant battle to remind staff. EOLC lockers are not being used, I bring it to the group again and again – I have to remind people continuously”.*
Today the group clearly articulated the frustrations that can arise and the tenacity and persistence needed to reiterate the same thing over and over again in an effort to create the urgency required to change at ward level.

The challenges participants faced when working on their wards between programme days and the chance to reflect on these with their colleagues helped them to develop strategies to face these challenges but also building resilience. Participants never lost sight why they were undertaking the programme as this quote below demonstrates.

When staff (on the wards) openly disregarded the programme, PD members decided to carry on without them, and be a resource for work colleagues that want to do the best and right thing for their patients.

INTENT

A sense of purpose

Participants were very aware that their participation in the programme was a privilege that came with responsibility. For two staff from six wards to be released for 15 days over a 1½ year period is a significant commitment and investment in that group. From the outset it was clear to the group that for the programme to deliver on its objectives, participants would have to invest a great deal of self and commitment. While the programme had certain expectations and anticipated outcomes, the group had to develop a sense of purpose for themselves that would sustain them through the PD process.

I know what I am here to do.

This is where I need to be.

The changes that occurred within the time of the programme have been demonstrated. Following completion of the formal programme, the group is now determined to take ownership of on-going development of person centered EOL practice. To this end, the group has evolved to become an EOLC PD group with wider ward and staff membership. They requested and have been given 2 seats on the hospital standing committee. They are engaging with the Nursing Practice Development Unit as a support in promoting their work with students and learners. They have also planned another awareness event for October. There is evidence on some of the wards that they are continuing with their action plans.

They really seemed to feel it is their responsibility to nurture others to develop person centered care.
The diagram below provides a succinct synopsis of their sustainability plans for the next phase. It articulates their plan in terms of their circle of influence (within their own wards) and also across the wider circle of concern (hospital).

**Circle of Influence:**
- Evolve the EOLC PD
- Membership on EOLC/HFH Committee
- Ward based development plans
- HCA Sessions
- WCCAT Observation
- EOLC Audit & Reviews

**Circle of Concern:**
- EOLC/HFH Standing Committee
- Final Journeys Programme
- Awareness Days
- Link Staff
- ADON’s, NPDU, CPC’s
STAKEHOLDERS

Engagement with key stakeholders was essential to ensure that the PD initiative was aligned with and supported as part of the hospital’s emerging strategy for EOLC. Key to the success of the programme was the support structures established at the outset. These included backfill for Health Care Attendants (funded by the ONMSD) and a formalized communication strategy with the Director of Nursing and the Hospital Standing Committee. This involved a group representative and a facilitator giving feedback from each programme day. The meetings provided a forum for sharing ideas, articulating expectations and seeking on-going support from peers and senior colleagues.

The Director of Nursing (DON) was an on-going support and provided valuable feedback to the group on regular basis. The DON’s reflection on the programme and participants emphasizes the value of this programme to the participants and stakeholders.

“As Director of Nursing I am the corporate lead for matters relating to the End of Life Care initiative. As a nurse I have always had a personal interest in this important aspect of patient care and based on my role within the hospital, I fully appreciate the requirement to influence improvement in this context throughout the organization. This has involved establishing and chairing the hospital’s Standing Committee and meeting with a variety of members of the interdisciplinary team to progress matters relating to end of life.

A key driver for this initiative has been the Practice Development Project and this has played a fundamental role in facilitating the development of Clinical Nurse Managers (CNM’s) and Health Care Assistants (HCS’s) in relation to developing their skills and end of life care knowledge base. The process has involved close involvement between me and representatives from the project team. Monthly meetings were arranged as it was important for the participants to keep me updated on their work and this forum also provided me with an opportunity to give support and recognition to project representatives. It is worth noting that this level of interaction with HCA and CNM colleagues has provided me with an opportunity to witness the personal development of participants in relation to this initiative”.

Communication, inclusion and collaboration with the ward based teams and support staff was essential if the programme was to change work place culture. At ward level, this was helped including the teams, patients and families in exercises such as the values clarification, Context Assessment Questionnaires and WCCAT observations. Support and guidance for the programme was received from the National Coordinator and HFH at the regular national programme days and during a site visit when they worked with the hospital’s PD group. Dissemination of the PD work to the wider hospital and public audience was aided by the development of a dedicated EOLC site on the intranet, hospital awareness days, and specific presentations to work based teams, poster and oral presentations at the hospital’s quality improvement seminar and a palliative care conference. In the future, the EOLC PD work will also be included in a presentation at Medical Grand Rounds in the autumn.
REFLEXIVITY

Learning in the group included
Hearing other people's opinions and openness in the group was valued. The programme provided an opportunity to focus on End of Life Care. Members learnt from each other including how be part of a team which had the shared purpose of improving end of life care. Participants note that they developed confidence in speaking out about end of life care issues. Brainstorming ideas was found to be very beneficial and group members noted that they became much more aware of the importance of respect and dignity around end of life care. There was challenge in the group in a safe environment and this was new for some. Having a group combining nurses and health care assistants helped to see issues from other disciplines point of view. "I learnt that there were other ways and means to get things done not just my way".
The National Day was helpful in looking at other practices in different centres across the country.

Transfer to the workplace
The exercises both in the group and at ward level provided an opportunity to discuss what was or is happening in the ward. It was helpful for members of the group to introduce the Context Assessment Index (CAI) questionnaires early on in the programme and helped ward staff to understand these and to understand what this programme was about. Using the flipcharts at ward level to carry out the language exercise ensured staff were aware of the programme and what it was about and also provided focus for individuals. Use of dialogue on wards and consciousness of language used was seen as a key part of the programme.
A participant who moved wards during the programme was aware of the need to introduce end of life resources to that area and did so. Individuals grew in confidence to speak up to promote change and they felt this was needed. Using Workplace Cultural Analysis Tool (WCCAT) helped individuals and teams to be aware of positive and negative issues in their ward.
Critical reflection of existing practices updated

- End of life issues weren't priority before but now are given more time and higher priority in the hospital and on the wards.
- Lack of time is a challenge and means that processes can be rushed.
- Staff are more aware of the need for a single room, but they are not always available.
- It was thought that resources that are available may not always be used and that these tangible resources help promote changes in practice.
- More aware of needs and resources available within the mortuary and of the aftercare the deceased person and their relatives after the deceased person leaves the ward-"The whole journey now seems clearer and priority of end of life care."
- Can bring it up on the ward and outside the ward with managing priorities and when dealing with other managers and the multidisciplinary team.
- Greater awareness of language used around end of life care.
- Belief that the things are done properly insofar as possible when "I am there."

Growth from reflections

Reflections written by participants were reviewed. Early in the programme these were brief and tended to focus on the physical environment rather than how change might be achieved and focussed on the HFH spiral "symbol" and other tangible resources. It was also evident that there were challenges in speaking out for some more than others.

"As a care attendant I am always following orders, so going back with ideas and information can be a little daunting at times".

As time progressed reflections began to go into more depth and to focus on interactions, behaviours and practices for patients and relatives at end of life.

"I have through the sessions taken a personal journey examining my own values and beliefs in relation to end of life care and through discussion with other nurses and attendants from other areas of the hospital I have more of an appreciation of the difficulties these colleagues face in their areas. Because I am involved in these sessions colleagues in my ward now look to me for guidance in EOLC and therefore I become a resource and a role model".

"What I am learning about end of life care is how I communicate is important-the time and way a thing is said can make a big difference".

"Firstly I have to adapt and change myself".

"All people can make a difference to practice and not just a certain discipline. I find end of life care an emotive subject at times".

"I am more confident and pro-active on end of life care issue now in my clinical area".

Identification of priority areas and action plans

The priority for the participants was need for more single rooms in most areas. All staff on the ward are more aware of the need for good communication with families and we will continue to help raise awareness of medical staff through discussion when the opportunity is there. The group are aware of the need for the programme to reach other wards and to support the use of resources in all ward areas where patients die. Members of the group also support the use of training resources such as Final Journeys training to promote principles for other wards and staff.
“What I believe are the key elements of person centredness-self-awareness, willingness to dig below the surface on emotive issues, giving people ‘space’ and allowing the person the autonomy to direct their own care path”

**APPROACHES**

**In the PD group**
Developing the vision statement in the PD group with the feedback from the wards worked well. Through open discussion and dialogue the group agreed the vision statement and negotiated so that key statements and words from their wards were included. The vision statement “helped us to keep focused on core beliefs and practices”. It helped us summarise what we thought the group should be about…. There was openness to say what you wanted to say”. The statement included all views and it was very important to use the wording that staff used from the ward exercise.

**In the ward areas**
Feedback was given to staff in the wards (involved in the programme) by everyone in the group. Staff were encouraged to read and adopt the vision statement as far as possible. The agreed vision statement is displayed in all areas involved in the programme. Reading the vision statement at the Launch of the Hospital HFH programme was very powerful.

![Vision Statement](image)

**Vision Statement**

We believe the purpose of person centered End of Life Care is that a person will die with dignity according to their wishes. The person will be pain free, peaceful and comfortable with respect to their physical, psychological and spiritual needs. The family will be involved in patient care and their wishes will be respected.

We believe this can be achieved by having a multidisciplinary approach in a calm environment. This shall be delivered by an adequate number of staff educated to provide continuous individualized care using good rapport and communication skills. Our aim is to provide privacy and the option of a single room. Staff will advocate for the patient and family.
Language exercise in PD group

The Group members feel that they have changed from previous practice for example: "More aware to be person centred. Call the person/patient by name as opposed to condition. More aware that hospital jargon is not perceived as being respectful. Felt the language exercise was useful to do to raise awareness".

Language exercise in the ward/area

The Group felt that language awareness must be on-going otherwise it can lapse at times. It can depend on the day and challenges present- Own awareness on the ward to think before we speak, need to be aware to pick the right time in order to be heard. Language awareness was felt to be improving and participants noted that they are aware of importance to lead by example and not to personalise issues. "Self-awareness of the common everyday language we use in practice and how especially that language can appear derogatory or offensive". The importance of focusing on the individual patient, staff member and relative was highlighted by all.

High Challenge/High Support

It was at times a challenge to get to the programme day and participants were glad not to be called back to the ward. Others noted that "It was also a challenge to arrange cover in order to attend these sessions". Everyone felt that all were open to challenge in the group and all felt they were able to say what they wanted. "If challenged I felt able to take this as a learning experience". "I developed more confidence and felt able to say things and to have input".

High Challenge/High Support in Work Area

Participants felt more confident when challenging work colleagues when required. "Can refer back to what is learnt at the PD group - more aware and more knowledge". "Feel that as a care attendant I cannot always challenge- need support from others".

Members of the group stated that they challenge colleagues when not using resources that are available on the ward. Having an End of Life Coordinator is seen an important support. Importance of challenging poor practice or inappropriate language was agreed.

"Facilitation is working well. Some negativity due to low morale but I fell it is important to persevere"

"I think there are a number of things I am learning about myself here. The fact that I am being challenged, in identifying my weaknesses and my strengths and outing them to the test occasionally. Key elements of person centredness for me are to listen to the patient, to take on board their needs as well as listen to the patient's family. To take the extra minute if only for the patient or their loved ones and to implement what I am taking on board, what I am bringing back"

"Sometimes I feel like I am being undermined. That by trying to facilitate Hospice Friendly Hospitals sometimes colleagues can take it the wrong way and end up taking things negatively instead of positively. Again, in trying to facilitate this, I find it a challenge. The (Staff) are already under so much pressure, which making a change from what they have been doing is more of a challenge and time constraint until they practice the culture of this change."
**Environmental walkabout learning/experience from being in the Group**

During this exercise participant felt more aware of noise and listening. This was considered good for reflection and increased mindfulness of their environment. Participants stated that they felt enabled to be more critical and open in the ward area.

“Highlighted how we used to pass by but now we are more observant”.

“Seeing the area from ‘an ordinary person’s’ point of view”.

Improvements were made following environmental walkabout in areas such as the patients’ day room and waiting areas.

**Claims Concerns and Issues** was used as an exercise to establish views on given topics and everyone had the opportunity to contribute using the Collaboration, Inclusion and Participation (CIP) principles. This provided an opportunity to think about issues that impede progress and find ways to improve them. Participants said that they felt "more aware of concerns of others in the group" and able to “Open up the issues and resolve them with discussion”.

Issues still arise regarding non-availability of the single room for persons who are dying and the group look to find ways to resolve or identify these and other issues in creative ways such as identifying a quieter area in the ward and raising staff awareness.

Not just problem raised but asking what can be done “Asking the million dollar question”.

**CAI Questionnaire**

Participants seemed to embrace this aspect of the programme. One participant expressed that it was “great to get snapshots of staff views at the beginning of the programme and at the end of the programme”. Participants felt that ward staff accepted the second questionnaire more readily as they were more aware of the End of Life Care Programme.

“Great to see what our colleagues and other members of the MDT thought of our current practice in relation to end of life care”

It was acknowledged that it was important to include the views of all ward staff. The group distributed CAI questionnaires to assess the context in which end of life care is provided in the clinical area. The questionnaires were analysed on a PD programme day together as a team and all engaged fully in this process. Results were considered and compared across areas. Scores were noted to be in the mid-sixties to seventy percent in the initial assessment in December 2010. The group felt that all 3 elements were moderately strong in colleague’s opinion at that time. The group were conscious that with this first questionnaire colleagues might be overestimating the elements as they had not yet been exposed to the awareness raising aspects that the programme participants were developing on each ward.

This exercise was repeated in June 2012 at the end of the PD programme. It was expected that colleagues would now be more aware of the expectations of end of life care and therefore scores would be more realistic. The group were pleased to see that scores demonstrated an improvement in every element. The group supported each other in the analysis and collation of the scores for the CAI and found it helpful to see what staff thought at this stage. Results included in Figure 10.
### Cultural Index Assessment (CAI) Findings

<table>
<thead>
<tr>
<th>Context element</th>
<th>Culture</th>
<th>Leadership</th>
<th>Evaluation</th>
<th>Average Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.12.10</td>
<td>66%</td>
<td>66%</td>
<td>71%</td>
<td>68%</td>
</tr>
<tr>
<td>04.07.12</td>
<td>70%</td>
<td>70%</td>
<td>73%</td>
<td>71%</td>
</tr>
<tr>
<td>Difference</td>
<td>+ 4%</td>
<td>+ 4%</td>
<td>+ 2%</td>
<td>+3%</td>
</tr>
</tbody>
</table>

**Workplace Cultural Context Analysis Tool (WCCAT)**

The WCCAT was used in all participating wards. Initial feedback included that the WCCAT Tool is long and some felt that this could be shortened. Participants knew that they could select appropriate sections once familiar with the content. The group had some mixed reactions to the tool. It was considered an “an opportunity to see the ward through the eyes of a patient”. Staff on the wards seemed pleased to get feedback and participants considered that it was good that ward staff were aware of negative aspects so that these areas could be improved. Feedback included “Good to take a step back and see what sometimes you don’t see when you are part of the organisation yourself-example-clutter and noise”. Group members were aware of the difficulty of maintaining silence-not chatting to staff when doing the WCCAT. “First time we did it we had too many in the review team and this worked better the next time with just two persons carrying out the WCCAT”. Ward staff including Cleaning and Catering Staff appreciated feedback given. Some participants felt it was more difficult to do in their own area - “when looking means that you see things that could be better; difficult not to intervene when observing something that could be improved; time consuming and this is a challenge in current climate”. “Although all staff were aware of the WCCAT going on some staff may interrupt you looking for advice on other ward matters”. Despite some challenges participants generally felt that this was a worthwhile exercise.

**Facilitation style used in PD Practice**

All agreed our terms of engagement and our aim to facilitate best practice in End of Life Care. All group participants were considered equal and everyone was encouraged to participate in all exercises. It was expressed that the “group gelled together from day 1”. There was a positive dynamic and interaction was very good. Participants gave feedback to their wards regarding activities and encouraged participation at ward level in exercises such as language exercise, vision statement and questionnaires. Creative exercises such as collage and Haiku were accepted more readily by some group members but everyone participated and could see the value of taking the opportunity to be creative. Personal reflections were an important aspect of each group day – this provided time and space for participants to consider own learning. Facilitation processes also included warm up exercises and opening group connection exercises.

**Balancing in the group and place in the group**

All participants expressed that they felt equal and there was openness and full participation in the group. Participants worked individually, in pairs, threes and full group for different exercises and changed places to work with different people. Feedback included that they “Felt at ease in the group”
All agreed that it was important to ensure buy in from everyone and to clarify expectations. Some members expressed that it was an opportunity to "Learn to speak more freely and participate more fully" than they may have done in a group previously. "Everyone invited to give feedback and to participate". "It is invaluable to listen to other members of the group"

We also used the **values clarification exercise** to develop the vision statement with involvement from all staff on the ward or who visited the ward regularly.

The group used the **Triad action learning** approach to enable participants to work on issues or problems they have and to support them as facilitators of change on their wards. Positive feedback resulted from this exercise.

![Example of PD group at work](image)

**Terms of engagement** were agreed in the group at the outset and regularly reviewed at each meeting. Below are our terms of engagement developed by us and used throughout the programme.

<table>
<thead>
<tr>
<th>Message</th>
<th>Applied as Term of Engagement</th>
<th>Consequence if not adhered to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strength</td>
<td>We have strength if we work together as a team. Give notice of nonattendance when know in advance (added day 8).</td>
<td>We will be less effective</td>
</tr>
<tr>
<td>Transformation</td>
<td>This process will transform what we do in regard to end of life care</td>
<td>Waste of time here</td>
</tr>
<tr>
<td>Sisterhood/Brotherhood</td>
<td>We are all equal &quot;sisters&quot; in team</td>
<td>We will fail</td>
</tr>
<tr>
<td>Truth</td>
<td>Programme will teach us to be truthful to the patient</td>
<td>Patients will not have trust in us</td>
</tr>
<tr>
<td>Faith</td>
<td>We have faith that this will work</td>
<td>Fruitless day/ process</td>
</tr>
<tr>
<td>Grace</td>
<td>We have grace/belief in ourselves</td>
<td>We will show lack of belief to patients/families</td>
</tr>
<tr>
<td>Gratitude</td>
<td>We are grateful that everyone is willing to share experience</td>
<td>We will achieve less.</td>
</tr>
<tr>
<td>Abundance</td>
<td>There is abundance in ourselves to go a bit further with programme</td>
<td>Great loss if not achieved</td>
</tr>
<tr>
<td>Efficiency</td>
<td>If we are efficient we are more effective for patients</td>
<td>May result in worst case scenario</td>
</tr>
<tr>
<td>Peace</td>
<td>If we develop the messages above for the group we will develop peace which will sustain us</td>
<td>People less likely to turn up</td>
</tr>
</tbody>
</table>
Creativity

We used various creative forms and mediums including art work, mime, poetry and reflections. One of the mediums used is called a HAIQU used as a creative way to capture reflections within a specified format. The following is a reflective HAIKU composed by the PD Group in May 2012 following a reflective walk in nature to explore where we have moved in our EOLC journey.

Our Vision of End of Life Care

Has it made a change?  
The Ward is a better place  
Keep it up indeed

The HSE has a role  
In a way to promote a goal  
To pursue and achieve soul

It’s unreasonable  
End of Life with trouble and strife  
When it can be nice

Much work to be done  
We can do it together  
One step at a time

Understanding patient wishes  
Making patient comfortable  
Importance of single room

Calmness is vital  
For Patient comfort and peace  
In End of Life Care

Patient dying in  
Calm Surroundings with family  
End of an Era

The group also engaged in creative drawing, something new but useful to promote creativity. See example below taken on one of our programme days.
CONTEXT

Here we explore the context changes that have taken place and the supports that were used to progress the work. This was considered at the end of the programme using a SWOT analysis.

SWOT analysis of the environment

Strengths
Tangible resources provided through the HFH Programme supported more dignified practice on wards and group participants promoted their important at ward level. Resources such as the Spiral Symbol were introduced to the areas involved in the Practice Development Programme first and then successfully implemented in all other wards and departments. The symbol when displayed helps communicate to everyone in the area that a significant event is happening. A Sympathy card format was discussed in the PD Group and then agreed by Hospital End of Life Standing Committee and introduced and is considered to show more thoughtfulness and has received very positive feedback from relatives. Practice Development Group members developed an information leaflet for relatives to let them know what will happen following the death of a patient.

Weakness
Resources not used as much on some wards as others. Number of single rooms not considered adequate. Overall patient activity has increased in wards with increased patient turn-over and increased dependency since the PD programme commenced means that staff do not feel they have adequate time to give to patients especially at end of life.

Opportunity
Staff would choose quieter area of ward for a patient who is dying if no room available. New Critical Care Block to be opened later in the year will provide facilities for families and individual room for patients

Funding allocated to develop mortuary facilities for relatives of patients

Threats
Extra patients on trolleys on wards
Pressure to vacate the bed as soon as possible when a patient has died

**SWOT analysis of the ward based team**

**Strengths**
Awareness of need for single room and peaceful and calm environment at end of life.  
Awareness of staff to support families has improved

**Weakness:**
Morale generally low in HSE and have to work on this.  
Communication is difficult with staff working so many different shifts, (Part time/flexi hours), don’t see each other on any regular basis.  
At times challenges arise in communications between staff/MDT/Relatives and Patients

**Opportunity:**
Roll out programme to other areas in the hospital  
Use CNM Forum and HCA meeting  
New staff can sometimes bring fresh viewpoints and helps to communicate to new staff and own motivation and awareness.  
Ward meeting provide an opportunity about end of life care.

**Threats:**
Staffing levels lower and can staff may be pulled for relief on other areas.

**INTENT**

Here we discuss the structures that are in place to support End of Life Care, what could have been different and our hopes for sustainability of the work. Programme participants expressed that there is greater awareness of End of Life Care concerns on all wards. A guideline for care of the dying person near death and after death has been developed with significant input from PD Group participants.

HFH End of Life Care Resource folder was launched in April 2012 and heads of department including CNMs and also programme participants attended this launch. This was very successful, highlighted in local media, newspapers and radio broadcasts. Resource folders were issued to all wards and departments.

Relatives’ information leaflet developed by the practice development group is used extensively and has been reprinted a number of times based on continued demand. Feedback on this is positive.  
Other resources including ward altars, end of life spiral symbol, concealment trolley drape, electronic candles, HFH/HSE Multicultural Guide are on all wards used by staff to care at end of life.

Examples of ward alter and spiral symbol.
A sympathy card was developed in consultation with the PD group and the result is a card that is sent to relatives of the deceased patient at an appropriate time shortly after the patient's death.

The Practice Development group has liaised with the End of Life care Standing Committee on a regular basis to support effective communication with clinical and management staff.

The first Remembrance Service for relatives of deceased patients was held in June 2012 and included active support and participation from PD group.

All PD participants and some staff from their areas have attended Final Journeys training on site to date.

PD group have been consulted regarding participating in sub groups which are currently working to put HFH End of Life Care Standards into Practice.

What could be different?
More single rooms required for end of life care. The group are aware of and involved in the annual audit which is underway to review location of patients when death occurs.

If possible to reduce the impact of staffing shortages which impact on time resources allowed for patient and family care at end of life.

Find a way to roll the principles of the PD programme to all wards across the hospital.

It would help if frontline staff could be released to attend on-going relevant training currently available (e.g., Final Journeys Training). Release of staff is cited as the challenge.

Sustainability
Members of the PD Group expressed a desire to give end of life care greater priority and sustain this over time. They aim to continue to promote principles and practices for dignity and respect at end of life for patients and relative.

What the group members will each do
PD group members pledge to continue to encourage staff to prioritise end of life care in their areas of work. They agreed to promote the use of current available resources in their ward and in other areas.

After the death of a patient they plan to discuss with staff to review what has happened, what worked went well and what needs to improve and aim to include all ward staff in this process.

As PD Group members expressed that they aim to support each other over time to maintain the principles. Some of the group who attend HCA meeting will provide an overview for their colleagues.

Group members on the CNM Forum will ensure that all CNMs are aware of end of life care and the progress of the PD programme. Two group members will continue to participate on the End of Life Care Committee. Some members may also become involved in sub groups.

STAKEHOLDER

The support we received from stakeholders.
Participants felt positive about the meeting structure with the DON using the guiding document. All group members participated in feedback process with the DON. Participants noted that they felt on a more equal footing with this process and that the DON was interested in what they were doing.

The group appreciated the support for the National programme Day.
End of Life Care Standing Committee represents all stakeholders and is a support for the group to feedback progress with the work the group are doing. The work of the Committee complemented the work of the group. Two members a CNM II and Health Care Assistant from the PD Group are members of the End of Life Care Standing Committee.

Workplace Peers and Colleagues were keen to use the resources provided and were supportive of participants attending the programme despite staffing challenges. They participated in exercises such as the language exercise and development of the vision statement and they were cooperative, interested and open to completing the CAI Questionnaires. This was noted especially for the follow up questionnaire.

The End of Life Development Coordinator was very helpful and supportive and proactive, easy to speak with and encouraging.

The entire group attended Final Journeys Training which they recommend for all staff and feedback following the programme was very positive. The challenge is for release of staff to this training.

The HFH PD National Coordinator spent a day on site and was very informative and the group felt they learnt a lot using the exercises provided on the day. Service was organised for relatives of patients who died in the hospital in the previous year and positive feedback was received. Relative invited to speak at the Launch of the HFH resources and communicating the programme to the public. Group expressed greater awareness of asking relatives about their needs and the leaflet the group compiled for relatives was well received and continues to be in demand.

**Our final thought**

"WE can make a difference and WE can change practice on the wards"
CORK UNIVERSITY HOSPITAL

Introduction

Cork University Hospital has continued to engage with the HfH practice development programme since its commencement. In the last year Grace was joined by Aoife as co-facilitator in an effort to keep pace with the national group. Reconfiguration of Services in the South has seen the transfer of additional services to the hospital. The effect of the National financial crisis and recruitment embargo has had an impact in releasing staff from the clinical areas to attend the programme days. Commitment to the programme remains high in CUH but staffing constraints have meant that on several occasions only one or two members were able to attend on the PD day arranged, and several sessions had to be cancelled.

REFLEXIVITY

The group in Cork University Hospital consisted of 6 Clinical Nurse Managers, 5 Health Care Assistants and 2 facilitators. Throughout the second year it was unusual to have the whole group present as priority had to be given to immediate patient care. The importance of language, and environmental issues created much discussion, with members expressing varying levels of concern around the different issues but there was general agreement that good intent towards the patient and his / her family was of paramount importance and needed to be an inherent element of hospital culture. To this end WCCAT, which was introduced at the National Group, was introduced in CUH. We see this as having the potential to be the single most effective tool for cultural change. We have piloted the process using a tool we derived from the promises of our mission statement. Our plan is to begin the process on each ward and then form links between the participating wards and their neighbouring wards until the process has spread throughout the hospital. The end result will be that each ward or unit periodically puts itself through the audit cycle, using the WCCAT process, for the long term.

The development of a mission statement was one of the first objectives of the group. The mission statement is now visible on wards and is often a point of interest for visitors. Its promise to the patient is comfort, dignity, respect, privacy, compassion and good communication. Part of our action plan is that each ward/unit should develop a strategy to ensure that staff are, in fact, living the promises of the mission statement. One ward, for example, has chosen to post a ‘promise of the day’ on the notice board to remind staff to check and reflect on their interactions with their patients to make sure they are incorporating that particular promise.

APPROACHES

In terms of facilitation of the group there were no hurdles to overcome. The issue of hierarchy did not arise as a mutual respect between all members coupled with ground rules and Grace’s baking, allowed for active, effective engagement from all and a natural development and growth within the group. Standard items included in National PD days such as ice-breakers and warm-up exercises were tried but found to be no more effective by the group than the normal settling down chat which happened naturally. The group was not in favour of continuing these. Reflection took place in the group but while staff found the verbal element of this very helpful we felt that having to write it down and submit it caused unnecessary pressure and developed into a paper exercise. Triad and Biad exercises were found to be beneficial and resulted in a sense of having learnt a valuable communication tool. More practice will be facilitated with these.
Issues such as use of certain elements of language and the ward walkabouts led to lively, challenging but healthy discussion. There was not always absolute agreement on finer details but ultimately the overriding principle of patient centred care was agreed by all. The group developed an image of a stairway to person-centred end of life care on one programme day and presented it to the national group.

Participant demonstrating a creative image of stairway to person-centred end of life care

**CONTEXT**

As the initiative progressed there was commitment from all disciplines at Standing Committee level and Policy Committee level. The Practice Development Group, however, consisted only of Nurses and Health Care Assistants. Since the PD group was the best hope for cultural change, a multidisciplinary approach here too would have been welcomed by the group. The inclusion of Health care Assistants was unusual for project work in the hospital and it was very much welcomed here. The enormous contribution made to the project by the Health Care Assistants clarified for all the importance of an all-inclusive approach in hospital projects which require a change in culture. We would like to take this opportunity to acknowledge the hard work and commitment of the Health Care Assistants and Nurses on our practice development group.

In terms of the visibility of a change in culture, there is a definite increase in appreciation, by the hospital staff, of the meanings of the HfH symbols and the expectation of appropriate behaviour when they are in use. Awareness of the programme through presentations and displays are held in the canteen periodically and these are very well received by relatives and visitors. A new awareness of the HSE Cultural Guidelines has also been created in the hospital.
INTENT

In the interim report our fear for the sustainability of the programme was expressed. This fear has been partially realised. We had kept pace with the national group until the spring but since then we are continuing to work at a pace we can manage locally. To date we have had 6 wards/units working together on the programme. These wards/units will be in a position to continue but at a different pace, with our work curtailed to those elements which we feel will be most effective in culture change. As mentioned above, we see the WCCAT process as the most effective way of sustaining growth and development of a Hospice friendly Hospital environment.

STAKEHOLDERS

The CUH group attended the National PD day which brought all the participants together to share and discuss their goals, challenges and achievements. Networking with our colleagues across the other hospitals has been beneficial as ideas have been shared and friendships developed.

The friendships and contacts developed through our national PD group were invaluable and a source of great encouragement in challenging times. We hope to maintain this network.

Besides the facilitators, two members of our group sit on the Standing Committee and feedback on the group activities at every meeting. The members of the Standing Committee represent the Allied Health Professionals, Chaplaincy, Medicine, Nurse Education, Quality, Mortuary, and the committee is chaired by the Director of Nursing. As stated above, apart from the awareness created among relatives and friends of the patients at ward level, the awareness days in the canteen are appreciated by visitors to the hospital also. Our practice development days gave the members an opportunity to reflect on challenging issues they had faced in the previous period. The final journeys workshops, delivered by the Centre of Nurse Education, were attended by some members of the group and were found to be really beneficial.

CUH does not have a dedicated development coordinator for the HfH initiative. The various elements of the programme included cultural change, physical environmental changes, policy developments, final journeys education and the design and purchase of various HfH symbols and supports. Without a coordinator it was difficult to maintain all of the various elements as a whole. There are many projects and programmes in progress in CUH and with the overriding concern over finance and staffing; it is difficult to keep the HfH programme visible.

The commitment from CUH is still strong. We will continue to work as outlined above and are confident that we will be successful in changing the culture to one that reflects that of the hospice.
CONNOLLY HOSPITAL

The Connolly Hospital Team
The Practice Development (PD) team in Connolly Hospital was facilitated by Ms. Anne Murphy Assistant Director of Nursing and six areas/wards participated. Initially the Director of Nursing Ms. Mairead Lyons and Ms. Anne Murphy reviewed the HIPE data available from the hospital to decide which areas in the hospital would benefit mostly from this PD programme. The areas selected were Elm, Emergency Department (ED), Intensive Care Unit (ICU), Redwood, Rowan and Silver Birch. As the programme proposed a Clinical Nurse Manager2/3 (CNM2/3) and a Health Care Assistant (HCA) were nominated from the chosen areas. At the commencement of the programme there was no permanent HCA in the ICU so the second team member from ICU was a staff nurse. The team members were Ger McVey and Pauline Strachan- Elm, Marian Butler and Ronnie Delaney- ED, Linda McEntee and Derek Cribbin- ICU, Margaret Whelan and Catherine Meagher- Redwood, Frances Talan and Sarah McNally- Rowan, Geraldine Murphy and Ellen Osomoko- Silver Birch. The programme was co-facilitated by Ms Fran McGovern Connolly Hospital HFH development Co-ordinator from September 2010 until December 2011 and by Ms Bernadette O Sullivan who assumed this position since December 2011. The Nurse Practice Development team members Ms Deirdre Brennan and Ms Dolores Dempsey Ryan also offered much support throughout the programme.

Some members of the PD Working Group

REFLEXIVITY

Over the 20 months of the programme the team developed knowledge and skills in facilitation and practice development processes that have been built on previous existing good practices in person centred end of life care. The team then applied this learning to their ward areas which enabled them and their colleagues as a team to critically reflect on the values and beliefs on End of Life Care (EOLC) that were present. This process enabled the development of a good culture of person centred EOLC that had a positive impact on patient care.
**Action Plans**

Through the process of Critical Reflection the individual team members were assisted to visualize care alternatives and identify actions to achieve these changes. The team members from each area worked together to develop action plans that would enhance the EOLC delivered within their specific areas.

One of the action plans developed were noise related. This was related to the waste disposal bin within the ward area. There are new soft close waste disposal bins available that don't bang close, making excessive disturbing noise on a continuous basis when closing. These bins are now the standard bin ordered and in time it is envisaged that all bins within patient areas will have these soft close bins in place. Another action plan developed involved the teams hoped to identifying final wishes of their patients and they endeavouring to fulfill these wishes if at all possible. One lady requested to see her two pet cats prior to her death. The team asked her daughter if it would be possible to bring them in and the daughter was delighted to be able to do so. To date most of the wishes have been feasible and this has given the team, the patient and the relatives a great sense of achievement.

**APPROACHES**

The main style of facilitation adopted throughout the programme was one of Participative. Through this method of facilitation much discussion took place and the team members were encouraged to share their personal experiences. Using this facilitation process the lead facilitator ensured the integration, inclusion, involvement, participation and equality of all members of the team at all times. The CIP principles were an integral part of each programme day - Collaboration, Inclusive and Participation. Initially some barriers existed where different team members appeared shy and less willing than others to share their experiences. The lead facilitator enhanced the participation of all members by breaking into smaller teams for discussion purposes. Through this process the quieter, shy members of the team gained increased confidence and trust. As the programme progressed all the team members put themselves forward at different intervals to be the nominated person to deliver the feedback from their smaller teams to the entire group. This is then replicated by the PD members on the wards giving them the confidence to challenge colleagues and members of the multidisciplinary team when non person centred practices are observed.

Throughout the programme many different facilitation approaches were applied. These approaches enabled the team to critically explore the current practices in place. These practices were supported by the national audit findings and the quality EOLC standards.

A Vision Statement for End of Life care was developed through a Values Clarification Exercise. This involved the participation of the multidisciplinary team within each area. Five flip charts were displayed in each area with the following questions:

1. I believe the ultimate purpose of Person Centred Care is:
2. I believe this purpose can be achieved by:
3. I believe the factors that help us achieve this purpose is:
4. I believe the factors that hinder us from achieving this purpose are:
5. Other values and beliefs I consider important in relation to person centred practice for end of life care:

The purpose of this exercise was to establish the existing values and beliefs and to identify common themes. Through this process an End of Life Vision Statement was developed which is now displayed on the multimedia screens and the information notice boards throughout the hospital.
Throughout our programme days much discussion took place in relation to Person Centred language. On the ward area involved in the programme a **Language Exercise** was undertaken. This involved the ward staff working collaboratively to develop a list of the most commonly used words and expressions both verbal and written used on a daily basis that were recognised as Non Person Centred and the alternative Person Centred word identified beside it. This heightened the awareness of the ward staff to recognise when colleagues used non person centred language thus giving them the confidence to challenge each other.

Other approaches that the team found beneficial were the **Environmental walk about** and the use of the **Workplace Culture Critical Analysis Tool (WCCAT)**.

The participants within the team undertook an **Environmental Walk About** in their area. Prior to undertaking this walk about the participants were asked to view their care environment from the perspective of a patient or visitor. They were very surprised with what they observed within their own working environment when they actually took time to stop, look and listen. Some of the things of note that surprised the team were the excessive amount of noise within the ward setting and the signage or lack thereof on display. They observed that some signs were displayed numerous times and sometimes signage giving relatives /visitors directions were often scarce. This exercise has sharpened the team members to be more aware of their surroundings on a daily basis.

With the use of the **WCCAT** the team were enabled to observe/review their work setting with the lead facilitator. This in turn informed them and their colleagues of changes in practices that were needed to bring about a sustained change in the culture of care and in time to improve person centred care. On one particular area as the facilitator and the team member were carrying out the WCCAT a staff nurse on the ward spoke in a loud voice to another staff member that “Mr. X was to start fasting as he was for a particular test later that day”. When giving feedback to the team they agreed that this does happen and they said that having had it pointed out to them it would certainly make them more sensitive when speaking with each other about patients in their care.

On most programme day the lead facilitator included some form of **Creativity**. It emerged that the team were extremely artistic and talented and always stepped up to the challenge presented. Here is a sample of a poem composed by Ger McVey. This was composed for the **National Practice Development day** in February 2012 when all participants from the eight hospitals nationally were invited together to share their experiences and to develop a network.
Poem for those who had a 'rocky' journey to palliative care.

Oh, the pain is bad I just don't feel right,  
I think I will go to see my GP tonight.

The GP thought I had a virus or stress as he looked at me,  
I will write you up for some pills, have them with a cup of tea.

Many weeks later, the pain would not go away,  
I will have to get a second opinion today.

This doctor listened carefully and did his best,  
He tried to organise a hospital admission for a few tests.

No bed was available, I went to A/E, no privacy, no screen,  
I spent 4 days on a trolley, upset, but glad to be seen.

On the ward, the team came to my bed, I was all alone,  
They told me I had cancer which had spread to the bone.

I wanted my family there but was never asked,  
Would this have been such a difficult task?

I sometimes wonder if months had not gone by,  
Could they have cured me, I try not to cry.

I am where I am, the palliative team are great,  
But deep down I wonder was I treated second rate.

I did not express these fears to my family, of my own volition,  
Who will ever know if it would have altered my condition.

In the hospital grounds, I see people silhouetted everywhere,  
Some, like me wondering what will happen and their future care.

Others, like my family, visiting those they hold dear,  
Exiting the hospital, who knows with what fear.

The staff are kind and anticipate my every fear,  
My family can visit anytime and we talk of thing we hold dear.

There is a lovely family room, it gets me away from the ward,  
I hope to get home soon and be minded by the home hospice team.

CONTEXT

Context is defined as the setting or environment where people receive health care services. At the start of the programme the group identified several practices within the hospital that were deemed to be good and were in line with existing best practice. These existing practices were added to and enhanced through the findings and recommendations from the programme.

The team members are certainly more aware of the importance of good communication. Improved communication between nursing staff, relatives and members of the multidisciplinary team came about by introducing sign outside each room or bay which identified the name of the nurse caring for the patient/s for a given shift. Throughout the programme much discussion took place about where things had not gone quiet as well as they could or should have. Communication breakdowns were identified to be the main contributing factor for many of these issues. Hence this has made all staff more cognisant of the importance of effective communication.
Problems with access to the mortuary out of hours and at weekends have been recognised and are identified as a work in progress for the team and the EOL standing committee. On the matter of the mortuary the facilities here have improved in recent times, the toilet facilities have been improved and a mural has been painted to brighten up the reception area in the mortuary. Overnight facilities in the hospital have improved for family members wishing to stay close to their dying relative. There is a family room on all the wards and throughout the programme the team members have taken a greater interest in making this facility a more homely and comfortable area for families.

Three elements have been identified that form the context to ensure there is person centred practice. These are culture, leadership and evaluation. At the outset of the programme it was suggested that a CNM and a HCA should be the nominated persons to participate. The CNMs involvement is critical to the culture and the motivation of their teams. Evidence has indicated that when CNMs are seen to drive change staff have the confidence to follow and this is so true for this programme. The leadership the CNMs displayed throughout this programme has been invaluable in the change process and one of the main reasons for it been such a success. In relation to the HCAs participation the programme has certainly increased their confidence and they now see themselves as valued members of the multidisciplinary team and champions in the area of End of life care.

**INTENT**

On the official last programme day we as a team decided that to date we had achieved small cultural changes within our areas and we believed that it was important to continue meeting as a forum at regular intervals to ensure the sustainability of the programme. We envisage this will give us an opportunity to share initiatives and share progress with each other. Additionally Ms Mairead Lyons A-DON invited all the PD team to join the End of Life standing Committee.

Throughout the programme each area involved linked up with a neighbouring ward area and to date have shared the person centred initiatives which have enhanced person centred care. An example of one of these is a laminated sign was placed at the entrance of each ward area stating: “The Nurse Caring for you today is”. This has proven to be very beneficial for the patient, their relatives and the multidisciplinary team. This is not just confined to the ward areas involved in the programme but to other areas as well.

At ward level the PD team and their nursing colleagues are continuing to try and involve all disciplines by making them more aware of Person Centred care that is acceptable and unacceptable. Certainly the PD members would now have the confidence to direct a Doctor or any member of the multidisciplinary team to a room within the ward area to have a discussion with relatives rather than this conversation taking place on a corridor. It is well recognised that cultural changes are always slow to achieve but as one of the team members said on the final day:

“Progress is slow but we have to keep chipping away at this to keep things improving”

**STAKEHOLDER**

From the onset of the programme the hospital management team were in full support of this programme. At the end of each programme day the team members together prepared a progress report for the DON and a team member was selected to facilitate feedback directly to Ms. Mairead Lyons (Acting DON). These meetings were extremely valuable in identifying additional supports required by the team and also gave Ms Lyons an opportunity to link directly with all the team members throughout the programme.
Ms Lyons requested early on in the programme that a member of the PD team be nominated to attend the End of Life Standing Committee within the hospital and Ms Linda McEntee agreed to be this link person keeping both teams informed of the progress to date.

On the first day of the programme in Connolly we decided on dates for the entire programme. I believed this was extremely beneficial as the team members worked around these dates where possible ensuring maximum attendance on each programme day.

Following each programme day the team members filled out an evaluation on the day. The last question on this evaluation was “What are the key things you are going to share with your colleagues when you go back to the workplace” Here are a selection of some of the comments received at different intervals throughout the programme.

- “Change some language used, try and make everyone more aware of acceptable language”.
- “The importance of communication and support for the patient dying and their families”.
- “Encourage my colleagues to ask patients at EOL if there is anything specific they would like”.
- “Try to encourage my colleagues to get the palliative care team involved in a more timely fashion”.

Within the health care setting there are always challenges to change and gaining engagement and interest but I believe that through the good leadership of the PD team the changes in culture we have already accomplished will continue. The HFH co-ordinator co-facilitated on all the programme days. Within the current financial restraints the possibility of being released for study days is greatly reduced and it was decided to incorporate Final Journeys training as one of our programme days. The team found this to be extremely beneficial. One thing that the programme identified is that despite the current financial constraints most of the changes required to improve Person Centred Care are thankfully not resource dependant.

To conclude this is the Vision Statement we developed at the commencement of the programme and we as a team endeavour to continue to deliver this care.

VISION STATEMENT

We, the multidisciplinary team, believe the ultimate purpose of ‘Person Centred End Of Life Care’ is to provide holistic care for the patient/resident and their families. We believe this can be achieved by focusing on their individual needs, with the best available resources and having a team that communicates effectively. In this way we can endeavour to provide a peaceful, comfortable and dignified death with quality after care support for families and staff.
BEAUMONT HOSPITAL

“HUMANKIND HAS NOT WOVEN THE WEB OF LIFE. WE ARE BUT ONE THREAD WITHIN IT. WHATEVER WE DO TO THE WEB, WE DO TO OURSELVES. ALL THINGS ARE BOUND TOGETHER, ALL THINGS CONNECT, OUR WEB GOES ON.”

This is a quote from a patent who sadly died, which was presented to one of the participating wards in the form of a tapestry.

This report evaluates how a 20 month practice development programme for Clinical Nurse Managers and Healthcare Assistants who used emancipatory practice development processes as a means to developing a person centred culture for end-of-life care. For this report a PRAXIS framework is used, as it is a tool used to effectively evaluate emancipatory PD. The six core components of this evaluation framework are purpose, reflexivity, approaches, context, intent, and stakeholders. Praxis in PD refers to the bringing together of theory and practice in order to transform care. Traditionally the focus of evaluation is on outcomes but in this work the focus will be on processes as well as outcomes that helped to bring about a change.

The Beaumont Hospital Emancipatory Practice Development group for End of Life Care (EOLC) consisted of two members of staff from six wards/units. Five areas had a Clinical Nurse manager (CNM) and a Health Care Assistant (HCA) representative and one had a CNM and a staff nurse to represent them. Wards and unit had representation from five of six of the Clinical Directorates.

The programme participants are seen in the photograph above and include Maeve Hevey, Martin Igunbor, Petrina Donnelly, Georgina Carr, Claire Donnellan, Joanne Dunne, Adrianne Daly, Sarah Garvey, Teresa Lim, Grace Joseph, Siobhan Quinn, and Mary Coogan. The program was facilitated by Susan Hawkshaw and Fran McGovern (September to November 2010, now retired).
PURPOSE

The purpose of the practice development (PD) plan for end-of-life care (EOLC) was to support Beaumont Hospital to target cultures and contexts of care practices to bring them in line with best practice. This programme focused mainly on nursing and care support teams focusing on the ward cultures and contexts of care. The purpose of the programme is explored in more detail through the general text of this document.

REFLEXIVITY

Reflexivity is about the programme group, the learning within the group and the transfer of that learning into the work place. Throughout the programme group members gained knowledge and skills of emancipatory practice development processes and how to apply them to EOLC in the practice environment. Some of the content is best expressed by their reflections expressed below.

"I see positive aspects of End of Life (EOL) care in hospital. From an audit this group have done, we found that staff do their very best with resources available and their knowledge is good in relation to EOL resources. I have raised awareness among staff, developed my own confidence and am more knowledgeable about EOLC”.

"This programme is a positive thing; it promotes a culture where the team support the dying and their families. I have learnt practical things especially from the tour of the mortuary”.

"It is important to bring what we do in the programme back to staff. We’re there to make end of life care as near to the individual patient’s wishes”

"I have learned more about the rest of the hospital. It’s a time to reflect as we don’t have time on the wards. We try to meet patient’s needs”

"I am now better able to communicate with patients and families and this work has improved communication between staff.

"This programme has given me time to stand back and think about EOLC from personal and work perspective. I need to do that to understand it. Things have changed in clinical environment with increased pressures. I’m very proactive about palliative care and learning from the group. The PD tasks were different but always got us involved”.

"I have increased confidence talking to patients and relatives. I am now able to listen to them and not be as anxious. EOLC not a negative thing for me now”.

"It’s an opportunity to know what’s going on in the wards. We are insular in the unit. Efforts made for patients for e.g. Skype to talk to family in Australia. I have had two recent deaths of family and friend in the hospital and all gave very positive feedback of their experience. This is the ripple effect of the HfH programme”

"This Programme enables me to provide good EOLC and work better as a team member. I have increased confidence and I am more aware of patient’s choices and decisions. I now have improved communication with patients and families”.
"I have a greater awareness of EOLC. I have improved communications and increased self-esteem. I can support staff”

"This programme helps me to reflect 'Am I doing this right?'. I work better as a team member and share any information with my colleagues. I gained increased confidence and competency”.

The transfer of learning in to practice

The transfer of learning to practice can be demonstrated through the action plans participants have developed for their workplaces and for work completed in the six participating wards and units. From the action plan it can be seen that different areas are at different levels on their emancipatory practice development journey. All have committed to continue to promote person centred care as defined by the National PD Programme (2007) and adapted as the definition of person-centredness for this programme:

"Person-centeredness is an approach to practice established through the fostering of therapeutic relationships between all care providers, patients/clients/residents and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approach to practice development”.

As well as committing to promote person centred EOL care, participants and their colleagues in participating ward have focused on different aspects of care. The following is a brief outline of that focus.

Ward A – concentrated on the physical environment where care is provided. They have developed a space where patients can meet the healthcare team in private and this space can also be used for relatives comfort and privacy when a patient is receiving end of life care during the final stages. They have also ensured all staff are aware of the HfH symbol, equipment and policies that support good care at end of life. Staff are encouraged to use ward alter – non faith based that provide a dignified piece of equipment that contain artefacts that are used at time of death, patient property bags, and the use of the HfH symbol when a patient is dying to alert staff and visitors of the event in order to maintain a dignified environment.

Ward B – Reviewed their visiting policy. They also engaged staff and patients in providing ideas for making the day room more comfortable for patients and relatives. They have actively promoted a patient centred approach to care. They also introduced person centred language and redesigned their white board to be less ‘task oriented’.

Ward C – This unit continues to focus on person centred care, changing the language used at report time, to ensure patient names are used as opposed to bed numbers. They also continue to promote the EOLC philosophy of care developed on the programme. In order to improve staff knowledge, they have been given the opportunity to go on a tour of the mortuary and its services. They have made plans for staff to visit a local hospice to work as an observer for a day. The aim is for them to reflect on EOLC there and see what can be learned and applied back in their ward. Plans are in place for this to occur in 2013.

Ward D – Implemented the use of the HfH symbol when a patient is dying and it has improved communication and privacy for this client group. Staff have been released to attend HfH final journeys training and the feedback from same is very positive. They
plan to continue to raise awareness of EOLC by keeping it an item on team meeting agenda’s and by informally talking about it.

Ward E – are currently working on areas identified in their observations of care exercise undertaken in the WCCAT tool. They have initiated a plan to provide a welcome sign for visitors on the ward. This will also be complemented by a display of staff photographs, so patients and their relatives can easily identify each team member.

Ward F – The participants continue to encourage all staff to follow hospital guidelines and use HfH equipment available for the dying patient. They promote awareness of EOLC to ensure it continues to be a team agenda item.

Facilitator’s learning
On reflection this programme created a positive learning base for me as a facilitator. Throughout the programme I used different facilitation strategies such as observing, role modelling, listening and feeding back, critical dialog, high challenge and high support, and creative artistry. Although implementing these strategies was often a challenge, all of these strategies have enabled me to develop in the role of facilitator within this programme. This is a skill set which I now apply to many other work situations.

As Nursing Practice Development Coordinator, I have an inherent interest in emancipatory practice development. It would recommend a manager at ADON grade from the operational side be involved in future programmes also.

APPROACHES

Approaches are the processes used in facilitation of PD work both within the PD group and in the workplaces. Principles of collaboration, inclusion and participation, also known as CIP principles were the core principles used within the group on every programme day and the participants were encouraged to role model these principles back in their work environment.

It was important to provide safety within the group on programme days and terms of engagement were developed by the group, to provide a structure for how they would work together and what is important to them. Angel cards were used to inspire themes for the terms of engagement. These terms of engagement were reviewed at regular intervals and updated when it was felt that a change was required. Please see below our terms of engagement.
Terms of Engagement

<table>
<thead>
<tr>
<th>Message</th>
<th>Applied as a term of engagement</th>
<th>Consequences if not adhered to</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kindness</td>
<td>Being kind to each other, listening and looking after each other</td>
<td>Group won’t function to the best of their ability</td>
</tr>
<tr>
<td>Gratitude</td>
<td>Always appreciate what you receive from others</td>
<td>Discouragement</td>
</tr>
<tr>
<td>Patience</td>
<td>Giving people time to participate at their own level</td>
<td>People feel intimidated</td>
</tr>
<tr>
<td>Grace</td>
<td>Approach people in an appropriate way</td>
<td>Resistance, Friction, Dissatisfaction. People don’t co-operate</td>
</tr>
<tr>
<td>Commitment</td>
<td>Participate as fully as you can in the group and be as attentive as possible</td>
<td>Group would not gel as well.</td>
</tr>
<tr>
<td>Clarity</td>
<td>All have to seek clarification in grey areas of the programme</td>
<td>Misunderstanding and wrong information to colleagues.</td>
</tr>
<tr>
<td>Communication</td>
<td>Communicate openly and clearly</td>
<td>Conflict, Confusion, Disagreement</td>
</tr>
<tr>
<td>Openness</td>
<td>Need to be open to what others in group suggest or say</td>
<td>Not work well as a group if not open</td>
</tr>
<tr>
<td>Courage</td>
<td>Not to be afraid to share our views and experiences</td>
<td>Missed valued experiences and things which people improve or take on</td>
</tr>
<tr>
<td>Honesty</td>
<td>Honest about how we feel or what we think</td>
<td>Mistrust</td>
</tr>
<tr>
<td>Expectancy</td>
<td>We will look at end of life care for persons</td>
<td>No Change</td>
</tr>
<tr>
<td>Depth</td>
<td>Seek support</td>
<td>No Change</td>
</tr>
<tr>
<td>Inspiration</td>
<td>Encourage people to think outside the box and be open to new ideas.</td>
<td>Less innovation</td>
</tr>
<tr>
<td>Dignity</td>
<td>Respect of Privacy</td>
<td>Mistrust</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Respect what is said within the group. Not discussed outside.</td>
<td>Mistrust, Closeness</td>
</tr>
</tbody>
</table>

Values clarification exercise
The values clarification exercise set the scene for the whole programme. The purpose of this exercise was to agree a vision about end of life care in the six participating wards and units. This was achieved by establishing the common values and beliefs staff had about EOL care, in participating areas. This exercise gave a structured approach that was inclusive of everyone in the workplace and enabled a common understanding of the value placed on EOL care and the attitude individuals held about it. The vision, which applies to the workplaces where this was developed, is displayed below.
Claims, concerns and issues
The Claims, Concerns and Issues exercise were used as a democratic process to gather information throughout the programme. Below is an example of where we used a claims, concerns and issues exercise to evaluate the progress made at the end of the PD programme. A strict adherence to the process ensures that everyone had the opportunity to contribute in identifying the positive statements about the topic - claims, the concerns, negative statements or challenges – concerns, and action questions that arise from the claims and concerns.
<table>
<thead>
<tr>
<th>Claims (Positive statements)</th>
<th>Concern (Negative statements)</th>
<th>Issues (Action questions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• More aware of patient (dying) &amp; relatives feeling.</td>
<td>• Senior management Support for EOLC – i.e. not fill HFH co-ordinator post.</td>
<td>• Fill HFH Co-ordinator post</td>
</tr>
<tr>
<td>• PD programme gave an opportunity to come from diverse areas looking at a common goal of EOLC.</td>
<td>• Keeping momentum going on focusing on EOLC. Other work priorities (targets)</td>
<td>• How we get the message to CEO and Senior Executive.</td>
</tr>
<tr>
<td>• Highlighting good work already been done in EOLC.</td>
<td>• Staffing levels. Give EOLC priority and maybe neglect other patients.</td>
<td>• How do we sustain the programme</td>
</tr>
<tr>
<td>• Patient centred approach made us more aware of the patient as an individual and their right to participate in their plan of care.</td>
<td>• Feel guilty if don’t have time for EOLC.</td>
<td>• Can we make a room for all EOLC/Ed/Patients</td>
</tr>
<tr>
<td>• Programme gave participants more confidence to talk to patients and relatives.</td>
<td>• Overcrowding impacts on ED – EOLC.</td>
<td>• Bed Manager &amp; IP &amp; C Team cohort infectious patients. Use side rooms for EOLC patients.</td>
</tr>
<tr>
<td>• We appreciate how much support we have in place, as compare to other hospitals (national day).</td>
<td>• Concern re: releasing staff for training.</td>
<td>• Link Bed manager / IPC in education Programme.</td>
</tr>
</tbody>
</table>

**Action learning**

An action learning approach that we learned called ‘triads’ enable us to work on issues or problems in the workplace. The triads involved three persons: (1) the presenter who presents the problem/issue/concern, (2) the enabler who enables the presenter to explore, reflect and challenge the issue from a variety of perspectives, and (3) the observer who offers feedback primarily to the enabler on what skills enabled the presenter most effectively. Feedback from group on programme day 11 on what they found it most useful: “triads were great”, “they helped me focus” and “working a problem out through a triad was really beneficial for me”. Triads were incorporated in other programme days because of the positive feedback from the group.

**Reflection**

Reflection was incorporated through the whole programme but in particular the group enjoyed the Reflective Walk in Nature. The aim of the exercise was to stimulate a critical reflection in a creative way to help uncover hidden insight. Using creativity, participants walked outside in pairs, reflecting on EOLC in their area and they used nature to symbolise issues about the topic. The aim of the exercise was to create space for individuals to reflect using stimuli to trigger reflection in a different way from the norm. On returning from the walk participants captured their learning creatively in images incorporated from nature and here are some photos of the images produced by the group on this exercise.
Photographs from reflection exercise
An example of a reflection from one participant

1. What am I learning about myself in this programme?
   *Exploring my approach to person-centred practice. The techniques in negotiating, I really enjoyed.*

2. What am I learning about my EOLC practice?
   *Importance of person-centred approach.*
   *Importance of seeing patient as an individual.*
   *Listening*
   *Importance of negotiating*

3. What do I believe are the key elements of person-centeredness?
   *Patient, relatives, language*
   *Listen, interact, respect*
   *Quality, professional care*

4. What am I learning about facilitating change in my workplace?
   *Importance of involving all members of staff*
   *Importance of regular feedback and listening to options and employ same."

5. What aspects of facilitation are not working for me?
   *Limited resources*

6. What differences do I see in my workplace?
   *Patients name being used instead of bed numbers etc.*
   *Everyone aware of EOLC programme*

7. What do I want to see now happening and how am I going to support it?
   - *Importance of all staff engaging in person centred approach to care.*
   - *Regular feedback to staff when end of life care occurs.*
   - *Highlighting care at each meeting to help build and improve EOLC care.*
   - *Facilitate study days when they occur.*
   - *Person centred approach – encouraging staff to use names instead of bed numbers etc.*

The Context Assessment Index (CAI)

Context is defined as the setting or environment where people receive health care services. Three elements have been identified that form the context to ensure there is person-centred practice (McCormack et al, 2001). These elements are: culture, leadership and evaluation. The CAI assesses these three elements.

The CAI enabled group members to assess their contexts where end-of-life care is provided. It was completed by the PD group members involving their colleagues in their wards and units as a team.

It is suggested that a positive culture, strong leadership and on-going evaluation is required to be open to change. The PD group carried out a CAI at the beginning and at the end of the programme. The overall average for contexts at the beginning was 72% and at the end was 78%. Although we cannot make a direct correlation with the increased scores and the impact of programme work alone, we do hope that our work on the programme has influenced some of the positive increases in scores in all three aspects: leadership, evaluation and culture.
The Workplace Culture Critical Analysis Tool (WCCAT)

This tool was used by the group to observe what was happening in their workplace setting from a person-centred perspective. It provided a structure for identifying what was and was not considered person-centred based on the Person-centred Theoretical Framework (McCormack and McCance 2009). The site facilitator and a group member from each ward and unit undertook an observation together. All six of the observations received positive feedback from the members of the group. It provided participants with an opportunity for time-out to observe what was happening in their clinical area. Many highlighted areas that could be improved, for example one ward changed the information on their white board to be more person centred and another ward is looking at welcome signs for patients and visitors coming to the ward. It formed the basis for many of the wards PD action plans. Again this is a tool the group members said they would use again.

While undertaking A WCCAT on one ward, a patient was actively dying. “It was lovely to see that while the family were outside the cubical, a member of the catering staff stopped to talk to them. It was obvious there was a rapport between the relatives and this member of staff and after a short chat, offered them a cup of tea which was accepted. It was a positive experience to see all the ward team involved in the care of this family and to feed this back to the staff that were on duty on that day”.
HAIKU

The Haiku is a creative way of capturing reflections using 3 lines with 5 syllables on 1st line, 7 syllables on 2nd line and 5 syllables on 3rd line. This is a HAIKU developed by Beaumont HFH PD group completed on the last day of the programme.

Empathy Always
Comfort Guaranteed
Respect their wishes

Respect Everyone
Best practice for all concerned
Understand people’s needs

Peaceful space to die
Time to spend with family
Patient centred care

Calm for the patient
Respect for the patients
Time for the patients

Talk with the patients
Listen to them, their wishes
Make it happen, if we can

Hold the patients hand
They are our priority
Comfort is needed

I came here to learn,
to share, to talk, to listen.
I have achieved this.

The Beaumont PD Group at the National PD Programme Day (2011)
CONTEXT

The Beaumont PD Group using patient quotes to show how the national programme is having a positive impact in each of their areas. Putting the programme into context is about demonstrating how the care setting influenced the care approach and how that is starting to change. How better to put the programme into context than by giving examples of person–centred practice given by members of the group, that clearly show a positive culture of end of life care for the participating areas.

“A man was a patient here, his wife died down the country, we arranged for his wife to be brought to Beaumont Mortuary, so the patient here could see her and we organised a service here”.

"Mr X lived alone with his dog to which he was very close. He was missing his dog terribly so the nurses organised to have the patient’s dog to visit him. This meant the world to the patient in his last days”.

“A patient dying in the ward, the CNM organised to Skype family in China, supported by the IT Department”.

“I’m a HCA and last week the family of a patient’s who had died on the ward, came back in to thank the staff, they left chocolates and a card specifically for me. This programme gave me the confidence to provide better care for this gentleman and his family”

“I laundered patient’s night clothes, when they had no family. This allowed them to stay in their own clothes”.

"We set a programme and support in place, with the interdisciplinary team so a young person, in EOL could go home to his wife and family…..”

"I made arrangements for family to take a patient home, for their last few hours of life”.

INTENT

The intent is about what is currently in place now and what could be different. The group plan to sustain the program by feeding into the governance structures within the hospital such as the Dying, Death & Bereavement Committee and the Directorate Management Team Structures. Other resources to be used include Nurse Practice Development Co-ordinator and the Hospice Friendly Hospital Co-ordinator when in post.

1. The group sustainability plan includes feeding back to stakeholders and Directorate Nurse Managers on what are seen as the key learning and outcomes from the PD programme.

Action:
- A Health Care Assistant and Clinical Nurse Manager representing the group will feed back to the Dying, Death and Bereavement Committee and outline the sustainability plan for moving forward and hopefully engage them in the process.
- The CNM’s on the group will feedback to each Directorate Nursing team at the CNM directorate meetings. This action has been completed.
- The group will feedback to ward teams and keep EOLC on agenda a ward level. This action has been completed.
- HCA’s to feedback to HCA group at weekly Education Sessions. This action has been completed.
- To feedback to the general staff, the group plan an awareness day. They will have an EOLC newsletter, an information stand outside the canteen, screen savers on computers and a poster on display. The group will also give presentations to various groups that week that week. Organisation of this day is still in progress.

6. Set up PD forum on EOLC. Action: The group plan to meet every three months to look at EOLC and see how they can participate in moving the actions forward. Other interested parties will be encouraged to participate in forum. The forum can feed into the Dying, Death & Bereavement Committee within the Hospital.

2. Sharing of learning and knowledge
   - Action: The members of the group have identified parts of the programme they have found most beneficial and will participate in facilitating workshops on these areas for other members of the healthcare team.

   - Action: The facilitator of the programme has started to run workshops on the PD and facilitation techniques used in the program for the Nursing Practice Development team initially, but will open workshops to others also.

   - Action: The group identifies that key people within the organisation that may have an impact on providing the standard of EOLC that can be provided. They particularly want to present their work to members of the Infection Prevention and Control team and Patient Flow team as they have an impact on the availability of single rooms. The group felt this may generate discussion and understanding around areas of conflicting interest.

3. Sustainability action plans include:
   - Incorporating EOLC/ person centred care into staff meeting (agenda).
   - Keep HFH folders up to date.
   - Continue to use tools from programme.
   - Send staff to “final journey’s” training.
   - Maintaining standards of EOLC.
   - Look at staff debriefing after complex deaths

STAKEHOLDERS

Support from key stakeholder was available in many ways. As four of the participant CNMs were CNM1’s it was essential that they gained support from the CNM 2 or 3 back in the wards and units. On the whole the CNM in charge was fully supportive of the project but it did sometimes mean that the group participants had to adjust their action plans in line with conflicting priorities.

- Communication with the Director of Nursing. Following each programme day a HCA and CNM on a rotational basis would feedback to the Director of Nursing on the programme progress. The programme participants found this a very useful to talk to the Director of Nursing. They got used to meeting a senior manager and putting the programme in context with other organisational priorities. By the end of the programme a couple of the HCA’s felt comfortable enough to feedback without a CNM present, which shows an increase in their confidence about their contribution to the programme. This communication was not without its challenges as within the timeframe for the programme the Director of Nursing changed three times.

- Communication with Dying, Death and Bereavement Committee. As facilitator I provided regular feedback to the Dying, Death and Bereavement Committee. The HFH PD programme was a standing item on the agenda.
- Various members of the healthcare team shared their expertise with the group including a Palliative Care Nurse Specialist, the mortuary manager and a member of the chaplaincy department.
- The HfH Coordinator supported the facilitation of the group until November 2010.
- HfH Final Journeys facilitators facilitated a final journey programme for the group and for one of the participating areas also.

Communication
Members of the group found different ways of communication back to the staff at ward/unit level. Some had EOL communication boards or books for staff to read at a time suitable to them. Most added the programme to ward meeting agendas. As with any programme that spans a long timeframe, we had the usual challenges where we had members of the group go on leave and or one person moved jobs, we co-opted people on to the programme in their place where possible or creatively filled on for the person as much as possible. The group communicated to the hospital staff through a once off newsletter about the programme and through screen savers (as seen below).
Incorporated feedback from patients or relatives specifically for the programme, was mainly done around physical ward changes been made at ward level. There is a patient representative on the Dying, Death and Bereavement Committee. The group would love to incorporate feedback for the patient or their families in the future.
Screen savers were developed in Beaumont Hospital and used by the group to raise awareness of HfH symbol and resources. Please see examples below.
Conclusion

This programme ran over 20 months and included 15 programme days. Six areas commenced and successfully completed the programme. The objective for group was to develop and enhance person centred end-of-life care for patients and their families in Beaumont hospital. HIQA standards (2012) have identified the need for care providers to continue to strive towards the provision of a person-centred care. The processes used in this emancipatory practice development programme provided a systematic approach to working towards achieving a person-centred philosophy for end-of-life care. The groups’ narratives and reflections help to demonstrate the learning that has taken place and hopefully describes some of the programmes successes. This PD programme engaged groups of nurses and care attendants in work based learning and development using facilitation approaches that enabled them to explore their current practices. The emphasis was on a team approach to learning so that all nurses and support staff were engaged in exploring ways in which EOL practices could have been enhanced and changed.
CHAPTER 3 FINDINGS  PART 2: LEARNING THAT HAS TAKEN PLACE FROM FACILITATION AND PRACTICE DEVELOPMENT ACTIVITIES

This chapter will outline a synopsis of the PD and facilitation programme work undertaken on formal programme days. Sixteen programme days were held over the 20 months of the programme. Site facilitators met with the lead facilitators together as a group and their programme was replicated with PD working groups in their hospital sites. The site facilitators had an opportunity to explore and learn new knowledge and skills of ePD and facilitation and implement that learning with their PD groups who in turn had the opportunity to plan activities in clinical areas with team colleagues. This approach is in the spirit of workplace learning and ensures that opportunities are provided for new learning to filter into practice.

The overall aim of the programme days was to provide opportunities for participants to learn and develop confidence and competencies to affect changes to end of life care (EOLC) practices in their clinical areas. The site facilitators and participants had the opportunity to explore and learn skills that they could replicate with their PD groups. Participants in PD groups discovered over the course of the programme how to work with CIP principles of collaboration, inclusion and participation to influence their colleagues.

Year 1
The focus of the programme in year 1 was on providing space and time for participants to explore their end of life care practices. This involved exploring their values and beliefs about their EOLC, finding the evidence for change, how they engage and share new information with their colleagues, and how they challenge practices that are no longer acceptable to them. Learning about the methodology and principles of ePD and facilitation was a key focus in year one to drive this change. The focus on customs and practices in EOLC not previously challenged or recently evaluated was challenging for all participants as it called into question some long held traditions. Changing workplace cultures is a complex process and interacting with patients and their families is diverse (Bucknall et al, 2008) something that became evident as the programme progressed.

One of the critical reflective exercises undertaken on one programme day asked participants to reflect on the following:

What are you becoming aware of regarding person centred care?
1. Your feelings now about end-of-life care?

2. The links between your feelings and what you believe and value about end of life care?

3. How you will make links with your colleagues and with your work?

PD uses four types of evidence to inform practice: research; clinical experience; patient, client and carers; local contexts and environments (Mycroft-Malone et al 2004). The weight placed on each varied according to the context and the level of evidence required. By developing an appreciation for evidence from own and colleagues’ knowledge and experience, many participants gained confidence to plan change together as a team. Outcomes achieved in programmes such as this are shaped through discourse and the development of local theory according to Hoogwerf et al (2008). Therefore the importance of meeting together as groups to plan and discuss developing practice is an integral part of ePD. McCormack et al (2006) identifies three levels of the ‘how’ PD is:
1. How learning happens
2. How change happens
3. How knowledge is used and generated

Learning on this programme was dependant on an inclusive approach to developing practice, individuals and teams enabled by skilled facilitation. With a focus in and on practice, critical reflection is vital to fully appreciate the impact of actions on others. As a starting point participants had the opportunity to discover their own values and beliefs about EOLC and what constituted person-centred care for them. They then involve their colleagues in developing a vision for their EOLC as a team, based on their understanding of what person-centred EOLC means to them.

Change began with growing awareness of what constitutes a person-centred workplace and what person-centred EOLC means. This started to happen through dialogue on programme days with PD groups and with colleagues, patients/residents and their families. Through a growing awareness of their values and beliefs about EOLC, possibilities for how care practices could be different were explored and traditions and rituals around care at EOLC started to be unpicked. Evidence from and in practice was supported by written evidence both national and international, and from other similar programmes. A detailed account of the ePD programme plan similar to this programme can be found in the HSE report (link blow) on The Implementation of a Model of Person-Centred Practice in Older Person Settings (2010) with a detailed account of many of the processes and methods used adapted to suit the acute setting.

**Values clarification**

The programme was structured into individual workshops each building on knowledge from the previous one and each with a distinct focus. The continuity of participants on programme days was vital to this programme structure. However ability to get released for programme days got more challenging as the programme progresses due to containment restrictions. This had an impact on individuals who missed more than two programme days in particular due to the knowledge and skills building process used. The programme began with a values clarification exercise and each hospital group developed vision statements from the exercise that reflected the collective values and beliefs of their team and became something that participating wards and units aspired to achieve. This enabled participants to engage their colleagues in the activity of the programme from the outset.

The meaning of person-centred care was often a difficult concept to grasp:

> “We are very person-centred anyway”

A certain amount of defensiveness had to be overcome within the first year of the programme in order to take an honest look at current practice. The concept of knowing self was explored in order to develop skills in supportive challenge, an essential element when developing practice.

> “I do very much have a professional persona and a personal persona and do keep them separate to a degree”.

> “Learn how to express my feelings to others. Learn to take feedback”

Many participants found it difficult at first to consider challenging colleagues on taken for granted customs and practices as it was often viewed as risky or daunting,

> “I feel I have the knowledge but need the courage”.
Having a safe space to practice high challenge with high support was beneficial for confidence building and the level of challenge was increased gradually over the 20 months,

"I am happy to be challenged by others. I see it as a positive approach".

"Feel kicked in the stomach when something I hold dear or my ego is challenged. Know enough though to put it in perspective, reflect on it and keep going"

**Language used**

The struggle to ensure that the individuality of the person is always to the fore in healthcare is challenging. This is reflected in how individualised care planning processes are, the importance that is placed on patient/resident involvement in decisions about their care, and how much importance is placed on task focused care over individualised care. The way staff communicate to and about patients/residents and their families can be one indication of how much importance is placed on person-centredness. When participants explored the way they communicated they identified areas where they could make changes. The language exercise assisted in identifying common words or phrases that can be perceived as demeaning or depersonalising to individuals, such as referring to patients/residents by their bed number, medical condition or terms of endearment, something that was quite common. Considerable debate was generated about the use of terms of endearment with some participants finding it difficult to accept that using pet or love, granny etc. instead of the persons preferred name could be demeaning. This directly links to 'the way we do things here' as an unspoken, unchallenged form of communication that was simply part of the workplace culture.

This exercise also applied to the way staff spoke to and about each other. For example there was considerable discussion in some sites about the use of ‘girls’ ‘lads’ or ‘my staff’ when referring to each other and the message that this language can convey. Creating an understanding of the incongruity of using language such as ‘my staff’ when trying to develop shared decision making and power sharing structures within teams was challenging for many individuals on the programme. For some it hit at the heart of taken for granted assumptions that it was ok to refer to some groups of staff, particularly if perceived to be ‘lower’ in the hierarchy structure of the organisation as the girls or lads but not others. The language exercise provided a safe space for participants to discuss personal beliefs and how they fit with a team approach to decision making about language. The need to continually challenge inappropriate language is on-going and requires engagement by all staff to be fully effective.

**Year 2**

Much of the theoretical foundation work was set down in year 1 and the second year focused on the consolidation of learning and implementation of action plans in practice areas. The Person-centred Practice Framework (McCormack and McCance, 2009) was then used as a guide in identifying priority areas that needed to be addressed.

Strategies for engaging in professional learning through critical reflection were explored. Participants engaged in active learning processes working in triads (three person activity) and what it means to be a critical companion to colleagues (Critical Companionship by Titchen, 2003). Both processes are designed to provide opportunities for supporting/helping relationships through active learning. The principle of asking key questions to enable the person to find solutions for themselves is empowering for individuals. The principle of not giving advice is key to this empowerment and one that some participants found difficult. Both of these activities promoted self-awareness and greater understanding of how individuals engaged with each other. Site facilitators had the opportunity to review their own leadership styles and explore transformational
leadership approaches, in keeping with the philosophy of ePD. The focus on creativity remained throughout both year one and year two and participants engaged in creative reflection, drawing, poetry and creative ways to open and close programme days. This provided an opportunity for right brain thinking and the development of creative ideas and possibilities for how practices could be different.

Evaluative processes such as observations of the workplace culture and environment were undertaken in the second year and participants had an opportunity to engage their colleagues in this activity and provide feedback on observations. This further consolidated learning about the meaning of culture and how it impacts on progress and empowerment leading to emancipation.
CHAPTER 4 THEMES AND SUMMERY FINDINGS FROM THE PROGRAMME EVALUATION PROCESSES

This chapter will examine the programme evaluation and outline a summary of the findings under each data set. The overall themes will be identified from the findings and discussed. As outlined in chapter 1, the programme was evaluated using both formal and informal evaluation tools and processes. The formal evaluation tools and processes were used at intervals during the programme to measure progress. The informal evaluations were used frequently throughout the programme by participants and their colleagues to measure impact of changes made particularly when new practices were introduced. The formal evaluation methods and tools used were:

- Participant reflections
- Culture Analysis Tool (CAI)
- Workplace Culture Critical Analysis Tool (WCCAT)
- Programme day notes
- Director of Nursing follow-up feedback

PARTICIPANT REFLECTIONS

Participants were obliged to produce written reflections as part of their learning and development as well as contributing to the programme evaluation sets. Initially many individuals found the exercise challenging with most having little prior experience outside academia. In most cases the quality of reflections developed over the course of the programme with evidence of critical thinking in some. From time to time during the programme difficulties with obtaining written reflections from participants continued. Some participants saw the activity as unnecessary and discussions highlighted the general lack of critical reflection in practice generally. Much is written about the value of tacit knowledge and reflective learning and there is evidence that traditionally technical skills and knowledge are afforded greater value than tacit knowledge (Johns, 1999; Schön, 1983, 1987; Benner, 1984; Dreyfus & Dreyfus 1986, Clarke and Wilson, 2008). This was often evident on programme days when individuals wanted ‘quick fix’ technical solutions to complex non-technical issues for example sharing the programme work with colleagues by leaving notes in information folders without engaging in dialogue about the work and activities. Interestingly many participants in year two shared their ideas about the value to them of reflection and it is a significant to their practice now. Further questions about the use of critical reflection in practice were raised in the CAI evaluation process.

Key themes from participant reflections

The analysis of the reflections identified common themes throughout. The themes are set out in order of priority as follows:

1. Team work
2. Personal and practice learning
3. Communication
4. Care practices
5. Individuality of the patient
6. Involvement of family
7. The care environment

Team work

A significant value was placed on the importance of team work and as the programme progressed there was an obvious acceptance that for change to happen participants had to engage and involve their colleagues in the process. It is obvious in many reflections that the notion of simply ‘telling’ colleagues what to do is ineffective. Reflections reveal a sense of satisfaction for some participants in working together as a team. Where there is
an absence of engagement in the programme in some areas individuals reflect on their frustration and feeling of being alone with the work. There is evidence of increased awareness and acceptance that challenge is necessary for change to happen with many individuals feeling more confident to challenge colleagues and to be challenged. Some evidence emerged of health care assistants starting to acknowledge their role in engaging with colleagues on programme days, sharing the programme work with colleagues and in taking part in decisions about EOLC. Examples are given where HCAs challenged nursing colleagues on matters of comfort care and communication, something that almost never happened in an open direct way. There is still evidence of deference by HCAs to nursing colleagues and reluctance to be openly critical of practices within their teams or workplaces but a level of confidence in their own worth is growing and this may impact positively on their confidence to challenge more.

The difficulty encountered when trying to develop more person-centred team work practices was made more difficult when senior clinical nurse managers didn’t engage in the programme and in some cases would not engage in some of the workplace activities. For some this led to a feeling of being unsupported and frustrated with trying to influence EOLC.

<table>
<thead>
<tr>
<th>Valued by participants</th>
<th>Concerns of participants</th>
</tr>
</thead>
</table>
| - The importance of team work and being inclusive by involving everyone  
  "When staff are informed and included it is easier than just telling them that this is what we are doing. Asking them for their suggestions on changes we should make"  
  - Realisation that this work can’t be done by one person alone  
  - See their role as supporting colleagues to change  
  - The need to challenge self and colleagues to make changes happen  
  "Try to challenge and provide support as well so I can encourage change"  
  - Better understanding of different roles in the team and that everyone is important to the team  
  - HCAs finding their voice within teams  
  "I am voicing my opinions without fear or worried that they [staff] will think I’m ‘only the care assistant’. I feel I can offer what I am learning, I can pass it on to staff members and we chat a lot about it".  
  - End of life care is everyone’s responsibility  
  "Listen to staff reaction [how to influence change], respect their feelings, explore the issues collectively”. Enjoy sharing with staff”  
  - Better understanding of team work  
  - Giving and getting feedback from colleagues | - Resistance to change even by colleagues who are friends  
  - Conscious not to come across as “sounding too confident or sounding too bossy”  
  - Feeling unsupported by colleagues  
  "I do not feel supported and I feel that I am alone with this programme where I work"  
  - Working with low morals and staffing issues  
  "Staffing can be an issue but one needs to be resourceful”  
  - Difficulty getting cooperation from colleagues  
  - Issue of ‘overpowering staff’ and not listening to their issues  
  - The use of ‘my staff’ and ‘my ward’ fairly common in reflections from participants who are managers  
  "To instil this [communication] in my workplace area am ensuring all my staff attend the Final Journeys workshop. …I spoke to one of my nurses who attended the programme”  
  - Colleagues taking challenge the wrong way and undermining the local facilitator  
  - Destructive when there is an autocratic style of management |
**Personal and practice learning**

Many participants talked about growing in confidence and becoming more open-minded about changes. The notion of being able to ‘make a difference’ was valued and this helped to develop greater commitment and feeling ‘more positive’. Some individuals felt they were less defensive when challenged and better able to express themselves. There was a growing awareness by some participants of their own behaviour and that they were ‘not always right’. A key common theme identified in many reflections from both nurses and HCAs is a feeling of confidence when discussing EOLC with both colleagues and patients and their families. Surprisingly although there was resistance to writing reflections many participants said that they valued reflection and saw it as necessary when thinking about change. The reflection also included reflecting on the patients/residents journey and how patients/residents and families may have felt following incidences in care.

<table>
<thead>
<tr>
<th>Valued by participants</th>
<th>Concerns of participants</th>
</tr>
</thead>
</table>
| - Feeling more confident
  "I think there are a number of things I am learning about myself here. The fact that I am being challenged in identifying my weaknesses and my strengths, and putting them to the test occasionally. The fact that I am challenging myself, that if I didn't believe in this programme I wouldn't challenge myself as much”.
- Putting new knowledge into practice
- Less defensive and more open minded
  "Learned more about me”
- Taking time to reflect
- Knowledge of how to facilitate change
- Believe in what I am doing
- Necessary to dig deeper
  "Since I have joined this group it has made me look at myself and my behaviour on the ward. I have found that at times I was not strong enough to stand up for what I felt was right, but this has changed”
- Asking more questions like ‘why' and ‘why not'
  "I am more confident and proactive on EOLC issues now in my clinical area”
- More conscious of own behaviour
- Feeling more committed
- Acknowledge good care
  "I have forgotten to praise others – and the values/beliefs/changes that they can bring. I am passionate about helping to make changes”
- Taking time to reflect more
  "Reflect more on the patients EOLC journey instead of just putting it aside and moving on” | - Issues with colleagues reverting to old ways to save time
- Difficulty with maintaining momentum
- Lack of engagement by MDT
  "The PD programme needs to filter through the medical division in the hospital too”
- Difficulty with agreement on DNAR directives
- Difficulty with prioritising comfort care
- Can’t always deliver the care that staff want to
- Facilitating change is difficult |
"I am not always right"
"Have learned that the most important aspect of my job is the individual attention to patients and their families and endeavour to abide by their wishes"
- The achievement of a “good death” very important

**Communication**
A common theme throughout reflections was the need to develop awareness of the language used in work places. Many individuals talked about the way the language in their workplaces has changed. There is greater focus on using patients/residents name instead of their bed number or diagnosis, a practice that seemed to be reasonably common. Another common theme regarding communication was the need to develop confidence in having difficult conversations and being more open to talking about death and dying both with colleagues as well as patients and their families. Some individuals talked about their fear of talking about EOLC initially and how that has changed now for them.

<table>
<thead>
<tr>
<th>Valued by participants</th>
<th>Concerns of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Language is the biggest change</td>
<td></td>
</tr>
<tr>
<td>- Talk about the programme</td>
<td></td>
</tr>
<tr>
<td>“Be present, out there, talking about the programme, be passionate, positive, excited about EOLC”</td>
<td></td>
</tr>
<tr>
<td>- Fear of talking about death and dying is diminishing</td>
<td></td>
</tr>
<tr>
<td>“Using reflection has allowed my practice to develop from the fear of talking about dying to a client and has shown me ways to develop communication without it being a frightening situation”</td>
<td></td>
</tr>
<tr>
<td>- Ability to communicate and listen to patient’s/resident’s fears and concerns</td>
<td></td>
</tr>
<tr>
<td>- Confidence to communicate with colleagues regarding their concerns and fears about delivery of EOLC</td>
<td></td>
</tr>
<tr>
<td>“Communication and breaking bad news continues to be an issue at times”</td>
<td></td>
</tr>
</tbody>
</table>

**Care Practices**
When changes were referred to in the practice area it usually meant technical changes rather than culture changes. Changes such as using HFH resources were identified or the introduction of tea and coffee making facilities for relatives. Although referring to the changes within the team and how communication had improved when asked about changes in the practice areas many individuals separated those from the more technical changes. Interestingly there was very little reference made to lack of resources as being a barrier to change.
### Valued by participants

- "I am more aware of end of life care. EOLC is huge in my priority list, relatives need me to listen – I have improved in this area. I am the patients advocate”.
  - Little changes in practice more realistic and big changes take longer
  - Importance of person centred approaches to care
  - Need for more holistic approaches to care
- "This programme has changed my fundamental thinking around EOLC by making me more aware of the need for a more open holistic approach to patients and their families”
- "More awareness and confidence when faced with EOLC”
  - Evidence of the EOLC symbol in use
  - More facilities for families such as rooms, refreshments, overnight facilities
  - Cosmetic changes to ward
  - Need to personalise care
- "That our engagement with patients should be a priority, in spite of all busy schedules”
  - The use of sympathy cards becoming common practice

### Concerns of participants

- Time factor in facilitating change
- Seeing no real changes in practice
- Difficulty with getting agreement to use the ward alter

### The Individuality of the patient/resident

Evidence of growing awareness of the individuality of the patient/resident and the need to respect their wishes was evident in most reflections. Many said that they had developed greater awareness of the need to work with patients’ wishes. Linked with this was an awareness of providing greater choice for patients/residents regarding and the need to get to know the person and their family.

### Valued by participants

- Greater awareness of needs of patient/resident
- Dignity towards EOLC
- "I reflect more on the patient’s end of life care journey instead of just putting it aside and moving on”
  - The autonomy of the dying person
- "Involve the patient in decision making”
- Engagement with patients should be a priority
- Prioritise the dying person
- "I am becoming more aware of the dying patient"

### Concerns of participants

- Ethical concerns when patients/residents and family wishes differ
- Difficulty with securing single accommodation rooms when someone is dying
and relative and how they are feeling”
- Importance of listening to the patient/resident
  “I am more aware of end of life care. EOLC is huge in my priority list, relatives need me to listen – I have improved in this area. I am the patients advocate”

Involving the family
There is notable awareness of the importance of engaging with families and involving them in the overall care of the person. Many individuals refer to the needs of families when caring for patients/residents and the necessity to engage and communicate with them. Some individuals made reference to this being something new for them. There were no concerns expressed about involving families more.

<table>
<thead>
<tr>
<th>Valued by participants</th>
<th>Concerns of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It is a memory that will stay with relatives for ever and should be given the highest priority at all times”</td>
<td></td>
</tr>
<tr>
<td>- Important to listen to the family</td>
<td></td>
</tr>
<tr>
<td>“I think I was doing a good job with the patient who was dying, but I don’t think I included the family enough in their care. My way of thinking about their involvement has changed”</td>
<td></td>
</tr>
<tr>
<td>- More consciousness of the needs of families</td>
<td></td>
</tr>
<tr>
<td>“Involve the family in decision making”</td>
<td></td>
</tr>
<tr>
<td>“I like to see the job done properly and the family happy with care when a person dies”</td>
<td></td>
</tr>
<tr>
<td>- The need to be more inclusive</td>
<td></td>
</tr>
<tr>
<td>“It is a memory that will stay with relatives for ever and should be given the highest priority at all times”</td>
<td></td>
</tr>
</tbody>
</table>

The care environment
Although light on specifics many individuals referred to greater attention being paid to the environment and the need to encourage the personalisation of space when someone is dying. There is frequent reference to the importance of obtaining a side room when someone is dying (acute settings) and the difficulty often encountered in doing so.

<table>
<thead>
<tr>
<th>Valued by participants</th>
<th>Concerns of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Greater attention paid to the environment</td>
<td>“Conducive environment for patients/relatives is still a major issue to be resolved”</td>
</tr>
<tr>
<td>- Making changes to improve areas</td>
<td>- Difficulty with obtaining single room occupancy for persons dying because of competing priorities</td>
</tr>
<tr>
<td>- Cosmetic changes made</td>
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</tbody>
</table>
CONTEXT ASSESSMENT INDEX TOOL (CAI)

In order to guide the implementation of evidence into practice a framework was developed by Kitson et al (1998) and Roycroft-Molone et al (2002) known as the Promoting Action on Research Implementation in Health Services or PARIHS framework for short. In developing the framework key elements were identified that support the successful implementation of evidence into practice. These elements are: context, culture, leadership and evaluation. Defining contexts is complex, the components of which can be considered in a continuum from weak to strong (Kent and McCormack, 2010). For the purpose of this programme context was explored as a means of identifying readiness or receptiveness to change. Getting evidence into practice is not context free although research evidence is often presented without regard for variances in contexts.

In this programme the context of care was measured using the CAI (McCormack et al 2009) which is based on the PARIHS framework. It was used to assist participants to understand their contexts and measure readiness for change. The tool is in the form of a questionnaire with questions subdivided into the elements of culture, leadership and evaluation using a Likert scale to score under each element. The CAI was used twice during the programme, at the start and at the finish. Unfortunately not all sites completed the second measurement although the majority did. All ward-based staff were invited to take part in the evaluation process. The data was analysed by each PD group using the evaluation scoring system. Through the use of reflective dialogue groups discuss their findings, whether their scores are indicating strong or weak contexts, and whether or not they considered the scores a realistic indication of their workplace contexts. The next step in the evaluation process was to agree actions to address weaker contexts or challenge the findings together with their colleagues with a focus on why the scores were higher than would be expected and why they did not feel that they accurately reflect the reality of their workplace.

Findings

The overall scores of both the baseline and final CAI did not identify any major swings. Eight of the ten sites undertook the baseline audit and nine out of 10 sites undertook the final CAI evaluation. Scores were in the upper percentile averaging between 66% to 98% as an overall score for context. The evaluation element achieved the highest overall score with culture and leadership elements achieving similar approximate scores. Half the sites that undertook the exercise achieved a higher score for the second round of CAI evaluations and the other half scored a lower overall score. It can be expected that scores may be lower when the tool is used for the second time as participants become more aware of the meaning of contexts and the significance of the individual elements and questions. The initial high scores could indicate espoused values that on further reflection and discussion do not equate with the reality experiences by participants in the workplace. On the other hand the higher score may represent a change in the context in response to interventions and activities undertaken during the programme.
<table>
<thead>
<tr>
<th>High/Highest scoring questions</th>
<th>Mid-range score</th>
<th>Low/Lowest scoring questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regard for patients’ privacy and dignity.</td>
<td>Leaders acting as role models.</td>
<td>Education seen as a priority.</td>
</tr>
<tr>
<td>Regard for patients’ safety and wellbeing.</td>
<td>Staff having understanding of own values and beliefs.</td>
<td>Feedback given to staff when a complaint is made.</td>
</tr>
<tr>
<td>Patient participation in care planning.</td>
<td>Decisions planned between staff and patients.</td>
<td>Equality of decision making between staff.</td>
</tr>
<tr>
<td>The undertaking of comprehensive assessment.</td>
<td>Patients involved in evaluating care.</td>
<td>The use of audit and research findings to develop practice.</td>
</tr>
<tr>
<td>All aspects of care being based on evidence of good practice.</td>
<td>Common goals are shared between staff about care goals.</td>
<td>Staff reviews enabling reflection on practice and goals setting.</td>
</tr>
<tr>
<td>Documentation of decisions about care.</td>
<td>Challenges to practice are supported and encouraged.</td>
<td>Democratic and inclusive management structures.</td>
</tr>
<tr>
<td>Personal and professional boundaries between staff being maintained.</td>
<td></td>
<td>Organisation non-hierarchical.</td>
</tr>
<tr>
<td>Proactive approaches to care</td>
<td></td>
<td>Regard within organisation for staff autonomy.</td>
</tr>
<tr>
<td>Good working relationships between clinical and non-clinical staff.</td>
<td></td>
<td>Availability of resources for developing practice.</td>
</tr>
<tr>
<td>Opportunities to consult with specialist teams.</td>
<td></td>
<td>High regard for autonomy</td>
</tr>
<tr>
<td>Cultural diversity respected.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regard for patients psychological and spiritual wellbeing.</td>
<td></td>
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</tbody>
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Figure 10 below demonstrates some of the possible espoused values expressed the responses to questions where there were obvious contradictions. For example almost every respondent agreed strongly that ‘all care practices were in line with evidence of good practice’ at the same time giving low scores for the ‘availability of resources for developing practice’, ‘opportunities for education’, and ‘reflective staff reviews’. Although ‘leaders acting as role models’ averaged a mid-range score, there was almost a unanimous low-very low score for ‘the organisation is non-hierarchical’ and ‘regard by the organisation for authority’. Issues where there were obvious contradictions were discussed on programme days and it enabled participants to understand better the context in which they provide care and the characteristics of those contexts that can make them strong or weak. The information provided by the tool identified target areas for groups to develop action plans to address.
Figure 10.

- Professional boundaries maintained
- Not democratic and inclusive
- Choice for patients
- Audit and research findings
- Hierarchical organisation
- High regard for autonomy within organisations
- Lack of reflections staff reviews
- Education not a priority
- No equal authority in decision making
- Comprehensive assessment
- Lack of available resources for developing practice
- Staff know/don’t know own attitudes & beliefs
- Leaders do/don’t act as role models
- Proactive approach to care
- Evaluation
- Leadership
- Culture

- All care is based on evidence of good practice
- Good working relationships
- Patients’ privacy and dignity respected
WORKPLACE CULTURE CRITICAL ANALYSIS TOOL (WCCAT)

The authors of this analysis tool developed it with ePD philosophy and values in mind. The purpose of the tool is to observe areas in the practice setting to inform changes in practice. Observation is one of the key tools in emancipatory practice development and used to affect change in the culture of care (values, beliefs and attitudes) and the context (setting) in order to bring about sustainable change (McCormack et. al. 2007).

The WCCAT has been informed by a number of theoretical frameworks (McCormack et al. 2009) including those directly used in this programme including the Person-centred Practice Framework (McCormack and McCance, 2009); Critical Companionship (Titchen, 2001); and workplace culture (Manley, 2000).

Clarification as to the purpose and process and the implementation of the tool was discussed within all groups. Site facilitators took the lead in their hospitals/nursing homes to make arrangements with participants in each ward/unit to observe together, feedback to the team on each ward/unit and then facilitate colleagues in the team to also carry out the observation. The feedback process, essential to the activity, provided opportunities for action planning. The principle guiding the feedback process is that it is a non-subjective account of what was observed at that particular time without making assumptions about the observation and without identifying any individuals. The approach is supportive and facilitative.

The key areas observed in the WCCAT are captured under eight headings:

1. The care environment
2. Communication
3. Privacy and dignity
4. Patient and family involvement
5. Team effectiveness
6. A learning culture
7. Risk and safety
8. Organisation of care

Themes from WCCAT

Eight of the ten sites undertook the WCCAT evaluation exercise and the following is a summary of the combined themes. The general feedback indicated that participants valued the opportunity to view their workplace from a new and different perspective. Participants carried out the observations in pairs and out of uniform in most sites. This was a learning process for participants with the potential to be a valuable resource. As the activity was new to both the site facilitators and participants it can be anticipated that if repeated and if it involves all the ward based teams it could provide valuable insights in identifying person-centred practices. Common themes as follows:
With regard to the environment there was a lot of focus on noise such as phones (ringing and conversations), loud conversations between staff, noises from kitchen, pedal bins, call bells constantly ringing, televisions and radios, doors banging in and around patient areas. Many said that they were unaware of the level of noise that patients/residents had to endure particular when in final stages of life. Some remarked on how peaceful the environment was.

Communication featured highly in observations and this included communication between staff and patients/residents, staff and visitors and between staff and staff. Language used by staff was observed particularly with regard to how person-centred or not it was. Many observed body language and how open and welcoming it was, and how visitors were welcomed. Some observations highlighted interactions between staff and patients/residents that could be improved.
Privacy and dignity was also an area that received attention. Many observed that privacy and dignity was well respected although greatly challenged when there is over-crowding in departments or in multiple occupancy rooms. The provision of bathroom facilities and the possibility of holding private conversations between staff and patients were noted as difficult.

No examples were given of patients/residents/family involvement in care planning although this may be because it was not observed at the time. However if documentation was evaluated it may have provided useful evidence of whether or not this is taking place. Some observational feedback stated that such conversations take place but are not generally recorded.

Much of the feedback was linked to the Person-centred Practice Framework (McCormack and McCance, 2009) with evidence by many individuals of an understanding of the elements of person-centred care when undertaking the observations. An example of one site measuring their development against the framework can be seen in appendix 1. Some individual’s observations focused on task aspects of their observations with some justification stated for certain practices. This demonstrates the need for further clarification of the purpose and process of the activity and the need for the activity to be repeated.

**PROGRAMME DAY NOTES**

Programme notes were recorded following each programme day so that there was an account of the programme plan for the day, work undertaken with summery accounts of the discourse, activities, agreed actions and participant and facilitator evaluations that took place on the day. There was a template designed to capture this information and the programme lead facilitators wrote and distributed programme day notes from the national group and the site facilitators. Notes from site programme days were captured by the site facilitators with a copy distributed to each participant in their sites and to the lead facilitator. Copies of site programme notes were made available to the Director of Nursing and to the ward/unit team. The notes were used as a record of what was happening in each individual site and facilitators captured an account of their evaluation of the session. The following are examples of this evaluation and capture the progress and difficulties that site facilitators and the PD groups had at times throughout the programme.

"As a group starting year two we had all agreed that the participants would take on more responsibility however that has not happened and I do not want to become a nagging police person nor a micro manager checking that actions have happen. But, the programme needs the work to happen and the outcomes to be achieved. On reflection, I need to be more specific in delegation and remember to apply dates to all activities. I need to pull back as it is their programme, not mine and its continuation will rest with the group not me. I still have not let go of old ways of thinking”.

"For some unknown reason I felt that I as a facilitator couldn’t get into a proper frame of mind for the programme day. I think I lacked motivation. The team engaged will but I just think we need something more to get the team engaged and motivated”.

"The group are more confident in challenging each other however we are all on a learning curve. I need to challenge more also there is a great positive energy in the group for the programme and there is a great ‘can do’ attitude in the group for all exercises and actions. This attitude is very important to me as a facilitator.”
It is not about me, the group are in control of where the programme is going. The group are more creative in the suggestion to issues/problems. They are beginning to stop seeing me as the person with power to solves all their problems and now believe that they have the power themselves to do so. There was great discussion and debates on the day somewhat reduced by two members not being present however there was still powerful learning for all present. My learning from the day I am doing ok and keep on going.”

"The urgency of the programme coming to an end and the need to have outcomes seems to be on some participants agenda. The focus on culture change as opposed to technical change is still required. At the start of the day the group expressed their frustration at current work climate and difficulty they had in making time for the programme work. I felt I needed to adjust the day because of this by encouraging the group to take more ownership of the timetable, adapting the opening and closing exercises. The evaluations of the day appeared very positive. There is a concern that programme day notes and emails are not being read and some members are consistently attending programme days ill-prepared, or not attending consistently which will have an impact on their learning”.

"With respect to the PD programme it is very difficult to get follow on from participants, it does feel like we are pulling out of them instead of the individuals becoming energised in their facilitation role. Even now 12mos + we are still hearing the same reasons why they can’t commit as much as they would wish. I can only hope that in their role they are more aware and make an effort to consider what we have raised in discussion and that they do put into practice a more person centered focus when engaging with patients and families”.

"My concerns are that the frontline work in the hospital is extremely demanding, busy and with financial constraints on agency and budgets trying to get the participants released for the time is proving extremely difficult”.

- “As co-facilitators, I think x and I took our feedback on board and were able to improve some aspects of our facilitation today.
- The need for definitive forward planning really dawned on me today if this work is to reach its full potential and be sustained. This was the first day that time was allocated to the group to proactively plan it. It is obvious that it will take longer. I am cognizant that as a group the facilitators have not brainstormed this either. I am nervous about the sustainability of the work”.

- “As co-facilitator I find myself coming more into my own style of facilitation while at the same time working more and more in tandem with X.
- The set up and constrains the room in the morning was hindering the free flow of the work; a change of the sitting arrangement and focus of the room made a big difference to the afternoon session. There is a possibility that change of sitting arrangement or even venue could have a refreshing impulse when spending a whole day with a group in one room. This can be explored.
- Just as X said, the activity around sustainability of the programme and programme outcomes has brought the end of the programme in sight. We will have to focus on our last two days on this aspect of the work because this seems to be a key interest to the group”.

The following is a poem penned by Susan Hawkshaw, site facilitator for Beaumont Hospital.
A Poem

Today I finally got a handle
On my PD facilitators mantle
In my action learning set
My plan moving forward was met.

Using bright and colourful cards
We identified how to move culture work yards
The picture each story told
Was gold
How we work, how we behave and how we make decisions....
Has definitely cleared my vision.

By Susan Hawkshaw 23.11.2011

DIRECTOR OF NURSING FOLLOW-UP FEEDBACK

Directors of Nursing (DoN) were invited to give feedback on the programme via an open-ended questionnaire. From the outset the DoNs were involved in the planning and supporting structures for the programme and PD groups linked back to the DoN in their hospitals with updates and feedback following each programme day. The general themes from the directors related to the following headings:
1. The development of the facilitators, participants
2. Changes and learning
3. Challenges and sustainability

Development of facilitators
There was general agreement that significant facilitation skills were developed by site facilitators. There was evidence of more creative thinking and reflective processing taking place. There was an increase of confidence noted with participants during interactions with DoNs, and evidence of greater willingness to take responsibility and ownership for practices and issues in the workplace. There was also recognition for the level of personal growth and development that was evident with a growing confidence in roles, knowledge and ‘self-worth’. Respect for others roles was also noted along with skills to challenge colleagues when change is required. Although daunting at first for many participants, DoNs noted a growing confidence in giving feedback and updates on the work of the programme.
There was a particular recognition for the growth and development of HCAs on the programme with obvious enhancement of facilitation skills and for some the ability to lead out on aspects of education programmes with peers and other disciplines within their organisation. One HCA has become a facilitator for the HFH Final Journeys programme. There was also an obvious increase in levels of confidence in value of own roles notes.

Changes and learning
The most frequently notable developments related to in the growing confidence to reflect on and question practices and in taking ownership for making changes. The development of vision statements was seen as a positive action in supporting change. There was acknowledgement for the change in how staff referred to and about patients and their families and the obvious use of more person-centred language in interactions. The accepting of local ownership and ability to problem solve was also noted. It was noted that practical resources were in use now as routine and that participants continued to motivate colleagues to change and reinforce best practices in EOLC and palliative care. It was noted that the programme helped to improve standards of EOLC. The involvement
of both nursing homes was seen as a very positive element with opportunities to share experiences and create partnerships.

**Challenges and sustainability**

Challenges were highlighted by most DoNs regarding the release of staff to attend programme day. Difficulties with gaining buy-in from other disciplines was also raised. There were suggestions that the programme could have been shorter with a suggestion that it could be modular in format to reduce length. The challenges for further roll out and sustainability were also raised although many noted that sustainability plans were being discussed. It was suggested that consultant involvement may have increased levels of buy-in for the programme work.

In some sites the PD group were incorporated into EOLC standing committees. The need to promote the programme in order to embed the work within their hospitals was raised. One site is establishing a practice based EOLC committee to progress the work of the programme. Another site is incorporating the programme into their 2013 strategic plan. Plans are underway in some sites to establish ward-based development plans to transfer learning to other areas. Local initiatives and contracts will be established in some sites to encourage local participation. It was suggested also that the establishment of an end of life care coordinator in sites, where there are currently none, would enhance the sustainability of the work.

**KEY LEARNING AND MOVING FORWARD**

- The work of the PD programme in eight major acute hospitals and two nursing homes was modelled on a similar HSE research programme undertaken in Ireland for older persons in residential care (McCormack et al, 2007-2008). The evidence and learning from that programme guided the structure of this programme. The philosophy and methodology of ePD is designed to enable the development of critical reflective skills and creative thinking that focuses on teams and individuals with the aim of achieving person-centred care that is effective and meets the needs of the individual and their family. This approach to developing individuals, teams and practice may be culturally at odds with traditional hierarchical approaches based on negativism and deficit approaches that ‘tell’ rather than fully involve staff in identifying the need to make change based on their knowledge, experience and evidence from practice.

- Developing person-centred cultures focuses on the relationships between nurses and HCAs, patients and persons significant to them (McCormack et al, 2008). The focus of this programme was consistent in creating structures and processes that supported the development of person-centred end of life care within teams providing care. Participants developed skills together to explore and use evidence to inform their practice and critically question traditional customs and practices and espoused values unsupported by evidence. Where well supported and engagement was good within the wards/units, participants became more empowered to take the lead on making changes to their workplaces and practices and solving problems. Participants in many cases moved from a feeling of helplessness to making changes in their workplaces to viewing change was their responsibility and a necessary part of planning care.

- The support from the Directors of Nursing and senior nurse managers in each site was crucial to the success of the programme and structures were put in place to ensure that participants felt supported and directors were aware of on-going developments and ideas for change. In general this structure worked well for participants and directors alike and enabled the fostering of stronger links between both parties. What may have added greater value to this support could have been structures for greater engagement by the other senior nurse managers. There were various levels of support for the programme from this group of managers and where
support was low site facilitators often struggled to influence across and down in particular without it.

- The other significant group, as already mentioned in the report, were the clinical nurse managers (CNM) and how their engagement was key in motivating staff and moving the programme forward in their clinical areas. In some but not all cases when CNMs, and in particular CNM2s, were not directly involved on the PD working groups the level of engagement by other team members was adversely affected. Unfortunately in a couple of wards/units there was no engagement by senior CNMs which had a direct impact on the progress of the programme in those areas.

- It was acknowledged from the outset during the proposal stage that engagement by the wider multidisciplinary team would be very powerful in having an impact on cultures of care at a mezzo level within hospitals. In one nursing home where the senior executive engaged directly with the programme there was evidence of clear engagement by other staff with explicit expectations that improving care practices was everyone’s business. Participants on the programme were asked to include other disciplines in activities such as developing a vision statement, feedback on how the environment could be improved and challenging inappropriate language as examples. However there was limited engagement overall by other disciplines and this is something for organisations to consider if another programme such as this is considered in the future.

- Sustainability and action plans were developed at the end of the programme by participants and facilitators from their knowledge of person-centred end of life care and the knowledge and skills gained over the course of the programme. A level of capacity is now developed which could contribute significantly to the sustainability and further roll-out of the end of life care programme and indeed any other focused topic that requires culture change. The intensive coaching as well as work-place activities within the programme has equipped participants with the fundamental knowledge to influence culture change and practice development consistent with the Hospice Friendly Hospital themes within their organisations. As with any other new knowledge and skills unless utilised and shared with others as part of a focused workplace development process then the effect will be limited to those who took part.

To acknowledge a quote from James Green (2008:11) from his work in death practices: "Where death is seen as a ‘failure’ despite the best in contemporary medical skill, technology, and service, patients who acknowledge they are dying and work to achieve a state of acceptance do their part in turning medical failure into heartfelt triumph”.

Finally, one programme participant’s reflection on the programme:

"Being able to believe that my being confident in the job that I do is making me a more committed person".
APPENDIX 1
Examples of progress/achievements in relation to components of the Person-Centred Practice Framework

Prerequisites
Clarity of beliefs and values
- Belief in quality, privacy and choice, prioritize always patient and family choice especially side rooms for EOLC journey vs. isolation rooms.
- Staff nurse questioning beliefs and values in EOLC in relation to patient centered care – rituals are questioned.
- Belief in what is right and confident to say this to staff.

Developing interpersonal skills
- Care attendants presenting to groups.
- Sending patient home from ICU to die – required a lot of communication and breaking down of barriers.
- Increased confidence when giving presentation to fellow colleagues, at DON meeting and HCA in-service.

Commitment to the job
- Increased communication with person centered, family, staff. Not doing stereotype work. Enjoying the work what I do. Willing to know what patient wants.
- One of the MSc candidates is doing her dissertation on EOLC.
- Staff using EOLC initiative as part of degree programme assessment.
- Did not miss one day of EOLC programme – worked A/L around it and attended days on while night duty.

Know self
- Have changed my practice e.g. do not carry out ritual practices e.g. turning. More person-centered.
- Know your beliefs and values in EOLC.
- Elaine spoke with staff.
- I know how good I am in my job, how much I am qualified in my job. Changed my work after EOLC programme development.
- Strong, confident, motivated – example of this is this course and promoting change in the way we do things.

Professional competence
- Competency on Foundation Programme ICU surrounding EOLC and looking after yourself.
- Staff attending Final Journeys.
- Development with on-going education and feedback from this course.
- All staff has been trained in EOLC as they are professionally qualified. They are confident.

The Care Environment
The physical environment
- Small store room made out of a bathroom so the dayroom can be utilised as a quality area for patients and families.
- Electrical beds in X.
- Symbol.

Appropriate skill mix
- Difficult death – junior staff support each other.
- Very difficult to achieve: Some people shy away from EOLC situations – others are overloaded with EOLC situations.
- HCAs and staff both manage EOLC on the wards and help educate new staff re EOLC (students/agency nurses).

Potential for innovation and risk taking
- Care attendant challenging CNM in regards to care giving.
- Although some doctors don’t agree with EOL symbol in use.
• Giving prioritization for EOLC patients to side rooms vs. those who need isolation
• Challenged team re patient status, it was obvious to staff patient was dying for week. New team pushed for scans.

**Power sharing**
- HCAs/cleaner/kitchen staff/nursing staff all share the power to equip relatives with EOLC booklet.
- Difficulties with making changes as no medical involvement
- Positive shared with HCAs (empowerment).
- Between HCAs and nurses at times with teams and with SPC.

**Effective staff relationships**
- Everyone has a voice from HCA to catering staff & respect their decisions.
- Patient on EOL journey; staff nurse asked HCA how to best care for patients son’s needs.

**Supportive organizational systems**
- Time allocated to talk.
- Time allocated to attend study day.
- Time given for small in-services.
- EOLC group.
- EOLC PD group.
- Support of DON.
- Support and awareness after traumatic event.
- When anything comes up about EOLC ADON always gives encouragement.
- DON will give refill for CNM/HCA to attend EOLC SD.

**Person-centered Outcomes**

**Working with the patient’s beliefs and values**
- Patient in a side room on her EOL journey. Her side room was hers – all her own family pictures, photos, paintings etc. Décor was encouraged and infection control policies were deviated from.

**Engagement**
- Patient asked me about his prognosis “It’s not good is it?” I answered: “No its not, I am so sorry”. Felt huge relief being honest with him and he told me he had a lot of thinking to do.
- Family wrote detailed letter of thanks to staff for all care given to their dad and themselves. It quotes time all carers (kitchen/cleaner/doc/nurse/HCA/porters) took in asking patient how his day was. Time took to have a chat, to make a cup of tea, to disclose a piece of personal information to patient which kept him going and made him feel alive.
- Asking the family members to join us to wash the patient- they accepted. Did the makeup and thanked me for giving them the opportunity.
- HCA speaking with families.
- Work with staff helping them engage with patients families.

**Shared decision making**
- Everyone has a voice from HCA to catering staff & respect their decisions
- HCAs/cleaner/kitchen staff/nursing staff make a shared decision to equip relatives with EOLC booklet.
- Patient on an EOL journey had been prescribed thickened fluids by SALT. He hates same and had only few days left so all staff decided (nurse/doc/HCA’s) along with patient and family that even he was at risk of aspiration it was ultimately his decision to take normal consistency fluids. SALT agreed in the end after discussion but educate family on risks involved.
- With palliative care in discharge planning and care planning.
- Patient on EOLC journey – when we gave the booklet and when it is appropriate to use the symbol and if it’s appropriate to turn the patient.
- Allowing the most appropriate member of staff to break bad news and discuss resuscitation.

**Having a sympathetic presence**
• Staff member staying with dying patient so family can take a break knowing the patient is not alone.
• Need to work on it, not to be judgmental.
• Medical team, nurses, HCAs felt such sympathy for the patients son who was effectively on his own. He appeared to struggle with females and we organized for a male SPC to come daily to see him even though his mom was non-symptomatic.

Providing holistic care
• Considering patients body image.
• Patient is dying: all appropriate MDT members involved, SPC involved, no family only friends and open door visiting policy provided. Open communication given. Patient had a large beard and that wasn’t touched as he chose for it not to be shaved. He loved music & opera and this was played by the staff for the patient when he went unconscious.

Person centered outcomes
• Thank you card from brother of a deceased patient: “It was a long journey and it was great to have some company along the way”.

Feeling of well being
• Patient is palliative and voiced she felt so well and happy and thankful for all the care given as we prepared her for getting home.
• Staff member from another department came to ICU. Her neighbour’s husband died in ICU. The wife told her how impressed and happy they were with the care of all the staff in ICU. Staff member said she felt proud to work in X.

Satisfaction with care
• Letters and thank you cards from relatives following EOLC express satisfaction with care.
• Received phone call from family member in tears: thanks for the sympathy card sent. Called just when it arrived. Couldn’t say enough thanks for organising mass for everyone involved in care of her late husband.

Involvement with care
• Patient’s daughter was chief carer of her mum prior to admission. We always invited her to help nurse/HCA to attend the needs of her mum.
REFERENCES


Department of Health (UK) End of Life Care Strategy and Programme.


