



# Learning from Complaints

## Fourth Annual Event - 29 June 2017

During April 2016 to March 2017, 6189 issues of complaint were received by Health and Social Care Trusts, as well as 249 issues of complaint regarding Family Practitioner Services, and whilst this is in line with previous years, it was noted that there was a slight increase in the number of complaints received regarding treatment provided to patients in receipt of palliative care, to include the coordination of discharge packages. For this reason, it was decided that the focus of this year's learning event should be on this subject.

Palliative care has historically been synonymous with care of the elderly; however, it can apply to all stages of life. Therefore, it is essential that a person-centred approach to the coordination and delivery of high quality, reliable treatment, is provided to patients, thus ensuring that they can maintain control, dignity and crucially choice in how and where their care is delivered at the end of their life.

Death can be expected and peaceful, however it can also be sudden and traumatic. Therefore, the nature of the death and the context in which it has occurred will determine the level of immediate support required by family members. Communication has to be delivered in a sensitive and respectful manner and where applicable followed up by appropriate written information providing support to patients and

families through difficult times.

Failure to deliver a high standard of holistic care, coupled with inadequate communication will often result in complaints. Discharge arrangements also need to be taken into consideration, and appropriate communication made with either the next of kin and/or the appropriate nursing/residential home. In addition, the timing of discharge should be carefully considered, and referrals to district/palliative care nurses made in a timely fashion.

This newsletter highlights some of the key themes and messages delivered by each of the speakers at the event and we hope that you will find it informative, thought provoking, and that it will influence your future interactions with patients, clients, carers and families.

# Key Issues in Relation to End of Life Care Experience

Mr Richard Dixon, Complaints Services Manager, Patient and Client Council, (PCC) presented the findings of a report which was undertaken to understand the key issues patients and families experience in relation to end of life care.

It was explained that during 2016/17, the PCC received 79 new complaints, where the subject of complaint was the death of a patient or client. Within these cases the main issues of complaint included, communication, quality of treatment and care, delayed diagnosis, lack of coordinated care, lack of information, and pain management.

## Key Messages

Feedback from families has identified four main obstacles which prevent the provision of high quality end of life care:

- ❑ **Capacity and timeliness of discussions**  
Particularly the need to address end of life issues with the patient before capacity is lost.
- ❑ **Relationships**  
To include the development of relationships between families and clinicians where the issues of a relative's death and end of life care can be openly discussed.
- ❑ **Sharing and availability of information**  
Such as the need to ensure appropriate family and carer involvement, including the provision of information and

signposting to support services.

- ❑ **Adequate training of staff**  
Ensuring end of life interactions with families are conducted in an appropriate and respectful manner.

Mr Dixon highlighted the importance of managing families' expectations, and that staff should take cognisance of family dynamics, as not all family members are actively involved in the decision making process. He continued that complaints of this nature are extremely emotive and are associated with painful memories, therefore, timely communication of information between patients, families, carers and health and social care providers, is paramount in reducing complaints concerning end of life care.

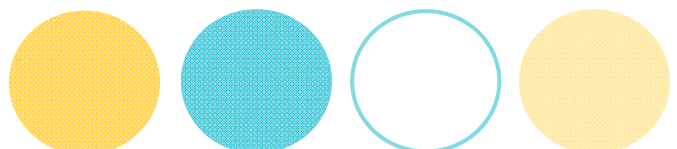
## Recommendations for Improvement

Information gathered by the PCC identified three key recommendations to improve interactions between clinicians, patients and their families:

- ❑ The implementation of measures to improve communication between staff, patients and their families at the end of life.
- ❑ The implementation of a formal process whereby relatives are able to meet with clinical staff following a relative's death to discuss any concerns that they may have.
- ❑ The provision of robust and timely responses to complaints, thus minimising the distress faced by families.

## Report

End of life - Key issues arising from complaints about end of life care experience - Year 2 (April 2017)



# Discharge arrangements out of hours (OOH)

Emergency Department (ED), South West Acute Hospital (SWAH), Western Health and Social Care Trust (WHSCT)

---

**Ms Nicki Hazlett**, Deputy ED Sister, SWAH, WHSCT, presented the learning arising from two complaints which were received and investigated by the ED of the SWAH during 2015 - 2016.

During this timeframe, there was a 5% increase in attendances at ED when compared to figures received for the previous year, which includes an 8% population increase of those over the age of 75. Therefore, the numbers of complaints received by the SWAH is small when compared with the number of patient interactions (34,158 attendances during 2016 - 2017).

**“The single biggest problem in communication is the illusion that it has taken place”  
(George Bernard Shaw)**

Both of the complaints received, concerned the timing and communication to families regarding the discharge of a family member. Within the first complaint, a very elderly patient with dementia was returned to their Nursing Home at 01:50hrs. Within the second complaint, the patient was discharged at 00:05hrs without their next of kin being informed.

## Improvements in Practice:

- ❑ A discharge policy has been implemented across the WHSCT EDs, whereby no patient will be discharged from hospital after midnight.
- ❑ Clear and concise communication with family members and/or residential accommodation should take place prior to discharge.
- ❑ Consideration should be given to the most appropriate means to transport the patient home, at the earliest opportunity, i.e. ambulance, taxi, or collection by a family member.
- ❑ Roll out the ‘purple tool kit’ for dementia patients.

Ms Hazlett concluded that continuous reassurance and informed communication and leadership, is the only way that patients’ voices are heard.

# How Complaints are making a Difference – Regional Palliative Care Programme

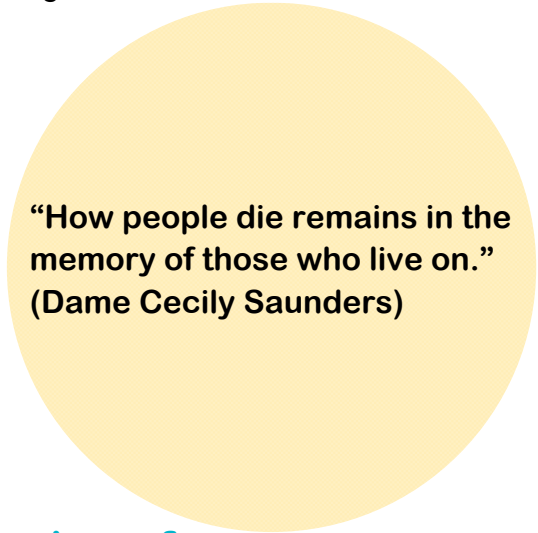
**Mrs Loretta Gribben**, Nursing Consultant, Public Health Agency (PHA), outlined the key messages and themes arising from complaints and how these have influenced the Regional Palliative Care Programme. It was explained that the ethos of palliative care is the ‘active, holistic care of patients with advanced progressive illness...and is a continuum of care that can evolve as a person’s condition progresses...which focuses on the person rather than the disease’, (Living Matters: Dying Matters Strategy, 2010).

## Key Messages

- It was noted that dependent on the patient’s life expectancy, various terminology is used, to include; palliative care; end of life care and terminal care and it is essential that staff are equipped and have the confidence to have potentially difficult conversations with patients and their families.
- Complaints in respect of palliative care, generally relate to the last few weeks and days of a loved one’s life, and are

submitted at a time when families are grieving. Therefore, the complaint has to be handled and investigated with sensitivity, with early engagement with the family.

- Similar to the findings of the PCC, the main issues of complaint relate to staff attitude, poor care planning, lack of pain control, inadequate communication and discharge arrangements.



“How people die remains in the memory of those who live on.”  
(Dame Cecily Saunders)

## Examples of Complaint Extracts

- “At a time when our family was experiencing intense emotional distress after hearing the devastating news that our mother’s illness was terminal, it was further exacerbated through the slow response to plan and execute her palliative care package in the days leading up to our mother’s recent death.”
- “We understand that this experience was always going to be a stressful and traumatic one, but the lack of co-ordination and straight forward empathy...made this experience much more difficult.”
- “As the day went on, my mother was still very agitated, moaning and in a lot of pain. She was not talking and couldn’t drink or swallow.”
- “We were so distressed and upset, and we felt that we had been left totally on our own to deal with it all.”



## Improvements in Practice

The Regional Palliative Care Work Plan, provides the regional direction, foundations and tools so that anyone identified as possibly in their last year of life (regardless of their condition) is allocated a keyworker; has the opportunity to discuss and record their advance care planning decisions and is supported with appropriate generalist and specialist palliative care services.

Moreover, adherence to these priorities ensures that there is an on-going process of discussion between the person, those close to them and their health care professionals focusing on their wishes and preferences for their care as they approach the end of their life.

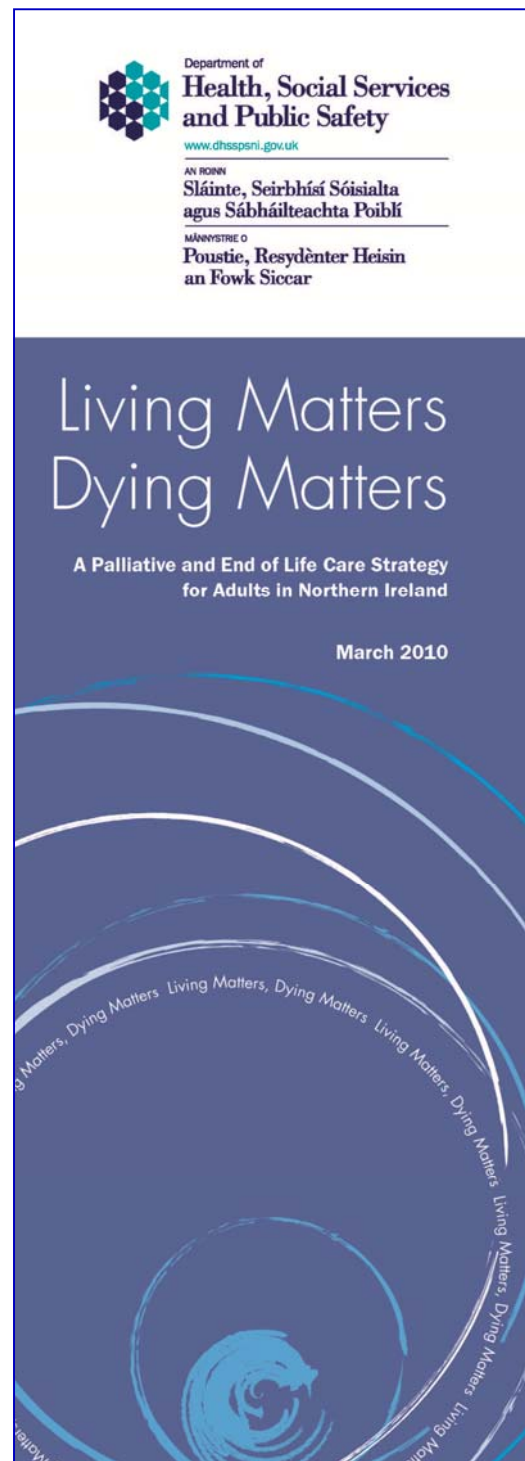
However, in terms of specialist palliative care services (SPC), it was explained that there are variations in the provision of SPC, specifically, lack of access to:

- nurses at weekends,
- palliative medicine consultants at home,
- allied health professionals in the community.

Which is in turn, exasperated by an aging population and a workforce nearing retirement.

**“The end-of-life deserves as much beauty, care and respect as the beginning.”  
(Loretta Gribben, PHA)**

Nevertheless, Mrs Gribben outlined that a SPC workforce review is currently underway, which will review, medical, nursing, physiotherapy, occupational therapy, speech and language, social work and pharmacy staffing levels. Therefore, complaints of this nature will hopefully decrease as time progresses.



# Moral Distress and ICU

## End-of-Life Decisions: The Perspectives of Relatives, Nurses and Doctors

Dr Una St Ledger (PhD), Belfast Health and Social Care Trust (BHSCT), spoke of the theory of 'moral distress' and the research she conducted between 2012 and 2013, with 20 relatives whose loved ones had died following treatment within the BHSCT's Intensive Care Unit (ICU), to include interviews with staff who provided the treatment.

### Key Messages:

- ❑ Moral distress is defined as 'A state of immense anguish caused by the sense of wrong doing, experienced when an individual knows the right thing to do but is constrained from acting in accordance with their moral judgement and moral responsibility.' (McCarthy and Deady, 2008).
- ❑ The majority of deaths within ICU have been preceded by decisions generally not to escalate treatment or withdraw therapy and therefore, whilst the consultant is responsible for making end-of-life decisions, the different and complex mix of values, beliefs, perspectives, coupled with families 'sense of responsibility' creates the potential for considerable 'moral distress'.
- ❑ It is important that staff recognise instances when individuals may experience 'moral distress', as they may have emotional, physical and psychological responses or 'moral

**"I won't rest until I find out. Could they have treated her better? Could they have saved her? Could they have done more...?"**

residue' which can include but is not limited to; guilt, shame, remorse and regret.

- ❑ Occasionally staff may feel that they have 'failed' in their duty to 'advocate' or ensure that the patient experiences a 'good death'. However this is very much dependent upon their experience and proximity to the patient.
- ❑ Clear, concise and consistent communication from staff to relatives is essential to ensure that they fully understand the seriousness of their loved ones condition.

**"Thank God," I said to him, "Love, you're going to the ICU. You're going to be alright." But I didn't know then how far on this was...how bad this was."**

## **Dr St Ledger also outlined the effects treating seriously ill patients within the ICU setting had on different staff members.**

Nurses and doctors.

- ❑ “You can express what you may think, but it’s not always heard.”
- ❑ “You’re with a patient, a 13hr shift...you see the patient is not improving...you see the distress of the family as they know it too and you’re just prolonging it...but that decision isn’t yours to make.”

Consultants.

- ❑ “I would be quite cautious about decisions and probably take too much time. Some of the nurses get quite frustrated about that, but I don’t think they understand what it’s like to be the one making the decision and having to go home to dwell on it.”

## **How to Improve Practice**

While nothing can ultimately prevent ‘moral distress’ the importance of clinicians maintaining regular involvement in a patient’s care is essential, thus ensuring enhanced continuity, consistency and timeliness of decisions.

**“You walk away thinking everything was done and at the right time. We were heard, and our opinions mattered, and mum’s opinion’s mattered... Being guided, we as a family reached a point where yes, that was the right decision.”**

**“They brought us with them on those decisions and we didn’t want Dad to suffer any more. He had been through a lot and there was only going to be one outcome...they really gave it their best shot to get him back’**

Greater interaction with families means that they have increased trust in doctors’ intentions, understanding and satisfaction with care provided, as well as readiness to receive bad news,

Those family members not involved in the decision making process, may feel resentment towards clinicians and are unable to accept the loss of their loved one, creating the impetus for complaints. Therefore, information must be relayed to patients and their families in a sensitive, appropriate manner, ensuring that the family is involved in each stage of the decision making process;

Whilst families may be emotionally and psychologically traumatised; it is important that they are satisfied with the treatment and care provided and that the right decisions were made at the right time;



