

**EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST****REPORT TO: BOARD OF DIRECTORS****DATE: 21 MAY 2015****SUBJECT: PATIENT STORY****REPORT FROM: CHIEF NURSE & DIRECTOR OF QUALITY****PURPOSE: Discussion  
Information****CONTEXT / REVIEW HISTORY / STAKEHOLDER ENGAGEMENT**

The Board of Directors have been using patient stories to understand from the perspective of a patient and/or a carer about the experiences of using our services.

Patient stories are a key feature of our ambition to revolutionise patient and customer experience. Capturing and triangulating intelligence pertaining to patient and carer experience from a variety of different sources will enable us to better understand the experiences of those who use our services.

Patient stories provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

**SUMMARY**

This month's story relates to the experiences of Diana, a woman in her forties who was admitted on a Friday to Cambridge J Ward for end of life care. The story is told by Coleen Kingston, Diana's sister, and Debbie Brown, Diana's cousin. Using Emotional Touchpoints methodology the family described a pathway of care that did not appear to be wrapped around the patient. There were issues with staff appearing disempowered and also dismissive of Diana's nursing care needs. They also discuss the difficulty in referring someone for Hospice care out of hours. The family felt very strongly that the Ward needed to learn from their experience and met with the staff to share their feelings. This story is presented as a DVD for the purposes of learning for the Trust.

**RECOMMENDATIONS:**

The Board of Directors are invited to note the key themes of this story and the actions in place to prevent reoccurrence.

**NEXT STEPS:**

None. The actions outlined in the story are being monitored by the Division.

**IMPACT ON TRUST'S STRATEGIC OBJECTIVES:**

Improving patient experience and satisfaction with the outcomes of care are essential elements of our strategic objectives.

**LINKS TO BOARD ASSURANCE FRAMEWORK:**

This story links to AO1 of the BAF: Implement the third year of the Trust's Quality Strategy demonstrating improvements in Patient Safety, Clinical Outcomes and Patient Experience / Person Centred Care.

**IDENTIFIED RISKS AND RISK MANAGEMENT ACTIONS:**

None identified.

**FINANCIAL AND RESOURCE IMPLICATIONS:**

None

**LEGAL IMPLICATIONS / IMPACT ON THE PUBLIC SECTOR EQUALITY DUTY:**

None

**PROFESSIONAL ADVICE TAKEN ON ANY NOVEL OR CONTENTIOUS ISSUES:**

None

**ACTION REQUIRED:**

- (a) Discuss
- (b) To note

**CONSEQUENCES OF NOT TAKING ACTION:**

If we do not learn from events such as these there is an increased risk of further occurrences which may adversely affect both patient experience and outcomes.

**Board of Directors  
Patient Experience Story – Diana's Voice  
April 2015**

**Introduction**

This month's story is presented as a film for the Board of Directors. It relates to the experience of a family during the last days of Diana, their sister and cousin's life. Diana was admitted for end of life care on Cambridge J Ward at the William Harvey Hospital. The two women were interviewed using the Emotional Touchpoints methodology. Since the event, the family have met with the Ward staff who have also heard first hand and face to face their story.

**Emotional Touchpoints**

Emotional Touchpoints is a way of learning about the patients' and visitors' experience of being in the hospital. It helps staff to recognise and celebrate good aspects of care as well as make improvements to their services. Touchpoints refer to important events or stages in care. The Touchpoints are listed for the patient or relative. They are invited to choose a particular Touchpoint that resonates with their experience. Touchpoints include topics such as 'coming to the hospital', 'meal times', 'getting help with things', 'talking with Doctors'. There are around 28 to choose from. The person is shown the Touchpoint card and asked to select the Touchpoints they feel are relevant to them. Taking each Touchpoint in turn, the person selects the emotions that summed up how they felt about the particular experience. These too are presented on a card and contain a selection of positive and negative emotions that are offered to the person. They are then asked why they felt that particular emotion. If a negative point is raised, the patient or visitor can be asked what we could do to improve things. It may be that they wish to be part of making the improvement, such as if we were to improve information leaflets for example, they may wish to be part of this. The feedback offered by the person is captured anonymously in writing. Emotional Touchpoints is a very powerful improvement tool because seeking feedback that is based on the person's emotional response to a situation is difficult to dispute as it helps challenge assumptions that we may make. Theming the feedback and triangulating with other sources enables us to focus our improvement work.

**The Patient Story**

Diana was admitted to Cambridge J Ward having been reviewed at her Outpatient appointment. She was admitted with progression of her lung cancer that had spread to her liver and brain. She had pneumonia, was constipated, unsteady on her feet and was in pain due to the side effects of her treatment. Her family were spoken to and they understood that her cancer was incurable. They were also told that she was not fit for chemotherapy or radiotherapy, nor would benefit from this. Her life expectancy was very short and a palliative care review was arranged.

Over the next few days, Diana became very distressed. Her family wanted her admitted to the Hospice as soon as possible. They were also concerned about her poor symptom control and wanted to ensure that she would not be resuscitated when she died. Diana was admitted to the Ward on a Friday. This was a key issue for the family as they sought to ensure her care was delivered appropriately and in a seamless manner over the weekend.

The story is told by Coleen Kingston, Diana's sister, and Debbie Brown, Diana's cousin. Both ladies work clinically in the NHS. The Touchpoints they chose to discuss were 'Care of a Relative' and 'Involved in decision-making'. The emotions they selected were 'frustration', 'sad', 'frightened', 'overwhelmed', 'powerless',



'shocked' and 'anxious'. They also chose a number of positive emotions which were 'inclusive', 'empathetic', 'respectful', and 'caring'.

Their story describes the difficulty they felt they had in ensuring a dignified death for Diana. They discuss how disempowered the staff appeared on the Ward and that there was a sense of fear around making decisions for Diana's care. They felt that the nursing staff lacked autonomy, and were not empowered to make decisions that would enhance Diana's care. They felt this was due to a lack of leadership on the Ward with junior staff managing her care. Coleen had to undertake Diana's mouthcare herself as the staff were not providing the care and rarely came behind the curtains to check the family's welfare. This resulted in Debbie feeling as though she needed to take the role of the nurse and on one occasion she called a friend on another Ward to obtain an ice-lolly for Diana to enjoy. Another area where the family felt let down was that Diana was being nursed in the main Ward. They explained that another patient offered and gave up her sideroom for the family. They gave an example where they asked a nurse for assistance with an aspect of care and she said she was unable to attend at that moment due to needing to undertake the drug round. This gave the family the sense that Ward routine came first and that the systems were not wrapped around the patient.

An additional problem was that they felt there were barriers with regard to Diana's referral to the Hospice and delays in the Hospice admitting Diana over the weekend. With, in their words, 'one chance to get it right' this was a very disappointing situation. For them, this demonstrated an NHS and Hospice service that was not responsive to patients and families out of hours. In their view there was no care pathway for Diana due to it being a Friday. The family did discuss with the Palliative Care Nurse the lack of palliative care support over the weekend.

Diana's condition deteriorated very quickly. Her 18 year old son was unable to cope with the situation and did not feel able to be with her at the end. However, the family spoke very highly of a number of staff who were extremely caring and frequently contacted medical colleagues for help. They spoke of the Registrar who titrated Diana's medication to ensure she remained as comfortable as possible. They said she was superb as she listened and acted on the family's wishes.

Diana died on Cambridge J Ward on the Sunday with her family present. Due to their experience, the family contacted the Trust and met with Julie Pearce, Chief Nurse and Director of Quality and also the Phil Higgs, Matron for the Ward, to discuss their care. Mr Higgs also arranged for them to meet the Ward staff so that learning could be shared.

### **Care and Service Delivery Problems**

The family describe the following areas as care and service problems:

- No access to the Hospice over the weekend;
- Unable to access the Palliative Care Team out of hours and at the weekend;
- The attitude of some of the staff;
- Systems not being wrapped around the patient.

### **Learning and Actions**

Following their meeting with Julie Pearce and Phil Higgs, the family have met with the Ward team, the Palliative Care Nurse and also agreed to film their story. There are three short films. One is the Exec summary, one is Emotional Touchpoints methodology and the final film on the DVD is the whole interview. They have requested that these films be used for teaching purposes and have requested a copy is shared with Canterbury Christchurch University College for student nurse training.

The Ward staff found meeting the family a very powerful experience. Hearing their experience has led the Ward to make improvements in their care. Staff are now more aware of providing person-centred care according to the specific needs of their patients, particularly at end of life. They are more aware of ensuring adequate symptom control when caring for a distressed patient. They are fully aware of the importance of acting in a professional manner with a caring empathetic attitude that ensures a high standard of care is consistently delivered.

The Trust is working closely via the End of Life Board with Community and Hospice colleagues to ensure a seamless pathway occurs for end of life patients whatever time of day, or day of the week they present. Plans are afoot to accelerate this by providing an End of Life Ward in the Trust so that dignified care can be delivered in a non-acute setting. Other actions in place include:

- Record of End of Life Conversations forms and Caring Conversations posters and flyers to all staff have been introduced. These are available on all inpatient Wards;
- Teaching sessions for Ward staff by the Specialist Palliative Care teams are taking place;
- Matron led assurance takes place to ensure that all nursing staff are aware of the syringe driver policies and are trained appropriately;
- Matron led assurance that all nursing staff are aware of the record of End of Life Conversations form and Caring Conversations Care Plan is routine. A second audit is currently being undertaken;
- Grand rounds on all sites have taken place to discuss the withdrawal of the Liverpool Care Pathway and to inform staff of the key principles in End of Life Care;
- 'In your shoes' sessions with bereaved relatives have taken place in order to gain feedback which has informed the End of Life work-plan;
- A recent Schwartz round at the WHH addressed End of Life Care where we heard stories from staff who have cared for dying people. This was a powerful forum for sharing and learning and was attended by over 100 staff;
- The End of Life Facilitator (funded by the Hospice) has provided multidisciplinary team training in End of Life care over the past 12 months. Feedback from this is being reported to the End of Life Board this month.

The issues around access to the Hospice have been discussed with the Hospice team. The new CEO for Pilgrims Hospices is currently working on the Hospices' five year strategy. The Divisional Head of Nursing for Specialist Services is meeting with her soon to ensure that the Hospice Strategy aligns with our Trust Clinical Strategy and short term End of Life Strategy.

Since these events occurred, the Ward have received feedback from another family who described the end of life care their mother. They praise the care in the A&E, through the Winter Pressures Ward up to Cambridge J. Their experience was one of professionalism and compassion by all staff.

### Summary

This is the story of Diana, a woman in her forties who was admitted on a Friday to Cambridge J Ward for end of life care. The story is told by Coleen Kingston, Diana's sister, and Debbie Brown, Diana's cousin. Using Emotional Touchpoints methodology the family described a pathway of care that did not appear to be wrapped around the patient. There were issues with staff appearing disempowered and also dismissive of Diana's nursing care needs. They also discuss the difficulty in

referring someone for Hospice care out of hours. The family felt very strongly that the Ward needed to learn from their experience and met with them to share their feelings. This story is presented as a DVD for the purposes of learning for the Trust.

**Acknowledgements**

To Coleen and Debbie for their courage and generosity in sharing their story;

To Phil Higgs, Matron for making and editing the film;

To Andy Schofield, Senior Matron for composing and providing the soundtrack.

