‘Family’s Voice’
 improving communication during end of life care.

Trust Member Event

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Nurse Consultant in Palliative Care
12th January 2013
Overview

Making a difference
Results from the year research
Results since the research
Combined results
Family’s Voice in community
Challengers/ongoing research
Making a difference

We are trying to deliver a principle of palliative care: **open and sensitive communication in end of life care** across all adult wards and community settings.

What I would like to show you is what we have achieved so far......
The problem in practice

- The experience of end of life care leaves an impact on informal carers.
- Informal carers should have a role that involves decision-making and their needs should be regularly addressed.
- In acute trusts over half of complaints about care relate to care of the dying.

*The End of Life Strategy (2008)*
The problem in practice

- Professionals lack skills and competencies
- Inability to recognise when someone is dying, communicate inadequately
- Uncertainty about how to deliver the best care
- Complaints mainly: poor communication, lack of basic comfort, privacy and psychological support.

Health care commission
A good death

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

*The End of Life Strategy (2008)*
Objectives of the research

- To develop engagement and collaborative practice between health professionals and relatives/carers.
- To empower relatives/carers to deal with specific perceived difficulties.
- To better prepare and involve relatives/carers in end of life care.
- To provide quantifiable data from a relative/carers’ perspective on the quality of care achieved in the last days of life.
- To contribute to the effective delivery of the end of life pathway (LCP) in an acute setting.
The diary
Research Findings (Mar 2011-Feb 2012)

- Study period March 2011 February 2012
- 561 patients were started on the LCP pathway
- 35% (195) of these were offered the diary
- 42% at North Tees
- 24% at Hartlepool
- 28% (55) did not complete the diary
- 72% (140) completed the diary
- 60% (84) made qualitative comments
- Average score of satisfaction (27/30)
195 patients
Uncompleted diaries 55
Daily entries 348
Avg. days 2.49
26.7 Avg. daily score

Scores below 25: 20.7% (72)
Scores of 25-29: 37.5% (200)
Scored 30 (maximum): 21.3% (74)
No score: 0.6% (2)

Average change in scores (first day vs. final day)

- Pain: 0.14
- Nausea: 0.26
- Calmness: 0.14
- Breathing: 0.12
- Staff with patient: 0.14
- Staff with carer: 0.07
## Ward Stats - Carer's diary

**Start date:** 01-Mar-2011  
**End date:** 01-Mar-2012

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<th>MaxDays</th>
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*13 March 2012*
Initial Research findings

- All wards used the diary over the year
- All wards over the 12 month period scored an average 90% satisfaction
- The research identified who was classed as ‘Carer’
- Questions needed alteration
- The revised diary gives ownership to the family member and a commitment to addressed the issues they have been highlighted.
- The diary to be known as the ‘Family’s Voice’.
- There is a need for further research to test reliability /validity/ value
Can we assume that the research indicates the following?

When family are invited to use the diary 72.9% will use it. They make a broad range of comments. They rate the care and staff highly. They are given a voice at a time of loss. It improves communication. In the year of the research there were no complaints related to 561 patients on the pathway. It is a challenge to the culture of wards and specialities.
Key research issues

• Further work is needed on the precision, validity and reliability of the communication tool.
• Low numbers can not generalise
• Further research required on the experience of carers using the tool and the impact on health professionals engaging in the process
• It is not retrospective but real time engagement.
• Need more evidence to determine the impact on bereavement.
• Unconvinced all carers are offered a diary all the time
Core Themes (140/84)

Respect for privacy (2 comments - 1 families)
Completion of the diary (26 comments - 26 families)
Negative staff services (10 comments - 10 families)
Positive staff services (63 comments - 42 families)
Suggestions for practice (15 comments - 14 families)
Negative communication (7 comments - 5 families)
Pain and symptom control (13 comments - 11 families)
Miscellaneous (12 comments - 11 families)
Respect for privacy

(263) Consideration should have been shown outside the room it was very noisy.

(263) We have spent 96 hours at Mum’s bedside- somewhere to lie down for a short while would have been helpful.

(176) I would like to see my mum wearing her own nighties and bed socks.
Completion of diary

(189) It is very easy to complete the diary. It is helpful to know that so much is being done to make my relative comfortable. I did not find completing the diary distressing at all.

(194) It is easy to complete.

(238) It has been very easy to fill this diary.

(204) Quite therapeutic-able to look back on the day objectively and record thoughts.

(241) It was easy reflecting on mam’s condition at the end of the day.
Negative staff services

(71) It would have been appreciated if we had the same care and attention over the past couple of days.

(83) Not sufficient staff on duty to be available when needed.

(235) Certain member of staff could do with training about how to talk to people.

(72) We appreciate EAU is a very busy place but some staff seem indifferent when approached-others friendly and helpful but twenty minutes for a bed pan is not good enough!
Positive staff services

(87) Nothing more could have been done for mum. Heart felt thanks to everybody.

(94) I feel my brother …..has been given excellent care

(229) Staff were brilliant as always

(230) They have done everything and more and we thank them all

(216) I am delighted with the standard of care given to my husband.
Suggestions for practice

(249) A cd player in the room to allow relatives to play music.

(70) Family should not have to pay for parking while family members on the end of life pathway.

(196) A more comfortable mattress quicker.

(146) I’m happy with the refreshments that have been offered to me and my family but it would be better if there was somewhere to sleep.

(235) More advice could be given on end of life care and what this care entails.
Negative communication

(263) Not being told of deterioration until I rang to enquire.
(181) The doctor I spoke to contradicted himself from one day to the next.
(142) My only comment is why tell an anxious man he is dying in the last days to make his life more traumatic.
(236) Our relative (husband/father) had a high temperature. Some staff felt he should be given paracetamol. Others felt he shouldn’t because he was on the pathway.
(72) We were only given detailed information about relative’s condition on the 4th day when she deteriorated.
Pain and comfort control

(92) Pain assisted with breakthrough.

(156) Appeared agitated and crying in pain. Struggled with breathing. Staff helped xx

(204) After talking with the registra re: palliative care-adequate analgesia was given as the patient required.

(233) Mam was in pain and distressed earlier today 9ish but once the pain relief and relaxant kicked in she settled down. Staff have been excellent.

(246) Pharmacy response to drug requirements is inadequate. Nursing staff have done all they can to secure comfort despite slow response from pharmacy.
Miscellaneous

(92) Mam’s birthday today. Very sad day.
(166) Put a catheter in several days earlier
(218) Breathing none of the time. This is due to Chenyne-stoking style of breathing.
(116) No. Nursing home asked for Nana to go back. I requested that she stay here as I have confidence in this hospital and the staff.
Between March-Dec 2012
(10 months)

• 179 family members were offered the diary
• 55 (31%) did not complete the diary
• 124 (69%) completed the diary
• 71 (57%) made qualitative comments
• Average score of satisfaction (27/30)
Combined results March 2011-Dec 2012 (22 months)

• 374 family members were offered the diary
• 110 (29%) did not complete the diary
• 264 (71%) completed the diary
• 156 (59%) individuals made comments
• 305 individuals comments
• Average score of satisfaction (27/30)
Is this what relatives think of the care?

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<td>40%</td>
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<td>Feb</td>
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Who completes the diaries and the reason for its new name?

• 50 unknown
• 28 daughters
• 18 sons
• 8 wife
• 3 husbands
• 5 brothers
• 1 cousins
• 1 sister
• 1 niece

• 1 granddaughters
• 1 Step daughter
• 1 Step son
• Partner
• Niece
• Nephew
• Sister-in-law
• Sister
• Friend

ACE Committee
There is a range of evidence (Stephen et al 2006) that the way those who have been bereaved experience the events around the time of death will influence the trajectory of their grief journey. Where health services get it right, showing empathy and providing good quality care, bereaved people are supported to accept death, and move into the grieving process as a natural progression. Conversely if the health services get it wrong, then bereaved people may experience additional distress, and that distress will interfere with their successful transition through the grieving process, with implications for them, those around them and for the social economy of the nation.

*Shaping bereavement care a framework for action for bereavement care in NHSScotland (2011).*
Family’s Voice in the Community

small numbers
Conclusion

Nursing Times April July 2012 article:
‘The Relatives/carers diary is an innovative tool for the acute hospital setting that promotes communication between family and carers in real time by the dying patient’s bedside. We believe it can contribute to a good death. It is an ongoing continuous evaluation of the quality of care by families.'
References

- Shaping Bereavement Care a framework for action for bereavement care in NHSScotland (2011)