

CONSULTATION ON IMPROVING DIGNITY IN CARE

SUBMISSION FROM THE KING'S FUND TO THE PARTNERSHIP ON DIGNITY IN CARE (AGE UK, NHS CONFEDERATION AND LOCAL GOVERNMENT GROUP)

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1. Introduction

1.1 The King's Fund seeks to understand how the health system in England can be improved. Using that insight, we work with individuals and organisations to shape policy, transform services and bring about behaviour change. This submission draws on the work of two King's Fund programmes: The Point of Care, launched in 2007, and Enhancing the Healing Environment (EHE), launched in 2000 by HRH The Prince of Wales, President of The King's Fund.

1.2 The scope of the Commission's work is wide and there is a wealth of evidence and experience that others will bring to it. Here we aim to draw your attention to insights, argument and evidence that we believe are original or unique to The King's Fund programmes and may not be submitted by others. The focus of the submission is hospitals only because neither of the two programmes works with nursing or residential care homes.

The Point of Care aims to improve patients' experience of care and to support staff to provide the sort of care that they would like for themselves or their families. The programme, which combines research with practical action and evaluation, has published widely on patient-centred and compassionate care.^{1,2} It is currently leading the practical testing, implementation and evaluation of evidence-based efforts to improve the experiences of patients and staff in 15 acute hospitals in England (for a complete account of the programme and access to publications see: www.kingsfund.org.uk/pointofcare).

Enhancing the Healing Environment encourages and enables local teams, led by clinical staff, to work in partnership with service users in order to improve the environment in which they deliver care. The bulk of its work has been with NHS trusts and hospices. See www.kingsfund.org.uk/ehe

2. Background: defining dignity and patient-centred care

2.1 It is useful to begin with a discussion about language and definitions. Language is important in organisations, especially in relation to care. The language the health service uses to talk about patients' experience of care, including references to dignity, is problematic.

2.2 The Point of Care asked a sample of managers, health professionals and other staff in four acute trusts to give us their views on the common terms used in the media, in the academic literature and in professional practice to describe 'good' care.³ We found that most people struggled to define good care, and that almost universally, our

¹ Goodrich J, Cornwell J (2008). *Seeing the Person in the Patient: Point of Care review paper*. London: The King's Fund.

² Cornwell J, Firth-Cozens (2009). *Enabling Compassionate Care in Acute Hospital Settings* [online]. The King's Fund website. Available at: www.kingsfund.org.uk/publications/articles/compassionate_care.html

³ Goodrich J (2009). 'Exploring the wide range of terminology used to describe care that is patient-centred'. *Nursing Times*, 19 May .

respondents said it was not something they talked about with their colleagues. For them, good care was not an abstract concept, it was either an attitude or a narrative about putting yourself in the patient’s shoes. Reactions to many of the standard terms – patient-centred care; basic care; personalised care; relationship-centred care – were mixed. They appealed to some people not to others; some thought they were buzz words or words managers might use, not the words they would use themselves.

2.3 As a rule, our informants said they preferred ordinary human words to describe good care, words such as respect, dignity, kind, understanding, friendly, welcoming, warm and so on. But it is also important to recognise that in hospital, the term ‘dignity’ of care has primarily been associated with nursing; it may not be a term that doctors, other health professionals and support staff relate to immediately.

2.4 The concept of ‘patient centred’ may not mean much colloquially, but there are two established, evidence-based definitions that are recognised internationally. Both define patient-centred care as multidimensional (see Box 1 definitions of patient-centred care).

Box 1 Definitions of patient-centred care	
Institute of Medicine ⁴	Picker Institute ⁵
Compassion, empathy and responsiveness to needs, values and expressed preferences	Involvement in decisions and respect for preferences
Co-ordination and integration	Continuity of care and smooth transitions
Information, communication and education	Clear, comprehensible information and support for self-care
Physical comfort	Attention to physical and environmental needs
Emotional support, relieving fear and anxiety	Emotional support, empathy and respect
Involvement of family and friends	Involvement of, and support for, family and carers
	Effective treatment delivered by trusted professionals
	Fast access to reliable health advice

2.5 The important point to note is that dignity is a product of patient-centred care. Patient-centred care is both about ‘*what*’ happens to patients – the process steps and the transactions that take place between patients and health care staff - and ‘*how*’ it happens – the tone, manner, language and human qualities brought to bear in the interactions between, in this case, older people and employed staff. Both the *transactional* and the *relational* aspects of care are important in determining the quality of the experience from the perspective of patients and their families; in the same way, the effectiveness of the clinical treatment and care and how care is delivered to patients all impact on the person’s dignity.

2.6 Dignity is often thought of in a reductionist way as a concern for privacy, respect for modesty, respect for what the patient wants to be called, or the responsiveness of nurses to a call for help. These are important, but the Point of Care programme takes

⁴ Institute of Medicine (2001). *Crossing the Quality Chasm: A new health system for the 21st Century*. Washington DC: National Academy Press.

⁵ www.pickereurope.org

the position that it is the totality of the patient's experience, including the quality of the physical environment, that shapes the dignity of care, because the dignity of the person is intimately connected to her identity and sense of self. The dignity of the person can be undermined by both illness and disability and poor care. Chochinov talks about dignity as being integral to 'personhood' and about 'dignity-conserving care,' which is dependent on attitudes, behaviours, compassion, and dialogue (ie, communication).⁶

3. The systemic causes of poor care

3.1 The Commission has asked three questions (Questions 2, 3 and 4) about the root causes of the failure to deliver basic aspects of care in hospital and to provide appropriate emotional and psychological support and the impediments to appropriate communication with individuals and families, and one (Question 7) about the tools for improving the quality of care for older people. We will reply to the questions about causes together because we think they share the same roots and because it is helpful to try to understand the systemic causes of these very complex problems.

Question 2: What in your opinion are the root causes of why some hospitals and/or care homes fail to deliver basic aspects of care and meet the needs of older people?

Question 3: What in your opinion are the main factors that contribute to the failure of some hospitals/and or care homes to provide appropriate emotional and psychological support to older people?

Question 4: What in your opinion are the main factors that inhibit appropriate communication with individuals and their families?

Systemic factors that underlie the quality and dignity of the care provided to older patients in hospital include the following.

3.2 *The massive increases in the volumes of activity in both planned and emergency care.* In England, over the past 25 years, the number of hospital admissions and discharges has doubled.⁷ There are about 20 million accident and emergency (A&E) attendances a year; roughly one person in three visits an A&E department at least once a year. Between 2002/3 and 2005/6 alone new attendances rose by more than 37 per cent, or 4.8 million attendances (total outpatient attendances have risen since the mid-1990s by 6 million (15 per cent)).⁸

3.3. *The trend in NHS trusts towards larger institutions and staff establishments.* Between 1999 and 2005, the number of hospital consultants increased by 38 per cent; between 1999 and 2004, the full-time equivalent figures for nurses and allied health professionals rose by 21 per cent and 23 per cent respectively. Non-medical NHS staff, including managers, porters and administrative staff, traditionally account for about half of all personnel in the NHS. Between 1996 and 2006, the number of non-medical staff increased by 26 per cent. This growth in size and staff numbers, along with the use of new technology and the increased pace of organisational life, have had knock-on effects on relationships between individuals and departments. On the one hand it has never

⁶ Chochinov H (2007). 'Dignity and the essence of medicine: the A B C and D of dignity conserving care'. *British Medical Journal*, vol 335, pp184-7

⁷ Tallis R(2004). *Hippocratic oaths: medicine and its discontents*. London: Atlantic.

⁸ Wanless D, Appleby J, Harrison A, Patel D (2007). *Our future health secured? A review of NHS funding and performance*. London: The King's Fund.

been so easy to share information. On the other, staff mourn the loss of personal relationships, face- to-face contact, corridor conversations and meetings in the doctors' cafeteria.⁹

3.4 Fragmentation and discontinuities in relationship and care. The increasing specialisation in medicine, nursing and the allied health professions, in the context of the continuous striving for greater efficiency, has reduced contact time between individual patients and individual members of staff. Since 1998/9 the average length of stay has fallen by more than 20 per cent. Patients are older, the burden of morbidity is higher and more complex and they are discharged sooner. More people, in more specialties and departments, are involved in looking after the same patient. The typical inpatient day is increasingly broken up; patients spend less time on their own ward and more time being transported around the hospital to investigations and treatments.

3.5 Loss of empathy and compassion. Stress and related burnout affect the ability of staff to provide high-quality care¹⁰. There is a clear relationship between the wellbeing of staff and patients' wellbeing, with staff reporting that how they feel affects how they care for patients.¹¹ Self-reported stress of health service staff in general is considerably greater than in the general working population - around 18 per cent of the British workforce suffer symptoms above the threshold levels on the GHQ compared to an average of 28 per cent for health service staff – with some groups - nurses, doctors and managers – being particularly at risk.¹²

3.6 Failure to tackle the causes of stress. The causes of stress and burnout can be identified at the level of the individual, the team and the organisation.² Depression levels are high.

- Depression and high stress affect the performance of staff in a variety of ways. With depression in particular, people withdraw, perhaps for their own emotional protection, and the uniforms, procedures and targets of modern health care provide barriers to retreat behind.¹³ Burnout is similar to stress, consisting of three key areas of a lowered sense of personal effectiveness, emotional exhaustion, and depersonalisation - which is the area most likely to limit compassion or, worse, to produce cruelty in dealings with patients.
- Studies have shown that members of good teams have lower levels of stress.¹⁴ Although most health service staff see themselves as working in teams, data from the national staff surveys show that a large proportion of them work in 'pseudo-teams.'
- The job-related causes of stress and burnout at work - both in health service jobs and beyond – are manifold, but the known principal causes are: high workload, time pressures, low autonomy and participation in decision-making, role conflict, lack of social support, and lack of feedback. Performance targets put pressures on staff that may not always be compatible with good care. Those that concern quality are sometimes performance managed in ways that create stress for staff.

⁹ NHS Confederation and Joint Medical Consultative Council (2007). *A Clinical Vision of a Reformed NHS*. London: NHS Confederation

¹⁰ Maben J (2008). 'The sustainability of ideals, values and the nursing mandate: evidence from a longitudinal qualitative study'. *Nursing Inquiry*, vol 14, no 2.

¹¹ Boorman S (2009). *NHS Health and Well-being Review: Interim Report and Final Report*. London: Department of Health

¹² Wall TD, Bolden RI, Borrill CS, Carter AJ, Golya DA, Hardy GE, Haynes CE, Rick JE, Shapiro DA, West MA (1997). 'Minor psychiatric disorder in NHS trust staff: occupational and gender differences'. *British Journal of Psychiatry*, vol 171, pp 519-523.

¹³ Menzies-Lyth I (1988). *Containing Anxiety in Institution*. London: Free Association Press.

¹⁴ Carter AJ, West M (1999). 'Sharing the burden: teamwork in health care settings' in Firth-Cozens J, Payne RL (eds), *Stress in Health Professionals*, pp 191–202. Chichester: Wiley.

This is likely to redirect staff away from providing compassionate care towards other more mechanical targets. Factors identified in health care most frequently are high patient contact and contact with patients with severe problems.¹⁵ One study found that working on overcrowded wards (bed occupancy of 10 per cent or more above the recommended top limit for six months) was linked to antidepressant use by doctors and nurses, and the higher the bed occupancy of the ward, the more likely the use of antidepressants.¹⁶ Moreover, higher patient workload was found, with burnout, to link to compassion fatigue.¹⁷

3.7 *Care is increasingly driven by protocol and reliant on technology.* While this has improved many aspects of its effectiveness, compassion can sometimes be forgotten. It may be that, when the protocol or technology is absorbed into more automatic practice, staff are able to adhere to it without affecting their interactions with patients. However, until then, the protocol or the use of technology is likely to take up too much mental processing to enable the type of person-person dialogue and recognition necessary for compassion.

3.8 *The physical tasks of washing patients, helping to make them comfortable, providing personal care, and helping them with eating and drinking all take time and are increasingly delegated to staff with the least qualifications and lowest status in the hierarchy.* By implication, spending time with patients is devalued, so that nurses say they are made to feel guilty if they do this when there are 'more important' things to be done.

3.9 *Risk management regimes and their unintended consequences.* Win Tadd and others' recent report eloquently documents the impact on the quality of care delivered to older people in hospital of risk management decisions that seem to make sense when they are discussed at board level¹⁸ ¹⁹ but translate at ward level into care that restricts patients' mobility and autonomy. Similarly, risk management regimes that for sound safety reasons require two members of staff to sign off pain control can result in unacceptable delays in meeting patients' urgent needs. If two members of staff are not in the area at the same time, patients can be left to suffer for long periods in intense pain.

¹⁵ Schaufeli W (1999). 'Burnout' in Firth-Cozens J, Payne RL (eds), *Stress in Health Professionals*, pp 17–32. Chichester: Wiley.

¹⁶ Virtanen M Pentti J, Vahtera J, Ferrie JE, Stansfeld SA, Helenius H, Elovainio M, Honkonen T, Terho K, Oksanen T, Kivimäki M (2008). 'Overcrowding in hospital wards as a predictor of antidepressant treatment among hospital staff'. *American Journal of Psychiatry*, vol 165, pp 1482–6.

¹⁷ Udipi S, Veach PM, Kao J, LeRoy BS (2008). 'The psychic costs of empathic engagement: personal and demographic predictors of genetic counsellor compassion fatigue'. *Journal of Genetic Counselling*, vol 17, pp 459–71.

¹⁸ Tadd W, Hillman A, Calnan S, Calnan M, Bayer T, Read S (2011). *Dignity in Practice: An exploration of the care of older adults in acute NHS trusts*. London: Department of Health.

¹⁹ Cornwell J (2011). 'Are hospitals any place for the elderly?' Blog, 7 June. Available at: www.kingsfund.org.uk/current_projects/the_point_of_care/

4. Improving the dignity of care

Question 7: What tools exist for improving the quality of care provided for older people?

We set out below a number of approaches to improving the dignity of care to which The King's Fund contributes. The first two - leadership and efforts to strengthen caring relationships – are interventions at the level of the organisation as a whole; the others are interventions that work at the level of the team or clinical microsystem and which can spread horizontally from team to team or, with good leadership, across the organisation as a whole.

Leadership

4.1 In a study for the Picker Institute and Commonwealth Fund, Shaller found that hospitals in the United States with a reputation for service excellence, which he calls 'patient-centred organisations', have seven success factors in common.²⁰ In these organisations, senior leaders feel directly responsible for the fate of staff and patients, and take their role in determining the quality of care and patients' experience seriously. They demonstrate clear leadership where the strategic vision for patient-centred care is clearly communicated.

- They actively inform themselves about the quality of service that is on offer, visiting clinical units and wards, talking to staff and patients in lifts and corridors and clinics.
- They receive training in patient safety and quality improvement and devote time at board and committee meetings to listening to and learning lessons from individual case reviews and groups of patients and families.
- They develop and resource strategies for improving quality of care and use communication within the organisation to make sure staff understand the strategic goals and their role in achieving them.
- They invite patients and families to participate in hospital committees and decision-making structures at all levels.
- They use measures for service quality and have a variety of sources of information about patients' experience including mystery shoppers, patient surveys, open days, focused discussions with groups, and telephone surveys.
- They are innovative in their use of technology to support patients and families with information.
They provide a supportive work environment for care-givers: Shaller describes this as '*care for the caregivers through a supportive work environment thattreats them with the same dignity and respect that they are expected to show patients and families*'.
- They pay a great deal of attention to the physical environment.

4.2 Leaders need to make it clear in their quality strategies that the quality of care patients receive, the way in which they are treated as human beings is fundamental and must always be a top priority, equal in importance to patient safety and clinical effectiveness. The attention senior managers and boards must give to achieving financial balance and meeting performance targets deeply affects the priorities and behaviours of

²⁰ Shaller D (2007). *Patient-Centered Care: What does it take?* Oxford: Picker Institute and The Commonwealth Fund.

staff throughout the hospital. If finance and productivity are perceived as being the only things that matter it can have profound negative effects on the way staff feel about the value placed on their work as care-givers. Senior leaders – both non-executives and executives – must make sure they keep themselves informed about and sensitive to what is happening at the front line. There is a host of ways in which they can do this: from making sure the board regularly hears patients' and carers' of stories; to deep dives into one or more complaints; through to walking the floor and talking informally to patients, visitors and staff.

4.3 The board needs to be constantly vigilant and it needs to receive reports that measure patients' experience. Dr Foster with The Point of Care has published detailed guidance on measures of experience; methods of collecting data on patients' experience; and how to analyse and report the data. The key is to find ways of combining sound quantitative data with qualitative data and stories that bring the issues under discussion alive for everyone.²¹

4.4 The King's Fund has published guidance for executive nurses to bring the quality of patient care to the attention of trust boards.²² The crucial importance of leadership and management to quality of care in a time of change was emphasised in the responses to The King's Fund's 2011 Commission on Leadership and Management in the NHS.²³

Efforts to strengthen caring relationships in hospital

4.5 Schwartz Rounds® Developed by the Boston-based Schwartz Center for Compassionate Care,²⁴ Schwartz Center Rounds ('Rounds') are a multidisciplinary forum designed for staff from across the hospital to come together once a month to discuss the non-clinical aspect of caring for patients – that is, the emotional and social challenges associated with their jobs. The underlying theoretical foundation for Rounds, as first articulated by the Center's namesake, Kenneth B Schwartz, during his experience of treatment for an aggressive form of terminal lung cancer,²⁵ was that the compassion shown by staff to patients can make all the difference to a patient's experience of care, but that in order to provide that compassion, staff must, in turn, feel supported in their work. Rounds are designed to provide this support, giving staff an opportunity to reflect on their experiences of delivering care, including both its rewards and frustrations – on what the Schwartz Center calls the 'human dimension of medicine'.²⁶ Rounds aim to improve relationships and communication both between staff and patients and, within the hospital hierarchy, among teams and staff.

4.5.1 Rounds have been running in hospitals in the United States for more than 14 years now, steadily expanding from the Northeast, where they were first piloted at Massachusetts General Hospital in Boston, to more than 200 sites spread throughout the

²¹ (<http://drfosterintelligence.co.uk/wp-content/uploads/2011/06/Intelligent-Board-2010.pdf>).

²² Machell S, Gough P, Steward K (2009). *From Ward to Board: Identifying good practice in the business of caring*. London: The King's Fund. Available at: www.kingsfund.org.uk/publications

²³ The King's Fund (2011). *The Future of Leadership and Management in the NHS: No more heroes*. Report from The King's Fund Commission on Leadership and Management in the NHS. London: The King's Fund. Available at: www.kingsfund.org.uk/publications

²⁴ www.theschwartzcenter.org

²⁵ Schwartz KB (1995). 'A patient's story'. *The Boston Globe Magazine*, 16 July. Available from www.theschwartzcenter.org/ViewPage.aspx?pagelid=50

²⁶ <http://www.theschwartzcenter.org/ViewPage.aspx?pagelid=20>

country, including a small number of nursing homes, community health centres and outpatient practices. In 2006–2007, the Schwartz Center commissioned research to evaluate the impact Rounds had on participating staff, on their beliefs about patient care, on teamwork, on staff perceptions of their levels of stress and support in the workplace, and on changes in institutional practices and policies.²⁷ In their statistical analysis of this research,²⁸ Lown and Manning found that following Rounds:

- participants reported better teamwork and perceived themselves as experiencing less stress
- Rounds enhanced participants' 'likelihood of attending to psychosocial and emotional aspects of care'
- Rounds 'enhanced their beliefs about the importance of empathy'
- the impact of Rounds on these outcomes increased with the number of Rounds participants attended.

The study begins to make the case for the efficacy of Rounds in helping staff to feel supported and in improving relationships among staff and with their patients.

4.5.2 In 2009 The Point of Care signed an agreement with the Schwartz Center to pilot Rounds in the UK. The pilot period for the Rounds was one year - between October 2009 and October 2010 and Rounds were implemented in two hospitals: the Royal Free Hospital and Cheltenham Hospital. Very often the Rounds raise issues for discussion which are about caring for difficult or challenging patients and their families - and have included Rounds where the issues of caring for frail elderly patients have been explored.

4.5.3 We have evaluated the pilot Rounds in England to see whether Rounds could transfer to this country and whether they are achieving a similar impact to that in the States. The evaluation shows that the Rounds have successfully transferred to England, are firmly established with support from the top of the organisations, have demonstrated a need, and are greatly valued by staff who take part.

I have really enjoyed them as they have helped me realise I am not alone! We all do a difficult job as well as we can.

(Rounds participant)

People are taking the concerns of staff seriously – opening ourselves to hear what people are struggling with. And in the context of mid-Staffs – staff are expressing things and the Rounds are a sign that it is safe to speak. It is all very well to say we have an open culture, but this demonstrates that value.

(Trust board member and participant)

4.5.4 Rounds are now running at six sites:

- Cheltenham Hospital
- Gloucestershire Royal Hospital

²⁷ Goodman Research Group(2008). *Schwartz Center Rounds Evaluation Report*. Cambridge, MA: Goodman Research Group.

²⁸ Lown BA, Manning MA (2010). 'The Schwartz Center Rounds: Evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Academic Medicine*, vol 85, pp 1073–81.

- The Royal Brompton Hospital
- Harefield Hospital
- Stoke Mandeville Spinal Injuries Unit

Six more sites are planning to start Rounds before the end of 2011.

See evaluation report at

www.kingsfund.org.uk/schwartzcenterrounds

4.6 A method for improving the quality of patients' experience that brings staff and patients together as equals: Experience based co-design

4.6.1 Experience-based co-design (EBCD) is an approach to service improvement whereby patients and staff work together to identify areas for improvement and then work together to make changes.²⁹ Briefly, the approach consists of several steps:

- patients talk about their experience of going through a whole pathway of care, and are filmed as they speak
- staff are interviewed about their experience of providing the service
- patients meet together to watch the film and identify common themes arising from their stories, and to map their 'journey' punctuating it with emotional 'touchpoints' and words to describe those moments (how they felt at particular moments)
- staff meet together and identify common themes.

The next step is crucial to bringing about change:

- an event is held where the films are watched by patients and staff together. Together they identify where changes need to be made, and form into working groups to tackle particular aspects of care.

It seems that bringing staff into contact with their own patients seems to have a catalytic effect. The groups continue to meet over the next 6 to 12 months.

4.6.2 The Point of Care worked with King's Partners' Integrated Cancer Centre (Guy's and St Thomas' and King's College hospitals in London), using this approach to improve breast cancer and lung cancer services. It was clear that many of the emotional 'touchpoints' were very often to do with whether patients felt their care was dignified or undignified.

4.6.3 The patients' stories draw attention to the detail that matters to patients and families. Without their input staff don't know what these are. In our project, for example, changes have been made in many areas of the service including surgery, day surgery, the outpatient clinic systems, communications about appointments and information for patients - and these changes are both *transactional* and *relational*. In many cases only small changes need to be made to make the difference between undignified to dignified care. One patient said that the way she was treated made her feel 'like a piece of meat'. After improvements were made to day surgery, for example, one patient commented

²⁹ Bate P, Robert G (2007). *Bringing User Experience to Healthcare Improvement*. Oxford: Radcliffe.

The whole design of the day surgery unit changed and the whole passage through the day became much more patient focussed as opposed to how easy it would be for the nurses. It just looked like it would be a much more comfortable, comforting, day than the one I had.

4.6.4 In itself, the EBCD approach models equal relationships and helps to restore patients' dignity and to remind staff of their personhood.

An evaluation of the project can be found at:

www.kingsfund.org.uk/ebcdreport

We have produced an **online toolkit** to help others wanting to use this approach to improve patients' experience of care, based on what we learnt in our project. It takes you through the approach step by step and is illustrated by film clips of patients or staff talking.

www.kingsfund.org.uk/ebcd

4.7 A practical method for making sure patients' needs are attended to regularly on acute wards: intentional nurse rounding

4.7.1 Intentional rounding is a systematic, proactive approach to providing fundamental patient care. The basic premise is this: frontline ward/unit/care home staff check on each patient/resident once an hour, asking specific questions and assessing the care environment. During intentional rounding visits, nurses use key words to open and close the visit, designed to reassure the patient and build confidence in them that their individual care needs will be met.

The 'round' involves performing key scheduled tasks, and addressing:

- pain
- position
- personal needs
- toileting needs.

4.7.2 In addition, nurses conduct an environmental assessment to minimise the risk of falling. The nurse will ensure the call bell is within easy reach and advise patients to 'call don't fall'. They will also check that everything patients need (water, tissues, walking aids) is within their reach. The nurse will actively encourage fluids and ensure the patient's water jug is filled and within reach. The most important thing is that the patients' basic care needs are met, they have confidence in their nurse/team and they know when the nurse will be back.

Origins of rounding

4.7.3 The concept of systematically 'rounding' on patients to ensure their basic care needs are met is not new. For many years nurses carried out 'back' rounds where particular attention was paid to patients' skin to avoid skin breakdown. With the advent of the holistic nursing care approach and the requirement for more technical skills, trained nurses started to move further away from the bedside and began to view such task-oriented processes as archaic, preferring to focus on the provision of 'individualised' care.³⁰

³⁰ Fitzsimons B, Bartley A, Cornwell J (2011). 'Intentional rounding: its role in supporting essential nursing care'. *Nursing Times*, vol 107, no 27, pp 18–21.

4.7.4 However, over the ensuing years the number of complaints about basic nursing care increased, and there have been high-profile, highly critical reports about the standards of nursing care which suggest the need to address patients' fundamental care needs in a more reliable and systematic manner. Intentional rounding is a way of achieving this. It does not replace 'individualised care', rounding merely helps to structure the workload of nursing and ensure that all patients receive attention on a regular basis.

4.7.5 The Studer group, a US management consultancy, developed a structured process for rounding and identified eight specific behaviours that would address fundamental care needs. A key aim of the process was to help patients build confidence in their carers. Owensboro Medical Healthcare system in Kentucky coined the term 'intentional rounding' or rounding with intent, placing a focus on the nurse/caregiver having some clear aim/purpose for undertaking the round.

4.7.6 The King's Fund and Health Foundation's Hospital Pathways Programme (HPP) has introduced intentional rounding as a way of improving experience for both patients and staff. Please see separate submission (appendix) from the HPP for a case study illustrating the intervention at Northumbria health care.

4.8 Improving the physical environment

4.8.1 Through the Enhancing the Healing Environment programme at The King's Fund more than 230 teams, mainly from NHS trusts and hospices, have delivered significant improvements to the care environment. Many of the projects have had an impact on dignity,³¹ but this submission focuses on two areas that are often neglected – transforming the environment to promote dignity and independence for people with dementia and dignity at the end of life for dying people and their families and friends.

4.8.2 The dignity of people with dementia is improved, as is that of other people in a care setting, if they can find their way to the toilet and their own bed space/room. There is emerging evidence from the EHE programme that relatively inexpensive changes to the physical environment of care can have a really positive impact. In particular, simple interventions such as ensuring the toilet doors are a distinctive colour and the toilet seat is of a contrasting colour to the sanitary ware. This enables people to locate the toilet independently and position themselves on it correctly thereby promoting continence, dignity and confidence and reducing agitation and distress. Similarly, using colour and images to differentiate between bed spaces/rooms helps people to find their own bed and personal possessions.

4.8.3 A vital area of care that is often missing from debates on dignity is the impact the care environment can have on the privacy and dignity of dying people and their families and friends. An extensive range of end-of-life care projects have been completed by EHE teams that promote privacy and dignity.³² These include the development of palliative care suites and relatives' rooms. Private spaces for relatives are often overlooked in hospital settings with very distressed people sometimes having to wait in busy corridors or resorting to sleeping in their cars. It is possible to create small spaces where relatives can stay overnight away from the patient's bedside together with a

³¹ Department of Health (2003). *Improving the Patient Experience: Evaluation of The King's Fund's Enhancing the Healing Environment Programme*. London: Department of Health.

³² Waller S, Finn H (2011). *Environments for Care at End of Life. The King's Fund's Enhancing the Healing Environment Programme 2008-2010*. London: The King's Fund.

kitchen and a shower so that they can go to relax and refresh themselves while visiting relatives who are in a critical condition or have died. Links with nature are very important for people at the end of their lives, and gardens can offer a private retreat for quiet reflection for dying people and their families and friends. Well-designed bereavement offices can significantly improve the care of the bereaved, meaning they no longer have to revisit wards where their loved one has died to collect personal belongings and the death certificate. The number of people wishing to view their loved ones in the hospital mortuary appears to be increasing, with many wishing to undertake appropriate religious observances before the deceased leaves the hospital. Mortuary viewing rooms have traditionally not attracted much attention in terms of their design but with thought and care they can offer a private, dignified, sympathetic and tranquil environment for both small and large families.

4.8.4 At its heart Enhancing the Healing Environment is about involving service users – patients, carers and staff – in improving service delivery through environmental redesign. Project teams include patients and carers as equal members, participating fully in the training and development that the programme provides. This involvement ensures that co-design principles are central to project outcomes, in terms of both service and environmental improvement, while developing strong teams who are able to take forward further change to improve the patient experience. For example, prior to their involvement in the Enhancing the Healing Environment programme very few of the staff had had an opportunity to learn about the cognitive and perceptual challenges that are experienced by people with dementia and how the environment can help to mitigate their impact. Also many staff were reluctant to approach palliative care patients or the relatives and the bereaved about service changes. However, once they were approached they had much to contribute.

Further information and photos of projects are available at: www.kingsfund.org.uk/ehe

5 Conclusion

5.1 In summary, the submission has set out some of the systemic problems in hospitals that contribute to poor standards of care and a lack of respect for older, vulnerable patients' dignity. It has drawn attention to the importance of the experience of staff doing the care work and argued that the conditions of work and the levels of depression and stress require serious attention.

5.2 Hospitals with a reputation for delivering high standards of patient centred care pay serious attention to staff development and support. The submission contains examples of the work at The King's Fund on leadership, staff experience, methods for improving patients' experience and the physical environment.

**The King's Fund / Health Foundation Hospital Pathways programme
submission to the Partnership on Dignity in Care**

1. INTRODUCTION

1.1 In partnership with the Health Foundation, The King's Fund Point of Care programmeⁱ has been running an eighteen month hospital collaborative called the Hospital Pathways programme that ends in November 2011. This submission should be read in conjunction with the separate King's Fund submission to the Commission.

1.2 The Health Foundation is an independent charity working to continuously improve the quality of healthcare in the UK. We are here to inspire and create the space for people to make lasting improvements to health services. Working at every level of the system, we aim to develop the technical skills, leadership, capacity and knowledge, and build the will for change, to secure lasting improvements to healthcareⁱⁱ.

1.3 The Hospital Pathways programme aims to demonstrate how the health service can put patients at the centre of care. This joint submission of evidence focuses upon the learning that is relevant to the Commission from the Hospital Pathways programme and aims to explain the approaches being tested.

1.4 We present three case studies from the teams we are working with, to show some of the practical means through which a focus on patients' dignity can be maintained. These case studies arise, in the words of the Dignity in Care Partnership, from "an honest look at the issues... [which means that staff] can properly come up with the right solutions that work on the ground."

2. BACKGROUND

2.1 The Hospital Pathways programme aims to achieve a breakthrough in patient and family experience in two care pathways within each of the participating hospital trusts. The approach focuses on developing patient-centred care alongside strong staff engagement. This relates directly to the Health Foundation's wider aim of transforming the relationship between people who use health services and those who provide themⁱⁱⁱ.

2.2 In practical terms, this means working with five hospital trusts to develop a small number of 'exemplar' hospitals and a group of professional staff and managers who can demonstrate how they have improved patient focus and staff engagement, and then share their expertise.

2.3 The programme gives participating hospitals a unique opportunity to use techniques which are not yet widely used in the NHS to improve both processes of care and staff-patient interactions. It is believed that together these will have a profound effect on how patients and staff experience health care.

2.4 The participating hospitals are working to:

- understand the drivers for quality of care. This will include what 'quality' means to patients
- transform the care of patients in the two care pathways so that it is reliably excellent in terms of safety, clinical effectiveness, patient focus, timeliness and efficiency, as assessed by patients themselves
- build capability, so that lessons from this work can be sustained and spread across a whole hospital
- improve staff engagement and wellbeing, helping in turn to focus the attention of staff on the patients' experience.

2.5 From the patient's point of view, the programme aims to make sure they:

- feel confident that the care they will receive will always be excellent, both clinically and in their own assessment
- participate in their own care at a level they feel confident with, by collaborating with health care professionals
- feel that their care has been designed in a way that acknowledges its place within their broader lives.

2.6 The programme is working with five hospital trusts (Taunton and Somerset NHS Foundation Trust, Salisbury NHS Foundation Trust, Royal Free Hampstead NHS Trust, George Eliot Hospital NHS Trust and Northumbria Healthcare NHS Trust).

3. INITIAL LEARNING RELEVANT TO THE COMMISSION

3.1 It is important to distinguish between dignity in the on-going provision of care, and the efforts to improve it. They are different but both require training and active support from senior staff.

3.2 Patients' dignity can be compromised by a number of things: the illness, health problems or disabilities they face; the procedures involved in delivering care and treatment; and staff attitudes and behaviours. The role of staff is to care for patients when their dignity is compromised and help them cope as well as making sure that they don't inflict further indignities upon them^{iv}.

3.3 Focusing on the totality of the patients' experience, from patients' perspective, is the key starting point for practical work to understand the way in which patients' dignity can be compromised, and therefore how to address these shortcomings.

3.4 Staff, therefore, must receive training and be encouraged and enabled to understand the experience of care from patients' perspective, as well as their own. In our work, we have found a variety of qualitative and quantitative methods useful for capturing patients' experience of care^v. These have included: patients' stories, observation, shadowing patients, comment cards, focus groups and questionnaires.

- 3.5 A clear sense of what dignified care **is** (rather than what it is **not**) helps staff to identify clear objectives for the improvements they wish to make.
- 3.6 Initiatives to promote dignity in care must be multi-professional if they are to reach their potential. Dignity is not simply a nursing issue.
- 3.7 Demonstrable organisation-wide and senior and middle management commitment and support for staff to “put themselves in patients’ shoes” is critical to success. This must be backed up by action and not be tokenistic. Examples we have seen include Boards’ focus on patients’ experience, through, for example, beginning Board meetings with patients’ stories. In addition we have seen examples of Board and executive ‘walks around’, and executive and other senior staff doing occasional shifts on wards to reconnect with staff and the day to day reality of patients’ care.
- 3.8 Senior managers and clinicians need to recognise where the culture of organisations or organisational systems or processes can contribute to a lack of dignity for patients.
- 3.9 Solutions are often low tech / low resource, requiring a change of mindset above all else.
- 3.10 Patients with some cognitive impairment will need particular consideration to protect and promote their dignity. This can involve simple adjustments to the environment, and arrangements for meal times, for example, which help them to navigate the environment and retain their autonomy.
- 3.11 Staff need to be treated with dignity and respect, if they are to deliver compassionate, person-centred care.^{vi}

4. EXAMPLES FROM THE HOSPITAL PATHWAYS PROGRAMME

- 4.1 There follows a description of work in progress at three NHS trusts in England who are participating in the Hospital Pathways programme. *These*

examples come from the teams themselves, and are written from their own perspective.

5. MUSGROVE PARK HOSPITAL, TAUNTON

Approach

On the Dunkery Stroke Unit at Musgrove Park Hospital, we have focussed on patients' and their relatives' and carers' journey of care, asking "What is it like to be a patient at Musgrove who has had a stroke?" We have gained patients' perspective in a number of ways including focus groups inviting patients and relatives to discuss their care experiences, by listening to patients' stories, patient shadowing and actively gaining feedback from patients and relatives on all aspects of their care and treatment.

Our Stroke team joined the Hospital Pathways programme in 2010 and have taken forward a number of improvements. The aspects of care focussed on were identified in partnership with patients as really important and those that would make a significant difference to the experience of stroke patients. In addition to the end of life care, these included ensuring direct admission to the Stroke Unit, personalising discharge and giving a named contact on discharge and focussing on continence care.

End of Life care

End of life care on a busy acute ward was something the team has placed at the forefront of nursing priorities and the whole team being very aware that in this aspect of care there are no second chances to get it right.

5.4 We have introduced the 'Abbey Pain Score' to assess the pain in the cognitively impaired patient on the Liverpool Care Pathway. This allows the team to monitor the pain/discomfort of stroke patients more effectively allowing for those who are not able to express their feelings.

Intentional Rounding

We have introduced intentional rounding on the Stroke unit. Intentional rounding is a systematic, proactive approach to providing fundamental patient care. It is a structured way of regularly checking patients to ensure that they are pain free, comfortable, check skin condition and address any nutritional or toileting needs. This care regime performed for patients every two hours has real benefits for patients. It has been shown to reduce call bell use, be proven in the management of falls and reduce numbers of concerns and complaints that patients may have. It is designed to increase patients' confidence in the care they receive, as an important aspect of the regime is that the nurse will return regularly. A key part of intentional rounding is asking the patient or their relatives if there is anything else that the nurse or member of the team can do for that patient and ensuring that the call bell is within reach and the patient knows how to use it.

Team Working

The core multidisciplinary team meet every week to review progress and agree actions for improvement. Key success factors have included strong and effective clinical leadership from the lead consultant, a highly engaged and committed team and visible support from an executive director to help empower the team and remove blocks to taking improvements forward.

6. NORTHUMBRIA HEALTHCARE

Background

People with dementia and their relatives often report poor experiences of care in general hospital settings, and it is recognised that this is a national problem relating to capacity, knowledge, training and culture on hospital wards.

In Northumberland we recognised the problem some years ago, and were part of a multi disciplinary/multi agency Acute Care and Dementia Working Group. In recognition of this work the group was awarded the regional health and social care award for partnership working in 2010 for their work to improve patient experience. Prior to its involvement in the Hospital Pathways Programme, Northumbria participated in the development of the "This is me" booklet – in collaboration with neighbouring organisations, informal carers and the Alzheimer's Society. This aims to support staff to provide person-

centred care by helping them to get to know the individual and understand their needs, thus providing more personalised care. The Trust participated in the original working group to develop the tool and has taken a measured approach to its implementation within the organisation. Our initial pilot areas were at Wansbeck General Hospital, following a patient journey from emergency admission, to an older persons' ward and then onto a community hospital site. An electronic audit tool was used to gather information about use and demonstrate when successful implementation had been achieved.

Charitable funds were obtained to enable the supply of the "This is me" document across all sites in the organisation and we are currently looking at ways of sustaining a reliable and consistent supply for all wards and departments. Although the work on "This is me" was already underway when the teams joined the Hospital Pathways programme, we decided that while on the programme we would continue to promote the use of this document and evaluate its use.

Participation in the Hospital Pathways Programme

The acute dementia team joined The King's Fund / Health Foundation Hospital Pathways programme in 2010, and has continued to work to improve patients' and families' experience of care, with a particular focus on dignity in care.

We are making improvements to the care we provide to patients with dementia and delirium to ensure that patients are at the centre of their care. This includes the establishment of a person-centred care group and the design and implementation of staff training and development.

The Person Centred Care Group is a multi-professional strategic group who are supporting the delivery of person-centred care in the trust. The group:

- defines and provides appropriate education and training to clinical teams
- challenges current service delivery and suggests new ways of working
- reviews national and local guidance, taking action to implement best practice
- acts as a forum for communication allowing focused debate and the dissemination of ideas, facts and reports to staff

- allows group members to present areas of excellence, projects and recommendations.

Training and Development

As part of its work in the Hospital Pathways programme, we secured funding from NHS North East to develop a training programme for staff. The two-day innovative programme, developed and taught by a team of clinical staff, is aimed at educating all types of staff about the complexities of caring for patients with dementia and delirium; empowering them to make improvements.

Our research department has previously identified the learning needs of hospital staff in relation to managing the confused older patient by means of a two year grounded theory study. We found that, though specific skills are important, the learning needs are underpinned by attitudinal deficiencies, a lack of ownership of this vulnerable group, communication difficulties, a failure to recognise the importance of the carer partnership and deficiencies in person centred care. Importantly, we also found that effective care is compromised by power relationships in the work place, a focus on task based practices and organisational barriers to good care.

Based on these findings, and alongside our work on the Hospital Pathways programme, we designed a bespoke training programme which addressed these learning needs and closed the knowledge and skills gap. The four key components of the programme were:

- an emphasis on inter-professional education to develop relational expertise
- learning from patients and carers in order to challenge the ageist stereotypes of the confused older patient
- focusing ward teams on generating their own practice development plans to directly improve care in their work place
- introducing a system to sustain learning and empower previously disempowered staff.

The impact of the educational initiative has surpassed all of our expectations. As well as the highly positive evaluation of learning, all staff reported an increased confidence in caring for the older confused patient. There was a

marked positive change in attitudes towards confused patients and their carers.

The success of the programme rests on the fact that teams are taken away from the busy ward setting and learn together. As such they have the opportunity to understand each other's roles and understand how together they can provide individualised care for patients with memory problems. These teams have gone on to introduce important changes in their workplace using PDSA (Plan Do Study Act) cycles of change developed during the course.

Initiatives include:

- noise reduction programme
- prompt and organised mealtimes
- early discussing with carers about levels of involvement in care
- introduction of intentional rounding (a structured approach to nursing care on the ward^{vii})
- more frequent and regular cognitive assessments
- introduction of the award winning tool to improve person centred care "This is me".^{viii}
- simple changes to the ward environment including colour schemes, signage and crockery.

6.12 "Learning from patients: Two stories about dementia" which helps staff to understand more about patients with memory difficulties.

7. THE TREAT PROJECT AT THE ROYAL FREE HOSPITAL NHS TRUST

Background

The TREAT (Triaged Rapid Elderly Assessment Team) project, which commenced in September 2010, is a project which the overall aim is to be a responsive and flexible service to older people, and respond rapidly and expertly to their specific needs. One of the key features of the project has been to prevent hospital admission for elderly patients as many of them find it a distressing experience.

Approach

The dignity of the people we treat has always been a driving force within our project, from both within the team and at board level. The Board recognised that to improve the patient experience we need strong leadership and effective team working.

It is often difficult to define what is dignity and dignified care, however it is very easy to define the lack of dignity and people can readily articulate when they have not received dignified care. One of our aims was that the people we treat have a positive experience and we felt this sat comfortably with the concept of dignity. The design and delivery of the TREAT service pathway has enabled and supported us to provide care with compassion, and communicate with patients and carers in a manner that maintains and respects individuals' dignity.

We have successfully implemented the TREAT programme, with our data illustrating a significant number of patients being assessed by the team and supported at home, who would otherwise have been admitted to hospital. (For example, in the first half of 2011, the team saw 395 patients, of whom 70% were discharged). Patients' experience data, with highly positive feedback from patients, suggests dignified care is being delivered. This is supported by qualitative feedback from patients.

We acknowledge that the shared working with our colleagues and departments, such as our emergency department colleagues, radiology department and many others, has and will always impact upon the receipt of dignified care.

The paradox may be that the usual performance driven targets have been criticised in the past for not prioritising compassionate and dignified care, however in the case of TREAT the driving force that is preventing hospital admission, compliments our drive to deliver the care that keeps the patient central in the process and out of hospital.

By being present within A&E, and having our office within the location, has had a significant impact on our team's responsiveness. This responsiveness ensures that patients get the right care at the right time by the right person, in real time.

In conjunction with this we run daily rapid access clinics, which GPs and other allied healthcare professionals may refer into. This means the patients will be seen quickly and any issues or concerns will be addressed immediately, rather than having to wait for a comprehensive geriatric assessment in an out-patients setting. This drive to respond to people quickly and effectively strengthens our principle of person-centred care. Receiving rapid assessment and treatment from a specialist team whose focus is solely upon that group of patients is an improvement on the previous model of having to be seen by at least two doctors prior to referral to a geriatrician. This project has had a positive impact upon patients as evidenced by our routine monitoring of patients' experience of the service.

7.9 Many elderly patients who are taken into A&E feel unhappy about the possibility of being admitted. They welcome the opportunity to be assessed and treated and returned either to their own home or to their nursing / residential home with support. We have been contacting patients 48 hours after their time in A&E and the majority have expressed pleasure at being able to return home and avoid a hospital admission.

8. FUTURE PLANS

8.1 The Hospital Pathways programme will be completed in November 2011 and an evaluation report will be published in the Spring of 2012. The King's Fund Point of Care and the Health Foundation will be embarking on a second phase of this programme, the Patient and Family Centred Care programme, in January 2012, working with 12 NHS trusts.

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ⁱ www.kingsfund.org.uk/pointofcare

ⁱⁱ For further information about the Health Foundation's work to put patients and their families at the heart of care visit: <http://www.health.org.uk/areas-of-work/topics/person-centred-care/>

ⁱⁱⁱ For further information about how the Health Foundation is working to inspire improvement through changing relationships between people and health services visit:

<http://www.health.org.uk/our-approach/our-priorities/changing-relationships/>.

^{iv} For a definition of dignity we refer to Chochinov, H (2007) Dignity and the essence of medicine: the A B C and D of dignity conserving care. *BMJ* 335: 184-187

^v <http://www.kingsfund.org.uk/publications/measures.html>

^{vi} The Boorman review [Department of Health (2009) *NHS Health and Well-being Review: Interim Report*. And Department of Health (2009) *NHS Health and Well-being: Final Report*.] also pointed out the economic costs of staff stress, and urged trusts to be exemplar employers and to implement staff wellbeing strategies.

^{vii} B Fitzsimons, A Bartley, J Cornwell. Intentional rounding: its role in supporting essential care. *Nursing Times* 2011 vol 107, No 27, pp18 - 21

^{viii} http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1010&categoryID=200293