Article

Intelligent kindness: *responding to the needs of vulnerable adults in hospital: improving dementia care*

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We know that up to 40% of people over 75 years admitted to hospital have dementia, and only half have a prior diagnosis.[1] Too often patients with memory problems, and dementia are overlooked – even invisible - and their needs frequently misunderstood. Ignorance costs: a survey published by the Alzheimer's Society in 2009 found that the longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and the individual's physical health; discharge to a care home becomes more likely, and antipsychotic drugs are more likely to be used. In human terms, and financially the costs are huge[2].

As recently as 2011, the National Audit of Dementia Care in Hospital showed a low level of performance across the country, with a wide range of variation. Only 6% of hospitals had a care pathway in place for people with dementia at the time of audit, and only 44% had a pathway in development. Less than 25% of hospital Boards/Trust Executive Boards regularly looked at information about delayed discharges of people with dementia; and only 8% reviewed re-admissions of people with dementia[3]. Only 5% of hospitals had mandatory training in awareness of dementia for all staff; and less than a third of staff said they had sufficient training in dementia care.[4]

We are dealing with much more than the challenge of dementia. *Care and compassion? Report of the Health Service Ombudsman* (2011) points to an NHS '… that is failing to respond to the needs of older people with care and compassion and to provide even the most basic standards of care', highlighting '… the gulf between the principles and values of the NHS Constitution and the felt reality of being an older person in the care of the NHS in England'. *Delivering Dignity* (2012) speaks of the 'discrimination and neglect evident towards older people in British society' and calls for 'policies which promote the rights of older people and challenge and change attitudes'[5]. Ballatt and Campling (2011) argue that we need to return to, and reclaim a way of working which is based on 'intelligent kindness'[6] and compassion, have a better understanding of that which liberates kindness at an individual, team, organizational, and system level; and put in place measures to mitigate against the potentially inhibiting or depersonalizing effects of a culture of productivity, performance management, regulation and competition (p175).

South West improvement programme

A joint review of dementia services in the South West, carried out by the South West Dementia Partnership in 2009[7], concluded that that dementia care was not seen as a corporate priority or core business in some hospital settings, the quality of care varied significantly, with carers reporting that dementia was neither understood nor catered for in hospitals, describing their experiences as poor. Particular mention was made of lack of support at mealtimes; one carer reported having to make a 40 mile round-trip three times a day to feed her husband. The review also found that many hospital wards had poor environments, unsuitable for the care and support of people with dementia; and delayed discharges were reported in a number of hospitals.

The South West Dementia Partnership has focused not on dementia care alone, but on fundamental questions about health care today. How do we protect, and promote people's rights? How do we change people's expectations and behaviours in complex health systems, in a climate in which productivity threatens to undermine quality and safety? How do we ensure we care for the person, and individual needs in a system designed for high volume/throughput?

Changing expectations; changing systems

Clinical leadership has been an essential factor. Following the joint review of dementia services in the South West (2009), Board-level clinical leads for dementia were identified by each of the 18 general hospitals in the region. A Regional Champion for Dementia Care in Hospital has provided a focus and sustained drive for quality of care in hospital, influencing practitioners, senior teams, and health and care leaders across sectors. A regional Expert Reference Group has brought clinical leads and local partners together to design, sign up to and deliver an improvement programme over a sustained period. This reaches beyond the NHS: members include people living with dementia, voluntary and community sector partners, and health and social care and commissioners and providers.

From the outset the group has focused on the ethical imperative. At the heart of this has been the co-design of eight standards for dementia care in hospital [Box 1]. The Standards and underpinning criteria have emerged from, and reflect lived experience: both of people living with dementia and their carers/families, and of staff and volunteers. This was achieved through an assiduous process of engagement, reflection and consultation, an iterative process that has secured commitment to and ownership of a movement for change, and its ambitions. Colleagues in the voluntary and community

sector consulted with people living with dementia, and their carers/families in order to establish what would make a difference, and how; and what was most important to them for improving their experience. Alison Moon, Regional Champion for Dementia Care in Hospitals recognised that , behind this was “the conviction that if we were to achieve these standards of care for people with dementia, we would be improving care for all hospital patients”.

Box 1: South West Standards for Dementia Care in Hospital (2010)

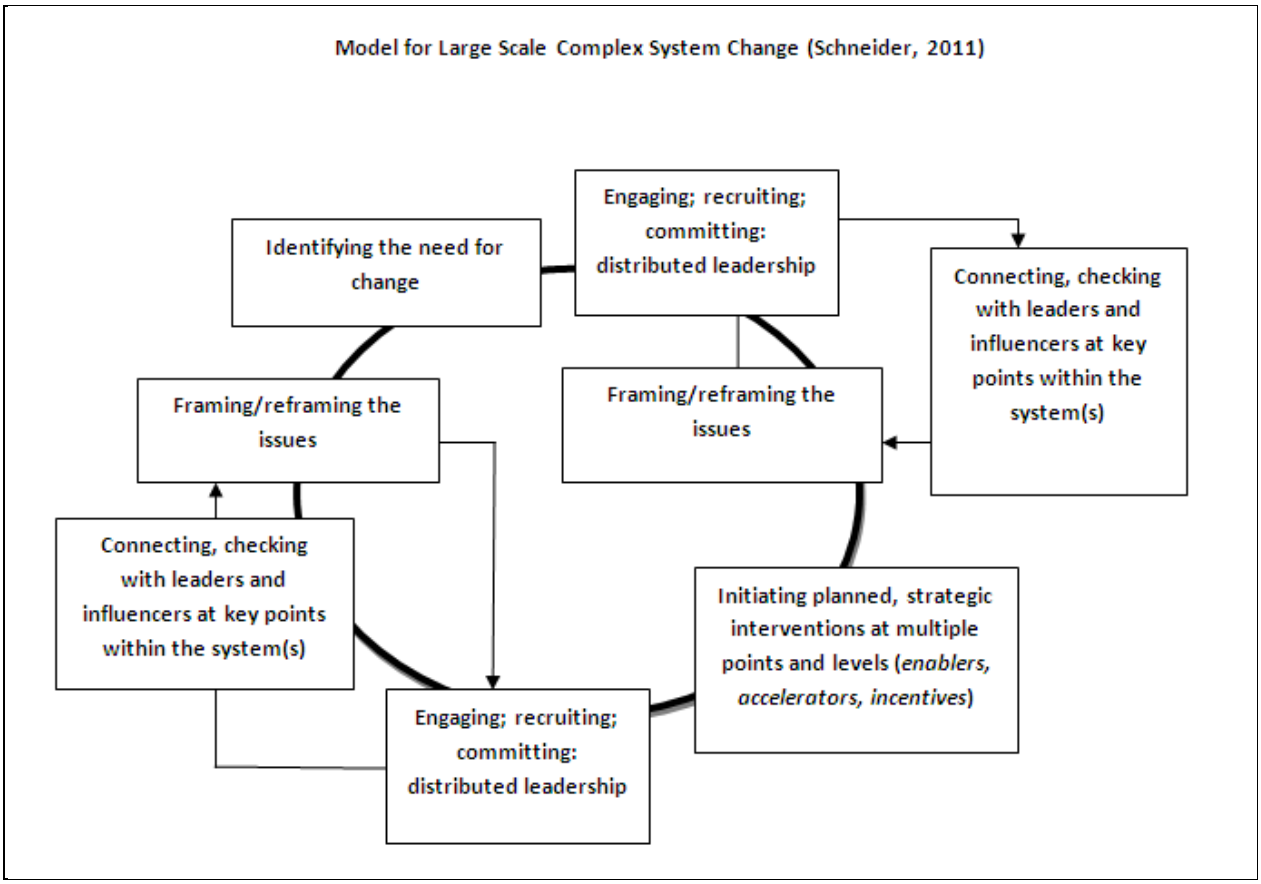
1. People with dementia are assured respect, dignity and appropriate care.
2. Agreed assessment, admission and discharge processes are in place, with care plans specific to meet the individual needs of people with dementia and their carers.
3. People with dementia or suspected cognitive impairment who are admitted to hospital, and their carers/families have access to a specialist mental health liaison service.
4. The hospital and ward environment is dementia-friendly, minimising the number of ward and unit moves within the hospital setting and between hospitals.
5. The nutrition and hydration needs of people with dementia are well met.
6. The hospital and wards promote the contribution of volunteers to the well-being of people with dementia in hospital.
7. The hospital and wards ensure quality of care at the end of life.
8. Appropriate training and workforce development are in place to promote and enhance the care of people with dementia in

general and community hospitals, and their carers/families.

We recognised that to make a difference, we would need to find a way to ensure that the Standards were implemented locally. We might simply have distributed the Standards and asked hospitals to implement them, in the tested and tried NHS way. We realised that the scale of the challenge, the interdependency and complexity of the changes called for a different approach; we needed to build on local positive practice and promoting sustained improvement in each hospital.

Complexity science suggests that it is often better to try multiple approaches and let direction arise by gradually shifting time and attention towards those things that seem to be working best (Zimmerman et al, 1998). In trying to improve dementia care in hospital, our hypothesis was that whereas change initiatives can be 'scaled up' and implemented within and across systems, the pervasiveness of change, change in 'knowledge depth' or understanding and thinking, and the sustainability of change (Ledford and Mohrman, 1986) are context- and resource-dependent .

Drawing on Plsek's model of emergent large scale change[8], we developed and introduced at key points a range of 'catalysts', 'enablers' and 'accelerators' to support local improvement processes. Our model for large scale complex system change introduces planned, sustained strategic interventions at multiple points, and at different levels and times within and across systems and sub systems. This model uses the design and deployment of initiatives or interventions which catalyse, accelerate and enable change: change is not incidental and emergent: it is tactical and driven (Diagram 1, below)[9].



Catalysts

A key catalyst for change has been a peer review of dementia care in hospitals, designed by the regional Expert Reference Group and mandated by the Strategic Health Authority. In the Autumn of 2011 each hospital signed up to, and undertook a self assessment against the South West Standards; produced and implemented an improvement plan; and hosted a visiting team of peers to review progress with implementing the Standards and improving dementia care. 'Support and enable' was the motto of the reviewers; it was explicitly not an inspection. We quickly established an approach which was about organisational appraisal, focusing on progress, challenges and learning.

Groups of approximately eight people formed Peer Review teams, representing carers, clinical leads for dementia, dementia champions, people with lived experience, voluntary and community sector partners, social services, GPs, and commissioners of both acute care and dementia services. Review days started with the hospital's top team, including Chief Executive, in order to establish local leadership, focus, commitment and intent, and ended with feedback to the same group. The hospitals planned their

respective visits: presentations, documentation, observation in different settings, and engagement with staff, patients and carers allowed the Peer Review teams to discern strengths, and opportunities for improvement. Most importantly, they heard people's stories and took account of the challenges which individuals, organisations and their partners - living systems - were facing. Acknowledgement and recognition of progress, sharing of positive practice and learning, and a focus on solutions ensured that the review visit and process was an important milestone for hospitals and their Boards, and a practical support in continuing to drive improvement in dementia care.

Accelerators

At the outset we invested in a range of resources in response to needs identified by the Expert Reference Group, in order to accelerate and enhance local action for improvement. These included regular e-bulletins and thematic briefings; a knowledge portal carrying an extensive resource bank for service commissioners and providers; a workforce portal which carries a learning framework for dementia and extensive education materials; and an information and resource pack for hospitals. Knowledge management and communications have played a key by providing easy access to information and resources to address the specific needs of stakeholders. Within a month of completion of the Peer Review, a compendium of positive practice was published and disseminated (www.dementiapartnerships.org.uk/hospitals). In March 2012 our third annual regional conference on dementia care in hospitals provided a platform for sharing and disseminating learning and evidence of better quality care for these patients, better outcomes, safer care, less time in hospital, more people returning to their usual place of residence, and improved productivity.

Enablers

Organisational commitment to change has been an essential component. Leadership has emerged, and been sustained across systems via the regional Expert Reference Group, and within hospitals by Board-level clinical leads for dementia. The needs and rights of people living with dementia and their carers and families are being articulated, and are becoming much more visible in our hospitals: new roles and new ways of working are ensuring that dementia care is integrated within hospital-to-community pathways of care. These include the dementia champion [Box 2]; partnership working between general hospitals and care homes to enable people to die in their place of choice, [Box 3]; meal time companions

on an acute ward for older people [Box 4]; and dedicated teams such as the Older Person's Assessment and Liaison Team in the Royal Bournemouth and Christchurch Hospital [Box 5].

Next steps

The Peer Review of dementia care in hospitals has demonstrated a significant shift in hospitals' awareness of, and response to the needs of patients with dementia and their carers/families. It has highlighted and acknowledged the achievements of many staff and local partners to improve care, and identified much outstanding practice and immense commitment from individuals and teams. Overwhelmingly the peer review has harnessed the enthusiasm and commitment of staff to keep striving for improvement; a number of hospitals have subsequently continued to share and exchange expertise and positive practice through networking and follow up visits. Bringing together people as a community of interest, articulating shared concerns, values and ambitions, giving both 'permission' and opportunity, and recognising and acknowledging change and improvement has given a foothold to promoting care and compassion, and working with 'intelligent kindness'[10] in our hospitals.

There remains to be demonstrated the pervasiveness and depth of these improvements, and competence across all hospital settings. In 2012-13, to reflect the changing NHS structures a locality approach is being adopted in order to promote local accountability, with second stage peer reviews taking placing in PCT cluster areas. The needs of people with dementia, and their carers/families are more visible, and better catered for in many wards and settings: the challenge remains to extend these standards of care across all hospital settings and to demonstrate real capacity to deliver this. It takes a whole hospital approach to care well for patients with dementia, and to sustain that level of care.

For more information go to www.dementiapartnerships.org.uk/hospitals.

Box 2
Dementia Champions in Bristol

University Hospitals NHS FT and North Bristol NHS Trust have combined their approach to establish a cohort of Dementia Champions – 'guides, supporters, inspirers, monitors, mentors, change agents, leading by example and modelling good practice'. Champions,

- support people with a dementia as and when they come into the working area;
- see the person first, recognise the person with dementia as an individual;
- lead the local implementation of the 'This is Me' information pack;
- share information and knowledge about dementia care with their team and other Dementia Champions
- raise awareness about the needs of the person with dementia, and their families/carers.

Anyone who works with people with dementia can become a Champion; the role is for staff who have a passion to improve the quality of services and improve people's lives to enable them to 'live well with dementia'. The aim is that all staff – clinicians and non-clinicians alike - will become a Dementia Champion; and that every team will have at least one Dementia Champion. Contact: carly.hall@uhbristol.nhs.uk

Box 3
End of life care

Royal Cornwall Hospital NHS Trust, GPs and seven local care homes have signed up to a pilot to ensure that people's wishes about their end of life are respected, as far as possible. By March 2012, over 300 patients had been treated according to their best interest plans; feedback from relatives was positive; more people were dying in their own care homes; and there were fewer admissions before death. Contact: Beverley.chapmany@cpft.cornwall.nhs.uk

Box 4
Better nutrition: meal time companions

Torbay Hospital has recruited 12 meal time companion volunteers and a luncheon club on Cheetham Hill Ward to encourage better nutritional intake. The hospitals' Dementia Specialist Nurse provides basic teaching sessions for the meal time companions. Contact: sue.dolan@nhs.net

Box 5

Mental health liaison service

The Older Persons' Assessment and Liaison (OPAL) team routinely screens all patients over 65 who attend the Emergency Department, Acute Admissions Unit, and patients triaged to Medicine for the Elderly, and has an outreach service into the community. This supports assessment and early diagnosis of dementia, averts unnecessary admissions, and enables timely referral to specialist services and discharge. By March 2012 the average length of stay for patients over 65 years reduced from 35 to 18 days. Contact: gemma.brittan@rbch.nhs.uk

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[7] South West Dementia Partnership (2009) Joint Review of Dementia Services, NHS South West.

[8] Plsek, P. (2008a) **An Introduction to the Theory and Practice of Large-Scale Change, and Its Relevance to the NHS**. **Drafted by Paul Plsek (Director, ALSC), on behalf of the faculty of the Academy for Large-Scale Change**. Working paper version 6: 11 October 2008, p. 3. Available from: http://www.institute.nhs.uk/general/general/shared_resources.html [Accessed 08 January 2011.]

[9] Schneider, K. (2012) Improving rates of diagnosis for people with dementia: more means better? MSc dissertation submitted to Health Services Management Centre, Birmingham University.

[10] Ballatt, J & Campling, P. Intelligent kindness reforming the culture of healthcare. RCPsych Publications, 2011.