

# UK Advisory Forum on Ageing

## Delivering more dignified care for vulnerable older people in hospital

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I: What values are we *officially*  
signed up to in the NHS?

## 2008 (Rights and Responsibilities)

- “A *comprehensive service available to all, irrespective of age, gender, ethnicity etc*”
- “Accessed on *clinical need, not ability to pay*”
- “Must reflect *needs and preferences of patients, families and carers*”

# European Convention on Human Rights

- **Article 2.** Right to Life (including duty to prevent foreseeable loss of life)
- **Article 3.** Right to freedom from torture or degrading or inhumane treatment
- **Article 8:** right to privacy and family life
- **Article 14.** Right to freedom from discrimination

# Key Principles of Equality Act 2010

(Oliver D BMJ 2009)

- *“Unjustifiable age discrimination and unfair treatment have no place in a fair society which values all its members”*
- *“meeting individuals’ needs should be based on individual circumstances and not arbitrary assumptions about their age”*
- *“services should be differentiated by age only when justifiable or beneficial”*

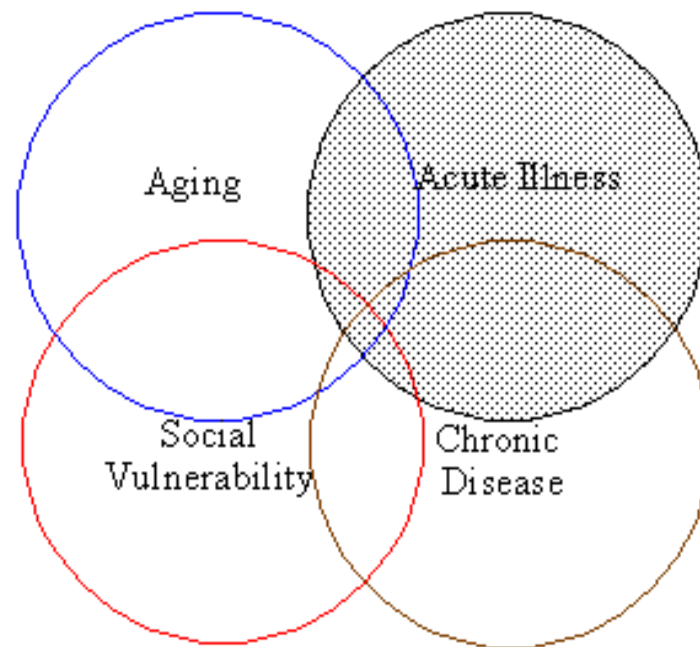
II: Are older people in hospital a  
“disadvantaged majority”?

## Life Course Approach e.g.

- “Preparing for old age”
- “Active old age”
- “Vulnerable old age” (due to long-term medical conditions or disability)
- “Dependent old age” (frail, requiring care from others)
- “End of life”
- Relatively few people (even over 80) are in the dependent or “frail” stage (only around 6% over 65)
- Most of those with long term conditions self-reported health and wellbeing are good
- There are c 1.2bn disabled people over 65 in England and Wales (Brayne et al CFA study) but most have low-level care needs
- **But....people *do* get ill and when they are ill they are more vulnerable than usual**

# High intensity users of hospital services have overlap of physical and social vulnerabilities

## Interaction of Aging, Environment and Disease



## Hospitals. Why (vulnerable) Older People R US?

- 60% of admissions, 70% of bed days in over 65s
- Usually people with multiple long term conditions
- 80% of “delayed transfers” (to community services)
- 80% of deaths in hospital
- 1 in 4 adult beds occupied by someone with dementia
- Falls, mobility problems, confusion etc very common
- Older people with complex needs not a minority
- Even active, independent older people can become very vulnerable and disempowered when acutely ill

# Have hospitals and health systems caught up with this reality?

- *“If we design services for people with one thing wrong at once, but people with many things wrong turn up, the fault lies not with the users but with the system. Yet all too often these people are deemed inappropriate or labelled as a problem”*
- Rockwood 2005
- *“We need to make services age proof and fit for purpose”*
- Philp 2007

# Rt Hon Stephen Dorrell MP 2011 (HSJ)

- *“Some of the greatest problems in care are because traditional institutions and structures are being used to deliver care to a quite different type of patient”*
- *“Systems designed to treat occasional episodes of care for normally healthy people are being used to deliver care for people who have complex and long term conditions. The result is often that they are passed from silo to silo without the system having ability to co-ordinate different providers”*

III: What do older people say they  
want *for themselves* when they are  
ill?

Much the same as younger people  
but with some “allowances” ...

# Dignity in Older Europeans Project.

*Woolhead et al Age Ageing 2006*

- 400 people in focus groups (6 countries) with substantial agreement about significance and importance to maintaining self esteem
- Three key themes
  - *Respect and recognition* “
  - *“Participation (equality, choice, control, autonomy)”*
  - *“Dignity in care”*
- Other sources back this up (e.g. Age Concern and Help the Aged Reports on End of Life Care)

# Dignity in Older Europeans Project (Woolhead) *(Themes closely mirrored in focus groups for 500 under 65s)*

- **Dignity of identity**

- Maintain self respect
- Undermined by disrespectful address or labelling
- Attitudes of staff or family
- Neglect of appearances and clothing
- Exposure
- Lack of privacy in personal care and mixed wards
- Toileting
- Nutrition (and assistance with feeding and drinking)
- Care when suffering or dying

- **Human Rights**

- Importance of being treated as an equal, regardless of age
- Fighting discrimination
- Choose how you live and how you die (including advanced decisions)

- **Autonomy**

- Retain independent control over lives for as long as possible
- Even where need for nursing home, can still be kept clean and tidy

# RCPsych Audit of Dementia Care in General Hospital 2010. What *were* carers' priorities?

- Care planning and support in relation to the dementia (i.e. not just the acute condition) from admission to discharge
- Care of patients with acute confusion
- Maintaining dignity in care
- Maintenance of patient ability
- Communication and collaboration: staff and patients/ carers
- Information exchange
- End-of-life care
- Ward environment

## IV. How well are we delivering on this?

I will attempt a more balanced view  
than the one often presented...

- The Downside..





From [www.dailymail.co.uk](http://www.dailymail.co.uk)

- “Scandal that shames Britain: Join our campaign to end appalling treatment of the elderly on NHS wards as complaints reach record high”



# Patients Association website

- “Will elderly patients suffer further as we are left with fewer resources and fewer nurses on our wards? Every day at the Patients Association we hear story after story from older patients phoning our Helpline telling us that they are:”
- “Being left hungry and thirsty”
- “Suffering in pain without adequate pain relief”
- “Suffering the indignity of being told to soil themselves in their bed”
- “Leaving hospital without the right support systems in place to help them once they are back in the community”
- “The situation is completely unacceptable. The NHS should always get these basic patient needs right.”
- “There isn’t an on cost to this – it is an entitlement that every individual has a right to.”

# Patients Association

- ....”based on the findings of the national inpatient survey, every year....around 2% of inpatients surveyed rated their care as poor. This could equate to over 1 million patients over the course of the years the survey had run”
- “Our intention was simply to highlight that if a service is delivered to millions of patients every year, substandard care being given to even a small percentage equates to very large numbers of people.”



## Foreword



Claire Rayner OBE, 22 January 1931 - 11 October 2010

# Jay Rayner 2010

In the last, difficult months of her life my mother, Patients Association president Claire Rayner, received some truly exemplary care. For the most part Claire, who died in October 2010, was looked after with true compassion and consideration. But there were times when things went wrong: when her nursing was assigned to agency staff who knew little or nothing about her and made absolutely no effort to find out, when calls for assistance went unanswered, when doctors treated her less as a person than as a set of conditions and readings on a chart. She found this hugely distressing, but it also made her very angry. As she said time and again if even she, with her public profile, reputation for straight talking and acute knowledge of the mechanics of nursing and medicine could not get the treatment she was entitled to what hope was there for others?

Indeed. If she had been alive today my mother would have been infuriated by the distressing accounts of poor nursing and medical care experienced by older people, contained in this very important report. Claire was never one for blanket statements and would have been the first to point out that many nurses and doctors are hugely considerate in the way they deal with older patients, who may be confused, distressed or simply frightened by the situation in which they find themselves. The positive comments at the front of this report, made by relatives of those whose stories are told here, attest to that. But any health system is only as good as its failings, and those detailed in these pages are truly dismal. The Patients Association makes absolutely no apologies for the fact that this document will prove very difficult reading.

# Report of Parliamentary Ombudsman



## Care and compassion?

Report of the Health Service Ombudsman on  
ten investigations into NHS care of older people

Fourth report of the Health Service Commissioner for England  
Session 2010-2011

Presented to Parliament pursuant to Section 14(4) of the Health Service Commissioners Act 1993

Ordered by  
The House of Commons  
to be printed on  
14 February 2011

HC 778

London: The Stationery Office  
£15.50

### 11 Mr and Mrs J's story

Hospital staff at Ealing Hospital NHS Trust left Mr J forgotten in a waiting room, denying him the chance to be with his wife as she died.

### 13 Mr D's story

Royal Bolton Hospital NHS Foundation Trust discharged Mr D with inadequate pain relief, leaving his family to find someone to dispense and administer morphine over a bank holiday weekend.

### 17 Mrs R's story

Mrs R's family were concerned that she would not receive food and drink while in Southampton University Hospitals NHS Trust unless they themselves helped her to eat and drink.

### 21 Mrs Y's story

Mrs Y died from peritonitis and a perforated stomach ulcer after her GP Surgery missed opportunities to diagnose that she had an ulcer.

### 23 Mrs H's story

When Mrs H was transferred from Heart of England NHS Foundation Trust to a care home, she arrived bruised, soaked in urine, dishevelled and wearing someone else's clothes.

### 27 Mr C's story

Staff at Oxford Radcliffe Hospitals NHS Trust turned off Mr C's life support, despite his family's request that they delay doing so for a short time.

### 29 Mr W's story

Mr W's life was put at risk when Ashford and St Peter's Hospitals NHS Foundation Trust stopped treating him and then discharged him when he was not medically fit.

### 31 Mrs G's story

Mrs G's doctors at her local surgery failed to review her medication after she left hospital, with serious consequences for her health.

### 33 Mr L's story

The care and treatment that Surrey and Borders Partnership NHS Foundation Trust gave Mr L contributed to a loss of his dignity and compromised his ability to survive pneumonia.

### 37 Mrs N's story

While doctors at Northern Lincolnshire and Goole Hospitals NHS Foundation Trust diagnosed Mrs N's lung cancer, they neglected to address the severe pain that she was suffering.

# “Care and Compassion” Report of the Parliamentary Ombudsman. 2010. Foreword

- “These stories, the results of investigations concluded by my Office in 2009 and 2010, are not easy to read. They illuminate 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. The investigations reveal an attitude – both personal and institutional – which fails to recognise the humanity and individuality of the people concerned and to respond to them with sensitivity, compassion and professionalism. The reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital is not being fulfilled. Instead, these accounts present a picture of NHS provision that is failing to meet even the most basic standards of care.”

# Parliamentary Ombudsman

- “These are not exceptional or isolated cases. Of nearly 9,000 properly made complaints to my Office about the NHS in the last year, 18 per cent were about the care of older people. We accepted 226 cases for investigation, more than twice as many as for all other age groups put together. In a further 51 cases we resolved complaints directly without the need for a full investigation. The issues highlighted in these stories — dignity, healthcare associated infection, nutrition, discharge from hospital and personal care — featured significantly more often in complaints about the care of older people.”

# All parliamentary enquiry into Human Rights of Older People in Health and Social Care 2008

- “Many witnesses including inspectorates, providers and organisations supporting older people expressed concern about poor treatment e.g.”
- Malnutrition and dehydration
- Abuse and rough treatment
- Lack of privacy in mixed sex wards
- Lack of dignity especially for personal care needs
- Insufficient attention to confidentiality
- Neglect, carelessness and poor hygiene
- Inappropriate medication and use of physical restraint
- Inadequate assessment of needs
- Too hasty discharge from hospital
- Bullying, patronising and infantilising attitudes to older people
- Discriminatory treatment on the grounds of age, disability or race
- Communication difficulties, especially in dementia or deafness

# All parliamentary enquiry into the human rights of older people in healthcare 2007

- *“The committee heard that while some older people receive excellent care, there are concerns about poor treatment, neglect, abuse, discrimination and ill considered discharge.”*
- *“ It considers that an entire culture change is needed. It also recommends legislative changes”*

# **Ageism and age discrimination in mental health care in the United Kingdom**

**A review from the literature**

commissioned by the  
**Department of Health**

carried out by the  
**Centre for Policy on Ageing**

# CPA Review findings on frontline clinical services

*[www.cpa.org.uk/reading/age\\_discrimination.pdf](http://www.cpa.org.uk/reading/age_discrimination.pdf)*

- Decisions made arbitrarily on chronological age
- Older people receive systematically worse diagnosis, treatment, specialist referral etc than younger with same condition
- Common conditions of ageing are relatively neglected when compared to conditions of youth and mid-life
- Older people with frailty and functional impairment go undiagnosed
- Attitudes, basic care, communication etc...

# Other evidence around poor or patchy care e.g.

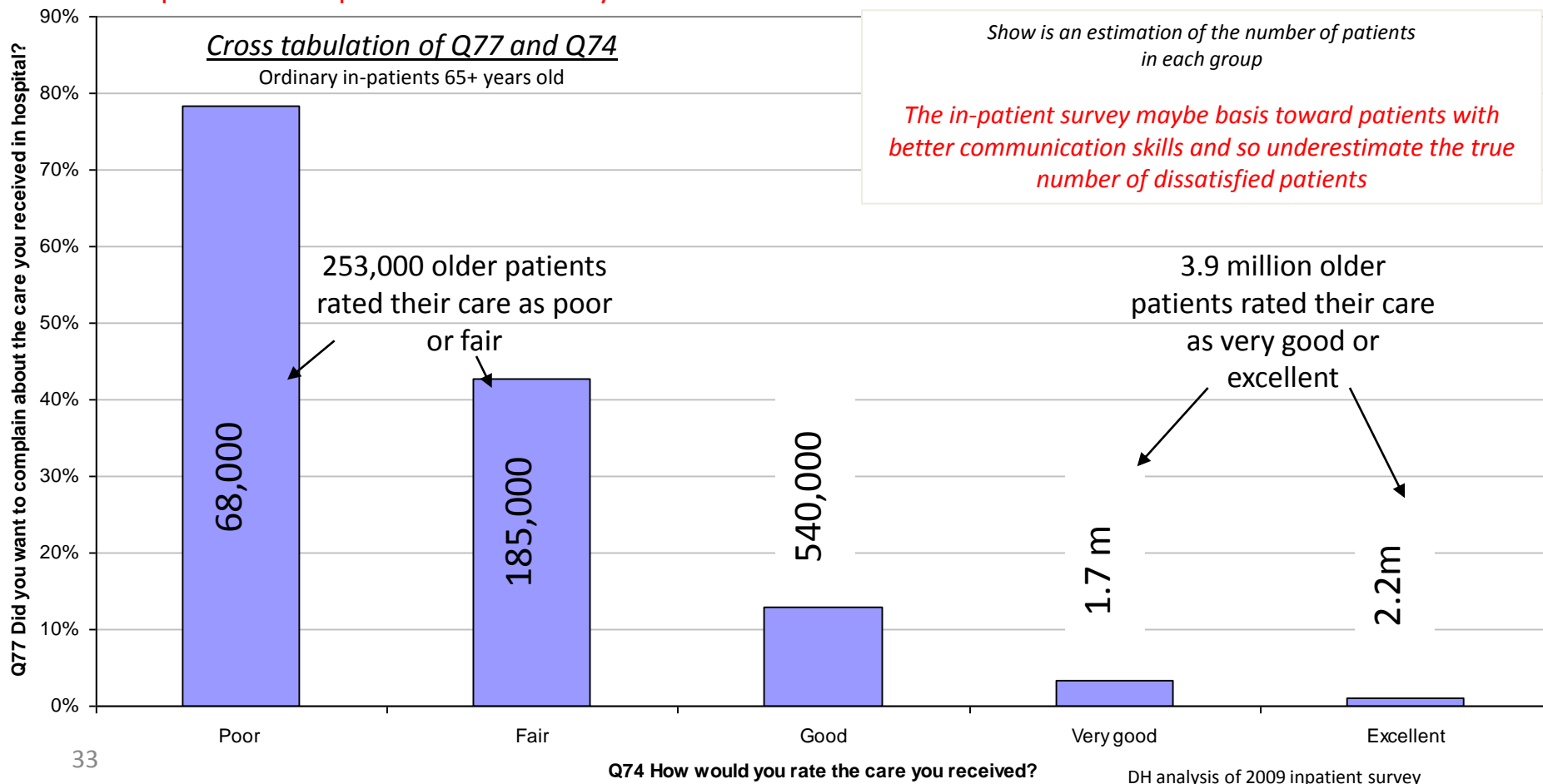
- Care Quality Commission 2011 Inspections on dignity and nutrition to 100 hospitals...
- RCP Continence Audit
- Age UK “Hungry to be Heard” report on nutritional assessment and support
- NCEPOD report on postoperative care for older people
- RCPsych audit of dementia care in general hospital

- The Upside....



# We can estimate from the in-patient survey that around quarter of a million older patients rated their care as fair or poor in 2009

- Unsurprisingly there is a strong relationship between in the inpatient survey question Q77 (did you want to complain about the care you received?) and Q74 (How would you rate the care you received?).
- 83% of patients rated their overall care as very good or excellent. In this group fewer than 5% of patients felt there was anything to complain about.
- **Of the estimated quarter of a million patients who would rate their care as fair or poor, over 40% felt they would like to complain about aspects of the care they received.**



# Complaints and Ombudsman...

There are over 400 m NHS / Patient interactions per year



14 m hospital admissions using 52m bed days/year  
(The over 65's use 54% of all bed days)



151,832 written Complaints In 2009-10 to providers



14,429 complaints received by Ombudsman



346 Complaints accepted by Ombudsman for Investigation<sup>2</sup>

34



The majority of complaints to the Health Services Ombudsman were closed because they were premature, not properly made or the body had been judged to have acted correctly and reasonably



63% of complaints investigated were upheld or partly upheld

<sup>2</sup>Plus 219 were resolved by intervention by the Ombudsman without investigation.

# From patients' association report..(I hear lots of similar tales in both my jobs)

*"I was admitted to an assessment ward and had excellent treatment there. I can't thank enough the staff nurse for taking me through a crisis. I am also grateful to the other staff who were there as needed in a very busy ward with lots going on. The staff nurse kindly came to see me before she went off shift, to say that I would probably be transferred to another ward, so I probably would not see her again. A very nice and important touch."* Brigid Wainwright

*"We had had contact with the Royal Devon and Exeter hospital for over 20 years and when he first attended there he had what can only be described as 5\* treatment with fantastic care at all times. His life was saved several times."* Margaret Clarke

*"Firstly I would like to praise and thank the many wonderful nursing staff, physiotherapists and doctors that have helped with the care of my husband David J Perkins. He had previously been at Southend Hospital in February and March for chemotherapy where the staff had been extremely kind and courteous."* Maureen Perkins

*"Besides when she was having children my mother has only ever been in hospital once before... She tells us that the care then was wonderful."* Carole Brown

V. Moving towards constructive solutions that are relevant to the 21<sup>st</sup> century NHS

- *“For every complex problem there is a solution that is simple, obvious and wrong”*
- HL Mencken
- *“I’m drowning here..and you’re describing the water”*
- Melvin Udall in *“as good as it gets”*
- *“Insanity. Doing the same thing again and again and expecting different results”*
- Albert Einstein

# NHS Confederation/Age UK commission on dignified care for older people...

- 10 questions asked in initial consultation around:
  - Dignity
  - Nutrition/Hydration
  - Psychological and emotional support
  - How to support good practice and tackle poor practice
  - Communication
  - Patient/Carer Involvement
  - Underlying factors leading to poor care or enhancing ability to deliver good care

# Solutions...

- Workforce with the right skills, values and attitudes to care for an ageing population
- Education and training rebalanced to focus much more on the care of older people
- Leaders of clinical services need support, coaching, development (e.g. ward managers)
- All staff (not just nurses) need to challenge undignified care whenever they see it, set an example and mentor/develop others
- Leaders of organisations (boards, directors etc) need to value and prioritise dignified care

*Dignity in practice: An exploration of the care of older adults in acute trusts. 176 post discharge interviews of older people and their carer and 617 care observations*

- **“Right place wrong patients”**
- Some patients not seen as belonging in that ward especially those who are confused, demented, outliers, delayed transfers so needs unmet/ignored
- **“Seeing the person in the bed”**
- Wards are nurses spaces rather than patients emphasis on tasks and completing work so missed opportunities to build relationships. Social engagement and isolation
- **“Whose interests matter?”**
- Significant conflict between perceived interest of trust, ward and patient which impacts on dignity
- **“What makes dignity difficult to achieve and what makes it easier”**
- Resource, health and safety, ward culture, leadership, education and training

# Solutions..

- Need to involve older people and their carers in design of services, feedback on quality and helping to participate in care and planning
- Build in learning from patient stories, complaints or praise into governance, training and organisational culture
- Early and open communication and information from staff to patients/carers can reduce misunderstanding or complaints
- Prompt, open responses to complaints can prevent escalation and further dissatisfaction
- Better communication between agencies/less duplication/more continuity

# From “Acute Awareness”

## Ann Reid’s hospital experience

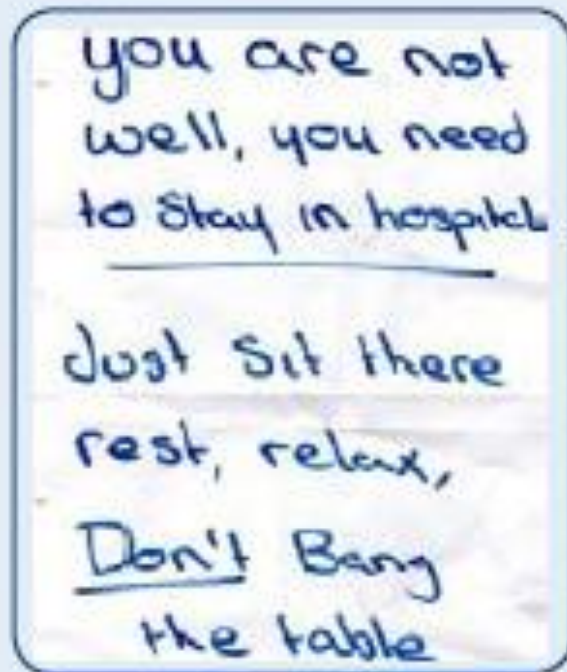
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I have experience of caring for two people with dementia: my mother and my husband. Both of them have been to hospital.

My husband Jim went to hospital when he had a stroke. He was moved around wards. He found the experience very confusing, which made him stressed. Because of this, he was sedated to help him ‘comply’. The problem is I believe it was this long sedation that made him incontinent – he was fully continent when he went into hospital and also during the first days, before he was sedated. To add to this, Jim did not receive a full assessment on discharge, which left me relying on friends’ help, battling my way around the system and not giving me enough time to do the most important job: care for my husband.

# Ann Reid..”Acute Awareness”

My mother went into hospital because of a chest infection. Having dementia, she also found the situation very confusing. At one instance, she began banging the table. Instead of talking to her, one of the staff members left this note on her bedside table:



you are not  
well, you need  
to stay in hospital

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Just sit there  
rest, relax,  
Don't Bang  
the table

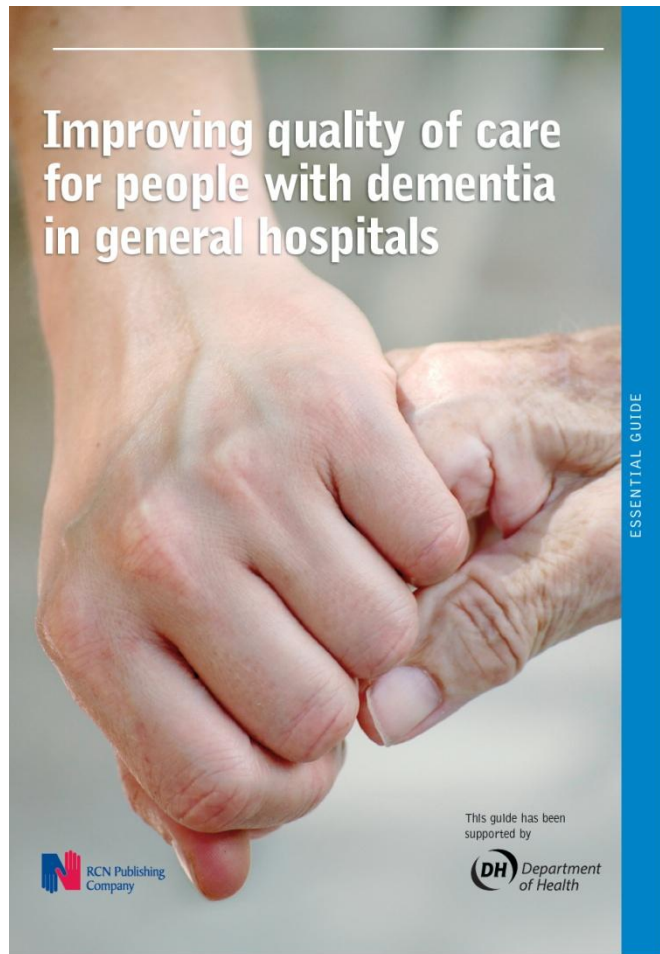
I am sure improving care for people with dementia does not need to be either costly or complicated:

- Have more flexible visiting times, so carers can help care for the patient, for example by feeding them. This will also help the patient to feel more comfortable.
- Involve carers in issues surrounding the care of patients. After all, their carers have been doing it for a long time and so they are often the best source of information. This goes beyond family members: care home staff can also help.
- Have a dementia lead or a specialist team: we can't expect all the hospital professionals to be specialists in dementia. After all, people are not normally in hospital because of their dementia and we need someone to treat the condition they have been to hospital for. But if staff know they can call on a team who will help them understand how the care plan can be adapted to include the needs of people with dementia too, we can improve the care of the patient and probably help them leave hospital earlier.
- Increase the level of dementia awareness among all staff: even if they are not specialists, they should have an appropriate level of understanding about dementia, especially as so many patients have dementia.<sup>12</sup>

# Solutions

- Inspection and Regulation which looks at “bedside care” including areas that matter most to the public
- Use of law (negligence, rights, equality, mental capacity, criminal) where appropriate
- Advocacy from charities, patient groups, public etc etc
- Leadership from colleges, professional societies (NHS Commissioning board..)
- A real focus on celebrating good practice, showcasing examples and disseminating the learning. There is lots out there..

# Spreading good practice e.g.



- Key information, guidance and references on each aspect of the care pathway
- Backed by good practice examples from English Hospitals

# Solutions

- The right system incentives
- e.g. national outcome indicators on patient experience and safety
- e.g. national quality standards
- e.g. transparent data from national audits and surveys with trust-by-trust comparison
- More joined up care, more focus on prevention, keeping people well and independent
- **So we can ensure that only older people who really need a hospital bed (or nursing home) are in one and they can remain at home wherever possible**

# Thank you

- Questions.....?
- [David.Oliver@dh.gsi.gov.uk](mailto:David.Oliver@dh.gsi.gov.uk)

