Response to Implementing a ‘Duty of Candour’: A new contractual requirement on providers
Consultation

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Alzheimer’s Society response to Implementing a ‘Duty of Candour’: a new contractual requirement on providers.

Summary
Alzheimer’s Society welcomes the opportunity to respond to this consultation. The Society believes that a culture of openness and transparency in healthcare when things go wrong is an important driver in improving health care services for all people. It is especially important for people with dementia who make up 25% of hospital patients, many of whom receive poor quality care. Last month’s National Audit of Dementia Care in Hospitals¹ identified

“a need for significant improvements in hospital ward environments, staff training and the overall approach to care delivery for patients with dementia.”

Having a robust national framework for openness is an incentive to prevent things going wrong in the first place. If untoward incidents do occur, it can facilitate a speedy, honest and apologetic response to the patient and their carer from the professionals responsible and the providers can learn from the incident how to improve practice in the future.

People with dementia are particularly vulnerable and they and their carers need to know that there is access to information, support and redress if things go wrong.

The Society does not believe that the Duty of Candour proposals being consulted upon, provide the robust national framework necessary. This consultation response discusses ways that the consultation proposals can be strengthened. However, given the numbers of people with dementia in hospital and recent reports, such as the audit of dementia care mentioned above, we concur with the position of other organisations concerned with patient safety, such as National Voices, who have campaigned for a statutory Duty of Candour to rectify this situation. Alzheimer’s Society believes that the Duty needs to be given the force of law for it to be effective.

1 About Alzheimer’s Society
Alzheimer’s Society is the UK’s leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and

¹ Royal College of Psychiatrists’ Centre for Quality Improvement (2011) National Audit of Dementia
support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

2 Key facts about dementia:

- There are 750,000 people with dementia in the UK. This is forecast to increase to over 1 million by 2021 and 1,735,087 by 2051. One in three people over 65 will end their lives with a form of dementia.
- In just 10 years a million people will be living with dementia in the UK.
- Only 40% of people with dementia get a formal diagnosis.
- Dementia is one of the main causes of disability later in life.
- 25% all hospital beds are occupied by people with dementia. Yet, a third of nurses don’t receive enough dementia training and more than half don’t receive any.
- Up to 150,000 people with dementia in the UK are being inappropriately prescribed antipsychotic drugs and these are contributing to 1,800 deaths a year.
- Dementia costs the UK £20 billion each year.

3 General comments

Current situation
It is six years since, in 2005, the National Patient Safety Agency (NPSA) issued a Safer Practice Notice advising the NHS to develop a local Being open policy and to raise awareness of this policy with all healthcare staff. Despite its revision and promotion in 2009 we believe that Being open is neither widely known nor widely implemented. It has certainly not led to a culture of openness nor an improvement in the quality of healthcare for people with dementia, nor an effective system of redress for them and their carers when things go wrong.

Poor quality of hospital care for people with dementia
Being in hospital may be confusing and frightening at the best of times. People with dementia in hospital are particularly vulnerable in an unfamiliar environment, where, as evidence is increasingly showing, their needs are often not met. They are also vulnerable as they may have communication needs, and memory may be affected by the condition. If people receive poor,

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neglectful or harmful treatment or care they may not be able to remember what happened or to complain about it. This makes it imperative that an effective system is in place to incentivise a culture of openness support and redress when things go wrong.

The Alzheimer's Society report *Counting the cost*\(^7\) (2009) found that people with dementia are receiving poor quality dementia care when admitted to a general ward for a physical health problem. 77% of carer respondents were dissatisfied with the overall quality of dementia care provided and only 20% were satisfied.

*Counting the Cost* found that the longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used. 47% of carer respondents said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn’t a direct result of the medical condition, and a further 21% said it had a little effect (68% in total). For example perceived weight loss, constipation, pressure sores. 54% of carer respondents said that being in hospital had a significant negative effect on the symptoms of dementia and a further 25% said it deteriorated a little (79% in total), such as becoming more confused and less independent.

Recent reports have highlighted serious failings in NHS care. The recent National Audit of Dementia\(^8\) has identified a need for significant improvements in hospital ward environments, staff training and the overall approach to care delivery for patients with dementia. Observations of care carried out for the audit found that care is often delivered in an impersonal manner, by staff who did not fully understand the needs of patients. This resulted in staff not greeting or talking to patients during care, explaining what they were doing or offering choice. Sometimes, staff were seen failing to respond to patient’s requests for help. More than two thirds of hospital staff do not believe they have had sufficient training to deliver quality care to people with dementia, and half of staff had not received sufficient training in communication with people with dementia, whilst 54% had not had enough training in dealing with challenging behaviour. Only 15% of wards used colour schemes to help people with dementia find their way around the ward.

**Complaints**

When things go wrong a robust complaints system is essential. Alzheimer’s Society’s report *Counting the Cost* (2009) found that over a third of carers of people with dementia respondents, used the complaints system. 35% of people had made a complaint; 38% would have liked to make a complaint but didn’t and 25% did not make a complaint. Of those who had made a complaint, only 7% were happy with the outcome, with 44% not at all happy

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\(^7\) Alzheimer’s Society (2009) *Counting the cost: Caring for people with dementia on hospital wards*. Alzheimer’s Society, London

\(^8\) As 1 above
and 45% only partly happy. It is clear from the accumulating evidence that the current complaints system is not providing redress for serious failings in care. A major overhaul is needed.

In conclusion
The ongoing evidence that the healthcare system and its complaints system is consistently failing people with dementia makes it imperative that whatever system of candour is adopted is effective. We believe that a statutory duty would be ideal as the force of law gives the clearest message.

However, the consultation proposals can also be strengthened by including primary care, by providing a national system of robust and specific penalties for breaches and empowering and appropriate support and advocacy for people with dementia and their carers.

Consultation questions

1. Do you think the contractual mechanism described here including the requirement for a declaration or commitment on openness, provides an effective mechanism for requiring openness?
   No

   Comments
   The mechanism is not robust enough to create a culture of openness. We have doubts about commissioners’ central role in policing it. We are concerned about whether commissioners have the general skills and capacity, and in particular whether they have enough knowledge about dementia. We believe the proposed mechanism could lead to yet another postcode lottery of patchy and ineffective implementation.

2. Do you think there should be a range of consequences available for use depending on circumstances?
   Yes

4. Should the level of escalation include suspension / termination of the contract?
   Yes—both, depending on the circumstances.

5. Do you think a requirement should be placed on primary care contractors and if so how might this be achieved?
   Yes

10. What additional support and advice would assist patients in raising concerns that could be made available through Local HealthWatch services?
    Comments
    Healthwatch would need to be adequately resourced to provide support eg. as in Question 11 below. Healthwatch’s links to CQC, which is currently facing serious concerns about its ability to regulate effectively,
may mean that it is not a trusted provider of support. Independent support and advocacy is needed.

11. Does a ‘road map’ or ‘flowchart’ of ‘What To Do When Things Go Wrong’ sound like a useful tool for patients?
   Yes

Comments
This will need to be produced in accessible formats for all including people with dementia, those with sensory impairments and in community languages.

12. Are there any equalities issues with this proposal? Will any groups be at a disadvantage and therefore less likely to receive openness?*
   Yes

Comments
The Duty of Candour’s Equalities Impact Assessment says:
“In terms of disclosure itself, it is likely that any disabilities resulting in communication or comprehension problems could reduce the ease of communication and therefore impact on the effectiveness or likelihood of disclosure. This is speculative however.”
Alzheimer’s Society’s view is that there is evidence that some people with dementia will have more difficulty than other patients in knowing or remembering that something has gone wrong with their care and may also have difficulty in communicating. All of these difficulties are likely to increase as dementia progresses. Knowing something is wrong may be a prerequisite for demanding disclosure if disclosure is not happening. Having a condition which affects memory and/or cognition and communication is likely to make people with dementia more vulnerable to cover ups of untoward incidents and is discriminatory on the grounds of disability. As the likelihood of having dementia increases with age, discrimination against people with dementia is also age discrimination. People with dementia will require specific support and advocacy to safeguard their rights in relation to candour. Since dementia affects all groups in society, some people with dementia will also belong to all the groups with protected characteristics under the Equalities Act 2010 and may have needs arising from that which are relevant to their rights under a Duty of Candour.

General comments
Do you have any other comments you would like to make in relation to this consultation?

*By equalities group, we are referring to any group with a protected characteristic. These are groups with the following protected characteristics; age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation.
Social care funded under NHS funded Continuing Care is not mentioned in the consultation document. Arguably it should be covered if it’s about NHS funded services. This leads to the question about whether social care and health should be treated the same in relation to candour.

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