

**National Institute for Health and Clinical Excellence**

**NICE Quality Standards Consultation**

**Closing date: 15<sup>th</sup> January 2010**

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Are you happy to be named as a consultee to the Quality Standard on the NICE website? <input checked="" type="checkbox"/> Yes	

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Please provide comments on the draft Quality Standards on the form below. When feeding back, please note the draft quality statement number and indicate whether you are referring to the statement, measure or audience descriptor.

In order to guide your comments, please refer to the general points for consideration on the NICE website as well as the specific questions detailed within the Quality Standards.

Please add rows as necessary.

<b>Draft Quality Statement No.</b>	<b>Comments about statements, measures and audiences.</b>
	<p>This response draws upon the conclusions and recommendations of the Nuffield Council on Bioethics' report 'Dementia: ethical issues', published in October 2009 (available at: <a href="http://www.nuffieldbioethics.org/dementia">www.nuffieldbioethics.org/dementia</a>). Paragraph numbers in brackets refer to paragraph numbers in the report.</p>
Dementia 1 & 3	<p>We strongly agree that people with dementia should receive services tailored to their needs. We very much welcome the increasing emphasis on services which are flexible and appropriate to the individual, and which enable them to live well with dementia. It could be further emphasised that this approach is based on respect for the needs, preferences and personhood of the individual person with dementia. In addition, a commitment to making services as flexible and responsive as possible does not necessarily entail spending more money; rather, it involves listening to the needs and wishes of the person for whom the service is being provided and adjusting the support on offer in order to help them in what they value most. The 'small things' of care are particularly important in ensuring that care is genuinely supportive of the individual, and enhances that person's autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity (paragraph 3.31).</p> <p>Risk assessment is also relevant to this Quality Standard. Those caring for people with dementia may often feel the need to do all they can to reduce risk to an absolute minimum. Unfortunately, minimising risk often means forgoing benefits and restricting freedom, which in turn may be highly detrimental both to the person's sense of autonomy and to their overall well-being. It is clearly important that those providing care for people with dementia assess and manage risks appropriately. However 'risk assessments' can often focus only on the possible risks, without considering what opportunities and benefits are being forgone as a result. For this reason we believe that the term 'risk assessment' should be replaced by 'risk-benefit assessment' (paragraph 6.17).</p>

<p>Dementia 2</p>	<p>We strongly agree that people with dementia should not be discriminated against on the basis of their diagnosis, age or coexisting learning disabilities. The Council's report includes an ethical framework to help those who face these ethical problems in the care of people with dementia. The framework states that the person with dementia remains the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their cognitive and other functions (Box 2.1).</p> <p>The emphasis in our ethical framework on the value and equality of people with dementia, and the importance of solidarity in responding to the challenges that dementia poses, put the onus on society as a whole to make itself as inclusive as possible towards people with dementia. Indeed, we note that this is not only a moral obligation, but also in some circumstances a legal one. The Disability Discrimination Act 1995 requires any “provider of services” to make “reasonable adjustments” to ensure that disabled people may use their services, while public bodies such as the NHS and local authorities have a positive duty to take active steps to promote equality for people with disabilities. Good practice guidance on building ‘dementia-friendly’ environments is becoming available with organisations such as the Dementia Services Development Centre in Stirling, and the Oxford Centre for Sustainable Development, publishing checklists on both interior and exterior design for people with dementia. Indeed, the development of ‘dementia-friendly’ premises within the NHS is highlighted in the Scottish dementia priority paper, and could be highlighted in this Quality Standard (4.19-4.21).</p>
<p>Dementia 3</p>	<p>We agree that people with dementia should have a care plan that identifies and addresses their specific needs and those of their carers. The Council's report highlights the enormous importance of families and friends in the care of many people with dementia. It is our view that an attitude of working with families and other carers, supporting them in their own care of the person with dementia, is most conducive to the interests of the person with dementia and best recognises the centrality of relationships with family and friends for many people with dementia. We suggest that the appropriate attitude of professionals and care workers towards families should be that of partners in care, reflecting the solidarity being shown within the family (paragraph 3.12). Such a partnership would involve a relationship of trust between professionals and carers, based on mutual respect for each other’s role and expertise.</p>

	<p>We found that many carers are concerned that professionals may be hesitant about sharing confidential information if the person with dementia lacks capacity to agree to disclosure, even where the carer feels that they need that information in order to make a proper decision on behalf of the person. We recommend that professionals should be made aware of the legitimate reasons why carers may ask for medical or other confidential information, and ordinarily start from the assumption that if a carer is involved in making a decision on behalf of the person with dementia, then they will need the same level of information as any other member of the care team. In short, carers should be provided with any information that it is necessary for them to know in order to carry out their caring role (paragraph 7.26).</p>
Dementia 4	<p>We agree that people with dementia, while they still have capacity, and their carer/s should discuss decisions about their care and treatment that may have to be made by others at a future point when they lack capacity to do so.</p> <p>The Council's report highlights the much broader concept of 'advance care planning' which is an important part of palliative and end of life care, and which aims to encourage all people who may be approaching the end of their lives to discuss and document their wishes about their future care. Wishes set out in an advance care plan may include the refusal of particular forms of treatment in particular circumstances. However, they may also include wishes about where the person would prefer to be as they are dying; the people they would most want to have around them; whom they would wish to be consulted about their care; and other aspects of their lives that they find most important and that may help make the end of their life as peaceful and supported as possible. Where individuals wish to make decisions about their future care, we strongly support the notion that this is best achieved within the broader context of advance care planning (paragraph 5.48). We suggest that such planning should begin early, and should be regarded as an ongoing process and not as a one-off event, with any documented wishes regularly reviewed.</p>
Dementia 5	<p>In relation to policies on safeguarding adults, we would like to emphasise that most carers provide a level of care that compromises their own health and well-being, and are concerned to help and support the person with dementia as much as they are able. Given this trust-based relationship between the person with dementia and their carer(s), we suggest that unless there is evidence to the contrary, there should be a presumption of trust in carers by health and social care professionals and care workers. Such trust is a key part of any 'caring partnership', and without such trust it is highly unlikely that the person with dementia can be given the best</p>

	possible support (paragraph 7.23).
Dementia 6	<p>We agree that people with dementia should receive care that is coordinated and integrated across all relevant agencies. However, people with dementia experience a number of disadvantages in the current care system, especially in the way services are divided into ‘social’ and ‘health’ services. Many of their needs, for example for help with personal care, are classed as ‘social’, despite the fact that the direct cause of their symptoms is progressive damage to the brain. Under the current system, this means that support services may only be made available when a crisis has already been reached because of the pressure on social services departments to prioritise those in greatest need. We argue in Chapter 2 that dementia is a medical disorder and that the needs arising out of the disorder should therefore be met in the same way as those arising out of other serious illnesses such as cancer. It is not acceptable to make people with cancer wait until their support needs have reached a crisis before providing that support and nor should it be regarded as acceptable for people with dementia to wait in this way. The essential ethical point to be made is that the access of people with dementia to the services they need should not be determined by classifications of care. In allocating resources, and in determining standards of care, it should make no difference whether the intervention is classified as ‘health’ or ‘social’ (paragraph 4.41).</p>
Dementia 7	<p>We strongly agree that people with dementia should receive care from staff that have been appropriately trained in dementia care.</p> <p>Ethical dilemmas arise on a daily basis for all those providing care for people with dementia. Such dilemmas may arise in mundane situations, but they are problematic and stressful, and those providing care often feel isolated and unsupported in responding to them. Yet the way in which they are handled may have a significant effect on the quality of life of both the person with dementia and others surrounding them. Professionals are in a position to support both carers and care workers, in addition to facing ethical problems themselves. They should have access to ongoing education to help them in both these roles. Education in ethical decision making, however, should not be limited to those with ‘professional’ roles: care workers are required to respond to ethical problems as part of their daily work, and should have access to the ongoing education needed to equip them to respond appropriately. All those involved in direct care should also have access to forums for sharing and receiving support in making ethical decisions (paragraph 6.3).</p>

<p>Dementia 12</p>	<p>We agree that people with newly diagnosed dementia and/or their carers should receive written information about their condition and available treatment and support options in their local area.</p> <p>There is ample evidence that, in many cases, people are presented with a diagnosis of dementia and simply told to come back in a year's time. It was argued forcefully in one of our fact-finding meetings with people in front-line dementia care that such a lack of information and support in the immediate aftermath of diagnosis is simply morally wrong. We agree (paragraph 3.26). Access to supportive care, including appropriate information, emotional support, and a variety of forms of practical support, is essential for people to live well with dementia, making the most of all their retained abilities. People also need help in accessing what is inevitably a fragmented support system, given the wide range of health and social services that people with dementia and their families may potentially use.</p> <p>We suggest that an important element will be the identification of a single individual to liaise with the person with dementia and their family, and with whom a trusting relationship can develop. We welcome the proposal in the English dementia strategy to pilot possible models of 'dementia care advisers', whose role would be to help people diagnosed with dementia access appropriate services and support. We suggest that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible (paragraph 3.27).</p>
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**PLEASE NOTE:** The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion of the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.