

**National Institute for Health and Clinical Excellence**

**NICE pilot quality standards for social care:**

**Consultation on the draft quality standard for Dementia: Supporting people to live well with dementia**

**Closing date: 5pm – 16 October 2012**

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Are you happy to be named as a consultee to the Quality Standard on the NICE website? Yes	
For information about endorsing quality standards please visit <a href="http://www.nice.org.uk/guidance/qualitystandards/indevelopment">http://www.nice.org.uk/guidance/qualitystandards/indevelopment</a>	

Please provide comments on the draft quality standard using the forms below, putting each new comment in a new row.

When feeding back, please note the section you are commenting on (for example, section 1 Introduction). If commenting on a specific quality statement, please indicate the particular sub-section (for example, statement, measure or audience descriptor). If your comment relates to the standard as a whole then please put 'general'.

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 standard.

Please add rows as necessary.

Section	Comments
	<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>).</p> <p>Paragraph numbers in brackets refer to paragraph numbers in the report.</p>
Draft quality statement 1 - statement	<p>We agree it is important that people who are concerned that they or someone they know may have dementia are listened to and have opportunities to discuss such concerns.</p> <p>This is very much in line with the conclusion of the Council's report that people should have access to good quality assessment and support from the time they, or their families, become concerned about symptoms that relate to a possible diagnosis of dementia. We caution, however, that the timeliness of a diagnosis will depend on the person and family concerned. We also emphasise that uncertainties about diagnosis should never be used as an excuse not to communicate openly with a person who is aware of changes in themselves and is actively seeking explanations (paragraph 3.18).</p>
Draft quality statement 1 – audience description	<p>A further suggestion the Council makes is applicable to <b>social care and healthcare staff</b>. We concluded that doctors responsible for communicating a diagnosis of dementia should actively encourage the person with dementia to share this information with their family, making clear that the diagnosis is of importance to those providing informal care and support, as well as to the individual concerned. Practical ways in which professionals could promote information sharing in this way include encouraging the person to attend appointments with a friend</p>

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	<p>or family member they trust, so that all information is given to both parties together; being willing to listen to those concerned about the person with dementia; and if necessary acting as an intermediary within the family (paragraph 3.23).</p>
<p>Draft quality statement 3</p>	<p>One of the main conclusions of the Council's report was that people supporting and caring for people with dementia need much more support in tackling the ethical problems that they meet every day. We therefore welcome the proposal for a local adviser who would provide information and about dementia and how to access support.</p> <p>In our report we suggested that there is a strong ethical justification for such a role to be introduced throughout the UK as soon as possible. We think there is a clear case for providing help for people to access what is inevitably a fragmented support system, given the wide range of health and social services which people with dementia and their families may potentially use. We agree that a key element will be the identification of a single individual to liaise with the person with dementia and their family (paragraph 3.27).</p>
<p>Draft quality statement 4 – statement</p>	<p>We strongly agree that people living with dementia (as long as they have capacity to do so) and their carers should have choice and control in decisions affecting their care and support. We support any means by which people with dementia can be supported to help them take part in decisions as much as possible.</p> <p>The Council very much welcomes the increasing emphasis on services which are flexible and appropriate to the individual and which enable them to live well with dementia – an approach based on respect for the needs, preferences and personhood of the individual person with dementia. Clearly, the development of a particular level of high-quality services will be dependent in part on resources, both in terms of money and in terms of a workforce with the appropriate skills. However, it is our view that 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</p>

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	<p>what <i>they</i> value most. Some people who have difficulty doing their own shopping, for example, may prefer to go shopping with a home care worker, rather than having the shopping done for them. Similarly, in some cases where the person with dementia needs more intimate personal care in the home, in terms of washing, dressing and using the toilet, but has a carer able and willing to provide this support, the person and their family may best be supported by offering other forms of assistance instead of insisting that only personal care is available. Responding to need with this degree of flexibility does not necessarily involve increasing budgets, or making difficult trade-offs between the needs of one group and the needs of another (paragraph 3.31).</p>
Draft quality statement 4 – audience description	<p>The Council's report also suggests that the appropriate attitude of <b>professionals and care workers</b> 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>
Draft quality statement 5 – statement and audience description	<p>We agree that people with dementia should have a care plan that identifies and addresses their specific needs. The needs of carers must also be considered - caring for people with dementia must also involve caring for the carers.</p> <p>The needs of a person with dementia and their carer are often complex and intertwined. In a family, it will rarely be the case that a single person's interests always take priority: rather some consideration will be given to everyone's interests and some degree of compromise found. However, it may be very difficult for a carer genuinely to consider their own interests alongside those of the person for whom they care, even if they know that this is what the person with dementia would have wished. Professionals such as <b>social care staff</b> have an important role to play in supporting carers explicitly to consider their own needs and interests when weighing up difficult decisions, particularly around future care options (paragraph 7.37).</p>
Draft quality	We endorse the involvement of people in the early stages of dementia and their carers in planning their palliative

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statement 7	<p>and end-of-life care.</p> <p>The Council's report highlights the 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>
Draft quality statement 8	<p>In relation to supporting people with dementia to take part in activities, the Council's report highlights the importance of people with dementia remaining active within their existing networks such as lunch clubs, coffee mornings, social events, religious activities and voluntary work. Responses to the Council's consultation showed that many activities can be adapted around the needs of a person with dementia (paragraph 4.22), and that in practice, it is likely to be the <i>attitudes</i> of all involved (people with dementia, carers, those managing services and the general public) that determine the extent to which people with dementia can continue to participate in activities they enjoyed before they developed dementia (paragraph 4.24).</p> <p>We strongly agree with a focus on activities that are of interest, and chosen by, the person with dementia.</p>
Draft quality statement 9 – statement and audience	<p>In relation to supporting people with dementia to maintain relationships, the Council's report sets out an ethical framework for dementia, which includes promoting interests in autonomy. Enabling and promoting autonomy involves enabling and fostering relationships that are important to the person. The interests of the person with dementia, including their autonomy interests, are closely linked to the interests of those close to them, and</p>

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description	<p>particularly to the interests of their family and friends who are caring for them. This is an important reason why carers should receive advice and support, and this in itself can be helpful to the person with dementia as a way to enhance their autonomy (paragraph 2.32).</p> <p>A key focus of the report is the importance of normalising dementia wherever possible, so that people with a diagnosis of dementia can participate, to the extent that they themselves wish, both in activities which reflect their general interests and in ‘dementia-specific’ services. However, it is important to go one step further and recognise that people with dementia are not only able (and morally entitled) to participate in the activities of wider society: they are also able to make an active <i>contribution</i> to those activities, particularly in the earlier stages of their dementia. One respondent to our consultation highlighted the possibility of people with dementia taking an active role in volunteering, with support available as necessary, while another suggested that day centres providing services and support for people with dementia should be run by participants (paragraph 4.27).</p>
Draft quality statement 10	<p>We agree that people living with dementia must be supported to access services that help maintain their physical and mental wellbeing.</p> <p>A person’s overall ‘well-being’ includes their moment-to-moment experiences and more objective factors such as their level of mental ability. Our view is that both effects are relevant in coming to a decision, and that the strength of each effect should be closely considered when determining whether or not certain services would enhance the person’s overall well-being (paragraph 2.38).</p>
Draft quality statement 11	<p>The Council’s report considered a range of assistive technologies including ‘smart homes’ with built in technologies to react to the movements and activities of the person with dementia in their own home. Whilst we welcome the focus on people’s <i>specific needs</i>, and broadly recognise the potential of adapted accommodation in supporting people with dementia to live a better life, the report raises additional considerations in relation to such assistive technologies:</p>

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	<p>It is clear that technological devices of various types have the capacity to contribute to a person’s autonomy and well-being interests. However, use of technology in these ways also has the capacity to act in ways which go <i>against</i> these interests. Concerns raised by consultation respondents about the use of assistive technologies in caring for people with dementia were mainly related to privacy, stigma (particularly with reference to tracking devices), and the worry that the use of such technology would replace, rather than be in addition to, valuable human care. All these issues have the potential to affect both a person’s autonomy (for example through feeling controlled, being under surveillance or feeling devalued) and their well-being (for example through impoverished human relationships (paragraph 6.8).</p> <p>The involvement of the person with dementia in choosing or rejecting particular forms of technology is also critical. Where a person actively decides or agrees that a particular form of surveillance device will enable them to live an easier or more fulfilling life, that decision enhances their autonomy. Where a person has such a device imposed on them, either for the convenience of others or because they are seen as being incapable of being involved in the choice, then there is a far greater risk that their autonomy will be undermined. In practice, this suggests both that early discussion about the possibilities of using technology in everyday life is beneficial, and that those proposing such technology (whether carers, professionals or care workers) should do their very best to involve the person in the decision in whatever way is possible or appropriate (paragraph 6.10).</p> <p>The Council recommends that if a person with dementia lacks the capacity to decide for themselves whether to make use of a particular technology, the relative strength of a number of factors should be considered on a case-by-case basis, including:</p> <ul style="list-style-type: none"> <li>• the person’s own views and concerns, past and present, for example about privacy;</li> <li>• the actual benefit which is likely to be achieved through using the device;</li> <li>• the extent to which carers’ interests may be affected;</li> <li>• the dangers of loss of human contact (paragraph 6.12).</li> </ul>

Please also consider the general and specific questions relating to this quality standard on the next page:

General questions	Comments
How will this quality standard improve the quality of care provided?	We very much welcome the emphasis of this quality standard (as evinced in particular by statements 4, 5, 7 and 8) on providing care which is flexible and tailored to the individual, based on respect for the needs, preferences and personhood of the individual person with dementia. We consider this to an integral part of an <b>ethical</b> approach to care for people with dementia.
What important areas of care or services, if any, are not covered by this quality standard?	This quality standard does not include a statement on addressing stigma or promoting inclusion in <i>everyday</i> society. This is something that the Council places strong emphasis on: the equal value of people with dementia and the importance of acting in solidarity with those affected by dementia. We believe there is a clear moral imperative to tackle the stigma which is still pervasive in dementia. Such stigma leads not only to difficulties and delays in accessing services but also to exclusion from mainstream society. For dementia to be truly normalised, it needs to become an accepted, visible part of our society, in the same way that physical disability is increasingly recognised as part of the norm. Our report draws attention to the responsibility of service providers such as shops, restaurants and leisure facilities to make 'reasonable adjustments' to enable people with dementia to access their services.