

Dementia: Supporting people with dementia and their carers in health and social care

Consultation on draft scope of NICE clinical guideline (CG42)

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The National Institute for Health and Care Excellence (NICE) is in the process of updating its existing clinical guideline on ‘dementia: supporting people with dementia and their carers in health and social care’ (CG42). As part of this, stakeholders have been invited to comment on the draft scope of the forthcoming guideline, which is due to be published in March 2017. Dementia is one of the most important challenges facing our ageing society, where a growing number of older people live with the condition. Age UK welcomes the opportunity to comment on this draft scope, and help ensure the new guideline clarifies the pathway for those who receive a diagnosis of dementia and their families.

Key points and recommendations

Age UK’s detailed comments can be seen in the NICE proforma below. Key points from our response include:

- Supporting the stronger emphasis within the draft scope on assessing and managing multiple long-term conditions (co-morbidities) in people with dementia;
- Ensuring that the new version of the NICE guideline clarifies the pathway following diagnosis by setting minimum requirements for high-quality post-diagnosis support.

Age UK’s comments

Please note:		Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly or arrive after the deadline. Developing NICE guidance: how to get involved has a list of possible areas for comment on the draft scope.	
Stakeholder organisation (if you are responding as an individual rather than a registered stakeholder please state name here):		<u>Age UK</u>	
Name of commentator (if you are responding as an individual rather than a registered stakeholder please leave blank):		<u>Léa Renoux</u>	
Comment No.	Page number or ‘general’ for comments on the whole document	Line number or ‘general’ for comments on the whole document	Comments Insert each comment in a new row. Do not paste other tables into this table, as your comments could get lost – type directly into this table.
Example	3	55	The draft scope currently excludes people who have already been diagnosed. We feel this group should be included because....

1	General	General	Age UK welcomes the opportunity to comment on the draft scope of the forthcoming update of the NICE Clinical Guideline on dementia (CG42). Dementia is one of the most important challenges facing our ageing society, where a growing number of older people live with the condition. Updating the NICE guideline offers a welcome opportunity to reflect changes and developments in the sector, but also to clarify the pathway for those who receive a diagnosis of dementia and their families.
2	General	General	Age UK particularly supports the stronger emphasis within the draft scope on assessing and managing co-morbidities in people with dementia, as studies have shown that around 95% of people with dementia live with at least one other health condition (Barnett K et al, <i>The Lancet</i> , 2012). This is particularly important as evidence suggests that people with dementia do not have the same access to treatment and monitoring for conditions such as visual impairment and diabetes as those with similar comorbidities but without dementia (Bunn F et al, <i>BMC Medicine</i> , 2014). The high rate of comorbidity – with the average of 3-4 comorbidities accompanying dementia (Poblador-Plou B et al, <i>BMC Psychiatry</i> , 2014) – also emphasises the need to provide person-centred, integrated care services which are suited to catering for a wide range of individual needs within a local population, and we welcome the renewed focus on integrated care within the scope of the guideline.

3	6	17	<p>While we understand that elements of what constitute good post-diagnosis support may be scattered throughout different sections of the guideline (e.g. advice on emotional support or managing functional features), we are concerned the draft scope may miss out on an opportunity to clarify the pathway following diagnosis of dementia, and set a benchmark for what good post-diagnosis support should look like. At the moment, access to help and advice on what happens after a diagnosis and the support available through the journey remains patchy throughout the country, and appropriate support is too often lacking (All-Party Parliamentary Group on Dementia, <i>Building on the National Dementia Strategy: Change, progress and priorities</i>, 2014). For example, a recent survey by the Dementia Action Alliance found that 89% of people with dementia felt they did not have enough information to get what they need following diagnosis (Dementia Action Alliance, <i>Annual report 2014/2015</i>, 2014).</p> <p>Comprehensive advice and support after diagnosis is, however, important in order to equip individuals and their families with the tools, connections, information and plans they need to live with dementia as well as possible, and prepare for the future, when they are ready to do so. Unlike Scotland, there are still no minimum requirements of post-diagnosis support in England – although we understand that NHS England is currently looking at this issue (NHS England, <i>Business Plan 2015/16</i>, 2015) – and it is unclear whether responsibility for support should sit with the NHS or social care, or both. We also know that a number of GPs still do not diagnose dementia in people because they feel that ‘nothing can be done to support them’ (Department of Health, <i>Dementia – A state of the nation report on dementia care and support in England</i>, 2013). Tackling inadequate provision of post-diagnosis support as well as raising awareness among GPs of what services are available locally therefore seems essential to encouraging timely diagnosis and support for people with dementia.</p> <p>This is why Age UK believes that there should be a national minimum standard of good-quality post-diagnosis support for people with dementia and their carers. Specifically, ensuring that the new version of the NICE guideline covers a set of minimum requirements for high-quality support following diagnosis would be helpful in clarifying and spreading good practice in this field, building on recommendations from existing relevant NICE quality standards (QS1 and QS30). This should include recommendations around the type of information, advice and support that should be provided to people with dementia and their families following diagnosis, and the ways in which these should be delivered (e.g. timings, level of detail, presentation, etc), recognising the current role of the voluntary sector in providing such support. We would therefore recommend that a key issue be added to section 1.5 on ‘key issues and questions’, below line 17 on page 6, as follows: ‘Provision of good-quality post-diagnosis support’. Questions to explore may include:</p> <ul style="list-style-type: none"> - What type of information, advice and support should be provided to individuals and their families following diagnosis? - How should post-diagnosis support be provided in practice, e.g. who should be responsible for it and in which manner should this be provided?
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