

## SIGN guideline on Dementia

Consultation report on: Plain language version

<b>The consultation</b>			
Open consultation took place from 26 June to 24 July 2023. Interested stakeholders were invited to complete a survey to provide feedback on the draft information. Eleven individuals and representatives from third sector organisations took part in the consultation exercise. All participants completed a DOI form.			
<b>1. Please tell us about the way the booklet is written. Is the language and tone appropriate?</b>			
<b>Responses:</b>			
<b>Yes – 100%</b>			
<b>No – 0%</b>			
	<b>Feedback</b>	<b>Group Response</b>	<b>Editorial response</b>
	The language is clear and appropriate. The document is quite long and a clear summary/introduction and contents page would be helpful	Agree this is a long document. When we met people with dementia and carers they advised that they would prefer all the information with colour codes sections, index or similar to make this user friendly. Comms/graphic design to advise.	Happy to support this suggestion
	The guideline is written well and easy to read, with relevant and useful information. One person noted that the quotes don't seem to fit very well within the diagnosis section but this may be different once it is fully formatted.	Removed carer quote on worrying about future as this is in 'How might I feel after diagnosis' section. The quote "I may have dementia but I'm still the same me". (Person with dementia) has been moved to PDS section to sit with positive brain health message.  Page 2 – statement that it will be useful for carers etc tweaked slightly so quote on that page fits better.	✓
	Sensitively written	Thank you	✓

## SIGN guideline on Dementia

Consultation report on: Plain language version

	Very good use of simple language, rather than medical terminology.	Thank you	✓
	Inclusive language is always used. It's a hard thing to do because you need to give people the facts while being sensitive at the same time. Really well done. Not sure how else you could give the information.	Thank you. We co-produced this with people with dementia and carers to help us to get the language right.	✓
	The booklet is overlong for many readers.	The people we worked with to develop this felt it had to be long as they wanted all the information to allow people to read the sections at various stages of care. They suggested that we also produce an Easy Read version for people who require something shorter and simpler. We will do this.  Cut down text slightly in table of tests.	✓
<b>2. Please tell us what you think of the content.</b>			
<b>Does the content help people understand what the latest research and good practice is in dementia?</b>			
<b>Responses:</b>			
<b>Yes – 100%</b>			
<b>No – 0%</b>			
	<b>Feedback</b>	<b>Group Response</b>	<b>Editorial response</b>
	Content is good. I would however suggest that page 5 might be amended to state 'that MAY impact' as not all dementias affect memory or indeed the other cognitive domains mentioned. As this is a booklet about dementia assessment, I feel it would be important to state that not all memory problems equal dementia and that there are other non-dementia causes and	Changed to 'can'.	Agree with decision not to call out that not all memory loss equates to dementia.

## SIGN guideline on Dementia

Consultation report on: Plain language version

	that this may be the conclusion of the assessment. An additional resource which might be helpful to signpost to is <a href="http://rarementiasupport.org">rarementiasupport.org</a> -this particularly talks about some types of dementia that do not predominantly affect memory		
	We believe that the content within the guideline is clear and will aid people to understand recent research and good practice. However, it may be worthwhile to highlight and give clear reference to where someone might find further information.	We have signposted to relevant sources in Where can I find out more section and linked to resources in some sections where the group felt it was helpful.	✓
	This is very helpful, for someone who wouldn't have had prior knowledge of Dementia.	Thank you	✓
	Good resource. Table of tests with evidence symbols helpful. Lets people know that not everyone will get some scans or see a specialist so good it's upfront about that. Last thing you want is people wondering why they are not getting things while some things will be done in limited number of cases. But then should everyone not be getting the same? Is that not the whole point of the guideline?	Thank you. Yes, we produce guidelines to reduce variation in practice but sometimes not all Health Boards have the same equipment such as scanning machines.	✓
	Good quotes which will be helpful to the carers/relatives.	Thank you	✓
	It does but not sure if things will change. It's so hard to get support after diagnosis. We were banging on and on and no one gave us answers or helped. I hope this document people know what they are entitled to and makes difference	We hope that our information will empower and support people to ask for the help they are entitled to.	✓
	But how may it be used, and implemented? How will SIGN gather feedback from the territorial health boards so that use and implementation has a useful result e.g. in terms of keeping people with dementia safely in the community for as long as	This guideline will be promoted widely when published. A webinar is being held to launch this and people working in dementia settings will be invited. Health Boards will be notified of	✓

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	possible?	the publication.	
	<ul style="list-style-type: none"> <li>- I don't think anyone should be given a diagnosis based on a rapid direct test that takes 5 minutes- these are screening tests only and not indeed to be used to diagnose.</li> <li>- Extended testing usually takes a minimum of 1 hour</li> <li>- I think the way the diagnosis section is written places too much emphasis on cognitive assessment - rather than on the skills in pulling together the history, the family, the health status etc - too simplified as is currently written</li> <li>- we often don't use scans as people would tolerate them or don't want them</li> <li>- blood tests should be mentioned as are often used to rule out reversible causes of cognitive changes</li> <li>- discuss of driving post-diagnosis should be added</li> <li>- feelings after diagnosis should could also include relief (particular for those who have been frightening for a diagnosis) and also nothing / numbness initially is common</li> </ul>	<p>Pg6&amp;7 have been amended in the draft to hopefully make it clearer that the table refers to the types of tests that may be part of a wider assessment and that a rapid test on its own should never be used to diagnose dementia. Also changed some of the content of the table so that mention of how the test is used is not included to hopefully further reduce possible confusion</p> <p>Amended so information about seeing a specialist is on the one page (page 8) and table of scans on one page (page 9).</p> <p>The main SIGN dementia guideline states "Blood tests should be undertaken to exclude reversible causes of cognitive decline if these have not already been addressed." So have added 'blood tests' to the list of things that may be included in an assessment on pg6</p> <p>Two sentences added to first paragraph in How might I feel after a dementia diagnosis? 'It is common to feel nothing or numbness initially. It is also common to feel relief if you have been concerned for some time and just want a diagnosis to confirm what is wrong with you.'</p>	<p style="text-align: center;">✓</p>

## SIGN guideline on Dementia

Consultation report on: Plain language version

		We have mentioned support to stay safe including driving in 'What support can I expect after diagnosis' section.	
<b>3. What is your view on the amount of information presented in the booklet?</b>			
<b>Responses:</b>			
<b>Too much – 22.22%</b>			
<b>About right – 66.67%</b>			
<b>Too little – 11.11%</b>			
	<b>Feedback</b>	<b>Group Response</b>	<b>Editorial response</b>
	We have concerns that there is a lack of information about Frank's Law and the right to free personal care. As an organisation working nationally to improve access to and quality of social care this right is often confused in conversations about self-directed support so it is important that people reading this booklet have full understanding of their rights.	Outwith guideline scope but have added a bullet into 'Provision of information' section in clinical guideline as something to be discussed with people. Bullet point added to information box about on page 18 of plain language version on where to find information on Human Rights, including access to free personal care.	✓
	We have heard from several people that although the booklet is thorough, and may prove useful to carers or third sector organisations, an easy read booklet with headlines and pictures may be more accessible and beneficial to some people.	Agree and we plan to do this.	✓
	The document gives all the information that people will need. Wouldn't want a short leaflet with half the information. People can choose what and what not to read. My husband was keen to read everything and wanted the same information that I as his care was getting so good it's given in this way.	Thank you	✓
	Enough to allow people to be informed, without being too much information. It is laid out nicely to allow it be separated into smaller chapters.	Thank you	✓

## SIGN guideline on Dementia

Consultation report on: Plain language version

	Again this is hard thing to get right. If you offer the information, people with dementia and their families can choose which bits to read.	Thank you	✓
	It is very well-intentioned, but all too long. Some bits would so help unpaid carers come to terms with their hard work up to a diagnosis and thereafter, but it is daunting.	We co-produced this with people with dementia and carers. They wanted to provide all the information from the guideline and people could choose which bits to read and when.	✓
	There is a lot of information in the research evidence sections. Is it possible to condense this? Too much information can be overwhelming and may make it difficult for the reader to process.	The purpose of plain language versions of guidelines are to share the research evidence so we need these. People with dementia and carers attended a pre consultation meeting and advised that we should provide all information from the guideline to give people full access.	✓
<b>4. What is your overall impression of the booklet?</b>			
	<b>Feedback</b>	<b>Group Response</b>	<b>Editorial response</b>
	It's a justification of work done rather than something to enable territorial health boards and their social work partners to give best support. And the booklet seems to believe that all the described support is available, which it isn't.	We have acknowledged that support will depend on what's available in Health Boards. Highlighted in bold for emphasis that the recs may be conditional on resources in each HB (page 3)	✓
	Very well put together document. Were doctors involved? It will only help though if people know it's there. Will doctors give this to patients?	Thank you. Yes, a range of health and social care professionals were involved in the production of this. Agree, people need to know this is available. We will promote this widely and the third sector organisations we worked with are keen to promote this for us.	✓

## SIGN guideline on Dementia

Consultation report on: Plain language version

	Clear, concise, relevant and informative. It is very versatile, useful for those getting investigations done without scaremongering and ideal to inform carers of support they can access before, during and after diagnosis.	Thank you	✓
	Useful information that will be appreciated by the people with dementia & their carers.	Thank you	✓
	Very well written document and easy to understand. Hasn't been dumbed down too much which is really not what people want.	Thank you	✓
	Useful content, very well written, and easy to read. The booklet will be helpful to those caring for someone with dementia	Thank you	✓
	Overall it is a very thorough piece of work. Some of our lived experience members did note however that there are many words, and few pictures. It has also been noted that an audio version of the booklets should be available online. This will ensure the information is widely accessible. One unpaid carer notes that they would like to see a mention of access to respite care and rehabilitation support, as well as transition support into hospitals or care homes. They also note the importance of signposting information for funding and the benefits process.	<p>We are currently seeking advice from our comms department re producing an audio version as people with dementia were very keen on this at our pre consultation meeting.</p> <p>Guideline does not discuss funding for benefits process but we have signposted to resources where people get information about benefits. We have stated that where people can get information on benefits process should be discussed. Guideline does not make recommendation on transition to care homes/hospitals but we have said in post diagnostic support section that this information should be discussed when moving from one setting to another.</p>	<p>Agree we should provide audio version.</p> <p>✓</p>

## SIGN guideline on Dementia

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		Access to respite care and rehab mentioned in information box page 18, bullet point 6. Added sentence under 'Care Information Scotland' to say they offer information for carers on how to access respite care (page 34).	
	Some mention of positive/brain health would be good addition for those assessed to have dementia and those not.	Agree – added information box in to PDS section signposting to Brain Scotland's website (page 16).	✓
	I found the different boxes and colours relating to research evidence and clinical experience detracted from the content and made it difficult to follow.	This is an evidence based layout that has been tested with a range of users. The idea of the boxes was to split the information up and show which parts were evidence based and which parts were generic information. The Easy Read version will not have information in boxes or show the strength of the evidence.	✓
	Well written, about the right length. I like the quotes. I think the diagnosis section perhaps needs more work	Thank you. Suggestions on how to improve the diagnosis section are welcome.	✓
<b>5. Which image would you prefer for the front cover?</b>			
<b>Responses:</b> <b>No preference – 33.33%</b> <b>No image – 11.11%</b> <b>Specific image from draft – 44.44%</b> <b>Collage of all images – 11.11%</b>			
	<b>Feedback</b>	<b>Group Response</b>	<b>Editorial response</b>
	A positive brain health image	When we spoke to people with dementia and carers at pre consultation meeting they suggested avoiding any images of the brain.	Agree you should stay with what you heard at the pre consultation meeting



## SIGN guideline on Dementia

Consultation report on: Plain language version

	<p>One unpaid carer noted that the pictures of the brain were not necessary but that other images were better. When deciding which images to include, we note they should be simple and unbiased.</p> <p>Images used traditionally tend to be of old people with wrinkly hands and grey hair, which may lead to unintended "ageism". Dementia affects all ages.</p>	<p>Thank you</p> <p>Agree, we need to avoid this.</p>	<p>✓</p>
	<p>Image 4</p>	<p>Thank you</p>	<p>✓</p>
	<p>Image 6. The other images are too "happy". I have given many people the diagnosis of dementia &amp; it's a very worrying time for patients and their relatives. Some people are upset &amp; tearful. Image 6 gives the impression that the diagnosis will involve the whole family, and there are things the whole family can do. Gives the right message.</p>	<p>Thank you</p>	<p>✓</p>
	<p>Dementia doesn't have one look, so a collage of different scenarios would best</p>	<p>Thank you for your suggestion. The group like this idea and feel the images are positive, diverse, show people engaging with meaningful activities and having fun.</p>	<p>✓</p>
	<p>Avoid any negative images. The ones you have as options are all fine</p>	<p>Thank you</p>	<p>✓</p>
	<p>Please no image of a person or people.</p>	<p>Thank you</p>	<p>✓</p>