SIGN guideline for Assessment, diagnosis, care and support for people with dementia and their carers

COMMENTS RECEIVED FROM EXTERNAL REFEREES AND OTHERS

All reviewers submitted declarations of interests which were viewed prior to the addressing of comments.

Invited reviewers			
Initials	**Name**	**Role**	**Type of response and declared interests**
AT	Dr Amanda Thompsell	Consultant Old Age Psychiatrist, NHSE&I and West London Mental health NHS Trust	*Individual response.* *Personal financial interest* - For transparency I am a non-executive director of Target Healthcare REIT (they build purpose built care homes) but I do not see any conflicts of interest I am also national specialty advisor on older adults' mental health for NHSE&I but again I do not see any conflicts of interest.
AFr	Ms Anthea Fraser	National Professional Lead for Social Services, Healthcare Improvement Scotland	*Individual response.* Nothing declared.
EH	Ms Elaine Hunter	National AHP Consultant, Alzheimer Scotland	*Individual response.* Nothing declared.
EV	Professor Emma Vardy	Consultant Geriatrician, Salford Care Organisation (part of the Northern Care Alliance NHS foundation trust), Stott Lane, Salford, M6 8HD and Honorary Clinical Chair, Manchester Academic Health Science Network, School of Health Sciences and NIHR Applied Research Collaboration Greater Manchester (NIHR ARC GM) Health Ageing theme, University of Manchester, Oxford Road, Manchester, M13 9PY	*Individual response.* Nothing declared.
JE	Professor Jonathan Evans	Professor of Clinical Neuropsychology, University of Glasgow	*Individual response.*

Invited reviewers			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Non-personal financial interests - Co-author of a training manual relating to cognitive rehabilitation in dementia produced by NHS Education for Scotland. Co-developer of an online training programme relating to the Addenbrookes Cognitive Examination.
JC	Professor Judith Carrier	Professor Primary Care, Cardiff University	*Individual response.* Nothing declared.
JH	Mr Julian Heng	Planning and Development Manager, NHS Greater Glasgow & Clyde	*Individual response.* Nothing declared.
JM	Dr James Morton	General Practitioner, Glasgow West Medical Practice, NHS Greater Glasgow & Clyde	*Individual response.* *Personal financial interest* - Employment: Glasgow West Medical Practice, NHS Greater Glasgow and Clyde and NHS Education for Scotland. *Non-financial personal interest* - SIGN Council member. RCGP West of Scotland Faculty Board. RCGP West of Scotland Sustainability Lead.
JS	Dr Juliet Spiller	Consultant in Palliative Medicine, Marie Curie Hospice Edinburgh	*Individual response.* *Non-financial personal interests* - Published work on Anticipatory care planning *Any other interest of relevance* - Chair of Scottish ReSPECT collaborative and vice chair of RCUK ReSPECT sub-committee
MP	Dr Marie Prince	Consultant Clinical Psychologist, GGC Young Onset Dementia Service	*Individual response.*

Invited reviewers			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Nothing declared.
MR	Martin Robertson	Person with lived experience	*Individual response.* Nothing declared.
SP	Dr Suvankar Pal	Consultant Neurologist/Senior Clinical Lecturer, University of Edinburgh	*Individual response.* Nothing declared.

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
AMcK	Alison McKean	AHP Post Diagnostic Lead, Alzheimer Scotland	*Individual response.* Nothing declared.
AF	Angela Flynn	Advanced Nurse Practitioner, NHS Greater Glasgow and Clyde	*Individual response.* Nothing declared.
ALD	Anne-Lise Dickie	Professional Lead, commenting on behalf of Adult Learning Disability Service- Argyll & Bute	*Group response.* *Nature and purpose of your group or organisation* - Specialist Adult Learning Disability Health Team covering Argyll & Bute area of NHS Highland *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - the Draft guideline will continue the health Inequalities for adults with a Learning Disability (LD) and Dementia. If Dementia services are to be improved for everyone -it is important that all aspects of the service need to be considered. there are currently

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			very few effective assessments that can support diagnosis, accessing medical intervention can be very slow to be effective and most local Dementia services that are set up often exclude adults with a LD. Having a learning disability seems to allow services to exclude and as long as Sign Guidelines etc also do not advise and make recommendations of the extra considerations that are needed for this group of individuals it will allow primary and secondary care services also to exclude them from Dementia services through lack of knowledge. Conversely if a little bit of information is known such as the fact the majority of adults with a learning disability who do have Dementia will show signs at a much younger age then that can become the reason for all health and behavioural issues going forward without any proper assessment. There is research and work nationally on Adults with LD and Dementia so unsure if this was considered. No consent given for publication.
Anon	Anonymous	Person with lived experience (name not given)	*No declarations and no consent given.*
CS	Carleen Smith	SDRC Officer, commenting on behalf of Scottish Dementia Research Consortium	*Group response.* *Nature and purpose of your group or organisation* - The Scottish Dementia Research Consortium are a membership organisation including researchers, healthcare professionals, people living with dementia and anyone else with an interest in research the purpose of which is to celebrate and support all dementia research taking place across the country. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - The Scottish Dementia

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Research Consortium (SDRC) are pleased to see the new dementia guidance from SIGN. The guidelines are of the high quality we expect from SIGN and clearly a lot of work has went into creating the materials. However, the recommendations in the document are limited due to a lack of relevant research evidence. The SDRC are acutely aware of the need for more, and better quality, primary dementia research. It should be a wake up call to researcher funders and policy makers that we still do not have sufficient research evidence to guide clinicians on even fundamental issues like which cognitive test to use or how to manage common complications of dementia. We are entering an uncertain period for research in Scotland and we are aware that research support will be limited. However, if Scottish Government and other research funders want to make a real difference to the lives of people affected by dementia, then investment in research will be money well spent.
DB	David Berry	Dementia Policy Officer, commenting on behalf of Scottish Government	*Group response.* *Nature and purpose of your group or organisation* – Scottish Government *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - Help inform policy development and evidence base
DC	Dave Colville	Nuclear Medicine Physician, Clinical Lead for PET CT services NHSGGC, commenting on behalf of Scottish Clinical Imaging Network - PET CT Group	*Group response.* *Nature and purpose of your group or organisation* - National PET CT Group representing all four Scottish PET CT Centres with responsibility in regards to the provision and development of PET CT services in Scotland

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity? - Draft information in this guideline does not reflect the current service position in Scotland with regards to PET services and availability. Although some aspects would be aspirations for future service, the implementation of the guideline in its current version is unfortunately not feasible and has the potential to overwhelm the national PET service with a detrimental effect on both cancer and dementia services across Scotland.
FG	Fay Godfrey	Post Diagnostic Lead, Alzheimer Scotland	*Individual response.* Nothing declared.
FM	Fiona Mack	Pharmacist, Royal Edinburgh and Associated Services	*Individual response.* Nothing declared. No consent given.
GH	Gayle Henry	Senior Dementia Consultant, commenting on behalf of Dementia Service Development Centre, University of Stirling	*Group response.* *Nature and purpose of your group or organisation* - Charity linked to Stirling University providing national and international consultancy in dementia care and design. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - Draft information in this Healthcare Improvement Scotland position statement will have no discernible impact on the function or productivity of our organisation. We will utilise it when delivering education on best practice in dementia care as a reference.

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
GB	Gillian Bowie	Consultant Psychologist, NHS Dumfries and Galloway	*Individual response.* Nothing declared.
GMc	Gillian McMillan	Advanced Dietetic Practitioner, Dept Nutrition and Dietetics (Mental health), Houldsworth Centre, Wishaw - NHS Lanarkshire	*Individual response.* Nothing declared.
JK	Jacqueline King	Professional Nurse Lead - Mental Health Services, commenting on behalf of NHS Greater Glasgow and Clyde - Quality and Excellence in Specialist Dementia Care (QESDC) Group	*Group response.* *Nature and purpose of your group or organisation* - Health Service. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - Draft information will have direct impact on clinical practice and provision of dementia care within Scotland
JLJ	Jane-Louise Jackson	Principal Clinical Psychologist, NHS GG&C	*Individual response.* Nothing declared.
JCa	Jill Carson	Consultant in Public Policy, Alzheimer Scotland	*Individual response.* *Non-financial personal interests* - Publication of various papers on post diagnostic support for dementia.
JB	Janice Birrell	Person with lived experience	*Individual response.* Nothing declared. Consent only given for responses attributed.
KP	Kate Pestell	Head of Arts Therapies, commenting on behalf of NHS Lothian Arts Therapies Service	*Group response.*

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Nature and purpose of your group or organisation - Psychological therapists - HCPC registered. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - The Arts Therapies are not referenced in the statement and so those needing access or those commissioning will not be aware of the benefits Arts Therapies, especially, Music Therapy, can bring to this population of people.
KA	Kerry Anderson	Nurse Consultant Learning Disabilities, NHS Grampian	*Individual response.* Nothing declared.
LH	Lynsey Homer	CPN, East Lothian	*Individual response.* Nothing declared.
MC	Matthew Colyer	Consultant Psychiatrist, NHS Grampian	*Individual response.* Nothing declared.
MH	Maureen Huggins	Person with lived experience	*Individual response.* Nothing declared.
MS	Mehar Shagufta	Policy & Public Affairs Officer, commenting on behalf of Playlist for Life	*Group response.* *Nature and purpose of your group or organisation* - Enabling personalised music support for people living with dementia. *How might the statements and recommendations in the*

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			draft SIGN guideline impact on your organisation's functions/status/productivity? - Our organisation would be strengthened by the uptake of personalised non-pharmacological management of dementia
PMac	Pamela MacKay	Senior Educator, Mental Health, Learning Disability and Dementia Team, NMAHP Directorate NHS Education for Scotland, commenting on behalf of Mental Health, Learning Disability and Dementia Team, NMAHP Directorate NHS Education for Scotland.	*Group response.* *Nature and purpose of your group or organisation* - Education and training body for health and social care. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - The Draft information in this Health Improvement Scotland position statement will impact on the content of some of our dementia related training materials.
PC	Peter Connelly	Consultant Psychiatrist, NHS Tayside	*Individual response.* *Non-personal financial interests* - Investigator in clinical trials sponsored by Biogen, Eisai, Bial, Abbvie, Roche, Novartis, Novo Nordisk, University of Edinburgh. *Any other interest of relevance* - Chair, Advisory Panel on Psychiatric Disorders, DVLA
RK	Rebecca Kellett	Speech and Language Therapy Clinical Lead for Dementia, NHS Lothian	*Individual response.* *Non-personal financial interests* - Successful bid for a full time therapist to develop use of the 5 good communication standards in care homes. I am currently supporting the post holder with the project. This came from Government covid recovery money.

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Non-financial personal interests - Created the "Manual for Mealtimes" guidance which is currently being promoted in Lothian and used with the Care Inspectorate. I was also involved in developing the Alzheimer Scotland on line resource "Tips for Talking"
RH	Roanna Hall	Consultant Geriatrician, Royal Infirmary of Edinburgh	*Individual response.* *Non-personal financial interests* - I work with a multi-disciplinary group who diagnose dementia in frail elderly people who are in-patients in Medicine of the Elderly wards.
RB	Dr Rosie Begbie	Principal Clinical Psychologist, commenting on behalf of NHS Greater Glasgow & Clyde Older People's Psychology Service	*Group response.* *Nature and purpose of your group or organisation* - Older People's Psychology Service. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - Draft information in this Healthcare Improvement Scotland position statement will have no discernible impact on the productivity of our organisation but it will undoubtedly impact on the quality of care patients receive across Scotland
TP	Tharin Phenwan	Lecturer, University of Dundee	*Individual response.* *Non-personal financial interests* - Academic member of staff publishing journal papers and presenting conference papers on topic of dementia – University of Dundee – ongoing Non-financial

Open consultation			
Initials	**Name**	**Role**	**Type of response and declared interests**
			Academic institution with broad range of research and teaching work about dementia– University of Dundee – ongoing – specific
YM	Yann Maidment	Dentist, commenting on belhalf of College of General Dentistry	*Group response.* *Nature and purpose of your group or organisation* - Professional body for the dental care team:- representing them(with patient input as well) to stakeholder consultations, highlighting dental implications of wide ranging interventions, dental producing Good practice guidelines and some leadership in relevant domains. *How might the statements and recommendations in the draft SIGN guideline impact on your organisation's functions/status/productivity?* - It is likely that the 3rd option will apply -as oral health and dental care are not specifically mentioned in the guideline (Something that I would seek to address). If some specific mention WAS included, then I feel that the position would shift towards the first option and might lead to a modest increase in uptake of dental services to dementia patients - most of which (I feel- as I have no ready access to data on this)is probably provided in general dental practice, supported by personal carers of these patients. Some care(mostly late-stage) will be provided by special providers in the Public Dental Service.

Section	Comments received		Development group response
	YM	It is a large document - well done, but would be improved by some specific recognition of oral health as part of overall care and support for people with dementia and their carers.	No response required
	AT	My title is incorrect 12.3.2. - Consultant Old Age Psychiatrist in older adult community mental health team West London Mental health Trust , England and National Specialty Advisor older adult's mental health NHSE&I England	Title amended as requested.
	JB	I understand and support the focus on non-pharmacological interventions but the Scottish context, PHS data, for pharmacological interventions needs to be provided with a strong link to NICE Dementia Guideline that does provide guidance on the use of AChE Inhibitors for people with Dementia. If however the guidance is to purely focus on only non-pharmacological interventions then this needs to be made abundantly clear and why.	Thank you. We have now made it clearer that our focus was non-pharmacological intervention, we have provided signposting to relevant national guidelines concerning drugs in dementia. Section 1.2.2 includes: *"The National Institute for Health and Care Excellence (NICE) guideline on dementia: assessment, management and support for people living with dementia and their carers was published in 2018. To avoid duplication this guideline refers to the NICE guideline and other professional agencies where relevant to this guideline. As an example, we do not provide recommendations around the use of cognitive enhancing medication in dementia as the guideline development group agreed with the guidance provided in the NICE guideline."*
	JC	Needs to be clear which studies the JBI appraisal scores are referring too	This is SIGN style that we give a indication of the quality of the body of evidence. So if a number of studies have the same score this is only presented once for brevity. Your feedback will be taken will be taken to SIGN methodology group for consideration of how we present our evidence in future.
	GMc	Although published in 2014 The Alzheimer's Disease International Nutrition in Dementia Review of Evidence remains one of the most relevant resources in relation to nutrition and dementia	We have made it clear in Introduction that the scope of the guidance does not include prevention: 1.2.1 includes:

		https://www.alzint.org/u/nutrition-and-dementia.pdf	*"Prevention of dementia is a rapidly evolving area and would need its own guidance to do justice to the field, and as such was also considered by the guideline development group to be out of scope."* The role of nutrition in treating established dementia is still emerging and we did not find evidence relevant to the key questions prioritised by our group.
	AFr	An excellent document and i really enjoyed reading it, very comprehensive, informative and encouraging. It highlights areas where it would have liked to have gathered more information especially those with living experience	No response required
	MR	guidelines skewed to carers, requires more pateint input/representation; see above	The SIGN team have engaged with a variety of stakeholders including people living with dementia. Despite invitations no person living with dementia was able to join the working groups. We are pleased that people living with dementia engaged with our open sessions (we met with members of the Scottish Dementia Working Group and engaged with people with living experience on the Key Questions and issues for consideration) and have provided written feedback. We will ensure that this is incorporated into the guideline.
	FM	This is a report not a guideline. The recommendations for action how and by how need to be clearer. it is difficult to read by those who are involved in providing care around dementia because it includes so much background information. It is too long to be taken notice of by those at health board level; it needs to be better presented and focused.	We have followed internationally agreed processes in guideline development and standardised SIGN templates. The detail within the guideline is necessary to show the evidence base that supports the recommendations. There will be a quick reference guide and a version for people with lived experience and their families and carers. Extensive editorial has restructured the document and clarified the recommendations and evidence on which they are based.
	KA	Although referenced in some parts of the guideline - it is not clear if people with learning disabilities / Down's syndrome is included. From research we know the health inequalities people with a learning disability experience around differences in diagnosis, treatment, and presentation, including	Thank you for your response. The inequality dimensions and further detail on learning disabilities were covered in section 1.1.4.

		access to post diagnostic support. This contributes to the ever increasing challenges in providing reasonable adjustments and addressing unmet health needs.	We have added more detail on learning disabilities in section 1.2.1: “*There are specific subgroups of the dementia population and types of dementia that have highly specialist needs, and the guideline development group agreed that covering these groups in this guideline would not provide the in-depth information required to support such groups. Two examples are dementia in people with learning disabilities and those with alcohol-related dementia. Sources of further information about dementia in people with learning disabilities are listed in section 9.4.”*
	RK	I'm aware this is rather a random and hurried response to a detailed and thorough document.	*No response*
	EH	I would like to add comments on some of the recommendations: could you explain in the beginning the use of the information points ? are these evidence based or based on the opinion of the SIGN group ? e.g. page 22 the PDS recommendations on page 35-36 are confusing with the use of bullet points its not clear what is being asked. also not sure why you mention advanced dementia in a PDS section (page 36 2nd chapter) page 36 why only mention GP specifically, primary care now has a much wider workforce ? page 47 recommendation one - for tailored activities based on a comprehensive assessment - this also needs supported by staff training and support as noted in the recommendation below - activities as part of a treatment intervention are complex and all staff need support/education to deliver this that is wider than care homes only	Covered in section 1.1.7. Information points, to support informed discussion with people with dementia or suspected dementia, their families and carers, are denoted throughout the guideline with the symbol ⓘ. Further information for people with lived and living experience, their families and carers can be found in section 9. The postdiagnostic support section extensively revised to clarify the recommendations.
	JCa	There is perhaps an over-concentration on some narrower issues (use of bio markers; remote assessment) without including some really fundamental stuff - Scottish context, who should make the diagnosis, addressing inequalities. An EQIA should be completed.	Section 4 extensively revised to emphasise routine tests and clarify the recommendations. An EQIA was started prior to the guideline commencing and the issues raised were discussed and considered at the initial group meetings. The EQIA will be published alongside the final version of the guideline.

	DC	I would be happy to meet with the development group on behalf of the national PET CT services to discuss further.	SIGN have met with the national PET group and discussed implementation issues.
	PMac	‘Thank you for the opportunity to comment on the Draft SIGN Guidelines for dementia. Some excellent, constructive guidelines documented, which will in practice provide positive outcomes for people living with dementia and their carers. As a team we looked at the recommendations and good practice points and commented next to these. I have placed these comments as accurately as possible into the relevant sections.	No response
	JE	No, thanks for the chance to read the guideline and to comment.	No response
	JM	I think this is a sensitively completed guideline. I can see it is difficult to walk the line between practical recommendations for carers and primary care physicians, and an examination of the up to date evidence at the forefront of diagnosis and treatment. I think it is absolutely sensible not to combine with a treatment guideline for dementia as the scope is too large. I think that a basic guideline summary for non medical professionals(as mentioned 1.2.5), especially if this is easily mobile accessible, would be ideal.	Thank you. No response required. A patient/public version will be published at the same time as the guideline.
	YM	Below I shall enter "ok" to denote agreement, leave blank if neutral/no opinion and text comment for disagreement or additional matters.	No response
	JC	No issues noted	No response
	PC	Clear and well-written	No response
	AFr	This provides a comprehensive clinical overview of dementia providing the lanscape of the totality of the increasing number of people expected to develop dementia	No response
	MR	NON POLITICAL SENTENCE ADMITTING FINANCIAL PRESSURES ON NHS, EG;”NOT ALL THE POLICIES IN THESE GUIDELINES CAN BE ADMINISTERED DUE TO FINANCES”. OTHERWISE GIVING FALSE HOPE TO READERS. OR SECTION 10 SHOULD BE NEXT	Throughout the guideline we have considered the economic implications of the recommendations given, resourcing is considered in section 10.
	FM	Too long. Written as a report not as a guideline introduction	The introduction has been extensively edited to improve flow and readability.
	KA	Rationale for guidance is clear within the introduction. Is there a in scope / out of scope for the guideline	Now included in section 1.2.1: *“This guideline provides recommendations based on*

			current evidence for best practice in the assessment, treatment and support of adults with dementia. The guideline applies to all settings, including home, long-term care, care homes, hospital, hospice, day-care centres and primary care. Person-centred care should be the focus of the implementation of this guideline. *The focus for this guideline is adults living with dementia. Older people with dementia represent the majority of people living with dementia in Scotland, however young-onset dementia in adults is also included. The guideline covers the adult population, as a true dementia in children (ie an incident, progressive, neurodegenerative disorder) is extremely rare.* *There are specific subgroups of the dementia population and types of dementia that have highly specialist needs, and the guideline development group agreed that covering these groups in this guideline would not provide the in-depth information required to support such groups. Two examples are dementia in people with learning disabilities and those with alcohol-related dementia. Sources of further information about dementia in people with learning disabilities are listed in section 9.4.* *Prevention of dementia is a rapidly evolving area and would need its own guidance to do justice to the field, and as such was also considered by the guideline development group to be out of scope."*
	KP	(General) - NICE guidelines People with dementia should be offered activities that can help promote wellbeing (28th June 2019) NICE. Available at: http://www.nice.org.uk/news/article/people-with-dementia-should-be-offered-activities-that-can-help-promote-wellbeing (Accessed: November 14, 2022). Health and Social Care Secretary Matt Hancock said: "As a society there's so much more we can do to help people live well with dementia. Whether it's joining a choir, gardening or enjoying art classes, so many activities can help people live better and can trigger precious memories and help	We have made reference to NICE throughout the guideline and support their recommendations. We considered evidence on arts based interventions in relevant sections of the guideline. We do not include quotes from outwith the literature or lived experience. Prevention and deceleration of decline were not featured in the Key Questions for this guideline.

		reconnect them with their communities.” Lee, Rachael, et al. "Art therapy for the prevention of cognitive decline." The Arts in Psychotherapy 64 (20psycholog19): 20-25. “The feasibility of structured art therapy and music reminiscence activity was evaluated in a RCT with N = 68 older adults with MCI.” “Older adults receiving art therapy had improvements in memory and attention at 3 months, with sustained improvement in memory after 6 months.” “The significant improvement with art therapy, highlights the potential cognitive benefits of structured art therapy in older adults with mild cognitive impairment.” Yu, Junhong, et al. "The art of remediating age-related cognitive decline: art therapy enhances cognition and increases cortical thickness in mild cognitive impairment." Journal of the International Neuropsychological Society 27.1 (2021): 79-88. “Results: Significant gains in immediate memory and working memory span were observed in the art therapy (AT) group, relative to the control group. Significantly increased cortical thickness (CT) in the AT group, relative to controls, was observed in a right middle frontal gyrus (MFG) cluster. Furthermore, CT changes in this cluster were significantly and positively correlated with changes in immediate memory. Conclusion: These findings highlighted the role of MFG neuroplasticity in enhancing certain cognitive functions in AT. AT is a neuroplastic intervention capable of engendering significant cognitive gains and associated cortical changes in the context of age-related cognitive decline, even when executed as a low-intensity intervention across 3 months. Given the preliminary nature of these findings, future larger sampled studies are needed.”	
	DB	General comment is that the Scottish Government would welcome an	SIGN have met with Scottish Government

		opportunity to offer some additional policy context for the document.	representatives.
	JE	All clear, no suggestions.	Thank you for your comment.
	JH	Very clear and comprehensive. The focus on health inequalities, lived experience, carers experience and equality & human rights from the outset of the guideline is incredibly valuable in providing the broad context of health and social determinants within which the guideline operates. While Section 1 clearly articulates these determinants, an Equality Impact Assessment (EQIA) of the guideline itself would also afford an opportunity to measure whether the revised guideline has a positive impact - or any unintended consequences - of its application upon people living with dementia and their carers. This section is well structured, flows logically, and has a style and voice which is easy to follow.	An EQIA has been completed and will be published alongside the guideline.
1.1	YM	OK	Thank you for your comment.
	LH	I'm interested to know if nurses of alzscot link workers were included in the development group	Alzheimer Scotland were included in all aspects of the guideline and nominated representatives. We received feedback from Alzheimer Scotland link workers in open session and written responses.
	JB	Angela Timoney advised that this guideline was required 'To address variation in practice and gaps in evidence" Omitted from the draft guideline and this section is Public Health Scotland data in Scotland on AChE inhibitor useage across Scotland. Data from 2010/11 - 2019/20 show great variation in prescribing across all NHS Boards in Scotland. This guideline in its current format will not address this variation.	The introduction to section 6 now includes: *"As distressed behaviours are usually a manifestation of an underlying unmet need in the person with dementia, most guidance recommends non-pharmacological interventions in the first instance. Guidance on use of pharmacological approaches is available in the NICE guideline on dementia: assessment, management and support for people living with dementia and their carers."*
	JC	Clear and concise.	Thank you for your comment.
	MH	It's stated that the number of people with dementia in Scotland will increase to 164,000 by 2036 (from 90,000) but at the end of the paragraph it's written: Estimated annual diagnosis is 20,000 with roughly the same amount dying each year. Would this not result in the numbers staying the same?	Section amended. The source document (Scottish Government website) no longer carries the figures used in the consultation draft. Section amended to read: *"An estimated 90,000 people are living with dementia in*

			Scotland, an estimated 3,000 of whom are under the age of 65 (people with young-onset dementia). Around two-thirds are living at home at any one time with the remainder in acute or residential care. The latter accounts for at least 66% of the care home population in Scotland and continues to increase. The estimated annual incidence of diagnosed dementia is 20,000."
	AFr	There is an absolute need for a guideline on supporting people and their carers living with dementia. This document provides a clear and again comprehensive outline of the context and direction of travel of what has happened and what the aims are. It is essential that this takes a human rights-based approach.	Thank you for your comment.
	KA	Evidence base requirement for guideline documented	Thank you for your comment.
	RK	I'm not clear about numbers. My understanding from this is that the same number of people die each year from dementia as are diagnosed, therefore it is not obvious from this why the numbers are increasing	Section amended, removal of: "with roughly the same number of people dying with dementia each year."
	JE	All clear, no suggestions.	Thank you for your response.
	JM	Sorry to start by nitpicking. Last sentence: "The estimated annual diagnosed dementia incidence is 20,000, with roughly the same number of people dying with dementia each year." is in apparent contradiction to the expected increase and justification for guideline. Which one is correct? Would suggest cutting last sentence and reference for simplicity.	Thank you for your comment. Edited as suggested.
	JH	Very clear and comprehensive, with a logical flow to the information presented. For example, the information in section 1.1 prompts a question regarding the experience of dementia by demographic profile and Protected Characteristic, which in turn is articulated in subsequent sections.	Thank you for your comment.
1.1.1	JC	Main Scottish drivers captured	Thank you for your comment.
	GMc	It may be useful to mention the work of Brain Health Scotland here as a key policy and how this links.	Prevention is out of scope for this guideline.
	PC	Clear and well-written	Thank you for your response.
	AFr	Essential to highlight the impact on unpaid carers	Thank you for your comment. Carers were key contributors in all aspects of the guideline development and the evidence base and recommendations make references to carers/care-givers.

			Revisions made to section 1.1.3.
	KA	Policies and strategic drivers noted but no reference to those that are key for people with a learning disability	The specificity of this is out of scope.
	RK	There is no mention of "Connecting People, Connecting Support" in spite of the importance of a multidisciplinary person centred approach. AHPs are key to delivery of many aspects of care and rehabilitation.	This has been added to the provision of information section as useful resource.
	EH	On the first line of the chapter you mention The charter of Rights for People with Dementia and their Carers in Scotland - like the other strategic drivers in this section could you also create an electronic link to this document for your readers. Second chapter, line 9 - The delivery of of the strategy is supported by the….can you add in the national AHP Dementia policy Connecting People, Connecting Support 2017, 2020 a framework for restructuring and integrating the contribution of allied health professionals (AHPs) to dementia care https://www.alzscot.org/sites/default/files/images/0002/7355/AHPReport_2017_WEB.pdf	A hyperlink has been added. Connecting People, Connecting Support added to the provision of information section (9.3) as useful resource.
	JCa	ICD-11 has changed reference to MCI to Mild Neurocognitive Disorder. The guideline should make sure this updated terminology is used throughout.	In section on definitions we have made reference to the differing terminologies used to describe the syndrome of mild cognitive impairment.
	AMcK	Addition of AHP Dementia Policy, Connecting People, Connecting Support: https://www.alzscot.org/sites/default/files/images/0002/7355/AHP_Report_2017_WEB.pdf	Connecting People, Connecting Support added to the provision of information section (9.3) as useful resource.
	JE	All clear, no suggestions.	Thank you for your comment.
	JM	Consider need for statement referencing covid pandemic as current. Suggest refer to in past tense to avoid guideline being seen as 'of it's time'; risk it could seem outdated.	We recognise ongoing implications of COVID-19 in section 1.1.2.
	JH	It may be worthwhile referencing the Equality Act (2010) as all NHS services will be subject to both the Act and the accompanying Public Sector Equality Duty. As such, all Protected Characteristics (Age,	This is included under section 1.1.4.

		Disability, Gender Reassignment, Marriage & Civil Partnership, Pregnancy & Maternity, Race, Religion & Belief, Sex, and Sexual Orientation) are in scope in terms of access to services and service delivery.	
1.1.2	AT	It could be worth adding People with dementia stay in hospital twice as long as other people over age 65	For brevity, we have kept the introduction text as written.
	GH	I feel that the statement about delaying onset is a barrier as not all dementias have modifiable factors that would make this achievable. Perhaps by saying that living well with dementia for an additional 5 years (ie reducing/managing symptoms) would be more inclusive and potentially achievable.	The statement describes the population level and we recognise that at the individual level some dementias may not have modifiable risk factors
	PC	Clear and well-written	Thank you for your comment.
	AFr	Good information	Thank you for your comment.
	KA	Is there any research in terms of the socioeconomic impact in areas of deprivation and impact to individuals' living with dementia	For brevity, we have kept the introduction text as written.
	JE	All clear, no suggestions.	Thank you for your comment.
	JM	First sentence: unreferenced sweeping generalisation. Those with dementia are more likely than whom? Those without dementia including the vast majority of younger population? Need clarification.	Thank you for your comment. Text edited for clarity.
1.1.3	JC	Diagram very helpful	Thank you for your comment.
	GMc	Given the information presented and the significance of vascular risk factors there should be reference made to the importance of nutrition at each life stage as a key risk factor.	Thank you for your comment. See earlier comment on nutrition.
	MC	Learning disabilities in general and Downs Syndrome in particular not listed despite the much higher rates of dementia in these populations (although they are mentioned as high-risk populations in other parts of the guideline).	Thank you for your comment. The modifiable risk factors in section 1.1.3 have been drawn from the evidence base listed. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	AFr	The figure in this section is good and provides excellent illustrative information	No response required

	KA	Doesn't mention learning disability as high risk for dementia, including Down's syndrome	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	EH	You are missing a key reference that builds on the Lancet paper. Add in Ritchie et al The Journal of Prevention of Alzheimer's Disease volume 9, pages348–358 (2022) The Scottish Brain Health Service Model: Rationale and Scientific Basis for a National Care Pathway of Brain Health Services in Scotland https://link.springer.com/article/10.14283/jpad.2021.63#	Brain health and prevention are out of scope of this guidance
	EV	Worth mentioning delirium as a preventable risk factor	Thank you for your comment. Delirium was not listed in the Lancet paper that notes preventable factors.
	AMcK	Brain Health Scotland Model paper: https://link.springer.com/article/10.14283/jpad.2021.63#:~:text=Brain%20Health%20Scotland%2C%20established%20by,to%20reduce%20neurodegenerative%20disease%20incidence.	Thank you for your comment. Brain health and prevention are out of scope of this guidance
	JE	All clear, no suggestions.	Thank you for your comment.
	JM	Great graphic. Evocative. Specifically, makes me think about my own dementia risk and what I can do to stop it.	Thank you for your comment.
1.1.4	AT	What about women having most of carer roles and being disproportionately impacted see PowerPoint Presentation (alzheimersresearchuk.org) What about delay in diagnosis if young onset Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service | International Psychogeriatrics | Cambridge Core	Thank you for your comment. Text added: *“Carers – it is recognised that informal carers for people living with dementia are disproportionately female and often from areas of socioeconomic deprivation.”*
	JC	Well captured	Thank you for your comment.
	AFr	Should the data in 1.1.4 have some explanation i.e., there are higher % of women with dementia as they live longer than men and a higher %?	Thank you for your comment. For brevity, we have kept the introduction text as written.

	TP	Dementia policies tend to have strategies that are gender neutral. As a result, current policies may overlook effects on gender on dementia experience and care e.g. female PwD, female family carers. As such, we need policies that will address this issue too. This ineuities in policies are also applicable to people who live with young onset dementia since the support tend to tailor towards 'normal' PwD who are older than 65 years old.	Thank you for your comment. *Section 1.1.4 contains "67% of people with dementia are women"* We have added a recognition of gender in section 1.1.4 carers: *"Carers – it is recognised that informal carers for people living with dementia are disproportionately female and often from areas of socioeconomic deprivation."*
	KA	This section discusses the research from PHS which highlights the high prevalence of dementia in the learning disability population compared to the general population, including higher risk within individuals with Down's syndrome. However, there does not appear to be any further reference to supporting people with a learning disability within the guidance. Given the evidence base and health inequalities people with a learning disability experience will this population group be included?	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	KP	The Arts Therapies offer a form of psychological therapy, including therapeutic relationship, experience of being heard and understood, which is not dependent on verbal dialogue. To omit this from the guidelines would actively increase inequalities.	Thank you for your comment. This falls outwith the scope of the key questions.
	DB	We would like to offer some additional policy information in this section	Thank you for your comment. SIGN have since met with Scottish Government representatives.
	JE	All clear, no suggestions.	Thank you for your comment.
	JM	Copy and paste from Public Health Scotland website. Given these stats are going to be in a reference national guideline of the highest evidence, should they not be put in more context?	Thank you for your comment. We hope the supporting text provides context.
	JH	Very clear. It may be worthwhile adding any information on Disability Adjusted Life Years, if relevant information is available? Appreciate that this information is detailed by various measurements under sections 1.1.3 and 1.1.4.	Thank you for your comment. For brevity we have not added this.
1.1.5	AT	I did not understand this sentence	We have edited the sentence for clarity:

		From evaluation of responses, from approximately 58 clinics or services providing assessment and/or treatment for cognitive complaints, the majority of respondents did not mention of the; involvement of psychiatry or neurology, home visit, postdiagnostic support, young-onset services, and remote appointment options; (psychiatry was referred to most often 36 %) I also do not like manage as a term Those working in long-term care settings should be able to recognise dementia, and manage and monitor and support those in their care. You could consider deleting as I am not sure what it adds and add support instead	*"Evaluation of responses from approximately 58 clinics or services providing assessment or treatment for cognitive complaints found the majority of respondents did not mention involvement of psychiatry or neurology in their care, home visits, postdiagnostic support, young-onset services or remote appointment options. Psychiatry was referred to most often (36% of respondents)."* We have added text around the term 'manage' in section 1.3.11: *"The term 'management' has been used through this guideline for brevity and consistency, but the central tenet of dementia care throughout this document is that it is person-centred and responsive to the array of dementia-related symptoms and needs. The guideline development group recognise that language is important and have been guided by various stakeholders around terminology for this guideline, eg the use of 'management of the condition' where appropriate."* Section 1.1.5 now includes: *"Quality improvement programmes in Scotland have shown that progress is being made, and there is potential to improve clinical practice and reduce variation in the assessment and non-pharmacological management of the condition for people with dementia. All healthcare professionals working with people with dementia need to assume responsibility for detection and treatment. Those working in long-term care settings should be able to recognise dementia, and support and monitor those in their care."*
	JB	Omitted from the draft guideline and this section is Public Health Scotland data in Scotland on AChE inhibitor useage across Scotland. Data from 2010/11 - 2019/20 show great variation in prescribing practice across all NHS Boards in Scotland - the spreadsheet setting out useage by Scotland and individually by NHS Board can be found here - https://publichealthscotland.scot/publications/medicines-used-in-mental-	See earlier response.

		health/medicines-used-in-mental-health-years-between-2010-to-2011-and-2019-to-2020	
	JC	Scoping exercise captures key information	Thank you for your comment.
	PC	The continued variation in the assessment and management of people through the diagnostic pathway is a source of concern and prevents meaningful comparisons being made about consistency of diagnosis, in contrast to Scandinavian countries for instance. Could SIGN recommend that a national working group is set up to try to harmonise the diagnostic process? The figure of 36% mention of psychiatry is hard to understand in light of figures in the same report (ref20) which identify that 93% of diagnostic services have psychiatrist input. It would be helpful if the guideline took account of the recent RCPsych report on how poorly services are prepared for the advent of disease modifying agents, especially as fluid biomarkers and scanning are discussed later.	Thank you for your comment. Recommending a national working group is outwith our scope. The report from Alzheimer's Research UK is now included in sections 1.3.1 and 4.1.
	MP	Paragraph 3 Should it be acknowledged that adult mental health service and neurology are often involved in the assessment and diagnosis if suspected dementia, or if they were excluded from the scooping exercise, this could be noted?	The scoping exercise was not commissioned by SIGN. We are using the report as background information.
	AFr	What about the input from Alzheimer Scotland and how tis impacts variance	Thank you for your comment. We had no data on this.
	KA	People with a learning disability are often excluded from post diagnostic support following on from diagnosis, unless they are supported by learning disability teams. This	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	EH	First chapter, second sentence – equality should this not be equity of access?	Thank you, we have amended to equity.
	EV	There is mention of diagnosis in long term care but primary care and hospital should also be mentioned	In the previous section we emphasise that 'all healthcare professionals' should be able to assist in detection.

	JE	All clear, no suggestions. Really important section.	No response required
	JM	It is my experience that there is wild variation even between mental health times within a single health board and a complete lack of standardisation of the process of diagnosis and support, agreeing with your quoted survey on variations in practice. Agree re: lack of specialist provision for young onset dementia - locally this simply goes to the general adult psychiatrists. No specialists are involved.	Thank you. No response required.
	JH	As per comment at section 1.1.1, it may be worthwhile to reference the potential for variation in experience of assessment and care planning by Protected Characteristic? For example, the BSL Scotland Act, requires us to take action to ensure that people whose first language is British Sign Language have equality of user experience. Clear information promotes improved access and uptake of services. This includes the availability of information in all community languages required, including BSL and easy read. Further, any communication plans should also consider the range of accessible formats required.	Thank you for your comment. Text added to section on inequality and other groups in section 1.1.4.
1.1.6	AT	The impact of the COVID-19 pandemic – There have also been concerns expressed re remote v face to face which you may wish to reference as being covered later eg 3.1.2 page 16	Thank you for your comment. We have not cross referenced but have expanded this point, including three sub-points: *“For people with dementia and their carers during the COVID-19 pandemic:* • *Separation and loss* • *Confusion, despair and abandonment* • *Stress and exhaustion”*
	MP	Paragraph 2, line 1: typo 'the Scottish The Scottish	Thank you for your comment. Edited to remove duplication.
	AFr	Line 2 of the second paragraph in this section needs attention as a couple of words need deleted. I also find the word "lived experience" problematic as people with dementia have not lived experience with it but are living with it.	Thank you for your comment. Edited to remove duplication. We recognise the importance of language and have added a section on this in the introduction. Term amended to lived and living experience throughout.
	KA	To include people with a learning disability would increase opportunities for carers and people with a lived experience to be active involved in guidance	Thank you for your comment.

		can support development of a person centred guideline. Down's syndrome Scotland were not included as part of consultation. This would contribute to health equality agenda.	We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	People with lived experience raise the issue of communicating with people with advanced dementia. The need for a workforce highly skilled in communication techniques, supported by Speech and Language Therapists, is key to good outcomes for both carers and the people with dementia.	This is covered in a recommendation and good practice point in section 5.2.
	EH	Page 4, second chapter, 6th line - Tide should be capitals TIDE and on page 5 top of page 5 - check the accuracy of only keeping people in care settings ? surprised this was also not a concern for those at home too impact of the COVID 19 pandemic could you add a bullet point to share what the impact is ?	1.1.6 edited to capitalise TIDE. These suggestions were provided by people with lived experience and carers groups and supplement the guideline, rather than address key questions. We acknowledge that this is an important consideration, regardless of setting but was not raised by people/carers (which this section lists).
	EV	In common issues, falls and delirium should also be mentioned	The list is based on feedback from people with lived experience.
	JE	All clear, no suggestions.	No response required
	JM	I really like this section - the clarity of the source (ie carers/patient perspective) and the empathy that this evokes. Very important and would be good to include in all guidelines	Thank you. No response required.
	JH	Further equality impacts may be illuminated through engagement with communities utilising a Human Rights Based approach and the PANEL principles (Participation, Accountability, Non-discrimination and Equality, Empowerment and Legality). This ensures that communities who are currently more distant from services and the required information to have confidence in using those services can be supported to have their voices heard. This allows for communication plans around the Guidance to consider both targeted information relevant to protected characteristics and also wider socio-economic determinants including social class, stigma, and recognition of the caring role whether someone is an established or recent carer.	The SIGN guidance development process follows a structured framework and efforts are made to consult widely and engage with a broad range of expertise and experience. However, we recognise there may be limitations to our strategy and take on board useful suggestions to improve this in the future. Not possible for this guideline but feedback noted by SIGN for consideration in future guidelines.

1.1.7	JC	This may come later but has this work been included: https://storiesofdementia.com/ https://storiesofdementia.com/stories/	We have focussed on the feedback from people with lived experience that we gathered as part of the guideline process. This has been added to the resources.
	AFr	Collecting data from people living with dementia is imperative for this document. How will professional/organisation explore how this can be developed in a more meaningful way?	Thank you for your comment. We have drawn on literature and from organisations representing people living with dementia in the development of this guideline.
	MR	many papers not read by committee have people with dementia own experiences, (currently only carers quoted): innes, szmczynska et al 2012, innes, cox et al 2005, innes, sherlock et al 2005. found within five minute search. gap obvious in all sections, inherently wrong. see 11.2. these academic papers highlight the paucity of support for rural areas on the mainland, only one dementia organisation has any meaningful presence, there is very poor online coverage in remote areas; 50% of over 55's find it hard/impossible to get online (age scotland). see 3.1.2	Our comprehensive searching of the literature will have included those papers relevant to each section. Within a focussed guideline, it is not possible to reference all dementia research.
	KA	People with a learning disability are not included in the lived experience data. There are a number of research studies available that could contribute to guideline	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	DB	We can provide some new narrative on lived experience evidence	No response, we would welcome any suggestions
	JE	All clear, no suggestions.	No response required
	JM	as above, good empathetic treatment with wide scope	Thank you. No response required.
	JH	Very comprehensive and helpful. Logical flow of information throughout section 1.1.	Thank you. No response required.
1.2	PC	Clear and well written	No response required
	MH	In the overall objectives state the areas such as drug treatment where there have been relatively recent coverage by NICE and refer the reader to that document.	Text added 1.2.2.

	KA	Is supporting people with a learning disability included in the remit?	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	JE	All clear, no suggestions.	No response required
	JH	Very clear and comprehensive. At point 1.2.5 "A version for people with lived experience", consideration will need to be given to access requirements and clear communication plans across the range of community languages including BSL, and alternative formats for people with a learning disability.	We will consider access requirements in the production of the lived experience materials.
1.2.1	PC	Clear and well written	No response required
	KA	Same as 1.2	No response required
	EH	First paragraph, 3rd line - delete GP surgeries, this should be primary care unclear what you mean by long term care ? unsure why care homes is not included in your list when they are mentioned later in the guidance ?	Edited: *"This guideline provides recommendations based on current evidence for best practice in the assessment, treatment and support of adults with dementia. The guideline applies to all settings, including home, long-term care, care homes, hospital, hospice, daycare centres and primary care. Person-centred care should be the focus of the implementation of this guideline."*
	JE	All clear, no suggestions.	*No response required*
1.2.2	AT	Again I don't like managing can it be removed	Text on language added to section 1.3.11: *"The term 'management' has been used through this guideline for brevity and consistency, but the central tenet of dementia care throughout this document is that it is person-centred and responsive to the array of dementia-related symptoms and needs. The guideline development group recognise that language is important and have been guided by various stakeholders around terminology for this guideline, eg the use of 'management of the condition' where appropriate."*

	MP	Title 'managing' people with dementia, I wonder if the word managing may be perceived as pejorative and 'othering', perhaps could be rephrased as 'when working with people with dementia'	Text on language added to section 1.3.11: *"The term 'management' has been used through this guideline for brevity and consistency, but the central tenet of dementia care throughout this document is that it is person-centred and responsive to the array of dementia-related symptoms and needs. The guideline development group recognise that language is important and have been guided by various stakeholders around terminology for this guideline, eg the use of 'management of the condition' where appropriate."* Title of 1.2.3 changed to *"Comorbidities to consider when managing the care of people with dementia"*
	MH	In the first paragraph its stated that one of the most common comorbidities is 'painful conditions', but I don't see obvious painful conditions included in the bullet point list of those being considered in the guideline. Why not. I would have thought arthritis would be such a painful condition and would have an impact on someone with dementia (mobility, distress, medication).	*See previous, the list came from people with lived experience*
	KA	Learning disability is discussed but not throughout the guideline. Is there an opportunity to cover more around unmet health needs experienced and identification of these.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	Could there be a greater focus on Learning Disabilities	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	EH	This is good to see this section included but this is then not included in the guidance that I can see?	We included papers on comorbidities where relevant to key questions, unfortunately there is limited research looking at comorbidity effects in dementia

	JE	All clear, no suggestions.	No response required
1.2.3	AT	Mild cognitive impairment page 8 What about referencing (PDF) Mild Cognitive Impairment: The Manchester consensus (researchgate.net) Dementia due to Lewy body – Could be worth referencing Dementia with Lewy bodies - Symptoms, diagnosis and treatment | BMJ Best Practice sept 2022 McKeith IG, Boeve BF, Dickson DW, et al. Diagnosis and management of dementia with Lewy bodies: fourth consensus report of the DLB Consortium. Neurology. 2017 Jul 4;89(1):88-100.Full text Abstract Other types of dementia I found this confusing what medications are you saying cause dementia ? I think broader statement would be better that there are ,many other types of dementia some caused by other conditions ,psychoactive substances and ...	We feel that the summary of Dementia with Lewy Bodies (now in section 1.3.5) is largely sufficient. We have added the McKeith et al reference in section 1.3.5. The text is a summary of the reference used in that paragraph (from ICD-11 https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/546689346 Amended now section 1.3.7
	JC	Pg 10 1.2.3 Appears to be a contradiction between the definition of a carer in the Carers Act in relation to contacted or voluntary work and the statement below which states: paid carers will be referred to as 'carers'? If the focus of the guideline is unpaid and informal surely paid carers should not be included?	We have made a distinction between unpaid and paid carers in section 1.3.10.
	MH	Carers, last line of 1st paragraph: 'The term 'young carer' will be used forthwith in this guideline and 'adult carer'or 'young carer' when both are referred to'. Should that be: 'The term 'young carer' and 'adult carer' will be used forthwith in this guideline, and 'carer' when both are referred to.' Also please check consistent usage throughout guideline.	Amended. We have distinguished between carers and young carers and made this distinction where there is research that relates to these each specific group. See section 1.3.10 for carer definitions.
	KA	This is very detailed but does not include people with a learning disability as a population group for consideration	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be

			proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	65 is no longer the usual retirement age, though it is the usual cut off point in services.	Edited to include all terms for young onset dementia and avoid retirement age.
	EH	Page 10, 4th chapter - dementia and associated needs. What do you mean by 'hollistic approach' could this be expanded? Wonder why you do not include a biopsychosocial approach here to emphasize the interconnection between biological, psychological and socio-enviromental factors?	We have edited out this section for brevity. We believe holistic would encompass a bio-psycho-social approach – edited to reflect this in the introduction to section 8: *"Dementia affects an individual's wider physical and mental health, as well as their cognitive abilities, and thus a biopsychosocial approach is needed."*
	EV	Greater Manchester dementia united have done some good work around MCI, worth looking up DLB-worth looking up diamond lewy guidelines for diagnosis FTD-also has genetic basis on some cases, some linked to MND Other types, HIV, syphilis worth a mention	We have added some new references, we have not specifically added reference to Manchester criteria around MCI for this dementia focused guidelines. We have added some text around scope and that dementia syndromes requiring specialist assessment and care are out of scope
	JE	I wonder if it is worth noting that some classification systems have moved away from using the term dementia and instead refer to major cognitive impairment.	We have used the ICD classification systems throughout.
	JM	Careful not to reference subjective papers as fact: "The progressive nature of dementia and as such all dementia care should be considered palliative. Not recognising dementia in this way drives the stigma and misrepresentation that dementia is a syndrome of old age." - suggest 'can' rather than 'should' and 'may drive' instead of 'drives'.	Edited as suggested, now in the introduction to section 8.
1.2.4	YM	OK	No response required
	GH	I think that 'non-qualified', lower literacy and NESB staff should have access to this in an understandable format.	A plain language version of the guideline will be made available.
	GMc	Accessible version should be encouraged for all users including professionals to increase ease of use, visibility within practice and increase readability.	A patient/public version of the guideline will be made available.

	MH	I can't see where to leave feedback on this form for 1.3 so I'm putting it here. 1.3 Statement of Intent,2nd paragraph, 2nd sentence: family/carers should be involved in decision making about diagnosis and treatment if the person with dementia lacks capacity and the family/carer has Power of Attorney for Welfare.	*Shared decision making is emphasised throughout, e.g. 9.4:* *"Discuss the importance of making plans for the person's financial and personal welfare as soon as possible. Discuss the need for power of attorney and guardianship and explain the difference, as well as where to access help to appoint an attorney or guardian. "* Text added: 1.4 *"Family/carers should be involved in decision making about diagnosis and treatment if the person with dementia wishes it, or if the person with dementia lacks capacity and the family/carer has Power of Attorney for Welfare, or a guardianship order is in place. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be documented in the person's medical records at the time the relevant decision is taken."*
	AFr	I think care at home staff should be part of this group due to the complexity of people living at me requiring care and support	*Thank you we have added care home staff:* 1.2.4 *"This guideline will be of interest to primary and secondary healthcare professionals, social care professionals, community, care home and care at home staff, involved in the care of people at risk of, or diagnosed with, dementia, as well as people living with dementia and their families and carers."*
	KA	To include how to support individuals with a learning disability, including Down's syndrome would support to reduce health inequalities and assist with discussion regarding diagnosis / post diagnostic support and addressing any unmet health needs	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	EH	You are missing third sector? higher education (for your recommendations on education)	We have emphasised the multi-professional nature of the guideline throughout.

	JE	All clear, no suggestions.	No response required.
	RB	This comments relates to section 1.3 Statement of intent...there isn't a box in this form therefore adding it here: This section doesn't say what the intent is – it tells us what it's not, and how clinical judgement should be employed.	This is standard for this section, all of the first chapter covers the intent. Section 1.3 includes: *"The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at through a process of shared decision-making with the individual, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be documented in the person's medical records at the time the relevant decision is taken."*
	JM	Not related to this but 1.2.5 not included and neither is 1.3 1.2.5 - Again I think this is an excellent idea for inclusion but will be a lot of work. Especially if there's an interactive website. 1.3 - such an important statement / caveat for healthcare professionals. Suggest make more prominent!	No response required
	JH	Clear and comprehensive. Will be useful to have this information distilled/summarised within the version for people with lived experience.	Thank you. No response required.
	SP	More information can be provided about the need to consider a broad differential diagnosis for functionally impairing cognitive impairment in the young to include inflammatory disorders (e.g. multiple sclerosis), neuro-infection (like HIV and syphilis), autoimmune encephalitides, and neurodegenerative causes of dementia, to include autosomal dominant and recessive causes. Some mention also needs to be given to the differential diagnosis of rapidly progressive dementia to include prion disease, autoimmune encephalities, vasculitis, and paraneoplasia.	We have updated the text to include reference to this in section 1.3.1 and 1.3.2. However the latter details the identification of the dementia syndrome. the differential of the cause is very wide indeed but is established good practice rather than evidenced and as such should be noted as a good practice point.
	MP	I think this section needs more info added, it currently reads as if the assessment and diagnosis of dementia is based on a cognitive screen and a scan. Complete guidance re a comprehensive and evidence based	Added to 3.1 which includes MDT. Neuropsychological assessment now included in section

		assessment delivered by an MDT should be documented here. I am concerned that there is absolutely no mention of neuropsychological assessment in the entire document. I raised this repeatedly at the consultation event last week but feel it is important to include it here too. A theme of the discussion at the consultation event was that the SIGN authors did not want to repeat info contained in the NICE 2018 guidance, I amongst others fed back that this is unhelpful, the Scottish guidance should reflect Scottish practice, and therefore neuropsychological assessment should absolutely be included. In addition, the draft SIGN guidance reads as if a scan and a cognitive screen constitute an assessment, again this is because other elements of the assessment are in the NICE guideline, however I strongly feel this should be all within the SIGN guidance. The 2018 NICE guidance also did not contain any reference to neuropsychological assessment until psychologists across the UK opposed this. You will see that the mention of neuropsych assessment in the NICE 2018 guidance is brief (see page 15, section 1.2.10 and 1.2.11). We need at least this level of info reflected in the SIGN guidance, if not more. I understand that you do not want to repeat the guidance noted in the NICE 2018 document, however this Scottish document should reflect Scottish practice fully. I do not see in this document any mention that it should be read in conjunction with the NICE guidance. Equally if this was the model used then reference would need to be made to areas where Scottish practice differed form the English guidance contained within NICE. This seems cumbersome, my opinion is that the SIGN guidance should be a stand alone and comprehensive document. If not, it runs the risk that there will be pressure within services to make a diagnosis based on a cognitive screen and a scan only.	3.1.6: *“Neuropsychological assessment carried out in secondary care settings can help when dementia is not clinically obvious. This can include when there is disparity between a person's performance on cognitive screening and their presentation, when it is unclear if a person's cognitive impairment is caused by dementia or when it is uncertain what the correct subtype diagnosis is”.* NICE guidance covered in the introduction. NICE guidance is now included in the introduction section 1.2.2.
	KA	No reference to diagnosis and identification specific for people with a learning disability / Down's syndrome and specific diagnostic tools available. How to make reasonable adjustments to support inclusive involvement in the assessment processes.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be

			proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RB	Brief cognitive tests – in this section the purpose of cognitive tests should be made clearer and the fact that they are on their own are not diagnostic tools should be explained. I wondered about being clear about training required, as per clinical governance, to use these tests (e.g. MoCA website guidance and ACE-III trainer) due to the range of Health Care professionals who may use this document as guidance for working with this population. I also wondered about introducing research that looks at explanations for varied performance on these screens – though this may not be in keeping with the focus on this section?	A section has been added in 3.1.1 A link to training is included in this section in Table 1 in section 3.1.5.
	EV	Excellent section, especially that any competent specialist should be able to convey diagnosis.	No response needed.
	GB	Would like to see highlighted of complexities in undertaking a dementia assessment and this can explain time involved, need for further assessment, scans etc. So whilst early diagnosis is important there are several factors that make this difficult and is more helpful to make an accurate probable diagnosis (most people aren't aware of above challenges)	Included in 3.1: *"Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and functioning.* *This section covers tests that can be used to assess cognition, however, it is important to note that these are one part of the assessment process, which can often be complex, with a level of uncertainty. Differential diagnosis can be wide when considering both other causes of cognitive impairment such as delirium and depression, and the wide range of causes of dementia. Further in depth cognitive testing, functional assessment, and imaging (eg magnetic resonance imaging (MRI) and computerised tomography (CT)) and other investigations can help with diagnosis but may extend the time to diagnosis."*
	JCa	There should be a best practice statement initially on how dementia should be diagnosed - ie that there needs to be specialist assessment.	This is now included in the beginning of section 3 after editing and restructuring.
	JE	All generally clear and helpful. Only suggestion is whether it would be good to expand the discussion of assessment of persons from different	Included in Table 1, but limited other evidence of use interpreters etc

		cultural and linguistic backgrounds (e.g. ethnic minorities), including use of interpreters?	
3.1	JLJ	A thorough psychological and holistic assessment with the person with suspected dementia and their families/carers is key to understand qualitative, observed changes in their presentation, personality and functioning over time.	This is now included in the beginning of section 3 after editing and restructuring.
	MC	This section lacks guidance on the screening and diagnostic tools used to assess possible in dementia in people with learning disabilities, despite this group being identified as being at high risk earlier in the guidance and requiring different assessment tools to the general population. Guidance in this area would be very helpful.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. There has been a response from the Guideline Group to key leads within the learning disability community. The issue of Dementia in people with learning disabilities is highly complex and with the resources available we could not do justice to this topic within this guideline. As such was decided as outwith the scope for this guideline. We would welcome a proposal for a SIGN guideline relating to people with Learning Disabilities.
	MP	I note the term 'cognitive tests' is used throughout the document. I think a more accurate term is cognitive screening tools. 3.1.1 Cognitive screening tools have not only been translated into various languages but also adapted for people with sensory impairment and low literacy levels (see additional comment & reference below) Should this document make reference to adaptations to be made when working with a translator using a cognitive screening tool?	Most of these tools are used to demonstrate a cognitive impairment how these results are then used to inform practice can vary and so screening may not always be the most appropriate descriptor, thus we will retain the cognitive test terminology. No evidence for using a translator unfortunately.
	KA	Same comment as section 3	Responded to above
	RK	We need to have much closer working between psychology and speech and language therapy in the diagnosis of primary progressive aphasias. At the moment there is a lack of clarity about the added value of the different assessments is, and how they contribute to rehab and the person's well-being.	Editing and restructuring of section 3 now includes an introduction including: *"The diagnosis of dementia is a clinical diagnosis, based on information from different sources."*

			Section 3.1 includes reference to a multidisciplinary team assessment: *"Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and functioning."*
	RB	We are concerned that there is absolutely no mention of neuropsychological assessment in the entire document. Whilst there is acknowledgement that this might repeat some info contained in the NICE 2018 guidance, this is a separate document, the Scottish guidance should reflect Scottish practice, and therefore neuropsychological assessment should absolutely be included. In addition, the draft SIGN guidance reads as if a scan and a cognitive screen constitute an assessment, again this is because other elements of the assessment are in the NICE guideline, however we strongly feel this should be all within the SIGN guidance. It is also worth noting that that the mention of neuropsychological assessment in the NICE 2018 guidance is brief (see page 15, section 1.2.10 and 1.2.11). We need at least this level of info reflected in the SIGN guidance, if not more.	This is now included in section 3.16.
	GB	would like to see more emphasis on pre-diagnostic counselling (conversation) should be done routinely otherwise not gaining informed consent for assessment. People often aren't aware that dementia could be an outcome until have discussion (though family might be more aware of this) Would also like to see role of other MDT in cases where hard to ascertain differential diagnosis- role of OT - functional assessment and Psychology for a neuropsychological assessment.	This is covered in section 3.2.3, including a recommendation on prediagnostic counselling. Section 3.1 includes reference to a multidisciplinary team assessment: *"Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and*

			functioning." Section 1.3.11 introduces the multidisciplinary and team approach to care.
	AMcK	? Inclusion of additional assessments such as occupational therapy	Section 3.1 includes reference to a multidisciplinary team assessment: *"Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and functioning."* Section 1.3.11 introduces the multidisciplinary and team approach to care.
	JE	All clear, no suggestions.	*No response*
	JH	A range of standardised tests are referenced within this section of the guideline. If these tests are written in English language, it will be helpful to think through the necessary adaptations and translations required for their use with people whose first language is not English. This will have an impact both upon tests which are performed by a Clinician and also any self-reported assessment tools for use by people living with Dementia and their carers.	We have noted in the table which tests require written English Literacy tests. We did not see literature on translating these tests to other languages and so cannot make recommendations on this.
3.1.1	JB	Too many cognitive tests recommended to reduce variation in identification and diagnosis of dementia.	This was discussed and considered in the group – no test had better evidence than the others and thus we cannot recommend one test. The table gives information to allow clinicians to pick the "right" one for their setting and situation.
	JC	Captured through primary research, SR evidence and Cochrane Review	No response
	JLJ	These should be named cognitive screening tools rather than cognitive tests. Neuropsychological assessment requires to be in this section. Although the group do not wish to duplicate NICE 2018, mention of neuropsych assessment in the NICE 2018 guidance is brief (see page 15, section 1.2.10 and 1.2.11). Scottish guidance should reflect Scottish practice, and therefore it is imperative that neuropsychological assessment is included. A scan and a	Most of these tools are used to demonstrate a cognitive impairment and used as a basis for dementia diagnosis and thus we will retain the cognitive test terminology. Neuropsychology now included in 3.1.6: *"Neuropsychological assessment carried out in*

		cognitive screen is more often than not unsuitable in establishing a diagnosis with a dementia type and/or formulating a supportive plan for the individual moving forward. Neuropsychological assessment are routinely carried out as essential to clarifying differential diagnosis, monitoring MCI symptoms, and assisting in the understanding of the functional impact of cognitive changes. Neuropsychological assessment outcomes allow inform individualised cognitive optimisation strategies and gives the person and their carers/ family a better understanding of the specific areas of cognitive strengths and difficulties as they apply to the individual. Neuropsychological assessment will also identify cognitive change where brief screens and imaging investigations (e.g. CT scans) are not sensitive enough to identify change.	*secondary care settings can help when dementia is not clinically obvious. This can include when there is disparity between a person's performance on brief cognitive testing and their presentation, when it is unclear if a person's cognitive impairment is caused by dementia or when it is uncertain what the correct subtype diagnosis is."*
	RH	Several brief cognitive tests are recommended. In order to reduce variation in practice across Scotland, it would have made sense to recommend one brief test, or perhaps 2 or 3. I understand that the consultation team did not find sufficient evidence to recommend only one test however.	This was discussed and considered in the group – no test had better evidence than the others and thus we cannot recommend 1 test. The table gives information to allow clinicians to pick the 'right' one for their setting and situation.
	PC	It is important to remember that many of the tests listed were developed in a secondary care environment where the prevalence of dementia was high e.g 50% for the 6-CIT. In a community PPV of these tests can be very low The comprehensive list provides further impetus for a national group looking at harmonisation of the diagnostic pathway.	We agree with this point and support further research. 3.1.1 states that that most tests relate to secondary care settings and that setting of the test is an important consideration
	MP	In-person Testing Paragraph 4, Line 7: the version of the ACE being referenced used should be documented Table 1: the table should report which version of the ACE was used Literacy levels impact on a person's performance on cognitive screening tools, this often leads to mis-diagnosis: https://www.pure.ed.ac.uk/ws/portalfiles/portal/255444019/MaherCCaliaC2022JCENTheEffectOfIlliteracyOnPerformance.pdf Perhaps the literature re the remote use of the MoCA-Blind should also be	Changed to ACE3 in 3.1.2. We considered MOCA Blind but there was not enough published information on this to date.

		considered. If this guideline is going to be relevant to people with a learning disability, it needs to make reference to the different cognitive screens used.	
	KA	Detailed research base. No reference to reasonable adjustments under Equality Act 2010. Use of accessible information to support	Reasonable adjustments are the responsibility of the service and healthcare professional conducting a test. We have included a Good Practice Point that includes the following: • *"training requirements in use of the test for healthcare professionals" should be considered."* • *"ease of use for the person completing the test, considering literacy and language, additional support needs and cultural sensitivity"*
	RB	The sentence that begins "Many instruments...." The wording here masks the fact that the majority of services/health professionals are actually not well equipped to undertake culturally appropriate and valid screening and assessment when assessing an individual from a different cultural background/ethnic group	Unclear of the evidence that this is the case for the majority of services/health professionals – no masking of the issue was intended. We have included a Good Practice Point that includes the following: *"ease of use for the person completing the test, considering literacy and language, additional support needs and cultural sensitivity"*
	GB	Problems in assessing remotely- feel should only be carried out in exceptional circumstances, especially if assessment is helping to detect dementia.- too much at stake. Connection issues could affect accuracy of cognitive test and thus accuracy of diagnosis	The evidence does not support this – the evidence is that the decision should be considered on an individual basis
	PMac	No reference to baseline assessment of functioning (e.g. testing for those at higher risk in the absence of symptoms) or any adapted early detection screening tools. Good to see additional support needs included here. Will this be removed if decision is made not to include people with LD? If not, where is the line, what is deemed as an acceptable level of additional support for these guidelines? If removed from the guidance it may be expected that the workforce won't recognise the value of differences in (early) screening	Some of this is included in section 3, but there is no evidence to support screening in the general population. Additional support needs will not be removed as this applies much more widely than just to people with learning disabilities. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach,

		requirements for people with Down's syndrome or learning disabilities.	beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. There has been a response from the Guideline Group to key leads within the learning disability community. The issue of Dementia in people with learning disabilities is highly complex and with the resources available we could not do justice to this topic within this guideline. As such was decided as outwith the scope for this guideline. We would welcome a proposal for a SIGN guideline relating to people with Learning Disabilities.
	JM	Punctuation on last sentence in first paragraph of brief cognitive tests I like the reference to secondary care specific testing and thought that's put in to primary care. I recommend this piece of guideline be kept under regular review. With the ease of developing cognitive tests, the ease of study and the inevitable imminent impact of AI, a list of (sometimes branded/marketed) diagnostic tools must be kept up to date	Changed – thank you. Our focus is on evidence for validated tests rather than research tools. In keeping with our methodology, the guideline will be reviewed three years after publication.
	JH	As per comment 3.1 above.	See response above.
	JE	All clear, no suggestions.	No response required
3.1.2	AT	End of 3rd paragraph Page 17 English -This sentence does not read well Carers' concerns related to denying any need for help, cost, technical challenges and frustration and personalisation of system. Para 6 is missing close of bracket difficulties with remote healthcare (phone consultations issues if hard of hearing or memory issues, required carer organisation, preference for face-to-face, lack of visual changes being noticed, harder to convey changes over phone, issues arranging appointments, digital barriers, but some adult-child carers preferred online, benefit of shorter waiting times and quicker access	This section has been edited and these sentences removed for brevity.
	JC	At the start of this section it says the evidence relates to management only but then on p.17 and p.18 there are sections on feasibility and	This section has been modified and edited to reflect the comments. Section 3.1.2 now focuses on perspectives of

		acceptability? p. 17 paragraph 6 not clear what is meant by adult-child carers? Bracket needs closing in final sentence. p18 paragraph 1 adult-child carers, should this be adult and child carers?	using technology for remote assessment in the diagnosis of dementia which did not identify sufficient literature to answer the question. The remaining section on perspectives of using technology to support the remote management of dementia in now in section 6.5 Adult-child carers refers to adults who are children of a parent they care for. This has been clarified where it appears later in the guideline.
	PC	Clear and well written	No response required
	MP	The title does not reflect the content of the section as it focuses on management. As noted above the term management could be deemed to be pejorative. This whole section refers to working with people with dementia and carers to meet their support needs. It does not fit within the assessment section and should be reordered. Current order of sections is: Assessment, Remote management/support, back to diagnosis, investigation procedures, PDS then non-pharmacological management etc It would flow better as: Assessment (section should be expanded), Investigations, Diagnosis, PDS, Remote support/management, non-pharm etc This section is very repetitive and could be abbreviated significantly Page 17, paragraph 7, replace 7 with & Page 18, paragraph 5, correct references on line 5 Page 19 Recommendations: should comment be made to difference between various populations such as BAME communities, people where English is not first language and work may take place via an interpreter or people living with sensory impairments or learning disabilities Should mention be made of staff training/knowledge/skills and access to adequate technology for the relevant staff.	Thank you for your feedback. We have edited this section to move the people's perceptions of dementia management using technology to section 6.5. References have been checked and corrected throughout this section. Sections have been restructured at editorial for better flow and brevity. While the included studies do reflect international evidence, the reporting of ethnicity and BAME is poor. The information available from included studies was included in this section (now, section 6.5) however, there was no information on language needs or sensory impairments. The focus of this section was related to people living with dementia and their carers, therefore no literature regarding staff was included.
	AFr	This is particularly interesting and the results from the mixed methods study. This comes to the point all interventions need to take on a human rights-based approach and need to be individualised for each person living	Thank you. No response required.

		with dementia. Technology can assist and support the person and the person and carer living with dementia and should always be explored - not used as an "instead of face-to-face intervention"	
	MR	Remote assessment is not feasible in many areas due to slowness of broadband, nor is it suitable in many cases as many people over 55 find it hard to use, see 1.1.7	Thank you for this comment, while broadband speed was not a specific finding from the included literature, the lack of internet connectivity was which could also span poor internet connections. Additionally, it was noted (page 18, 1st & 3rd paragraph and now in section 6.5.1) that remote technology use may not be feasible due to people living with dementia and carers not having the skills to use it.
	KA	Same as 3.1.1	The included literature on the perceptions of people living with dementia and their carers' on the use of technology to support the remote management of dementia did not report these aspects. Therefore, there was no evidence on this to inform the guideline.
	EV	Bit about technology, cost of electricity etc worth a mention	This is included in section 6.5.1 (agency).
	GB	Good for routine follow up to offer especially rural areas or if family member can't leave person with dementia to attend an appt	Thank you. No response required.
	JCa	This covers much more than remote assessment therefore most of this content does not belong here. There is no mention of bio markers/scans prior to the recommendations on how to give diagnosis. There is no mention of CT scans as part of the assessment process.	Section moved as above to section 6.5. Other investigations as part of assessment including scanning now included in the text in section 3.1. This is now covered at the start of section 3 – indicating that such tests are covered by NICE.
	JE	Given that it is noted that there was insufficient evidence relating to carers perspective on remote assessment and the section focuses on remote management I wonder if this is better presented in a separate section that specifically relates to remote management?	This section has moved to management section 6.5.
	JM	Great to look at carers' perspective but this section wanders from the scope of the title (assessment/diagnosis) to basically cover all technologies / apps involving dementia care and monitoring. Suggest new title and maintain broad scope. Possibly subtitles to break up too.	Agreed – section moved to management section 6.5.
	JH	Consideration will be required in terms of digital exclusion and the balance	We feel this is reflected in the guideline.

		of in-person and remote services.	
3.2	JC	Pg 20 paragraph 2 . Should read included interviews with ..... rather than interviewed....	Amended.
	JLJ	This should be done prior to assessment, as a possible outcome of the assessment. This will enable the person to make an informed choice as to whether to proceed with the asessment.	The group presume this refers to prediagnostic counselling. This is covered in the text.
	PC	All the subsections are clear and informative, and importantly non-prescriptive	Thank you. No response required.
	MP	Prediagnostic counselling should precede assessment	See above response.
	KA	How are reasonable adjustments made to support discussion	This is covered in recommendations and GPP under 3,2.3– refers to - being aware of the differing communication needs of the person with dementia and their carer(s) and provide the opportunity for questions to be asked. Reasonable adjustments should be made in keeping with legislation and the processes of the services involved.
	RB	The document talks about brief cognitive screens and medically based investigations but there is no mention of the role of neuropsychological assessment in the assessment of all types of dementia. Neuropsychological assessment can be essential to clarifying differential diagnosis, monitoring MCI symptoms, and assisting in the understanding of the functional impact of cognitive changes. It guides individualised cognitive rehabilitation strategies and gives the person and their carers/family a better understanding of the specific areas of cognitive strengths and difficulties as they apply to the individual. Neuropsychological assessment will also identify cognitive change where brief screens and imaging investigations (e.g. CT scans) are not sensitive enough to identify change.	Neuropsychological testing is now include in section 3.1.6: *“Neuropsychological assessment carried out in secondary care settings can help when dementia is not clinically obvious. This can include when there is disparity between a person's performance on brief cognitive testing and their presentation, when it is unclear if a person's cognitive impairment is caused by dementia or when it is uncertain what the correct subtype diagnosis is.”*
	GB	I strongly believe (20yrs+experience) this can only delivered well if had a pre-diagnostic conversation- so aware what person wants to know and have prepared them for news. Not all people wish to know, so if not had this conversation- deciding this for them! Pre-diagnostic conversation raises dementia as one possibility but only in context of lots of other causes eg normal ageing, physical health, stress,	Comment is in line with the recommendations. Thank you.

		low mood etc. Asks person would they want to know cause and if thought to be dementia. This helps open u a conversation about dementia, without this reinforces stigma that can't talk about dementia, can challenge misperceptions re illness and also check preferences around knowing that informs diagnosis. need for training on prediagnostic conversation- in my health board carry out jointly with Psychology and Psychiatry	
	JE	All clear, no suggestions.	Thank you. No response required.
3.2.1	JC	Clear and concise	Thank you. No response required.
	JLJ	Clinical Psychologists need to be included here	We have suggested competent person, instead of narrowing it down to a professional
	RH	I think this should be done by a member of the MDT involved with the person's care who has a rapport with the person and family, and sufficient knowledge and training to deliver the diagnosis sensitively and be able to answer questions or signpost to information which can answer any questions.	In line with the recommendations.
	AFr	Really interesting area. This may also depend on the stage of the dementia and their relationship the person has with their carer. Advance and anticipatory care plans can assist with this	The stage of dementia and changing needs is discussed in section 8. ACP is covered in section 8.
	KA	Agree with recommendations and important to consider person centred approach which includes family and carers.	Thank you. No response required.
	RK	There's an assumption here that a carer should be present when a diagnosis is communicated. My experience is that the reluctance of the person with dementia to have someone with them at appointments can be a barrier to diagnosis and treatment. Carers can only be present with the person's permission and there isn't much acknowledgement of this in the literature.	Yes agree with the comment. The guidelines encourages the inclusion of carers where possible as standard practice. Acknowledging specific caveats.
	GB	MDT should make diagnosis, lead by Psychiatry or Consultant Psychologist- in memory clinic. Any qualified person can deliver diagnosis- but importance on training around delivering bad news. In D&G model is now CPN sharing diagnosis, provides continuity in care. Psychology will provide diagnosis when they have been involved in the assessment.	Comment is reflective of guideline recommendations.
	PMac	All health care professional involved in discussion about diagnosis with the person and family should be at Expertise level of Promoting Excellence in relation to Keeping well and finding out it is dementia this should include	Promoting Excellence is now referenced in section 1.1.3. We have recommendations in section 3.2.1 that relate to

		expertise re additional support needs for example LD. There is very little reference to mental wellbeing support for people and families around time of /prior to diagnosis. There is evidence of suicide in people at time of diagnosis –what will the guidance advise about assessing for suicidal ideation, and for the significant mental health impact and who will deliver such assessment, and related intervention /support for mental health. There is very little recognition in the guidance of the significant mental health impact of a dementia diagnosis. There is no reference to social care workforce and their involvement in supporting someone through the diagnostic process. Guidance on collaboration would be helpful. Much dementia care provision is delivered by social care, health and social care work together – there is a gap in the guidance about role of social care. Think the focus should be on conversations with the person's next of kin, family or significant other as most people will not identify as a carer in lead up to diagnosis. Also, very important that they have access to conversations, information and support in their own right. It is important to be aware where the person with dementia does not want families and significant others involved in diagnostic discussions, they will still need to be supported by health and social care professionals, this should be a good practice point. It should be regarded as best practice do be a continuous process of personal outcome focused conversations from first point of contact before diagnosis and before undertaking any extended direct test. Very often social care workforce will be involved in these conversations eg someone living in supported accommodation with a diagnosis. The good practice point should be to engage the person and their family, or significant other in personal outcome focused conversations where the healthcare professional has advanced communication skills and experience, can actively listen and respond to emotions over time. It is unrealistic to expect the person to have 'accepted the changes' if it is a	the multidisciplinary team and the involvement of carers. We have included a Good Practice Point in this section, noting the professional domains and collateral history to be taken into account, and that multimodal assessment is required to exclude delirium. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. Thank you we have now included the important point you make re suicide. Guidelines are deliberately agnostic about specific type of health or social care professional and place emphasis on competency. But we acknowledge your point and have made reference to this in section 1.2.4: *"This guideline will be of interest to primary and secondary healthcare professionals, social care professionals, community, care home and care at home staff, involved in the care of people at risk of, or diagnosed with, dementia, as well as people living with dementia and their families and carers."* We have presented the evidence and this comment is in line with the recommendation of delivering a dementia diagnosis in stages. In section 3.2.3 we make recommendations on the sensitivity required in providing diagnosis and have added a Good Practice Point on the increased risk of suicide.

		one off discussion. Ideally the guidance will remind the workforce that acceptance of diagnosis is very individual and that there is no right or wrong here. We cannot expect people to conform to service led expectation. How does the guidance help workers to assess negative impact on wellbeing – this should not be suggested as a once and done or transactional /task approach The issue with this is- ‘where it can be competently made’. Would expect as a minimum that the person had received immediate care, treatment and support for delirium before any extended direct assessment was conducted or a diagnosis was considered. High risk of diagnostic overshadowing and misattribution of symptoms and potential inappropriate longer-term care and support. Health care professionals must be knowledgeable about where this post diagnostic support can be found.	
	JE	All clear, no suggestions.	Thank you. No response required.
	JM	GPs will provide a diagnosis of cognitive impairment only on the basis of cognitive testing, mental state examination and with the exclusion of other illnesses (ie delirium); some may utilise CT scanning. We often say ‘probable dementia’ or ‘unspecified dementia’. We’ve done this more and more while patients have waited months or years for memory assessment by a consultant. They will not provide specific diagnoses of a type of dementia in the vast majority of cases. They have a key role to play in preparing patients and their carers for this diagnosis, though.	Thank you. No response required.
3.2.2	JC	Clear and concise	Thank you. No response required.
	KA	Agree with recommendations as so post diagnostic support can be offered and onward referral for any other support needs	Thank you. No response required.
	GB	As soon as MDT is aware what differential diagnosis is and fairly confident re this, otherwise further assessment- OT, neuropsy or scans are required or a period of follow up.	This would be out of scope of the remit of the guideline.
	JE	All clear, no suggestions.	Thank you. No response required.

3.2.3	AT	Age 21 3.2.3 1st Paragraph English -This sentence does not read well This concurred with another mixed-studies systematic review which found the person with dementia–carer dyad need for guidelines on dementia before and after diagnosis. perhaps instead the need of the person with dementia–carer dyad for	Revised thank you: *"This concurred with another mixed-studies systematic review which found a need of the person with dementia and their carer was for guidelines on dementia prior to and after diagnosis."*
	GH	It should be tailored to the person receiving the diagnosis.	Thank you, this is in keeping with the wording.
	JC	Clear and concise	Thank you. No response required.
	RH	I agree with the information point that people with undiagnosed dementia may first come into contact with professionals during a hospital admission +/- delirium, and that this should not delay diagnosis where this can be made. I think in some frail older people, this is a not uncommon scenario where dementia can be first recognised, and it is important to make the diagnosis at this point (if the picture is clear enough), to allow people and families to plan ahead and access appropriate support.	Thank you. No response required.
	MP	Prediagnostic counselling should take place in advance of the assessment, not just in advance of the diagnosis. This is part of the process of giving people time to adjust to the potential diagnosis and decide if they wish to undertake the assessment process at all or if they wish to access support from family/friends/advocacy etc. This should be reflected in the body of the section and in the recommendations.	Recommendation added in 3.2.3: *"Healthcare professionals should consider offering information or prediagnostic counselling (a session that takes place in advance of a meeting to inform a person of a dementia diagnosis) for people with dementia and their carers to:* • *discuss and address the beliefs, expectations and potential misconceptions of people with dementia and their carers* • *help them better absorb and understand the information provided to them."*
	AFr	The need for clarity, sensitivity and empathy in the communication of a dementia diagnosis is essential - also providing some hard copies of information to take away that covers what has been discussed	Thank you for your comments, these are included in the recommendations in this section.
	KA	Written information should be accessible and reasonable adjustments made	The recommendations include written information. It is the responsibility of service providers to comply with equality and all other legislation.
	RK	As my comment in 3.2.1, I challenge the statement that "carers should be included as active participants". Yes, I agree they should, but only with the	Thank you for your comment. 1.4 updated to:

		person's clear consent. I agree they can"assist with communication and recall of the discussion", but it is important not to disempower the person with dementia by relying on this. I fully endorse that the healthcare professionals providing a diagnosis should do so in a "clear, sensitive and empathetic manner, being aware of the communication needs..."This may involve some preparation in advance to make sure the communication needs can be met.	*"Family/carers should be involved in decision making about diagnosis and treatment if the person with dementia wishes it, or if the person with dementia lacks capacity and the family/carer has Power of Attorney for Welfare, or a guardianship order is in place."* Recommendation in 3.2.1 now includes *"multimodal assessments including collateral history… from family members/carers".*
	GB	Revisit the pre-diagnostic conversation- you said before you wished to know outcome what cause is, is this still the case (as can change), helps prepare person and family that might be delivering bad news. Need to be open and use terms of illness- AD, Vad if person states wants to know, if don't do this can reinforce stigma that cannot be named, the person can then choose after how names the illness e.g. memory problems rather than dementia. Need to be honest about prognosis but also instill hope- possible to live well and encourage wellbeing and ways of coping. Need space to explore what diagnosis means to person and family before moving on to ways to support, signposting etc Ideally same person provides follow up 2-3 months later to help explore any questions once had a chance to process this. Can then take in more useful information re future planning etc	Recommendation added in 3.2.3: *"Healthcare professionals should consider offering information or prediagnostic counselling (a session that takes place in advance of a meeting to inform a person of a dementia diagnosis) for people with dementia and their carers to:* • *discuss and address the beliefs, expectations and potential misconceptions of people with dementia and their carers* • *help them better absorb and understand the information provided to them."*
	PMac	Where good practice in personal outcome focussed conversations is in place as standard the need for additional pre diagnostic counselling would be identified. To be offered as standard best practice, opposed to a consideration. Will the guidance define pre-diagnostic counselling, and say who this should be delivered by, and how this may be tweaked for people with additional communication needs such as those with LD/Down's syndrome. All information must be in a format and at a pace that suits the person, or it will risk a negative impact on the person's wellbeing and adjustment to diagnosis. The person should also be asked what information they would	Recommendation added in 3.2.3: *"Healthcare professionals should consider offering information or prediagnostic counselling (a session that takes place in advance of a meeting to inform a person of a dementia diagnosis) for people with dementia and their carers to:* • *discuss and address the beliefs, expectations and potential misconceptions of people with dementia and their carers*

		like and in what format. The communication of a diagnosis should be a 2-way process of conversation not just imparting a diagnosis and the person gets to ask questions. Agree that discussion should have positive and hopeful yet realistic messages but important to appreciate that the process of accepting dementia can be very lengthy process and not occur until well after the diagnosis but can be supported by providing information in the format and pace that suits the person. Real risk of giving too much information in one conversation/ discussion and an over reliance on providing leaflets and written information. How would you advise this discussion take place for people with additional communication needs as mentioned earlier, or vulnerable groups such as people with Learning Disability /Down's syndrome –they have additional and different support requirements.	• *help them better absorb and understand the information provided to them."* The delivery of services such as counselling is outwith the scope of the guideline. We expect service providers to offer accessible services and information, in compliance with legislation and within their agreed good practice policies and practices.
	JE	All clear, no suggestions.	No response required
	JM	"One mixed-studies systematic review recommended that information about memory assessments could be made available more widely (eg at GP surgeries and community locations), so that people knew what to expect when attending a meeting to inform the person of the diagnosis of dementia. 7" Suggest specifically that GPs communicate to patients that, when they are referred to a memory clinic, it is made clear that the concern is that they may have dementia. This also acts as an effective 'warning shot' so that the clinic diagnosis does not come as a shock.	We have added this as a recommendation in section 3.2.3, thank you.
	JC	I have not commented on this section as biomarkers and imaging are not within my expertise	No response required
	MC	Overall, would be helpful to know if there is any benefit in following the same investigative procedures for people with Downs syndrome as the rest of the population, as making a diagnosis can be more difficult on clinical grounds.	This was out of scope of the guideline. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.

	PC	It is very helpful to have this section presented in detail though few services will be able to implement the use of CSF or PET scanning for the majority of people who access diagnostic services. The advent of blood based biomarkers may change this picture and a comment cobe included about that. However , the increased use of BBBM will create issues about dealing with asymptomatic people with a positive biomarker level.	Reviewed evidence for blood biomarker, which are not yet clinically validated. We have explicitly excluded asymptomatic/screening people from the guideline. There is no recommendation made for blood biomarkers for dementia at present.
	MP	Routine investigation should be documented in here such as CT/MRI/SPECT and blood work. this more accurately reflects Scottish practice. I am not sure if the investigations noted in this section are available across Scotland which raises equity issues. I am not aware of many of these investigations being routinely available for assessment/diagnosis purposes in Glasgow & Clyde. If this document is aspirational, this should be commented on.	The guidance does indicate the need for standard blood testing and structural imaging before considering these biomarker investigations. This is a guideline. We appreciate the challenges of implementation at board levels. We have restructured this section at editorial to emphasize routine investigations first.
	AFr	Very comprehensive overview of the investigative process	Thank you
	RB	Information relating to pre-diagnostic counselling – This section would benefit from a brief discussion around how this should be co-ordinated within a MDT setting. For example this should be discussed when a patient first has contact with a service regardless of which health care professional they see. It would also help to explain that this needs to be discussed/reviewed throughout the patient's assessment journey. We wondered about the benefit of it being noted that this is a core part of Clinical Psychologist's assessment to help to highlight the work that we do with this group of patients. This section is very focused on medical diagnostic tests. Some of these tests in this section are not routinely used across the NHS– as they aren't available in all health boards and/or may not be required to support a diagnosis/investigate a diagnosis. I'm aware that the document may be read by patients and family members and it is therefore important to explain as and when tests such as a lumbar puncture would be viewed as beneficial. From reading this section we worry that a family member/person with cognitive issues would assume that they will undergo the tests presented in this section. This section could be presented in a way that explains that these are tests that some people undergo as part of their dementia ax if indicated/if available. Again neuropsychological ax information is missing from this section.	*Neuropsychology testing in dementia assessment is now included in section 3.* *Similarly, the wider MDT input is now included in section 3.1:* *"Assessment of dementia is based on a history and examination which will ideally include information from an informant, usually a family member or carer. A diagnosis should be made in line with ICD-11, most often in the context of a multidisciplinary team assessment, and should demonstrate significant declines in cognition and functioning."* We have tried to objectively assess the evidence relating to biomarkers in the guideline. This section starts with the reference to NICE guideline on dementia (NG97, 2018) recommends further tests after a standard dementia assessment and structural

		While this is noted, in brief in the NICE guidance, we don't think it is appropriate to leave it out of this document or assume that people will refer to the NICE guidance alongside reading the SIGN guidance. As neuropsychological assessment can be the focus of some patient's investigations it should be discussed in this document. Also functional assessment information (as per OT input) is also missing from this document. As a dementia ax can involve a range of health care professionals this point should be made clearer in this document. Again this document can be accessed by a range of health care professionals, patients and family members and should contain information that is relevant. A lay person reading this document should come away with a good understanding of who may be involved in their care or a family member's care. Overall, it is felt that the way this section is written is misleading. It implies that CSF/PET scans are the only investigative procedures and then there's nothing else until PDS. In reality it seems this section is highlighting new evidence but at no point is that clear at all. Is the guidance only highlighting change to practice i.e. psychiatrists/neurologists should, as standard, order lumbar puncture and PET scans where they suspect DAT…in which case, it should probably be very clear that this is the case. If not, then they've neglected to include 95% of normal practice in this guidance, including neuropsych ax. Section 4.2.4 questions the use of PET in assisting diagnosis of dementia and the recommendation of it's use is, in my opinion, not grounded in the evidence (see comment below). I think the authors need to be A LOT more clear in their intentions.	brain imaging. We have also now added neurospsychological assessment in section 3.1.6. We have re-drafted this section for clarity. Thank you.
	EV	I believe there are amyloid PET studies for diagnosis of DLB. There is also no mention of use of DAT scan for DLB diagnosis, this needs mentioning, also cardiac MR	We didn't re-assess this evidence as it was covered in the NICE guideline. We have added a section on Dementia with Lewy Bodies (4.4) to refer to NICE. Thank you.
	GB	To highlight other MDT approaches- OT- functional assessmnent and role of Psychology- neuropsychological assessment.	As covered in response to RB.
	JK	Does not make intuitive sense. Extremely neurological in focus. Setting out aspirations however overlooks basics of best practice. Stepped process starting with basics should be clearly articulated. This would prove more	As covered in response to RB.

		valuable as teaching resource and would not set unrealistic expectations for patients and/or carers - such as perception there is a need for PET, lumbar puncture to accurrately diagnose dementia. Heavily weighted to and giving prominence to extensive neurological procedures. Silent around many steps beforehand drawing on other specialist input such as functional assessment by OT and neuropsychological assessment by psychology. This person centred care pathway should be more clearly articulated and not implied.	Neuropsychological assessment now covered in section 3.1 The first paragraph of this section clarified the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
	DC	Please see comments below on functional and PET imaging. Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	No response required.
	PMac	Benefit of a lumber puncture v risk in its usefulness for a diagnosis of dementia should be considered on an individual basis. CSF testing is not currently offered routinely as part of practice. Good practice point should be included in the recommendation.	Good Practice Point in 4.1.13: *“Testing of established CSF biomarkers should be arranged by dementia specialists following clinical assessment. The risks and benefits of undertaking a lumbar puncture should be discussed with the individual, and any risks managed.”*
	JE	Helpful section in relation to biomarkers. However I was surprised that there was no focus on neuropsychological assessment that is typically used in situations where there are uncertainties regarding diagnosis following brief cognitive assessment, or in relation to differential diagnosis of different forms of dementia. My concern is that the absence of any discussion of the use of more detailed neuropsychological assessment procedures for these purposes will lead clinicians to assume they are not recommended.	As covered in response to RB. Neuropsychological assessment now covered in section 3.1
	JH	Not within this reviewer's specific area of expertise.	*No response required.*
	SP	It is important to include neurodegenerative gene panel testing available via NHS Scotland for those with early age of onset and a positive family history. Also to consider autosomal recessive testing in those with early onset dementia to include screening for example metabolic disorders. More emphasis should be given on the role of structural imaging to include CT head and MR brain	The genetic topic was discussed extensively in the guideline development process. The issue was the lack of clarity in the evidence for specific gene testing. A Good Practice Point (GPP) has been added to section 4.5.
4.1	KA	This is not my area of expertise but is there any reference to biomarkers	We acknowledge that learning disabilities is a specialist

		specific to individuals with Down's syndrome?	area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	DC	Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	Thank you. No response required.
	JE	All clear, no suggestions.	Thank you. No response required.
	JM	I have never seen biomarkers used in clinical practice in any of my patients in work as a GP. Is it worth clarifying how widespread this use is?	At present these biomarkers are almost exclusively undertaken in small numbers of young onset dementia patients. Guidelines are developed based on the available evidence rather than frequency of approach.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	Thank you. The guideline group were made aware of this issue.
4.1.1	DC	Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	Thank you. No response required.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
4.1.2	JK	Routine use of amyloid PET not currently recommended as best practice, should therefore not be included?	The current evidence on aPET is presented in the guideline so readers can review this.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.

4.1.3	DC	Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
4.1.4	DC	Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
4.1.5	MR	guidelines for diagnosis should be reviewed thoroughly in three years as, after discussions with industry professionals(company called taurx) bio markers should be found within blood tests cheaper than at present.	We have reviewed the current literature. The guideline will be reviewed for updates as per SIGN process (3 years).
	DC	Cannot comment on CSF biomarkers - liaising with lab services is suggested to assess if feasible to implement	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	The reality in NHS Scotland is that there are no accredited labs providing CSF tau and amyloid analysis. These tests have historically been performed on a research basis by the National CJD Research and Surveillance Unit at the University of Edinburgh. The biochemist who delivers these tests is retiring in March 23 and the tests will no longer be available in Scotland.	The first paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity.
4.2	DC	There is a statement in the first paragraph that "FDG PET is already well established in the use for dementia diagnosis". Although there is growing evidence and opinion that FDG PET is superior to HMPAO SPECT imaging FDG PET is not a service that is currently available or funded in	Text accepted and now covered in section 4.1.13 alongside recommended tests Recommendation is to not use routinely.

		Scotland. The current infrastructure in Scotland does not have the capacity to deliver this service. The progression to FDG imaging would be something that should be a future goal but at present isn't feasible to implement. Investment in this area would be required. It may be more appropriate for a statement along the lines of - functional imaging is well established technique for use in dementia diagnosis and subtyping. HMPAO is widely available in Scotland with access to FDG PET remaining extremely limited. Where available FDG PET should be considered on a case by case basis in discussion with regional PET CT centre. Development of FDG PET imaging dementia should be a future goal of NHS Scotland. With regards to amyloid PET this is only available as a research tool currently in Scotland. Although it should also be a aspiration for future it should proposed recommendation requires revision/removal.	
	PMac	The current availability of this in Scotland?	Same as above (DC comment)
	JE	All clear, no suggestions.	Thank you. No response required.
	JM	as above - suggest reference to the scarcity and cost of amyloid PET. Both 4.1 and 4.2 may be relevant to the many research doctors on the guideline but they are irrelevant the average clinical practitioner currently.	None of the guideline group have been directly involved in amyloid PET research, but were tasked with reviewing the current evidence. The group have discussed with nuclear medicine colleague at a National level about the potential implementation issues related to the wider use of FDG-PET and amyloid PET. At present the later has only been undertaken at low frequency for research studies in Scotland and has additional implementation challenges to FDG-PET, which is currently available but mainly used for oncology practice. First paragraph of this section clarifies the purpose of further investigations. This chapter has been reordered and redrafted for clarity and brevity. Section 4.1.3 now includes:

			"Functional imaging is well-established technique for use in dementia diagnosis and subtyping. Perfusion SPECT is widely available in Scotland, while access to FDG-PET remains extremely limited. Where available FDG-PET should be considered on a case-by-case basis in discussion with regional PET-CT centres.."
	SP	Amyloid PET is not available in the majority of health boards in Scotland	The group are undertaking discussion with nuclear medicine colleague at a National level about the potential implementation issues related to the wider use of FDG-PET and amyloid PET. At present the later has only been undertaken at low frequency for research studies in Scotland and has additional implementation challenges to FDG-PET, which is currently available but mainly used for oncology practice. Section 4.1.3 now includes: *"Functional imaging is well established technique for use in dementia diagnosis and subtyping. Perfusion SPECT is widely available in Scotland with access to FDG-PET remaining extremely limited. Where available FDG-PET should be considered on a case by case basis in discussion with regional PET CT centre."*
4.2.1	AT	I personally found the change from using the term Amyloid PET or a PET depending on which paragraph I was reading unhelpful	Amyloid PET has been abbreviated to aPET in the document as appropriate for SIGN style.
	RB	The sentence beginning "For differential diagnosis, a study reported sensitivity of 89.6 %...." How does that translate to the real world? In this study they presumably know that the participants have/don't have DAT and the test isn't 100% sensitive/specific. If you don't know the base rate of DAT in the sample coming into the clinic…and I doubt that psychiatrists keep that information to hand, you run the risk FP/FN rates that would be higher than in this controlled study (has no one else read Bad Science by Ben Goldacre?!) Sensitivity and specificity of 61.6/57.1 (assuming it's data from the same study) is woeful, only just better than a coin flip!	Thank you we have reviewed and revised this section and following sections to address this.

		The recommendation below is to not use PET routinely but only in cases where diagnosis is uncertain…but I don’t think that can be squared with this data. And there needs to be an acknowledgement of the base rate issue by the SIGN authors.	
	DC	As mentioned Amyloid PET is only available for research at present in Scotland	See above.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	Amyloid PET is not available in the majority of health boards in Scotland	Section 4.1.3 now includes: *“Functional imaging is well established technique for use in dementia diagnosis and subtyping. Perfusion SPECT is widely available in Scotland with access to FDG-PET remaining extremely limited. Where available FDG-PET should be considered on a case by case basis in discussion with regional PET CT centre.”*
4.2.2	AT	I personally found the change from using the term Amyloid PET or aPET depending on which paragraph I was reading unhelpful	Amyloid PET has been abbreviated to aPET in the document as appropriate for SIGN style.
	DC	As mentioned Amyloid PET is only available for research at present in Scotland	See above.
	JE	All clear, no suggestions.	Thank you. No response required.
	SP	Amyloid PET is not available in the majority of health boards in Scotland	Section 4.1.3 now includes: *“Functional imaging is well established technique for use in dementia diagnosis and subtyping. Perfusion SPECT is widely available in Scotland with access to FDG-PET remaining extremely limited. Where available FDG-PET should be considered on a case by case basis in discussion with regional PET CT centre.”*
4.2.3	AT	I personally found the change from using the term Amyloid PET or aPET depending on which paragraph I was reading unhelpful	Amyloid PET has been abbreviated to aPET in the document as appropriate for SIGN style.
	DC	As mentioned Amyloid PET is only available for research at present in Scotland. We currently do not have access to FDG PET at present in Scotland and development of this service would need to be undertaken before taking considering extending services to Amyloid PET imaging.	See above.

	JE	All clear, no suggestions.	Thank you. No response required.
	SP	Amyloid PET is not available in the majority of health boards in Scotland. HMPAO-SPECT is more readily available than FDG-PET	Section 4.1.3 now includes: *"Functional imaging is well-established technique for use in dementia diagnosis and subtyping Perfusion SPECT is widely available in Scotland, while access to FDG-PET remains extremely limited. Where available FDG-PET should be considered on a case-by-case basis in discussion with regional PET-CT centres."*
4.2.4	EV	See above	
	JE	All clear, no suggestions.	Thank you. No response required.
	DC	There is a statement within this section about the radiation exposure from Amyloid being 2-3 times higher than FDG with no reference quoted for this. In our opinion and experience this is a highly inaccurate statement. The statement about the radiation effects in young vs elderly patients should also be revised. As mentioned above Amyloid imaging is not feasible as a clinical imaging tool in Scotland at present and it is felt this recommendation should be removed/revised.	The group reviewed this evidence. Text amended. Thank you. See comments above. This is now a good practice point and section 4.1.3 now includes: *"Functional imaging is well-established technique for use in dementia diagnosis and subtyping Perfusion SPECT is widely available in Scotland, while access to FDG-PET remains extremely limited. Where available FDG-PET should be considered on a case-by-case basis in discussion with regional PET-CT centres."*
	SP	Amyloid PET is not available in the majority of health boards in Scotland. HMPAO-SPECT is more readily available than FDG-PET	*Section 4.1.3 now includes:* *"Functional imaging is well-established technique for use in dementia diagnosis and subtyping Perfusion SPECT is widely available in Scotland, while access to FDG-PET remains extremely limited. Where available FDG-PET should be considered on a case-by-case basis in discussion with regional PET-CT centres."*
	YM	OK	*Thank you. No response required.*
Section 5			
	LH	There is no clear guidance on what PDS is and what constitutes an expert. The promoting excellence framework is massive, staff don't have time to go through it- but how do people evidence this.	We acknowledge and refer to the existence of the five pillar model of postdiagnostic support and the 8 pillar model of care coordination. The evidence from guidelines

		Individual localities deliver PDS so differently but there should be standardised guidance about what topics should be covered to help the novice practitioners	roughly aligns with these models.
	AF	Definitely need for this- dementia specialist nurses. Increased education to community and acute care teams.	Thank you. No response required.
	JC	Clear introduction	Thank you. No response required.
	MC	Would be helpful to have guidance on any additional support measures that might be needed for people with learning disabilities and dementia, given their overall higher support needs and relatively earlier age of onset.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	PC	Again, a very comprehensive discussion of the evidence base, and a well written section	Thank you. No response required.
	MP	Across Scotland the 5 and 8 Pillars models are used to deliver PDS, should this not be referenced explicitly in the document as the model of choice across much of Scotland? The Recommendations section does not specify the use of cognitive rehabilitation and CST (Spector, 2003), NES provide the training across Scotland.	See response above. We recognise the importance of a wide range of psychosocial interventions. The current evidence on PDS is framed within needs rather than explicit treatment response.
	AFr	This is a highly needed and valued area of the journey with someone living with dementia and it can be a make or break in terms of how well they can live with dementia. It is disappointing despite the dementia strategy in place in Scotland there is still such variance on how PDS is available and provided - this includes how independent "specialist" dementia organisations approach it	We acknowledge your comment and hope that the inclusion of 21 recommendations and 9 Good Practice Points in the section on postdiagnostic support will support improved access and provision. Focus on Dementia is the national improvement portfolio for dementia (based within Healthcare Improvement Scotland). A core part of their work is to improve the quality and access to postdiagnostic support. We have share your comment with them to support implementation of the guideline.

	KA	There is no reference to including people with a learning disability / Down's syndrome within the post diagnostic support section. This is often not offered to this population group following on from diagnosis and often a inequality of care in relation to PDS unless supported by specialist learning disability teams. This is includes carers/family.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	EH	you have missed key driver in Scotland for PDS and should consider including The 5 Pillars Model provides a framework for people living with dementia, their families and carers with the tools, connections, resources and plans to allow them to live as well as possible with dementia and prepare for the future. Noted here https://www.alzscot.org/sites/default/files/2019-07/Facing-dementia-together-post-diagnostic-support-pilot.pdf https://www.alzscot.org/sites/default/files/2019-07/110716_-_Updated_Getting_PDS_Right.pdf The last sentence in the first paragraph you quote the LDP BUT the key to this target is also "building a holistic and person centred support plan" as you can see from the wording in the reference below. can you add that into that last sentence : This Standard supports the improvement of local post-diagnostic services as they work alongside and support people with a new diagnosis of dementia, and their family, in building a holistic and person-centred support plan. https://www.gov.scot/publications/nhsscotland-performance-against-ldp-standards/pages/dementia-post-diagnostic-support/ in this introduction you may want to include the recent ADI report published this year https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf	Agree. We have add reference to the 5 and 8 pillar models in the section 5 introduction. It is outwith the scope of the guidelines to provide the aims of different policy documents. Thank you for highlighting this. We have not included as it is not specific to training and education resources.
	RB	Information such as the 5 Pillars and 8 Pillars of Dementia Care (as per Alzheimer's Scotland) is not referred to in this section. As this approach contributes to the Dementia Strategy and forms the basis of PDS in	Agree. We have add reference to the 5 and 8 pillar models in the section 5 introduction.

		Scotland it is not clear why it is not referred to in this document. The PDS section would benefit from specific mention (and hopefully recommendations) around people with dementia being offered Cognitive Stimulation Therapy and Cognitive Rehabilitation - they both have a robust evidence base and we think it is a significant gap that they are not specifically named.	We recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit treatment response.
	EV	Mention around delirium prevention specific consideration of LGBTQ community specific needs would be helpful some mention of joined up health records would be welcome, continuity of information.	The guideline does make reference delirium in section 1.2.3 Co-morbidities, section 3.1- assessment of dementia and section 3.2.2 diagnosis of dementia. We acknowledge lack of evidence around LGBTQ+ specific needs sections 1.1.7, in the checklist in section 9.5 and in the recommendations for research (Research into the experiences of postdiagnostic support on minority groups, those with protected characteristics, those with young onset dementia and young carers). As part of the EQIA for the guideline there was consideration of the needs of LGBTQ+, there was no research identified for LGBTQ+ for the key question for this PDS section. The provision of information section also provides a link to resources that includes LGBTQ+.
	GB	This is crucial and a menu of options needed to suit individual needs of person and carer. Helpful to have more mention on who provides, high demand and ageing pop means emphasis in secondary care and NHS on assessment and diagnosis, this will only increase with ageing pop and also raising awareness re brain health etc. Need to ensure SG resources are available NHS to support PDS. At present feel PDS options are limited- need to have a local implementation plan- role of health, social care and third sector in collaborating to provide this. Would be good to highlight specific groups where good evidence eg. CST,	Policy and funding at local level is beyond the scope of SIGN and this guidance. While we recognise the importance of a wide range of psychosocial interventions the current evidence on PDS is framed within needs rather than explicit treatment response. Focus on Dementia is the national improvement portfolio for dementia (based within Healthcare Improvement Scotland). A core part of their work is to improve the quality and access to postdiagnostic support. We have share your comment with them to support implementation of the guideline.

		as good as ACI meds and improve qol. is cost effective and says more money that is spent delivering groups (just staff time)	
	JCa	As stated at the online meeting, there is an incorrect definition of the LDP standard [ref no 133]. Scottish Government has incorrectly stated its own LDP.	The Local Delivery Plan reference and content has been checked and confirmed to be correct.
	AMcK	Inclusion of AHP led work around rehabilitation and self-management.	While we recognise the importance of a wide range of psychosocial interventions but the the focus of this section is on the needs and unmet needs of those accessing services rather than on specific treatments or specialists providing support.
	JK	Group noted that there was a lot of good content in this part of the guideline however were struck that the well documented work of Alzheimers Scotland around 5 and 8 pillar and Advance Practice models of care not acknowledged. Work has been subject to commendation internationally and opportunity should be taken to give SIGN guideline 'Scottish accent' and show case the approach. Was acknowledged that even thought AS PDS model may not yet have the 'so what' of the model, it is the model that Scotland uses and aspires to nationally. So it should be mentioned explicitly in the guideline. Group was aware that most studies are not UK studies however.	Agree. We have added references to the 5 and 8 pillar models in the section 5 introduction.
	DB	We would like to provide some additional Scotland-specific policy narrative and scene-setting	Thank you. We have discussed and reviewed this section, adding the 5 and 8-pillar models.
	JE	A very helpful section. One thing I was surprised about was that there was no reference to the evidence that relates to specific intervention approaches that have been demonstrated to improve everyday meaningful activities (e.g. Cognitive Rehabilitation that is evaluated in the GREAT trial and other studies by Professor Linda Clare). Additionally I was surprised that there was no coverage of Cognitive Stimulation Therapy (CST) given that this intervention has also been subject to multiple evaluations. It feel like there are quite a lot of general statements about people needing support to do meaningful activities but less on the specific techniques that may facilitate improving the ability to complete meaningful activities. .	While we recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit treatment response.
	JM	One my biggest frustrations is the lack of access to post diagnostic support for my patients with dementia, and their families and carers. PDS relies on significant funding (which isn't there) so what happens is existing resources are simply stretched. Often those carers with the highest levels	Thank you. We acknowledge your frustration and have proposed recommendations to evidence this need in the section on PDS supported by evidence based practice.

		of motivation or complaint, rather than need, get the best support.	Section 10.3 now makes recommendations for auditing current practice, including audit points on the number of people accessing high-quality post-diagnostic support and the outcomes of support.
	SP	There is a major shortage of community mental health nurses to provide bespoke post-diagnostic support for people with early onset dementia in Scotland	Thank you. We acknowledge your experience.
5.1	FG	Throughout the document the recommendations refer to healthcare professionals as delivering Post Diagnostic Support. As a specialist charity that delivers a significant amount of Post Diagnostic Support using the 5 pillar model, our Post Diagnostic Link workers are not healthcare professionals but are specialists in dementia care and should be recognised. There is a concern that HSCP may interpret the guidance that's PDS should be delivered by health.	Thank you. Where the evidence mentioned a healthcare professional this is the term that has been used. However, we have reviewed section 5 and altered the language to indicate that a wider range of professionals may be involved in delivering postdiagnostic support.
	Anon	My relative was diagnosed with dementia in February 2020 - as you can imagine, this hugely affected the availability of postdiagnostic support. Such that was available was only available 'online' which was completely hopeless for my relative. The main issue was that they were unable (and continue to be unable) to understand or accept the diagnosis. There seems to be no support available in these circumstances. I completely accept the 'living well with dementia' approach and the importance of involving people in their care and support as far as possible. however, my relative cannot understand this and it gets more and more wearing every time to try and involve them. Please include guidance on what to do in these circumstances.	Thank you for your comment and we are sorry that your experiences with postdiagnostic support have been unhelpful particularly during the pandemic. In the guideline we do emphasise the consideration of communication and communication support within the needs of the person with dementia-carer dyad (or partnership). Although this does not provide specifics on practical approaches to support acceptance and understanding of diagnosis, our recommendation encourages health and social care professionals to be supported in enhanced communication skills and person-centred approaches (section 9.3).
	JC	Clear and concise	Thank-you. No response required.
	MH	Last line of 2nd paragraph should read: 'There is a positive correlation among...'	Thank you. This section has been revised and this part removed during the editorial process.
	MR	There should be a pds worker on site; aberdeen royal have such a worker from a voluntary organisation full time in optical dept, a great help when diagnosed visually impaired.	There are a range of settings where it may be appropriate to situate a PDS worker as noted in the guidance.
	KA	As above (section 5)	You comment has been addressed above.
	EH	in this whole PDS section I think there are topic heading missing - you may have considered them and they did not meet your review criteria but could be acknowledged in your opening paragraph and include :	Thank you for your comments and highlighting these relevant and important emerging areas of practice in dementia care. As you've noted, these topics were not

		Driving and dementia e.g https://research.ncl.ac.uk/driving-and-dementia/consensusguidelinesforclinicians/Final%20Guideline.pdf Employment and dementia e.g. https://www.dementiauk.org/get-support/living-with-dementia/employment-and-young-onset-dementia/ Rehabilitation and dementia e.g. People with dementia are not routinely offered rehabilitation services despite experiencing disability associated with the condition and accumulating evidence for therapies such as exercise, occupational therapy, and cognitive or physical rehabilitation. Laver et al 2020 https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01940-x Self-management and dementia e.g. Quinn et al 2016 A Review of Self-Management Interventions for People With Dementia and Mild Cognitive Impairment https://journals.sagepub.com/doi/abs/10.1177/0733464814566852 These are all emerging and developing areas of practice in dementia care	identified within the evidence review process for postdiagnostic sutpport, which were developed to support key questions by the guideline development group (Annex 1). Within section 5.2 (Needs and unmet needs in postdiagnostic support), some of these issues are included, self-management and driving (5.2.4, 5.2.6). Section 9.3 now includes self-management resources.
	GB	Is crucial but current support is mixed and not sufficient.	We acknowledge that in practice there is a lot of variation in the delivery of postdiagnostic support.
	JCa	Why does this not highlight in recs that HSCPs should meet the LDP standard? Why does this section start with carers' experiences not with those of people with dementia?	The guideline is based on the evidence reviewed and provides recommendations based on that evidence. It is not within SIGN's remit to comment on Health and Social Care Partnerships meeting Local Delivery Plan standards. The first paragraph in section 5 has been re-ordered to put the person with dementia first. Thank you for highlighting this.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
5.2	GH	People in care homes are not generally in receipt of post-diagnostic support, however they should be and this could be reiterated in the guideline.	We can appreciate your concern that people living in care homes have the potential to be unintentionally excluded in dementia support. The Good Practice Point in section 5.2 on postdiagnostic support makes reference to all settings which can be taken to include people in care homes:

			“Postdiagnostic support should be available throughout all stages of the disease, and in all settings, aligned to the needs of the person with dementia or their carers.” In addition, section 1.2.1 (Overall objectives and scope of the guideline) now states: *“This guideline provides recommendations based on current evidence for best practice in the assessment, treatment and support of adults with dementia. The guideline applies to all settings, including home, long-term care, care homes, hospital, hospice, day-care centres and primary care. Person-centred care should be the focus of the implementation of this guideline.”*
	FG	Timely access to services that help maintain and prevent a deterioration is essential however accessing statuatory services is a challenge unless people are at crisis. We need a whole system approach to be more proactive to prevent this.	We agree that a systems approach is essential when supporting people with dementia.
	Anon	Meeting the needs of people who cannot understand or accept their diagnosis. Accepting that for many people online or telephone support is completely useless.	The evidence does highlight the need for emotional support as part of PDS but doesn’t specific talk about acceptance of a diagnosis. However, please refer to section 3 for guidance on how a diagnosis should be discussed with a person with dementia. Also refer to section 6.5.2 for a discussion of remote support for people with dementia.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	JC	It’s not evident which of the studies the JBI scores relate to, six references are included in this paragraph but three JBI scores?	This is SIGN style that we give an indication of the quality of the body of evidence. If a number of studies have the same score, this is only presented once for brevity. Your feedback will be taken will be taken to SIGN methodology group for consideration of how we present

			our evidence in future.
	MP	Line 3, the word years is missing	Thank you. This has now been added.
	AFr	Good overview of the needs and practicalities	Thank you
	KA	Unmet health needs are often missed within people with a learning disability / Down's syndrome and dementia, including sign posting and anticipatory care planning. Any reference to quality of life outcomes.	Thank you for your comment. We agree regarding co-ordinated services. Additionally, the recommendations make reference to a co-ordinated postdiagnostic support that encourages engagement with services (5.1.1) We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	Reports of poor experiences of post diagnostic support with communication implies a lack of Speech and Language Therapy provision, or signposting. Where post-diagnostic support is effective, there is good co-ordination between services.	We agree regarding co-ordinated services. Additionally, the recommendations make reference to co-ordinated postdiagnostic support that encourages engagement with services (5.1.1)
	JCa	Simply confusing.	We have edited the first sentence so that the meaning is clearer
	JM	I was hoping, after reading the initial sentences, that SIGN would recommend a minimum time for PDS. I see SIGN has stopped short. I can see why. But it makes sense that PDS gets more complex (and therefore more in need) the longer the time since diagnosis, given dementia's progressive nature. In my view, PDS should be available until after death (see grief).	The evidence does not support a specific time frame for postdiagnostic support as it covers a broad range of literature about people with dementia from different countries. We have, however, included a Good Practice Point in 5.2: *"Postdiagnostic support should be available throughout all stages of the disease, and in all settings, aligned to the needs of the person with dementia or their carers."*
	JH	As noted earlier, in addition to considering the impact of this Guidance upon Protected Characteristic groups, further equality impacts may be illuminated through engagement with communities utilising a Human Rights Based approach and the PANEL principles (Participation,	The SIGN guidance development process follows a structured framework and efforts are made to consult widely and engage with a broad range of expertise and experience. However, we recognise there may be

		Accountability, Non-discrimination and Equality, Empowerment and Legality). This ensures that communities who are currently more distant from services (and the required information to have confidence in using those services) can be supported to have their voices heard. This allows for communication plans around the Guidance to consider both targeted information relevant to protected characteristics and also wider socio-economic determinants including social class, stigma, and recognition of the caring role whether someone is an established or recent carer.	limitations to our strategy and take on board useful suggestions to improve this in the future. Not possible for this guideline but feedback noted by SIGN for consideration in future guidelines.
5.2.1	YM	At some point in early stage, before middle stage -carer in attendance for at least part of routine oral health care visits(both dental and hygiene therapy ones) will become necessary(to try an ensure that health and prevention messages are not forgotten)	We agree that this is important but it wasn't something that emerged from the review of the evidence. Specifically oral care was not within remit of review, however, it can fall within ADL support which is supported by the postdiagnostic support literature.
	JE	Helpful section. No additional suggestions.	Thank you, no response required.
	AF	Greater understanding particularly in care homes of the patient as a person. What matters to them?	We agree this is important but not specific to postdiagnostic support, nor was this identified or differentiated in the literature.
	JC	Needs that are well addressed and those that are overlooked are clearly identified	Thank you, no response required.
	GMc	No mention of the role of nutrition and impact this potentially could have on maintaining function - reduce risk of falls/fractures, maintain muscle strength and in turn mobility, management of co-existing physical conditions e.g. diabetes, bowel conditions, hypertension/hyperlipidaemia especially in vascular type dementias.	We recognise the importance of a wide range of interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response.
	AFr	Highlights the variance again	Thank you, no response required.
	KA	Same as 5.2	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	I haven't' spotted much about support with eating and drinking. There is mention of non oral feeding in the later stages even though that is rarely indicated. Difficulties with eating and drinking are common and I don't think	We recognise the importance of a wide range interventions but the current evidence on PDS is framed within needs rather than explicit treatment response.

		the guidelines acknowledge this enough.	This seems more related to anticipatory care planning which has covered a section on artificial hydration and feeding (section 8.4).
	KP	Music therapy can help to manage mood changes and stress and distress and assist with behavioural management, cognition management (memory loss and deteriorating cognitive functioning). Issues around inclusion, identity and meaningful occupation were also identified. The last Cochrane review (2018) looking at musical interventions with people who a living with dementia indicated they could reduce ' depressive symptoms and improve overall behavioural problems' and 'It may also improve emotional well-being and quality of life and reduce anxiety.' https://www.cochrane.org/CD003477/DEMENTIA_music-based-therapeutic-interventions-people-dementia Hsu, M.H., Flowerdew, R., Parker, M. et al. Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. BMC Geriatr 15, 84 (2015). https://doi.org/10.1186/s12877-015-0082-4 Therapeutic musical interventions can be personalised to reflect individual's identities and provide a source of occupation that is meaningful to the individual as well as uncovering strategies to offer support with emotional regulation and cognitive functioning. Odell-Miller, H. (2021). Embedding Music and Music Therapy in Care Pathways for People with Dementia in the 21st Century—a position paper. Music & Science, 4. https://doi.org/10.1177/20592043211020424 Bolton L M, Jiang J, Warren J D. Music as a person centred intervention for dementia BMJ 2022; 376 :o518 doi:10.1136/bmj.o518	We recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. This is covered in section 6.
	GB	knowledge about what is happening- education dementia and brain-opportunity to talk and make sense of changes and understand what happening if wish importance of peer support groups- reduce stigma and normalise changes, develop relationships	We recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response.

		Chance to maintain skills and promote independence e.g. CST, cog rehab groups	
	PMac	The needs of the person with dementia should include emotional support. Health and social care professionals supporting the person with dementia should also be aware of the increased risk of suicide in the months following a diagnosis and should have the knowledge and skills relevant to their role as set out in the Mental Health Improvement and Suicide Prevention framework. There is quite a bit of literature on what should be included here for people with LD or Down's syndrome, as this is more nuanced. It would also be good practice to include the use of adaptive and accessible communication, as well as sensory regulation strategies. Health and social care professionals providing post diagnostic support should have the knowledge and skills set out at the Enhanced and Expertise level of Promoting Excellence in relation to Keeping well, prevention, and finding out it's dementia and Living well with dementia stages of the dementia journey,	We agree as highlighted in the needs of person with dementia should include emotional support. While suicide prevention is hugely imperative, it did not emerge as a finding from our evidence synthesis. However, we could see a link to mental wellbeing particularly in the person with young onset dementia and have included a GPP (3.2.3): *"Healthcare professionals should be aware of the increased risk of suicide in people with dementia younger than 65 within 3 months of a diagnosis."* We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. We have now referenced the Promoting Excellence Framework throughout.
	JH	As per comment above at section 5.2.	See previous response.
5.2.2	JC	Needs identified	Thank you no response required
	GMc	Impact of carer stress/distress on their own mental and physical health. Self care including nutritional wellbeing to enable the carer to stay well enough to actively contribute to the needs of the person with dementia who may also be a loved one.	We agree that this is important, but nutritional wellbeing did not specifically emerge as a theme in the review of the evidence.
	MH	Can you rephrase 'One of these reviews identified in advanced dementia, in the absence of verbal communication from the person with dementia, carers reported not being able to identify when something was wrong or causing distress to the person with dementia which was distressing.' as it is confusing. This sentence is repeated in 5.2.5	Edited in both places. The duplication in 5.2.2 has been removed. This has been removed from 5.2.5 during the editorial process.
	KA	Same as 5.2	See above

	KP	The guidelines identified carer-specific needs including emotional support and coping with the absence of verbal communication from the person with dementia. Music therapy can be provided in carer- person living with dementia dyads to support relationships and develop communication strategies to assist with understanding and support carer wellbeing. Kristine Gustavsen Madsø, Helge Molde, Kia Minna Hynninen & Inger Hilde Nordhus (2022) Observing Music Therapy in Dementia: Repeated Single-case Studies Assessing Well-being and Sociable Interaction, Clinical Gerontologist, 45:4, 968-982, DOI: 10.1080/07317115.2021.1978121 Quail Z, Bolton L, Massey K Digital delivery of non-pharmacological intervention programmes for people living with dementia during the COVID-19 pandemic BMJ Case Reports CP 2021;14:e242550. Clark IN, Baker FA, Tamplin J, Lee Y-EC, Cotton A and Stretton-Smith PA (2021) "Doing Things Together Is What It's About": An Interpretative Phenomenological Analysis of the Experience of Group Therapeutic Songwriting From the Perspectives of People With Dementia and Their Family Caregivers. Front. Psychol. 12:598979. doi: 10.3389/fpsyg.2021.598979	We recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit treatment response. See responses in section 6.
	GB	Change attend training and education- on illness and future planning- explore own needs and resiliency to cope with future changes. Need peer support- adequate time to help with caring needs- respite, care packages etc Good example free carer training- Dementia Carers Count and has an online virtual carers centre Role of local carers centre	We have added the Dementia Carers Count webpage to the resources at the end of the guidelines (section 9.3).
	JK	The group noted that there should be more around building capacity of carers and how this is supported as a whole. Literature outlining this would be beneficial or evaluation of the Scottish experience with examples of best practice.	We have added the Dementia Carers Count webpage to the resources at the end of the guidelines (section 9.3). This is out with the remit of SIGN, however agree this would be a useful piece of audit or service evaluation for

			future research or organisations to undertake.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	JH	As per comment above at section 5.2.	See comment above
5.2.3	JC	Needs identified	Thank you, no response required.
	MP	For consistency throughout the document, should the term 'distressed behaviours' as per section 6 be used rather than behavioural problems as noted on line 2? Across Scotland, many areas use the Newcastle Model which is the psychological management of stress and distress in dementia. The training and implementation of this model is supported by NES. I wonder if the document should reflect that this model is used acorss Scotland.	This language directly reflects the language in the paper that is being cited. Thank you, we have now included this in section 6. There was insufficient literature to make a recommendation on the model. We have included a recommendation for research on section 11.2: *“Better evidence for non-pharmacological therapies and the effectiveness of such therapies for distressed behaviours.”*
	AFr	Well highlighted of the complexity of the relationship and the need for intervention from those specialised in these areas	*Thank you, no response required.*
	KA	Same as 5.2	*See response above.*
	KP	Music therapists who specialise in working with older people and dementia conditions can help offer education, emotional support and develop strategies to support wellbeing within the person with dementia-carer dyad. Music therapy is currently being used as a strategy to help support relationships between people living with dementia and their family members as well as with formal care providers, in care homes in Midlothian as part of NHS music therapy provision. Tamplin, Jeanette, and Imogen N. Clark, 'Therapeutic Music Interventions to Support People With Dementia Living at Home With Their Family Caregivers' in Amee Baird, Sandra Garrido, and Jeanette Tamplin (eds) Music and Dementia: From Cognition to Therapy New York, 2019; online edn, Oxford Academic, 23 Apr.2020), https://doi.org/10.1093/oso/9780190075934.003.0013	We recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. See section 6.

		Baker FA, Bloska J, Braat S, et al HOMESIDE: home-based family caregiver-delivered music and reading interventions for people living with dementia: protocol of a randomised controlled trial BMJ Open 2019;9:e031332. doi: 10.1136/bmjopen-2019-031332	
	JE	Helpful section. No additional suggestions.	Thank you, no response required.
5.2.4	JC	Safety issues are identified. I'm not sure if this study on restrictive practices is complete yet but will fit here: https://storiesofdementia.com/restrictive-practice-study/	Thank you for sharing this information. As yet the research is unpublished and will not be included in this guideline.
	AFr	Good section - it is essential of balancing safety issues with those of the needs and human rights of the individual with dementia	Thank you, no response required.
	KA	Quality of life outcomes and capable environments that can support individuals/family and carers	Quality of life was an outcome that was considered in relation to postdiagnostic support, and we have reported on the evidence specifically the need to explore the caregiver's individual values and emotions towards caregiving to provide a basis for health and social care professionals to discuss factors that are important to their quality of life.
	KP	Music therapy can be used to support people with the Behavioural and Psychological symptoms of dementia, including apathy and agitation. Hsu, M.H., Flowerdew, R., Parker, M. et al. Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. BMC Geriatr 15, 84 (2015). https://doi.org/10.1186/s12877-015-0082-4	We recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. See section 6.
	GB	Could mention Herbert Protocol, good national strategy to help find people who get lost or leave house quickly	We have added the Herbert protocol to sections 5.2.4, 5.2.8 as an information point and to the provision of information section. Thank you for highlighting this.
	JE	Helpful section. No additional suggestions.	Thank you, no response required.
5.2.5	Anon	Online and telephone support may be completely useless for some people with dementia	Agree and this is covered in part in sections 3 and 6.
	JC	Needs identified	Thank you, no response required.

	AFr	Miscommunication can lead to increased stress and distress with the person with dementia. It can also increase the stress and distress with the carer if they have not got sufficient knowledge, understanding and insight into the type of dementia their cared for person has	This is also supported by the literature, evident by the recommendation supporting the review and training needs surrounding communication and skills support for professionals and person with dementia/carers.
	KA	Use of accessible information to support communication - Equality Act (2010)	Agree that this is important legislation but not appropriate to include in the evidence review.
	RK	Good to have this flagged.	Thank you. No response required.
	KP	Music therapy can be used to support communication, particularly in later stages of the disease as the ability to use and process spoken language can decline. Amy Clare, DClinPsych, Paul M Camic, PhD, Sebastian J Crutch, PhD, Julian West, BA, Emma Harding, Bsc, Emilie Brotherhood, Msc, Using Music to Develop a Multisensory Communicative Environment for People with Late-Stage Dementia, The Gerontologist, Volume 60, Issue 6, September 2020, Pages 1115–1125, https://doi.org/10.1093/geront/gnz169	We recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit interventions
	JCa	Seems to rather narrowly focus on communication in relation to physical concerns or illness.	The topics reflect the research that was found in the evidence review.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
5.2.6	AT	However, support does need to be flexible and sensitive, or tailored, to the needs of the individual, taking into account cultural needs. Is this really" or" tailored rather than an "and" tailored	Changed to "and".
	AF	Individualized patient care What matters to the service user?	We hope we have covered the separate needs of people with dementia and carers.
	JC	Needs identified	Thank you. No response required.
	AFr	This seems very clinically focused when a lot of professionals such as social workers who will be assessing, providing PDS and liaising with carers/family members will focus on a more social model than a clinical/medical model	We have changed the language that refers specifically to healthcare professionals to recognise that other disciplines may be involved in the delivery of postdiagnostic support.
	KA	Training needs / stress and distress	The content relating to stress and distress across the different dyads that emerged from the evidence review has led to the recommendation on an opportunity for

			training needs, including communication skills and person-centred approaches (also see section 9.3).
	KP	Music therapy can be used as a means of supporting person-centred care and can be tailored to reflect a person's identity, background, current support needs, individual preferences as well as potentially providing a source of meaningful occupation. This is recommended as the optimal approach by the following study. Hackett K, Sabat SR, Giovannetti T. A person-centered framework for designing music-based therapeutic studies in dementia: current barriers and a path forward. Aging Ment Health. 2022 May;26(5):940-949. doi: 10.1080/13607863.2021.1931029. Epub 2021 Jun 17. PMID: 34139133; PMCID: PMC8678363. Bolton L M, Jiang J, Warren J D. Music as a person centred intervention for dementia BMJ 2022; 376 :o518 doi:10.1136/bmj.o518	We recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit treatment response. This section addresses the needs to be considered in communicating and approach in the context of delivering post diagnostic support which can be interpreted to include music therapy. Section 6 has made further references to the evidence of music therapy.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	JM	GPs are aware of person-centred approaches to care. it's what we do.	We acknowledge your clinical expertise.
5.2.7	Anon	Signposting is rather useless. Real genuine inter-professional support is necessary - not just passing from pillar to post.	We can appreciate your concern from your comment. We have removed signposting from the section heading. The recommendations were based on the themes that emerged from the evidence where there was a lack of knowledge about different aspects of dementia care from diagnosis to postdiagnostic support. To supplement this, the recommendation also proposed patient-centred care with a key worker that supports continuity of care and good communication which should foster a genuine and supportive environment.
	JC	Clear and concise	Thank you. No response required.
	AFr	Being aware of the person's identity and dignity' - I really like this	Thank you. No response required.
	KA	Making this accessible for people with a learning disability / Down's syndrome.	Thank you for your comment. We acknowledge that learning disabilities is a specialist

			area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	KP	Meaningful activities were highlighted as a potential means of emotional support. Therapeutic musical activities can potentially be used by both the people living with dementia and their carers or family members in community, inpatient and residential settings, at all stages of the disease and possibly provide a means of emotional support for both parties. https://musicfordementia.org.uk/news-and-media/blog/2021/03/our-journey-with-music-through-dementia/	We highlight emotional support need as part of postdiagnostic support access to services and signposting. However, the evidence synthesis literature does not indicate/recommend specific interventions to achieve this.
	GB	Range of written info and online info required	Agree this is reflected in the good practice point that -The format of information shared should be tailored to the needs and preferences of the person with dementia and their carers.
	JH	The Public Sector Equality Duty includes a Procurement Duty. This means that when any Public Sector Body (such as the NHS) purchases a service from an external agency, the purchasing Public Body must ensure that all service provision complies with the legislation.	Thank you for clarifying this. The responsibility for compliance with the Duty is already within services and we did not encounter evidence to suggest it is not understood or followed.
5.2.8	JC	Title should include stigma	We feel that stigma is an example of a belief and attitude.
	MP	1st paragraph: does the systematic review refer to people with dementia or carers?	Thank you for asking to clarify this. The systematic review pertained to experiences of spousal/partner caregivers providing care for adults with dementia i.e., carers. We have made this clearer in the guideline.
	AFr	Totally agree with these findings and need to be shared more widely to reduce stigma and discrimination	Thank you. No response required.
	KA	Same as above	Response as above.
	KP	Participation in music groups may help to reduce stigma as people become more aware of the possibilities of living well with dementia. Harris PB, Caporella CA. An intergenerational choir formed to lessen Alzheimer's disease stigma in college students and decrease the social isolation of people with Alzheimer's disease and their family members: a pilot study. Am J Alzheimers Dis Other Demen. 2014 May;29(3):270-81.	We recognise the importance of a wide range of psychosocial interventions but the current evidence on PDS is framed within needs rather than explicit treatment response.

		doi: 10.1177/1533317513517044. Epub 2014 Jan 10. PMID: 24413542.	
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	GB	Importance of addressing societal attitudes re dementia- media, public health, raise awareness to challenge this. Role of dementia friendly communities- role of dementia awareness and training for all. e.g. shops, banks, taxis	We agree that these are important issues but outwith the remit of a SIGN guideline. Evidence on attitudes and beliefs is included in section 5.1.1. We have also included resources on the following in section 9.4: • A guide to making general practice dementia-friendly. • Guidance for dental professionals to help understand dementia and its implications for dental practice, and adapt their patient management and clinical decisions accordingly. • Developing supportive design for people with dementia. A range of resources to enable hospitals, care homes, primary care premises and specialist housing providers to become more dementia-friendly. • School teaching resources to make it easy to teach and learn about dementia
	JH	Excellent - useful to have this information articulated.	Thank you. No response required.
5.2.9	JC	Clear and concise	Thank you. No response required.
	MR	P2p support should be available online for all, inappropriate behaviour should be dealt with by formulated procedures; so written warning given first; sudden decisions, bad news or diagnosis etc do adversely affect people with dementia.	Section 3 talks in detail about how a dementia diagnosis should be disclosed and discussed with the person with dementia.
	RB	Is it worth asking the question “How are services supposed to do all of these things and ensure they can act on the recommendations?” Presumably there’s some joined up thinking with SG in that there’s funding for all the training, support and, probably, staffing that’s going to be required to make this possible. One of the points above is that GPs need to be aware of person centred care, but there’s nothing to say why, or how this kind of thing could happen. Guidelines and strategy are obviously different things, but without	We agree that this is an important question but one that is beyond the scope of the guideline. We hope that policy makers and professionals will use the guidelines to support the adoption of good practice. Focus on Dementia is the national improvement portfolio for dementia (based within Healthcare Improvement Scotland). A core part of their work is to improve the quality and access to postdiagnostic support. We have

		some form of top-down intervention/financing a lot of this stuff is going to remain stuck on the page rather than having a material benefit.	share your comment with them to support implementation of the guideline. The publication of this guideline is acknowledged in the new national Dementia strategy.
	KP	There is the potential for online interventions, which include music therapy to be delivered to effectively offer support for people living with dementia and their carers or family members. Quail Z, Bolton L, Massey K Digital delivery of non-pharmacological intervention programmes for people living with dementia during the COVID-19 pandemic BMJ Case Reports CP 2021;14:e242550. Quail,Z. Bolton I., Massey K Online therapeutic activity programmes for people living with dementia during COVID-19 Journal of Dementia Care May/June 2022 Quail, Z Doxford, H. Feedback process for online therapeutic activities Journal of Dementia Care June/July 2021 https://www.goldster.co.uk/media/rkpcqx5x/feedback-process-online-therapeutic-activities-jdc-julaug-2021.pdf	We recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. Evidence around music reviewed under section 6
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	JCa	Recs - communication is not just affected in advanced dementia. Enhanced communication skills training should cover ALL stages of dementia since potential communication difficulties can occur right through.	The Good Practice Point has now been amended (5.2.8) to include 'particularly' (as is referenced in the preceding text): *"Health and social care professionals should be aware of potential communication difficulties for people, particularly in the advanced stages of dementia. Health and social care professionals may need enhanced communication skills training to communicate effectively with people with advanced dementia."*
	AMcK	AHP Dementia twitter account @AHPDementia Let's Talk About Dementia Blog: https://letstalkaboutdementia.wordpress.com/ Online self-management resources (www.alzscot.org/ahpresources) and	Resources added to the provision of information section of the guidelines

		webinars (www.alzscot.org/ahpinnovation)	
5.3	JC	Succinctly summarised	Thank you. No response required.
	MP	I am delighted to see people with young onset dementia referenced throughout the document. However, for equity I wonder if the document needs to reflect the need of our LGBTQ+ communities, people with sensory impairments and people with learning disability, especially Down's syndrome where prevalence rates of dementia are high.	Thank you for your comment. Unfortunately, the review evidence did not provide specific information on postdiagnostic support for these groups (and people with learning disability and dementia were out with the scope of this guideline). We do emphasise at the start of the guideline the need to be aware of diversity amongst people with dementia and respond to individual needs and circumstances. See also responses in previous sections regarding the EQIA and sections that include LGBTQ+ considerations. We have also included the following recommendation for further research: *"Research into the experiences of postdiagnostic support on minority groups, those with protected characteristics, those with young onset dementia and young carers."*
	MH	Is there any literature about the deaf community re diagnosis and their access to post diagnostic support? Also about people with learning difficulties?	As noted, learning disabilities was beyond the scope of the guidelines. No evidence was found on people from the deaf community.
	AFr	Language translation is a real challenge to support people living with Dementia for people from ethnic minority groups, more attention to hard-to-reach groups needs to be implemented	Agree and the evidence and recommendations reflect this.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	KA	How signposting to resources that include supporting individuals with a learning disability / Down's syndrome. Third sector support groups	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.

			We have now highlighted useful resources in the provision of information section for learning disabilities.
	KP	Music therapy can be used in a flexible way to support people from diverse cultural background by using either live or recorded music to reflect people's preferences and backgrounds. Susan Hadley, PhD, MT-BC, Marisol S. Norris, MA, MT-BC, Musical Multicultural Competency in Music Therapy: The First Step, Music Therapy Perspectives, Volume 34, Issue 2, 2016, Pages 129–137, https://doi.org/10.1093/mtp/miv045	While we recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. However, section 6 on non-pharmacological interventions has touched on the evidence for music therapy. The choice of treatment should still be discussed holistically between physician and person with dementia.
	JH	Very useful to include this section and to articulate where there are gaps in research.	Thank you. No response required.
5.4	JC	Succinctly summarised	Thank you. No response required.
	MP	PDS is delivered by link workers across Scotland, this is a Scottish Government initiative, should this be reference in the Recommendations section?	We have added reference to the 5 and 8 pillar models and link workers in the section 5 introduction.
	AFr	A single point of contact and consistency of care/intervention and case management is even more essential to people living with dementia and their carer. In relation to their declining cognition and memory, it is imperative to keep them the same as much as possible	We agree and as such this is a recommendation in this section.
	MR	One year PDS should start when dyad wish, not from time of diagnosis. One year PDS from consultation is mandatory. Currently, not met by any health partnership.	This is an important point but unfortunately not one that is supported by the evidence reviewed for the guideline.
	KA	No reference to supporting individuals with a learning disability / Down's syndrome	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. We have now highlighted useful resources in the provision of information section for learning disabilities.
	RK	When post-diagnostic support comes to an end, often when the12 months is up, people often feel stranded. There has been no funding for identified key workers following the post diagnostic phase, even though it has been	We strongly agree with the need for continued care and care management as evident in Section 5.

		a clear ask from service users. Although demonstrator sites did come up with strategies to meet this need, services elsewhere have not found ways to do so. Although this is really a task for the dementia strategy, I feel there should be more in the guidelines to highlight the need for care co-ordination that helps people to access support from different disciplines.	Section 5.2 recommends the need for continuity of care within the different needs of the person and carer. This is supplemented by recommendations to support the transitional periods (section 8) and information on access to services for age-related services and minority population supported by the literature. The evidence synthesis is restricted to broader recommendations rather than specifics that may only be applicable to certain settings.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	RB	This seems to focus on YOD and age-related service transitions rather than all transitions for all dementia patients. Transitions from wards to carehomes and vice versa, for example, can often be really poorly executed. Especially if the patient journey is living at home, ward admission then care home, two huge transitions that can cause so much distress in the carer-patient system. Link to NES framework - Will the recommended expertise level be specified?	Evidence for young onset dementia only specified the need for age-appropriate services. postdiagnostic support does not usually apply to transition from wards to care homes etc. The issue of transition for all ages of dementia is covered to some extent in sections 7.3 and 8.3. We did not make recommendations based on the NES framework specifically because the SIGN Guidance only incorporates empirical evidence.
	JCa	Where is the evidence for PDS being delivered by a health professional? There is a blurring of approach to PDS early following diagnosis, to PDS when difficulties have increased.	The literature referred to ‘healthcare professionals’. The guidance has now been revised to recognise the broader range of practitioners involved in postdiagnostic support. See section 1.3.11 (Multidisciplinary sector and team approach to care). Throughout the recommendations, where it is known that the delivery of postdiagnostic support is delivered across professions, the term ‘health and social care professional(s)’ has now been used.
	JM	I think the PDS recommendations are bold and wonderful and I am delighted to see them. Specifically, a single point of contact in dementia care should have the same place in society as a health visitor, a district nurse or a CPN. I am glad that you specifically clarify that this expert healthcare professional should not be the GP themselves. “Postdiagnostic	Thank you. No response required.

		support should incorporate continuity of care, including a ‘onestop’ service or single point of contact, a single professional or case manager. This should be a healthcare professional with appropriate skills, knowledge and expertise in dementia (link to NES framework), working with the GP, to ensure a tailored support package is delivered in a timely manner. “	
5.5	AT	Would it be worth referencing Risk of Suicide After Dementia Diagnosis | Dementia and Cognitive Impairment | JAMA Neurology | JAMA Network 3rd Oct 2022	This has been added as a Good Practice Point in section 3.2.3.
	JC	Clear section	Thank you. No response required.
	MH	Was there no evidence about people with young onset dementia and continuing to work?	One systematic review highlighted work as a challenge post diagnosis. This is included in section 5.5. A search of the literature suggests that evidence is still emergent with two primary qualitative studies (a recent one published 2023) but clearly supports the need for employment support. Therefore, we have edited the text in the guideline for section 5.5 to supplement this recommendation to include “support with work and employment”.
	AFr	Much support and information on dementia is still aimed at people over 65 having dementia. Increased access to appropriate support for younger people with dementia is essential to promote quality of life. Younger people with dementia do not want to access services for "older people", also many care homes are not registered to take people under 65 and the environments are not suitable. Increased access to Self-directed support needs to be available	Thank you for your comment. Agree thus the section and recommendations specific to YOD.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	MR	Aberdeen have an early onset worker at clinic. Should be rolled out throughout Scotland	Thank you. Implementation is out with the remit of SIGN.
	RK	There is acknowledgement of the need for emotional support and non-pharmacological management. The guidelines do mention later the need for communication skills training for carers, but I think there is a much bigger gap here. It comes in to pre-death grief as well. Psychotherapeutic interventions are seen as particularly important for people with dementia in this age group, and their families. It should be noted that the early onset	Thank you for your comment. There is a section on grief (section 7) and non-pharmacological intervention (section 6) which cover these topics specifically in greater detail.

		dementias often involve aphasia, and I think much more needs to be done to enable people with aphasia to access "talking therapies." Psychology and speech and language therapy should be working together to provide aphasia friendly interventions. This applies to assessment too.	
	EH	See my comments in box 5.1 in regard to the emerging work on work and dementia and driving and dementia - important for people with young-onset dementia	This is out of scope for guidelines, regarding legal structures. We agree with your comments on the importance of employment and felt that this has been addressed in section 9.4
	KP	Music therapy is typically used as an intervention to support wellbeing in all types of dementia- music therapy is a person-centred intervention which can be adapted to specific support needs and preferences of the individual. Loi, S.M.; Flynn, L.; Cadwallader, C.; Stretton-Smith, P.; Bryant, C.; Baker, F.A. Music and Psychology & Social Connections Program: Protocol for a Novel Intervention for Dyads Affected by Younger-Onset Dementia. Brain Sci. 2022, 12, 503. https://doi.org/10.3390/brainsci12040503 Van't Hooft JJ, Pijnenburg YAL, Sikkes SAM, Scheltens P, Spikman JM, Jaschke AC, Warren JD, Tijms BM. Frontotemporal dementia, music perception and social cognition share neurobiological circuits: A meta-analysis. Brain Cogn. 2021 Mar;148:105660. doi: 10.1016/j.bandc.2020.105660. Epub 2021 Jan 7. PMID: 33421942.	While we recognise the importance of a wide range of psychosocial interventions the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response. We would like to signpost you to section 6 which covers the literature on non-pharmacological interventions including music therapy
	GB	Good model of separate support required, for age appropriate services, peer support and have different needs- work, dependents (young children at home) Need commission additional services in some areas.	Thank you. Implementation is outwith the remit of SIGN.
	JCa	Recs for PDS for people with YOD are not all in this section. At least one appears in 5.4	This Recommendation was included in 5.4 as it thematically aligns to continuity of care which was applicable to all person with dementia. However, we have now moved it to the young onset dementia section (5.5) for clearer relevance.

	PMac	People with Ld /Down's syndrome require some nuanced support in these areas -eg peer support but also peer psychoeducation. Info in literature. The exclusion of people with a learning disability and/or DS in this section may prevent health professionals from having awareness of a large proportion of the young-onset dementia population group. The exclusion of people with Down's Syndrome in this section can pose as a major barrier in the access of care among people with young-onset dementia and their families, as a large proportion of this group will have a diagnosis of DS. The WHO states "Alzheimer's disease is the most common type of dementia and accounts for 60–70% of cases". A known genetic link to younger onset dementia (namely Alzheimer's) is found within the extra chromosome present in trisomy 21 DS.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	JH	Any criteria to access services by age would need to be objectively justified as a proportionate means to a legitimate end, i.e., if the evidence shows that the needs and experiences of people with young-onset dementia is markedly different to others with dementia.	The guideline is based on rigorous review of best evidence.
5.6	JC	Highlights specific issues facing young carers	Thank you. No response required.
	MH	I would have thought the following considered judgement: 'All professionals (eg health visitor, teacher, healthcare professional/case manager) involved in the education and care of very young carers in full-time education who are related to, live with or support a person with dementia should consider the support needs of the child, independently of the needs of the person with dementia.' would also apply in principle to carers of all ages ie the carer's support needs should be considered independently of the needs of the person with dementia (and therefore included in the recommendations after section 5.2.9)	We agree and have listed the distinct/ separate needs of carers to people with dementia and the patient-carer relationship (section 5.2.3). In addition to this, an infographic is included to be added to further emphasise these separate needs.
	JE	Helpful section. No additional suggestions.	Thank you. No response required.
	KP	Music therapy can potentially be used to help offer an additional means of support to carers of all ages Melhuish, R., Grady, M., & Holland, A. (2019). Mindsong, music therapy and dementia care: collaborative working to support people with dementia and family carers at home. British Journal of Music Therapy, 33(1), 16–26. https://doi.org/10.1177/1359457519834302	While we recognise the importance of a wide range of psychosocial interventions but the current evidence on postdiagnostic support is framed within needs rather than explicit treatment response
	PMac	Whilst there is mention of emotional support, the mental and physical impact of being a young carer may be better understood if explained explicitly. Young carers often don't know this is what they are, or they don't	Thank you for your comment, we have addressed this issue within the limits of the evidence that is available in the literature.

		self-identify with this role. A sensitive topic that requires greater focus, or reference to a young carer needs assessment within the guideline. What about workplace support for carers -eg partners There may be an educational/workforce development requirement here.	While we recognise that this may be an important need, the evidence has not highlighted this need specifically.
	JH	Any criteria to access services by age would need to be objectively justified as a proportionate means to a legitimate end, i.e., if the evidence shows that the needs and experiences of young carers is markedly different to other people caring for someone living with dementia.	Thank you for your comment, we have addressed this issue within the limits of the evidence that is available in the literature. While we recognise that this may be an important need, the evidence have not highlighted this need specifically.
	AT	Whilst I appreciate that this is about non pharmacological measures I do think it is a shame in paragraph 2 where you mention biological causes to have missed mentioning the need to consider pain (Randomized Controlled Trial BMJ 2011 Jul 15;343:d4065. doi: 10.1136/bmj.d4065. Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial Bettina S Husebo 1, Clive Ballard, Reidun Sandvik, Odd Bjarte Nilsen, Dag Aarsland) and side effects of medications	Thanks for your comment. Agree that unrecognised pain is important, we have added to the end of the paragraph *"…for example untreated pain, anxiety or unfamiliar surroundings"* to the introduction in section 6.
	GH	Environment and design was not included which is a big miss as it is a large contributor to non-pharmacological management. file:///C:/Users/gh30/OneDrive%20-%20University%20of%20Stirling/Generalmulti-use%20sources/Bowes%20and%20Dawson%20Literature%20Search%202019.pdf This is a recent lit search carried out in the area.	We reviewed this paper and noted the conclusion that the environmental modifications required may differ from person to person. We think this fits with our wider recommendation about individualised assessment. We would hope that if environmental modifications are identified as being required during such an assessment that they would then be made accordingly (where possible). At this time, in line with the Cochrane review on the subject, we do not think there is sufficient evidence to specify environmental modifications as an intervention suitable for all individuals with distress.
	Anon	As a family we have been provided with absolutely no advice on these issues despite bringing them up with GPs and social care staff. It dismays me that help might have been available before my relative moved into a care home and that now that they are in a care home it is assumed that everything is fine and so no further help will be provided now.	Thanks for sharing your experience with us. We hope this guideline helps improve care in this area in the future.
	AF	See the service user as an individual. What matters to them- life history, which may account for some of there actions. Identify why the service user is aggressive- communication issues, agitation- exclude physical cause- hungry, thirsty, constipated, needing the toilet, infection, pain- greater	Agreed. This is in line with what the guideline recommends.

		understanding of what could be tried first. Use behavioural charts to identify triggers.	
	JB	Why is there no clear direction on pharmacological management or signposting to the National Institute for Health and Care Excellence Dementia Guideline - https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#pharmacological-interventions-for-dementia Why are more females than males dispensed dementia drugs? Public Health Scotland advise that - dispensed volume of antipsychotics, antidepressants and drugs for dementia and ADHD has been steadily increasing over the past ten years. In 2019/20 63% of people dispensed dementia drugs were female while 37% were male - consistent with previous years for which data are available. This together with the disparity across Scottish NHS Boards in prescribing AChE inhibitors to dementia patients is not addressed in this Guideline. More information can be found at https://publichealthscotland.scot/media/5941/2021-02-23-prescribingmentalhealth-report.pdf Patients, carers, families and NHS Professionals need to understand why there are these differences and variations.	Thanks for your comment. Addition made. Out with scope. Out with scope. Out with scope.
	JC	Introduction highlights the problem	Thank you no response required.
	JLJ	The NES Psychological Interventions in Response to Stress and Distress in Dementia approach should be detailed more comprehensively here and an MDT approach to this should be made imperative.	There was insufficient evidence to support this specific intervention, but it is consistent with our proposed guidance.
	AFr	Interesting to see how distressed behaviors are measured	Thank you, no response required.
	KA	Use of positive behaviour support strategies / capable environments / training for stress and distress. Focus on unmet health needs and communication needs. No reference to training resources specific to supporting individuals with Down's syndrome (Supporting Derek)	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	RK	Good to see mention of communciation skills training here.	Thank you, no response required.
	EH	I would relook at how you start this section for our readers with lived	Thank you for your suggestion. A patient and public

		experience, maybe commence with your third chapter first : Within the literature ...and your reference 157 and the power of language?	version of the guideline has been developed.
	RB	Why just these three things?	We explain the rationale in the introduction to the section.
	KP	There is evidence to support that music therapy – practiced by qualified, HCPC registered music therapists in dementia-care settings – is an effective, person-centred, non-pharmacological intervention that can alleviate symptoms of aggression and agitation in people with dementia; and can stop or pause the increase of psychotropic medications, in comparison to standard care when psychotropic medication is significantly increased. “Evidence from meta-analyses of randomised controlled trials2 3 suggests that music based therapeutic interventions in dementia can reduce depressive symptoms and ameliorate behavioural disturbance and may also reduce anxiety and improve emotional wellbeing and quality of life. Benefits may be further enhanced by personalised playlists holding resonance for the patient,4 potentially even in the later stages of the illness when opportunities for intervention can be limited. Music is a source of meaningful occupation in dementia5—a cornerstone of wellbeing in the delivery of person centred care. By facilitating communication, it may also reduce the frustration and helplessness that contribute significantly to challenging behaviours. As a therapeutic intervention, music is innocuous, accessible, flexible, and relatively easy to implement. Beyond its beneficial effects on standard neuropsychiatric symptom indices of dementia, music is a lifelong source of pleasure and resilience for a great many people, and may help to maintain social connectedness in ways that are difficult to quantify. Music is a unique source of solace against the loneliness and despair that too often attend the disease: a lesson that the covid-19 pandemic has poignantly affirmed.” Bolton, L.M., Jiang, J. and Warren, J.D., 2022. Managing neuropsychiatric symptoms in dementia: Music as a person centred intervention for dementia. British Music Therapy Journal 2022;376:o518. DOI: 10.1136/bmj.o518 2. Van der Steen JT, Smaling HJ, van der Wouden JC, Bruinsma MS, Scholten RJ, Vink AC. Music-based therapeutic interventions for people with dementia. Cochrane Database Syst Rev 2018;7:CD003477. doi: 10.1002/14651858.CD003477.pub4. pmid: 300336233	Thank you for the comment and information. We agree that music therapy can be a useful intervention and could be considered as part of the individualised approach that we advocate. We included the Cochrane review on music in our assessment. However, we did not find sufficient evidence to support its uniform use in people with dementia and agitation, aggression and sleep disturbance. Hence, it is not specifically mentioned but that does not preclude its use.

		3. Dorris JL, Neely S, Terhorst L, VonVille HM, Rodakowski J. Effects of music participation for mild cognitive impairment and dementia: a systematic review and meta-analysis. J Am Geriatr Soc 2021;69:2659-67. doi: 10.1111/jgs.17208 pmid: 34008208 “...we examined the use of therapeutic singing, music and movement, and a tonal protocol specifically created for individuals with moderate to severe dementia in long-term care settings. Our findings revealed that when compared to usual care, our music therapy intervention reduced symptoms of depression and agitation but not wandering behaviors. Our results suggested that the music therapy interventions had effects on symptoms of depression and agitation, over and above any medication effects. We believe this evidence has important implications for music therapy practitioners’ and long-term care professionals’ consideration of music therapy as a nonpharmacological treatment.” : [Kendra D. Ray and Mary S. Mittleman (2017). Music therapy: a nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. Dementia, Vol. 16(6) p689-710. https://journals.sagepub.com/doi/pdf/10.1177/1471301215613779] Below is a reference list for excerpts listed, as well as references made within the excerpts about music therapy used throughout section 6 and its subsections. Blackburn, R., & Bradshaw, T. (2014). Music therapy for service users with dementia: A critical review of the literature. Journal of Psychiatric and Mental Health Nursing, 21(10), 879–888. https://doi.org/10.1111/jpm.12165 Brotons, M., & Marti, P. (2003). Music therapy with Alzheimer’s patients and their family caregivers: A pilot project. Journal of Music Therapy, 40(2), 138–150. Dorris JL, Neely S, Terhorst L, VonVille HM, Rodakowski J. Effects of music participation for mild cognitive impairment and dementia: a systematic review and meta-analysis. J Am Geriatr Soc 2021;69:2659-67. doi: 10.1111/jgs.17208 pmid: 34008208	

		Hanne Mette O. Ridder, Brynjulf Stige, Live Gunnhild Qvale and Christian Gold (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial, Aging & Mental Health, 17:6, 667-678. https://doi.org/ 10.1080/13607863.2013.790926 Kendra D. Ray and Mary S. Mittleman (2017). Music therapy: a nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. Dementia, Vol. 16(6) p689-710. https://journals.sagepub.com/doi/pdf/10.1177/1471301215613779 Ledger, A. J., & Baker, F. A. (2007). An investigation of long-term effects of group music therapy on agitation levels of people with Alzheimer's disease. Aging and Mental Health, 11(3), 330–338. DOI:10.1080/13607860600963406 Legere, L.E., McNeill, S., Schindel Martin, L., Acorn, M. and An, D., 2018. Nonpharmacological approaches for behavioural and psychological symptoms of dementia in older adults: A systematic review of reviews. Journal of Clinical Nursing, 27(7-8), pp.e1360-e1376. https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.14007 Narme, P., Clement, S., Ehrle, N., Schiaratura, L., Vachez, S., Courtaigne, B., ... Samson, S. (2014). Efficacy of musical interventions in dementia: Evidence from a randomized controlled trial. Journal of Alzheimer's Disease: JAD, 38(2), 359–369. DOI:10.3233/JAD-130893 Sung, H., Chang, A., & Abbey, J. (2006). Application of music therapy for managing agitated behavior in older people with dementia. Journal of Nursing, 53, 58–62. Sung, H. C., & Chang, A. M. (2005). Use of preferred music to decrease agitated behaviours in older people with dementia: A review of the literature. Journal of Clinical Nursing, 14, 1133–1140. Sung, H., Chang, S., Lee, W., & Lee, M. (2006). The effects of group music with movement intervention on agitated behaviours of institutionalized elders. Complementary Therapies in Medicine, 14, 113–	

		119. Ueda, T., Suzukamo, Y., Sato, M., & Izumi, S.-I. (2013). Effects of music therapy on behavioral and psychological symptoms of dementia: A systematic review and meta-analysis. Ageing Research Reviews, 12(2), 628–641. https://doi.org/10.1016/j.arr.2013.02.003 Van der Steen JT, Smaling HJ, van der Wouden JC, Bruinsma MS, Scholten RJ, Vink AC. Music-based therapeutic interventions for people with dementia. Cochrane Database Syst Rev 2018;7:CD003477. doi: 10.1002/14651858.CD003477.pub4. pmid: 300336233 Wall, M., & Duffy, A. (2010). The effects of music therapy for older people with dementia. British Journal of Nursing (Mark Allen Publishing), 19(2), 108–113. https://doi.org/10.12968/bjon.2010.19.2.46295 Findings suggest that creative arts therapy is effective for treatment of behavioural and emotional challenges of the disease. Cowl, Andrielle L., and Joseph E. Gaugler. "Efficacy of creative arts therapy in treatment of Alzheimer's disease and dementia: A systematic literature review." Activities, Adaptation & Aging 38.4 (2014): 281-330.	
	EV	Important to mention that should be assessed for delirium and diagnosis excluded as a cause for behaviour	Thank you. We have added text re delirium and signposted to SIGN delirium.
	GB	Importance of training for staff working in health and social care, often care at home, care home staff are undervalued, receive very little training and not much space for reflection or tailored activities. Legal staffing levels for care homes also does not support activity or the other non pharmacological interventions suggested in guidelines.	Thanks for comment. We hope the guidelines stimulate thought for training and skill set required.
	AMcK	It is highlighted that work is ongoing around language but would this section be better headed as 'Non-pharmacological management of stress and distress behaviours and sleep problems'?	We considered this and explain why we focussed only on these three behaviours. For consistency in the text we used the term *"distressed behaviours"* in the title rather than *"stress and distress"*, our rationale for using distressed behaviour is in the body of the text.
	JK	Language not consistent with national approach, should use common language of stress and distress. No mention of nationally adopted Newcastle Model. Group felt section should be more prescriptive in approach and clearly articulate non-pharmacological responses to stress	We use the term "*distressed behaviour*" as a more concise and easily to use version of the NES "*Stress and Distress in dementia*" terminology. We have added specific mention of 'stress and distress' in the

		and distress in dementia. Overlooks legal basis of least restrictive options. Should make reference to the Act and need for balanced, systematic and clinically indicated response that may required pharmacological response at certain juncture.	introduction so it is clearer that ‘distressed behaviour’ is a synonym for this terminology. No specific evidence was found to support the Newcastle Model, but our recommendations would be consistent with support for its use. We found no evidence for any prescriptive and clearly defined non-pharmacological responses. This section does not consider pharmacological treatment or its legal basis. We hope the guideline is useful beyond Scotland and specific reference to Scottish law may not be helpful.
	JE	Helpful section. The final recommendations regarding management of distressed behaviour are rather general, but I guess that reflects the limited research evidence available.	Thanks. Agreed, we cannot be more specific with our recommendations based on the current literature available.
	JM	I was hoping for more specific recommendations here. But they seem to boil down to ‘recommend training in non-pharmacological management of dementia’ to staff involved, but without being able to give a reference to what to the best non-pharmacological managements that work. Is it worth recognising the lack of evidence and focus on the holistic nature prior to further recommendations?	Thank you for your comment. We feel we do make the lack of evidence clear.
	JH	This section is not within this reviewer's area of expertise.	No response required.
6.1	AF	See the service user as an individual. What matters to them- life history, which may account for some of there actions. Identify why the service user is aggressive- communication issues, agitation- exclude physical cause- hungry, thirsty, constipated, needing the toilet, infection, pain- greater understanding of what could be tried first. Use behavioural charts to identify triggers. Consider what is happening in the environment- noise, poorly lit, scary.	Thanks and agreed. We support an individualised approach and is exactly what we recommend.
	JC	Relevant studies appear to have been captured	Thank you. No response required.
	MC	No mention of specific assessments/interventions that might be needed for people with learning disabilities - are these needed?	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-

			a-topic/.
	PC	It would be worth pointing out that the scales described in this section need training to ensure consistency and, while they have the advantage of bringing structure into how distress is measured, the language is often cumbersome, esp CMAI. Also, results on one scale do not easily translate to another, making comparisons difficult.	Thanks. We mention that some of the measures mentioned in the systematic review required to be administered by a 'trained interviewer' (section 6.1). Whilst not all scales require specific training, service providers should take training into consideration when considering use of a scale.
	MP	Paragraph 2: should the term distressed behaviours be used rather than neuro psychiatric symptoms, for consistency and promotion of non-labelling language?	Agreed and changed. We will look to be consistent in terminology in this section.
	MH	Could there be somewhere how to distinguish distressed behaviour from delirium and then refer to SIGN guideline on delirium. Speaking from experience, a delay in delirium diagnosis can result in long-term harm to someone with dementia.	Than you, see comment above re delirium.
	AFr	It is problematic to measure behaviors in an environment where people supporting the individual have not been appropriately trained/provided with knowledge and understanding as this can exacerbate behavior with consequences of the person with dementia having interventions that they might not need if those around them understood them better.	Thanks and agreed. We recommend this training be provided.
	MR	Glad mental health is seen as separate but important for those with dementia, however [REDACTED]. [REDACTED]. [REDACTED]. Dementia organisations (not just nhs) must have properly trained staff, otherwise they can create mental health problems by inappropriate actions, eg; ignoring someone with dementia for whatever reason, in whatever capacity is the worst possible action. P2p should be available through non judgemental dementia services, professional knowledge of distressed behaviours should be known by all workers in NHS and other appropriate organisations.	Thank you for comment. We hope the guideline helps improve consistency and level of care for people with dementia. Note: The reviewer then included details of their personal experience which have not been included in this report.
	KA	As above	As above.
	RK	I would like to see mention of behaviour assessments which are not just reacting to distress. When care staff also have a profile of happy behaviours and their antecedents they are more able to pre-empt distress. There's a lot we can learn from people working in multidisciplinary learning disability teams	Thank you. We looked specifically for literature around both prevention and management of distress behaviours but found little distinction in the evidence base. Therefore we think approaches recommended can be applied to both situations.

	RB	No mention of the NES Psychological Interventions in response to stress and distress in dementia, and the whole suite of training courses related to this. Stress and distress and associated language is not evident/discussed in this section at all. As this approach is integral to the way that distressed behaviour is understood and supported within Scotland, is the core training model that is used throughout Scotland, is embedded within OA services in Scotland (in terms of assessment, intervention approaches and supervision provision), is associated with a HEAT target (around reducing anti-psychotic prescribing) it feels like a missed opportunity not to highlight this approach in this document. Again thinking of who can access this document and how it will be used it would be helpful to include this model of support that is widely used in Scotland. Finally, should we keep the language consistent? The paper mentions that there are several terms in use to mean the same thing but then goes on to state "distressed behaviours" and then "neuropsychiatric symptoms". We have an agreed terminology via NES so it should probably be that?	We found no specific evidence to support this particular training resource. We have included a Good Practice Point on the importance of staff training: *"Staff training in the management of distressed behaviours, to improve the quality of life for people with dementia, should be linked to the Promoting Excellence Framework. Training should be part of ongoing multidisciplinary skills development and supported by appropriate leadership, infrastructure and resources to facilitate sustained implementation and staff engagement."* We have included links to the NES resources in our provision of information section, under education and training resources. We agree re using consistent terminology and have corrected this.
	GB	To state that all distressed behaviour is an unmet need not some!! Never just a part of illness Importance of stepped care model- see BPS doc- rule out physical causes- pain often in the mix and under diagnosed Importance of MDT re distressed behaviour and able to take individualised formulation e.g. newcastle model to help identify underlying needs and then target intervention to this, role of functional analysis as part of this. Therefore all health boards should have access to stress and distress team, care home liaison service etc	Thank you. We think the sentence is correct and does not imply that distressed behaviours may not need attention. We found no evidence to support any particular model for assessment, but the BPS model is consistent with the recommendations made.
	PMac	The use of the term 'non-compliance,' puts the emphasis on the person being the 'problem,' when this is frequently not the case. Early recognition of the person with dementia becoming stressed should be commented on where individualised activities could be offered as described to avoid distressed behaviour. Feel that as mentioned above there is a step missing, interventions are more proactive if offered to reduce stress thus avoiding distress. Staff training and support should focus on this.	Term non-compliance changed. As noted above we looked specifically for literature around both prevention and management of distress behaviours but found little distinction in the evidence base. Therefore we think approaches recommended can be applied proactively too. The term 'aggression' is used because it is the term that

		Terms like aggression have no place in the guidance –they are not values based and reinforce stigma around dementia. The good practice points are essential and should be a recommendation, training on possible reasons for distressed behaviour, with a holistic approach being imperative. The discounting of a physical cause, the rapid/ gradual element of the distressed behaviour is an important consideration. Functional analysis can aid identification of possible triggers but should be completed after nursing and care interventions based on biopsychosocial individual to that person have been exhausted. This should avoid a delay in the support of the individual. A further consideration should be that the person could be living with an undiagnosed neuro diverse condition.	is used within the literature and that is also regularly used by those involved in dementia care, we could not identify a suitable synonym. Functional analysis was part of the evidence reviewed.
6.2	GH	Signpost to NICE if this is the resources that should be referred to.	Agreed, we have now referenced NICE, thanks.
	AF	Greater understanding of side effects of pharmacological interventions to care home staff, not a quick fix.	Thanks for your comment. Agree knowledge of side effects is important for those caring for people with dementia. Pharmacological interventions out with scope of this guideline we now refer the reader to NICE re pharmacological interventions.
	JC	Clearly written	Thank you. No response required.
	PC	This section is somewhat disappointing. References to antipsychotics are superficial and do not allow the reader to make comparisons. Many study populations in non-pharmacological studies do not score highly on the instruments used for assessment, whereas in many cases baseline scores are much higher in antipsychotic studies. This should be acknowledged. In addition, recommendations for the use of non-pharmacological therapies “first” often fail to recognise that those interventions can fail and that comparisons of antipsychotics vs non-pharmacological therapies in “treatment failure” groups are not the same as comparisons in “treatment naive” groups. I would like to see a balanced recommendation which allows for the inclusion of drug therapy as part of an overall treatment plan, accepting that there can be benefits or possible synergy if drugs and non-pharm interventions are used in tandem	Thank you for your comment. The issue of when and how to prescribe medication was out with the scope of this section. We agree that there can be a role for medication and refer to NICE for the recommendations regarding this. We are not making recommendations around drug versus non-drug approaches.
	MH	The statement: 'This is in keeping with the NICE guideline (2018) that recommends non-pharmacological treatments as first line.' - could this warrant a recommendation? Or at least reiterate that pharmacological interventions weren't considered and why in the recommendations section	Thanks for your comment. We have added additional text to the introduction of section 6 to explain our focus on non-pharmacological interventions and link to the NICE guidance.

		so that professionals don't miss the point.	
	MR	If inappropriate behaviour in care settings, or online, professionals must look for reason, as it is communicating an unmet need, otherwise behaviour will spiral out of control. any living will (unless sectioned), such as mine, that states no pharmaceutical intervention without next of kins permission must be upheld.	Thank you for your comment. Our good practice point (6.3.6): *“When a person with dementia presents with distressed behaviour, a holistic assessment should be undertaken, including consideration of the possible reasons underlying the person's distress. Structured and objective measures can assist in the identification of distressed behaviour. Functional analysis can help identify possible triggers or reasons for the behaviour.”*
	FM	This is a good summary of the study. It needs to be clearer what the recommendation is for use of pharmacological interventions	Updated with link to NICE
	KA	Research available around positive behaviour support strategies	Positive behaviour support is approach used within learning disability services and unfortunately these are out with the scope of the guideline.
	EH	Some interventions that I cannot see in your literature and not sure if they did not meet your criteria the work on COPE e.g. Implementing a Reablement Intervention, “Care of People With Dementia in Their Environments (COPE)”: A Hybrid Implementation-Effectiveness Study https://academic.oup.com/gerontologist/article/61/6/965/5893197 TAP An intervention to reduce neuropsychiatric symptoms and caregiver burden in dementia: Preliminary results from a randomized trial of the tailored activity program–outpatient version https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.4958	The COPE study did not meet criteria due to its implementation-effectiveness hybrid design, non RCT. TAP-O as a 2018 randomised trial with relatively small numbers (n 21) would not have been included on its own but The TAP data will have been part of the Cochrane review we included and may have been included in the systematic reviews covered.
	KP	Relational interventions, including music therapy have been demonstrated to significantly reduce the unwanted symptoms of dementia compared to anti-psychotic medications Macfarlane S, Atee M, Morris T, Whiting D, Healy M, Alford M and Cunningham C (2021) Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia. Front. Psychiatry 12:652254. doi: 10.3389/fpsyt.2021.652254 In a 2013 randomized controlled trial exploring the effect of individual music therapy on agitation in dementia, it was found that six weeks of	Thank you for the comment and information. We agree that music therapy can be a useful intervention and could be considered as part of the individualised approach that we advocate. We considered music therapy as part of our evidence synthesis. However, we did find sufficient evidence to support its uniform use in people with dementia and agitation, aggression and sleep disturbance. Hence, it is not specifically mentioned but that does not preclude its use.

		individualised music therapy, in comparison to the control six weeks of usual/standard care, contributed significantly to a lack of increase in psychotropic medicantions, and at times contributed to a decrease in these medications, while during standard care, the prescription of these medications increased significantly more often. See excerpt from this study below: [Hanne Mette O. Ridder, Brynjulf Stige, Live Gunnhild Qvale and Christian Gold (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial, Aging & Mental Health, 17:6, 667-678. https://doi.org/ 10.1080/13607863.2013.790926] “Objectives: Agitation in nursing home residents with dementia leads to increase in psychotropic medication, decrease in quality of life, and to patient distress and caregiver burden. Music therapy has previously been found effective in treatment of agitation in dementia care but studies have been methodologically insufficient. The aim of this study was to examine the effect of individual music therapy on agitation in persons with moderate/severe dementia living in nursing homes, and to explore its effect on psychotropic medication and quality of life. Method: In a crossover trial, 42 participants with dementia were randomized to a sequence of six weeks of individual music therapy and six weeks of standard care. Outcome measures included agitation, quality of life and medication. Results: Agitation disruptiveness increased during standard care and decreased during music therapy. The difference at 6.77 (95% CI (confidence interval): 12.71, 0.83) was significant (p ¼ 0.027), with a medium effect size (0.50). The prescription of psychotropic medication increased significantly more often during standard care than during music therapy (p ¼ 0.02). Conclusion: This study shows that six weeks of music therapy reduces agitation disruptiveness and prevents medication increases in people with dementia.” “Moreover, during music therapy the prescriptions of psychotropic medication were not increased, whereas they were increased for seven participants during the standard care period. In a 2015 study examining music therapy as a nonpharmacological treatment for symptoms of agitation and in people with dementia, it was found that music therapy significantly reduced symptoms of agitation and depression. See excerpts below: [Kendra D. Ray and Mary S. Mittleman (2017). Music therapy: a nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with	

		dementia. Dementia, Vol. 16(6) p689-710. https://journals.sagepub.com/doi/pdf/10.1177/1471301215613779] “Abstract: Depression, agitation, and wandering are common behaviors associated with dementia and frequently observed among nursing home residents. Even with pharmacological treatment, behaviors often persist, hindering quality of life for elders, their family, and paid caregivers. This study examined the use of music therapy for treatment of these symptoms among 132 people with moderate to severe dementia in nursing homes. Participants were evaluated for depressive symptoms, agitation, and wandering to determine their predominate behavior. There were two assessments, two weeks apart, prior to intervention, followed by a two-week intervention, and two follow-up assessments, also two weeks apart. A repeated measures ANOVA determined that after two weeks of music therapy, symptoms of depression and agitation were significantly reduced; there was no change for wandering. Multivariate analyses confirmed a relationship between music therapy and change in neuropsychiatric symptoms associated with dementia. Results suggest widespread use of music therapy in long-term care settings may be effective in reducing symptoms of depression and agitation” “In the current study, we examined the use of therapeutic singing, music and movement, and a tonal protocol specifically created for individuals with moderate to severe dementia in long-term care settings. Our findings revealed that when compared to usual care, our music therapy intervention reduced symptoms of depression and agitation but not wandering behaviors. Our results suggested that the music therapy interventions had effects on symptoms of depression and agitation, over and above any medication effects. We believe this evidence has important implications for music therapy practitioners’ and long-term care professionals’ consideration of music therapy as a nonpharmacological treatment.” A 2017 systematic review of reviews to investigate the evidence of nonpharmacological approaches to care for behavioural and psychological symptoms of people with dementia found that “Music therapy had the highest yield of reviews exploring its effectiveness on BPSD, with mostly positive results supporting its use.” See excerpts below: Legere, L.E., McNeill, S., Schindel Martin, L., Acorn, M. and An, D., 2018. Nonpharmacological approaches for behavioural and psychological symptoms of dementia in older adults: A systematic review of reviews.	

		Journal of Clinical Nursing, 27(7-8), pp.e1360-e1376. https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.14007 “Music therapy had the highest yield of reviews exploring its effectiveness on BPSD, with mostly positive results supporting its use. One meta-analysis included 20 studies of varying designs, with the majority of studies using a combination of music therapies (e.g., listening to familiar or preferred forms of music or playing musical instruments) (Ueda et al., 2013). The review found that overall, music therapy had moderate effects on anxiety and small effects on depression and behavioural symptoms in persons with dementia. In a smaller systematic review of six trials, the use of both active (playing instruments, singing, group therapy) and passive (listening to music individually) music therapy techniques was examined (Blackburn & Bradshaw, 2014). The researchers found that although there were potential benefits of music therapy in reducing anxiety, depression and agitated behaviour in older persons with dementia, there was a great deal of methodological weaknesses within the included studies. Similarly, the last review that also explored the use of music therapy on behaviour in older people with dementia found that specifically live, individualised music therapy may exhibit short-term effects on reducing levels of agitation in persons with dementia (Wall & Duffy, 2010)”	
	JK	Section not robust in meta analysis focuses on three broad manifestations of distress; aggression, agitation and sleep problems. Overlooks psychosis, anxiety. Group wondered if this was because this is included in NICE guideline? Noted however that there should be no requirement to go and consult alternative sources and all should be contained within SIGN.	Rationale for focusing on agitation, aggression and sleep disturbance is explained within introduction. The recommendations in this guideline are based on three specific presentations of distressed behaviour: aggression, agitation and sleep disturbance. These are frequently cited as reasons for a person with dementia to be transferred to a care home, from their home or admitted to a specialist dementia unit.
6.3	JC	Clearly written	Thank you. No response required.
	PC	This is a good section and importantly emphasises that the effect of non-pharmacological therapies is generally small. This is worth highlighting as a conclusion as it is important that people recognise that there is no single therapy which will solve problems of distress and one must keep an open mind. It is also helpful to show the evidence that initial benefits are not maintained and that agitation/aggression should lead to a long-term treatment plan being put in place. Indeed, given the relationship between agitation/aggression and admission	Thank you for your comment. We have added to Section 11.2 Recommendations for research to highlight some of the current limitations in the literature. We agree about the importance of preventative and proactive approaches and hope these recommendations can apply there too.

		to either hospital or a care home there is a case to be made for proactive identification of people with these problems complication their dementia in the community. The inclusion of material about the lack of effect of person-centred care may be considered controversial by some but it is important to highlight that even if (presumably) done well it is not a panacea and I am pleased to see that no recommendation has been made about it in this section. The kay is always to think of additional interventions which might help, not to be fooled by dogma.	
	AFr	As 6.1	Response made in 6.1
	RB	Sentence beginning "WHELD led to a statistically significant improvement in mean CMAI (secondary outcome)..." - This seems a strange way to report a study outcome. First up…what was the primary outcome measure and why isn't that relevant? Is something shady going on with the reporting of the results? Secondly, the change in scores of the CMAI is reported in a very clumsy manner that makes it hard to decipher. And…where's the ES? A change of 4.13 might be pointless…I have no idea what the score range is on the CMAI or what constitutes a clinically relevant change! The reporting of evidence throughout needs to be tightened up and conform to journalistic standards, IMO…the lack of ES reporting makes it difficult to get real meaning of the significance of the results.	Reporting of data in this section is standard and based on the data as reported in the paper; for many of the scales there is no MCID etc The quality of the data are incorporated into the strength of recommendation. We have updated the WHELD section for clarity in relation to your comments.
	KP	In a 2013 randomized controlled trial exploring the effect of individual music therapy on agitation in dementia, it was found that six weeks of individualised music therapy, in comparison to the control six weeks of usual/standard care, individualised music therapy was found to significantly decrease agitation in people with dementia, while agitation increased during those being given usual/standard care. See excerpts below from this study: "Objectives: Agitation in nursing home residents with dementia leads to increase in psychotropic medication, decrease in quality of life, and to patient distress and caregiver burden. Music therapy has previously been found effective in treatment of agitation in dementia care but studies have been methodologically insufficient. The aim of this study was to examine the effect of individual music therapy on agitation in persons with	Thank you for the comment and information. We agree that music therapy can be a useful intervention and could be considered as part of the individualised approach that we advocate. However, we did find sufficient evidence to support its uniform use in people with dementia and agitation, aggression and sleep disturbance. Hence, it is not specifically mentioned but that does not preclude its use

moderate/severe dementia living in nursing homes, and to explore its effect on psychotropic medication and quality of life. Method: In a crossover trial, 42 participants with dementia were randomized to a sequence of six weeks of individual music therapy and six weeks of standard care. Outcome measures included agitation, quality of life and medication. Results: Agitation disruptiveness increased during standard care and decreased during music therapy. The difference at 6.77 (95% CI (confidence interval): 12.71, 0.83) was significant (p ¼ 0.027), with a medium effect size (0.50). The prescription of psychotropic medication increased significantly more often during standard care than during music therapy (p ¼ 0.02). Conclusion: This study shows that six weeks of music therapy reduces agitation disruptiveness and prevents medication increases in people with dementia.”

“This study shows that six weeks of music therapy significantly reduced average agitation disruptiveness scores in persons with dementia, compared to standard care.”

In a 2015 study examining music therapy as a nonpharmacological treatment for symptoms of agitation and in people with dementia, it was found that music therapy significantly reduced symptoms of agitation and depression. See excerpts below: [Kendra D. Ray and Mary S. Mittleman (2017). Music therapy: a nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. Dementia, Vol. 16(6) p689-710. https://journals.sagepub.com/doi/pdf/10.1177/1471301215613779]

“Abstract: Depression, agitation, and wandering are common behaviors associated with dementia and frequently observed among nursing home residents. Even with pharmacological treatment, behaviors often persist, hindering quality of life for elders, their family, and paid caregivers. This study examined the use of music therapy for treatment of these symptoms among 132 people with moderate to severe dementia in nursing homes. Participants were evaluated for depressive symptoms, agitation, and wandering to determine their predominate behavior. There were two assessments, two weeks apart, prior to intervention, followed by a two-week intervention, and two follow-up assessments, also two weeks apart. A repeated measures ANOVA determined that after two weeks of music therapy, symptoms of depression and agitation were significantly reduced; there was no change for wandering. Multivariate analyses confirmed a

		relationship between music therapy and change in neuropsychiatric symptoms associated with dementia. Results suggest widespread use of music therapy in long-term care settings may be effective in reducing symptoms of depression and agitation” “Studies have shown that music therapy can decrease symptoms of agitation (Narme et al., 2014; Sung & Chang, 2005). Music therapy may provide a safe and active environment that meets the social and emotional needs expressed by people with dementia who demonstrate agitated behaviors (Ledger & Baker, 2007). Sung, Chang, Lee, & Lee (2006) presented results indicating that the number of agitated behaviors was significantly reduced after music therapy. Through both quantitative and mixed methods studies, researchers observed a short-term reduction in agitation after the use of music therapy (Brotons & Marti, 2003; Ridder et al., 2013; Svansdottir & Snaedal, 2006). Ledger and Baker (2007) evaluated the long-term effects of music therapy on agitation and concluded that while music therapy reduced agitation for short periods of time, there were no significant differences in the frequency, range, and severity of agitation between the control and treatment groups over the long term.” “We measured agitation scores two weeks after the conclusion of the intervention and found that the scores had not changed much (49.86 15.71, $p > .05$) but were still significantly lower than at baseline (59.11 22.04, p ¼ .018) suggesting that the two-week intervention had immediate and lingering effects on agitation.” “In summary, from the results of both the multiple regression analyses and the repeated measures analysis of variance, we can conclude that the music therapy intervention significantly reduced symptoms related to depression and agitation. The multiple regression analysis indicated that the only other factor to influence depressive symptom was dose; the number of times music therapy was provided significantly influenced depressive symptoms.” Visual art therapy could be effective in improving cognitive functions and the associated psychological symptoms. Therefore, it can be adopted as an effective non-pharmacological intervention for preventing cognitive decline and dementia. [Masika, Golden M., Doris SF Yu, and Polly WC Li. "Visual art therapy as a treatment option for cognitive decline among older	

		adults. A systematic review and meta-analysis." Journal of advanced nursing 76.8 (2020): 1892-1910.] “Twelve articles published between 2004–2019 involving 831 participants were identified. VAT significantly improved global cognitive function compared with different control groups (Hedges' g = 0.348 [95% CI = 0.026–0.671], p = .034, I2 = 66.570%). VAT also demonstrated psychological benefits in reducing depressive symptoms and anxiety. By systematic comparison of the intervention designs, it seems that those with greater cognitive benefit involved a higher level of creativity and optimized the use of essential components including art education, reminiscence, art processing, cognitive evaluation, art crafts/modelling, and socialization.”	
6.4	GH	Some addressing of positive risk enablement is required due to the risk averse nature of care. Practitioners require some guidance around this especially when it comes to dementia, as well as understanding restraint ie locked doors etc not allowing someone to participate in activities rather than adapting them.	Thanks for your comment. Risk enablement is an important aspect of how guidelines may be implemented in practice. We hope our wording around the importance of person centred care and activities tailored to individual interests will support services to take a more positive approach to risk enablement. We also hope that by stipulating the importance of implementation support in our good practice point that this highlights the need for interventions to be looked at through a positive risk enablement lens.
	JC	Clearly written	Thank you. No response required.
	PC	Again, low certainty, small effect. Worth highlighting that although useful, tailoring of non-pharm interventions is a complex are, with no clear candidate therapy for what should be tried first, in why “dose” for how long etc.	We have added a comment to Section 11.2 to highlight research limitations: *“Better evidence for non-pharmacological therapies and the effectiveness of such therapies for distressed behaviours.”*
	AFr	Really positive section	Thank you. No response required.
	KP	Music therapy, which has the benefit of being a therapeutic intervention that is, in its very nature, person-centered and tailored to an individual’s specific needs, personality and preferences. Because of this, music therapy should be considered by this guideline as a meaningful therapeutic activity that can be individually tailored to people living with dementia. A 2013 randomized controlled trial exploring the effect of individual music	Thank you for the comment and information. We agree that music therapy can be a useful intervention and could be considered as part of the individualised approach that we advocate. However, we did not find sufficient evidence to support its uniform use in people with dementia and agitation, aggression and sleep disturbance. Hence, it is not specifically mentioned but

		therapy on agitation in dementia this topic was discussed - see excerpt below: [Hanne Mette O. Ridder, Brynjulf Stige, Live Gunnhild Qvale and Christian Gold (2013). Individual music therapy for agitation in dementia: an exploratory randomized controlled trial, Aging & Mental Health, 17:6, 667-678. https://doi.org/ 10.1080/13607863.2013.790926] “Agitation in persons with dementia is worldwide considered a serious problem that leads to increased use of psychotropic medication as well as caregiver burnout. In this study we investigated individual music therapy for persons with dementia – an intervention that previous research and clinical experience suggest can be highly relevant for this population. The study protocol allowed for a person-centered approach where the music therapist carried out the intervention adjusted to the needs of the participant. We found that agitation disruptiveness decreased and we therefore recommend music therapy as a valid treatment of agitation and as a possibility to reduce psychotropic medication, as well as to prevent caregiver burnout.” A 2017 systematic review of reviews to investigate the evidence of nonpharmacological approaches to care for behavioural and psychological symptoms of people with dementia found that music therapy is an evidence-based individualised intervention that can contribute to the relief of agitation in people with dementia. See excerpts below: Legere, L.E., McNeill, S., Schindel Martin, L., Acorn, M. and An, D., 2018. Nonpharmacological approaches for behavioural and psychological symptoms of dementia in older adults: A systematic review of reviews. Journal of Clinical Nursing, 27(7-8), pp.e1360-e1376. https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.14007 “Although there remains a paucity of high-quality research in this area, the existing evidence indicates that behavioural and psychological symptoms of dementia require a range of nonpharmacologic sensory-focused approaches that are tailored to the individual.” “The most conclusive evidence supported individual, sensory-focused interventions such as music therapy, interventions targeting pain, person-centred approaches and education for family caregivers.” Emblad, Shayla YM, and Elizabeta B. Mukaetova-Ladinska. "Creative art therapy as a non-pharmacological intervention for dementia: A systematic	that does not preclude its use.

		review." Journal of Alzheimer's Disease Reports 5.1 (2021): 353-364. “Results: We identified four outcome domains: wellbeing, quality of life, biological and bsychological symptoms of dementia (BPSD), and cognitive function. One or more significant outcomes as having an impact on the efficacy of the intervention were reported in 88% (15/17) of the studies, whereas 17% (3/17) demonstrated significant outcomes across quality of life, wellbeing, and BPSD.” “Conclusion: People with dementia benefit from art therapy. These interventions when incorporating elements of being ‘in the moment’ increase opportunities for communication between people with dementia and their caregiver(s) and facilitate person-centered therapeutic activities.”	
	GB	Emphasis on tailored activities is good but need to consider context and systemic issues- care homes lack of staffing, how to help address this	Thank you for your comment, we agree that there are wider systemic issues which stakeholders should review, and if necessary address, when implementing these guidelines.
	AMcK	A body of literature available on occupational therapy interventions, the Tailored Activity Program (TAP) and Care of People with Dementia in their Environments (COPE): Gitlin, L. N., Winter, L., Earland, T. V., Herge, E. A., Chernett, N., L., Piersol, C. V., & Burke, J. P. (2009). The tailored activity program (TAP) to reduce behavioral symptoms in individuals with dementia: Feasibility, acceptability, and replication potential, The Gerontologist, 49, 428-439. https://doi:10.1093/geront/gnp087 Additional references are available and can be provided.	See comments above
6.5	PC	Surprising that there is no mention of hypnotics as a comparison, esp as it is likely that such a comparison would not favour hypnotics.	Thank you for your comment. Not a deliberate omission, there were no papers found on hypnotics.
	AFr	Education to carers is so important	Agree as reflected in recommendations.
6.5.1	GH	There is some additional work being done around this as my colleague is involved and there may be some additional information regarding the promotion of circadian rhythm and other health benefits of blue light and optimal times to be outdoors.	Thank you for this information, we look forward to reading about it further once it is published.
	JC	One review highlights lack of effect. Any studies since January 2014?	There was one further relevant paper published in Feb 2022, we have included it in our evidence tables,

			however its conclusions do not alter our recommendations.
	AFr	Really interesting	Thank you. No response required.
6.5.2	MS	Many charities have a wide range of expertise and experience with providing non-pharmacological support for people living with dementia. It might be useful to consider commissioning these organisations to train professionals/service providers around these types of support. In the long-term it can help reduce the cost of the disease and the burden on care-givers.	Thank you for your comment. Stakeholders may wish to consider how services are commissioned and configured when they are implementing these guidelines.
	JC	Draws on NICE guideline and additional RCT	Thank you. No response required.
	GMc	Role for nutritional management of behavioural symptoms especially. sleep disturbance - constipation management, adequate hydration, hunger.	Thank you for your comment, we did not identify sufficient evidence to be able to specify nutritional management as a particular intervention for behavioural symptoms
	PC	Similar to 6.4 above	Response as above.
	MP	Across Scotland the Newcastle Model is widely in use and training and implementation I supported by NES. Should this be reflected in the document and recommendations?	Unfortunately no specific evidence was found to support the Newcastle Model, but our recommendations would be consistent with support for its use.
	AFr	Absolutely essential	Thank you. No response required.
	RB	Is there scope to define what would be considered ‘comprehensive’? Use of term "holistic assessment" - This needs to be clearer. I have the impression this paragraph is talking about identifying a person’s unmet needs through the use of formulation but nowhere in the document is the Newcastle model explicitly mentioned. There doesn't seem to be consistency within this document in terms of language used…nor is it consistent with other NHS/SG guidance/strategy language use	We were unable to recommend, based on the evidence base, one particular comprehensive structured assessment. The term comprehensive is used to hopefully emphasise the importance of structured assessment containing appropriate level of detail for each individual, with recognition that level of detail required may vary from person to person. Unfortunately there is no sufficient evidence to recommend the use of formulation or specifically the Newcastle model at this time. This good practice point is designed to recognise that whilst the evidence is not there this We have reviewed the document to ensure consistency in language used around terminology of distressed behaviour; but in some instances we have kept the

			language used in the original research papers (particularly around descriptions of intervention types).
	KP	A 2017 systematic review of reviews to investigate the evidence of nonpharmacological approaches to care for behavioural and psychological symptoms of people with dementia mentioned the effectiveness of multi-component approaches, suggesting that music therapy fits within this category. See excerpts below: Legere, L.E., McNeill, S., Schindel Martin, L., Acorn, M. and An, D., 2018. Nonpharmacological approaches for behavioural and psychological symptoms of dementia in older adults: A systematic review of reviews. Journal of Clinical Nursing, 27(7-8), pp.e1360-e1376. https://onlinelibrary.wiley.com/doi/abs/10.1111/jocn.14007 “Considering the findings from both the individual therapies and targeted interventions, we examined within this systematic review, there was the most conclusive evidence to support the use of sensory-focused interventions such as music therapy, interventions targeting pain and behaviour outcomes, person-centred approaches, and education and support for family care givers, with limited evidence to support the use of physical activity or massage therapy. For organisational interventions, the implementation of care planning using a consultation or mapping process has demonstrated modest benefits.” Expert Opinion (NHS Lothian Music Therapist) In considering organisational interventions and the implementation of care planning, as a music therapist working in the NHS Lothian Inpatient Service, I am a part of multidisciplinary team meetings and discussions and have an active role in contributing to the care planning and discharge planning for the people I work with on dementia assessment wards. Not only is music therapy a multi-component approach that is tailored to each individual I work with, but my role of music therapist sits within a multicomponent, service-wide, multidisciplinary approach that the NHS Lothian Impatient admissions service provides.	Thank you for the comment and information. We agree that music therapy can be a useful intervention and could be considered as part of the individualised approach that we advocate. However, we did find sufficient evidence to support its uniform use in people with dementia and agitation, aggression and sleep disturbance. Hence, it is not specifically mentioned but that does not preclude its use.
	AT	I am concerned that this chapter could be seen as potentially increasing the stigma outlined in the dementiauk document (attached) Perhaps this could be addressed at the start of the chapter Understanding-and-challenging-stigma-and-discrimination.pdf (dementiauk.org)	Stigma is noted in subsection 7.6 in this section. Stigma is noted in the introduction and throughout the document (1.1.3, 1.1.7, 5.1.1, 5.2.1, 5.3, 5.5, 5.6, 7.6, 8).

		I also wonder if you wanted to reference this recent article suggesting In patients younger than 65 years and within 3 months of diagnosis, suicide risk was 6.69 times (95% CI, 1.49-30.12) higher than in patients without dementia Risk of Suicide After Dementia Diagnosis | Dementia and Cognitive Impairment | JAMA Neurology | JAMA Network 3rd Oct 2022	Thank you, risk of suicide is now covered in diagnosis section (3.2.3).
	AF	Self help groups- using dementia charities	This point is acknowledged in second paragraph of section 7 – language consistent with literature
	JC	Clear introduction outlining the problem	Noted with thanks. No response required.
	RH	This is an important, often unrecognised issue which has been highlighted.	Noted with thanks. No response required.
	PC	A well written chapter again benefitting from a focus on people with dementia themselves rather than carers or family members. The recognition of the change from the status of "family member" to "carer" can be profound for people with dementia se working in the field need to be careful about the language they use when discussion matters with people with dementia. This may be worth highligniting as a good practice point	Thank you. We have now included in section 1.3.10 as it relates across the guideline: *"It can take time for a family member, or other relation to a person with dementia, to acknowledge their role as a carer for a variety of reasons. It may only be at a time where the caring role has increased, that this becomes more evident to the carer. It is important to consider that where the recommendations refer to carers they may not have acknowledged that role or title."*
	MR	If inappropriate behaviour in care settings, or online, professionals must look for reason, as it is communicating an unmet need, otherwise behaviour will spiral out of control. Any living will (unless sectioned), such as mine, that states no pharmaceutical intervention without next of kins permission must be upheld.	Refer to section on non-pharma logical interventions.
	KA	How this can be adapted and accessible. Training to support carers / families	There will be a version of the guideline for people with dementia and their carers.
	KP	The multi faceted nature of grief and the enormous variation in individuals responses to loss means that for dementia patients, there is no 'one size fits all' approach to grief, with this as true in dementia care as any other healthcare setting. Music therapists can provide a unique perspective, with well developed skills in personalised musical interaction, and training in psychodynamic approaches. This allows music therapists to employ approaches to grief resolution and management that are unique to the modality, in a manner that is adapted to each individual. Bright R. Music therapy in grief resolution. Bull Menninger Clin. 1999	The formal literature review process did not identify this paper as an intervention for grief in the context of dementia. The year range covered for our searches and papers was 2000-2021, see section 11.1.

		Fall;63(4):481-98. PMID: 10589140.	
	GB	Good to include this, but highlights need staff further training and provision of support re grief to people and families if identified. Older Adult Psychology Services are currently across Scotland under resourced (esp in comparison Children and Adult services) so would struggle if more demand arises.	This SIGN guideline aims to highlight evidence based intervention that drive service improvement, implementation is outwith the remit of SIGN.
	JK	Group encouraged to see inclusion of grief and dementia. Opportunity to continue to work and aspire to person centred outcomes at every stage of dementia journey. Should prioritise work to help those living with dementia have best and most dignified death.	This is in line with the guidelines aims and sections on ACP.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
	JM	I really like the extensive focus on pre-death and anticipatory grief and I like that there are specific references to these in the recommendation. If healthcare professionals can give carers a name for their feelings (for most, the idea of anticipatory grief will be new to them), that can enhance feelings of validity and a sense of shared burden. It can be a diagnosis in itself. Perhaps recognises that the carers are often the patients of the GP as well.	Thank you. No response required.
	JH	Previous comments capture all Equality and Human Rights aspects.	See responses above.
7.1	GH	Provision and acknowledgement required that this should/could be included in post-diagnostic support.	We have made a recommendation on this in section 7.6, that relates to this
	AF	Implementing self help groups within care home settings. Training care home staff to deliver sessions.	Recommendations around peer support and third sector involvements are included in this section. Educational awareness is addressed.
	MH	Duplication of 4th paragraph	Deleted duplication.
	AFr	Well highlighted and captured	Noted with thanks. No response required.
	KP	Music Therapy in the Treatment of Dementia: A Systematic Review and Meta-Analysis This 2020 systematic review and meta analysis of relevant literature found that for people living with dementia, music therapy proved a positive intervention in the treatment of long term depressive states in dementia patients. When studying the depressive state of patients 6 months after the intervention to know if there is a long-term effect (4 studies, 290 cases),	Our literature search was purely based on grief not depression The literature review process did not identify these papers

		the result indicated that music therapy could have a positive effect on the depressive state of people living with dementia. Faw, M.H. et al. (2021) “Surviving and thriving: Qualitative results from a multi-year, multidimensional intervention to promote well-being among caregivers of adults with dementia,” International Journal of Environmental Research and Public Health, 18(9), p. 4755. Available at: https://doi.org/10.3390/ijerph18094755. Anticipatory grief during COVID-19: a commentary The British journal of community nursing explored the impact of anticipatory grief during the COVID-19 pandemic and acknowledged that Music therapy sessions provided recreational opportunities and creative expression for patients; In addition, music therapy empowered the therapeutic team to more effectively address problems related to quality of life and certain conditions and emotions, such as anticipatory grief, depression, anxiety, and hopelessness. As a palliative approach, music therapy helps patients, families and healthcare professionals involved in anticipatory grief express their feelings and cope better with grief. Khanipour-Kencha, A., Jackson, A.C. and Bahramnezhad, F. (2022) “Anticipatory grief during COVID-19: A commentary,” British Journal of Community Nursing, 27(3), pp. 114–117. Available at: https://doi.org/10.12968/bjcn.2022.27.3.114.	
	JK	Very important inclusion as we advance towards 8 pillar models of care in Scotland. Need for ongoing dialogue and placing this at centre of agenda within SIGN legitimises this very often overlooked issue in both patients and their carers.	Noted with thanks. No response required.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
7.1.1	JC	General well written intro to anticipatory grief. Not clear what the JBI score is in relation to as the review includes several literature sources?	The SIGN style is that we give an indication of the quality of the body of evidence. So if a number of studies have the same score this is only presented once for brevity. Your feedback will be taken will be taken to SIGN methodology group and further to this for qualitative and mixed methods work the individual paper grading will be given.

	AFr	Much is need around this and again education is key to prepare for the anticipatory grief	Noted with thanks. No response required.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
	KP	Development and efficacy of music therapy techniques within palliative care This study explores the use of four broad areas of music therapy in end of life care: receptive, creative, recreative and combined. The study found that at the end of life, music therapy proves not only to be beneficial to patients with anticipatory grief, but it is also valuable in supporting grief and bereavement of family and friends. While the patient is actively dying, music therapy sessions which focused on the patient and caregivers were shown to have significant benefits in the grief process for caregivers and even positively contributed to bereavement. Clements-Cortés, A. (2016) "Development and efficacy of music therapy techniques within Palliative Care," Complementary Therapies in Clinical Practice, 23, pp. 125–129. Available at: https://doi.org/10.1016/j.ctcp.2015.04.004 Music therapy: A nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia. This study shows it is important for people with dementia to be provided with a creative outlet for expression, especially during times of distress, dysfunction, and deflated mood that often occurs due to the diagnosis and associated losses. For people with dementia, music therapy leads to feelings of positive self-esteem, increases feelings of competence and independence, and diminishes feelings of social and emotional isolation. Ray, K.D. and Mittelman, M.S. (2015) "Music therapy: A nonpharmacological approach to the care of agitation and depressive symptoms for nursing home residents with dementia," Dementia, 16(6), pp. 689–710. Available at: https://doi.org/10.1177/1471301215613779.	These are older papers outside the date range of our search. For palliative area we referred to the NICE review.
7.1.2	JC	General introduction to the topic including definitions	Noted with thanks. No response required.
	MH	I'm not sure that the difference between anticipatory grief and pre death grief is clearly explained. If there isn't any difference I don't believe it	The group acknowledge your point and discussed this at length. See paragraph 4 in section 7.1.1

		warrants a separate section, but just say the 2 terms can be used interchangeably.	
	AFr	As 7.1.1	Noted with thanks. No response required.
	KP	Life is an activity and is performed, even to the end. And we perform this act of living, and eventually dying, with others. It is this aspect of mutuality, the relationship, that is important to all healing endeavours. Music is what we do together when we play together as musicians, or take part as listening audiences, or engage with it in that sublime activity of dancing. Actively making music reminds us all that something can be done, that there is an available cultural form of expression that allows us to express ourselves personally and communally. Singing together allows both the person dying and her carers to actively participate in the end stages of life. Journal of Holistic Healthcare . May2011, Vol. 8 Issue 1, p41-44. 4p	The literature review process did not identify these papers
	JK	Understanding the asynchronous impact of pre-death grief in those people diagnosed with dementia enables services consider need to match responses. A valuable section to include in the guideline	Noted with thanks. No response required.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
7.2	AF	Early anticipatory care conversations	This is acknowledged in sections 8 and 5.
	JC	Line 3 indicates the qualitative synthesis was based on 23 papers. Line 7 discusses three specific qualitative studies, needs to be clearer whether these were the only ones in the review that focused on pre-death grief, i.e. was this a specific theme within the synthesis? Are the JBI scores based on the individual qualitative studies?	Section focusses on people with dementia and the three papers referenced cover this while the 23 papers include carers as well. See comment above re grading of evidence- individual grading of papers will be added for qualitative/mixed methods.
	AFr	Really interesting and would be good to see more research on this in time	Noted with thanks. No response required. Recommendations for future research included in the guideline.
	RK	I mentioned earlier my hope that psychologist and speech and language therapists can work together to enable people with limited verbal communication to access psychotherapeutic interventions. Could arts and music therapies also be mentioned here. Sorry if I've missed it.	The guideline makes reference to the value and importance of multi-disciplinary teams.
	KP	A study comparing the impact of different individualised music interventions in those with severe Alzheimer's found that interactive music	The literature review process did not identify these papers.

		interventions have the greatest improvements on emotional state compared to passive music interventions and no-music control group. The interactive intervention also caused a significant reduction in symptoms such as stress, however, this disappeared after three weeks, highlighting the importance of regular engagement with music to maintain its benefits. Osman, Sara Eldirdiry, Victoria Tischler, and Justine Schneider. 2016. '"Singing For The Brain": A Qualitative Study Exploring The Health And Well-Being Benefits Of Singing For People With Dementia And Their Carers.' Dementia 15 (6): 1326-1339. doi:10.1177/1471301214556291 A qualitative study looking at the impact of the musical intervention 'Singing For the Brain' in those with dementia and found that singing improved mood and memory, but also enhanced relationships and inclusivity. More importantly, attending the program helped dementia patients come to accept and come to terms with their disease, and promote coping strategies for the conditions they have to live with.	We have made recommendations for research in section 11.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
7.3	Anon	I have struggled with this in particular when my relative moved to a care home. Any support was entirely to do with dealing with finding a home and then it was assumed that everyone (my relative, family members) would be fine. The 'problem' had been solved by removing my relative from the community and moving them to a setting where they are contained and no longer a risk to society. This breaks my heart. There seems to be no ongoing support available.	We recognise these issues and have made recommendations particularly regarding transition points in section 7.3.
	AF	Counselling groups- locally in care homes	Recommendations around peer support and third sector involvements are included in this section.
	JC	Highlights the problem	Noted with thanks. No response required.
	AFr	Do we know what spouses may dela with pre death grief better than adult colleen of the person with dementia?	No clarity on this point from the literature review.
	KP	Expert opinion: Music Therapy in Context (NHS Lothian, NHS Fife) In my work as a music therapist, when conducting sessions with family members and their loved one who is living with dementia, family members have used the songs and the sessions to reminisce with me about their loved one, sharing stories about their lives together. When they observe	The literature review process did not identify these papers

		the response from their loved one to the music, family members have reported it being the most responsive they have seen their family member in many visits. In two of these instances, a family session took place the day before the person with dementia died. The family members reported a sense of connectedness with their loved one, and a sense of closure. O'Callaghan, C. 2013. 'Music therapy Preloss Care though legacy creation' Progress in Palliative Care, 21 (2), pp. 78–82. Available at: https://doi.org/10.1179/1743291x12y.0000000044. "Two studies examining reflections about music therapy, expressed by carers of children and adults who received music therapy at the end-of-life, indicated that session memories and patients' song compositions brought the bereaved carers comfort. It is suggested that music therapists consider preloss care as an aim when working in palliative care." "Preloss care can be defined as the intentional creation of opportunities with patients with life-threatening conditions and/or their families (or close friends) that may enable the mourners' improved bereavement experiences if the patient dies."	
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
7.4	MH	I don't understand the sentence. 'Interventional strategies should be considered carefully because coping strategies, such as avoidance of grief and distancing from the person with dementia, can be protective of the carer in enabling them to cope with caring and their daily tasks.' Could it be elaborated? Perhaps it would help if this section came after 7.6.	Amended accordingly, thanks
	AFr	This must be difficult to capture and will be so individualised	Noted with thanks. No response required.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
	KP	This study is an exploratory inquiry into the role of music therapy with pre-bereaved informal hospice caregivers. The study intends to articulate (a) what pre-bereavement needs are present for informal caregivers, (b) which of those needs were addressed inmusic, and (c) the process by which music therapy addressed those needs. Resource-oriented music therapy provides a unique clinical avenue for supporting caregivers through pre-bereavement, and was acknowledged by caregivers as a unique and integral service. Within this model, caregivers are better positioned to	The literature review process did not identify this paper.

		develop meaning from the experience of providing care through the death of a loved one. Potvin, N., Bradt, J. and Ghetti, C. (2018) “A theoretical model of resource-oriented music therapy with informal hospice caregivers during pre-bereavement,” Journal of Music Therapy, 55(1), pp. 27–61. Available at: https://doi.org/10.1093/jmt/thx019.	
7.5	AFr	I have come across a lot of this during my experience	Noted with thanks. No response required.
	RB	RE "• Pre-death grief experienced by the carers of people with dementia can be distressing and disabling, and has an impact on well-being. " - This isn’t a recommendation. It is just a statement about carers’ grief	Amended accordingly, thanks.
	KP	McMahon, K., Clark, I. N., Stensæth, K., Odell-Miller, H., Wosch, T., Bukowska, A., & Baker, F. A. (2022). Exploring Shared Musical Experiences in Dementia Care: A Worked Example of a Qualitative Systematic Review and Thematic Synthesis. International Journal of Qualitative Methods, 21. https://doi.org/10.1177/16094069221127509 McMahon et al. (2022) found that shared musical activities fostered experiences of connection and wellbeing for people living with dementia and their family care partners. Clinical Opinion. Music Therapy in Context (NHS Lothian) As a music therapist working in end of life and dementia care I have witnessed how music therapy can be used as part of a holistic approach to carer support. Carers and family members are encouraged to attend weekly open group music therapy sessions. In these sessions, a combination of precomposed music and improvisation is used, all group members are invited to contribute musically and there is space for reflection and conversation. Carers and family members have reported an increased sense of connection with their loved ones during sessions, with renditions of songs that hold significance for patients and carers often promoting creative expression, shared singing and shared memory forming. These experiences promote the reflection back to, and the affirmation of shared life stories. When engaged in improvisational playing, both carers and patients can connect in a manner that is not reliant on words, and that draws both parties into the ‘here and now’. In the face of a condition that, for carers and patients alike, may cause rumination on the past and anxiety about the future, these moments of connection in the	The formal literature review process did not identify these papers

		present moment appear highly valuable. Music Therapy Intervention to Reduce Caregiver Distress at End of Life: A Feasibility Study This study acknowledges that carers of those in end of life care are at risk of anxiety, emotional distress and experience anticipatory grief as the patient nears death. The study sought to explore the potential benefit of music therapy for care givers of end of life patients. Twenty caregivers of patients in end of life care were enrolled. MT was provided by a board-certified music therapist, and sessions included pre-MT assessment, 20-45 minutes of MT, and post-MT assessment. Caregiver stress was measured with the Pearlin Role Overload Measure (ROM), QoL was measured with the Linear Analogue Self-Assessment (LASA), and depression and anxiety were measured with the Patient Health Questionnaire for Depression and Anxiety (PHQ-4). These three measures were taken pre-MT, post-MT and 6 months post-MT. Caregivers were also asked to complete a Music Therapy Program Survey post-MT. The study found that 100% of caregivers were very satisfied with music therapy and would recommend to others, 78% found music therapy effective for stress relief, 69% for relaxation, 71% for spiritual support, 86% for emotional support, and 71% for feeling of wellness. Whitford, K. et al. (2021) "202 - music therapy intervention to reduce caregiver distress at end of life: A feasibility study," International Psychogeriatrics, 33(S1), pp. 7–7. Available at: https://doi.org/10.1017/s1041610221001368.	
	PMac	While it is important to avoid misdiagnosis of depression, given the age profile of many families and carers and the associated and significant increased risk of depression in older people, the experience of pre death grief related to dementia is an important risk factor for the development and aggravation of depressive symptoms and would require appropriate treatment. There is little ref to anticipatory and premature grief around diagnosis and the wellbeing support required / recommended. Social care workforce have a role here too.	We have inserted good practice point surrounding co-occurrence of depression and grief in section 7.5 Where the literature references health and social care this is reflected in the guideline, see also introduction section which explains this. "Grief and depression can co-occur and grief should not preclude the carer from receiving treatment for depression."

			We have also now amended recommendations to include social care professionals.
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
	JM	I especially like the recommendation in 7.5 of the association with depression; GPs are in the unique position of having both the patient with dementia and their carer (ie spouse, child) as their patient too. It can be very hard to differentiate between a grief experience and depression. like above, giving a name for the carer's suffering (or diagnosis) in lieu of an ICD mental health diagnosis could again enhance validity and aid in recovery.	Thank you. No response required.
7.6	JC	Highlights effective strategies	Noted with thanks. No response required.
	AFr	Again, education is key - supporting the carers with education and support will in turn support the person with dementia. Carer support groups and resources where people with dementia can come along where carers can access carer support groups while the person with dementia is supported in a meaningful activity	Noted with thanks. No response required. Recommendations and good practice points reflective of this.
	KP	United Kingdom — Homeside - Partnership in dementia care (homesidestudy.eu) Homeside: A international research project The primary aim of the project is to demonstrate, for the first time, the effectiveness of a 3-month caregiver-delivered, home-based music intervention on the short-term behavioural and psychological symptoms of dementia. This home-based intervention will be compared to standard care. The project will also evaluate the effectiveness of the music intervention compared to a reading intervention. Secondary aims include examining relationship quality between the caregiver and the person living with dementia. This means measuring levels of depression, resilience, competence and quality of life in the caregiver, and quality of life in the person living with dementia. Our randomised controlled trial will compare the music intervention delivered by trained caregivers and standard care, with standard care alone (primary comparison), and with reading and standard care being another active	The literature review process did not identify these papers.

		intervention. Cost effectiveness of the music interventions compared to standard care and reading interventions will be done to determine whether the music interventions are clinically effective and cost-effective. Clinical studies have provided evidence suggesting individuals in mid-late stage dementia can not only actively participate in music, but that this participation, in the context of a properly designed music therapy experience, can function to re-establish verbal and non verbal connections between care receivers and their carers. These studies show that music therapy offers a way to compensate for some of the inexorable losses associated with the disease process. This loss affects both the cared for and the carer and music therapy has shown to enhance quality of life measures, improve self-esteem and diminish feelings of loneliness and grief in both parties. Edwards, J. (2017) The Oxford Handbook of Music therapy. Oxford: Oxford University Press. Surviving and Thriving: Qualitative Results from a Multi-Year, Multidimensional Intervention to Promote Well-Being among Caregivers of Adults with Dementia This study acknowleges that the arts can play key role, amongst a multidimensional approach, in ameliorating the negative outcomes associated with caregiving while enhancing its more positive attributes. As a person living with dementia begin lose their ability to remember and communicate, individuals can no longer ‘perform relationships’ and caregivers must negotiate their sense of grief. The study highlights that extensive research on music therapy involving carers have illustrated the power of these experiences to lower caregivers levels of subjective depression and burden. Faw, M.H. et al. (2021) “Surviving and thriving: Qualitative results from a multi-year, multidimensional intervention to promote well-being among caregivers of adults with dementia,” International Journal of Environmental Research and Public Health, 18(9), p. 4755. Available at: https://doi.org/10.3390/ijerph18094755.	

		A qualitative systematic review of the experiences of sharing music for people living with dementia and their family care partners: the thread of connection This study acknowledges the global need for interventions that support the wellbeing of people living with dementia and their family care partners, and highlights that studies show musical interventions may achieve this. The study concluded that shared musical experiences foster experiences of connection for people living with dementia and their family care partners. Experiences of connection are supported through professional facilitation and the structural aspects of music, and are influenced by the setting and changes over time. These experiences of connection play a central role in supporting dyadic and individual wellbeing. McMahon, K. et al. (2022) "A qualitative systematic review of the experiences of sharing music for people living with dementia and their family care partners: The thread of connection," Arts & Health, pp. 1–28. Available at: https://doi.org/10.1080/17533015.2022.2128381. The effects of music therapy on interactions between family caregivers and their care receivers with late stage dementia. This study examined the effects of music therapy programming, including singing and rhythm playing, on participation engagement frequencies of family caregivers and their late stage dementia caregivers. The study found that caregivers participation engagements were higher in music applications when compared to conversation. This increase in caregiver participation may allow for opportunities for meaningful connection between carers and those living with late stage dementia. Clair, A.A. and Ebberts, A.G. (1997) "The effects of music therapy on interactions between family caregivers and their care receivers with late stage dementia," Journal of Music Therapy, 34(3), pp. 148–164. Available at: https://doi.org/10.1093/jmt/34.3.148.	
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required

	JM	I really like the specific therapies recommended here. Specifics are sometimes lacking in other recommendations.	Thank you. No response required.
7.7	JC	Good use of qualitative research which highlights the problem	Noted with thanks. No response required.
	AFr	This is dependent on the stage of dementia of the person. Education to those around them is essential to minimise the risk of stress and distress and support a quality of life.	Noted with thanks. No response required.
	KP	Stewart, A.J. 2019. Supporting people with dementia who are experiencing loss and grief; developing student music therapy practice.' Available at: https://doi.org/10.26686/wgtn.17139734. "Five themes of: sensing over speaking; human connection; honouring spirituality; knowing individuals closely and therapist self-care are presented in the model of a human hand. The palm of the hand holds the core theme valuing the person, as inspired by Kitwood (1997)'s model of personhood. The research's findings valuing spiritual care, and an emphasis on nonverbal connection aligns with Kirkland, Fortuna, Kelson, and Phinney (2014)'s study of a spiritual care and music therapy group."	The formal literature review process did not identify these papers
	JK	Opportunity for read across and mention of role of S&D formulation approaches where support is required for people with dementia following bereavement.	There is a link to section 6 in the last paragraph of this section: *"People with dementia may require support after the death of a family member, spouse or friend, to process the loss and to manage the distress, agitation and confusion associated with the loss (see section 6). However, there is a lack of guidance, education and training for professionals on how to support people with dementia following the death of a spouse, relative or friend."*
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required.
7.8	AT	Would it be worth referencing Grief in family carers of people living with dementia: A systematic review Published online by Cambridge University Press: 28 January 2022 International Psychogeriatrics, First View , pp. 1 - 32 DOI: https://doi.org/10.1017/S1041610221002787 Complicated Grief criteria post-death. Being a spouse, less educated, caring for somebody with advanced dementia, and greater burden and	This paper was published after our search dates which is why it was not included. Noted with thanks, some of these points are addressed within the recommendations in section 7.8

		depression were associated with higher pre-death grief. Lower education level and depression were predictive of higher post-death grief. Pre-death factors found to influence post-death grief were grief and depression	
	JC	Well written section	Noted with thanks. No response required
	KP	Gataric, G. et al. 2010. 'Reflections on the under-researched topic of grief in persons with dementia: A report from a symposium on grief and dementia.' American Journal of Hospice and Palliative Medicine, 27 (8), pp. 567–574. Available at: https://doi.org/10.1177/1049909110371315. Interventions allowing for sharing memories of care-receivers following their death, included: storytelling, use of picture books and personalised music facilitated some sense of relief from the distress felt by grieving carers and their families.	The literature review process did not identify these papers
	JE	Good to see a strong focus on this important aspect of the experience of dementia.	Noted with thanks. No response required
	JM	My experience is absolutely replicated in this paragraph. This is really excellent. I often see that grief, in the traditional sense of the word, can be less following the death of a patient with dementia. There is a lot of anticipatory grief, and potentially a lot of trauma, and if there is distress then often death can come as a relief both for patient and carer. But I absolutely see the huge change; the carer's life can be defined by caring duties and home is adapted for the patient. When the patient is gone they can be left alone.	Thank you. No response required.
	YM	Oral health care management needs to be responsive and adaptable to individual circumstances and experiences and agile in terms of coordinating general dental practice and community(PDS) delivered care.	Thank you for your comments. This was not covered under the scope of this key question. We have made explicit some of the other conditions and general needs that co-exist with dementia in the introductory paragraphs to this section.
	GH	A clearer definition or explanation may be required ie recognition that palliative can be many years long and not just end of life. Maybe an infographic of disease trajectory ie cognitive and physical decline and symptomology would be useful. I have used an example from Australia in the past where appropriate.	Thank you for your comment. We explored this possibility but because there is no definitive and nationally accepted model and given the different underlying neuropathologies we have decided not to include such a model in order not to oversimplify the trajectories. We have addressed this comment in 8.1.1 as a narrative. We will bring this to attention of those preparing the version for people with dementia and their carers.

	AF	Frequent updates to relatives from care home staff	Thank you for your comment. We acknowledge the importance of good communication throughout the guideline.
	PC	Again, clear, well written and informative	Thank you for your comment. No response required.
	AFr	Well presented	Thank you for your comment. No response required.
	MR	Annual review by GP or consultant must happen (by law), rarely does. This must be a statistical measure that is used. Anticipatory care plans should be discussed at each review.	Thank you for your comment. There is not a legal requirement for an annual review of people living with dementia or of ACPs. However it is good practice for ACPs to be reviewed regularly and we have changed the text within the recommendation section to reflect this.
	KA	How does the guideline support anticipatory care planning for people with a learning disability / Down's syndrome and inclusion of family / carers and other specialist services Care pathways / Power of Attorney / Adults with Incapacity and Guardianship power support to inform care planning Meeting unmet health needs	Thank you for your comments. We recognise the importance of this area but was out with the scope of this guideline.
	RK	Clinically, problems with eating and drinking arise very frequently, leading to exacerbation of health problems and loss of quality of life. I think more about the need for skilled support with eating and drinking needs to go in somewhere.	Thank you for your comments. This was not covered under the scope of this key question. We will make explicit some of the other conditions and general needs that co-exist with dementia section 8.1.1: *“People with dementia may also have other pre-morbid conditions and later life conditions which require support and care, for example oral health, tolieting and all activities of daily living.”*
	GB	Need more awareness and training to help staff identify that approaching end of life. This often overlooked and this has implications of quality of end of life care and ability to prepare family.	Thank you for your comment. 8.2.1 acknowledges the difficulties of prognostication so would be unable to make a recommendation on this point at this time.
	JK	Opportunity again for read across and to add Scottish accent - linking benefit of robust PDS approaches including ACP and in need for formulation led S&D approaches to manage and palliate symptoms at eolc stages of dementia. Group were encourage to note guideline highlights dementia does not follow typical palliative care trajectory. Training implications for services to support nurses to deliver person centred end of life care in final stages of person's life.	Thank you for your comment. In section 8.2 this is captured in the clarification about dementia specific palliation with the example of Palliare. *“People with advanced dementia can benefit from a dementia-specific palliative approach to care, for example ‘Palliare’ approaches,194 However people with dementia are less likely to receive palliative care, because of the complex and*

			unpredictable disease trajectory. This can result in unmet needs and potentially burdensome interventions until death. *A Dementia Palliare best practice statement aims to promote a consistent and cohesive approach to advanced dementia care. It advocates a biopsychosocial spiritual model of dementia care that places the person and caring relationships at the centre of health care, with the management of symptoms encompassing the biopsychosocial, spiritual needs and preferences of the person with dementia, their family and friends."*
	DB	We would like to offer some material on care settings	Thank you for your comment. We have met and considered where settings apply. 1.2.1 now includes: *"The guideline applies to all settings, including home, long-term care, care homes, hospital, hospice, day-care centres and primary care. Person-centred care should be the focus of the implementation of this guideline."*
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
	JM	Recommendations -great and sensitively treated set of recommendations. It reads as a 'how to' on which medical schools can base their anticipatory care discussion teaching.	Thank you. No response required.
	JH	Previous comments capture all Equality and Human Rights aspects.	See above response.
8.1	AF	Anticipatory care discussions, should be continual, not put in place and left. These should be revisited and frequently discussed, to support any unmet needs or concerns.	Thank you for your comments. This is addressed in the recommendation at the end of section 8.4.4: *"Anticipatory care planning may involve a series of conversations over time, to allow clarification, reflection and updates to the plan to reflect any changing needs. Early discussions are beneficial, as the capacity of the person with dementia diminishes as the disease progresses.."*
	AFr	Good overview	Thank you for your comment. No response required.

	KP	McDermott, O., Orrell, M. and Ridder, H.M. (2014) ‘The importance of music for people with dementia: The perspectives of people with dementia, family carers, staff and Music Therapists,’ Aging & Mental Health, 18(6), pp. 706–716. Available at: https://doi.org/10.1080/13607863.2013.875124. “The importance of relationship-building through music making were particularly highlighted as valuable. The psychosocial model of music in dementia was developed. The model revealed the importance of music to support the personal psychology of people with dementia and the social psychology of the care home environment. Conclusion: The effects of music go beyond the reduction of behavioural and psychological symptoms. Individual preference of music is preserved throughout the process of dementia. Sustaining musical and interpersonal connectedness would help value who the person is and maintain the quality of their life.”	Thank you for sharing this resource. This intervention would not be in within the scope of this section.
	PMac	Health and social care professional should be aware of their role to engage with families and carers, help them understand all aspects of palliative and end of life care, not just about cause of death.	Thank you for your comment. This is an important principle which we acknowledge which is covered in the recommendation and information point as below. Recommendation: *“Healthcare professionals and those involved in the care of people with dementia should be aware that palliative care is ongoing from diagnosis to end of life.”* Information point: *“People living with dementia, and their family and carers, should be provided with information about the progressive course of the condition, that dementia can be a cause of death and that a palliative approach to care is appropriate at all stages.”*
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.1.1	AF	The use of tools to recognise changing needs to evidence to carers is useful.	Thank you for your comment. No response required.
	JC	Problem highlighted and summarised	Thank you for your comment. No response required.
	AFr	Person centered assessment and support planning is key to meeting the needs of those living with dementia and their carers	Thank you for your comment. No response required.
	KP	Baker, F.A., Grocke, D. and Pachana, N.A., 2012. ‘Connecting through music: A study of a spousal caregiver-directed music intervention designed	Thank you for your comments and for sharing this resource. This intervention would not be in within the

		to prolong fulfilling relationships in couples where one person has dementia.' Australian Journal of Music Therapy, 23, pp.4-21. "Study piloted a home-based music intervention designed to stimulate meaningful interaction between the spouses and discover its value in affecting the quality of the spousal relationship, satisfaction with caregiving, and caregiver wellbeing. Five couples consented to participate in the study and were provided with an education and demonstration session designed to train the caregiving spouse to use music with their spouse. They were asked to selfdirect a program involving three sessions per week for six consecutive weeks. Measures of anxiety, depression, spousal relationship, and measures of caregiving experiences were administered pre-post program. Spousal caregivers completed a diary during the six weeks and participated in a postprogram interview. A thematic analysis of the data indicated that music-sharing experiences were beneficial to the spousal relationship, satisfaction with caregiving, and caregiver wellbeing, and enhanced the mood of both the caregiver and spouse with dementia."	scope of this section.
	JS	People with advanced dementia can benefit from a dementia specific palliative approach to care (Palliare), that assists them to live the best life possible for the months and often years of living with advanced dementia. I would remove the word 'Palliare' here as it reads as if this is a very commonly use term when I don't think it is. 'and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.' Highlight this is English wording - Scottish AWI wording is 'overall benefit'	Thank you for your comments. We have qualified the use of this term as an innovative dementia specific approach to palliation. This sentence is a direct quote from the NICE guidelines hence this terminology. We have now made reference to the Scottish legislation for Adults With Incapacity Act.
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.1.2	JC	Highlights lack of research in this area	Thank you for your comment. No response required.
	AFr	As above	Thank you for your comment. No response required.
	JS	Until further high-quality evidence is produced, no recommendations specific to the assessment of unmet needs in people with young-onset dementia can be made. Rewording suggestion to add in the sentence below However it is suggested that a person centred approach to early care	Thank you for your comment. This has been discussed at length by the group. The recommendation is based on the available evidence so we are unable to speculate, however we acknowledge the research gap. We have highlighted this in the recommendations for research section.

		planning would be helpful in this group as it is with older individuals with dementia - (evidence of reducing carer stress and distress in older individuals likely translatable to younger individuals too)	The guideline emphasises rights-based and person centred approaches are integral to dementia care policy and practice in Scotland (1.1.3.) therefore should meet the needs of the individual irrespective of age.
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.1.3	JC	Clear overview	Thank you for your comment. No response required.
	MR	This should be done at time of patients choosing, but asked at each review. Sufficient time should be given for such an appt; I received 30 minutes for palliative care assessment with GP.	Thank you for your comment. We agree that sufficient time should be allocated for these types of discussions.
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
	JM	Should all patients with dementia be added to primary care’s palliative care register under the gold standard palliative care framework? Often these patients, I find, are left on their own with family or carer support only. They are rarely referred to hospice / community palliative care teams and hospice and, if in a care or nursing home, much of their holistic care is taken care by care staff.	We have explored a number of tools and approaches in preparing the recommendations but have not made a specific recommendation for a particular approach.
8.1.4	AT	This review on transitions says All studies included transitions from inpatient hospital settings, and/ or residential aged care facilities, and/or outpatients/people living at home and that Six themes were identified for people with dementia and carers in relation to transitional care outcomes, I was very surprised re the statement below around Carers especially if the person was going home re Physical decline (falls, ADL, personal care and task assistance and balance) in older people living with dementia are important indicatorsCarer physical decline was not considered a priority for intervention. Also the English in this sentence is confusing Decreases in transitions for older people living with dementia with better service utilisation and the need for a greater focus on carer-relevant services.	Thank you for your comments. Carer physical decline was not considered a priority however, poor quality of life of carers sees important components of caregiving come to light. We have removed and amended section for clarity. The evidence also focuses on carer-relevant services. We have included carers needs in the recommendation. The needs of carers are also addressed elsewhere in this guideline (see section 5 for carer needs relating to postdiagnostic support and section 7 for carer needs relating to grief).
	AFr	Comprehensive overview. What about transitions for unscheduled hospital admissions? There is an increased need for pro-active emergency care and support plans to be in place	Thank you for your comment. 8.3 includes*: “All studies included transitions from inpatient hospital settings, and/ or residential aged care*

			facilities, and/or outpatients/people living at home."
	KP	Lee, S. et al. 2022. 'Integrative Review of singing and music interventions for family carers of people living with dementia,' Health Promotion International, 37(Supplement_1), pp. i49–i61. Available at: https://doi.org/10.1093/heapro/daac024. "The review found that singing and music interventions may improve family carers' social and emotional well-being, enhance their ability to cope and care and ameliorate the caring relationship, contributing to experiences of flourishing. However, it highlighted that this area is under-researched and pointed to the need for larger, more rigorous studies." Expert Opinion: Music Therapist (NHS Lothian) I work in both an acute admissions ward, and a Hospital Based Complex Clinical Care unit within Edinburgh Lothian. For the ward staff, it has proved useful for the Consultant and nursing staff to have a staff member with whom the patients who are transferred are familiar, as well as being able to share first hand historical knowledge of the person. For the patient, it appears comforting to have a familiar feeling brought about immediately upon seeing me with the instruments, and in the music therapy session. Even if the patient is unable to remember my name, they recognise the sessions and gravitate towards them as a place of seeming familiarity and comfort.	Thank you for your comments and for sharing this resource. This intervention would not be in within the scope of this section.
	JS	P62 R – second bullet Rewording suggestion – instead of 'setting goals or care plans to address…' Recommend 'setting person-centred and realistic goals with care plans to address…'	Thank you for your comment. Amendment made to reflect the evidence. So now reads person-centred goals and care plans.
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.2	GH	This should include Social Workers as sometimes they are the first people to come into contact with someone with dementia or their carer especially when being discharged from hospital, assessed for a package of care or in crises/adult safeguarding,	Please refer to Figure 2. There was no specific evidence found that examined the role of social work in Anticipatory Care Planning (ACP). The umbrella systematic review defined ACP as discussions between the individual and healthcare professional; the person with dementia and informal carer; or the person with dementia, carer and healthcare professional.

	AF	Should be continual, not just put in place and left at that. This requires to be discussed at regular intervals recognising stage of trajectory the service user is on.	We have added a good practice point to state: *“Anticipatory care planning decisions should be reviewed and updated; the frequency of this will be influenced by the pace of disease progression and any changing needs.”*
	JB	This takes place in a variety of settings and not always face-to-face. Personal experience is that it has taken place via an e-mail from a Nursing Home to families seeking end of life preferences and suggesting discussions with loved ones. Reality is that the grade of staff suggested in the Guideline to carry out ACP discussions simply does not exist across all settings or indeed in many settings. Its challenging to correlate the guideline with the reality of resources on the ground.	The guideline makes recommendations based on the evidence. The guideline group acknowledge the challenges of implementation and hope the guideline will lead to service change. Implementation is out with the remit of SIGN.
	JC	Clear overview	Thank you for your comment. No response required.
	AFr	Anticipatory care plans are essential however they need to drawn up with a qualitative approach, ensuring all those significant are involved in the process and review	This aligns with the recommendations and good practice points made.
	TP	Disclamier: this is my review that was conducted in 2019-2020. This narrative review provides several themes regarding factors that have influences over the initiaion of ACP : PwD factors, family, HCPs, organisations and temporal Phenwan, T, Sixsmith, J, McSwiggan, L & Buchanan, D 2020, 'A narrative review of facilitating and inhibiting factors in advance care planning initiation in people with dementia', European Geriatric Medicine, vol. 11, no. 3, pp. 353-368. https://doi.org/10.1007/s41999-020-00314-1	These papers were not identified in the strategic searches and evidence review. Please see section 11 of this guideline for methodology.
	JS	The terms Advance Care Planning (used in most other countries) and Anticipatory Care Planning (used in Scotland) are synonymous. ' This statement as written is incorrect - Advance care planning as per its international definition is limited to patients who have mental capacity at the time of decision making. Anticipatory Care Planning was an intentional step in Scotland to widen the future care planning process to include those who already lack capacity to be involved in decision-making around their future care. ‘Advance care planning enables individuals who have decisional capacity	Thanks for this helpful suggestion. We have re-written the introduction to the chapter to include this information. – see 8.4.

		to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.' Rietjen JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol 2017; 18: e543e51.	
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.2.1	GH	Needs to be a bit more clarity that capacity is not always clear cut and that someone can still make some decisions even if they are assessed as not having capacity. This might not be within the remit of the guideline, but I think it is important that clinicians know it can be fluid as well and change especially if there is an acute illness and that just having the diagnosis of dementia does not mean you do not have capacity.	Thanks for this helpful comment. We have added a sentence in section highlighting that fluctuations in capacity can occur. See section 8.4.1: *"In clinical practice, fluctuations in capacity can occur and the ability of the person to contribute to decision making can change."*
	JC	Wide range of evidence included	Thank you for your comment. No response required.
	AFr	Really comprehensive and more education about earlier anticipatory care plans is so important	Thank you for your comment. No response required.
	RK	There's a sentence in here about proxy decisions when the person loses verbal skills. I think it is important to flag that the person with dementia should be supported to use non-verbal means of communication and participate to their maximum potential.	Text changed to reflect this.
	KP	Clare, Amy, Paul M Camic, Sebastian J Crutch, Julian West, Emma Harding, and Emilie Brotherhood. 2019. 'Using Music To Develop A Multisensory Communicative Environment For People With Late-Stage Dementia.' The Gerontologist 60 (6): 1115-1125. doi:10.1093/geront/gnz169 Eight late-stage dementia patients, four care staff and three musicians took part in weekly live 'Music for Life' sessions, in addition to having one hour long recorded music listening sessions. The use of live music created	Thank you for sharing this resource this is out with the scope of this section.

		a multisensory communicative environment, allowing for an interactive way to communicate and develop cognitive abilities such as turn-taking and mirroring behaviour. The researchers discuss how, often, non-verbal communication can be overlooked in cases of later-stage dementia, and consequently, the abilities of patients can be underestimated. Working with the potential to acquire new skills can be especially important for someone with dementia as it can create a sense of achievement and purpose. This spontaneity in improvisation tasks and interaction in real time can really enhance the musical experience and its therapeutic effects, not only in providing a sense of connection, but also promoting cognitive functioning.	
8.2.2	AT	If there is an advance care plan it should be shared with those looking after the person with dementia where appropriate	Thank you. Good Practice Point has been added to reflect this: *"It is important that the most up to date anticipatory care plan is shared with the people who are looking after the person with dementia. This should be easily accessible whenever health or care decisions are being made."*
	GH	As early as possible and as close to diagnosis as possible with the support of professionals and at the very least signposted to information or relevant person.	The recommendations and good practice point reflect the identified evidence as to when.
	AF	At diagnosis, and revisited at regular intervals.	The recommendations and good practice point reflect the identified evidence as to when.
	JC	Equivocal evidence	The recommendations and good practice point reflect the identified evidence as to when.
	AFr	As soon as practically possible and in response to the needs and wishes of the perron with dementia. Again this needs to be person led and depending on the stage and timing of the diagnosis can vary for each individual	The person-centred approach is reflected in this section.
	TP	I agree with the literature that we should discuss ACP early on. However, PwD who are in the moderate or advanced stage can still initiate and reise their ACP as well provided that they receive sufficient, relational support from HCPs and family. For PwD, their input regaring their wishes in ACP will shift as the disease progresses. For PwD during the early stages, their ACP can be fully autonomous with the focus on their individual needs. But as the disease progresses and	The recommendations and good practice point reflect the identified evidence as to when and updated text reflects the capacity issues to consider.

		their cognition declines, this will shift to co-constrcuted needs between PwD and their family. As such, for PwD, they need a customised ACP that will reflect this changing needs as well. The 'crisis' moments can be leveraged for PwD and familt to initiate and revise their ACP as well. For instance, if PwD has multiple falls at home, HCPs can leverage this to initiate or revise ACP, along with relational support PwD may need. See: https://discovery.dundee.ac.uk/ws/portalfiles/portal/86847992/21._Exploring_the_initiation_and_revision_of_ACP_with_and_for_people_with_dementia_a_narrative_study.pdf	
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.2.3	AF	At the right time, at the right place by the right person.	Thank you for your comment. No response required.
	AFr	Again this needs to be person led and will also depend on the timing for each individual	A person centred approach is reflected in this section overall and and recommendations and good practice points based on evidence from the strategic search.
	JS	The importance of embedding ACP conversation outputs in a robustly accessible electronic clinical record should be highlighted here and as a recommendation in 8.2.4. Information that will impact the patient and carers experience of care, especially emergency care is essential to be placed where any health and social care professional can access it in a time of crisis. An emergency care plan such as the ReSPECT process can both prompt and support the conversations and to enhance the ability of planning conversations to transform care experience when it matters. https://doi.org/10.1016/j.resuscitation.2016.07.177	A helpful comment. As the evidence base does not suggest that one type of electronic ACP is better than another (e.g. KIS or ReSPECT) no recommendations have been made around the use of ReSPECT. However we have added an additional good practice point to say: *“It is important that the most up to date anticipatory care plan is shared with the people who are looking after the person with dementia. This should be easily accessible whenever health or care decisions are being made..”*
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
8.2.4	AF	Allocate time to allow discussions to take place, and appropriate support	We have added this to the relevant good practice point, Healthcare professionals and others involved in anticipatory care discussions should allow sufficient time, etc: *“Healthcare professionals and others involved in anticipatory care discussions should allow*

			sufficient time, and ensure a quiet location, free from distractions, that facilitates a supportive discussion and safeguards confidentiality..”
	JC	Clear evidence highlighted	Thank you for your comment. No response required.
	AFr	Well presented	Thank you for your comment. No response required.
	TP	Apart from PwD and family carers, the extended family should be informed of the discussion and ACP decisions as well. The reason being some of the decisions that PwD made early on tend to involve more than family carers. e.g., PwD may wish to stay at home as long as possible. As the disease progresses, this may not be practical hence the family will need to adjust this decisions etc. The revision of ACP at ths stage tend to involve more than family carers hence if the rest of the family are not informed, this can lead to conflict over care and decisions for PwD.	This is a helpful comment. There is no specific evidence base around the ‘extended family’, however we have added a good practice point recommendation to say that: *“It is important that the most up to date anticipatory care plan is shared with the people who are looking after the person with dementia. This should be easily accessible whenever health or care decisions are being made..”*
	JS	Important to mention the CQC report (Review of Do Not Attempt Cardiopulmonary Resuscitation decisions during the coronavirus (COVID-19) pandemic: our methodology - Care Quality Commission (cqc.org.uk)) highlighting the inappropriate focus on DNACPR decisions as often the only aim of ACP documentation and conversation. Also that blanket DNACPR decisions in care home settings are unlawful practice. This is the place to emphasise the importance of early conversations with the individual and family around ‘what matters’ and values based goals of care and that any mention of CPR decisions is placed in context of wider realistic planning conversations with the individual. Ref DNACPR decisions during Covid-19: An empirical and analytical study | Medical Law Review | Oxford Academic (oup.com)	This has now been incorporated into the introductory text in 8.4 and referenced. Thank you. *“A report by the Care Quality Commission following the start of the COVID-19 pandemic emphasised that discussions about Do Not Attempt Cardiopulmonary Resuscitation may form part of an ACP, but should be part of a much wider conversation about future care and treatment preferences.”*
	JE	Useful section. No additional suggestions	Thank you for your comment. No response required.
	AFr	Totally agree that a range of education and information needs to be available for a variety of people	Thank you for your comment. No response required.
	KA	Although the guidance makes reference to the evidence base relating to the prevalence of dementia within the learning disability / Down's syndrome population compared to the general population there is no further reference throughout the guideline that addresses inclusion. There is a lot of transferrable information that could include support to this population group. People with a learning disability experience greater health needs / health inequalities and inclusion within the guidance would support clinicians with assessment / early diagnosis / post diagnostic	This is outwith the scope of the guideline.

		support, as well as palliative and anticipatory care pathways. It would also increase greater links with specialist learning disability services and contribute to equity of care	
	EH	First paragraph last sentence conversations, self-management and treatment and delete care ?	Thank you. Have amended to person-centred conversations, care and self-management.
	JE	Useful set of resources	Thank you for your comment. No response required
	JH	Clear and comprehensive. Previous comments within Section 1 have application across section 9 also.	Thank you for your comment, we have reviewed and actioned the comments in section 1.
9.1	GH	An 'easy read' version would be good to promote accessibility and understanding.	A version of people with dementia and their carers is in development.
	AFr	Excellent material	Thank you for your comment. No response required
	RB	This statement would be good in the “Intent” section at the start of the document.	Thank you. We are content that this text best sits in this section.
	JE	Useful set of resources	Thank you for your comment. No response required
9.2	YM	I would recommend adding this weblink to an online version of a published set of Good Practice Guidelines:- https://cgdent.uk/dementia-friendly-dentistry/ these were published in 2017 and are still current. There is a lot of common ground with these draft Sign guidelines(but in less detail) . The attraction is that there are a number of Oral Health care -specific passages. In particular pages 41-47	Thank you for your response. We felt that dental care was out of scope of the key questions. It may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/. We have included the suggested resource in section 9.4.2.
	GMc	Mention of Alzheimer Society and Alzheimer Scotland. As the Alzheimer Society provides information for people living in England and Wales it may include information that is not accurate or relevant to people living in Scotland. There is also crossover in the information provided on the Alzheimer Scotland website and Alzheimer Society websites. The summary for what the Alzheimer Scotland website provides is also not complete as it also includes information and support.	Thank you for your response. Resources section contains links to a range of resources under Alzheimer Scotland and the Alzheimer’s Society.
	AFr	Not sure if it needs 9.2 and 9.3 - can they be combined?	Thank you for your response. Due to the volume of additional resources we have retained the separate sections.

	KA	No signposting to resources that are learning disability / Down's syndrome specific There are resources that would be helpful to include such as Supporting Derek and Down's Syndrome Scotland	Thank you for your response. We have included these in the resources section.
	KP	Participant quotes — Homeside - Partnership in dementia care (homesidestudy.eu) Home | Arts 4 Dementia	Thank you for your response. We have now included this resource.
	JE	Useful set of resources	Thank you for your comment. No response required
9.3	AF	Online, face to face,	Thank you for your comment. No response required.
	JC	Include https://storiesofdementia.com/	Thank you for your response. We have not included this resource as it was not possible to determine the ownership.
	AFr	It would be a challenge to list all source of further information but in Scotland the University of Stirling has a great education hub	Thank you for your response. We have now included this resource.
	JE	Useful set of resources	Thank you for your comment. No response required
	KA	As above	Thank you for your comment. No response required
	EH	You have missed all the AHP led resources so can these be added please: Scottish Government and Alzheimer Scotland Connecting People, Connecting SupportTransforming the allied health professionals' contribution to supporting people livingwith dementia in Scotland, 2017-20202020 https://www.alzscot.org/sites/default/files/images/0002/7355/AHP_Report_2017_WEB.pdf Scottish Government and Alzheimer Scotland Connecting People, Connecting Support in Action An impact report on transforming the allied health professions' contributionto supporting people living with dementia in Scotland https://www.alzscot.org/sites/default/files/2020-03/Connecting%20People%20Connecting%20Support%20in%20action%20report.pdf	Thank you for your response. Connecting People, Connecting Support is included in the resources, including the website containing the suite of tools and approaches. The impact report and the scoping review aren't as closely linked to the key questions so we have chosen not to include.

		Alzheimer Scotland What is the impact of the Allied Health Professional Dementia Consultants in Scotland? An evaluation commissioned by Alzheimer Scotland https://www.alzscot.org/sites/default/files/2019-08/AHP_Evidence_Research%20-%20Impact_of_the_AHP_Dementia_Consultants_in_Scotland.pdf Pentland D 2015 Dementia: A scoping review of AHP interventions for people living with dementia, their families, partners and carers https://www.alzscot.org/sites/default/files/2019-08/AHP_Evidence_Research%20-%20A_scoping_review_of_AHP_interventions_for_people_living_with_dementia__their_families__partners_and_carers_2015.pdf	
9.3.1	AF	More support and education required for professionals working with dementia. Counselling for staff looking after patients with dementia.	Thank you for your comment. No response required
	JC	Include https://storiesofdementia.com/learning/	Thank you for your response. We have not included this resource as it was not possible to determine who operates it.
	GMc	Connecting People, Connecting Support. Transforming the allied health professionals contribution to supporting people living with dementia in Scotland 2017-2020. @AHPDementia twitter account (daily hints and tips from AHPs) Let's talk about Dementia Blog (https://letstalkaboutdementia.wordpress.com) Dementia Friends Scotland (alzscot.org) AHP Webinars (alzscot.org) - cover a range of topics and provide practical advice on different aspects of living well with dementia	Thank you for your response. We have now included this resource. We do not include twitter accounts as resources. We have included links to Alzheimer's Scotland. We have include a link to the blog.

	PC	Either here or below I would be grateful if you would include a link to the NHS Research Scotland Neuroprogressive disorders and Dementia Network (NDN) https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease NDN undertakes clinical trials in the field of dementia across Scotland. It is not the same as the SDRC and recruits people independently of SDRC. NDN has supported some of the SIGN guideline membership with their studies and the mention of the “Neuro Progressive Network” on p81 is meaningless without a link to the NDN which as you rightly point out has been conducting ground breaking work with people with dementia.	Thank you for your response. We have now included this resource.
	AFr	There is a such a range if information but maybe some top tips for front line care staff would be good	Thank you for your comment. No response required.
	KA	As above	Thank you for your comment. No response required.
	JE	Useful set of resources	Thank you for your comment. No response required.
	EH	Alzheimer Scotland Nationally Allied Health Professionals worked colloboratively and created a suite of evidence based information resources for people with dementia and those who support them. https://www.alzscot.org/ahpresources Alzheimer Scotland and Lab4Living an interactive website with 32 resources and activities that have been tried, tested and recommended by people with dementia. https://dementiatogether.online/ Alzheimer Scotland AHP Dementia weekly blog https://letstalkaboutdementia.wordpress.com/ Alzheimer Scotland AHP dementia daily tweets, offering practical hints and tips @AHPDementia	Thank you we have included these resources. We did not include the twitter account as it this is not a defined resource.
	KP	NHS Lothian Arts Therapies Service: Arts and Self Care Resources: https://weare.nhslothian.scot/artstherapies/arts-for-challenging-times/	Thank you for your response. We have now included this resource.
9.3.2	AF	Evidence based practice- kings fund for dementia. Increase education to allow carers to recognize measures that could be put in place for pople living with dementia- clock, calendar etc	Thank you for your response. We have now included this resource.

	GMc	Alzheimer Scotland AHP resources (https://www.alzscot.org/ahpresources) - a range of written resources and recorded podcasts on topics affecting the lives of people living with dementia produced by allied health professionals from the Alzheimer Scotland AHP Group AHP Webinars (alzscot.org) - cover a range of topics and provide practical advice on different aspects of living well with dementia	Thank you for your response. We have now included this resource.
	AFr	Again some very practical tips information has always been well received	Thank you for your comment. No response required.
	KA	As above	Thank you for your comment. No response required.
	JE	Useful set of resources	Thank you for your comment. No response required.
	EH	Alzheimer Scotland Nationally Allied Health Professionals worked colloboratively and created a suite of evidence based information resources for people with dementia and those who support them. https://www.alzscot.org/ahpresources Alzheimer Scotland and Lab4Living an interactive website with 32 resources and activities that have been tried, tested and recommended by people with dementia. https://dementiatogether.online/ Alzheimer Scotland AHP Dementia weekly blog https://letstalkaboutdementia.wordpress.com/ Alzheimer Scotland AHP dementia daily tweets, offering practical hints and tips @AHPDementia	Thank you for your response. We have now included this resource. This has been included. This has been included.
	KP	VOCAL offers counselling and peer support opportunities for carers of people with dementia https://www..vocal.org.uk/news/vocal-launches-dementia-carers-counselling-service/ NHS Lothian Arts Therapies Service: Arts and Self Care Resources: https://weare.nhslothian.scot/artstherapies/arts-for-challenging-times/ Music in Hospitals & Care has community musicians who visit hospitals and care homes https://mihc.org.uk Tonic Arts https://ww.tonic-arts.co.uk/tonic-arts	Thank you. As this is a national guideline we have not included service information where it applies only to a locality. Thank you for your response. We have now included this resource. Included. Does not operate in Scotland.

		Scottish Chamber Orchestra musicians visit hospital and care home settings across Scotland https://www.sco.org.uk/about-us	Included (Reconnect).
9.4	AT	Under diagnosis bullet point 6 and also in post diagnosis section I think examples of living well would be worth adding eg stay socially active, attend to your physical and mental health I also think under after diagnosis The statement about Mental health Act not needed. Very few people will need MHA assessment .You may wish to consider mentioning mental capacity however If appropriate, inform the person with dementia and their carer(s) that as the condition progresses there could be times when the person with dementia may need to be sectioned under the Mental Health Act (1983).	This content was produced by, and reflects the contribution of a group of six people with dementia. We have added a line relating to the Scottish mental health legislation.
	JC	Summarises key messages	Thank you for your comment. No response required.
	PC	Given that this is a Scottish guideline, why is the Mental Health Act 1983 quoted? Surely this should be relevant Scottish legislation?	Thank you, this has been changed to the applicable Scottish legislation.
	MH	There is nothing in the at diagnosis section relating to young onset dementia, I'm thinking about advice about employment which might be an immediate thought at diagnosis. I think there is too much information at the diagnosis stage. The following sentence, which is in the after diagnosis section:'Carers from ethnic minority groups and those with additional support needs, such as the deaf community, have specific needs around language during discussions.' should also be in the diagnosis section. Is the 'after diagnosis' section meaning post diagnostic support? If so, the abundance of information isn't so bad as it can be delivered over a few visits. If it means at one follow up visit with the GP then there is too much information. I don't think the following point is appropriate at a point soon after diagnosis: ' If appropriate, inform the person with dementia and their carer(s) that as the condition progresses there could be times when the person with dementia may need to be sectioned under the Mental Health Act (1983).' Also, if this is a 2nd visit with the GP I don't think 'Inform the person with dementia and their carer(s) that there is no situation where	This content was produced by, and reflects the contribution of a group of six people with dementia. The group felt that this list of examples of information might be useful to people at these key stages.

		they should not be included in do-not-resuscitate conversations.' would go down very well at an early stage. Diagnosis 1. Ask them if they would like to be referred for post diagnostic support, if not give them a contact number for referral later. 2. Give them the leaflet about what to expect from post diagnostic support from Healthcare Improvement Scotland (https://www.alzscot.org/sites/default/files/2020-02/Making%20the%20most%20of%20your%20post%20diagnostic%20support.pdf) 3. 11th bullet change to 'Signpost the person with dementia, and their carer, to free education courses ...' After diagnosis 4. 6th bullet. I don't think it's appropriate to discuss living grief with the carer when the person with dementia is there, but if you do discuss living grief as it applies to the person with dementia and their carer.	
	AFr	This is vast - might be helpful to break it up more	This content was produced by, and reflects the contribution of a group of six people with dementia. The group felt that this list of examples of information might be useful to people at these key stages.
	EH	I am not sure why this is included this Guideline and if this should be included in a SIGN guideline. i think it is important but could be looked at in a different document and part of the implementation	This is a standard part of a SIGN Guideline Development process to gather patient and public feedback on what they feel is needed.
	GB	Good to provide checklists.	Thank you for your comment. No response required
	JE	Helpful checklist. Would it be helpful to add something about pre-assessment counselling?	This content was produced by, and reflects the contribution of a group of six people with dementia. The group felt that this list of examples of information might be useful to people at these key stages. We have a recommendation in 3.2.3 about counselling: *“Healthcare professionals should consider offering information or prediagnostic counselling (a session that takes place in advance of a meeting to inform a person of a dementia diagnosis) for people with dementia and their carers to:* • *discuss and address the beliefs, expectations and potential misconceptions of people with dementia and their carers*

			• *help them better absorb and understand the information provided to them."*
	JM	YES! I was hoping for a checklist. Could we look at an appendix for primary care doctors to be able to print or load in to patient notes as a literal checklist for each patient?	Thank you. We will explore ways to make this checklist accessible through our Right Decision Service.
	JH	Might be useful to move the comment "Information provided should be accessible and culturally appropriate to the person with dementia and their carer(s)." to the top of this section (Table articulating steps to take in providing a diagnosis, pages 77-78).	Thank you. Text moved as suggested.
	YM	Circulation to Public Dental Service clinicians likely to be involved with care of dementia patients. Also all General Dental Practitioners - with signposting to the Oral Health-specific additions that I have suggested(if adopted)	The final guideline will be made available from the SIGN website and distributed free of charge throughout Scotland. Dissemination of SIGN guidelines in NHSScotland is organised within each NHS board by local distribution co-ordinators, who are responsible for disseminating guidelines across their board.
	GH	Increase awareness in the first instance and provide easy to access and use resources. Target people who educate the workforce to faclitate dissemination, provide 'sound-bites' online. Make the website easier to navigate and user friendly including people with dementia and their carers so they know what they can expect.	The final guideline will be made available from the SIGN website and distributed free of charge throughout Scotland. Dissemination of SIGN guidelines in NHSScotland is organised within each NHS board by local distribution co-ordinators, who are responsible for disseminating guidelines across their board.
	AF	Greater buy in from care home providers and what is expected of them	Thank you for your comment. No response required.
	JB	Implementation and audit - how will this be achieved? Locally/nationally? How will data be made available - is it available? How will the disparate IT systems across health and care settings speak to each other? How will implementation be made transparent across Scotland and publically? Will it be annually?	Implementation of the guideline is the responsibility of the appropriate organisations, as is local audit. We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage).
	MP	I wonder if reference should be made to the context we are working in with regard to austerity for clients and recruitment difficulties	Thank you for your comment. No response required.
	MH	Suggestions for audit: Number of people receiving post diagnostic support. PWD and carer feedback on the quality of post diagnostic support. PWD and carer feedback on the quality of information provision at diagnosis. Number of carers of PWD experiencing complicated grief. Number of PWD having ACPs in place.	Thank you. We have included data recommendations from the national strategy where these overlap with the recommendations.

	AFr	This will need careful consideration on how this will be implemented. This will depend on the audience it is going to, their previous knowledge, understanding, role and awareness	Thank you for your comment. No response required.
	MR	This section should be nearer the front as the cost implications are discussed, most members of the public will not read this far.	Thank you for your comment. This follows our standard approach to presentation of a guideline.
	FM	This section is not at all helpful.	Thank you for your comment. No response required.
	JCa	The section on audit is very brief. Why not consider audit relating to current data collection eg delivery of PDS.	We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage). We have included data recommendations from the national strategy where these overlap with the recommendations.
	JE	I am not sure that the audit questions as they are formulated just now would be helpful as just knowing the number of people who have brief screens may not tell us much. I wonder if it would be useful to develop specific questions that assess against the specific recommendations that are made in the guideline? In relation to post-diagnostic support one might audit in relation to whether patients/carers receive the recommended support in relation to their areas of need, but also to identify what interventions are used to support people to maintain meaningful activity etc.	We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage). We have included data recommendations from the national strategy where these overlap with the recommendations
	JH	Clear, comprehensive and flows logically.	Thank you. No response required.
	YM	OK	Thank you for your comment. No response required.
	JB	Public Health Scotland dementia data needs to be included as a source of data - if not it's difficult to understand why not.	The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Information Scientist. This section provides a summary of the systematic review that underpins a guideline. It is not appropriate to signpost to service data.
	MP	It is very detailed, hope a draft version will be available	Thank you for your comment. No response required.
	Afr	This seems really comprehensive and aide range of research and data incorporated	Thank you for your comment. No response required.

	MR	Quantitative evidence can be incorrect; statistics can be “massaged”, i did this when a minor bureaucrat in the 1990’s; presumably still happens. These figures can slip through even cochrane standard papers. Some academic papers in journals can be actually harmful to patients; the mmr controversy is the most obvious but there must be other academic standard papers similar still out there. Qualitative evidence should be used to an equal extent, if not more, when discussing pds and time of diagnosis. with quotes from patients, see 11.2	Thank you for your comment. No qualitative evidence was found from patients.
	KA	There is reference to learning disabilities / Down's syndrome but not in greater detail as part of literature search. There are a number of studies available that could inform guidance. Aware of literature search undertaken recently by NES colleagues.	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	KP	See previous pages which include NICE guidelines and |Cochrane Review	Thank you for your comment. No response required.
	JCa	Why no reference to any AlzScot stuff eg 5 pillar/8 pillar model? Why no reference to any Scottish studies eg Kate Ann Levin, Stephen Lithgow, Martine Miller, Jill Carson, (2018) "Post-diagnostic support for dementia: What can be learned from service providers’ experiences, model variation and information recording?", Health Education, Vol. 118 Issue: 4, pp.320-338	Thank you, these have been included. The paper did not appear in our evidence searches at the time.
	DB	Not sure which section but is there narrative on the increased risk of people with Downs syndrome developing dementia	Thank you for your comment. We acknowledge that learning disabilities is a specialist area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	JH	Clear, comprehensive and flows logically.	Thank you. No response required.
11.1	JC	Database search didn't include JBI?	SIGN does not have access to JBI.
	AFr	Having a mixed methods model provides a more holistic approach to examining this vast and complex area	Thank you for your comment. No response required.
	Ka	As above	Thank you for your comment. No response required.
	RB	Why only a year? Especially given the pandemic was in full swing for a huge portion of that and research took a huge hit beforehand.	This has been an error in the consultation draft and should have read:

		It would be helpful to have the search strategies in the guidance to enable us to make a judgement on some of the claims and recommendations put forth above. Also, I'd like to know the credentials of those who undertake the SRs because there could easily be bias/COIs that we don't know about.	"The year range covered was 2000–2021." This is now updated in the final guideline and the search strategies will be published alongside the guideline. The register of interest is also published alongside the guideline.
11.1.1	JC	Provides clarity on scoring	Thank you for your comment. No response required
	AFr	Well pulled together	Thank you for your comment. No response required
	EH	Would be helpful to say why JBI was chosen ?	SIGN does not have its own qualitative critical appraisal tools. JBIs critical appraisal tools are suitable for a wide range of qualitative and mixed methods papers and are widely used, systematically developed and peer reviewed.
11.1.2	JC	Surprised there was no grey literature serach?	SIGN methodology is to use robust studies. See section 11.
	AFr	Well needed	Thank you for your comment. No response required
	MR	As already discussed not enough searching was done, i found three not used within five minutes amateur search. For whatever reason, there was no patient on the guidelines committee, and this is shown by the lack of patients' voices within the guidelines; see 11.2 as the way to rectify this. This lack of representative would not be usual with other conditions.	A thorough review of systematic reviews. We selected the most robust high quality studies in line with SIGN methodology. We sought to recruit people with dementia to the guideline group via third sector organisations and SIGN's PPI network. Two nominations were received, via Alzheimer's Scotland and Tide. Alzheimer's Scotland nominated a carer to participate in the guideline while Tide nominated a representative from the organisation who also had personal experience of caring for someone with dementia. We asked the Scottish Dementia Working Group if we could meet with some of their members with dementia to find out what matters most to them. SIGN staff met with members. We met with six people who had diagnoses of dementia to develop section 9, Provision of information.

	JE	It was a little unclear to me what, 'person-centred issues of relevance to the management of people with dementia' means in terms of what types of studies this would return. Was a more specific search conducted?	At the start of the GL process this is a general search for us to gain an overview of patient issues to inform the remit. Once specific key questions were agreed we used qualitative studies to tease out the patient issues where relevant.
11.1.3	AFr	This is problematic as it will determine what our understanding and value base is around cost-effectiveness - this is subjective	Looking at cost effectiveness helps to support the implementation of services
11.2	GH	There are definitely some gaps and more research is needing to be undertaken relating to non-pharmacological interventions such as person-centred activities and design. Also a lot of the research did not include social care staff or social workers who are involved a lot in dementia care and placing people into facilities or accessing community packages of care without necessarily understanding requirements or thinking outside the box to prevent admission to care - which would be better altogether socio-economically and for quality of life.	Much of the evidence related to ‘healthcare professionals’ due to the health (and social care) systems they drew upon. The evidence search draws on robust methodology to ensure that recommendations are evidence-based.
	AF	Are care homes supported enough to be equipped to manage patients with dementia? Consider what education do care home staff receive- predominantly untrained staff in care homes, what is there level of understanding of dementia. How to manage challenging behavior in people with dementia. Identifying a person centered approach to meet the needs of people with dementia Skill mix in care homes managing people with dementia. Environmental factors that may support people with dementia in care homes e.g Kings Fund dementia friendly environmental tool.	We hope that the guideline will support care home models and staff to support people with dementia. We have referenced the Promoting Excellence framework, which is for all health and social care staff.
	JC	Highlight key areas	Thank you for your comment. No response required.
	GMc	Improve the evidence base on the role of nutrition in dementia - from risk to interventions.	This falls outside of the scope of the guideline.
	MC	Additional research into diagnostic assessment and non-pharmacological interventions for people with learning disabilities.	Thank you for your comment. We acknowledge that learning disabilities is a specialist

			area and may benefit from a more targeted approach, beyond the scope of this guideline. A topic can be proposed at https://www.sign.ac.uk/get-involved/propose-a-topic/.
	PC	More research is needed on how to best integrate pharmacological and non-pharmacological interventions. Which therapies? Alone or in combination? For how long? In what order? To be fair this vexed the SIGN 86 group but it is a pity that the intervening 15 years haven't provided a workable solution. More research is required on how people would adapt to the assessment process if disease-modifying agents were to become available, esp for potentially asymptomatic people with positive biomarkers. Work on disclosure of ApoE status or amyloid positivity would suggest that these might not be major issues work has been done in selected research populations, not the general population.	The guideline and recommendations reflect the key questions. Pharmacological interventions were out of scope for the guideline so it was not possible to include a recommendation on whether further research was required.
	AFr	I agree with the recommendations. I also wonder about research into environments for people living with dementia as we know this can have major impacts on their behaviours and stress and distress	The guideline and recommendations reflect the key questions which did not include a review of literature about environment. As such we are unable to make a recommendation on research on this topic.
	MR	I strongly recommend that there is a pause whist a person with lived experience, such as myself (i would do it pro bono) and an academic researcher (in order to ensure rigour) trawl through papers so those with lived experience are given a voice on par with the carers. I found academic, published, papers within five minutes.	The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Information Scientist. Databases searched include Medline, Embase, PsycINFO and the Cochrane Library. The year range covered was 2000–2021. Internet searches were carried out on various websites for relevant guidelines. The main searches were supplemented by material identified by individual members of the development group. Each of the selected papers was evaluated by two Evidence and Information Scientists using standard SIGN methodological checklists before conclusions were considered as evidence by the guideline development group. We aimed to recruit people with dementia to the guideline group via third sector organisations and SIGN's PPI network. Two nominations were received, via

			Alzheimer’s Scotland and Tide. Alzheimer’s Scotland nominated a carer to participate in the guideline while Tide nominated a representative from the organisation who also had personal experience of caring for someone with dementia. We asked the Scottish Dementia Working Group if we could meet with some of their members with dementia to find out what matters most to them. SIGN staff met with members. We met with six people who had diagnoses of dementia to develop section 9, Provision of information.
	RK	The role of the MDT in diagnosis and in capacity decisions does need clarification.	This is included in 11.2.
	EH	It is unclear on how you decided on the recommendations for research ? there are gaps on the a number of developing self-management and rehabilitation interventions, staff attitudes to rehabilitation and dementia, but i may have missed this too ?	The guideline and recommendations reflect the key questions, in keeping with SIGN methodology. Where we found an evidence base lacking (including lacking in quality), the Guideline Development Group Members will make a recommendation for research.
	JE	Suggestions for additional areas: Assessment Effectiveness of cross-cultural assessment tools in the assessment of people from diverse cultural and language backgrounds. The added value of detailed neuropsychological assessment in supporting differential diagnosis of different forms of dementia. Post-diagnostic support Effectiveness of technology to support people with dementia in carrying out everyday activities independently. effectiveness of interventions to support new learning in people with dementia. What interventions improve the wellbeing of people with dementia.	This section is derived from the key questions and resulting process. As these points did not feature in the literature search we are unable to comment on whether evidence is lacking, or lacking in quality.

	YM	Oral health in dementia patients does not appear to have been given specific mention. However, it is now well-established that good oral health contributes significantly to Quality of Life , at all stages of life. Patients with dementia (and their carers) present challenges to good care management, which most dental teams are now well aware of. It can be as simple/challenging as pointing out that someone needs to check that the patient has not forgotten to brush their teeth!!!	We have now included signposting to dental guidance in section 9.3.1.
	JC	Wide representation	Thank you for your comment. No response required
	AFr	Appears to have a comprehensive and broad range of people in the development	Thank you for your comment. No response required
	MR	Again, halt development until further research into academic papers with patients voices actually used, academic to oversee, person with lived experience, such as myself to assist.	The evidence base for this guideline was synthesised in accordance with SIGN methodology. A systematic review of the literature was carried out using an explicit search strategy devised by a SIGN Information Scientist. Databases searched include Medline, Embase, PsycINFO and the Cochrane Library. The year range covered was 2000–2021. Internet searches were carried out on various websites for relevant guidelines. The main searches were supplemented by material identified by individual members of the development group. Each of the selected papers was evaluated by two Evidence and Information Scientists using standard SIGN methodological checklists before conclusions were considered as evidence by the guideline development group. We aimed to recruit people with dementia to the guideline group via third sector organisations and SIGN's PPI network. Two nominations were received, via Alzheimer's Scotland and Tide. Alzheimer's Scotland nominated a carer to participate in the guideline while Tide nominated a representative from the organisation who also had personal experience of caring for someone with dementia. We asked the Scottish Dementia Working Group if we could meet with some of their members with dementia to find out what matters most to them. SIGN staff met with

			members. We met with six people who *had diagnoses of dementia to develop section 9, Provision of information.*
	JCa	The guideline should be firmly set in a Scottish context. If it's necessary to have a Scottish guideline ie the NICE one won't do, then it should ensure reference to the current state in Scotland. Equally if it is to be the 'go to' place then it's not sufficient to decide that something is already covered in NICE and does not need repeating.	The SIGN Guideline Development Group felt that NICE recommendations were applicable in Scotland. It was not seen as a good use of resource to duplicate this work.
	DC	More involvement from the services involved in delivering diagnostic procedures such as PET may have been beneficial in the development stage	We have now had input and ensure we had radiologists in the peer review.
	JH	On p.86, can we change Mr Julian Heng Health Improvement Lead, NHS Greater Glasgow and Clyde, Equalities and Human Rights team, Glasgow, Scotland to Mr Julian Heng Planning and Development Manager, NHS Greater Glasgow and Clyde, Equalities and Human Rights Team, Glasgow, Scotland	Amended.
	YM	I make no excuse for promoting the weblink already mentioned again - https://cgdent.uk/standards-guidance/ It is hosted on my organisation's website (College of General Dentistry), so of course I am interested to promote it from a self-interested perspective. However, it does represent a first in Dentistry (in the UK, can't speak for elsewhere) and has been extremely well received everywhere.	We have now included signposting to dental guidance in section 9.3.1.
	AT	I personally don't like them as it is not consistent and I don't think add value As we all know everyone with dementia and their carers are unique. What are the quotes meant to be adding ? to a relatively technical review of the evidence. Perhaps it might be better to have the quotes at the beginning of the document rather than suddenly popping up.	Thank you for your comment. No response required

	AF	Yes	Thank you for your comment. No response required
	JB	Yes - these quotes are powerful addition to Guidelines that otherwise would feel too academic/professionally focussed.	Thank you for your comment. No response required
	JC	These add considerable value	Thank you for your comment. No response required
	GMc	It is important that these are included as it adds weight to what is being said. It is also important that these quotes come from a range of people living with dementia and not only those who are active in groups as this could provide an inaccurate or skewed account of experiences.	Thank you for your comment. No response required
	RH	I think these add value and context to the guideline.	Thank you for your comment. No response required
	PC	Yes they are useful, more so for some readers than others. However, I think they could be balanced by some quotes from professionals given that most professionals carry quite a burden in dealing with people with dementia. Quotes might reduce the “them and us” rhetoric which comes from some of the PLWD groups	Thank you for your comment. No response required
	MP	Very helpful I think the client perspective is correctly at the heart of the document	Thank you for your comment. No response required
	MH	I think the quotes are helpful to bring the reader back to the point that interaction with the person with dementia and their carers should be person centred.	Thank you for your comment. No response required
	AFr	They absolutely add value - these are important to add a more personal perspective to this very complex and vats area	Thank you for your comment. No response required
	MR	Too many, have given academic papers to be looked at. Prepared to do this if given a bloc of time and an academic researcher to oversee. no further action should be taken until this is done	Thank you for your comment. No response required
	KA	Yes - they include a person centred inclusive approach	Thank you for your comment. No response required
	RK	I'm fully in favour. They back up the recommendations with lived experience.	Thank you for your comment. No response required
	EH	I strongly recommend quotes are NOT added - they add a prejudice to what quote you used and take away from the guidance and do not add to the content.	Thank you for your comment. No response required
	GB	Quotes are helpful and brings the doc alive more	Thank you for your comment. No response required
	JE	Yes, good to have quotes to illustrate points being made. I liked them!	Thank you for your comment. No response required

	JS	I would agree that these add value and enhance the sections in which they are added. I wonder if the addition of a brief case study might also be useful especially in the ACP section to bring it to life.	Thank you for your comment. No response required
	JM	I think these add a lot of value. They absolutely stand out in a national guideline and really bring home the patient's perspective. I think using more of them would add further value, especially such as in anticipatory care planning where examples differing opinions are used. This makes it especially clear SIGN is not advocating the given perspective as policy. I would like to see quotes from reviewers and guideline development group themselves - especially when it comes to any decisions you regard as difficult. Justify them. This allows people to disagree.	Thank you. No response required.
	JH	The addition of quotes adds great value to the Guideline and provides an insight into the lived experience in a meaningful way.	Thank you. No response required.
	YM	The mixed methods probably makes the whole document longer - but the individual sections, in my view, benefit from the mixed methods approach. Yes we could ask for more graphical illustraion, but I am not convinced that that would enhance the document- most readers will go to the section(s) that most concern them for what they need and might then return for a more comprehensive look, depending upon what they need from it.	Thank you for your comment. No response required
	AT	I think on the whole it is helpful although there is some repetition	Thank you for your comment. No response required
	JC	Mixed methods are increasingly important and provide a wider perspective	Thank you for your comment. No response required
	GMc	It is important to have a mix of methods included.	Thank you for your comment. No response required.
	RH	I think the mixed methods approach incorporating qualitative as well as quantitative research is very important to this topic.	Thank you for your comment. No response required.
	MP	I think it gives a comprehensive picture	Thank you for your comment. No response required.
	MH	In a guideline like this the mixed method approach is a necessity. The level of evidence is clear.	Thank you for your comment. No response required.
	JE	Good to see consideration of both qualitative methodology.	Thank you for your comment. No response required.
	AFr	I agree with the mixed methods approach to try and gather a variety of information and data from different methods to gain a more holistic overview of the complexities and needs of people living with dementia and their carers	Thank you for your comment. No response required.

	MR	Yes, but as above, no voices from actual patients; must be rectified.	Thank you for your comment. As noted, steps were undertaken to secure patient involvement.
	KA	Provides an overview of available research	Thank you for your comment. No response required
	RK	I welcome the increased value placed on qualitative evidence. I think readers are able to judge the level and type of evidence. There are so many aspects of life that are hard to measure and test numerically. Although the qualitative measures and accounts are less objective, we would miss opportunities to improve if we ignored them.	Thank you for your comment. No response required
	EH	I thought the mixed method was helpful	Thank you for your comment. No response required
	GB	Would like to see more non pharmacological approaches highlighted even when evidence base is still developing. To give equal value to qualitative research as well as quantitative	Thank you for your comment. No response required
	JM	See below - I think it is used appropriately but specificity of recommendations suffers. This has an impact on meaning. I think this is most apparent in section 6, where all recommendations contain the word 'may' and reference no specific training or education. I think there are advantages to this though - in the case of a patient unhappy with the care of their loved one, this is suitably vague that they would not be able to use this SIGN guideline for litigation purposes. In sections 7 and 8, you have used a mixed method approach masterfully and I think it is really sensitively done.	Thank you. This relates to the strength or lack of evidence.
	JH	Methodology and presentation are clear. Will need to be distilled/summarised for any version provided to people with lived experience.	Thank you. A public version is planned in plain English.
	AT	I think asking if non pharmacological interventions have been tried before giving antipsychotic would be better when a person with dementia has behaviours indicating stress or distress To ensure access number of people less than 65 seen along with a break down of the ethnicity of all of those seen compared with local demographic's would give you a good idea of accessibility Also number of Anticipatory discussions had	We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage). We have included data recommendations from the national strategy where these overlap with the recommendations (this includes data on those under 65 and protected characteristics).

	JB	See previous comments.	Thank you for your comment. No response required
	JC	Consider all potential outlets including local and national charities and groups	The final guideline will be made available from the SIGN website and distributed free of charge throughout Scotland. Dissemination of SIGN guidelines in NHSScotland is organised within each NHS board by local distribution co-ordinators, who are responsible for disseminating guidelines across their board.
	AFr	Education is key - to those with dementia, to unpaid carers, front line care staff, professionals and the general public. An increased commitment to raise awareness and understanding so we all modify our language and behavior to understand and respond to people with dementia better	The final guideline will be made available from the SIGN website and distributed free of charge throughout Scotland. Dissemination of SIGN guidelines in NHSScotland is organised within each NHS board by local distribution co-ordinators, who are responsible for disseminating guidelines across their board.
	MR	As above prepared to do literature search. Patient rep should be put on guidelines board now, to make up for lack to present. again, willing to attend as member of sign	The final guideline will be made available from the SIGN website and distributed free of charge throughout Scotland. Dissemination of SIGN guidelines in NHSScotland is organised within each NHS board by local distribution co-ordinators, who are responsible for disseminating guidelines across their board.
	RK	Having an evidence based resource such as this is a very powerful tool to inform strategy, quality improvement work and service developments. I think a big flaw in taking projects forward is short term funding that stops once improvements have been shown in the demonstrator units. Spread and sustainability needs long term effort and support. It will also be more effective if there is consistency in structures and services between areas.	We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage). We have included data recommendations from the national strategy where these overlap with the recommendations (this includes data on those under 65 and protected characteristics).
	GB	To address lack of evidence base of non-pharmacological approaches by stake holding events with key clinicians e.g. Heads of Older Adult Psychology Services (HOOPS) To include more field observation from staff at front line who are aware of needs and gaps in services, what works, what doesn't as well as the	We have proposed application of quality improvement methodology (which includes aspects of audit in the preliminary stage). We have included data recommendations from the national strategy where these overlap with the

		literature and evidence base	recommendations (this includes data on those under 65 and protected characteristics).
	JM	From my point of view, when it comes to implementing in General Practice, what we need are specific goals and targets. We want to know what to do prior to referring a patient for assessment, how much of the assessment we can do ourselves and what the patient and carers should expect from secondary care. We want justifications for our decisions. Many recommendations are quite vague and that has a role in supporting us in what we already do. But in terms of adapting to best-practice, tweaking certain statements to be more specific can be helpful.	Thank you. This relates to the strength or lack of evidence.
	JH	Utilisation of PANEL Principles, as referenced earlier.	The SIGN guidance development process follows a structured framework and efforts are made to consult widely and engage with a broad range of expertise and experience. However, we recognise there may be limitations to our strategy and take on board useful suggestions to improve this in the future. Not possible for this guideline but feedback noted by SIGN for consideration in future guidelines.