

Guideline scope form

This guideline scope form serves to clearly define the boundaries and objectives of a guideline. It outlines key elements such as the target audience, practice areas to be covered, and intended outcomes, ensuring all Guideline Development Group members and stakeholders have a shared understanding of the guideline's purpose and remit.

1. Provisional guideline title:

'Maintaining meaningful occupations and maximising independence while living with dementia'

2. Why a guideline is needed in this topic area and how it will support occupation-focused practice:

In the Royal College of Occupational Therapists' (RCOT) new programme for guideline development, topics must support an occupation-focused approach to practice, education and related research. Topics for guideline development follow a clear process of selection, driven equally by RCOT priorities, national policy priorities, occupational therapy expertise and impact on the occupational therapy profession, and ensuring a sufficient systematic review evidence base to enable recommendations.

After considering RCOT and national policy priorities, we short-listed potential guideline topics. The RCOT Digital Library then carried out scoping searches of published systematic review evidence to determine which of these topics a) have a sufficient quality and quantity of research to base the development of a robust guideline on and b) would also have a significant impact on the profession. After screening the results of these searches, we determined 'maintaining meaningful occupations and maximising independence while living with dementia' to be a feasible topic for guideline development.

Currently there is no profession-specific, evidence-based guidance for occupational therapists working with people living with dementia in the UK. This is a priority area based on the growing prevalence of dementia in the population, its impact on the person's ability to do the things they want and need to do and the impact on their supporters, the emerging evidence to support brain health across the lifespan, and our commitment to public health. In addition, occupational therapists across different practice settings are likely to encounter people living with dementia and need to be confident that they are following evidence-based practice recommendations. Because of this, we considered 'maintaining meaningful occupations and maximising independence while living with dementia' as a potential guideline topic.

To confirm that the topic would be of relevance and interest to members, we consulted with occupational therapist experts in the field via informal discussions on MS Teams. Following their confirmation, we agreed to proceed with the development of the guideline.

Our guidelines follow an occupation-focused rather than a condition-focused approach and we want to ensure this is reflected in the guideline title. We will review evidence and make recommendations that help occupational therapists to support the promotion of a healthy lifestyle and to enable people who are living with dementia carry out the occupations they

need, want and have a right to do and to assist them to retain optimum health.

In this scope when we refer to 'people living with dementia', we are including people diagnosed with dementia and their supporters (such as family members and informal carers).

3. Practice question:

What is best practice for occupational therapists in:

- a. enabling those living with dementia from early diagnosis to end of life to maintain meaningful occupations and maximise independence, and
- b. reducing the risk of people developing dementia through occupation-based health promotion?

4. The objectives of all our guidelines are to:

- **Improve outcomes for people who access services:** Support the delivery of evidence-based occupational therapy interventions that are designed to increase participation in both necessary and meaningful occupations, contributing to improvements in wellbeing, quality of life and independence.
- **Promote best practice:** Ensure that occupational therapists have access to the most current, evidence-based recommendations to support clinical decision-making and enhance the quality of care.
- **Standardise care:** Provide a consistent framework to support the occupational therapy process of assessment, person-centred goal setting and individualised interventions, rehabilitation and review, which reduces variability in practice and improves outcomes.
- **Enhance professional competence:** Foster the professional development of occupational therapists by enhancing their understanding of evidence-based practice and empowering them to deliver more informed and effective interventions, thereby promoting occupational therapy leadership in this area of practice.
- **Facilitate collaborative care:** Promote interdisciplinary collaboration by providing clear recommendations that align occupational therapy interventions and recommendations with broader health and social care objectives and the contributions made by other health and social care professionals.
- **Promote ethical and person-centred practice:** Ensure that occupational therapy interventions adhere to ethical, co-produced standards, respect the person's rights, and are tailored to the person's needs, preferences, and values.
- **Positively contribute towards the effectiveness of health and social care delivery:** Contribute towards the streamlining and optimisation of service delivery, ensuring that resources are allocated and utilised effectively.
- **Identify need for further research:** Highlight gaps in the evidence where further research is needed.

5. The intended outcomes from the guideline are:

People diagnosed with dementia, regardless of age:

- Interventions, strategies and support to enable people diagnosed with dementia to engage in both necessary tasks as well as the things of importance to them.
- Interventions to promote self-management for as long as possible.
- Increased awareness of how occupational therapists can support people who are concerned about their memory, cognition or are diagnosed with dementia, and how they can access occupational therapy.
- Information and resources in a range of accessible formats on the following:
 - Supporting healthy lifestyles to support good brain health and prevention of dementia
 - Continuing to undertake both necessary and valued activities
 - Maximising independence and self-management
 - Encouraging and facilitating conversations about life decisions, including end-of-life preferences.

People supporting a person diagnosed with dementia:

- Increased knowledge and ability to maintain their own health and wellbeing.
- Increased awareness of how occupational therapists can assist those supporting a person diagnosed with dementia to continue in this role for as long as they want and are able to.
- Education, strategies and support to those in a supporting role, including how to maximise independence and self-management of the person diagnosed with dementia.

Occupational therapists:

- Enhanced professional skills, knowledge and confidence for promoting independence and quality of life, including optimising the environment and the effective use of technologies.
- Improved collaborative care with a range of disciplines to deliver tailored, person-centred interventions and rehabilitation at all stages of the dementia trajectory.
- Increased consistency of use and selection of occupation-focused assessment and intervention to empower the person diagnosed with dementia and their supporters.
- Increased engagement in research as consumers, collaborators and leaders and encouraging people living with dementia to consider participating in research.
- Maintaining the person diagnosed with dementia and their supporters at the centre of occupational therapy practice, positioning the people living with dementia as the experts by experience by maintaining a person-centred perspective during assessment, interventions and review.
- Acting as ambassadors for promotion of a healthy lifestyle which supports brain health and prevention of dementia.

6. Intended impact of the guideline and how it might be measured:

We recognise that the evaluation of outcomes is complex and will be influenced by a variety of factors. The ability to quantify the achieved outcomes will depend on the personalised goals set with each individual person and their supporter(s). The person diagnosed with dementia and their supporters should be encouraged to provide ongoing feedback on their experiences of occupational therapy.

The intended impact of the guideline is the achievement of its objectives and intended outcomes and ensuring its usefulness to its target audience. By 'useful' we mean the guideline:

- Embeds evidence in practice
- Evidences the value of occupational therapy to inform workforce and service planning
- Opens occupational therapy to new areas of practice
- Is viewed as a valuable resource by occupational therapists.

These can be measured through the following methods:

- Evaluating whether guideline recommendations have been implemented, for example through audits, surveys and intelligence gathering
- Counting the number of occupational therapists using the guideline through download figures and member surveys
- Collating the number of guideline citations
- Recording guideline usage among occupational therapy education programmes
- Understanding satisfaction or dissatisfaction with the guideline through member surveys, feedback forms and by speaking with members
- Case studies.

7. Target population:

The guideline's target population is people who are concerned about their memory, cognition or have been diagnosed with dementia and their supporters.

8. Are there any under-represented groups that should be considered or included in the target population?

The following groups will be considered when developing the guideline:

- Historically excluded communities, those who are marginalised in society, or people who struggle to access services, such as those who are homeless or in prison, people with learning difficulties, and people who identify as being part of the LGBTQIA+ community.
- Communities where a dementia diagnosis is stigmatising
- People diagnosed with young onset dementia and their supporters, and those with complex needs and/or multiple long-term conditions.

9. How we will ensure under-represented groups have the opportunity to be involved in the development of the guideline:

We are committed to valuing diversity and multiculturalism within the occupational therapy profession, our membership, those who access occupational therapy services and the wider working environment. We understand that each person is unique and should be treated with fairness, consistency and transparency, and without discrimination.

The above statement will be a defining principle guiding the development of this guideline. From reaching out to a range of voices in the consultations, to assessing a range of evidence

sources with diverse perspectives, the Guideline Development Group will work to optimise the range of voices contributing to the development of this guideline.

We will seek the expertise of outside organisations in reaching under-represented groups, as well as reviewing existing literature on the views of marginalised or minoritised groups with respect to dementia. We have asked for the involvement of four Expert Advisory Groups, made up of RCOT members: BAME OTUK, Carers OT, Able OT and LGBTQIA+.

We will also ensure sufficient time is given to people living with dementia to meaningfully engage in our consultations and provide a range of ways for them to comment.

10. How health inequalities and social determinants of health will be considered within the guideline:

By social determinants of health we mean factors, aside from medical ones, that affect health. For instance, this could be where a person is born, how much money they have, what support from friends and family members they have, the quality of their home and access to green spaces.

Health inequalities and social determinants of health will be considered in the following ways:

- Incorporate a person-centred approach, which ensures interventions are tailored to the person's unique background and preferences and takes disparities into account.
- Consider barriers to accessing services, recognising that particular groups may face greater barriers to accessing occupational therapy dementia services, such as lack of social support, financial constraints, limited transportation or geographic isolation.
- Acknowledge cultural and ethnic diversity, where cultural beliefs and practices concerning dementia and caregiving can vary widely and may impact how people seek and engage with occupational therapy.
- Consider economic and social resources, such as income, housing stability, social support networks, and how these shape health and psychosocial outcomes.
- Consider people with all forms of dementia and of all ages.
- Encourage occupational therapists to advocate for policy changes that address the broader social determinants of health affecting people living with dementia, such as historically excluded communities and those who are marginalised in society, such as people with learning difficulties, who are homeless and/or with multiple complex needs.

11. Inclusion and exclusion criteria for determining relevant research:

While we will use systematic reviews as the basis for recommendation evidence, different types and sources of evidence are needed to contextualise the recommendations.

By systematic review, we mean the following: 'A review that summarises the evidence on a clearly formulated review question according to a predefined protocol, using systematic and explicit methods to identify, select and appraise relevant studies, and to extract, analyse, collate and report their findings. It may or may not use statistical techniques, such as meta-analysis.' (National Institute for Health and Care Excellence Glossary <https://www.nice.org.uk/Glossary?letter=S>)

The inclusion and exclusion criteria for recommendation evidence are the following:

Inclusion criteria:

- Research on assessments, interventions and outcomes involving and concerning people diagnosed with all forms and stages of dementia
- Research involving and concerning supporters of people diagnosed with dementia
- Research involving and concerning strategies to maintain brain health or reduce the risk factors for dementia
- Research must be relevant to occupational therapy
- Research published from 2016 onwards (to manage the volume of research)
- Research utilising a systematic review methodology, as defined above
- Peer-reviewed literature

Exclusion criteria:

- Research not involving or concerning dementia, brain health or dementia prevention
- Research on assessments, interventions and outcomes not relevant to occupational therapy
- Research not published in English
- Research published before 2016
- Research methodologies that are not systematic reviews, as defined above
- Grey literature

12. Draft literature search strategy:

Draft literature search strategy for the guideline:

#	Query	Limiters/Expanders
S1	TI dement* OR AB dement* OR SU dement*	Search modes - Boolean/Phrase
S2	TI alzheimer* OR AB alzheimer* OR SU alzheimer*	Search modes - Boolean/Phrase
S3	TI lewy bod* OR AB lewy bod* OR SU lewy bod*	Search modes - Boolean/Phrase
S4	TI brain health OR AB brain health OR SU brain health OR TI dementia prevent* OR AB dementia prevent* OR SU dementia prevent*	
S5	S1 OR S2 OR S3 OR S4	Search modes - Boolean/Phrase
S6	TI occupational therap* OR AB occupational therap* OR SU occupational therap*	Search modes - Boolean/Phrase

S7	TI (occupation or occupations or occupation-) OR AB (occupation or occupations or occupation-) OR SU (occupation or occupations or occupation-)	Search modes - Boolean/Phrase
S8	S6 or S7	Search modes - Boolean/Phrase
S9	TI (systematic* N3 (overview* or review*)) OR AB (systematic* N3 (overview* or review*)) OR SU (systematic* N3 (overview* or review*))	Search modes - Boolean/Phrase
S10	S5 AND S8 AND S9	Search modes - Boolean/Phrase
S12	S5 AND S8 AND S9	Narrow by Language: - english Search modes - Boolean/Phrase
S13	S5 AND S8 AND S9	Limiters - Publication Date: 20160101- Date of search Narrow by Language: - english Search modes - Boolean/Phrase

13. National documents, strategies, policies or care pathways that link to the guideline:

The following are important to consider when developing the guideline:

- [Allied Health Professionals dementia framework for Wales](#) (Welsh government and NHS Wales, published 2022)
- [Assessment, diagnosis, care and support for people with dementia and their carers: a national clinical guideline](#) (SIGN guideline, published 2023)
- [Connecting people, connecting support: looking back, looking forward](#) (Alzheimer Scotland, Scottish Government, published 2024)
- [Dementia](#) (NICE quality standard, published 2019)
- [Dementia action plan for Wales](#) (Welsh Government, published 2018)
- [Dementia: applying All Our Health](#) (UK Government, updated 2022)
- [Dementia: assessment, management and support for people living with dementia and their carers](#) (NICE guidance, reviewed 2023)
- [Dementia, disability and frailty in later life: mid-life approaches to delay or prevent on-set](#) (NICE guidance, published 2015)
- [Dementia in Scotland: everyone's story](#) (Scottish Government, published 2023)
- [Dementia programmes](#) (Health Improvement Scotland, updated regularly)
- Livingston, Gill et al. (2024) Dementia prevention, intervention, and care: 2024 report of the Lancet Standing Commission. *The Lancet*, 404 (10452), 572 - 628
- [Package of interventions for rehabilitation: Module 3 neurological conditions](#) (World Health Organisation published 2023)
- [Prime Minister's challenge on dementia](#) (Department of Health 2015)

- Shearsmith-Farthing, K (2024) *Occupational therapy dementia standards*
- [The role of integrated care systems in improving dementia diagnosis](#). (The King's Fund, published 2024)
- Anticipated publication from Alzheimer's Disease International focusing on rehabilitation. Expected September 2025.

14. Intended audience:

The main, intended audience is **all** occupational therapists, irrespective of their area of clinical practice, including occupational therapy educators developing curriculum content and occupational therapy learners. However, there are other audiences we want to reach:

- People living with dementia, through content developed for them from the guideline, as we acknowledge the guideline is written for healthcare professionals
- Other healthcare professionals who work with people living with dementia, including but not limited to:
 - Allied health professionals, including art therapists, dietitians, drama therapists, music therapists, orthoptists, orthotists, osteopaths, paramedics, physiotherapists, podiatrists, prosthetists, radiographers, speech and language therapists
 - GPs, geriatricians, nurses, psychiatrists and psychologists
 - Social workers and paid, employed carers
 - Case managers or care coordinators
 - Care home managers
- Healthcare administrators, commissioners and policy makers who shape healthcare delivery
- Advocacy organisations and non-profit groups.

15. Identified stakeholders:

- Occupational therapists
- People diagnosed with dementia
- Supporters of people diagnosed with dementia
- Alzheimer's Society
- Age Scotland
- Age UK
- Allied Health Professional Consultant Wales
- Alzheimer's Disease International
- Alzheimer Europe
- Alzheimer Scotland
- Alzheimer's Research UK
- Association of Clinical Psychologists UK
- British Association of Social Workers
- British Dietetic Association
- British Geriatrics Society
- British Heart Foundation
- British Psychological Society
- Carers Northern Ireland

- Carers UK
- Chartered Society of Physiotherapists
- Chief Allied Health Professions Officer for each nation
- Commissioner for Older People (Northern Ireland)
- Community Rehab Alliance (England)
- Dementia UK
- Homecare Association
- Lleisiau Dementia
- Macmillan
- Marie Curie
- Marie Curie Scotland
- Meeting Centres (healthcare policy)
- National Care Association
- Neurological Alliance
- Northern Ireland Dementia Regional Group
- NI Assembly All Party Group on Dementia
- Older Persons Commissioner (Wales)
- Parkinson's UK
- Rare Dementia Support
- Right to Rehab (Scotland)
- Right to Rehab (Wales)
- Right to Rehabilitation Coalition
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Paramedics
- Royal College of Podiatry
- Royal College of Psychiatry
- Royal College of Radiologists
- Royal College of Speech and Language Therapists
- Royal Pharmaceutical Society
- Scottish Government Dementia Policy team
- Society and College of Radiographers
- The Alliance Scotland
- The Carers Trust
- The Lewy Body Society
- UK Dementia Research Institute
- Young Dementia Network

16. Identified conflicts of interest for each guideline development group member:

Occupational therapist guideline development group members are members of RCOT, and some are members of other professional bodies (such as the Higher Education Dementia Network, or the Association of Occupational Therapists of Ireland). One person with lived experience is part of the Alzheimer's Society Research Network Volunteers and a joint

research project between Marie Curie and Alzheimer's Society.

The following members have published research papers, contributed to research or other guides for occupational therapy practice (such as competencies or standards): Dr Pat Chung, Professor Claire Craig, Suzannah Evans, Dr Aisling Flynn, Dr Emma Hooper, Professor Elaine Hunter, Mary McGrath, Jessica Moss, Professor Gail Mountain, Karen Shearsmith-Farthing, Zoe Williams Dr Sandie Woods.

17. Funding sources:

There has been no funding or support sought from potential collaborators. All funding sources must be acknowledged and declared in the final guideline to ensure transparency.

The guideline will be developed as described in our Evidence-based guideline development manual.

Scope form prepared and submitted by:

Name Date
Guideline Development Group Lead

Scope approved by:

Name Date
Chair RCOT Guidelines Governance Group

Name Date
RCOT Research and Development Manager

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RCOT Head of Research and Innovation