



A summary of prescribing recommendations from NICE guidance

Dementia

Assessment, management and support for people living with dementia and their carers

NICE NG97; 2018

This guideline covers the diagnosis and management of dementia including Alzheimer's disease.

	Definition of terms
AChE	acetylcholinesterase inhibitor
ACB	anticholinergic burden
NMDA	N-methyl-D-aspartate
CI	contraindicated

Diagnosis

Initial assessment in non-specialist settings

- ◆ At the initial assessment take a history (including cognitive, behavioural and psychological symptoms, and the impact symptoms have on daily life): from the person with suspected dementia, and if possible, from someone who knows the person well (such as a family member).
- ◆ If dementia is still suspected after initial assessment:
 - conduct a physical examination, **AND**
 - undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline and use cognitive testing.
- ◆ When using cognitive testing, use a validated brief structured cognitive instrument such as the:
 - 10-point cognitive screener (10-CS),
 - 6-item cognitive impairment test (6CIT),
 - 6-item screener,
 - Memory Impairment Screen (MIS),
 - Mini-Cog,
 - Test Your Memory (TYM).
- ◆ **Do NOT** rule out dementia solely because the person has a normal score on a cognitive instrument.
- ◆ When taking a history from someone who knows the person with suspected dementia, consider supplementing this with a structured instrument such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) or the Functional Activities Questionnaire (FAQ).
- ◆ Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:
 - reversible causes of cognitive decline (including delirium, depression, sensory impairment such as sight or hearing loss, or cognitive impairment from medicines associated with increased ACB) have been investigated, **AND**
 - dementia is still suspected.
- ◆ If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt-Jakob disease and similar conditions.

Diagnosis in specialist dementia diagnostic services – see [NICE Pathway](#)

Further tests for Alzheimer's disease, dementia with Lewy bodies, frontotemporal dementia, vascular dementia – see [NICE Pathway](#)

Telling the difference between delirium and dementia in people without a diagnosis of either

- ◆ For people who are in hospital and have cognitive impairment with an unknown cause, consider using one of the following to find out whether they have delirium or delirium superimposed on dementia, compared with dementia alone:
 - the long confusion assessment method (CAM),
 - the Observational Scale of Level of Arousal (OSLA).
- ◆ **Do NOT** use standardised instruments (including cognitive instruments) alone to distinguish delirium from delirium superimposed on dementia.
- ◆ If it is not possible to tell whether a person has delirium, dementia, or delirium superimposed on dementia, treat for delirium first. See [NICE Pathway: Delirium](#).

Review after diagnosis

- ◆ After a person is diagnosed with dementia, ensure they and their family members/carers (as appropriate) have access to a memory service or equivalent hospital or primary care based multidisciplinary dementia service who should offer a choice of flexible access or prescheduled monitoring appointments.
- ◆ When people living with dementia or their carers have a primary care appointment, assess for any emerging dementia related needs and ask them if they need any more support.

Transferring information between services and care settings – see [NICE Pathway](#)

Making services accessible – see [NICE Pathway](#)

Involving people in decision-making

- ◆ Encourage and enable people living with dementia to give their own views and opinions about their care.
- ◆ If needed, use additional or modified ways of communicating (e.g. visual aids or simplified text).
- ◆ Consider using a structured tool to assess the likes and dislikes, routines and personal history of a person living with dementia.

Providing information

- ◆ Provide people living with dementia and their family members /carers (as appropriate) with information that is relevant to their circumstances and the stage of their condition.
- ◆ Be aware of the obligation to provide accessible information as detailed in the [NHS Accessible Information Standard](#). See [NICE Pathway: Patient experience in adult NHS services and People's experience in adult social care services](#).
- ◆ At diagnosis, offer the person and their family members/carers (as appropriate) oral and written information that explains:
 - what their dementia subtype is and the changes to expect as the condition progresses,
 - which healthcare professionals and social care teams will be involved in their care and how to contact them,

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- if appropriate, how dementia affects driving, and that they need to tell the DVLA and their car insurer about their dementia diagnosis,
- their legal rights and responsibilities,
- their right to reasonable adjustments (in line with the Equality Act 2010) if they are working or looking for work,
- how the following groups can help and how to contact them:
 - ❖ local support groups, online forums and national charities,
 - ❖ financial and legal advice services,
 - ❖ advocacy services.
- ◆ After diagnosis, direct people and their family members/carers (as appropriate) to relevant services for information and support.
- ◆ For people who do not want follow-up appointments and who are not using other services, ask if they would like to be contacted again at a specified future date.
- ◆ Ensure that people living with dementia and their carers know how to get more information and who from, if their needs change.
- ◆ Tell people living with dementia (at all stages of the condition) about research studies they could participate in.

Interventions to promote cognition, independence and wellbeing

- ◆ Offer a range of activities to promote wellbeing that are tailored to the person's preferences.
- ◆ Offer group cognitive stimulation therapy to people living with mild to moderate dementia.
- ◆ Consider group reminiscence therapy for people living with mild to moderate dementia.
- ◆ Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.

Pharmacological treatment

Alzheimer's disease

See [NICE TA217](#)

- ◆ The AChE inhibitors donepezil, galantamine and rivastigmine as monotherapies are recommended as options for managing mild to moderate Alzheimer's disease.
- ◆ The NMDA receptor antagonist memantine as monotherapy is recommended as an option for managing Alzheimer's disease for people with:
 - moderate Alzheimer's disease who are intolerant of or have a CI to AChE inhibitors, **OR**
 - severe Alzheimer's disease.
- ◆ Prescribers should only start treatment with an AChE inhibitor or memantine on the advice of a clinician with the necessary knowledge and skills. This could include:
 - secondary care medical specialists such as psychiatrists, geriatricians and neurologists,
 - other healthcare professionals (such as GPs, nurse consultants and advanced nurse practitioners), if they have specialist expertise in diagnosing and treating Alzheimer's disease.
- ◆ Once a decision has been made to start an AChE inhibitor or memantine, the first prescription may be made in primary care.
- ◆ For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor:
 - consider memantine in addition to an AChE inhibitor if they have moderate disease,
 - offer memantine in addition to an AChE inhibitor if they have severe disease,

- primary care prescribers may start treatment with memantine without taking advice from a specialist clinician.
- ◆ **Do NOT** stop AChE inhibitors in people with Alzheimer's disease because of disease severity alone; discontinuation of AChE inhibitors can cause a substantial worsening in cognitive function.
- ◆ If prescribing an AChE inhibitor (donepezil, galantamine or rivastigmine), treatment should normally be started with the drug with the lowest acquisition cost (taking into account required daily dose and the price per dose once shared care has started). An alternative AChE inhibitor could be prescribed if it is considered appropriate when taking into account adverse event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profiles.
- ◆ Ensure that local arrangements for prescribing, supply and treatment review follow [NICE Pathway: Medicines optimisation](#).

Assessment

- ◆ When using assessment scales to determine the severity of Alzheimer's disease take into account any physical, sensory or learning disabilities, or communication difficulties that could affect the results and make any adjustments considered appropriate. Healthcare professionals should also be mindful of the need to secure equality of access to treatment for patients from different ethnic groups, in particular those from different cultural backgrounds.
- ◆ When assessing the severity of Alzheimer's disease and the need for treatment do not rely solely on cognition scores in circumstances in which it would be inappropriate to do so. These include:
 - if the cognition score is not, or is not by itself, a clinically appropriate tool for assessing the severity of that patient's dementia because of the patient's learning difficulties or other disabilities (e.g. sensory impairments), linguistic or other communication difficulties or level of education, **OR**
 - if it is not possible to apply the tool in a language in which the patient is sufficiently fluent for it to be appropriate for assessing the severity of dementia, **OR**
 - if there are other similar reasons why using a cognition score, or the score alone, would be inappropriate for assessing the severity of dementia.
- ◆ In such cases healthcare professionals should determine the need for initiation or continuation of treatment by using another appropriate method of assessment.
- ◆ **Do NOT** offer the following specifically to slow the progress of Alzheimer's disease, except as part of a randomised controlled trial:
 - diabetes medicines,
 - hypertension medicines,
 - statins,
 - non-steroidal anti-inflammatory drugs, including aspirin.

Do NOT offer...

- ◆ acupuncture to treat dementia.
- ◆ ginseng, vitamin E supplements, or herbal formulations to treat dementia.
- ◆ cognitive training to treat mild to moderate Alzheimer's disease.
- ◆ interpersonal therapy to treat the cognitive symptoms of mild to moderate Alzheimer's disease.
- ◆ non-invasive brain stimulation (including transcranial magnetic stimulation) to treat mild to moderate Alzheimer's disease, except as part of a randomised controlled trial.

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Non-Alzheimer's dementia

- ◆ For people with mild to moderate dementia with Lewy bodies:
 - offer donepezil^U, or rivastigmine^U.
 - only consider galantamine^U if donepezil^U and rivastigmine^U are not tolerated.
- ◆ Consider donepezil^U or rivastigmine^U for people with severe dementia with Lewy bodies.
- ◆ Consider memantine^U for people with dementia with Lewy bodies if AChE inhibitors^U are not tolerated or are CI.
- ◆ Only consider AChE inhibitors^U or memantine^U for people with vascular dementia if they have suspected comorbid Alzheimer's disease, Parkinson's disease dementia or dementia with Lewy bodies.
- ◆ **Do NOT** offer AChE inhibitors or memantine to people with:
 - frontotemporal dementia,
 - cognitive impairment caused by multiple sclerosis.

Parkinson's disease dementia

- ◆ For guidance on pharmacological management see [NICE Pathway: Parkinson's disease](#)

Medicines that may cause cognitive impairment

- ◆ Consider minimising use of medicines associated with increased ACB, and if possible look for alternatives:
 - when assessing whether to refer a person with suspected dementia for diagnosis,
 - during medication reviews with people living with dementia.
- ◆ Be aware that there are validated tools for assessing ACB (e.g. Anticholinergic Cognitive Burden Scale) but there is insufficient evidence to recommend one over the others.

Managing non-cognitive symptoms**Agitation, aggression, distress and psychosis**

- ◆ Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:
 - explore possible reasons for their distress, **AND**
 - check for and address clinical or environmental causes (e.g. pain, delirium or inappropriate care).
- ◆ As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia.
- ◆ Only offer antipsychotics* for people living with dementia who are either:
 - at risk of harming themselves or others, **OR**
 - experiencing agitation, hallucinations or delusions that are causing them severe distress.
- ◆ Be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions. For more information, see [NICE Pathway: Parkinson's disease](#). Be aware that interventions may need to be modified for people living with dementia.
- ◆ Before starting antipsychotics, discuss benefits and harms with the person and their family members/carers (as appropriate). Consider using a [decision aid](#) to support this discussion.
- ◆ When using antipsychotics:**
 - use the lowest effective dose and use them for the shortest possible time,
 - reassess the person at least every 6 weeks, to check whether they still need medication.

- ◆ Stop treatment with antipsychotics:
 - if the person is not getting a clear ongoing benefit from taking them, **AND**
 - after discussion with the person taking them and their family members/carers (as appropriate) into account.
- ◆ Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.
- ◆ For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.
- ◆ **Do NOT** offer valproate to manage agitation or aggression in people living with dementia, unless it is indicated for another condition.
- ◆ See [NICE Evidence summary: Management of aggression, agitation and behavioural disturbances in dementia: carbamazepine.](#)

Depression and anxiety

- ◆ For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments.
- ◆ **Do NOT** routinely offer antidepressants to manage mild to moderate depression unless they are indicated for a pre-existing severe mental health problem.

Sleep problems

- ◆ **Do NOT** offer melatonin to manage insomnia in people living with Alzheimer's disease.
- ◆ For people living with dementia who have sleep problems, consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

Parkinson's disease

- ◆ For guidance on managing Parkinson's disease symptoms in people with Parkinson's disease dementia or dementia with Lewy bodies, see [NICE Pathway: Parkinson's disease](#). Be aware that interventions may need to be modified for people living with dementia.

Recommendations – wording used such as 'offer' and 'consider' denote the [strength of the recommendation](#).

Drug recommendations – the guideline assumes that prescribers will use a drug's [Summary of Product Characteristics \(SPC\)](#) to inform treatment decisions.

U unlicensed indication. Obtain and document informed consent.

*See [MHRA 2012](#); Antipsychotics: initiatives to reduce prescribing to older people with dementia.

** In October 2018 the only antipsychotics with a UK marketing authorisation for this indication were risperidone and haloperidol. **Risperidone** covers short-term treatment (up to 6 weeks) of persistent aggression in people with moderate to severe Alzheimer's disease unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. **Haloperidol** covers treatment of persistent aggression and psychotic symptoms in people with moderate to severe Alzheimer's dementia and vascular dementia when non-pharmacological treatments have failed and when there is a risk of harm to self or others.

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Assessing and managing co-morbidities

- ◆ Ensure that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities to people who do not have dementia. See [NICE Pathway: Multimorbidity](#) and [NICE Pathway: social care for older people with multiple long-term conditions](#).
- ◆ Also see [NICE Pathway: Care and support of people growing older with learning disabilities](#).

Pain

- ◆ Consider using a structured observational pain assessment tool alongside:
 - self-reported pain and standard clinical assessment for people living with moderate to severe dementia,
 - standard clinical assessment for people living with dementia who are unable to self-report pain.
- ◆ Consider using a stepwise treatment protocol that balances pain management and potential adverse events.
- ◆ Repeat pain assessments for people living with dementia:
 - who seem to be in pain,
 - who show signs of behavioural changes that may be caused by pain,
 - after any pain management intervention.

Falls

- ◆ For guidance on managing the risk of falling for people living with dementia (in community and inpatient settings), see [NICE Pathway: Preventing falls in older people](#). When using this guidance:
 - take account of the additional support people living with dementia may need to participate effectively,
 - be aware that multifactorial falls interventions may not be suitable for a person living with severe dementia.

Diabetes

- ◆ For guidance on setting HbA1c targets for people living with severe dementia who have type 2 diabetes, see information on when to relax target levels in [NICE Pathway: Type 2 diabetes](#).

Incontinence

- ◆ For guidance on pharmacological treatment of overactive bladder, see [NICE TA290: Mirabegron for treating symptoms of overactive bladder](#).
- ◆ For guidance on treating faecal incontinence, see [NICE Pathway: Managing faecal incontinence in specific groups](#).

Sensory impairment

- ◆ For guidance on hearing assessments for people with suspected or diagnosed dementia, see assessment and referral in [NICE Pathway: Hearing loss](#).
- ◆ Encourage people living with dementia to have eye tests every 2 years. Consider referring people who cannot organise appointments themselves.

Risks during hospital admission

- ◆ Be aware of the increased risk of delirium in people living with dementia who are admitted to hospital. See [NICE Pathway: Delirium](#) for interventions to prevent and treat delirium.
- ◆ When thinking about admission to hospital for a person living with severe dementia, carry out an assessment that balances their current medical needs with the additional harms they may face in hospital:
 - disorientation,
 - a longer length of stay,
 - increased mortality,
 - increased morbidity on discharge,
 - delirium,

- the effects of being in an impersonal or institutional environment.
- ◆ When thinking about admission to hospital for a person living with dementia, take into account:
 - any advance care and support plans,
 - the value of keeping them in a familiar environment.

Palliative care

- ◆ From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.
- ◆ For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process. Involve the person and their family members/carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.
- ◆ For guidance on care for people in the last days of life, including quality standards and measures on palliative care, see [NICE Pathway: Caring for an adult at the end of life](#).
- ◆ For guidance on best interests decision-making, see [NICE Pathway: Decision making and mental capacity](#).
- ◆ Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs.
- ◆ Consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking.
- ◆ **Do NOT** routinely use enteral feeding in people living with severe dementia, unless indicated for a potentially reversible comorbidity.

Resources

[NICE NG16; 2015: Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset](#).

[NICE KTT7; 2015 Antipsychotics in people with dementia , Updated February 2018](#).

ACB calculator

www.acbcalc.com/

Decision aids

[Antipsychotic medicines for treating agitation, aggression and distress in people living with dementia \(patient decision aid\)](#). June 2018.

[Enteral \(tube\) feeding for people living with severe dementia \(patient decision aid\)](#). June 2018.

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