

Dementia overview

NICE Pathways bring together all NICE guidance, quality standards and other NICE information on a specific topic.

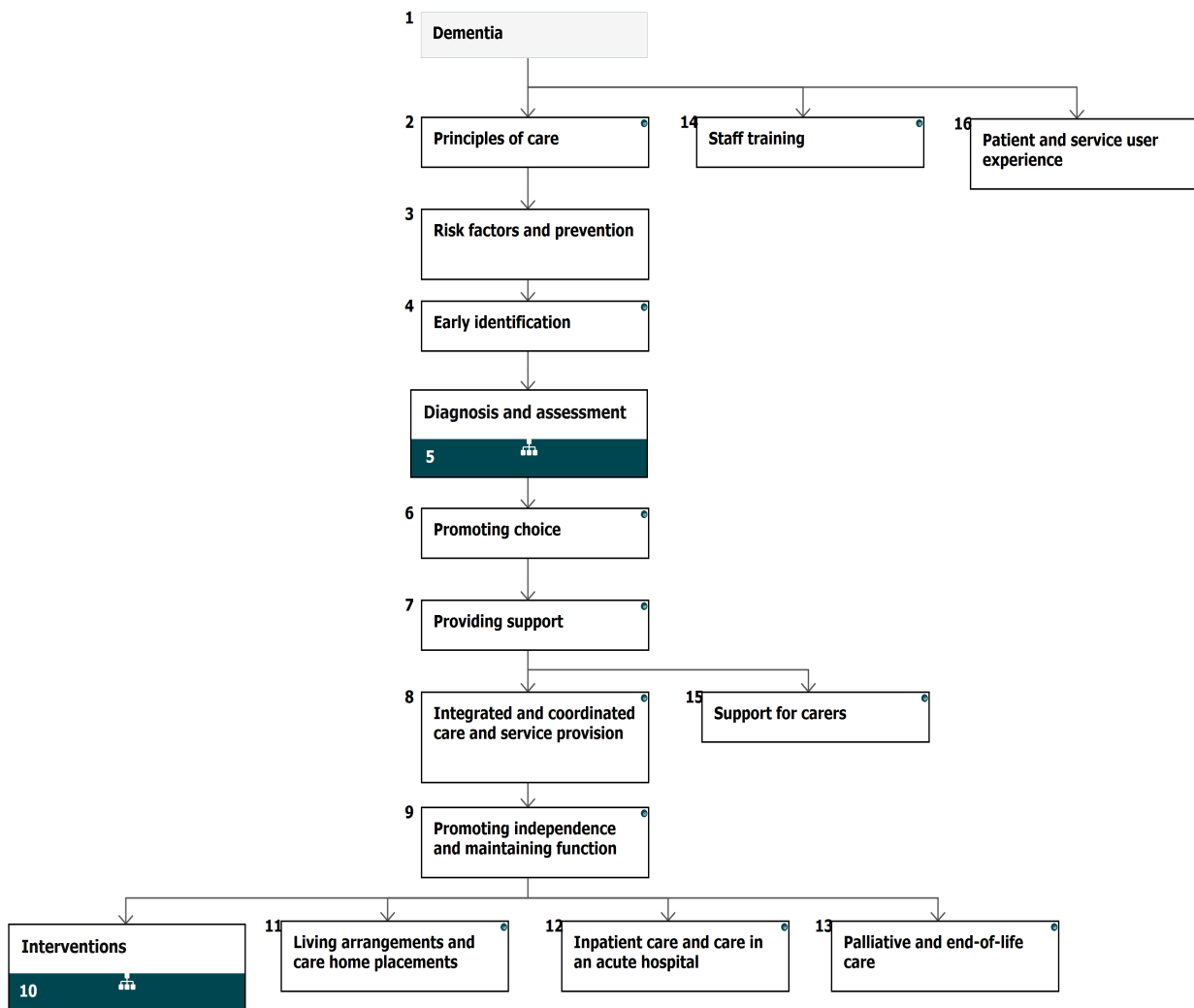
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<http://pathways.nice.org.uk/pathways/dementia>

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This document contains a single pathway diagram and uses numbering to link the boxes to the associated recommendations.

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1 Dementia

No additional information

2 Principles of care

Community-based care

Support people with dementia in the community as far as possible. If considering psychiatric inpatient admission see [accommodation and hospital care](#).

Diversity and equality

Always treat people with dementia and their carers with respect.

Ensure people with dementia are not excluded from services because of their diagnosis, age (whether regarded as too old or too young), or any learning disability.

If there is a language barrier, offer:

- written information in the preferred language and/or an accessible format
- independent interpreters
- psychological interventions in the preferred language.

Ensure that people suspected of having dementia because of cognitive and functional deterioration, but who do not have sufficient memory impairment for diagnosis, are not denied access to support services.

Needs and preferences of people with dementia

Identify specific needs, including those arising from:

- diversity (such as sex, ethnicity, age, religion and personal care)
- ill health, physical and learning disabilities, sensory impairment, communication difficulties, problems with nutrition and poor oral health.

Identify and wherever possible accommodate preferences (such as diet, sexuality and religion), particularly in residential care.

Record and address needs and preferences in the care plan.

Younger people with dementia

Specialist multidisciplinary services, allied to existing dementia services, should be developed for the assessment, diagnosis and care of younger people with dementia.

People with learning disabilities

Health and social care staff working with people with learning disabilities and other younger people at risk of dementia should be trained in dementia awareness.

People with learning disabilities and those supporting them should have access to specialist advice and support for dementia.

Ethics and consent

Always seek valid consent from people with dementia.

- Explain options and check that the person understands, has not been coerced and continues to consent over time.
- Use the Mental Capacity Act 2005 if the person lacks capacity.

Encourage the use of advocacy services and voluntary support. These services should be available to people with dementia and carers separately if required.

Allow people with dementia to convey information in confidence.

- Discuss with the person any need to share information with colleagues or other agencies.
- Only disclose confidential material without consent in exceptional circumstances.
- As the dementia worsens, any decisions about sharing information should be made in the context of the Mental Capacity Act 2005.

Discuss with the person with dementia, while he or she still has capacity, and his or her carer the use of:

- advance statements (stating what is to be done if the person loses the capacity to communicate or make decisions)
- advance decisions to refuse treatment
- Lasting Power of Attorney
- a Preferred Place of Care Plan.

Other principles of care

Impact of dementia on relationships

Assess the impact of dementia on personal (including sexual) relationships at the time of diagnosis and when indicated subsequently. Provide information about local support services if required.

Because people with dementia are vulnerable to abuse and neglect, health and social care staff should have access to information and training about adult protection and abide by the local multi-agency policy.

Financial support and NHS Continuing Care

Explain to people with dementia and their carers:

- that they have the right to receive direct payments and individual budgets (where available); offer support to obtain and manage these if needed
- the statutory difference between NHS care and care provided by local authority social services to help them decide whether they are eligible for NHS continuing care.

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Mental wellbeing of older people in care homes

4. Recognition of sensory impairment
5. Recognition of physical problems

3 Risk factors and prevention

Risk factors

Do not conduct general population screening.

In middle-aged and older people, review and treat vascular and other risk factors for dementia, such as smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels.

For further information, see what NICE says on [smoking](#), [alcohol](#), [diet](#), [diabetes](#), [hypertension](#) and [dementia, disability and frailty in later life](#).

Genetic counselling

Offer referral to genetic counselling to those thought to have a genetic cause of dementia¹ and to their unaffected relatives.

- Genetic counselling should be provided by regional genetic services.
- Do not use clinical genotyping if a genetic cause for dementia is not suspected, including late-onset dementia.

Prevention

Do not use the following as specific treatments for the primary prevention of dementia:

- statins
- hormone replacement therapy
- vitamin E
- non-steroidal anti-inflammatory drugs.

For the secondary prevention of dementia, review and treat vascular and other risk factors in people with the condition.

4 Early identification

In primary care, consider referring people with signs of mild cognitive impairment (MCI)² for assessment at memory assessment services.

If undertaking health checks, including those conducted as part of health facilitation, be aware of:

- the increased risk of dementia in people with learning disabilities and
- the possibility of dementia in other high-risk groups (for example people who have had a stroke or have a neurological condition such as Parkinson's disease).

Memory assessment services that identify people with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementias) should offer follow-up to monitor signs of possible dementia.

For further information, see what NICE says on [stroke](#) and [Parkinson's disease](#).

¹ Examples include familial autosomal dominant Alzheimer's disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL) and Huntington's disease.

² MCI is a syndrome defined as cognitive decline greater than expected for an individual's age and education level that does not interfere notably with activities of daily living. It is not a diagnosis of dementia of any type, although it may lead to dementia in some cases.

People with learning disabilities

Include the following in annual health checks:

- a mental health review, including any known or suspected mental health problems and how they may be linked to any physical health problems
- a physical health review, including assessment for the conditions and impairments which are common in people with learning disabilities
- a review of all current interventions, including medication and related side effects, adverse events, interactions and adherence
- an agreed and shared care plan for managing any physical health problems (including pain).

During annual health checks with adults with Down's syndrome, ask them and their family members, carers or care workers (as appropriate) about any changes that might suggest the need for an assessment of dementia, such as:

- any change in the person's behaviour
- any loss of skills (including self-care)
- a need for more prompting in the past few months.

For more information about annual health checks, see what NICE says on [early detection: annual health check](#) for mental health problems in people with learning disabilities.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Mental wellbeing of older people in care homes

3. Recognition of mental health conditions

5 Diagnosis and assessment

See [Dementia / Dementia diagnosis and assessment](#)

6 Promoting choice

NICE has published quality statements on promoting choice for people with dementia (see below).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia

5. Decision making

Supporting people to live well with dementia

2. Choice and control in decisions
4. Leisure activities of interest and choice
9. Independent advocacy

7 Providing support

NICE has published quality statements on providing support to people with dementia (see below).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia

4. Assessment and personalised care plan

Supporting people to live well with dementia

3. Reviewing needs and preferences
6. Physical and mental health and wellbeing
9. Independent advocacy

8 Integrated and coordinated care and service provision

Integrated health and social care

Use the Department of Health's publication 'Everybody's business. Integrated mental health services for older adults: a service development guide' in conjunction with this guideline as a framework for the planning, implementation and delivery of:

- primary care
- home care (see what NICE says on [home care for older people](#))
- mainstream and specialist day services
- sheltered and extra-care housing
- assistive technology and telecare
- mainstream and specialist residential care
- intermediate care and rehabilitation
- care in general hospitals
- specialist mental health services.

Ensure that people with dementia and their carers are given up-to-date information on local arrangements (including inter-agency working) for health and social care, including the independent and voluntary sectors, and on how to access such services.

Health and social care managers should coordinate and integrate the work of agencies involved in the care of people with dementia, including:

- jointly agreeing written policies and procedures
- involving service users and carers in joint planning to help identify local problems.

Management and coordination of care

Plan and provide care of people with dementia and support for their carers within the framework of care management/coordination.

Care managers/coordinators should ensure that:

- there is coordinated delivery of health and social care services, including:
 - a combined care plan agreed by health and social services that takes into account the changing needs of the person with dementia and carers
 - named health and social care staff to operate the care plan

- endorsement of the plan by the person and/or carers
- formal reviews of the plan at a frequency agreed with the person and carers and recorded in the notes
- care plans are based on the person with dementia's:
 - life history, social and family circumstances, and preferences
 - physical and mental health needs and current level of functioning.

See what NICE says on [social care for older people with multiple long-term conditions, transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) and [oral health for adults in care homes](#).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia

1. Appropriately trained staff
4. Assessment and personalised care plan
8. Liaison services

Supporting people to live well with dementia

8. Planning and evaluating services

Mental wellbeing of older people in care homes

6. Access to healthcare services

9 Promoting independence and maintaining function

Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia.

Care plans should address activities of daily living (ADL) that maximise independent activity, enhance function, adapt and develop skills, and minimise need for support. They should also

address the varying needs of people with different types of dementia. Essential components are:

- consistent and stable staffing
- retaining a familiar environment
- minimising relocations
- flexibility to accommodate fluctuating abilities
- ADL advice and skill training from an occupational therapist
- advice about independent toileting skills (if incontinence occurs, all possible causes should be assessed and treatment options tried before concluding it is permanent)
- environmental modifications to aid independence, including assistive technology, with advice from an occupational therapist and/or clinical psychologist
- physical exercise, with assessment and advice from a physiotherapist when needed
- support for people to go at their own pace and take part in activities they enjoy.

See what NICE says on [mental wellbeing and independence in older people](#).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia

4. Assessment and personalised care plan

Supporting people to live well with dementia

5. Maintaining and developing relationships
10. Involvement and contribution to the community

Mental wellbeing of older people in care homes

1. Participation in meaningful activity

10 Interventions

[See Dementia / Dementia interventions](#)

11 Living arrangements and care home placements

When organising or purchasing living arrangements or care home placements, health and social care managers should ensure that the design meets the needs of people with dementia and complies with the Disability Discrimination Acts 1995 and 2005.

- Built environments should be enabling and aid orientation. Attention should be paid to lighting, colour schemes, floor coverings, assistive technology, signage, garden design, and access to and safety of the external environment.
- Consideration should be given to size of units, mix of residents, and skills of staff to ensure that the environment is supportive and therapeutic.

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Supporting people to live well with dementia

7. Design and adaptation of housing

12 Inpatient care and care in an acute hospital

Inpatient care

Support people with dementia in the community as far as possible. However, consider psychiatric inpatient admission if necessary, including if:

- the person is severely disturbed and needs to be contained for his or her own health and safety and/or the safety of others (this might include those liable to be detained under the Mental Health Act 1983)
- assessment in a community setting is not possible, for example if there are complex physical and psychiatric problems.

Care in an acute hospital

Acute and general hospital trusts should:

- provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason

- ensure that people with suspected or known dementia using inpatient services are assessed by a liaison service that specialises in the treatment of dementia. Care should be planned jointly by:
 - the trust's hospital staff
 - liaison teams
 - relevant social care staff
 - the person with suspected or known dementia and carers.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Dementia

8. Liaison services

13 Palliative and end-of-life care

A palliative care approach

Adopt a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing.

- Consider physical, psychological, social and spiritual needs.
- Ensure people with dementia have the same access to palliative care services as others.
- Primary care teams should assess the palliative care needs of people close to death. Communicate the result within the team and to other health and social care staff.
- Encourage people with dementia to eat and drink by mouth for as long as possible.
 - Specialist assessment and advice about swallowing and feeding should be available.
 - Dietary advice may be useful.
 - Do not generally use tube feeding in severe dementia if dysphagia or disinclination to eat is a manifestation of disease severity.
 - ◇ Consider nutritional support, including tube feeding, if dysphagia is thought to be transient.
 - ◇ Apply ethical and legal principles to decisions to withhold or withdraw nutritional support.
- Clinically assess fever in severe dementia (especially in the terminal stages).
 - Treatment with simple analgesics, antipyretics and mechanical cooling may suffice.

- Consider palliative use of antibiotics after an individual assessment.

Resuscitation

Institutional policies should reflect the fact that cardiopulmonary resuscitation is unlikely to succeed in people with severe dementia.

- If the person with dementia has not made an advance decision to refuse resuscitation:
 - take into account any expressed wishes of the person with dementia and the views of the carers and the multidisciplinary team
 - follow the [Resuscitation Council UK's guidance](#)
 - follow the Mental Capacity Act 2005 if the person lacks capacity
 - record decisions in the notes and care plan.

Pain relief

If there are unexplained changes in behaviour or signs of distress, assess for undetected pain, using an observational pain assessment tool if helpful. However, do not rule out other causes.

In severe dementia, treat pain both pharmacologically and non-pharmacologically. Consider the person's history and preferences when choosing non-pharmacological therapies.

See what NICE says on [opioids for pain relief in palliative care](#) and [end of life care for people with life-limiting conditions](#).

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Dementia

5. Decision making
9. Palliative care needs

14 Staff training

Training in dementia care

Health and social care managers should ensure all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training (skill development).

- According to the needs of the staff being trained, trainers should consider the following when developing educational programmes:
 - early signs and symptoms suggestive of dementia and its major subtypes
 - natural history, signs and symptoms, and prognosis
 - impact of the condition on the person with dementia and carers, family and social network
 - assessment and treatment, including administration of medication and monitoring side effects
 - person-centred care in dementia
 - communication skills
 - assertive outreach techniques for people not engaged with services
 - roles of staff and agencies involved in care and basic advice on how they should work together
 - introduction to local adult protection policy and procedures, including the reporting of concerns or malpractice and who to contact
 - palliative care approach.

Training programmes should be adjusted for staff caring for people with learning disabilities.

In local mental health and learning disability services:

- managers should set up consultation and communication channels for care homes and other services
- liaison teams should offer regular consultation and training for healthcare professionals in acute hospitals who provide care for people with dementia. This should be planned by the acute hospital trust in conjunction with mental health, social care and learning disability services.

In primary care, there should be an evidence-based educational intervention, such as decision-support software and practice-based workshops, to improve the diagnosis and management of dementia.

Training in behaviour that challenges

Health and social care staff should be trained to anticipate behaviour that challenges and how to manage violence, aggression and extreme agitation, including de-escalation techniques and methods of physical restraint.

Healthcare professionals who use medication in the management of violence, aggression and extreme agitation should:

- be trained in the use of drugs for behavioural control (benzodiazepines and antipsychotics)
- be able to assess the risks of pharmacological control of violence, aggression and extreme agitation, particularly in dehydrated and physically ill people
- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dose to effect
- recognise the importance of nursing people who have received these drugs in the recovery position and monitoring pulse, blood pressure and respiration
- be trained in the use of resuscitation equipment and undertake annual retraining in resuscitation techniques
- understand the importance of maintaining an unobstructed airway.

For more information on interventions for non-cognitive symptoms and behaviour that challenges, see [interventions](#).

Working with people with learning disabilities

For more information on staff training for staff who may come into contact with people with learning disabilities, see what NICE says on [staff training and supervision](#) for mental health problems in people with learning disabilities.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

Dementia quality standard

1. Appropriately trained staff

15 Support for carers

Assessment

Health and social care managers should ensure that the rights of carers to an assessment of needs as set out in the Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 are upheld.

Carers' assessments should seek to identify any psychological distress and the psychosocial impact on the carer, including after the person with dementia has entered residential care.

Interventions

Care plans for carers should include tailored interventions, such as:

- individual or group psychoeducation
- peer-support groups tailored to the needs of the individual (for example, the stage of dementia of the person being cared for)
- telephone and internet information and support
- training courses about dementia, services and benefits, and dementia-care problem solving.

Consider involving the person with dementia and other family members as well as the primary carer.

Ensure support (such as transport or short-break services) is provided to enable carer participation in interventions.

Offer psychological therapy (including cognitive behavioural therapy) with a specialist practitioner to carers who experience psychological distress and negative psychological impact.

Practical support

Health and social care managers should ensure that carers of people with dementia have access to a range of respite or short-break services.

- Services should meet the needs of both the carer (in terms of location, flexibility, and timeliness) and the person with dementia.
- Services should include, for example, day care, day- and night-sitting, adult placement and short-term and/or overnight residential care.

- Transport to these services should be offered.

Respite/short-break care should include therapeutic activities tailored to the person with dementia provided in an environment that meets their needs (the person's own home wherever possible).

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia

6. Emotional, psychological and social needs of carers
10. Respite services for carers

16 Patient and service user experience

See what NICE says on:

- [patient experience](#)
- [service user experience](#).

Sources

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54

Dementia: supporting people with dementia and their carers in health and social care (2006 updated 2016) NICE guideline CG42

Your responsibility

The guidance in this pathway represents the view of NICE, which was arrived at after careful consideration of the evidence available. Those working in the NHS, local authorities, the wider public, voluntary and community sectors and the private sector should take it into account when carrying out their professional, managerial or voluntary duties. Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

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