

LIVING WELL WITH DEMENTIA

A UK information booklet on long-term condition management

For people living with dementia, families, carers and care staff

This booklet explains dementia as a long-term condition, why it matters, how it affects people and families, and how person-centred, evidence-based care can improve quality of life.



"With the right support, dementia care can protect identity, safety, dignity and family life."

- Practice message

LCHS7003 - Community Care and Management of Longer-term Conditions

Component 1: Information Booklet of Long-term Condition Management

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WHAT IS DEMENTIA?

Dementia is not a single disease. It is a clinical condition that results from a disease or injury to the brain. Causes progressive problems with memory, thinking, language, perception, behaviour and everyday functioning that are more severe than normal ageing (World Health Organization, 2025; NICE, 2018).

The most prevalent type is Alzheimer's disease, which represents approximately 60-70% of the cases globally. There are other forms of dementia too, such as vascular dementia, dementia with Lewy bodies, frontotemporal dementia and mixed dementia (World Health Organization, 2025; Alzheimer's Society, 2024a).



"Dementia should never be reduced to memory loss. It affects the whole person, relationships and everyday life."

- Key message

Why this booklet matters

This booklet is written for people living with dementia, families, carers and frontline staff in the UK. It uses accessible language, but it also includes Harvard citations because it is designed for a Level 7 assessment.

SIGNS AND SYMPTOMS

The early signs are a loss of short-term memory, repeating questions, having difficulty following conversations, getting lost, having trouble with familiar tasks, word finding difficulties, decreased judgement, mood or personality change, and failing to manage medicines, money or appointments (NHS, 2023a; Alzheimer's Research UK, 2024). Different dementias have different symptoms. Sometimes vascular dementia can develop in a step-wise progression following a stroke; fluctuating attention and visual hallucinations are features of Lewy body dementia; and changes in personality, behaviour and language can be an early sign of frontotemporal dementia (NHS, 2023a).

- ▶ Getting lost in familiar places or losing track of time.
- ▶ Difficulty planning, cooking, handling money or taking medicines safely.
- ▶ Mood changes, anxiety, apathy, suspicion, irritability or social withdrawal.
- ▶ Problems with words, names, conversations, judgment, or decision-making.

WHY DEMENTIA IS A PUBLIC HEALTH PRIORITY

Dementia is a serious public health and social care problem. In 2021, the WHO estimated that globally, there were 57 million people living with dementia, with nearly 10 million new cases every year, and more than 60% of these cases occurring in low- and middle-income countries (World Health Organization, 2025). Dementia also causes disability, dependency and mortality in older people and therefore has impacts beyond specialist health services on families, housing, employment, welfare and social care.

In the UK, there are approximately 1,000,000 people with dementia. There are currently an estimated 982,000 people living with dementia in 2024, and 1.4 million people will have dementia by 2040 (Dementia Statistics Hub, 2024; Alzheimer's Society, 2024b). Alzheimer's Society estimates that dementia costs the UK about 42 billion pounds in 2024 and could rise to 90 billion pounds by 2040, with

unpaid care and social care form a large share of the burden (Alzheimer's Society, 2024c).

Critical point

Prevalence statistics can hide inequalities. Diagnosis rates and post-diagnostic support differ between regions, ethnic groups and levels of deprivation. NHS Digital reported a dementia diagnosis rate of 65.4% among people aged 65 and over in England in January 2025, below the former two-thirds ambition (NHS Digital, 2025).

RISK FACTORS AND PREVENTION

The biological, psychological, social and environmental factors all contribute to dementia risk, and age is the biggest risk factor. The Lancet Commission on dementia prevention and public health care concluded in 2024 that, by tackling 14 modifiable risk factors over the lifespan, around 45% of dementia cases could be delayed or prevented (Livingston et al., 2024).

Risk reduction doesn't equate with blame. There are multiple risk factors that are linked to poverty, poor housing, work conditions, racism, loneliness, access to health care and local environments. Individual guidance needs to be complemented by action on broader determinants of health in a fair prevention strategy (Marmot et al., 2020).



"Prevention advice should support people, not blame them. Many risks are shaped by the conditions in which people live."

- Public health message

- ▶ Treat high blood pressure, diabetes, high LDL cholesterol and depression.
- ▶ Support hearing and vision checks and access to hearing aids or glasses.
- ▶ Encourage safe physical activity, smoking cessation and reduced harmful alcohol use.
- ▶ Promote education, social connection, cognitive activity and clean air.

IMPACT ON THE PERSON AND FAMILY

Dementia is a condition that impacts the whole person. Physical symptoms include: decreased mobility, falls, poor nutrition, swallowing difficulties, sleep disturbances, pain that is hard to express, incontinence, frailty and increased risk of hospital admission (NICE, 2018; CQC, 2025). The psychological impacts might be anxiety, depression, fear, anger, loss, loss of self-confidence, distress and behaviours that are challenging to services. Socially, dementia can impact work, driving, friendships, sexuality and intimacy, culture, money and community involvement.

Family members can become unpaid carers and may be responsible for administering medicines, cooking, arranging appointments, keeping patients safe, with personal care, money and emotional support. While the person is living, carers can feel isolated, lose their income, suffer from stress and experience poor sleep. Hence, a quality dementia pathway should include an evaluation and support of the individual and their carer (Carers UK, 2024; NICE, 2018).

Whole-person care

A purely biomedical approach misses the lived experience of dementia. The biopsychosocial model helps professionals consider brain changes, physical health, emotions, relationships, culture, housing, finances, family roles and community support together.

DIAGNOSIS AND NHS TREATMENT

A timely diagnosis can provide opportunities for people to access treatment and support, for legal, financial and advance care planning (NICE, 2018), identify treatable causes of the cognitive symptoms and clarify the nature of the dementia. Assessment typically starts with the GP who will assess history, medicines, mood, physical health, blood tests and cognitive screening before making a referral to a memory service if appropriate.

Most causes of dementia have no cure. The overarching goal of management is to preserve quality of life, minimise distress, foster independence and assist families. Treatments for the NHS may involve 'cholinesterase inhibitors' such as donepezil, rivastigmine or galantamine.

Memantine is used in moderate Alzheimer's disease if the other medicines mentioned above are not suitable, or severe Alzheimer's disease (NICE, 2018; NHS, 2023b) and is sometimes used for Lewy body dementia and moderate to moderate-severe Alzheimer's disease.

There is also non-drug support that is important. NICE says cognitive stimulation therapy can be recommended for individuals who have mild to moderate dementia. Encouraging safer daily living involves reducing distress and encouraging more meaningful activities, exercise, home adaptations, occupational therapy, social prescribing, pain management and medication review to support this (NICE, 2018; NHS England, 2025a). Antipsychotic medication should not be standard practice and should only be considered when there is a significant level of distress or risk which warrants its use (NICE, 2018).

Dementia support pathway

1. Notice memory, mood or daily task changes	2. Assess GP review, tests and memory clinic	3. Plan diagnosis, goals, carer needs and risk plan
4. Support medication where suitable, CST, OT, social prescribing	5. Review care plan, medicines, capacity, safety and crisis plans	6. Advanced care palliative approach, comfort and family support

MODELS AND FRAMEWORKS FOR BETTER CARE

A useful UK model is the House of Care (Coulter, Roberts and Dixon, 2013), which features an informed, engaged individual and a prepared, proactive team, supported by organisational systems and commissioning. This model is useful in dementia as it highlights the principles of personalised care planning, shared decision making and coordinated support. It is also problematic if there is no named coordinator, no carer support, or no local resources to provide a focus, as it can become a symbolic post-diagnostic service.

The Chronic Care Model (Wagner, Austin and Von Korff, 1996; Coleman et al., 2009) is an international model that suggests that self-management support, delivery system design, decision support, clinical information systems and resources from the community are key components that improve outcomes. This is useful for dementia for proactive reviews and multidisciplinary working. However, the model must be adapted because cognitive impairment can limit independent self-management and require carer involvement, capacity assessment and safeguarding.

Model/framework	What it contributes to dementia care	Limitation
House of Care (UK)	Combines engaged people, committed professionals, organisational systems and commissioning to support personalised care planning.	It can become a diagram only if local services remain fragmented.
Chronic Care Model (international)	Shows that outcomes improve when self-management support, decision support, delivery design and information systems work together.	Needs adaptation for cognitive impairment and carer involvement.

Critical comparison

The UK House of Care is strong on personalised planning and local commissioning. The Chronic Care Model is strong on system design and information systems. For dementia, the best approach combines both with person-centred values and carer support.

POLICY, RIGHTS AND LOCAL IMPLEMENTATION

National guidance, law and local commissioning have an influence on dementia care in the UK. NICE NG97 offers evidence-based recommendations for post-diagnostic support, medication, carer support, staff training and coordinating care (NICE, 2018). Priority areas for high-quality care, such as diagnosis, care co-ordination and support to remain independent, are outlined in NICE QS184 (NICE, 2019). Personalised care, integrated services and prevention are all supported by the NHS Long Term Plan; local authorities have duties in relation to needs assessment, carer assessment and wellbeing under the Care Act 2014.

The Mental Capacity Act 2005 is a key part of dementia care, which safeguards individuals who are unable to make certain decisions. The Mental Capacity Act 2005 places a positive obligation on professionals to make what is known as 'a presumption of capacity' unless that assumption is challenged, to assist in decision making, not to assume that someone is not capable of making a decision because they have done it unwisely, and to act in their best interests and to choose the least restriction (MCA 2005). Important in consent, medicines, homes, money, things to do, risks and death.

The real question is how to implement it. Policies are good, but may result in delayed diagnosis, inconsistent access to memory clinics, fragmented communication, limited respite, cultural barriers, transport issues and inconsistent care planning. In addition, workforce training, better connectivity between primary care, mental health services, social care and voluntary services, and meaningful support for carers are needed locally.

PERSON-CENTRED CARE AND SELF-MANAGEMENT

The Person-Centred Dementia Care approach is to see the person prior to the condition. It places value on the person's biography, culture and preferences, strengths, relationships and what is important to the person (Kitwood, 1997; McCormack and McCance, 2017). This is not a kindness, this is a safety, dignity and effective care approach as it enables staff to understand behaviour, distress and communication needs.

Self-management in dementia should be a realistic process that is supported. Individuals can organise calendars, medication reminders, productive activities, exercise, social interaction and planning immediately after diagnosis. With the progression of dementia, self-management is then shared with carers and services. A person-centred plan should include routines, strengths, risks, communication preferences, nutrition, sleep, pain, mobility,

finances, crisis contacts and future wishes (NHS England, 2020).



"The person is still present. Good care starts by learning their story, not just their symptoms."

- Person-centred reminder

END-OF-LIFE AND PALLIATIVE CARE

Dementia is a progressive and life-limiting condition. The transition to end-of-life care does not have to start only in the last few days and should include earlier discussions with the person about preferences, comfort, place of care, spiritual needs, involvement of family and decisions on hospital admission or treatment (NICE, 2015; NHS, 2023d). Advance care planning is most respectful when it starts when the person is able to share their wishes and should be reviewed as wishes may change.

Marie Curie (2023) and Alzheimer's Society (2024f) cite five key principles for good palliative care for people with dementia: Comfort and dignity, familiar relationships, assessment of pain, mouth care, and decisions about nutrition and hydration, prevention of pressure damage, managing breathlessness and agitation, and bereavement support for the family. Not admitting to hospital may be appropriate when home, hospice or care home care can be provided safely to meet needs.

Recommendations for improvement

1) Provide a named dementia care coordinator. 2) Offer a written personalised care plan and carer assessment soon after diagnosis. 3) Strengthen culturally appropriate memory assessment and post-diagnostic support. 4) Review medicines, falls, pain, nutrition, hearing, vision and home safety regularly. 5) Introduce advance care planning early and sensitively. 6) Expand respite, peer support and dementia-friendly community services.

QUICK ACTION CHECKLIST

For people and families	For professionals and services
Ask for a clear diagnosis and written information. Keep a medicine list and use reminders if helpful. Ask for a carer assessment and local support groups. Plan legal, financial and care wishes early.	Use clear communication and accessible information. Review medicines, pain, falls, hearing, vision and nutrition. Treat carers as partners and assess their wellbeing. Record what matters to the person and revisit the plan.

WHERE TO GET HELP

Support may begin through the GP, memory clinic, community mental health team, adult social care or local voluntary organisations in the UK. Practical information, peer support, benefits advice, carer assessment and signposting can be provided by Alzheimer's Society, Dementia UK Admiral Nurses, Carers UK, local dementia cafes and local authority adult social care. In immediate danger, call 999; for urgent non-emergency health advice, use NHS 111.

FINAL MESSAGE

Dementia is more than just a decline in cognition. It is about supporting a person to be able to live with dignity, identity, safety and connection as long as they can. The good approach is to diagnose early in time, treat with evidence, offer support based on individual needs and preferences, support carers, prevent, and engage in rights-based decision making and future planning. Dementia care is more humane and more effective when services cooperate around what is important to the person.

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