

Module Code: LCHS7003

Component 1

Information Booklet of Long-term Condition Management



Living Well with Dementia

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**Supporting Individuals and Families Through Person-Centred Care in the
United Kingdom**

UNDERSTANDING DEMENTIA

Information and support for people living with dementia, their families and professionals

Compassion • Respect • Support

A person-centred approach to living well with dementia



WHAT IS DEMENTIA?

Dementia is an umbrella term for a group of symptoms that affect memory, thinking, behaviour and everyday abilities. It is caused by diseases of the brain and is not a natural part of ageing.

There are many types of dementia, the most common being Alzheimer's disease, followed by vascular dementia, Lewy body dementia and frontotemporal dementia.

Dementia is progressive, which means symptoms worsen over time; however, with the right support, people can live well for many years.



KEY FACT

Dementia is not just about losing memory – it affects how a person thinks, feels, communicates and manages day-to-day life.

DEMENTIA AT A GLANCE



>55 MILLION

people worldwide are living with dementia (WHO, 2023).



≈900,000

people in the UK are living with dementia (Alzheimer's Society, 2024).



1 IN 3

people born in the UK today will develop dementia in their lifetime.



£42 BILLION

The estimated cost of dementia to the UK economy in 2024 (Alzheimer's Society, 2024).

Introduction

Dementia is one of the greatest public health issues in health and social care systems globally. It impacts hundreds of thousands of people and is significant for families, carers, health professionals and society (Alzheimer's Society, 2024). This booklet aims to give an overview of dementia, including information on its causes and prevalence and the impact it has on the individual and their family. It has a critical appraisal of the current evidence-based interventions and policy initiatives that underpin dementia care in the United Kingdom and examines person-centred approaches that support a good quality of life and self-management.

Understanding Dementia

What is Dementia?

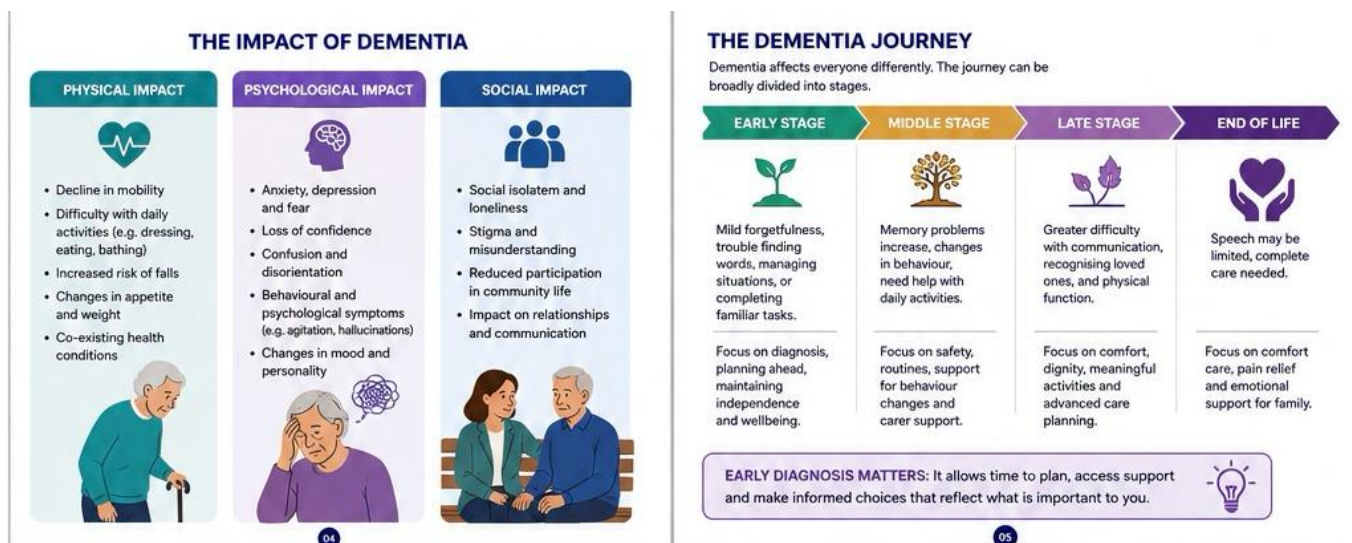
Dementia is an umbrella term for a group of progressive neurological diseases involving impaired cognitive function that is more severe than would be seen with normal ageing. The syndrome impacts memory, thinking, orientation, comprehension, learning capability, language and judgement, and in the end, the ability to do daily activities on their own (World Health Organisation, 2023). Dementia is not a single disease, but rather a group of symptoms due to various pathological conditions. It is most frequently seen in Alzheimer's disease type dementia (60-70%). Other types of dementia include: vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Alzheimer's Society, 2024).

GLOBAL AND UK PREVALENCE OF DEMENTIA

Dementia is a significant health issue in the world at present. The World Health Organisation (2023) estimates that over 55 million people have dementia in the world today and that around 10 million new cases are diagnosed every year. This figure is expected to grow to 139 million by 2050, as a result of demographic ageing and higher life expectancy. Dementia is still among the top causes of disability and dependency in the United Kingdom among older people. NHS England estimates that there are around 982,000 people with dementia in the UK and that this figure will reach over 1.4 million by 2040 (NHS England, 2024).

The Alzheimer's Society (2024) estimates that in the UK, dementia costs the economy more than £42 billion per year in terms of healthcare spending, social care spending and unpaid family carer time.

The financial cost of dementia is also high. A significant percentage of the cost of dementia is out of the health service system and is paid by informal carers, as opposed to many other chronic conditions.



TYPES OF DEMENTIA

Alzheimer's Disease

The most common type of dementia is Alzheimer's disease. It's defined by a buildup of amyloid plaques and tau protein tangles in the brain, leading to progressive damage to the neurons. First symptoms are a decrease in memory, followed by communication problems, confusion and behavioural changes (WHO, 2024).

Vascular Dementia

Vascular dementia is caused by a reduction of blood flow to the brain, which is usually caused by strokes or blood damage. Excess risk factors like hypertension, obesity, diabetes, and cardiovascular diseases greatly increase people's susceptibility. Progressive or step-wise course of symptoms after vascular events as opposed to Alzheimer's disease (Brooker, 2016).

Lewy Bodies Dementia (LBD)

This form is linked with abnormal protein deposits called Lewy bodies. People often have changes in thinking, seeing things that aren't there or symptoms of Parkinson's disease. Symptoms overlap with Alzheimer's disease and Parkinson's disease, and this condition can present diagnostic difficulties (WHO, 2023).

Frontotemporal Dementia

The frontal and temporal lobes of the brain are the main areas involved in Frontotemporal dementia. As a result, personality changes and behavioural

1. DEMENTIA PREVALENCE IN THE UK



982,000

people in the UK are living with dementia (NHS England, 2024)

THE NUMBER IS GROWING

It is estimated to rise to:

1 MILLION+
by 2025

1.2 MILLION+
by 2030

1.4 MILLION+
by 2040



Around 1 in 6 people over the age of 80 are estimated to have dementia.



Women are more likely to develop dementia than men.

Source: NHS England (2024); Alzheimer's Society (2024)

2. DEMENTIA PREVALENCE GLOBALLY



More than

55 MILLION

people worldwide are living with dementia (WHO, 2023)

A RAPIDLY INCREASING GLOBAL CHALLENGE



55 MILLION



78 MILLION



139 MILLION

people projected to be living with dementia

● ● Around the world, one new case of dementia

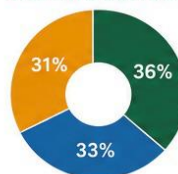
3. THE ECONOMIC BURDEN OF DEMENTIA



£42 BILLION

The estimated annual cost of dementia to the UK economy (2024) (Alzheimer's Society, 2024)

WHERE THE COSTS COME FROM (UK, 2024)



- Unpaid family and friend care (£15.1 billion)
- Health and social care services (£13.9 billion)
- Other costs (e.g. lost productivity) (£13.0 billion)



Without action, the cost of dementia to the UK economy could rise to **£90 billion by 2040.**

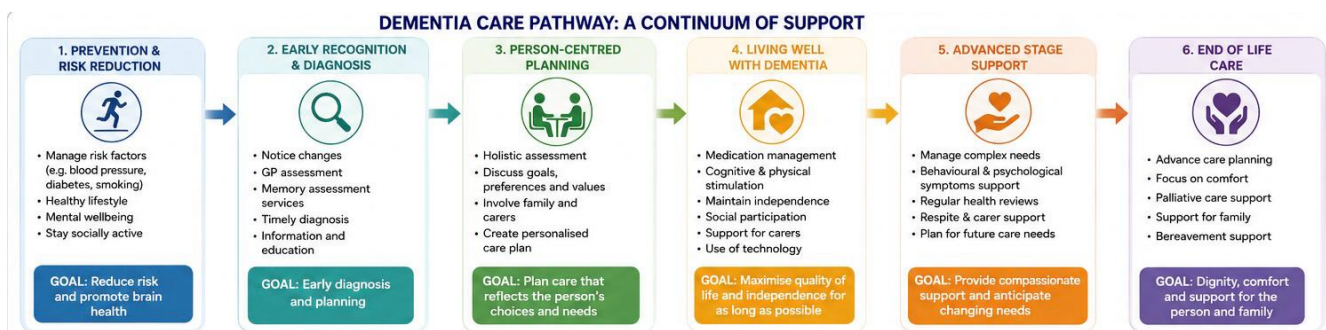
Source: Alzheimer's Society (2024)

disturbances, along with language impairments, often occur before memory loss. It tends to happen to people at a younger age than other dementias.

These forms have similar features but have different pathophysiological causes, requiring a different approach to assessment and management (Carers UK, 2024).

Risk Factors/Aetiology

Several genetic, biological, environmental and lifestyle factors have an interaction that influences the development of dementia.



Non-Modifiable Risk Factors

Age is still the most important factor for the risk of dementia. The risk for having dementia increases dramatically after the age of 65, but younger-onset dementia can happen. There is also a risk factor that is contributed by the genetic predisposition, especially in people with a family history of Alzheimer's disease. Sex differences have also been found. Alzheimer's disease is more likely to affect women, likely in part due to their longer lifespan and possible biological influences of ageing (Zucchella et al., 2018).

Modifiable Risk Factors

The significance of modifiable risk factors is growing in the research literature. The Lancet Commission (Livingston et al., 2020) estimated that about 45% of dementia may be attributed to potentially modifiable factors. These include:

- Hypertension**
- Diabetes mellitus**
- Smoking**
- Physical inactivity**
- Obesity**
- Excessive alcohol consumption**
- Hearing impairment**
- Depression**
- Social isolation**
- Low educational attainment**
- Air pollution exposure**

WHY DEMENTIA REQUIRES A WHOLE-PERSON APPROACH?

There has been a predominant emphasis on cognitive decline and management in the care of people with dementia in history. Recent research indicates that these would be inadequate as dementia related issues permeate every facet of one's life. Cognitive symptoms interact with the physical health, emotional well-being, social relations and environment. Kitwood's theory of personhood continues to influence the care of people with dementia as it states that they are not just a product of the loss of their brain function, but still unique persons whose emotional, psychological and social needs continue. This view has shaped contemporary approaches to person-centred care that are used across the NHS and social care services (NHS England, 2019).

MANAGEMENT & SUPPORT OPTIONS

There is no cure for dementia, but many treatments and interventions can help manage symptoms and improve quality of life.

MEDICAL TREATMENTS	NON-MEDICAL INTERVENTIONS	PRACTICAL SUPPORT
 Medications may help improve symptoms or slow decline in some types of dementia. • Cholinesterase inhibitors • Memantine • Treatment of co-existing conditions	Evidence shows these can improve wellbeing and support independence. • Cognitive stimulation therapy • Reminiscence therapy • Exercise and physical activity • Music and art therapy • Occupational therapy • Social engagement 	Support is available to help people live well at home for as long as possible. • Home care services • Assistive technology • Day centres • Financial support • Welfare benefits advice



GOOD TO KNOW

Your GP is the first point of contact. They can refer you to memory services for assessment and diagnosis.

THE IMPACT OF DEMENTIA ON INDIVIDUALS AND FAMILIES

Dementia is more than changes in intellectual functioning. This condition gradually impacts the ability to function physically, emotional well-being, social roles and interactions and family relationships. Therefore, health and social care workers need to understand the nature of dementia as a complex condition that needs to be assessed and addressed holistically. An understanding of these multi-dimensional impacts is fundamental to providing effective person-centred care and to working towards improvements for the individual and their caregiver (Public Health England, 2020).

SUPPORTING FAMILY CARERS

Carers play a vital role in dementia care, but looking after yourself is just as important.



LOOK AFTER YOUR WELLBEING

Take breaks, eat well, stay active and seek emotional support.



CONNECT WITH OTHERS

Talk to friends, join support groups or online communities.



USE AVAILABLE SUPPORT

Respite care, day services and practical help can ease pressure.



KNOW YOUR RIGHTS

You may be entitled to benefits, Carer's Allowance and local authority support.

REMEMBER: You cannot pour from an empty cup.
Caring for yourself helps you care for others.



<i>Physical effects of dementia</i>	<i>Psychological effects of dementia</i>	<i>Social impact of dementia</i>
As the disease worsens, the physical impact of dementia is more likely to be noticeable. While cognitive symptoms are often the first to be the focus of diagnosis, physical deterioration plays a significant role in disability, dependency, and quality of life. The most frequent physical effects are reduced mobility. With the progression of dementia, you can lose balance, coordination, and spatial awareness, which can make you more prone to falling. Studies show that individuals with dementia are significantly more likely to fall than cognitively intact older adults, and that falls can lead to fractures, hospitalisation and prolonged (NICE, 2018)	The mental aspects of dementia can be significant and upsetting for persons impacted and their families. After diagnosis, many people feel fearful, uncertain and concerned about the future about a decline in their cognitive functioning and independence. Those who have dementia are at higher risk of depression. A sense of loss of functioning may lead to hopelessness, frustration and low self-esteem. Research indicates that depression often goes undiagnosed due to the misdiagnosis of depression as the result of dementia (Livingston et al., 2024).	The impact of dementia on society can be as significant. Communication difficulties are often associated with cognitive decline, making interaction with others more difficult. People may have trouble understanding what is being said, may forget names, or may find it difficult to engage in social events they have enjoyed in the past. One of the key issues is social isolation. Stigma, embarrassment and loss of confidence often prevent people from participating in the community. Loneliness can lead to depression and speed up cognitive decline, and lower social

disability (NHS England, 2024).		participation can cause this (Department of Health and Social Care, 2022).
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Although awareness campaigns are increasing, there remains a stigma attached to dementia. There are reports that after the diagnosis, some people feel they are treated differently, which can lead to loss of identity and feelings of exclusion. Gove et al. (2017) suggest that society continues to focus on the weaknesses and not the strengths and abilities of people living with dementia. Employment opportunities may also be impacted, especially for those who are diagnosed with younger-onset dementia. Premature retirement may result in financial difficulties, loss of purpose and diminished social networks. Also, those who depend on others for financial support may be unable to manage their personal finances on their own, which can also pose problems with autonomy and care. Social exclusion is not only personal, but involves the caregiver's family members who could be affected by their reduced opportunities for leisure, work and social interaction. So dementia must be not only considered a problem for the person with dementia, but a problem for the family and community (WHO, 2017).

THE MULTIDISCIPLINARY CARE TEAM

A team approach ensures that people living with dementia and their carers receive the right support at the right time.



IMPACT ON FAMILIES AND INFORMAL CARERS

In the UK, the majority of people caring for someone with dementia are relatives. Caregiving is rewarding, but it's also often very costly, especially in emotional, physical and financial terms (Orrell et al., 2017). A carer may take on more and more responsibility for:

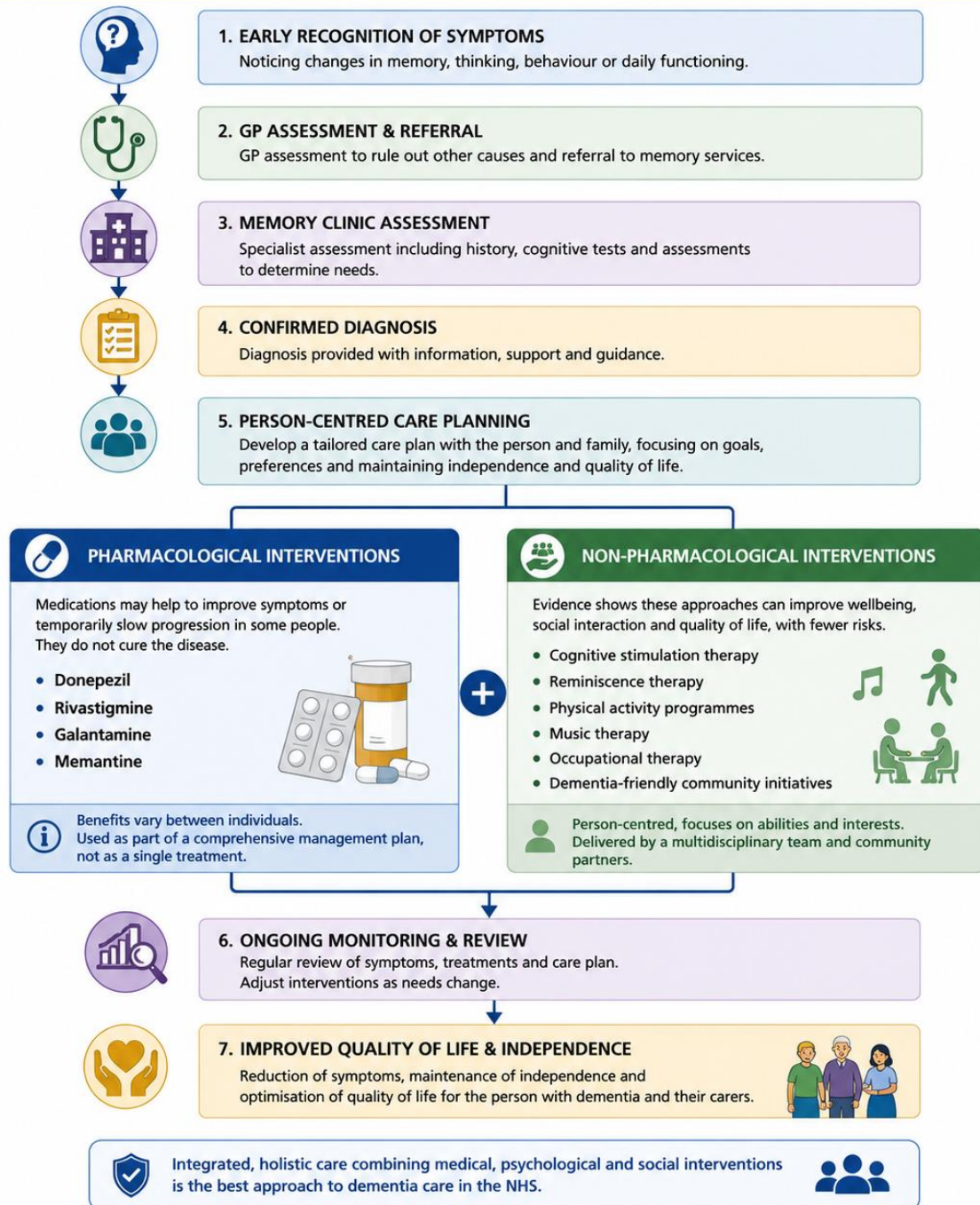
- Personal care
- Medication management
- Financial administration
- Appointment coordination
- Emotional support
- Household management

Most of the time, as the disease advances, the care needs increase. The Alzheimer's Society estimates that in the UK, unpaid carers contribute £2 billion to dementia care each year, and contribute billions of pounds to the UK's economy. Caregivers often suffer from chronic stress, anxiety and depression, and this is a psychological phenomenon. The term caregiver burden has been established in the field of dementia research and is used to describe the physical, emotional and social burden that can mount over time due to the caregiving role (Department of Health and Social Care, 2024).

The dynamics of the relationship can also shift dramatically. Spouses may experience a feeling of ambiguous loss, where the person is physically absent but changes in psychological and cognitive ways over time. There can be role reversals as the adult children take on parenting roles for their parents. Financial stress can be significant. Working hours are curtailed, and some carers become unemployed, in order to provide care. This can thus result in lower income for the household and higher care costs. One of the crucial problems in existing service delivery is that the needs of the carers are not always taken up until the stress situation is already established. Whilst policy is more attuned to seeing carers as partners in care, evidence indicates that there is not equal access to respite services, psychological support or financial help across regions of the UK (Fabricatore et al., 2020).

Evidence-Based Treatment and Management in the NHS

EVIDENCE-BASED TREATMENT AND MANAGEMENT OF DEMENTIA IN THE NHS



For the majority of dementias, there is no cure. Reduction of symptoms, maintenance of independence and optimisation of quality of life are the two main goals of treatment.

Early diagnosis and assessment

Early diagnosis is encouraged in the NHS by means of memory assessment services and specialist memory clinics. Early diagnosis allows treatment, care planning and services to be provided before individuals lose decision making capacity. There is evidence that early diagnosis increases opportunities for advance care planning and provides access to psychosocial interventions. However, critics say that diagnoses are not enough to improve outcomes unless there is support service (Integrated Care Support, 2024).

Pharmacological Interventions

There are a number of medications on the NHS that can be used for symptoms. Common treatments include:

Donepezil
Rivastigmine
Galantamine
Memantine

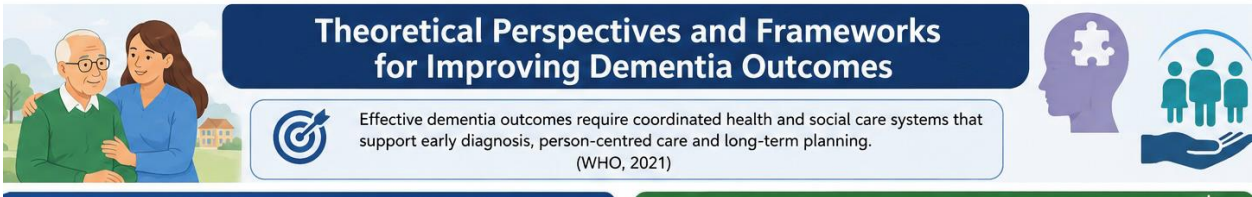
Some people may find that these medicines enhance their mental ability or temporarily slow symptoms from getting worse. However, they do not stop the disease advancing and there is variation in the benefits of the treatment between patients (NICE, 2018). Therefore, the use of pharmacological treatment should be considered as one of the many pillars of a comprehensive management strategy and not as a single treatment.

Non-Pharmacological Interventions

There has been a growing body of evidence that non-pharmacological methods can be used, such as:

Cognitive stimulation therapy
Reminiscence therapy
Physical activity programmes
Music therapy
Occupational therapy
Dementia-friendly community initiatives

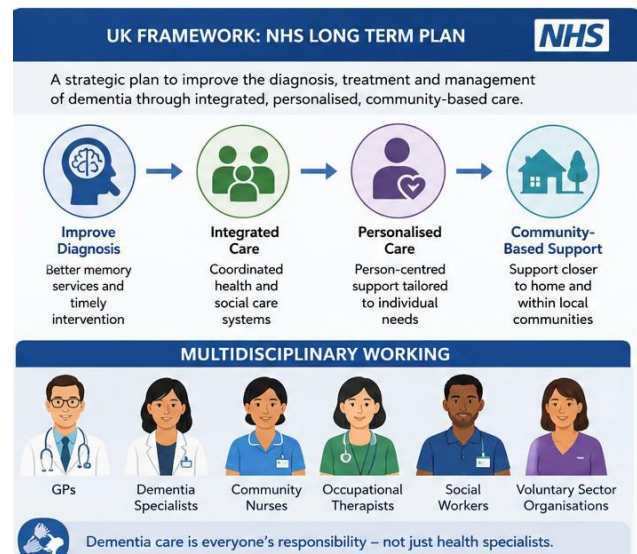
Many of these interventions have a greater impact on wellbeing, social interaction and quality of life and are less risky than the pharmacology methods. From a person-centred perspective, many researchers believe psychosocial interventions are more person centred, due to the way they take a focus on abilities rather than on deficits. Recent developments in dementia care have led to an increasing focus on multi-disciplinary and holistic care, involving a combination of medical, psychological and social interventions (NICE, 2023).



The rise in dementia has led to the emergence of policy approaches and care models that seek to enhance the care and support of people and families. There is a need for coordinated health and social care systems which can facilitate early diagnosis of dementia, person-centred care and long-term planning as part of effective dementia management (WHO, 2021).

UK Framework: NHS Long Term Plan

The NHS Long Term Plan (NHS England, 2024) outlines a strategic plan for the improvement of the diagnosis, treatment and management of long-term conditions such as dementia. The plan highlights integrated care, prevention, personalised care and community-based support. A primary goal is to increase the proportion of people diagnosed with dementia, via better memory services and timely intervention. The NHS Long Term Plan also encourages multidisciplinary working, by enabling collaboration between:



General practitioners
Dementia specialists
Community nurses
Occupational therapists
Social workers
Voluntary sector organisations

Such an integrated approach is indicative of increasing understanding that dementia care is not strictly a healthcare specialist's responsibility.

National Strategy: Dementia Strategy for Scotland 2010–2020



The World Health Organisation's Global Action Plan on the Public Health Response to Dementia 2017–2025 sets out an international action plan for the public health response to dementia worldwide (Nuffield Trust, 2023).

The action plan comprises seven strategic areas:

Use of an Alzheimer's and dementia diagnostic service in the local community.

Dementia awareness and inclusivity

Risk reduction

Diagnosis and treatment

Support for carers

Information systems

Research and innovation

The WHO framework is different from the traditional medical model, which focuses on the health of individuals. It promotes prevention, social inclusion and the promotion of human rights in addition to clinical management. Its great strength is its recognition of the fact that dementia is not just a health issue, it is a community, economic and social issue. The framework, therefore, calls for the establishment of dementia-friendly societies, which foster inclusion and minimise stigma, in countries (Feast et al., 2016).

SHARED GOAL: BETTER OUTCOMES FOR PEOPLE LIVING WITH DEMENTIA AND THEIR FAMILIES



Collaborative
working



Person-centred
approach



Support for
carers and families



Equity, inclusion
and human rights



Evidence, innovation
and continuous
improvement

END OF LIFE CARE

Planning ahead and focusing on comfort can help ensure dignity and peace.

WHAT MATTERS MOST



Respecting wishes and values



Relieving pain and other symptoms



Emotional and spiritual support



Supporting families and carers

PLANNING AHEAD



Advance care planning
(when you can)



Lasting Power of Attorney



Discuss preferences for care
and treatment



Consider preferred place of care



PALLIATIVE CARE IS APPROPRIATE AT ANY STAGE

It focuses on comfort, quality of life and supporting
the whole person and their family.

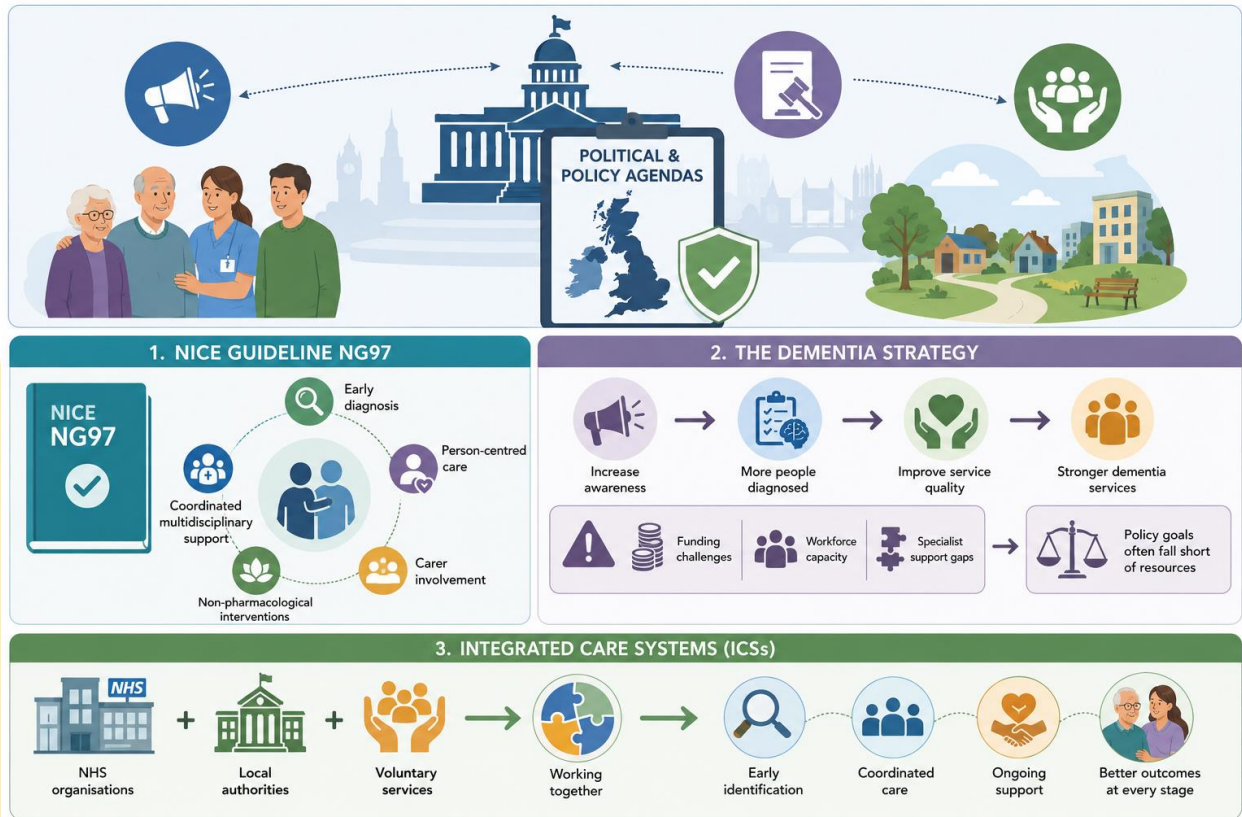


Critical comparison of the two frameworks

Both frameworks acknowledge the need for person-centred care, for example, and early diagnosis and support for carers. But they have different interests. The primary focus of the NHS Long Term Plan is service delivery in health systems, while the WHO framework focuses on a broader public health and societal lens.

The NHS model provides practical advice for clinical implementation in the UK setting.

On the other hand, the WHO model has a vision of long-term strategies for global prevention, awareness and social inclusion. These two are complementary approaches. The NHS model meets short-term health care requirements, while the WHO model is a step towards more fundamental societal change, which can have a future impact on outcomes (Health Education England, 2022).



Political and policy agendas

Policy is vital to the delivery of dementia services across the United Kingdom.

NICE Guideline NG97

The National Institute for Health and Care Excellence (NICE, 2018) guideline on dementia assessment, management and support continues to be a strong evidence base for practice. The guideline emphasises:

Early diagnosis
Person-centred care
Carer involvement
Non-pharmacological interventions
Coordinated multidisciplinary support

The Dementia Strategy

All of the successive dementia strategies in the UK have aimed to increase awareness, the number of people diagnosed with dementia, and to enhance service quality. The policies have helped to raise awareness and build up dementia services in the public domain. However, there are still issues to be addressed with respect to funding, the capacity of staff and specialist support. Policy goals often fall short of the available resources, creating a mismatch that hinders the effectiveness of policies (Giebel et al., 2020).

Integrated Care Systems (ICSs)

To enhance NHS organisations, local authorities and voluntary services working together, they have been introduced to the NHS through the use of ICSs. For people with dementia, integrated care could help to minimise fragmentation and enhance the continuity of support throughout the phases of the dementia pathway (Yu et al., 2018).

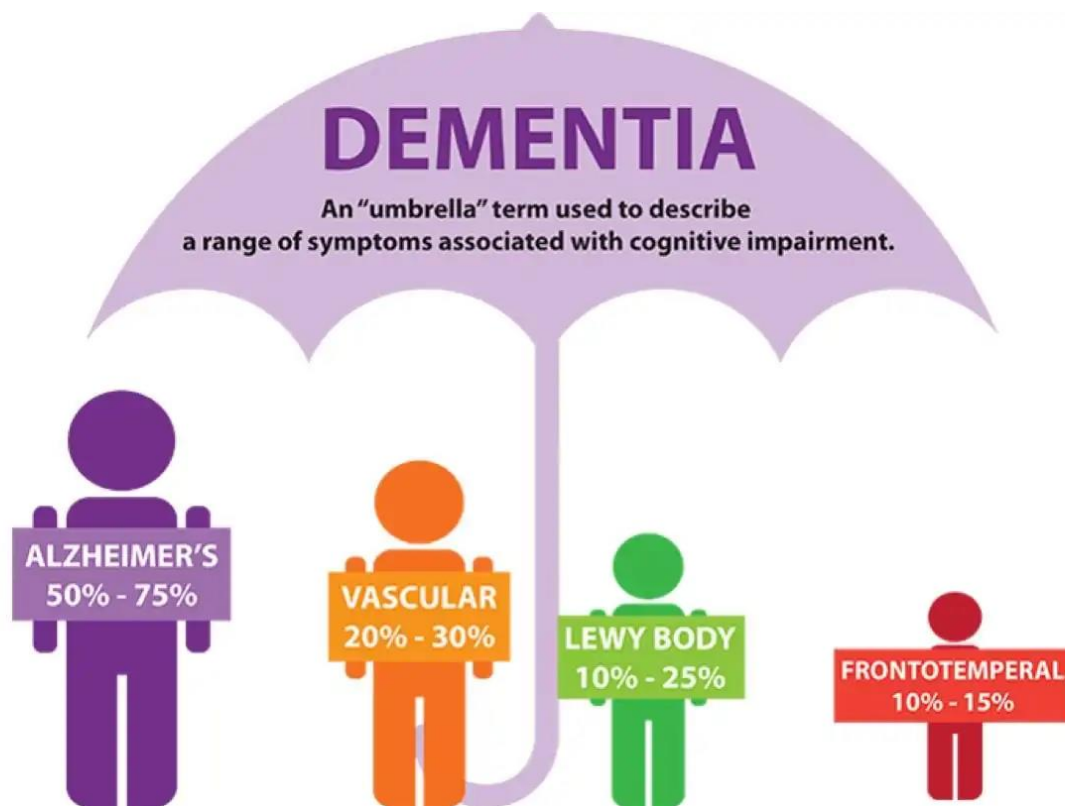
Recommendations

While a progressive condition, dementia still allows many people to be part of care decisions at an early stage of the disease. Professionals should assist with self-management by providing education and personalised care planning, and community resources.

Awareness and inclusion-building community-based programs can help destigmatise and improve social engagement. Dementia friendly environments enable people to continue being independent and participating in society for longer.

Technologies like telehealth, e-care plans, and assistive technology can help to promote independence and streamline care coordination. Implementations should, however, take into account barriers to access and to digital literacy.

Dementia is a condition that gets worse over time and will eventually be fatal. Therefore, the notion of end-of-life care should be a part of the disease process from the beginning rather than late in the disease's course.



Conclusion

Dementia is a long-term condition with many physical, psychological and social impacts for the person and their family. It is an increasing problem, both domestically and globally, in health and social care systems. The management of dementia needs to be based on evidence, delivered as integrated services, and be person-centred to recognise the individual's needs and preferences. Through actions that increase support for carers, encourage self-management, establish policy frameworks and optimise end-of-life care planning in the UK, healthcare professionals can help to improve the quality of life and outcomes for those living with dementia.

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