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Component 1

Title: Information Booklet of Long-term Condition Management



Dementia- Information Booklet

Living Well with Dementia: Community
Care and Management of a Long-Term
Condition in the United Kingdom

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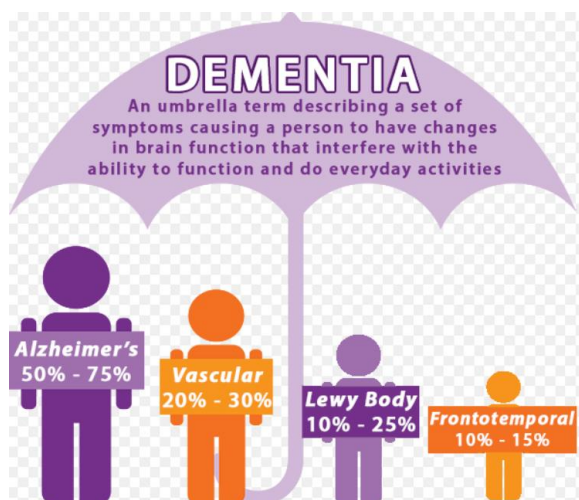
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Introduction

Dementia is a 'progressing neurological syndrome' that affects a person's memory, thinking, behaviour, communication and independence in everyday life (Dementia UK, 2024). It is caused by damage to nerve cells in the brain, which results in a loss of brain function from disease or injury that is greater than normal. Dementia is not simply an illness but a combination of diverse conditions such as Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Overall, about 60-70% of all dementia cases in the world are due to Alzheimer's disease (World Health Organization (WHO), 2025).

As dementia becomes more common, it has become a significant public health challenge worldwide (Public Health England, 2021). Population ageing, an increase in life expectancy and improved survival from other chronic diseases are responsible for this huge increase in the number of people with dementia. The WHO (2025) reports that more than 55 million people globally are currently living with dementia, and almost 10 million new cases are being identified every year. Nearly one million people in the United Kingdom have dementia, and this number is expected to rise significantly in the next few decades (Alzheimer's Society, 2024). The burden of the condition on health and social care systems is significant, and has an impact on the well-being of people, carers and families.

Treatment of dementia is only the beginning, and treatment should be comprehensive, addressing the physical, psychological and social needs of the person with dementia (Wittenberg et al., 2019). Person-centred care, the provision of self-management support, the role of integrated services in the



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community and multidisciplinary working are all part of modern health policy and practice, and are now prioritised to enhance the outcomes and quality of life for individuals with multiple long-term conditions. Supporting family carers whose care and support often have high emotional, physical and financial costs is also an important aspect of effective management (Brooker and Latham, 2016).

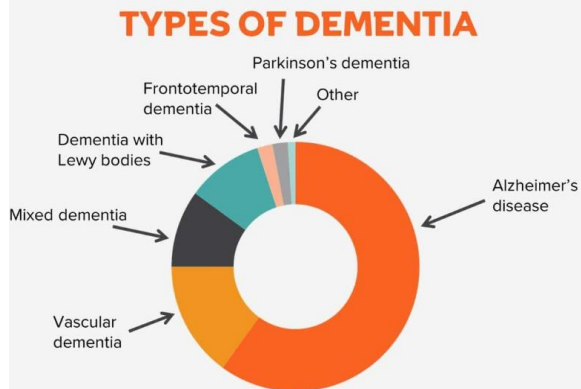
This information booklet looks at dementia in the UK critically as a long-term condition. It looks at the prevalence, burden and risk factors of dementia, assesses the individual and family impact of dementia, considers evidence-based support and treatment that can be accessed through the National Health Service (NHS), reviews key theoretical models and policy frameworks, and offers recommendations for improving person-centred care, self-management and long-term support for people experiencing dementia (Fazio et al., 2018; Surr et al., 2022).

Understanding Dementia: Definition, Prevalence and Aetiology

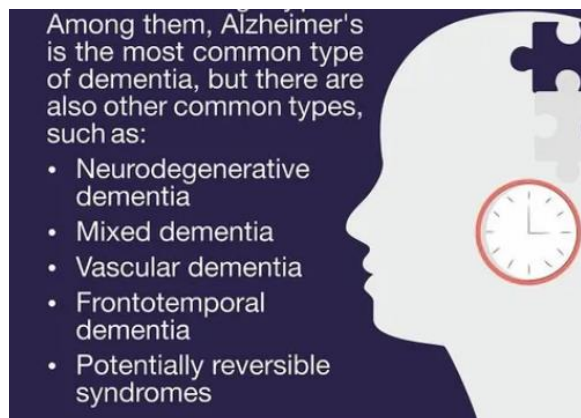
Dementia is a long-lasting and worsening condition in which a person's thinking and memory abilities decline to a level that is required for their age (Age UK, 2024). The disease involves problems with memory, learning, language, judgment, orientation, behaviour, and the performance of everyday tasks (Feast et al., 2016).

Dementia is caused by different types of disorders of the brain, which involve the destruction of brain cells and the loss of communication between the brain cells. While dementia is a common condition among older people, it is not a normal part of ageing and may also happen in younger people, i.e. young-onset dementia (WHO, 2025; Department of Health and Social Care, 2024).

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Alzheimer's disease is the most prevalent type of dementia, representing around 60-70% of dementia cases around the world. Other types of dementia are vascular dementia, dementia with Lewy bodies and frontotemporal dementia. They have different pathological features, but symptoms often overlap, while diagnosis and management can be difficult (NICE, 2024).



Dementia is becoming more common as life expectancy is increasing and the

ageing population. According to the World Health Organization (2025), more than 55 million people in the world are currently living with dementia, and by 2050, the number of people living with dementia in the world is estimated to reach 139 million. Dementia is now acknowledged as one of the most common causes of disability and dependency in older people in the world. In addition, economic cost relating to dementia amounts to more than \$1.3 trillion per year and includes the costs of healthcare, social care expenditure and the unpaid provision of social care (The King's Fund, 2023).

In the UK, dementia is a major public health issue. Around 1 million people in the UK are currently living with dementia, and this is likely to rise significantly in the next 20 years due to population ageing (Alzheimer's Society, 2024). Dementia is a major cause of death in England and Wales and a significant burden on the NHS, local authorities and informal carers. The cost of dementia to the UK economy has reached over £40 billion a year, much of which is due to our unpaid family care

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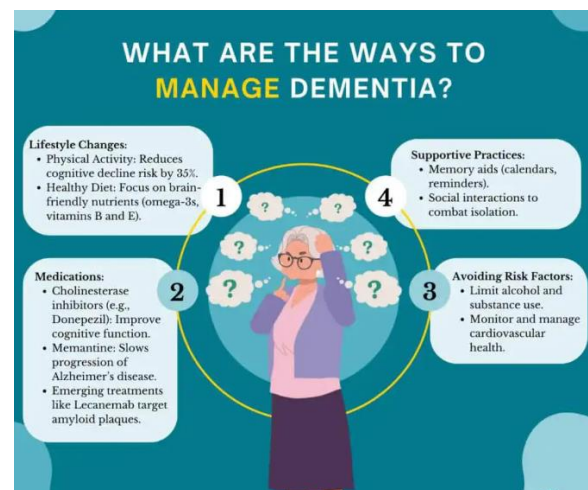
and social support needs (Alzheimer's Society, 2024; Tucker et al., 2020).

Dementia is a complicated condition, and there are several causes involving genetics, biology, environment and lifestyle. Alzheimer's is caused by abnormal clusters of proteins, called tau protein tangles and amyloid-beta plaques, in the brain.

In contrast, vascular dementia is caused by diminished blood flow to the brain tissue, typically as a result of stroke, high blood pressure, and/or cardiovascular disease. Recent studies have indicated the presence of several pathological processes often occurring together, especially in elderly people, making diagnosis and treatment difficult.

There are many factors that help to develop dementia, some of which can be changed. Non-modifiable risk factors are age and family history/genetic risk. The most important risk factor is age, i.e. the prevalence rises significantly with people over the age of 65 years. But, as the evidence increasingly shows, modifiable factors are important. These include smoking, obesity,

hypertension, diabetes, physical inactivity, excessive alcohol consumption, social isolation, hearing loss and low education (Livingston et al., 2024). By addressing these risk factors over the lifespan, as many as 45% of all dementia cases in the world could be prevented or delayed.



Most importantly, dementia is no longer a natural part of the ageing process, although now there are some prevention and management aspects to it. This view can assist public health efforts related to risk reduction, early diagnosis, and proactive management of people and families affected, working towards improving long-term outcomes (Brodaty and Donkin, 2019).

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Impact of Dementia on Individuals and Families

The physical, psychological and social impacts of dementia are profound and have a significant impact on the quality of life of people and their families. As the condition worsens, the need for increasingly complex care and for increasing dependency creates significant problems for formal health services and informal carers. Thus, a multi-faceted perspective is needed for effective dementia care to address these impacts (Brodaty and Donkin, 2019; Tucker et al., 2020).

Physical Impact

As the disease advances, the physical effects of dementia can be more evident. Some people may have trouble functioning, moving, coordinating or balancing, and doing activities of daily living, like dressing, eating and bathing. Frequently, cognitive impairment can make it difficult for the person to take

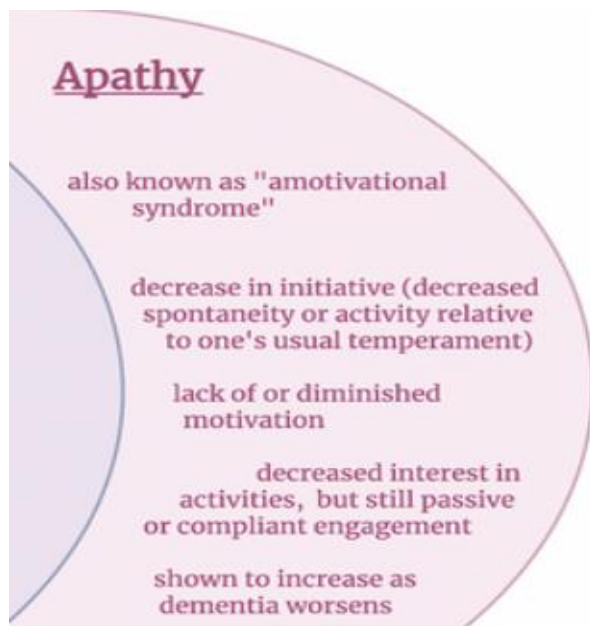
care of medications, get adequate food or identify environmental hazards, making them more susceptible to accidents and injuries. Falls, urinary incontinence and swallowing difficulties, along with increased weakness and susceptibility to infections, are common features of advanced dementia. These complications can lead to hospitalisation and increased health service use. But other experts say that a lack of community support may be a major cause of many physical problems in people with dementia, not the disease itself. This highlights the need for early intervention and for a comprehensive care plan (Brooker and Latham, 2016).

Psychological Impact

Psychological effects of dementia can be serious and can happen during the entire course of the illness. Frequently, these problems with memory, confusion and impaired decision-making result in frustration, anxiety and loss of confidence. Awareness of progressive cognitive decline and uncertainty about the future is what can cause depression after diagnosis in many people (Clare

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and wood, 2018). Around 90% of people experience behavioural and psychological symptoms of dementia (BPSD) at some point in their illness, such as agitation, aggression, hallucinations, apathy and sleep disturbances (NICE, 2024).



These symptoms contribute significantly to distress, reduced quality of life and increased caregiver burden. Some scholars have depicted that neurological deterioration is not the only factor that increases psychological distress in patients suffering from dementia, and that the stigma and discrimination of society can also contribute to the distress. Poor attitudes towards

dementia can cause people to isolate themselves from others, which only worsens their mental health and feelings of isolation (Feast et al., 2016).

Social Impact

Social relationships, community participation and independence are often affected by dementia. As the disease progresses, communication skills may be affected, making social interactions more difficult. People become less confident and feel less safe in participating in community activities, withdraw from social networks and from participating in meaningful occupations. The issue of social isolation is of particular concern as it can adversely affect physical and psychological outcomes. There is some evidence that people with dementia who have a high level of social engagement tend to have better emotional health and wellbeing and quality of life.

Consequently, the concept of dementia friendly communities and dementia care policies on social inclusion are now an integral component of the current dementia care policy landscape.

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Financial worries are also a factor, as people are forced to retire early or require a significant amount of support services. These economic impacts can affect the patient and family, and can negatively affect well-being and cause further stress.

It doesn't just affect the individual

Dementia has physical, psychological, social and economic impacts – not only for sufferers but also families and communities.

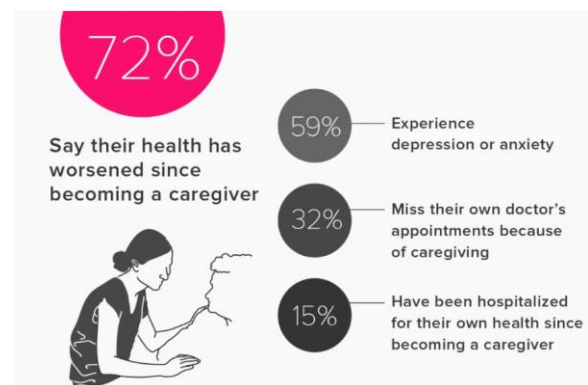
The more the disease progresses, the greater the need for help with personal care.

Those with dementia become stigmatised, creating barriers to diagnosis and care, which often result in irreparable damage to relationships.

Impact on Families and Informal Carers

Families are expected to be the main caregivers of people with dementia.

Care-giving relationships can be fulfilling and reinforcing, but can also be a heavy physical, emotional and economic commitment. Chronic stress, anxiety, depression and social isolation are very common in family carers (Brodaty and Donkin, 2019). A large number of people say they struggle with work and family life. Some studies have shown that carers of people with dementia are more psychologically distressed than other carers of people with long-term health conditions (Alzheimer's Society 2024).



Other financial pressures can also occur due to reduced employment, increased household spending and the costs of accessing formal care services. In extreme cases, the carers' own health may suffer due to their caregiving responsibilities, leading to increased risk

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of chronic diseases and burnout. Policy has acknowledged the need to recognise carers' contribution, but there is no clear picture of carers' support in the UK. Carers often have limited respite care, lack training and are unable to receive services which are integrated and continuous. So, better support for carers should be embedded within person-centred dementia care (Fazio et al., 2018; Tucker et al., 2020).

Evidence-Based Treatment and Management within the NHS

There is no cure for dementia, so treatment is about managing the symptoms, keeping people independent and improving their quality of life (Giebel et al., 2021). The NHS has a multi-disciplinary focus, with medical, psychological and social interventions.

Pharmacological treatments can involve the use of cholinesterase inhibitors like Donepezil, Rivastigmine and

Galantamine in mild-to-moderate Alzheimer's disease. Moderate to severe dementia, with symptoms that are progressing, may require the use of Memantine. These drugs might temporarily enhance cognitive performance, but research shows that they may have only mild effects and fail to stop or slow down the progression of the disease (Clare and wood, 2018).

Non-pharmacological interventions are also very important. There is evidence that cognitive stimulation therapy (CST), reminiscence therapy, physical activity programmes and occupational therapy are all effective treatments for cognitive functioning, wellbeing and daily functioning. To treat behavioural symptoms, non-pharmacological interventions are recommended as a priority (NICE, 2024).

The NHS also offer memory assessment services which help to detect and plan for memory problems at an early stage. Early diagnosis allows for access to support services, financial support and care planning for the future. But, there are still differences between

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the regions in terms of diagnostic rates and access to specialist services (Feast et al., 2016).

EARLY STAGE:

- Trouble remembering recent events
- Difficulty recalling names
- Frequently loses personal items



It is recognised that having a good community care plan is essential to effective dementia care and management. A multidisciplinary team of General Practitioners, nurses, OT, psychologists, and a dementia specialist to provide coordinated support. This is in line with the principles of person-centred care, meeting medical, psychological and social requirements (Feast et al., 2016).

While dementia services have made significant improvements in the NHS, there are still issues. Accessibility of

services remains restricted by a lack of staff and by growing demands and resource limitations. Therefore, more investment is needed to bring high-quality dementia care to those in need and to ensure that this care is equitably accessible across the UK (Brooker and Latham, 2016).

Models for Long-Term Condition Management

The House of Care Model

The House of Care Model has been created to enhance the management of long-term conditions with a person-centred, coordinated approach to care. Collaborative care planning, informed decision-making and active patient involvement are highlighted in the model. These four elements are the basis of the model, i.e. engaged individuals, partners between individuals and health service professionals, organisation structure and processes to support integrated working and

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commissioning processes. One of the key elements of the House of Care Model is the focus on shared decision-making and holistic assessment. The model has a focus on person-centred care planning for those with dementia, taking into account physical, psychological and social needs. But, in practice, there can be difficulties as a person's cognitive ability to engage in decision-making may diminish (Fazio et al., 2018).

The Chronic Care Model

Based on Wagner et al.'s (2017) Chronic Care Model, the model emphasises proactive and coordinated management of chronic diseases based on six key components: self-management support, delivery system design, decision support, clinical information systems, community resources and health care organisation. The model has been shown to improve patient outcomes in a large number of chronic conditions and has been widely implemented globally (Alzheimer's Disease International, 2024). It advocates for early intervention and

integrated service delivery with regard to dementia care. However, critics say that the model was developed specifically for chronic diseases that are physically oriented and that it may not fully represent the complex cognitive, social and psychological burden of dementia. As such, adaptations are often necessary to meet the specific needs of people living with dementia (Feast et al., 2016).

Comparative Evaluation

Both models focus on person-centred and integrated care, but the House of Care Model places greater emphasis on collaborative care planning in the UK healthcare system. The Chronic Care Model, on the other hand, is a more comprehensive systems-based approach that is relevant globally. There may be a strong need to integrate the best of both models to manage dementia (Fazio et al., 2018).

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Critical Analysis of Long-Term Condition Models

Care for people with dementia is evolving, and there is a growing acceptance of the need to have a number of models of care to meet the complex and changing needs of people with dementia. The House of Care Model is a good model for managing chronic conditions, as is the Chronic Care Model. These must be implemented successfully within local health care systems. Evidence indicates that these models can be effective in achieving their goals when linked to a positive culture, staff capabilities, funding and interprofessional working within the organisation (NHS England, 2024).

Both models are good at encouraging proactive rather than reactive care. Conventional health care solutions tend to be reactive and react only when things are in a crisis. These models encourage early intervention and prevention measures as well as ongoing monitoring, especially in the context of dementia, where early care can prevent

functional decline and enhance quality of life. In addition, both frameworks acknowledge the need to include community resources and social support systems with clinical services (Royal College of Psychiatrists, 2023).

But there is a problem with implementation, as critics say, it is not uniform in healthcare facilities. Different levels of local provision may lead to differences in access to specialist support for dementia, multi-disciplinary teams and personalised care planning. Also, both models encourage a patient's participation in decision-making, but cognitive decline can restrict a person's ability to participate in decision-making activities. It is therefore not unusual for family carers to be major players in care planning and service co-ordination (Brodaty and Donkin, 2019).

Managing dementia, therefore, could be a combination of both approaches, i.e. person-centredness, as in the House of Care Model and a systematic and integrated type of approach, as in the Chronic Care Model. This would more accurately capture the multi-faceted

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nature of dementia and lead to more holistic, coordinated and sustainable long-term care outcomes (Fazio et al., 2018).

Health and Social Care Policies Influencing Dementia Care

There are policies at national and international levels in the UK that seek to enhance diagnosis, treatment and long-term support for dementia care (Prince et al., 2023). The NHS Long Term Plan focuses on earlier diagnosis, community services that are integrated and better support for people with a dementia diagnosis. Likewise, NICE Guideline NG97 gives evidence-based guidance on assessment, diagnosis and delivery of treatment and care (Nuffield Trust, 2023). The WHO Global Action Plan (2017) on the Public Health Response to Dementia has a global goal to increase awareness, decrease stigma, enhance diagnosis and strengthen research efforts all over the

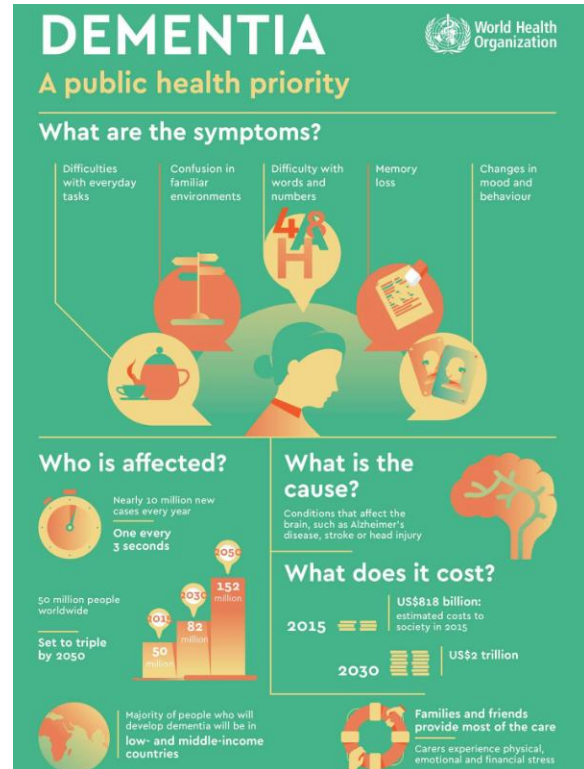
world. Although all these policy developments have taken place, there are implementation difficulties. Care quality continues to be impacted by regional inequalities in service provision, limited workforce and funding (Department of Health and Social Care, 2022). Importantly, policies continually promote person-centred, integrated care, while on the ground, this is rarely delivered. Lack of improvement in partnerships between healthcare organisations, local authorities and voluntary sector providers leads to problems in handling (Fazio et al., 2018).

Actions for Improving Person-Centred Dementia Care

There are multiple approaches that might improve the management of the disease of dementia and achieve better outcomes for the patient. First, the public needs to be made aware of the possibility of earlier diagnosis, and access to services for memory

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assessment needs to be expanded (Public Health England, 2021). Early intervention allows the treatment to be instituted and the future care program to be planned. Second, there is a need to make better use of multidisciplinary working by improving the involvement of healthcare and social care professionals to deliver coordinated, integrated services. Thirdly, there is a need for increased investment in care-giving services (Bunn et al., 2020). Easy access to respite care, education programs and psychological assistance can substantially lessen caregiver burden and enhance the sustainability of home-based care (Owen et al, 2021). Fourth, digital technologies, including remote monitoring systems, assistive devices and telehealth services, should be increased and used for supporting independence and safety. Lastly, advance care planning and long-term conversations would be better to deal with earlier in the illness, with a view to ensuring care remains in keeping with personal preferences and values (Downs and Bowers, 2018).



Conclusion

Dementia is a complex and progressive long-term condition which poses a challenge to the individual, family and health services around the world. Its importance has grown as it has become more prevalent and has been accompanied by rising life expectancy, especially in the United Kingdom. The condition impacts physical functioning, psychological well-being and social participation and creates a significant emotional and financial burden for family members taking care of the condition.

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There is no cure, but interventions that have been proven to work and delivered in the NHS can help to improve quality of life and maintain independence. The House of Care Model and Chronic Care Model are useful models for supporting person-centred and integrated care. But often the limits of drive-in policy stem from resource constraints and service fragmentation. Future improvements need to be directed at earlier diagnosis, improved community support, improved health and social care service integration and increased support from the caregiver. By adopting a holistic and person-centred approach, people with dementia can have the best possible outcomes for their future and continue to live a dignified life with an enhanced quality of life along the journey of dementia (NHS England, 2019).

Useful Links

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