Dementia

# Summary

## Introduction

Dementia describes a group of symptoms that include problems with memory, thinking or language, changes in mood, emotions, perception and behaviour. The most common types are Alzheimer’s Disease and Vascular Dementia which will account for around 70-80% of total cases nationally. Dementia is the leading cause of death in England. In 2019, the total cost of dementia in England amounted to £29.5 billion. Costs are predicted to increase to £80.4 billion by 2040.

## Key issues and gaps

Between April 2019 and March 2020, the Medway population had a significantly lower dementia diagnosis rate of 52.8% compared to the overall Kent and Medway average (59.6%). It was also significantly lower than the England average (67.4%). An earlier diagnosis of dementia can help people with dementia to have access to relevant information, resources and support, make the most of their abilities and potentially benefit from drug and non-drug treatments available.

It is projected that there will be 4,635 people aged 65 and older who are living with dementia in Medway in 2030. This presents a 46.2% growth compared to 2019. The highest increase is projected in the number of people with severe dementia which may mean that associated health and social care costs are projected to increase significantly. The need for dementia support services will therefore substantially increase in the future.

## Recommendations for commissioning

1. Initiatives that will help recognise the true dementia diagnosis rates in primary care such as the Diagnosing Advanced Dementia Mandate (DiADeM) tool should be actively promoted. Furthermore, the benefits of receiving a diagnosis should be emphasised to encourage people to seek a formal diagnosis. This will include addressing stigma related issues. Targeted work should be undertaken by GPs with Enhanced Role (GPwERs) and dementia co-ordinators with healthcare professionals in areas with significantly lower diagnosis rates than the Medway and national averages.
2. The remote memory assessment tool for dementia assessment and diagnosis should be promoted to GPs by dementia co-ordinators to offer more varied services and strengthen patient choice.
3. Everyone can contribute to making Medway more dementia friendly. The Alzheimer’s Society defines a dementia-friendly community as a ‘city, town or village where people with dementia are understood, respected and supported’. The Medway Dementia Action Alliance, formed in 2015, is striving to make Medway more dementia friendly. Commissioners should look to ensure the Medway Dementia Action Alliance is adequately resourced.
4. Commissioners should ensure that there is continuation of the role of dementia co-coordinators who should work with support groups such as Carers First to raise awareness of the dementia connect support telephone line administered by Alzheimer’s UK. This will help families and carers to access appropriate support.
5. The offer of respite care and support services that includes community support officers should be expanded, particularly in light of projected increases in the number of people living with dementia in the future. This will enable informal carers and families to take a break from caring whenever needed.
6. There is a lack of capacity in the care and nursing home settings to support people living with dementia. Health and social care commissioners need to take account of the projected increases in the number of people living with dementia and align commissioning intentions through the market positioning statement to ensure appropriate capacity is in place within the community residential and nursing home sectors.
7. Dementia awareness training should be resourced and offered annually to staff in public and private sector organisations. This should be reviewed by the local dementia partnership.

# 1) Introduction

Dementia is “a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning”.1 Dementia is used as an umbrella term to summarise various forms of cognitive deterioration including Alzheimer’s disease and vascular dementia2 (Table 1). Each form of dementia is linked to different brain cell damage in particular regions of the brain.3 Table 1 gives an overview of the most common types of dementia and their prevalence, cause, and early and middle-stage symptoms. There is currently no cure for dementia.3

***Table 1****:* *Most common types of dementia and their causes and symptoms*3

|  |  |  |  |
| --- | --- | --- | --- |
| **Type of dementia** | **Estimated Prevalence**4 | **Cause** | **Early and middle-stage symptoms\*** |
| **Alzheimer’s disease** | 50-75% | Formation of ‘plaques’ and ‘tangles’ in the brain, causing nerve cells to die and brain tissue to be lost | Difficulties with memory, difficulties with thinking, reasoning, language or perception |
| **Vascular dementia** | Up to 20% | Reduced oxygen supply to the brain due to narrow or blocked blood vessels, causing some brain cells to be damaged or die. | Difficulties with problem-solving or planning, thinking quickly or concentrating, short periods of confusion; difficulties with memory, language, spatial awareness and mood changes may also occur. |
| **Mixed dementia** | At least 10% | Multiple types of dementia; the most common being a combination of Alzheimer’s disease and vascular dementia | A mixture of the symptoms of the respective types of dementia |
| **Dementia with Lewy bodies** | 10-15% | Lewy bodies (tiny structures) form inside the brain where they should not, disrupting brain activity and causing brain cells to die | Problems with mental abilities and alertness, hallucinations and delusions, movement problems, sleep disturbance, problems with how the body works; many symptoms are similar to Parkinson’s disease symptoms |
| **Frontotemporal dementia (including Pick’s disease)** | 2% | Damaged front and side parts of the brain due to small clumps forming inside nerve cells, causing nerve cells to die | Changes in personality and behaviour; difficulties with fluent speech or forgetting the meaning of words, but symptoms depend on which areas of the brain are damaged |

\*Symptoms can differ for every person and the list given in the table is not exhaustive

Tackling the impact of dementia is a major public health priority. It is the leading cause of death in England1. It is a progressive condition that has a devastating effect, on the person with dementia, their families, carers, and wider society.

In 2019, the total cost of dementia in England amounted to £29.5 billion. The majority of the cost (£13.6 billion) was incurred by social care (46%). Unpaid families and carers bore 40% of the financial burden (£11.8 billion). Health care costs were 14% of the total (£4.1 billion)5. The total cost associated with dementia is expected to increase to £80.4 billion in 2040.

# 2) Who’s at risk and why?

In 2022, an estimated 944,000 people across the UK are living with dementia.6 In England, an estimated 748,000 people are living with dementia.5 In England the majority of people diagnosed (434,600), have severe dementia followed by moderate dementia (206,300), and mild dementia (107,100). The number of people with severe dementia may be as a result of the progressive nature of this disease. It may also reflect issues such as late diagnosis. Between 2019 and 2040, the number of people with dementia in England is projected to rise by 81% to 1.35 million. The majority of this increase is expected to be people diagnosed with severe dementia (an increase of 109%).5 This means that the number of people with severe dementia is projected to double in the next 20 years as a result of an aging population.

Although most people who have dementia in the UK are above the age of 65, over 42,000 individuals under 65 have dementia.7 These people may experience increased stigma and various other difficulties relating to employment and childcare.8 Almost two-thirds of people with dementia are female (62%), while one-third are male (38%). Dementia is the leading cause of death for women with 45,922 female deaths in 2020.9 Women are also more likely to care for someone who has dementia.8 Depression and feeling isolated are common among carers, which are also risk factors for developing dementia. Additionally, female dementia carers report feeling less supported than male carers.8

Patients who are diagnosed with dementia often have other physical health problems. In a UK study, 77% of dementia patients had at least one comorbidity. A comorbidity refers to where a person has two or more long term conditions at once. About 45% had two or more comorbidities, 22% had three or more comorbidities, and 8% had four or more comorbidities. Common comorbidities include hypertension (44%), diabetes (20%), stroke or transient ischaemic attack (TIA) (18%), coronary heart disease (CHD) (18%), depression (17%), Parkinsonism (11%), chronic obstructive pulmonary disease (9%), and asthma (8%).10

The National Institute for Health and Clinical Excellence (NICE) and the Alzheimer’s Society report various fixed and modifiable risk factors for dementia.11

## Fixed risk factors

These are risk factors that cannot be shown to change and include age, gender, learning disability, ethnicity, and genetics.

### Age

Age is the most critical risk factor for dementia.11 Brain damage can develop slowly over time, with the risk of development rising exponentially with age.5,11,12 Above the age of 69, the risk of developing dementia doubles approximately every five years.12 While two in every 100 people aged 65 to 69 have dementia, approximately 33 in 100 people over 90 years have dementia. Furthermore, aging individuals are likely to develop health conditions recognised as risk factors for dementia. This includes high blood pressure, damaged, twisted, or blocked blood vessels in the brain, stroke, less active brain cells, a weaker immune system, and a slower ability to recover from injuries.12

### Sex

More women than men have dementia.12 It is likely that this is attributable to women living longer than men on average.8,12 Although the risk of developing dementia is approximately equal for men and women, women above 80 years old currently have a higher risk of developing dementia than men of the same age.12 This may be due to lifestyle differences; for example, women typically have had more limited access to education and work opportunities than men. Gender also intersects with other risk factors: women are more likely to care for someone with dementia, resulting in feeling isolated and depressed which can increase the chance of developing dementia.8 Although the evidence is inconclusive, it has been suggested that an earlier onset of menopause may lead to an increased likelihood of developing dementia.

### Learning disability

Down’s syndrome and other learning disabilities are linked to a highly increased risk of developing dementia at a younger age, usually through Alzheimer’s disease.12 The prevalence of dementia is four times greater in people with a learning disability compared to the general population.8

### Ethnicity

Some evidence suggests that people from Black African, Black Caribbean or South Asian ethnic groups are at an increased risk of developing dementia, compared to White ethnic groups.12 The prevalence of dementia is up to four times higher in Black and South Asian ethnic groups.8 The number of people from Black and South Asian ethnic groups with dementia is expected to increase significantly over the coming decades.8 One suggested reason for the discrepancy in prevalence is the higher risk of developing diabetes and cardiovascular disease for these ethnic groups compared to White ethnic groups.12

## Modifiable risk factors

Modifiable risk factors are behaviours and exposures that can be changed to reduce risk. They include lower educational attainment, hypertension, hearing impairment, smoking, obesity, depression, physical activity, diabetes, low social engagement and support, alcohol consumption, traumatic brain injury (TBI) and air pollution.11

It is estimated that around one third of dementia cases can be attributed to modifiable lifestyle risk factors13. However, misconceptions around dementia remain widespread. About a quarter of the British adult population think that the risk of developing dementia cannot be reduced, and 65% cannot identify more than two risk factors.14

A person’s ability to cope with disease in their brain is referred to as ‘cognitive reserve’. Cognitive reserve is developed by keeping the brain active throughout life. A large cognitive reserve can postpone the onset of dementia symptoms, while a smaller cognitive reserve increases a person’s risk of developing dementia.12

Various health conditions and diseases have been linked to an increased risk of developing dementia. This includes cardiovascular factors comprising high blood pressure, atherosclerosis, high blood cholesterol levels, being overweight and physically unfit, and type 2 diabetes. The association between these risk factors and dementia is strongest for vascular dementia. Generally, these risk factors start to influence the risk of developing dementia in a person’s mid-life, ranging from 40 to 65 years of age.12

Various lifestyle factors are associated with an increased risk of developing dementia, including physical inactivity, smoking, unhealthy diet, and a too high consumption of alcohol.12 In particular, smoking doubles the risk of dementia and is thus one of the most important lifestyle risk factors for dementia.15

# 3) The level of need in the population

Between April 2019 and March 2020, the Medway population had a significantly lower diagnosis rate of 52.8% compared to the overall Kent and Medway average. It was also significantly lower than the England average. This could mean that there is an underdiagnosis in Medway resulting in people not accessing treatment and support at the earliest possible stage. An earlier diagnosis of dementia can help people with dementia to have access to relevant information, resources and support, make the most of their abilities and potentially benefit from drug and non-drug treatments available. Table 2 highlights the differences as well as the variation in Medway at for each Primary Care Network (PCN). There is significant variation across Medway, with diagnosis rates being lowest in Strood and Peninsula PCN areas.

***Table 2:*** *Dementia* *diagnosis rates at PCN area level*16,17

|  |  |  |  |
| --- | --- | --- | --- |
| **Area name** | **Recorded 65 and over** | **Expected 65 and over** | **Diagnosis rate (%)** |
| England | 454,599 | 674,912 | 67.4% |
| Kent and Medway | 13,970 | 23,451 | 59.6% |
| Medway | 1,530 | 2,801 | 51.3% |
| Gillingham South | 154 | 311 | 49.5% |
| Medway Central | 298 | 316 | 94.3% |
| Medway South | 205 | 487 | 42.1% |
| Peninsula | 150 | 397 | 37.8% |
| Rainham | 348 | 674 | 51.7% |
| Rochester | 227 | 349 | 65.1% |
| Strood | 98 | 267 | 36.6% |

Due to the relatively small number of recorded people at each PCN area, caution is needed when interpreting these data. There are limitations when assessing dementia prevalence data at a small area level. For example, some PCN rates may be high if a large number of care homes are located within that PCN compared to another PCN. Caution must therefore be taken when looking at the numbers

***Table 3:*** *Dementia care plan that has been reviewed in the past 12 months 2020/21 at PCN area*18

|  |  |  |  |
| --- | --- | --- | --- |
| **Area name** | **Rate** | **Lower confidence interval value** | **Upper Confidence interval** |
| England | 39.7 | 39.4 | 39.9 |
| Kent and Medway | 36.8 | 35.5 | 36.1 |
| Gillingham South | 44.8 | 33.0 | 52.5 |
| Medway Central | 33.0 | 26.4 | 40.4 |
| Medway South | 32.6 | 23.9 | 42.7 |
| Peninsula | 21.0 | 13.5 | 31.0 |
| Rainham | 56.3 | 48.0 | 64.4 |
| Rochester | 32.3 | 23.4 | 42.6 |
| Strood | 45.5 | 31.1 | 60.6 |

NHS guidance states that dementia patients should have their care plan reviewed every 12 months as they are more likely to maximise their physical and mental wellbeing. There was variation across the different PCN areas in Medway in terms of the proportion of patients who have been followed up for their care plan review. Most areas are statistically similar to the England average, although the Rainham PCN area has a statistically higher proportion of patients followed up and Peninsula PCN has a statistically lower proportion.

# 4) Current services in relation to need

In response to the growing elderly population, and in turn the increasing number of dementia diagnoses, Medway offers a variety of local services. The current dementia pathway in Kent and Medway is illustrated in Table 4.

***Table 4:*** *Dementia pathway in Kent and Medway.*

|  |  |
| --- | --- |
| **Dementia pathway** | **Description** |
| Raising awareness and prevention | Improved public awareness, safeguarding awareness. Communities become dementia friendly. |
| Improving diagnosis | Individuals and their families are able to access timely and accurate diagnosis. |
| Support after diagnosis | Ongoing support and advice to enable people to continue to live well with dementia, including advanced care planning. |
| Supporting carers | Ensuring carers are able to access the right support at the right time to enable them to continue in their caring role and have a life of their own. |
| Care at home | People with dementia are able to access high quality health and social care to enable them to remain independent for as long as possible. |
| Care in hospitals and care homes | People with dementia receive high quality care in both care homes and hospital, and admission to hospital is avoided where possible. |
| End of life care | People living with dementia are able to die with dignity in the place of their choosing. |

The Kent and Medway Dementia Strategic Improvement Group (SIG) is currently devising a new Dementia strategy for Kent and Medway, guided by the following vision:

***“Every person with dementia, their carers and families are supported to live well and as independent as possible, receive high quality, compassionate care from diagnosis through to end of life care. This applies to all care settings, whether home, hospital or care home.”***

As part of this strategy, various new services and system changes are planned across the dementia pathway, some of which will be explored below.

The COVID-19 pandemic has affected dementia support service provision and service users. There has been a significant increase in the use of mental health services and wellbeing support. Among community mental health services for older people (CMHSOP), Kent and Medway have reported a 10.7% increase in contacts since April 2020.19 Research from the Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS) shows that the effects of the COVID-19 pandemic were challenging for many carers and individuals living with dementia, particularly for carers who are women, spouses, people living with a person with dementia, and people living in more deprived areas.20 Nevertheless, some also welcomed the increased simplicity of life that the pandemic brought. There have also been positive changes among services which can be expanded, including greater use of technology, flexible work patterns, and increased collaboration across a series of organisations.19

## Primary care

The majority of diagnoses are currently performed by Kent and Medway NHS and Social Care Partnership Trust (KMPT). Since the release of the 2014 JSNA, Kent and Medway have outlined a series of projects which aim to increase diagnostic abilities. Services projects include transformation to KMPT memory assessment pathways and an increased number of professionals that are able to perform diagnostic testing. A number of new initiatives are currently being introduced with many aiming to raise diagnosis rates in primary care. The DiADeM tool21 is being promoted to help GPs diagnose care home residents who have advanced dementia.

Furthermore, ten GPs with Enhanced Roles (GPwERs) across Kent and Medway are currently undergoing training to be able to offer memory assessment services. The GPwERs will also provide diagnosis and peer support to other GPs. Another issue is related to coding and data conversion between different systems which leads to some cases not being recorded on the dementia register. To address this, a Data Quality Toolkit for primary care has been developed and its use is currently being promoted. The tool helps to identify patients who have dementia but are not on the dementia register. Additionally, iRefer will be introduced to enable GPs to refer patients for diagnostic images. A remote memory assessment toolkit has been recently launched by Sussex Partnership NHS Foundation Trust (SPfT) and Brighton and Sussex Medical School, following a study that found high satisfaction with remote memory assessments among patients and carers.22,23 This can provide a valuable alternative to face-to-face appointments by improving access and patient choice of memory assessments.

In addition, the *Remote Memory Assessment Toolkit* (RMAS) seeks to deliver remote services to dementia patients. This tool is a bi-product of the diagnostic techniques developed during the COVID-19 pandemic. The toolkit offers evidence-based recommendations for commissioners, service managers and memory assessment clinicians to embed remote memory assessments among their services.23 Findings have suggested a significant positive experience for most patients and carers who have used RMAS and report it should be a modality option past the pandemic to increase access and patient choice.22

In addition to diagnostic services, Medway is seeking to improve dementia coordination services. A dementia care coordinator role will be provided for each PCN. Since September 2021, three coordinators are already in place across Medway, with more planned. The coordinator, who is assigned at the point of referral, will provide consistent support to people living with dementia and their carers and family throughout the dementia progression journey.19

Furthermore, Medway offers admiral nursing services. Admiral nurses are qualified Mental Health Nurses (RMN’s) with additional training to work with individuals with dementia. The recent Kent and Medway Combined Commissioning Group (CCG) strategy reports three admiral nurses in Medway. For these services, Medway offers an open referral system, meaning the patient does not need to be involved with any other service type. This service provides expertise and support among diagnoses, living with dementia, and end-of-life stages. The nurses offer a holistic assessment of family members caring for individuals with dementia, emotional and psychosocial support, sufficient dementia educational information, medication advice, health promotion, risk management, liaise with other clinical professionals and many other services. Admiral nurses seek to bridge primary and secondary care services effectively.24

## Secondary care and community care

Current services offer a range of support for individuals living with dementia, their families and care providers. Dementia services offered tend to operate differently within each area through a combination of commissioned and voluntary services.

Currently, Medway reports a series of peer support and group services specifically for dementia. The Alzheimer’s Society runs a dementia café which offers a friendly and supportive meeting place for people with dementia and their carers. Typically, this service is offered once a month in Chatham, Hoo, and Rainham.25 The Parish of Rochester organises the Rochester Dementia Memory Café every fourth Friday of the month. Additionally, the Alzheimer’s Society provides a Peer Support Group which targets individuals who are newly diagnosed with dementia. The group meets twice a month for three hours to discuss daily living and to explore shared experiences.

Additionally, day services are offered to individuals living with dementia. Age UK Medway offers specialist day care for patients with dementia, deploying services from two centres.26 Their services strive to provide respect, dignity and choice, while maximising opportunities for older individuals living with dementia. This particular service provides both practical help and support through a person-centred approach. The day includes two course meals, drinks, snacks, and a series of patient specific programmes. This service aims to improve daily living skills, encourage interests, enhance wellbeing, build relationships and confidence, maintain independence, and reduce isolation.

Zest workshops are a series of themed sensory activity sessions that bring a fun energy to individuals living with dementia offered in the Medway area.27 Activities including song, movement, music, story making, puppetry and other activities that can stimulate senses. Typically, the programme is offered to groups of 15 for approximately one and a half hours.

Most recently, the dementia crisis support services was implemented to support individuals living with dementia and their carers who live at home seeking to promote independent living.28 This particular service can provide short term support and home treatments for challenging behaviours, assessment of patients current physical and mental health needs, educational enhancement of carers skills, signposting any necessary additional services, and support early discharge of patients admitted to Medway Maritime Hospital or KMPT.

Kent Social Care Professionals Medway Branch is an additional service offered to individuals living with dementia. This service offers professionals who are specifically trained in dementia care the expertise and ability to successfully communicate and comprehend the patients’ needs.29 Typically this service offers activities such as conversation, music, story-telling, reading, walking, knitting, swimming, gardening and many more. These services are easily offered from the comfort of the patient's home.

## Residential services

Version 2 of the Framework for Enhanced Health in Care Homes (EHCH) was published by NHS England in March 2020 and should be fully implemented across England by 2024.30 The model aims to take a more proactive approach towards care that focuses on the needs of care home residents, their families, and care home staff. This includes assigning every care home to a named PCN and its multidisciplinary team (MDT), which conducts a weekly ‘home round’, as well as best practice recommendations for dementia care. Within Medway there are 12 independent sector nursing homes registered with the Care Quality Commission (CQC), with a larger majority of these providing support to elderly individuals, with many of them likely having degrees of dementia. As reported in the 2014 Dementia JSNA, Medway lacks nursing homes which provide care to individuals presenting complex and challenging needs as an outcome of their dementia. As a result, a pilot scheme was conducted to provide these care homes with additional support through the implementation of a multidisciplinary team using the integrative care model. The aim of the pilot was to improve both standard of care and decreased reliance on secondary care services.

Additionally, Medway Community Healthcare (MCH) runs the Darland House which provides live-in nursing services to older individuals with mental health needs.31 The Darland House is a modern style nursing home that offers residential care to individuals with mental health diagnoses such as Alzheimer’s and other forms of dementia. This service is specifically provided to individuals located within the Medway and Swale areas, having a total of 40 permanent beds available. The Darland House offers 24-hour holistic, person-centred care, while providing a clean, homely living environment. The staff pride themselves on promoting independence and individual choice to their residents. The Darland House was given a ‘Good’ rating in 2021 by the CQC.

## Telephone helpline and crisis services

Over the past ten years there has been a reported continuation of helpline and crisis services provided to assist individuals living with dementia and their carers. Organisations such as the Alzheimer’s Society provide a dementia telephone support line available to all individuals living within the UK seeking support advice or information.32 Additionally, the Age UK Advice Line is operated by Age UK and provides free and independent advice every day.33 Dementia UK also operates an Admiral Nurse Dementia Helpline.34 Furthermore, the Admiral Nursing DIRECT is a national helpline and email service which offers expert clinical and emotional support for families, professional carers, dementia patients and others worried about their memory.35 In Medway this particular service is provided by Medway Community Healthcare in partnership with Dementia UK.

# 5) Projected service use and outcomes in 3-5 years and 5-10 years

It is projected that the number of people aged 65 and over with dementia in Medway will increase by 46.2% until 2030, from 3,170 people in 2019 to 4,635 people in 2030 (Table 5). In 2025, an estimated 3,914 people will be living with dementia in Medway, a 23.4% increase compared to 2019. Although the number of people with dementia will increase for each severity category, the largest increase is projected for severe dementia, which is estimated to rise by 62.7% by 2030.5

***Table 5:*** *Projected number of older people living with dementia by severity (persons) in Medway*5

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Measure** | **Count 2019** | **Count 2025** | **Growth 2019 to 2025 (%)** | **Count 2030** | **Growth 2019 to 2030 (%)** |
| Total number of people living with dementia aged 65 and over | 3,170 | 3,914 | 23.4% | 4,635 | 46.2% |
| People living with mild dementia aged 65 and over | 449 | 509 | 13.4% | 591 | 31.6% |
| People living with moderate dementia aged 65 and over | 887 | 930 | 4.8% | 1,059 | 19.4% |
| People living with severe dementia aged 65 and over | 1,835 | 2,475 | 34.9% | 2,985 | 62.7% |

The projected total cost of dementia in Medway is projected to increase from £130 million to £233 million in 2030, a 79.4% increase (Table 6). Until 2025, costs are estimated to rise by 37.7% from £130 million to £179 million. Costs will increase for all sub-categories of health care, social care, unpaid care, and other care. The largest total increase is projected for social care costs, which are estimated to rise by 86.7% from £62 million in 2019 to £115.6 million in 2030. The largest relative increase is estimated to occur in other care, which is projected to rise by 131.9% until 2030, however still only accounting for a small fraction of the total cost.5

***Table 6:*** *Projected total cost of dementia (in million pounds, 2015 prices) in Medway*5

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Type of care** | **2019 (million pounds)** | **2025 (million pounds)** | **Growth 2025 (%)** | **2030 (million pounds)** | **Growth 2030 (%)** |
| Total | 130 | 179 | 37.7% | 233 | 79.4% |
| Health care | 17.5 | 23.0 | 31.4% | 29.7 | 69.5% |
| Social care | 62.0 | 88.1 | 42.1% | 115.6 | 86.7% |
| Unpaid care | 50.1 | 67.0 | 33.7% | 86.7 | 73.1% |
| Other | 0.6 | 1.1 | 83.3% | 1.5 | 131.9% |

# 6) Evidence of what works

## Current policy and implementation plans

The Department of Health has recently released a series of updated care plans implementations for dementia services to provide the highest standard of care.

[‘Department of Health (2016) Prime Minister’s Challenge on Dementia 2020 - Implementation Plan’](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf): This document outlines over 50 commitments that contribute to England being the leading country in the world for dementia care and support. The commitments are categorised among four main themes: risk reduction, health and care, awareness and social action, and research.

[‘House of Commons Library (2021) Dementia: policy, services and statistics’:](https://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf) This document summarises recent dementia statistics, current services and all existing policies updates resulting from current progress within England.

## NICE evidence

The National Institute for Health and Care Excellence (NICE) has issued numerous best practice guidelines related to different dementia care and research areas:

* [‘NICE Quality Standard [QS184] (2019) Quality Standard’:](https://www.nice.org.uk/guidance/qs184) covering dementia prevention, assessment, management, and support by health and social care.
* [‘NICE guideline [NG97] (2018) Dementia: assessment, management and support for people living with dementia and their carers’:](https://www.nice.org.uk/guidance/ng97/chapter/About-this-guideline) covering dementia diagnosis and management.
* [‘NICE guideline [NG16] (2015): Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset’](https://www.nice.org.uk/guidance/ng16): issuing recommendations that seek to prevent and delay the development of dementia, disability or frailty in later years.

## NHS evidence

The National Health Services has published several resources applicable to dementia care research, quality of care and outcomes within England:

* [‘NHS England (2021) Dementia Wellbeing in the Covid-19 Pandemic’](https://www.england.nhs.uk/wp-content/uploads/2020/09/C1280_Dementia-wellbeing-in-the-COVID-pandemic-v3.pdf): Report that seeks to build off the current Dementia Well Pathway with specific modifications in response to the current global climate. This publication was primarily curated for clinicians working with dementia patients, outlining recommended adjustments required in response to COVID-19.
* [‘NHS England (2018) My future wishes Advance Care Planning (ACP) for people with dementia in all care settings’](https://www.england.nhs.uk/wp-content/uploads/2018/04/my-future-wishes-advance-care-planning-for-people-with-dementia.pdf): Report that provides information and support for staff in health, social and community care settings regarding advanced care planning for people living with dementia.
* [‘NHS England (2017) Implementation guide and resource pack for dementia care’:](https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf) This report aims to provide local services with evidence of which dementia care is working, along with critical benchmarking data, emphasising the NHS’s commitment to consistent care improvement among dementia services.
* [‘NHS England (2017) NHS England Dementia: Good Personalised Care and Support Planning’:](https://www.england.nhs.uk/wp-content/uploads/2020/02/FINAL-_Update_Dementia-Good-Care-Planning-.pdf) This report targets primary care providers and commissioners who initiate care plan reviews among patients with dementia and seeks to support a standardised approach to care planning.
* [‘NHS England (2016) The Well Pathway for Dementia’:](https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf) This resource provides a visual representation of the Well Pathway for Dementia.
* [‘NHS England (2015) Models of Dementia Assessment and Diagnosis: Indicative Cost Review’](https://www.england.nhs.uk/wp-content/uploads/2015/09/mods-demntl-assessmnt-diag-cost.pdf): This review analyses three models of dementia and diagnosis currently used in England and provides insight into how local Clinical Commissioning groups may seek to review their services and make beneficial cost and service improvements.
* [‘NHS England (2014) Best Practice in Memory Service: Learning from Across England’:](https://www.england.nhs.uk/wp-content/uploads/2014/12/memory-clinics-final.pdf) This paper offers ten recommendations for implementation to improve memory services.

## Other associations evidence

[‘Dementia UK (2020) Only together: towards better specialist dementia support’:](https://www.dementiauk.org/wp-content/uploads/2020/11/Only-Together.pdf) This resource makes two key recommendations for service changes: 1) the provision of tailored information and 2) a single point of contact for families.

[‘Alzheimer’s Association (2018) Dementia Care Practice Recommendations’:](https://www.alz.org/media/Documents/alzheimers-dementia-care-practice-recommendations.pdf) This academic paper outlines a series of recommendations for person-centred care, detection and diagnosis, assessment and care planning, medical management, information and education, behavioural and psychological symptom mitigation, activities of daily living and staffing.

[‘The National Collaborating Centre for Mental Health (2018) The Dementia Care Pathway: Full Implementation Guidance](https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8)’: Building off previous documents supplied by the NHS, The National Collaborating Centre for Mental Health published a guide that outlines the dementia care pathway and the associated benchmarks that enable the delivery of quality of care and support. The scope of this paper seeks to address diagnosis and post-diagnostic support.

## Peer reviewed academic evidence

[‘BMC Geriatrics (2015) Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach’](https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-015-0053-9): This research brought together evidence surrounding the effectiveness of services aiming to support and sustain independent living among individuals with dementia, including supporting carers.

[‘Care Policy and Evaluation Centre (2019) Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040’](https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf): This report outlines projections of the number of individuals 65 and older with dementia and the costs of healthcare, social care and unpaid care from 2019 to 2040 for the UK as well as separately for England, Northern Ireland, Scotland and Wales.

## Pharmacological interventions

There are currently no medications available to cure Alzheimer's disease; however, three primary medications can help improve symptoms and slow progression. These include Acetylcholinesterase (AChe) inhibitors donepezil, galantamine, and rivastigmine.36 NICE guidelines suggest memantine monotherapy for individuals with Alzheimer's disease who are intolerant to AChE inhibitors or present severe Alzheimer's disease symptoms. NICE recommends that individuals with a pre-established diagnosis of Alzheimer's disease who are already taking AChE should consider taking memantine in addition if they present moderate to severe illness. There are additional pharmacological management recommendations for non-Alzheimer's dementia.36

## Non-pharmacological interventions

There are an increasing number of non-pharmacological therapies available for individuals with dementia. These therapies include behavioural therapies, alternative therapies such as art or music therapy, and brief psychotherapies such as cognitive behavioural therapies.37 These approaches are typically used in combination rather than in isolation and tailored to each patient's needs.

## Current projects and initiatives

Globally and nationally, there are currently several ongoing projects seeking to advance efforts to delay, prevent and mitigate the adverse impacts of dementia.

[‘Dementia UK (2021) Life Story Work’:](https://www.dementiauk.org/get-support/living-with-dementia/creating-a-life-story/) This programme offers a free, virtually downloadable template to assist individuals with dementia in building their life storybooks. Life Story Work encourages family and staff to come together with the patient to write a personal biography. This tool seeks to support patient-centred and positive care. It can also promote the development of strong relationships with family members and carers.

[‘Global Brain Health Institute (2021) Pilot Projects’](https://www.gbhi.org/pilot-projects): This source compiles a wide range of current pilot projects aiming to delay, prevent, and mitigate the effects of dementia.

[‘Alzheimer's Society (2021) Alzheimer’s Society supports funding for new global dementia-related projects’:](https://www.alzheimers.org.uk/news/2021-11-17/alzheimers-society-supports-funding-new-global-dementia-related-projects) The 2021 funding awards are dedicated to projects that aim to address existing disparities in diagnosis, treatment and care among vulnerable populations. Research award recipients span globally across 18 countries within five continents.

[**‘**Canadian Medical Association Journal (2018) Pilot project delivers dementia care that feels like home’:](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5995592/) This article explores new models for implementations within Dementia specific care homes. The “Butterfly” model seeks to provide a home in which its residents come before the tasks to create a homelike environment. The implementation of this model has reported significant improvements among health outcomes, encouraging further region rollout plans.

# 7) User views

## Service users’ views

Despite being experts due to their lived experience, the opinions of individuals with dementia are commonly neglected. The Alzheimer’s Society reports that 38% of people with dementia cannot decide how to live their life.38 The following paragraphs summarise national and local evidence of service users’ views of dementia support services.

NHS Kent and Medway CCG conducted extensive research with various stakeholders in 2021 entitled ‘[Improving care for people living with dementia and complex needs across Kent and Medway](https://www.kentandmedwayccg.nhs.uk/application/files/7416/1728/4373/Improving_Care_for_people_living_with_Dementia_Report_.pdf)’. Local area patient groups and forums stressed the importance of support for carers and the need for increased awareness of dementia symptoms and prognosis to improve early diagnosis rates. Participants also reported poor collaboration between dementia support services and the need for services to take a person-centred approach to care. There was a reported lack of respite care and night services. Care plans were suggested to require involvement from both individuals receiving care and their families to be beneficial and address individual needs. Lastly, it was perceived that increased staff training across various services was needed.

The [Dementia Experience Toolkit](https://www.alzheimers.org.uk/sites/default/files/2019-05/Example%20project%20update%20dementia%20experience%20toolkit%20Feb%202019.pdf) found that the primary concern of individuals living with dementia were missed opportunities to seek patient input on how and why services could be improved. Key themes were that ‘staff think they know better so don’t value lived experience’, that ‘staff lack dementia-awareness to engage with people with dementia about their care’, and that ‘people want to help services and commissioners learn from lived experience’.

A 2019 qualitative study entitled ‘[Subjective experiences of cognitive decline and receiving a diagnosis of dementia: qualitative interviews with people recently diagnosed in memory clinics in the UK](https://bmjopen.bmj.com/content/9/8/e026071)’ found four overarching themes in the experiences of people with dementia: 1) ‘Dissonance, threat to identity and visibility of dementia’; 2) ‘Vulnerability and being in limbo’; 3) ‘Loss of control and agency’; and 4) ‘Maintaining agency and self-worth’. Findings also suggest that the limited time spent in diagnostic appointments and poor pre- and post-diagnostic support leave little opportunity to address negative emotional impacts for many individuals.

A 2021 study entitled ‘[Knowledge Exchanges and Decision-Making Within Hospital Dementia Care Triads: An Ethnographic Study](https://academic.oup.com/gerontologist/article/61/6/954/6142301)’ found that care needs of hospitalised patients with dementia are often understood differently between themselves, their families, and hospital staff. Delays and difficulties in decision making often result from a lack of consistent engagement with families and individuals with dementia. Early engagement with dementia patients and their families, along with patient involvement, is essential to successfully meet current and future care needs. A [2019 qualitative review](https://reader.elsevier.com/reader/sd/pii/S0020748919301245?token=B57184B395D0410527420CC82C44D7A0060C770342F2252444DF85DE7A314C56EC00873754BFC9098CB3852B8515E9AB&originRegion=eu-west-1&originCreation=20220812083209)  found that dementia patients in acute care often report feelings of a rushed and task-based approach, poor communication, and feelings of exclusion. Acute environments were reported as unsuitable, sometimes aggravating concerning behaviours. This study suggests that further research is required to implement person-centred care, improvements on the physical environment, and explore possible interventions for care system improvements.

## Carers’ and health professionals’ views

A 2020 survey by Kent and Medway CCG reported in ‘[Improving care for people living with dementia and complex needs across Kent and Medway](https://www.kentandmedwayccg.nhs.uk/application/files/7416/1728/4373/Improving_Care_for_people_living_with_Dementia_Report_.pdf)’ found that whilst 81% of health and care staff thought that care plans assist in the management of an individual's changing health, 47% felt that information is not sufficiently detailed. Moreover, 70% of staff thought that families do not receive the required support to maintain their wellbeing. Nevertheless, 84% of staff said they would be able to signpost families to appropriate services if required. If a person with dementia is unwell or exhibits challenging behaviour, most staff indicated that their first point of contact is the local GP, followed by the specialist mental health team. Of those surveyed, 98.5% reported the need for a crisis/urgent care service. Most people thought this service should be available Monday to Sunday 24/7. Overall, the top three improvements proposed by respondents were ‘more support, education and help for carers and families’ (41%), ‘respite care’ (15%), and ‘more specialist dementia training and education for staff’ (12%).

The recent [Facing it alone](https://www.dementiauk.org/wp-content/uploads/2020/11/Facing-It-Alone.pdf) report from Dementia UK gathered perspectives from GPs and primary care professionals. Around 82% of respondents suggested that limited time and capacity present a significant issue in supporting individuals living with dementia. Further, 74% of respondents indicated that increased time in appointments would improve support for individuals. Many (53%) reported insufficient local support services for individuals with dementia with limited, disjointed services available and local services changing after the loss in funding. Regarding additional local support available, 49% of GPs felt they could know more about what was available, and only 76% of respondents were aware of Admiral Nurses.

Perspectives from Admiral Nurses were also collected. Approximately 58% thought that people are not given sufficient information regarding the condition and its effects at the time of diagnosis, suggesting a need for more patient-centred resources. Further, 89% of respondents said there is a lack of follow-ups from GPs after initial diagnosis. Approximately half of Admiral Nurses surveyed reported a significant gap in dementia support services due to fragmented services and barriers such as cost, accessibility, and transportation.

## Informal carers’ and families’ views

It is estimated that there are 700,000 informal carers who support people living with dementia in the UK.39 Accordingly, the views and experiences of informal carers and families are vital.

In the ‘[Improving care for people living with dementia and complex health needs, across Kent and Medway](https://www.kentandmedwayccg.nhs.uk/application/files/7416/1728/4373/Improving_Care_for_people_living_with_Dementia_Report_.pdf)’ report, Kent and Medway CCG consulted families, informal carers, and dementia support groups across Kent and Medway. The main themes mentioned included a lack of respite care, fragmentation of services, access to services, care plans, support services for carers, and health and wellbeing of carers.

The [Facing it alone](https://www.dementiauk.org/wp-content/uploads/2020/11/Facing-It-Alone.pdf) report by Dementia UK sought to understand the key challenges and unmet needs among families affected by dementia. Approximately 77% of respondents reported being dissatisfied to some extent with the support provided by their GP, and 35% indicated they had received no support or service. Of individuals who reported receiving support, 34% reported feeling dissatisfied or very dissatisfied with the quality of support. Reasons for dissatisfaction included insufficient dementia expertise among professionals, poor specialist support, the ‘postcode lottery’ for access to services, insufficient emphasis on carers and family, and insufficient coordination. Many respondents suggested a lack of information provided about dementia, leaving people to have to find it on their own. Individuals identified their interest in a single professional point of contact, in addition to emotional support, a named care coordinator, and information resources.

Furthermore, the 2018 study ‘[Home care in dementia: The views of informal carers from a co-designed consultation](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8564226/)’ collected views on home care from 52 informal carers. Respondents emphasised the need to invest into meaningful personalisation, acknowledging the value of providing care and appreciating formal carers, systemic failings of care coordination and provision, and the importance of continuous collaboration and care planning.

## General population views

Although approximately 40% of cases of dementia are a result of factors that individual actions can influence, only one-third of individuals in the UK believe it is possible to reduce dementia risk.40 In the [British Social Attitudes survey](https://www.basw.co.uk/system/files/resources/basw_60440-1_0.pdf), 22% of UK adults did not identify any of the major risk factors for dementia, and a further 43% only identified one or two risk factors. This suggests an urgent need for awareness-raising. Individuals consulted through the [Dementia Attitudes Monitor](https://www.dementiastatistics.org/wp-content/uploads/2021/09/ALZ_DAM_short-Report_21_LR-WEB_FINAL2.pdf#zoom=80) provided two primary motivations for seeking diagnosis: ‘to allow access to treatments that could help’ and ‘to enable the person concerned to plan for the future’. Nevertheless, 14% of individuals reported hesitation since ‘there are no treatments that can really make a difference’, suggesting the need for increased education on available treatment options. Additionally, public consultations from the ‘[Improving care for people living with dementia and complex needs, across Kent and Medway](https://www.kentandmedwayccg.nhs.uk/application/files/7416/1728/4373/Improving_Care_for_people_living_with_Dementia_Report_.pdf)’ report through KMCCG found that Kent and Medway residents thought that the three most important  forms of support that families and people with dementia require are ‘personal care in the home’, ‘regular contact with a care navigators/support worker/case worker’, and ‘quality of care’.

## The impact of COVID-19

During the COVID-19 pandemic, individuals with dementia were commonly isolated from others, unable to see their families and friends. A series of studies have been conducted to assess the impacts of COVID-19 restrictions among both patients and carers.

A 2022 study ‘[Covid-19 and the quality of life of people with dementia and their carers—The TFD-C19 study](https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0262475)’ ​​evaluated the impact of the COVID-19 pandemic on the quality of life (QoL) of individuals with dementia and their family carers. Findings reported no significant decline in QoL during the pandemic or the months following for the target population. However, the greatest impacts were seen among women, co-residents, spouses, and people living in more deprived areas.20 A 2021 study ‘[Impact of COVID-19 restrictions on carers of persons with dementia in the UK: a qualitative study](https://academic.oup.com/ageing/article/50/6/1876/6315067)’ sought to assess the impact of COVID-19 restrictions on carers of individuals living with dementia in the UK. Three main themes were identified: ‘changes to daily life’, ‘impact on carer health and wellbeing’, and ‘assistance from support networks’.

In the [Facing it Alone](https://www.dementiauk.org/wp-content/uploads/2020/11/Facing-It-Alone.pdf) report, 83% of family carers reported that they have had less opportunities to take a break from caring. Furthermore, 78% of respondents felt it was more difficult to cope and 78% thought that the wellbeing of the person they care for has declined. Access to services also deteriorated, as 71% of respondents had experienced cancellations of home visits from care and support staff.

A further 2021 study ‘[Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers](https://bjgp.org/content/71/709/e574)’ was conducted to evaluate the remote primary care experiences of individuals living with dementia and their carers during COVID-19. Findings suggest that although remote consultations could be beneficial, proactive calls must be more structured around individuals' needs. Patients report it is important that placements are provided to substitute non-verbal prompts to describe issues. It is also important to include and engage with both the patient and the carer.

# 8) Unmet needs and service gaps

It is projected that there will be 4,635 people aged 65 and older who are living with dementia in Medway in 2030. This presents a 46.2% growth compared to 2019. Furthermore, the highest increase is projected in the number of people with severe dementia.5 This means that associated health and social care costs are projected to increase significantly. The need for dementia support services will therefore substantially increase in the future. Services need to be prepared for this increased need, and capacity as well as resources need to be expanded.

Carers, professionals, and people living with dementia also mentioned gaps in service provision as part of the Kent and Medway CCG consultation.41 Overall, it was thought that there is insufficient support for carers and families. Respondents said that there is a need for increased community-based support for people living with dementia and their families to enable them to live well at home. Respondents also thought that there is a lack of respite care for carers, which would enable carers to have a break. Specific concerns were also raised about a lack of respite care that is available at short notice and in times of crisis. Staff almost unanimously reported that there is a need for a crisis or urgent care service for people with dementia, which supports them when their health declines and enables them to stay at home.

Meetings with stakeholders showed that one main issue is the lack of diagnoses in primary care. Several new initiatives such as the promotion of the DiADeM tool and the introduction of GPs with enhanced roles aim to increase diagnosis rates in primary care. Additionally, waiting times for diagnosis are often long, and people from ethnic minority backgrounds and those with learning disabilities are currently underrepresented in diagnosis. Stakeholders also reported insufficient post-diagnostic support, with a lack of ‘softer’ support such as coffee mornings and music therapy. Support immediately after diagnosis was thought to be especially scarce. Additionally, many carers are elderly and are affected by health conditions themselves. Stakeholders suggested there is a need for a helpline that people can call to obtain advice and support. The Admiral Nurses service was seen as very positive and should be continued, although more capacity is needed. The introduction of dementia co-ordinators may improve post-diagnostic support for people who are living with dementia and their families. Stakeholders also mentioned that there is a lack of care home beds for people with dementia. Furthermore, stigma remains and can discourage people from presenting to services. There is thus the need to make Medway more dementia friendly and for increased awareness raising that dispels the still widespread notion that dementia is a normal part of aging.

# 9) Recommendations for commissioning

1. Initiatives that will help recognise the true dementia diagnosis rates in primary care such as the Diagnosing Advanced Dementia Mandate (DiADeM) tool should be actively promoted. Furthermore, the benefits of receiving a diagnosis should be emphasised to encourage people to seek a formal diagnosis. This will include addressing stigma related issues. Targeted work should be undertaken by GPs with Enhanced Role (GPwERs) and dementia co-ordinators with healthcare professionals in areas with significantly lower diagnosis rates than the Medway and national averages.
2. The remote memory assessment tool for dementia assessment and diagnosis should be promoted to GPs by dementia co-ordinators to offer more varied services and strengthen patient choice.
3. Everyone can contribute to making Medway more dementia friendly. The Alzheimer’s Society defines a dementia-friendly community as a ‘city, town or village where people with dementia are understood, respected and supported’. The Medway Dementia Action Alliance, formed in 2015, is striving to make Medway more dementia friendly. Commissioners should look to ensure the Medway Dementia Action Alliance is adequately resourced.
4. Commissioners should ensure that there is continuation of the role of dementia co-coordinators who should work with support groups such as Carers First to raise awareness of the dementia connect support telephone line administered by Alzheimer’s UK. This will help families and carers to access appropriate support.
5. The offer of respite care and support services that includes community support officers should be expanded, particularly in light of projected increases in the number of people living with dementia in the future. This will enable informal carers and families to take a break from caring whenever needed.
6. There is a lack of capacity in the care and nursing home settings to support people living with dementia. Health and social care commissioners need to take account of the projected increases in the number of people living with dementia and align commissioning intentions through the market positioning statement to ensure appropriate capacity is in place within the community residential and nursing home sectors.
7. Dementia awareness training should be resourced and offered annually to staff in public and private sector organisations. This should be reviewed by the local dementia partnership.

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