Strong Foundations:

A Dementia Strategy for Jersey

Government of JERSEY

2024-2029

Dementia Jersey

Citation

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Forewords

Letter from the Minister for Health and Social Services

Most of us will be touched by dementia in our lifetimes, whether that be through having a diagnosis ourselves, caring for a family member or friend who has dementia, or knowing someone with a diagnosis of dementia. With dementia set to increase globally and in Jersey, and the personal, social, and economic impacts associated with dementia, it cannot be ignored.

People with dementia in Jersey and those who support and care for them, face many challenges, as they do across the world. There is no current cure for dementia, and it is a diagnosis feared in the same way that cancer was once feared. This strategy aims to reduce the misconceptions islanders have about dementia, raise awareness of the positive actions that can be taken by all of us to reduce our risks, and remove the stigma associated with dementia in Jersey,

It is important to ensure that information and advice about dementia is clear and accessible, and that islanders benefit from timely access to dementia assessment, treatment, and the post-diagnostic support and care they need. It is also important to ensure that people who provide informal and formal care or support are well informed, equipped with the skills they need, and have their own needs supported.

I am delighted, therefore, to introduce Jersey’s first Dementia Strategy, which identifies the requirements for dementia in Jersey over the next five years.

The strategy took a little longer to develop than was initially anticipated and was further delayed by several weeks when it became clear that the ambitions of the strategy went beyond the funds available for it to be delivered in its entirety.

At that stage, I decided that the best course of action was to devise a clear implementation plan, which identified that which could be delivered from existing resources, and that which could not. Accordingly, the strategy is accompanied by a short document entitled ‘Year 1 Implementation Plan’, and I believe this provides an honest view of what we can achieve, at least in the short term.

With regard to the longer term, I am committed to increasing investment in Public Health initiatives to prevent ill health across a wide range of ailments, including dementia. This is work in progress and would be subject to consideration by Council of Ministers and the wider Assembly. It is my sincere hope that this would result in the delivery of any areas of the strategy that are currently unfunded.

The strategy itself has been developed through true partnership working between representatives of the Government of Jersey and Dementia Jersey and draws strongly on the voices of islanders, particularly those with lived experiences of dementia, whilst drawing on local and global evidence.

With that in mind, I would like to express my sincere gratitude to the many islanders who gave their time and shared their experiences to help inform the strategy and clarify our priorities for action. This includes those people who contributed to the engagement activities, spoke to us about their services, were members of the steering group, and those on the strategy working group.

Deputy Tom Binet

Minister for Health and Social Services

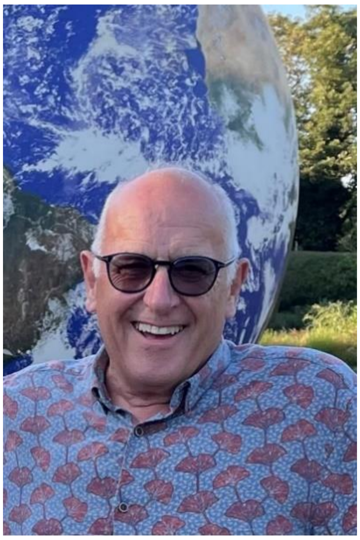
Letter from Allan Johnson, a person with dementia, and steering group member

I became a member of the steering group to help create a dementia strategy that would help others in the same boat.

I have been fortunate that I can live independently at home with help from my wonderful family. However, I was frustrated that when I did need a bit of extra help with cooking, I had to wait 3 months before someone came to talk to me. This paled in comparison with the realisation that others faced even more extended delays, such as a nine-month wait for a memory assessment appointment.

Seeing how quickly some people go downhill with dementia makes me feel that things really need to change so people can get help when they need it. I hope this strategy gets read by the right people to make a difference. It's time for a system that responds when people need it most, and I hope that by working together we will spark that transformation.

Letter from Peter Germain, a family member of a person with dementia, and steering group member



I cared for my wife for 10 years as she travelled along her dementia journey. From the onset I felt it was important to understand what lay ahead and learn how to cope with it. Hence, I involved myself, along with my wife, in as many activities as possible to make the path smoother. During this time, I met many others who were facing the same issues, and I was able and confident enough to speak out and assist others in the group. This continued over the years and much guidance had to be given on issues such as selecting the correct care providers, the lack of availability of beds and the cost of care / the benefits of LTC.

As the years progressed the services that Dementia Jersey provide have vastly increased for the benefit of the 'patient' and carers. An area which I feel is essential and needs much financial support. Such is my gratitude for the assistance given by Dementia Jersey since the passing of my wife, I have volunteered on a weekly basis giving advice to those starting the journey.

Letter from Dementia Jersey

Dementia is the biggest health and social care challenge of our time, and that challenge is growing as our society ages. The scale of the change needed in Jersey to conquer that challenge is huge, but by working in collaboration, we can transform the experience of those touched by dementia for generations to come.

In this strategy, we outline a vision that is both ambitious and achievable. It is a call to action for all – healthcare professionals, government, businesses, and the wider community – to unite in a collective effort to improve the quality of life for those living with dementia. To create an Island where every individual with dementia, and their families, receive the respect, support, and care they deserve.

We envision a future where timely diagnosis is the norm, where there is a clear and supportive care pathway, where stigma is eradicated, and where every person touched by dementia feels valued and understood. Through collaboration, education, and innovative services, we aim to empower individuals and their families, enabling them to navigate the challenges of dementia with dignity and strength.

This strategy is more than a plan; it is a pledge to uphold the rights and aspirations of our community members who face the huge challenges of dementia every day. It is a promise to strive tirelessly until Jersey becomes an exemplar of a truly dementia-friendly society.

Together, we can and will, make this vision a reality.

Claudine Snape

CEO, Dementia Jersey

Acknowledgements

With thanks to all of those who have contributed in any way to the development of this strategy, including the many islanders who shared their experiences and thoughts with us. The richness of the strategy would not have been possible without the valuable involvement of people who are living with dementia, family members and carers of people with dementia, and the wider Jersey community.

Thanks also to the many people who represented organisations and contributed to our understanding of local support services; to the members of the steering group who provided valuable guidance and support throughout development of the strategy; and to the consultants, analysts and statisticians from Health and Community Services Informatics, Public Health, and Statistics Jersey, who provided support, advice, and data to inform the Strategy.

Executive summary

The commitment to support the development of Jersey’s first Dementia Strategy was included in the Government of Jersey’s Ministerial Plan (2022).

Aims of this strategy

The aim of this strategy is to outline how dementia care and support will be approached in Jersey over the next 5 years. Five key areas for improvement have been identified: raising awareness; diagnosing well; supporting people with dementia and their carers; supporting, training and valuing the workforce; and developing Jersey to be an island that is dementia-friendly and inclusive. Key actions are outlined that when implemented, will result in improved information, support, and quality of care, and will build on the strong community foundations for which our island is proud.

The issues

Dementia is a term used to describe several diseases that affect memory, thinking, and activities of daily living for which at present, there is no known cure. The World Health Organization (WHO) estimates that more than 55 million people have dementia worldwide, and that there are nearly 10 million new cases each year. With the number of people living with dementia rising, the cost to world economies is projected to more than double by 2030. Dementia is recognised as a major cause of disability and dependency among older adults worldwide. The direct and indirect impact on people living with dementia, and on their families is vast and varied.

The extent of these factors has resulted in the WHO declaring dementia a global health priority. Most countries have responded by developing strategies to address issues related to dementia, and there is increasing research evidence that people can reduce their risk of getting dementia, through healthy lifestyle choices throughout their life. Although treatment options are limited there is evidence that people can live well with the help and support that they need, and by maintaining the connections and activities that matter to them.

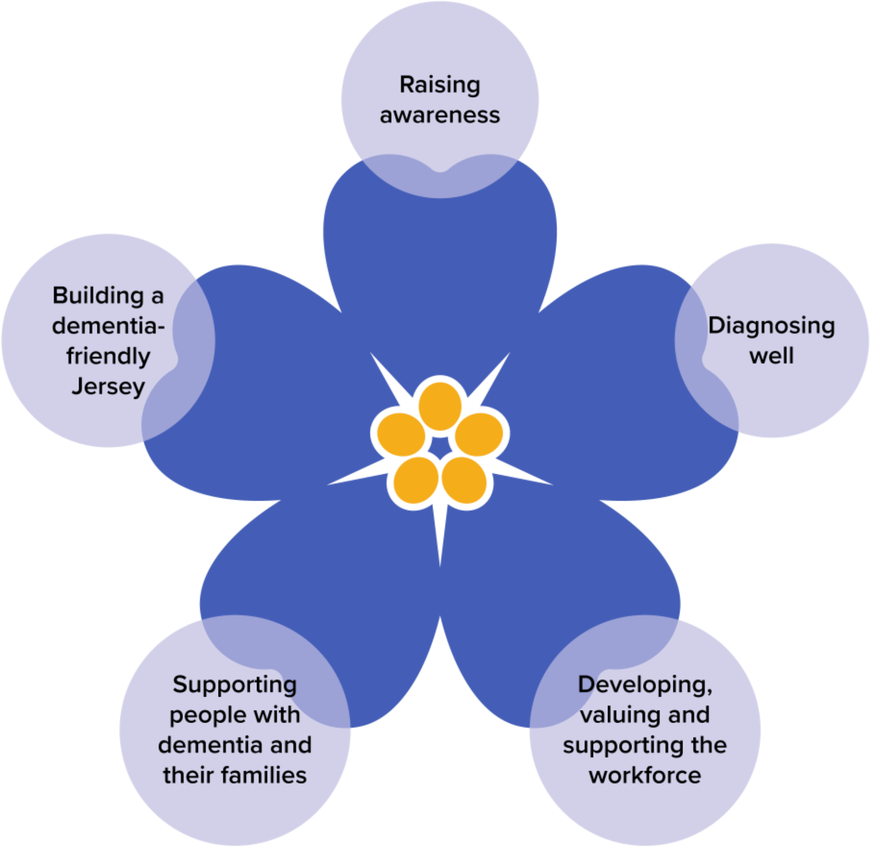
From our engagement with islanders, we have heard that dementia impacts many of us in some way, and that most people, including people with dementia, their families, and the staff caring for them do not have everything they need to thrive.

Our commitments

We are committed to:

- informing islanders about the actions they can take to maintain their brain health, reduce their risk of developing dementia, and to raise awareness and understanding of dementia.
- ensuring that all islanders have equal and timely access to quality diagnosis and post diagnostic support, regardless of age, stage of dementia, ethnicity, other health conditions, or where they live.
- ensuring that people with dementia and their families have their rights respected, their voices heard, and they receive the help, care, and support they need to live well in Jersey.
- developing a resilient workforce that feels valued, and has the skills, knowledge, resources, support, and leadership needed to deliver high standards of support and care.
- making Jersey a dementia-friendly and inclusive island where people with dementia can maintain their engagement and participation in their local community, and where their voice and experiences are valued and respected.

Figure 1. Our commitments:



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Vision

Our vision for Jersey is of a truly dementia-friendly and inclusive island where brain health and risk reduction messages are widely understood, where islanders have access to a timely assessment and diagnosis, and where people with dementia and those who care for them are well informed and feel supported and empowered. Our vision includes a workforce who are all well trained and feel valued and supported.

In this vision, Jersey is a dementia-friendly island that people with dementia want to call home, know they belong, and where the stigma that still exists in our island becomes a thing of the past.

Principles

The principles that have guided the development of this strategy have been to apply underlying values of integrity, respect, beneficence, and balance to ensure that:

- listening to and learning from the lived experience of people with dementia and their families is central.
- the strategy is evidence-based and informed by up-to-date global, national, and local data, research, and guidance.
- engagement with islanders is core to the development of the strategy.
- We build on existing strengths and opportunities.
- our commitments are ambitious but remain realistic in the local context.

Alongside these we have also kept in mind the disability rights slogan echoed in the 2019 Alzheimer's Europe conference of 'nothing about us without us' (1), and the Alzheimer Europe 'Glasgow Declaration' of 2014 (2). These both call for people with dementia and their carers to be involved in the development of national strategies.

This has ensured that we have kept our focus on people and what matters to them and have considered the whole system of health and social care around the person (3; 4).

Strategy development

The strategy is a partnership project between Dementia Jersey and the Government of Jersey, with engagement from a wide range of individual and organisational stakeholders. Governance was provided by the Government of Jersey.

Steering Group

A steering group was set up to provide direction and steer for the strategy, with the membership shown in Table 1.

Table 1. Steering group membership

Members	Organisation
People with dementia Family carers of people with dementia	NA
Associate Managing Director Commissioning and Partnership Manager Director of Mental Health and Adult Social Care Group Chief Nurse / Interim Chief Nurse Clinical Lead – Mental Health Care Group	Health and Community Services
CEO / Interim CEO	Dementia Jersey
Independent Capacity Advocate	My Voice Jersey
Jersey Care Federation representative	Jersey Care Federation

Working Group

A working group was set up to undertake the development, drafting and administration of the strategy. The roles of working group members are outlined in Table 2.

Table 2. Working group membership

Member	Organisation
Programme Manager, Jersey Dementia Strategy	Health and Community Services
Change Support Officer (Administration)	
Lead Partner	Dementia Jersey
Consultant in Public Health	Public Health

The unique context of Jersey

Jersey is a small island of forty-five square miles, located one hundred miles off the South coast of England and fourteen miles from France. It is a British Crown Dependency and therefore not part of the UK or the EU. It is self-governing with its own legislature known as The States of Jersey. It has a population of approximately 103,000, with finance and service industries leading the economy. Although all sectors of industry, including health and social care largely rely on recruiting staff from elsewhere, there are restrictions on who can live and work in Jersey.

Because of its independent status, Jersey's health and social care system is not part of the NHS. Jersey has different rules and funding arrangements to the UK, other Channel Islands, and other countries. Primary care is distinct from secondary care services, with GP practices and most dental services organised as independent private businesses. Patients are charged for such services, with some co-funding from government. Emergency treatment is free at the point of contact, whilst access to non-emergency treatment and social care for adults is dependent on criteria such as residency and social security contribution.

Most domiciliary and residential care providers are independent businesses, though Jersey does have a contributory Long Term Care scheme which supports eligible islanders with some of the costs of long-term care.

Jersey has a strong and deep-seated sense of community which is reflected in an active and extensive charitable sector. It is Jersey's community spirit that helps to make it a friendly, engaging, and characterful place to live and work. Over 400 charities are registered with the Jersey Charity Commissioner and, with the support of Jersey's many volunteers, they supply a sizeable proportion of help and support to islanders. Whilst some of their work is supported by government funding, most rely on donations and fund-raising.

The global picture

The World Health Organization (WHO) estimates that more than 55 million people have dementia worldwide, and that there are nearly 10 million new cases each year. Whilst over 60% of these people live in low to middle income countries, the human and financial impact of dementia for all countries is vast (5). The number of people with dementia worldwide in 2015 was 47 million. This is projected to rise to 75 million by 2030, and to 132 million by 2050. Dementia is recognised as a major cause of disability and dependency among older adults worldwide, with associated negative impacts to communities.

With the number of people living with dementia rising, the cost to world economies is projected to more than double between 2019 and 2030 to 2.8 trillion US dollars (6). Whilst it can be difficult to quantify costs, it is estimated that globally 50% of these costs are attributable to the care provided by informal carers, who on average supply 5 hours of care a day (5).

In the UK the estimated cost of dementia was £25 billion in 2021. By 2030 it is projected to be the costliest health condition in the UK, with costs likely to double to £47 billion by 2050. Of these costs, 50% fall under social care, 41% for informal care and 7% are health care costs (7).

In 2017 the WHO stated that dementia had become a global health priority. It called for every country to develop or update their national strategies, policies, plans, or frameworks for dementia (8). Since then, the number of countries with strategies, or strategies in development has continued to grow.

The development of this strategy has involved reviewing many of these strategies in detail, noting significant similarities and themes including:

- Raising awareness
- Risk reduction
- Improving the diagnostic process
- Improving care and support, with a particularly focus on person-centred care
- Supporting and informing carers
- Collecting data
- Research
- Improving community, day, and residential care
- Supporting and training the workforce
- Developing dementia-friendly communities

Introduction

This document is Jersey's first dementia strategy. It is therefore extensive in its content, setting the strong foundations for its priorities and actions, and for any subsequent strategies beyond this five-year plan. Evidence from around the world, as well as an in-depth review of the local picture that includes the voices and experiences of islanders has been drawn on to provide a comprehensive overview.

Definition of dementia

Dementia is an overarching term used to describe many diseases that affect memory, thinking, and activities of daily living (9). Because there are so many causes of dementia which affect people differently and which change over time, no two people will experience dementia in the same way. However, most dementias are irreversible and usually progressive in nature (10).

Subtypes of dementia

There are believed to be over 200 subtypes of dementia, each of which stops a person's brain cells (neurones) from working properly, and have differing disease causes (11). The most common diseases which cause dementia (12) are outlined in Table 3.

Table 3 - Dementia sub-types by %

Dementia subtype	%
Alzheimer's disease	60
Vascular dementia	15
Mixed dementia	10
Dementia with Lewy bodies	10
Frontotemporal dementia	2
Parkinson's dementia	2
Other	1

Symptoms

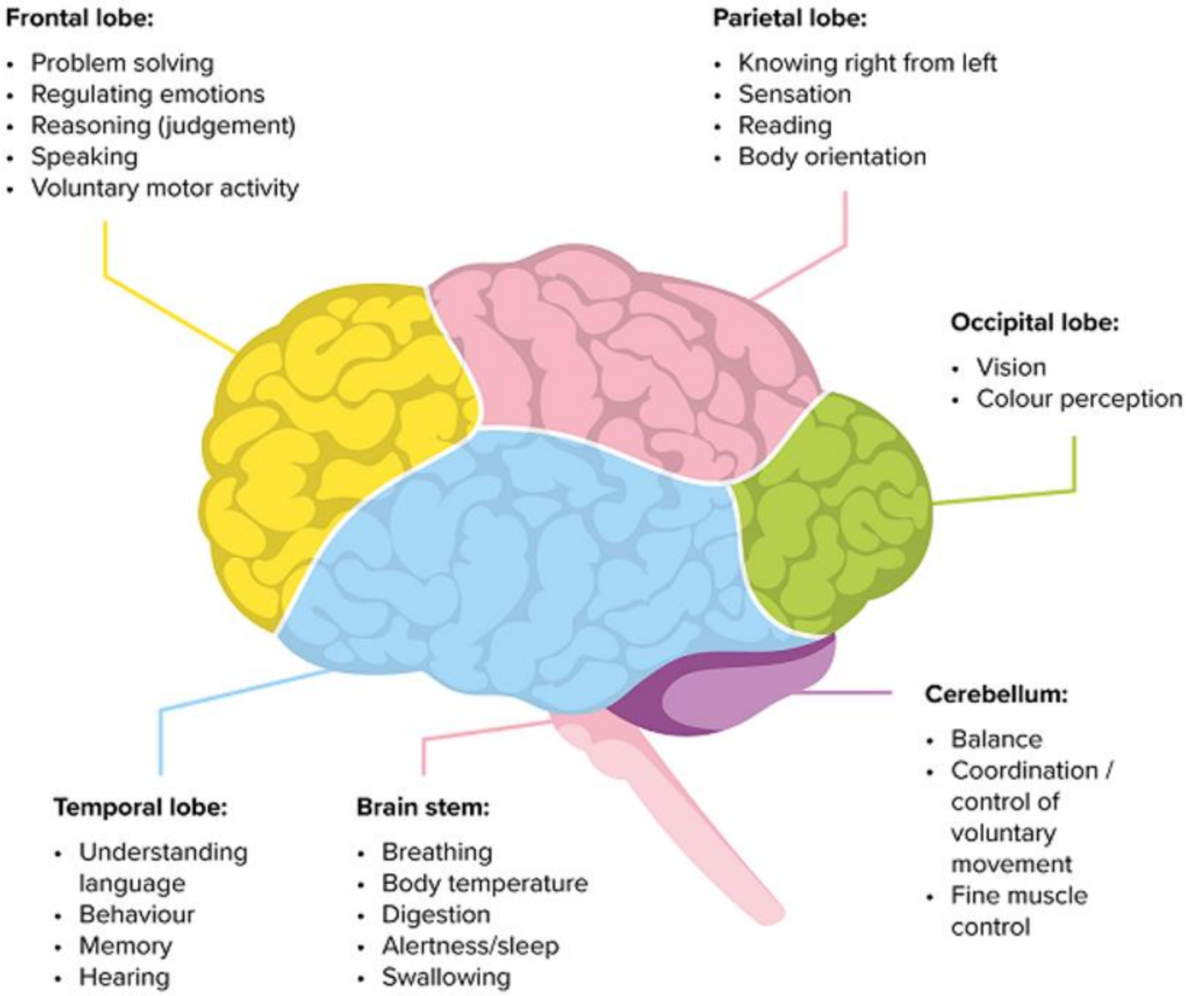
Symptoms of dementia that may be experienced include but are not limited to:

- Memory loss
- Problems with communication
- Difficulty with planning, judgement and/or problem-solving
- Disorientation to time, place and / or person
- Sleep cycle disturbance
- Withdrawal or apathy
- Agitation and rapid or intense changes in mood or emotion
- Disruption to movement for example restlessness, rigidity, pacing, or repetitive activity
- Psychosis – delusions and/or hallucinations
- Difficulty in carrying out complex tasks

Over time, activities of daily living such as eating, drinking, using the toilet, bathing and walking may become progressively more difficult (13).

Symptoms of dementia tend to appear gradually, and the symptoms each person will experience will vary depending on several factors, including which area of the brain is affected. This is shown in Figure 2.

Figure 2 - Functions of the brain



Risk factors

A risk factor is something that will increase the likelihood of a person developing an illness (14). Most people's risk of developing dementia is influenced by multiple factors. Whilst some cannot be changed, others are modifiable and can be reduced. The risk factors for dementia (15; 16), are outlined in Table 4.

Table 4 – Risk factors for dementia

Type of factor	Risk factor
Non-modifiable	Age Sex (greater risk in females) Learning disability Genetic factors – gene mutations and genes that increase risk
Modifiable	Limited mental activity in adulthood Hypertension Diabetes Hearing impairment Smoking Obesity Physical inactivity Depression Social isolation Alcohol use over the recommended limits Traumatic brain injury Air pollution Poor quality and duration of sleep

Health interventions and lifestyle choices made throughout our life can make a significant difference. There is evidence that if modifiable factors were addressed, this could reduce the risk of developing dementia by up to 40% globally (16), and potentially slow cognitive decline.

We can reduce our risk of getting dementia by up to 40% by making lifestyle changes and taking care of our mental and physical health.

Brain health and risk reduction

Increasing evidence for the importance of maintaining brain health, and reducing risk factors for dementia has become a focus for action globally (17; 6). There is much that can be done to reduce cognitive decline at any age, and to improve brain health. Some of the things we can do are:

- Keep physically active
- Sleep well
- Eat a balanced Mediterranean diet to keep a healthy weight
- Stop smoking – the sooner the better
- Protect your head.
- Look after your emotional wellbeing.
- Keep socially active
- Look after your health, including getting hearing tests
- Limit alcohol
- Engage with education in early life
- Limit your exposure to pollution
- Challenge your brain throughout your life

Diagnosis

A diagnosis of dementia is primarily based on clinical assessment (18). Due to the progressive nature of most types of dementia it can be challenging to diagnose at an early stage. Some people in the earlier stages of dementia may also deny or try to conceal their symptoms (14). People themselves, or their families, may initially speak with their GPs about their concerns, or these may be noticed when a person accesses other health or social care services. The role in diagnosis of general and specialist services (18) is outlined in Table 5.

Table 5 - Role of services in diagnosing dementia

Service type	Role in diagnosis
Non-specialist services: General Practice General Hospital	• Taking a full history • Physical examination and investigations to exclude other causes • Baseline cognitive assessment* • Referral for brain CT* and to specialist services
Specialist Services: Neurology Old Age Psychiatry Memory Assessment Service (MAS)	• Collecting a detailed clinical history • Neurological assessment* • Assessing ability to complete day to day tasks • Neuro-psychological testing* • More detailed neuro-imaging scans • Prescribing and monitoring

Whilst most people will not need more specialist diagnostic procedures, further diagnostic tests may be recommended for Alzheimer's disease in specific circumstances (18), and include:

- Positron Emission Tomography (PET) scan, or
- testing of cerebrospinal fluid via a lumbar puncture.

Where these are clinically indicated, such procedures may require an off-island referral.

New and emerging diagnostic techniques

Testing blood for biomarkers is proving a promising way forward in diagnosing Alzheimer's and other neuro-degenerative conditions. While these tests are increasingly being used in clinical research, they are not currently being widely implemented in clinical practice due to limitations in availability, costs, and validity of the testing. Such techniques are not available in Jersey but offer promising potential for the future.

Impact of a diagnosis of dementia

Over 55% of people with experience of dementia, and 40% of people who have no experience of dementia, agree that it is the health condition they fear most (19). Receiving a diagnosis is life-changing and can result in a range of emotions for the person receiving the diagnosis and for those around them. Common emotional responses include, shock, depression, anger, disbelief, hopelessness, grief for the future they hoped for but may not have, despair, and anxiety about what may be ahead for them. Others may experience a sense of relief after the initial shock has passed.

People who are younger when diagnosed can find a diagnosis of dementia particularly challenging. They may have additional worries such as their ability to work, their finances, and the impact on their young family. A diagnosis often impacts the families of people with dementia, particularly when carers are older and frail themselves and many fear that the burden of care could impact their own health both mentally and physically (20).

There is clear evidence that most people affected by dementia see clear benefits to getting a diagnosis (21). Diagnosis can help people to plan for the future, access the treatment and support they need, help them to understand their symptoms, and gain access to financial support for their care needs.

> Although getting a diagnosis of dementia may be very difficult to accept, it can also help people understand their symptoms and give them access to the medication, advice and help they need.

Current treatments and management

Medication related treatments and interventions

There are currently no known cures for Alzheimer’s disease and other related dementias or for vascular dementia.

With vascular dementia, treatment is generally focused on managing existing health conditions and the risk factors that contribute to vascular dementia. This may include medications to help protect the heart and blood vessels from further potential damage. By controlling the conditions that effect the heart and blood vessels the rate at which vascular dementia progresses can potentially be slowed. Control of such conditions has not only an effect on reducing dementia, but also important associated conditions such as stroke and cardiovascular disease (e.g., myocardial infarction).

In the case of Alzheimer’s disease, four drugs are currently licensed for use in the UK and Jersey that may help reduce the impact of symptoms for a time. These drugs may also be prescribed for people with Parkinson’s dementia, dementia with Lewy bodies, and vascular dementia if Alzheimer’s disease is also suspected. Of the four drugs, just one is recommended for moderate to severe stages of the disease, or when any of the other drugs have significant side-effects or are contraindicated (22).

As with all prescribed medications these should be reviewed regularly. The cumulative effect of a person taking several medications can lead to further unwanted effects including confusion, short term memory issues, constipation, pain, urinary retention, delirium, and falls.

There may also be times when the use of psychotropic medications, including antidepressants, antipsychotics, and hypnotics, may be needed, particularly if a person is very distressed, or puts themselves or others at risk of harm. Decisions to use these medications should only be taken after careful assessment. This should be discussed with the person themselves wherever possible and, where appropriate, with their family or a person with lasting power of attorney (LPA). Treatment should always start at the lowest dose possible and be reviewed regularly (23).

People with dementia may be prescribed medications to help manage their symptoms but will also benefit from continuing to take part in the activities they have always enjoyed, and from taking on new challenges.

Emerging treatments for Alzheimer's disease

There are a growing number of clinical trials of drugs to prevent the onset, slow progression, or improve cognitive and behavioural symptoms of Alzheimer's disease. In January 2023 over 187 trials relating to 141 unique drugs were underway globally (24). The extent of research offers hope for the possibility of new treatment options in the future.

Two drugs have recently been approved in the US for use in mild Alzheimer's dementia. However, evidence of the effectiveness of these medicines is mixed, and the reported side-effects can in some cases be serious (25).The use of these drugs in Europe, the UK, and Jersey have not yet been approved or licensed by regulatory authorities.

Alternative treatments and interventions

Some people with dementia may experience changes in behaviour or experience psychological symptoms. Often these are caused by underlying distress or unmet needs (26). In these circumstances, non-pharmacological interventions are recommended before considering the use of medications. This is because in most cases, with support that involves carefully listening to and figuring out what is troubling the person, and being creative in ways to resolve these situations, these changes are likely to pass.

A person may also benefit from exploring their thoughts and feelings with a trained therapist (27), or from a wide range of other therapies including, aromatherapy, reminiscence, art, music, dance, massage, and animal assisted therapy. Having access to accurate information and taking part in activities that people enjoy will also help them stay physically, mentally, and socially active and are therefore likely to be beneficial (28).

The lived experience of dementia for family carers

Following a diagnosis of dementia, a person may have some months or years of relatively good health with only mild symptoms. While these symptoms will be unique and experienced differently by each person, symptoms are likely to progress over time (29).

Studies of the lived experience of family carers have shown that most will feel burdened to some extent both mentally and physically (30; 31). Most carers have not chosen their caring role and often find the experience overwhelming (32), and whilst there are a growing number of male carers, women provide most care up to 70% of care hours, whilst often maintaining other care-giving roles (9; 33).

Carers may feel stressed, depressed, anxious, or angry, and while they may have many care professionals visiting their homes, they can feel lonely as social networks contract and their care-giving role increases (34). They may also feel a sense of anticipatory or ambiguous grief, and for those with less professional care available to them, these feelings are usually more significant and burdensome (35). As caring can affect every part of a person’s life, it is important that carers look after their own physical and mental health to enable them to stay well and to continue in their caring role (36).

> Family carers are likely to feel a range of emotions as they face new challenges, but getting support and meeting others who share similar stories can really help.

Research

The WHO has stated that research and innovation is integral to a comprehensive response to dementia (37). Whilst the number of people with dementia continues to rise worldwide, investment in research is notably less than for other health conditions. Investment in research has been linked to economic benefits, with every £1 invested in dementia research estimated to bring a £2.59 return to the economy (38).

Worldwide, investment in research for dementia is mirrored in the number of publications dedicated to dementia. In 2022 there were over ten times more publications dedicated to cancer than to dementia.

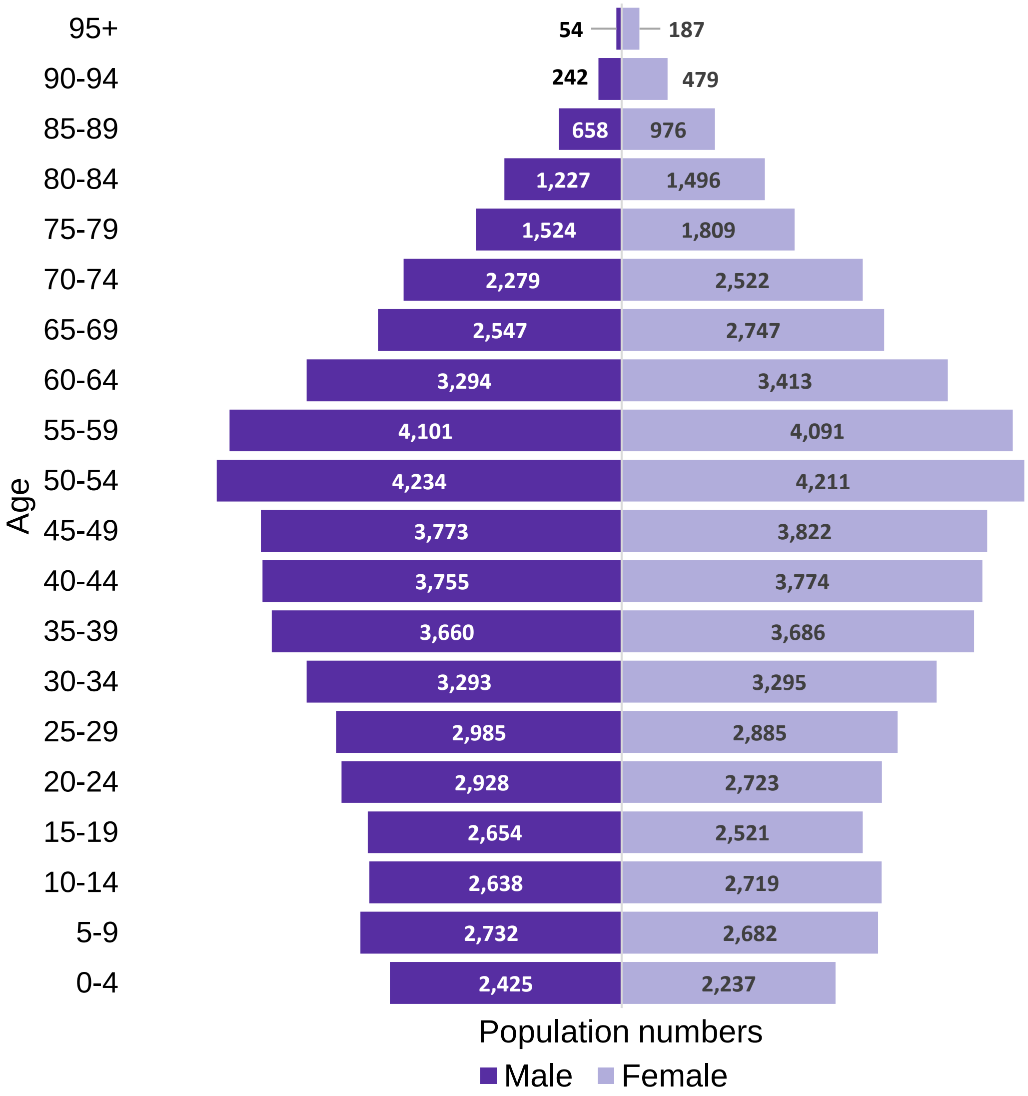
Key areas of focus for research include prevention, diagnosis, treatment (39), dementia care and support, and economics (37). There are particular challenges with dementia research however. Research in this area has one of the lowest uptake rates in health research, and it is estimated that just 1% of people who could take part in clinical trials do so. Barriers to uptake include poor recognition of symptoms, reluctance to seek assessment, and a lack of awareness that there are trials or research that people can take part in (40).

Dementia in Jersey

Our population

Jersey's resident population, as captured by the 2021 Jersey census was 103,267 (41), with a higher percentage of females than males in the older population. A breakdown of the population by age and gender is shown in Figure 3.

Figure 3. Jersey population breakdown by age and gender



Residents of Jersey have a higher life expectancy at birth (83.7 years) when compared with many other countries, with Jersey ranking the 4th highest worldwide and the highest in the top 10 European countries (42). With the greatest risk factor for dementia being ageing, this is a crucial factor to consider within strategic planning.

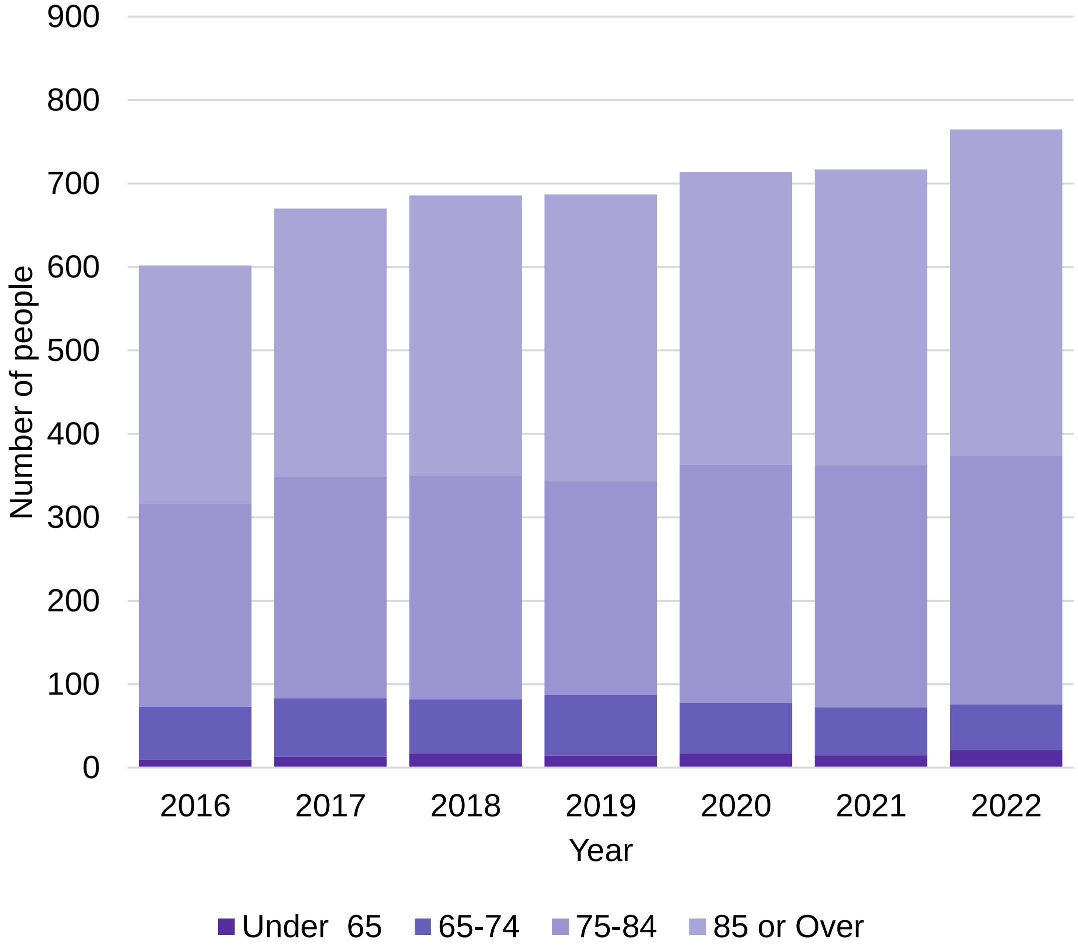
Data challenges

Data is collected and stored in multiple ways across primary and secondary care and across government departments in Jersey. While reviewing data for this strategy, gaps and inconsistencies became evident. Although improvements are being made to the information that is collected and to how systems interact, this remains a critical area for development.

Jersey Dementia Register

Dementia is one of twelve health conditions captured by GPs in Jersey on a long-term condition register. The number of people with a diagnosis of dementia recorded by GPs at the end of 2022 was 765 (43). The number of people on the register since 2016 is outlined in Figure 4.

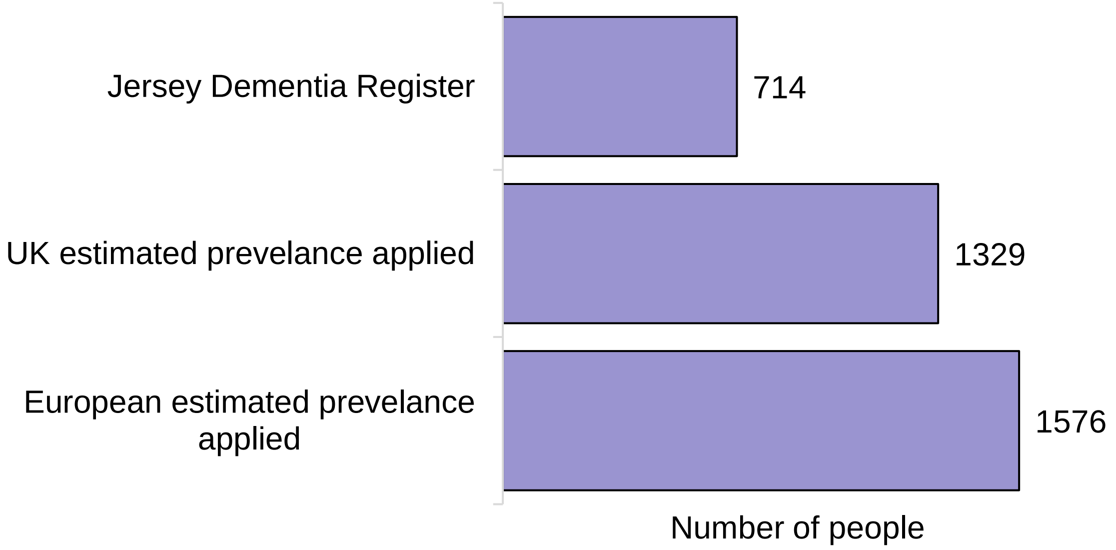
*Figure 4. Number of people on the Jersey Dementia Register by age 2016-2022 as captured on EMIS**



The proportion of males to females on the Jersey Dementia Register has remained largely stable over this period. Males make up 36% of the population and females 64%, a proportion largely consistent with the global picture.

Whilst there is no Jersey specific prevalence data, it can be assumed that rates are similar to those in the UK. Application of the UK 2019 average prevalence rates (44) to the Jersey population indicates that 1330 people over the age of 65 years are likely to have dementia. Application of the European average prevalence rate indicates a likelihood of 1576 people. European averages include countries with a wide range of social and economic factors that differ significantly from Jersey however, making this a less reliable comparison. Estimated figures are shown in Figure 5.

Figure 5. Comparison of Jersey Dementia Register (2021) and the UK and European prevalence rates, as applied to the 2021 Jersey population.



Reasons for the disparity in numbers between the Dementia Register and these estimates may include factors such as under-reporting, the length of diagnostic process, the financial and other barriers to accessing primary care, poor recognition of dementia by health professionals, or a lower prevalence rate in Jersey than in other countries. Barriers to people seeking diagnosis have been identified as a lack of awareness of symptoms, a belief that symptoms are a normal part of ageing or are too minor to seek help for, and a fear of the consequences of diagnosis (45).

Reducing the number of people with undiagnosed dementia is a global priority and is a key target for action in many countries. Whilst the diagnosis rate of dementia is not formally collected in Jersey, calculations indicate that in December 2022 the diagnosis rate in Jersey was approximately 55% compared with 62.5% in the UK (46), suggesting that this may be a priority for action locally.

Services for people with dementia

Community-based services

Primary care

Primary care includes general practice, community pharmacy, dental, and optometry services. Services within primary care provide the first point of contact in the healthcare system for islanders. They are usually the front door to secondary care services such as the hospital and specialist treatments. There are over 100 GPs in Jersey and they hold an important role in supporting people with dementia and their carers, offering treatment, referrals, advice, and information.

HCS Day services

Health and Community Services (HCS) provide day-services for older people at Sandybrook and The Hollies. A dementia daycentre is currently being rebuilt and is due to re-open in late 2024. These centres provide opportunities for social engagement, activities, and support for older adults, including people with dementia, though the new centre will be solely for people with dementia.

Sandybrook has been reconfigured to maintain some service provision for people with dementia whilst the dementia daycentre is being rebuilt, enabling people with moderate symptoms of dementia to attend up to three days each week. A further three days at Sandybrook, and five days at the Hollies can be accessed by people with mild symptoms of dementia. In response to changes to services during the Covid pandemic, an activities program was initiated within the community which has continued, with 6 people being supported in this way.

Recent figures indicate that 43 people with mild or moderate dementia currently attend these centres, with each person usually attending 2 sessions a week, though some attended only 1 and others 5. Although places are limited at these HCS centres, the service does not currently have a waiting list for attendance, nor for transport to the centres.

Barriers to attendance exist for people who do not meet the criteria for attendance due to their symptoms or stage of dementia. Other barriers include the limited length of sessions, or session times that do not fit with other family commitments. In these circumstances the alternative for social engagement or for short breaks for the carer is by sourcing support from domiciliary care agencies. This can result in the potential for inequity both financially, and in their options for care.

Domiciliary care

There are 39 domiciliary care providers registered with the Jersey Care Commission in Jersey who provide care at home to islanders. Domiciliary providers are registered to provide specific types of care for people with a range of care needs.

There are 24 domiciliary providers registered to provide care or support for people with dementia, offering a maximum of 38,068 care hours per week. Of these, three are registered to provide nursing care for people with dementia, though the two providing longer-term nursing care provide a maximum of 70 hours a week in total. Shorter-term nursing care, up to a maximum of 600 hours, that also includes care that may not be classified as nursing, is provided by Family Nursing and Home Care.

As with care home provision, domiciliary care providers are also registered to provide care for people without dementia, so the available hours provided for people with dementia will be significantly less than stated.

Care homes

There are 56 care homes in Jersey registered with the Jersey Care Commission, which provide services for people with a full range of nursing and care needs, across the whole age range. These care homes vary in size from 1 – 99 places, with 16 registered to provide nursing care, and the remaining providing residential support.

There are five care homes in Jersey registered for people with dementia over the age of 60, providing a maximum of 271 places. General nursing care is provided in addition to residential dementia care in two care homes, with a maximum of 63 nursing places available. As with domiciliary provision, care homes are also registered to provide care for people with other conditions, so fewer people with dementia will be occupying these placements.

There are no care homes registered to provide dedicated mental-health nursing, which in Jersey includes nursing care for complex dementia. Historically this level of support was met within mental health inpatient services, however the number of available beds has reduced significantly over the last fifteen years.

Dementia Jersey

Dementia Jersey is the only charity in Jersey with a specific focus on providing support for people with dementia and their families. They give advice and support on dementia, run a range of therapeutic activities, raise awareness, and campaign to improve services for people with dementia and those who care for them.

The number of occasions of support offered by the charity since 2016 is outlined in Table 6 below. The decrease in numbers of attendances at activities in 2020 and 2021 can be attributed in part to the Covid-19 pandemic and the closure of The Saturday Club which provided day care. Similarly, an increase in the same period of occasions of support for dementia advice, which was offered remotely, can be attributed to the impact of the pandemic on formal and informal services in this same period. An increase in the number and range of activities offered in 2022 to meet demand accounts for the increase in recorded attendances post Covid-19.

Table 6- Recorded contacts with Dementia Jersey 2016-2022

Contact type	2016	2017	2018	2019	2020	2021	2022
Activities	1,913	2,601	2,816	3,792	1,485	2,130	4,795
Dementia Advice	313	435	394	336	1,030	1,416	920
Carer Support groups	1,522	1,806	1,360	1,308	669	923	526
Totals	**3,748**	**4,842**	**4,570**	**5,436**	**3,184**	**4,469**	**6,241**

Older Adult Community Mental Health Team (OACMHT)

Older adult community mental health services provide assessment and treatment and, in some cases, care-coordination for people with dementia of any age who have ongoing complex needs. The team also provides support for adults over the age of 65 years who are experiencing an episode of mental ill-health, or who have complex ongoing mental health needs.

Other community-based local services

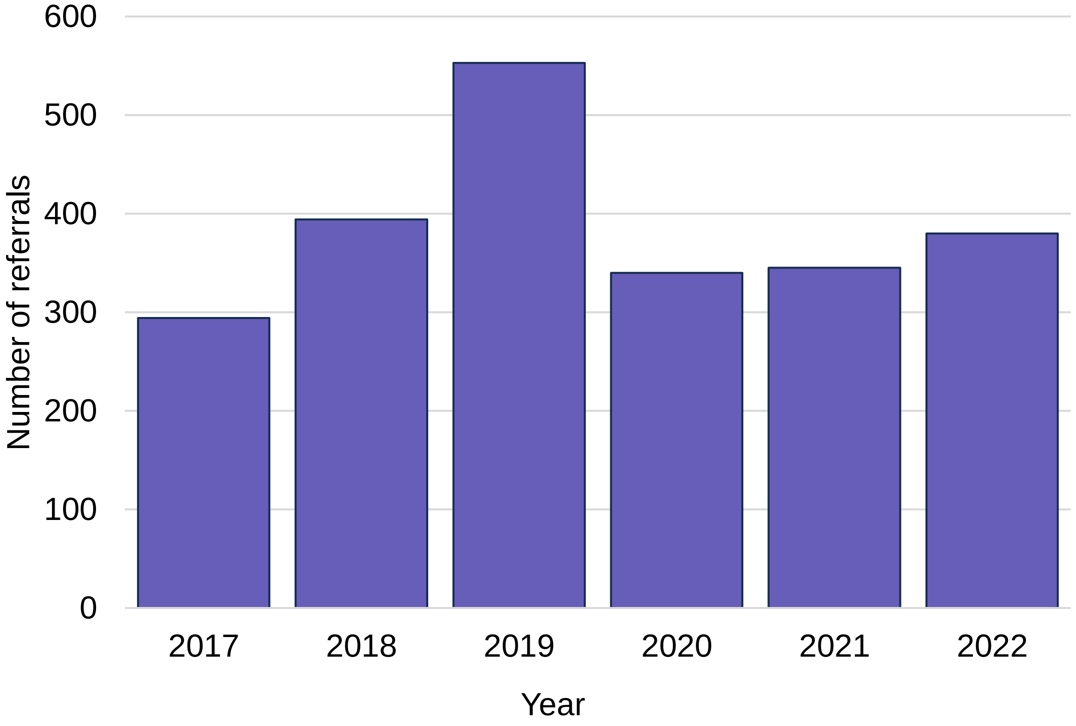
Other local services were contacted to ascertain their provision for people with dementia and their families. These included government, independent and charitable sector organisations which provide a range of day support, advice or information. Our contacts revealed that although these services were not designed for people with dementia, they are generally available to them with some restrictions. These restrictions were mostly due to people’s symptoms or the complexity of their needs. The exception to this was My Voice, an independent patient advocacy service, some of whose services are designed to meet the particular needs of people with dementia. A summary of all of these services and their primary functions is provided in Appendix 2.

Diagnostic services

In Jersey, the Memory Assessment Service (MAS) is the primary diagnostic specialist service for dementia. Diagnosis may also be made by the Older Adult Community Mental Health Team, and the Mental Health Liaison Team which supports the general hospital. The MAS has held accreditation with the Memory Services National Accreditation Programme (MSNAP) since 2010, most recently being re-accredited in 2023. MSNAP is a quality improvement and accreditation network for services that assess, diagnose, and treat dementia in the UK.

The number of referrals to the MAS over the last 6 years are shown in Figure 6. The disruptive impact of the Covid-19 pandemic can be seen by the reduction in referrals from primary care during 2020 and into 2021. Increase in referrals to MAS in 2022 and the first 6 months of 2023 indicates more people seeking advice from their GPs, from whom most referrals are received. It should be noted that the number of referrals recorded by the service exceeds that recorded on HCS information systems. Improvements to how information is recorded have been implemented in the last year and remain an area of focus.

Figure 6. Recorded number of referrals to the Memory Assessment Service 2017-2022



In October 2023, there were 201 people waiting to attend their first appointment with the MAS. National quality standards for the time from referral to diagnosis is 6 weeks in England and 12 weeks in Wales (47). In Jersey the average waiting time from referral to attending for assessment at time of writing was much longer. In October 2023 this was an average of 33 weeks for people 65yrs and over, and around 30 weeks for people under the age of 65yrs. This reflects a substantial increase from the waiting times reported by the service prior to the Covid 19 pandemic, which were in the region of 8-12 weeks, and show a significant current challenge in meeting and maintaining the national quality standard set for this.

Inpatient services

Dementia inpatient services

Beech ward at St Saviour's Hospital provides specialist multi-disciplinary inpatient care for people with dementia. In November 2023, 13 beds were available, though this is planned to increase to 16 in 2024, following the completion of refurbishment works. The purpose of the unit is the provision of specialist dementia assessment and treatment within a hospital setting, and also step-down care for people who have completed their period of assessment but are not ready to return home or transfer to a long-term care setting. It is often the case however, that because of people's discharge from the service being delayed, there are fewer places available for new people to access this assessment service. Reasons for delays to discharge include the current lack of availability of long-term beds for people with advanced or complex dementia, and a lack of capacity within care services that support people at home.

Mental Health Hospital Liaison

A small hospital liaison team provides psychiatric assessment, advice, and intervention for adults of all ages admitted to the hospital, who have symptoms of mental illness or dementia.

Jersey General Hospital

The general hospital provides emergency, outpatient, and medical and surgical inpatient services for islanders in Jersey, of all ages.

- In 2022, 512 people with recorded dementia attended the Emergency Department (ED) with total attendances of 932, many of whom arrived by ambulance.
- Over half of the people with recorded dementia were admitted to hospital.
- The proportion of acute inpatient episodes of care for people with recorded dementia has remained stable at around 5% of all episodes since 2012.
- On average in 2022 people with dementia remained in hospital for over twice as long as people without dementia.
- 67% of delayed discharges from acute wards in the 12 months to June 2023 related to people with dementia.

In the UK it is estimated that at any one time, one in four hospital acute beds are occupied by people with dementia (48). Whilst this level of occupancy is not reflected in local data, factors such as the inconsistent recording of diagnoses may contribute to an inaccurate picture. Information on delayed discharge and length of stay however is largely consistent with the situation in the UK where people with dementia are known to experience longer hospital stays and delays in leaving hospital (49).

It is widely evidenced that people with dementia experience greater distress, confusion, and delirium while in hospital. Older people with dementia are also at a higher risk of falls, dehydration, reduced nutrition, decline in physical and cognitive function, new infections, and even death (50). In addition to the impact of these risks, the lack of availability or capacity of domiciliary and care home places in Jersey contributes to prolonged hospital stays for people with dementia.

A programme of quality improvement relating to the care of people with dementia in the general hospital is underway, with a reduction in the prescribing of psychotropic medicines, and training for healthcare support workers being two examples of its positive outcomes.

Workforce

The roles that represent the workforce supporting people with dementia and their families were identified as part of a mapping exercise to inform the strategy. This included hundreds of people employed in very diverse roles, supported by people working as volunteers in all sectors. Appendix 3 shows the roles people have, working either primarily or occasionally with people with dementia and their families as part of service provision for customers, clients, or patients.

Views and experiences of islanders

How we listened

Key to the development of this strategy has been listening to what people have had to say about their experiences of dementia. This has included people with a diagnosis of dementia, their families and

, and professionals working with them. The engagement activities undertaken are detailed in Table 7.

Table 7 - Engagement activities

Activity	Details
Engagement sessions	Engagement sessions were advertised through Dementia Jersey, government communications, and by email invitation to all GP practices. The following sessions were offered: ○ One morning session for people with dementia at Communicare Centre (organised by Dementia Jersey) ○ Two morning sessions for family carers, and people with dementia at the Radisson Hotel (organised by Dementia Jersey) ○ One evening session at the Radisson Hotel for family carers of people with dementia (organised by Dementia Jersey) ○ One afternoon session for professionals at the Poplars Centre, Overdale Hospital ○ One morning session for professionals at Jersey General Hospital ○ One evening online session for professionals ○ One morning online session for professionals including HCS and primary care
Public Survey	A survey was hosted online by Smart Survey and accessed from the Government of Jersey website. ○ The survey was promoted over radio and social media channels, and by a poster campaign. ○ Posters were placed around the island in strategic locations. ○ Paper copies were available in 3 HCS locations and from Dementia Jersey. ○ A Portuguese language survey was available on Smart Survey and via paper copies.
Care Home and Domiciliary Care surveys	Surveys were sent to the managers of all care homes and domiciliary care agencies registered with the Jersey Care Commission as providers of services for adults. These were hosted online by Smart Survey and accessed from the Government of Jersey website.

Outcomes of our engagement with islanders

Surveys were sent to 25 care homes with 16 responding, and to 18 domiciliary care agencies from whom 10 responses were received.

What domiciliary care agencies told us:

- Over half of everyone receiving care from care agencies in Jersey, either have a formal diagnosis of dementia, or suspected dementia.
- Most care agencies said they did not have capacity to take on new clients.
- All care agencies reported barriers to taking on clients with dementia including:
    - delays in receipt of Long-Term Care funding payments.
    - concerns with the complexity of needs for some people with dementia.
    - insufficient dementia specialist knowledge, experience, and skills within the available workforce.

Survey responses indicated that most staff had accessed dementia awareness sessions. Many staff had not undertaken dementia specific training however, but indicated that provision of in-person, local training on dementia would be welcomed.

What residential care providers told us:

- Over 60% of all residents in these care settings have a diagnosis of dementia, or suspected dementia.
- Most reported they did not have capacity to provide care for more residents.
- All nursing and residential home providers reported barriers to taking on new residents with dementia including:
    - the person’s current or future complex care needs related to dementia.
    - lack of ‘secure facilities’ to prevent residents leaving the building.
    - not being registered by the Jersey Care Commission to care for people with dementia.
    - insufficient dementia specialist knowledge, experience, and skills within the available workforce. Whilst the majority of staff accessed a dementia awareness session, most had not had any dementia specific training.

As with domiciliary care providers, most staff working in care homes had accessed a dementia awareness session, but most had not undertaken dementia specific training.

What islanders told us in the public survey and engagement sessions:

There were 520 individual responses to the public survey. Islanders were asked about the challenges they experienced and identified 1,863 separate points. When asked what they believed could make Jersey a more dementia-friendly and inclusive island, most of the 1,558 points made by islanders echoed the challenges they noted in the previous question. Some comments about how things could be improved were also made.

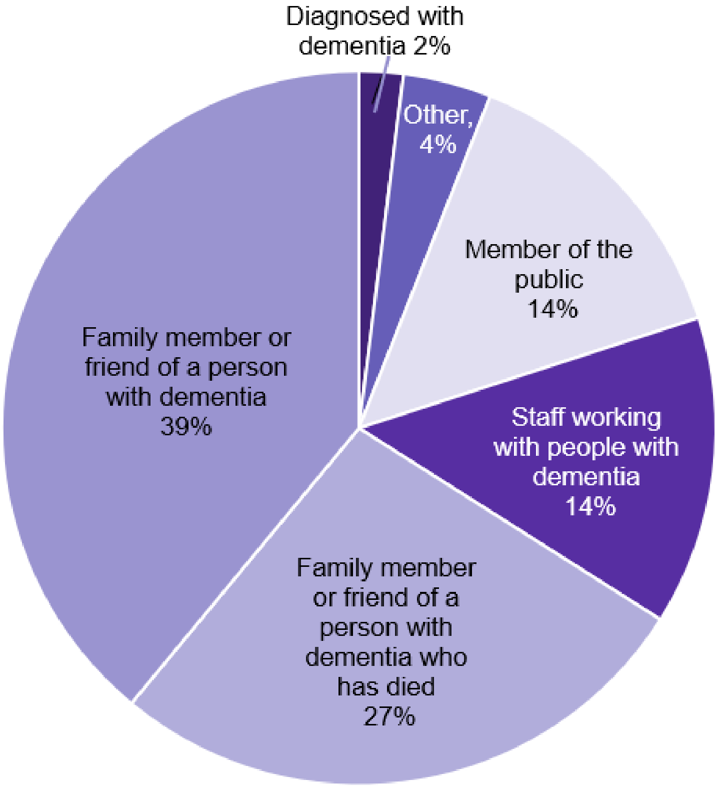
In-person and online engagement was undertaken at varying times of day, over a period of 2 weeks. Sessions were facilitated by two members of the working group. Each session was recorded and transcribed and then reviewed using an analysis software program. In total, 62 individuals met with us to share their thoughts and experiences.

Some information from the public survey has been outlined in the figures below. The subsequent section has been developed by amalgamating the data from the surveys and the engagement sessions to provide in-depth descriptions of people's lived experience of dementia locally.

Respondent's status, dementia knowledge and risk awareness

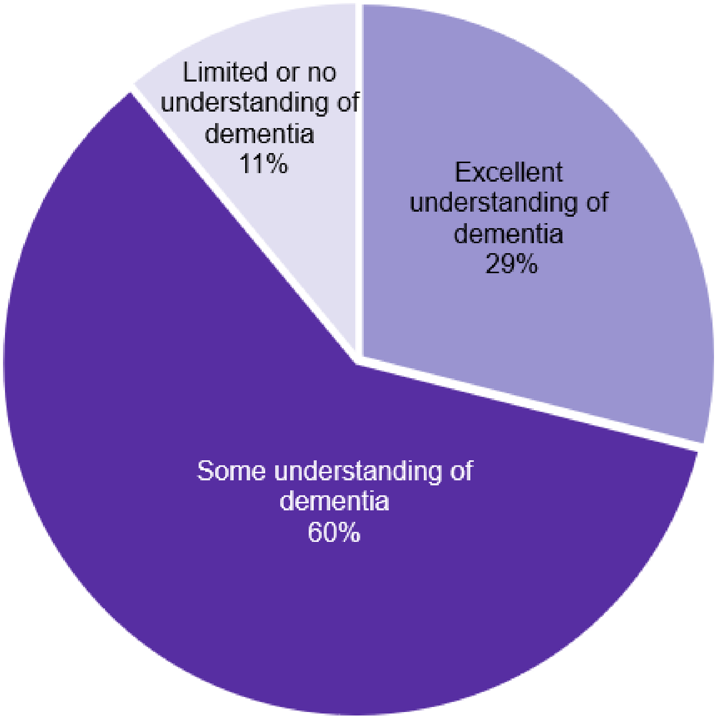
While some people responding to the survey named themselves in more than one category, about 75% of respondents have, or have had a family member with dementia, as shown in Figure 7.

Figure 7. Public survey: Dementia status



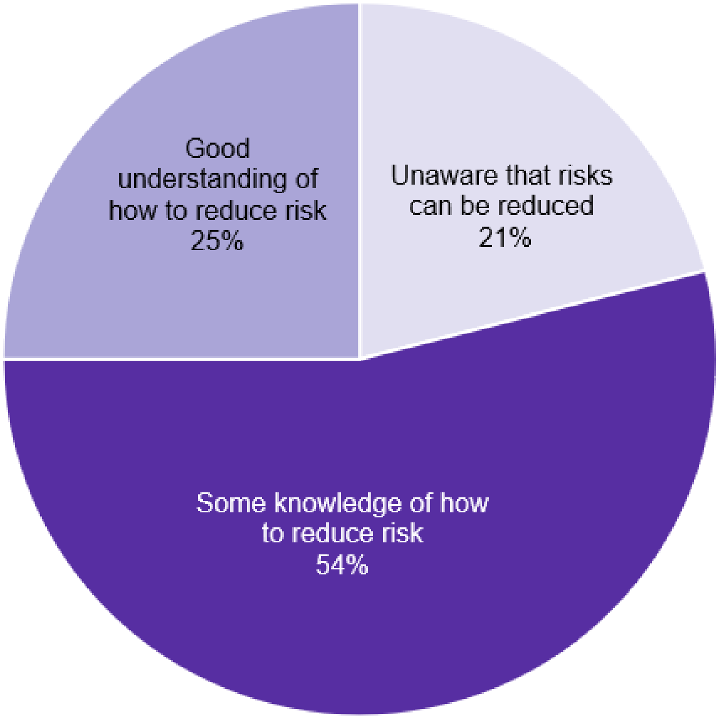
Just over 70% of all respondents said they had only some, limited, or no understanding at all about dementia and its associated symptoms, while less than 30% said they had an excellent understanding, as shown in shown in Figure 8.

Figure 8. Understanding of dementia



75% of respondents said they were either unaware that it was possible to reduce their risk of dementia, or had only some knowledge of this, as shown in Figure 9.

Figure 9. Knowledge of risk reduction



Public survey themes

The subjects noted in the public survey, and raised during the engagement sessions, were analysed, and are presented below under these four broad thematic headings.

- Information and awareness
- Services
- The impact of dementia
- The workforce

Information and awareness

Participants told us that they thought the public's awareness of dementia was generally superficial. They suggested this was limited to stereotypical images of people with advanced dementia in care home settings, who had little understanding of the world around them. Family members and people with dementia spoke about knowing little about dementia at first and some spoke of having associated memory difficulties with getting older. Some carers told us that when they reported memory difficulties to their GP, ageing was suggested to be the cause.

The fear associated with dementia was raised by people with dementia and carers. Some described the fear of admitting that they, or someone else had dementia because of how they thought others would react. Other people however, said that when they had been open about having dementia, they felt supported by their families and friends and the wider community.

> *"I've never known anyone with dementia, so I was mortified when I / we got the big prognosis /diagnosis. I just - it was just terrible - it upsets me even now." (carer)*
>
> *"If I want to go into a place the first thing I will say is - would you mind, I've got Alzheimer's, but everybody says yes, that's fine and that enables me to get on with what I want to do." (person with dementia)*
>
> *"I don't hide it and I've told people straight off. I told them that I have been diagnosed with dementia and they are a bit horrified first of all, but I don't make any secret of it." (person with dementia)*

Many people highlighted the need for clear public information about dementia. They said that this would help to reduce stigma and educate the public about the possibility of reducing their risk of dementia. Improved information was seen as a way to increasing understanding of the practical and social needs of people with dementia, and helping organisations become more dementia-friendly and inclusive.

> *“There needs to be an all-out effort to tell us how to prevent this.” (person with dementia)*
>
> *What would help would be educating the public to understand the emotional pain and embarrassment that people with dementia have to deal with and to know how to help.” (carer)*

A consistent theme raised by people with dementia and family carers concerned the availability of information about dementia and sources of support and help for them. Some describe a total lack of appropriate information and others said they were over-loaded with it at the wrong time for them.

Understanding of services and financial support for people with dementia and their families was not consistent across the workforce. Frequent and rapid changes in these services and in staffing, regulatory changes, and the volume of general communications received by staff, were identified as potential contributors to poor understanding. Clear, jargon-free, and up-to date information relating to dementia was identified as a need.

> *‘I felt that we were on a huge learning mission. We were having to delve into it to try and find out things ourselves.’ (carer)*
>
> *“It’s a journey in the dark for many of us.” (person with dementia)*

Services

Diagnosis

There were mixed accounts concerning people’s experiences of getting an assessment. Some family carers reported that they were unclear about when and where to go to raise concerns, and some had thought a GP would not be concerned about seemingly small issues such as forgetfulness or increasingly mislaying or losing objects. There were however accounts where the path to a memory assessment was smooth, usually where there was an established relationship with a GP, or when a person had arranged a private consultation with a specialist.

Some family carers described a sense of not having been heard or taken seriously by healthcare professionals or having to chase up scans and other test results prior to their specialist assessment.

> *“The doctor was telling us it was just old age, but by the time she was referred to a specialist it was too late, and she died even before getting the results of her brain scan.” (carer)*

Barriers to accessing assessment included the cost of GP appointments, lack of awareness or denial of symptoms by the person or their family, a fear of having to stop driving, and an inconsistent understanding of dementia amongst healthcare professionals. Some carers suggested that adding cognitive testing to ‘well person checks’ alongside other health conditions for over 65s could be a helpful method of identifying concerns.

> *“It was 2 years that I had been trying to get him to the doctor. He would go and come back and say, ‘yes the doctor says I am fine’. The third year I went in with him and made him have the test.” (carer)*
>
> *“We have been to the GP, and he is not hearing us, he says it just normal, but these are the things that are happening.” (carer)*

Family carers were generally satisfied with the assessment and diagnostic process at the Memory Assessment Service (MAS), though the long wait for an appointment was frequently mentioned, particularly since the Covid-19 pandemic. Carers described this period of waiting as ‘being in limbo’, unsure of what was happening and not knowing what to do or where to go for advice.

> *“The doctor, he was fantastic. And the nurse that was with him. Yeah. I cannot fault them at all.” (carer)*
>
> *“The Memory Clinic was a trauma for us both. My mother did not wish to know if she had dementia but needed the scans and other tests to get a diagnosis and to get funding.” (carer)*

Post-diagnosis

The lack of adequate post-diagnostic support was consistently raised by carers and people with dementia once discharged from MAS. Staff expressed a sense of frustration, and of having their hands tied when raising the negative and contrary impact this had. Models from other jurisdictions that give importance to the continuity of post-diagnostic support were cited as being a more effective service model.

Many family carers said that the current situation where people are discharged from MAS to the care of their GP after diagnosis did not work for them. Many said they did not think their GP was the best person to manage medications for dementia and they did not have the specialist knowledge about symptom management for people’s ongoing needs.

> *“There was no follow up. There's no social worker assigned. I had really no other source of help. You just get on with it, whatever you can do. That's it.” (carer)*
>
> *“They washed their hands and that's how I felt.” (carer)*
>
> *“You know, you walk out the door, you think you're just going over a cliff, you know.” (carer)*

In the surveys and across all the engagement sessions the lack of availability of care and support were frequently noted, and intensely discussed. This included the lack of respite and short break options, insufficient capacity within the domiciliary care sector and in care homes, particularly for people with complex needs related to dementia.

Respite

The importance of respite was voiced strongly and considered essential by many. However, most people said there were very few options, if any, for the respite they needed, sometimes just for a few hours and for short breaks.

Day centre provision was frequently mentioned because although people felt they or the person with dementia would both benefit, not all were able to access this type of support. Concerns were raised about recent reductions in places for people with moderate to advanced dementia, partly as a result of the temporary closure of one centre for refurbishment. Other barriers to day service attendance included the short length of sessions, limited transport options, and the fact that these centres are not able to provide options for people with advanced dementia or complex needs.

The need to balance breaks for family carers with ensuring a positive and meaningful experience for the person attending was raised as being key to successful day service provision.

> *“Because of her care needs she wasn't coping so she had a shorter day, so that meant the respite my dad was getting was only a few hours rather than a full day.” (carer)*
>
> *“There's nowhere to go. He's too bad to go [to the day centre]. They can't accept him because he needs a one-to-one.” (carer)*

The value of short-break and respite options provided by domiciliary care agencies and care homes were identified by family carers as being vital. Some carers however, said they found that when they tried to source such help, particularly at shorter notice, none was available, particularly if a person had complex care needs. The challenges for care homes to hold beds for respite rather than use them for longer term episodes of care, was also raised.

> *“Even if you've got a care agency going in, the spouse or family member isn't getting any rest because the person with dementia is just wanting to be with them all the time.” (staff)*
>
> *“I had to go urgently into hospital at the beginning of the year and to try and get my husband in a week for respite was horrendous.” (carer)*

Care homes

A lack of care home places for people with dementia, particularly for those with complex needs and whose distress significantly challenged others, was identified by family carers and hospital staff as a significant issue.

Some staff spoke of instances where a person was admitted to the general hospital, and due to the challenges of supporting them within an acute setting, added supervision was needed. There was a sense of frustration that this action often resulted in delays in discharge from hospital, even though the extra support had only been necessary due to the temporary impacts of an unfamiliar environment, or illness.

Family carers spoke of having to apply for care homes sooner than they would have liked in order to secure a place. They described coping at home for longer than they felt they had the physical and emotional capacity to manage.

> *“My husband needs special care. And there's only three homes in, in Jersey that can provide the level that he needs.” (carer)*
>
> *“My father spent the last 8 months of his life in hospital because no place was available for him in a care home. He finally moved into a home but died a few weeks later.” (carer)*
>
> *“I still don't want my husband to go into a care home. I'd rather spend – well so much money - but the care is at home with me as long as I can. But I'm - I'm now having to put my name down to care homes because it's such a long waiting list – you just can’t get them in.” (carer)*

Carers described the transition from care at home to a care home as challenging. Though some said they felt a sense of relief, others expressed feelings of loss, guilt, and betrayal, sometimes mixed with relief. Some said they were shocked at being asked not to visit their relative with dementia for a time following a move. Concerns were expressed about the potential of their relative’s social needs not being met, particularly where English was not their first language. Others said they worried that they may soon be forgotten by the person with dementia.

> *“We've just settled a gentleman into one of our larger care homes on the island, and the wife was advised not to visit for quite a few weeks while he settled - absolutely heart breaking for him.” (staff)*
>
> *“As a family, we try to be there as much as possible for her, but modern life doesn't allow us that privilege of spending more time with them, and they get so isolated and confused, especially if there is no one that speaks the language.” (carer)*
>
> *“I think there should be a more step like approach where we can come in and help lots in the beginning." (carer)*

Continuity

The lack of continuity in the support for people with dementia and their carers was often raised. Frequent changes of staff, having to recount the details of their situation many times, or having had multiple named workers allocated to them who then left the service or island, were identified as a significant cause of carer stress.

Some staff identified that the current practice of discharging patients from services following a period of support was counterproductive. The process of getting re-referred or referred to ‘the right’ service was described by both staff and carers as complicated and unclear, and led to delays in people being able to access essential support. There was agreement this was often the reason why people experienced crises needing more intensive intervention than would have otherwise been necessary. Staff said that this troubled them and added to the stress they experienced at work.

> *“It’s the continuity, isn't it? You desperately got to get the one-to-one and hang on as long as you can with the one person that you've actually met and talked to, and they know who you are, and that know how you feel.” (carer)*
>
> *“Alzheimer's and Dementia Jersey was the only stable thing I have had through the ten years.” (carer)*

Concerns related to domiciliary provision were regularly noted and voiced. Many people said that the care packages that had been recommended could not be provided by any domiciliary care agencies. Others said that the frequent changes of staff troubled their relative with dementia, particularly when this involved personal care, and was equally difficult for them as carers in having constant changes of people in their homes. This was described as creating a challenge to building trusting relationships, and a barrier for some people with dementia in accepting ongoing care.

> *“I had the agency - he got on well in the first 2 months with the same people but then when it started changing every other night - he refused. That meant that I had to do the care. What is the point in paying them - different people every night.” (carer)*

Navigating services

The difficulties of navigating services, the gaps between services, and not understanding the differing roles of the professionals involved in a person’s care were frequently mentioned. A sense of falling through the gaps between services and not knowing who to speak to for help and advice was described.

A suggested opportunity for improvement was identified as the development of a single dementia service, or ‘hub’, providing assessment, diagnosis, treatment, and care navigation. A single point of contact and regular follow-up throughout the journey was raised as a recommendation for development, and as an improvement need.

> *“I was meeting with a family today. I got them to describe what their journey through the services was like so far. They said it was like moving from one of these blocks to another block and falling between one block and the next.” (staff)*
>
> *“There needs to be a one-stop-shop for help and advice.” (carer)*

Acute care

The general hospital was mentioned frequently. Carers mostly spoke positively about individual nurses who they believed were doing their best, and who they generally described as being kind and compassionate. Many carers however wrote at length and spoke passionately about other issues. Some were clearly frustrated and often angry about the facilities and environment at the hospital not being right for a person with dementia, and often distressing for them. Some were angry about the length of time people with dementia remained in hospital because of the unavailability of domiciliary, residential, or nursing home places, and others were unhappy about a perceived lack of communication with staff, and about the inflexibility of visiting times.

> *“I'm so grateful to the staff and the nurses - they're just so full of love and compassion.” (carer)*
>
> *“People get stuck in hospital wards. It’s a dreadful situation.” (carer)*
>
> *“Well, my poor husband's been in hospital now for six months and he cannot find anywhere in Jersey - a home to go to. And there's nowhere for him to go. And it's quite distressing for me to see him deteriorating.” (carer)*

The staff spoke strongly about the challenges of supporting people with dementia in an acute hospital setting. The impact of agitation and other expressions of distress, and the challenges experienced whilst supporting or managing these situations were recurrent themes.

The physical hospital environment was described as unsuitable and not conducive to supporting people's social and psychological needs. Competing clinical pressures on wards were described as having resulted in the removal of day rooms or other quiet spaces that could be used to support a more holistic approach to care.

> *"We are using a medical model to sort of contain the person within an environment that's really not helpful for them." (staff)*

The need to build on existing services that provide alternatives to hospital admission and support timely and safe discharge were raised by staff as priorities. Barriers to this were identified as the absence of a short-term intensive period of support, insufficient workforce, service funding, and regulation of care considerations.

> *"We have nurses in the community that can give antibiotics. Then when you use the response nurses who can give IV antibiotics or whatever, you also need that added care component, which they never have." (staff)*
>
> *"They need someone to go in [to the care home] for those two days because their care needs will be increased for those couple of days. But for what we're having to spend by having patients stuck in hospital..." (staff)*
>
> *"It's like a hot potato and there is friction in the ward constantly. You know - and when there's a patient with dementia there's more negative than positive." (staff)*

Cost and funding of care

The costs of primary, domiciliary, residential, and nursing home care were raised by many people. The added pressure and stress related to care costs were described by carers who felt that they were potentially putting their own health at risk by feeling that they had to support their family member at home. This was more evident when care needs were advanced or complex.

“GPs are a very expensive service, so you don't want to keep calling your GP all the time.” (carer)

“When we tried to get private care, again there was no availability, and the costs were astronomical.” (carer)

“The long-term care scheme is too difficult to access. The care costs are unaffordable and cause more stress and anxiety for families.” (carer)

“I think my dad has now realised that yes, he can't handle her at home. But he was still, even when she was going [into a care home] he was like - if I can't afford it, then I'll just have to bring her home.” (carer)

Islanders shared their thoughts about how services should be funded. Family carers raised concerns that government funding for formal HCS services such as specialist long term nursing care and day care options for people with complex dementia, had been cut over recent years. They were also unaware of any clear and robust plan for developing this capacity differently or elsewhere, making them feel dementia was not taken seriously.

Carers asserted that charities should not be dependent on fund-raising for provision of essential services, and that the government should increase funding for support services for people with dementia provided by charitable organisations. Staff discussed the need for robust funding of essential, core HCS specialist services for dementia, which were described as the required foundation for quality dementia care.

“You see, that is difficult because they have closed down so many of the supports. I just feel health has just washed its hands of everything. You know that, that they think well, we've gotta save money. We'll get rid of that, and we'll get rid of that, and it's left the people and the carers high and dry.” (carer)

“They are just burying their heads in the sand. People are living longer, and this is gonna get worse. And... and yet there's nothing being done about it.” (carer)

“It’s been a very subtle dismantlement of services for dementia care very quietly and the expectations are there from all of us that services have been shrunk.” (staff)

Living with dementia

Whilst describing their experiences of having dementia or being a family member or carer of someone with dementia, the extensive effect on every aspect of life was evident in the experiences participants shared with us.

Recognising dementia

Many people with dementia and family carers said that initially they just put the symptoms they experienced down to getting older. Family carers said that subtle changes could easily be explained away, and described not wishing to admit to concerns, hoping that changes were temporary. This resulted in hiding early signs from those around them, including family members. Fluctuating symptoms in the early stages added to the challenge of recognising that there was a change that needed attention.

People said once they had decided they needed help they did not know where to go to for this, with some saying they thought the changes were too subtle for this to be a concern to take to their GP. Concern that they would not be believed by others, particularly where the person was able to communicate well, was described as another barrier to seeking help.

> *"We didn't want anybody to know, so we were sort of carrying on as normal." (carer)*
>
> *"When you look back and think - well hang on - maybe I am a bonkers old woman making all this up - you don't really know." (carer)*
>
> *"You don't go to a GP because your husband keeps losing his keys do you." (carer)*

Many carers described the challenges they faced due to both a person's forgetfulness and their denial of their symptoms. This lack of insight, awareness, or denial, created ongoing challenges whilst they were seeking and then receiving support and care. Discussing such things or asking their relative to go to the GP was a source of friction for many carers. Some said they had to speak with the GP themselves to raise concerns, or had to attend appointments with their relative to ensure that symptoms were discussed.

> *"She hated the idea that she had dementia, so didn't tell anybody. She always tried to hide it." (carer)*
>
> *"it's my husband too - He's got dementia – but there's 'nothing wrong' with him! So, I have that to contend with as well. Just now he's got it - he was told he had it, but it went straight over his head." (carer)*

Impact on people with dementia

People with dementia told us that dementia impacted every sphere of their day-to-day lives. Some described their symptoms and the impact this had on their confidence and social relationships. They told us they engaged less with people, because of their concerns about being in public and in places that were becoming increasingly unfamiliar. They described that using the buses, parking, and accessing public buildings and community spaces was getting increasingly difficult for them.

> *"I get frustrated because sometimes I can't get the words out and then I start to stutter and then I just keep quiet. But really, I'm quite happy in my little cocoon and because I sort of think I'm quite normal." (person with dementia)*
>
> *"I feel so lonely and cut off from life." (person with dementia)*
>
> *"It's scary when you just don't have confidence in - in yourself, what you're doing, and whether you have locked the door or not, and because I can't remember, I've just gotta go and check the door." (person with dementia)*

Impact on carers

Carers described a range of physical, social, emotional, practical, relationship and lifestyle burdens and how these affected their day-to-day lives and previously held images or plans for their futures. The weight of responsibility in shouldering a caring role, and the expanding demands on time and emotions as a person's dementia progressed, was raised. Feelings of loss were described that included the gradual loss of the person they knew, the loss of their own identity, the loss when a person transitioned to a care home, and the loss at the end of life. Some carers wrote and spoke of feeling guilty, that they were betraying the person with dementia, or that they were going behind their back when making decisions on their behalf.

> *"They feel like they are going behind that person's back, and that is not such a nice feeling as you are talking about somebody behind their back, but you have to do it. So, then they have the guilt as husband or wife." (staff)*
>
> *"I would often say to the social worker - she isn't going to tell you the truth – when you say can you cook supper, she will be saying yes - and that was really hard." (carer)*
>
> *"My husband was in [care home name] and one day he said to me 'I think we should get married' which is nice actually, but that meant - 'eurgh - it's real, you know it's really really happened.' And it's a big moment you know." (carer)*

Carers described having to remain alert and vigilant in order to maintain the safety of their partner and themselves and spoke of how they had to adapt routines and activities to achieve this.

> *“She went walkabout and went missing, and we had the police and the whole added search for her.” (carer)*
>
> *“He was an electrical engineer and one of the things is - especially now we've moved - every switch is on, or I don't know what he's gonna turn on next.” (carer)*
>
> *“I would often say to the social worker - she isn’t going to tell you the truth – when you say can you cook supper, she will be saying yes - and that was really hard.” (carer)*
>
> *“My husband was in [care home name] and one day he said to me ‘I think we should get married’ which is nice actually, but that meant - ‘eurgh - it’s real, you know it’s really, really happened.’ And it’s a big moment you know.” (carer)*

Issues related to driving assessments were raised by carers and staff. These included people’s uncertainty about when these were necessary and who was responsible for actioning them. The fear of having to stop driving was given as a reason why some people would not attend appointments at MAS, and some carers felt they needed to make decisions themselves about a person’s ability to drive.

The emotional impact of having to give up driving when the person with dementia was the sole driver for the household, meant not only the immediate loss of independence for the household, but also presented new practical difficulties. This led to problems with shopping, attending appointments, accessing support services and health promoting activities. This also restricted people’s opportunities for social connections and maintaining friendships.

Alternative means of public transport were described as either inaccessible or inappropriate for a person with dementia. The tight restrictions on the patient transport service were also raised as an issue, together with the high cost of taxis and inconsistencies in the help provided by parishes.

> *“Mobility, getting out, trying to get your drugs, trying to get your shopping, unless you've got family, it’s very, very difficult.” (carer)*
>
> *“I knew he shouldn't drive. Yeah, he went through red lights for a start, and I thought - I had to say to the doctor, and he said, ‘should I tell him or you?’ And I said, ‘no you please, cause he won't listen to me’.” (carer)*
>
> *“We invite people who can work in a group together and can follow instructions, but they have to be able to get themselves there. So, if you haven’t got someone to get you there and back, either family or parish, you can’t attend.” (staff)*

Many carers, being older themselves, mentioned problems with their own health, and how the pressures of their caring role made it difficult to take care of themselves. This was particularly significant for those with chronic health conditions.

> *"I found that I would get her up in the morning, 7-8, whatever, and then shower her and then by 10 o'clock I was absolutely knackered and had enough for the day." (carer)*
>
> *"I think sometimes family members see it – perhaps that aren't directly involved. Maybe a sister or a brother calls on you one day and you look absolutely haggard - maybe even crying." (carer)*
>
> *"She has no life outside of him now and the impact on her mental health has been devastating. She never gets a break." (carer)*
>
> *"I'm actually so exhausted that if I don't have a break at some time - I mean, I'm ill now anyway so I don't know what's gonna happen." (carer)*

The impact of dementia on family relationships, lifestyle and social activities was frequently raised, particularly the disruption to routines. Some carers said their caring roles had stopped them working and pursuing their own interests and activities. Some shared the feeling that their lives were either on hold or over, but spoke about how thinking this also left them feeling guilty.

> *"I used to have my own social life. You know I used to, well, I used to be a volunteer for Hospice, and I used to go to art classes, and I don't do any of that now." (carer)*
>
> *"I used to be able to go out. But now I can't, I only have to go upstairs and then he will come – 'Oh, where are you? Where have you been?' You know? And sometimes you feel really trapped by - by this." (carer)*
>
> *"It's about not losing yourself along the way as your batteries and friends can get drained at times." (carer)*
>
> *"We can't go on holidays - we can't. We will soon be at the point where we won't be able to go out for a meal at a restaurant on our own. We go out with the family - but he doesn't eat well, he won't sit down - it's lots of things." (carer)*

Coping and adapting

Carers told us about the importance of adapting and trying new ways of solving problems, and the importance of being flexible. They described the frustration and stress they felt as unfamiliar problems arose and being overwhelmed whilst trying to find solutions.

“You kind of have to swap moods yourself. If you're feeling a bit like that, it doesn't help when they make you a bit more…” (carer)

“There are so many unknowns that make one feel that it's quite daunting to even think about what it meant. I just felt that, coping day by day rather than looking ahead. Today he's okay - tomorrow he might not be.” (carer)

Support

The benefits of talking with others in similar situations was universally agreed to be a strong supportive factor. Opportunities provided by Dementia Jersey were described as creating a sense of shared community with other people who were going through similar challenges. Carers spoke of how they had gone on to develop networks of support amongst themselves outside organised events. People with dementia described the value of shared activities with other people with dementia, making new friends, and sometimes renewing old acquaintances.

“You know Dementia Jersey has helped me an awful lot – just by meeting other people who have gone through what I'm going through – ‘cause you don’t meet them in normal life.” (carer)

“Dementia Jersey’s advice and support was invaluable, and the groups and activities are amazing. There should be more of this.” (carer)

“Dementia Jersey must continue to do its work. It’s brilliant, they do a great job, are very professional and it has been an absolute lifeline.” (carer)

There was agreement amongst carers about what would help and support them in their caring roles. Getting advice and learning the practical skills of caring, opportunities to learn how to fulfil roles previously undertaken by the person with dementia, and practical trips for communication and diffusing frustration and limiting distress, were all mentioned. Some felt this learning should be supported or overseen by professionals, though the benefits of training from charitable organisations, and peer support were also noted.

“In some ways we’ve done caring with NO training - we learnt on the job.” (carer)

“How do you get somebody into the shower that is afraid of water?” (carer)

“I never used to do all the things, like tax and bank accounts and all that. Suddenly it’s all new – you have got to do it.” (carer)

Workforce

The importance of the workforce (people employed to work with or support people with dementia and their carers across all sectors, including the charitable and independent sectors) in delivering quality, compassionate care that supports the needs of people with dementia and their carers, was raised often.

Workforce availability

Recruitment difficulties and the challenges of ensuring adequate staffing levels were frequently raised. Problems with workforce retention were also cited as a barrier to the provision of excellent quality, safe care. Participants said that reduced staffing levels meant they had limited access to development opportunities and training, which they said significantly contributed to workforce stress.

> *“We had working groups to gain contact with care homes and actually go out and do the training and support. There was a lot of the care homes saying, ‘actually we don't have the time for you to come in here - I can't release staff’.” (staff)*
>
> *“Unfortunately, we're getting more and more dementia patients who just get stuck. They can't get out because there's no beds. And - and when there are beds, we're now being told there's no staff.” (carer)*
>
> *“We’ve got falls mats, but if you’ve not got the staff to answer you are still not going to stop that person falling.” (staff)*

Training, education, skills, and experience

Deficits in dementia specific knowledge and training was consistently raised and spoken about. Participants said there was a need for improved training for staff in care homes, domiciliary care, social care, the general hospital, primary care, and specialist dementia services. They also said that better knowledge about dementia and its impacts on the person and those around them was required across the whole workforce, particularly concerning communication skills.

Barriers to training were identified as workforce and time pressures, and the lack of availability of quality in-person, scenario-based training programmes. Others cited competing training priorities, funding delays, and the absence of a dementia specific standards and training framework on the island. Participants said there would be benefits from more opportunities for joint-learning and joint-working that would enable cross-pollination of skills and knowledge through teams, services, and providers.

> *“The people that come and look after you at home have got such a short amount of space and time, I feel that those workers could learn a little bit more about how to work with somebody with dementia.” (carer)*
>
> *“We've got so much e-learning to do these days that the nurses are having to do it in their own time, and we've got lots of other pressures on us as well. So, dementia isn't something, as an acute medical nurse, that we actually look at.” (staff)*
>
> *“Well, I'm sorry. They need to be taught how to - because they spoke to him as if he were a baby.” (carer)*

There was a belief amongst some carers that professionals’ knowledge about dementia and experience working with people with dementia was inconsistent and sometimes lacking, resulting in delays in people being diagnosed or receiving the care they needed. They said this needed to change and be prioritised. This was validated by staff who agreed there were deficits in some of the workforces’ knowledge, skills, and experience, which negatively affected quality of care and the experience of the person with dementia and the carer.

> *“Also, a GP - they're not experts in that field.” (carer)*
>
> *“My medical colleagues were saying that they are under a lot of pressure from care homes to prescribe psychotropic drugs because of behaviour that challenges.” (staff)*
>
> *“We talk about the care homes not having maybe the confidence to work with these clients, but we've also taken away within our own service the people that were doing that.” (staff)*

Workforce stress

Feelings of being under pressure and feeling stressed were described often by the workforce. Challenges included not having enough staff, competing demands, pressures on maintaining standards of care, and feeling under-valued. Participants also said they felt a lack of stability and consistency because of frequent changes in services, management approaches, and changes in successive governments’ priorities. Some participants from inpatient settings shared feelings of being overwhelmed by having to balance the needs of different patients with a wide range of needs within a single clinical setting.

Staff who did not regard themselves as specialists in dementia shared a sense of being out of their depth, unsupported and vulnerable. These feelings were particularly expressed by staff working at the general hospital. The challenge of maintaining safety and support for all patients in their care was a cause of stress. Whilst many staff described feeling supported within their own teams, some believed that the pressures they were experiencing were not well understood or acknowledged by senior management. Some hospital-based staff said they were fearful of being criticised, and of being ‘told off’ by specialist-service staff and management, rather than being supported to improve their skills and knowledge. Staff commented that they did not have opportunities for restorative supervision, and that even mandatory training sometimes had to be done in their own time.

> *“We get no emotional support. I’m hearing newly qualified nurses saying, ‘Eurgh, this isn't for me. I didn't do three years training to come in every day and be bombarded with this.” (staff)*
>
> *“I think we're just surviving here each day we go in, and we just - survive.” (staff)*
>
> *“We're feeling stretched, feeling pushed. You get exhausted, you burn out and you become unwell. That's across the board, and that's effecting dementia care on the island.” (staff)*
>
> *“People are crying out for ways to do things better. It's not that nobody wants to do it better - it's that either you don't know how to do it, you don't have the time to do it, you don't have resources to do it, or you've done it and it hasn't worked.” (staff)*

Job satisfaction

Despite the challenges outlined above, some staff also shared what they enjoyed about working with people with dementia. Some described the sense of value they gained from supporting people to maintain their skills and independence. Other staff described finding satisfaction in providing care for people with advanced dementia. Being able to get to know and build a trusting relationship with the people they cared for was identified as adding to job satisfaction for many. Where staff were providing longer-term support, there was a shared sense that their role was not only to care for the residents, but also to support their families.

The importance of a strong, supportive, and cohesive team was linked to a positive work environment, and where the work or achievements of the team was recognised by others, regardless how big or small these were, a shared sense of pride was described.

> *“When I am able to make someone smile, it me smile.” (staff)*
>
> *“I love that no two days are the same - even if there is a bad day the next will be better.” (staff)*
>
> *“When you see someone leaving and they are even that little bit better, it means a lot.” (staff)*
>
> *“As they are here for a while, we are able to build a relationship with them, and not just them, but their families too.” (staff)*

Our Priorities 2024-2029

The Government of Jersey in partnership with Dementia Jersey have committed to five key strategic priorities that we believe will result in strong foundations for an island that is informed, supportive, and inclusive of the needs of people with dementia, and where islanders can be confident that they will have clear access to joined-up, high standards of support and care.

These priorities for action for the next five years have been developed from reviewing evidence from around the world and from Jersey, from our local data and from our engagement with islanders.

Our priorities:

1. Raise islanders' awareness of brain health, and of dementia and its symptoms.
2. Ensure timely diagnosis, treatment, and post-diagnostic support.
3. Improve the accessibility, range, and continuity of support available to people with dementia and their families, to enable them to live well.
4. Develop, train, and support the workforce to deliver high quality person-centred care and support.
5. Lay the foundations for a dementia-friendly and inclusive Jersey.

These priorities are outlined in the following pages. Our commitment to each priority is outlined, along with the actions that will help to realise them. The timescales involved will vary depending on the necessary planning, collaboration, and potential allocation of the funding required. With this in mind, commitments have been split into three delivery phases.

An implementation plan will be developed, providing details of how each action will be delivered. Action owners will be identified together with expected outcomes and how success will be measured.

Phase 1 - 2024-2026

Actions that can be taken over the next 18 months by government and partners to improve awareness, support, and care. The actions, expected outcomes, and resource requirements for Phase 2 will be scoped and detailed during this time.

Phase 2 - 2026-2029

More complex actions, that require increased collaboration or further resources to complete, or that cannot be achieved within the timescale of Phase 1.

Phase 3 – 2029 onward

Long term actions that build on the foundations laid in phases 1 and 2 and enable us to continue to develop our vision for a dementia-friendly and inclusive island.

Priority 1: Raising awareness

We are committed to informing islanders about the actions they can take to maintain their brain health, reduce their risk of developing dementia, and to raise awareness and understanding of dementia.

Many people fear getting dementia, but do not realise that there are actions they can take to reduce their risk of developing it. We want all islanders to understand the importance of brain health, and what can be done to support it. It is clear from current research, including the findings from the WHO Global Health Dementia Observatory (51), that lifestyle choices will not only reduce our own risk, but will also reduce the impact on our families. There is much that we can do as individuals, within our social networks and community, across the independent and private sector, and in government, to promote understanding and prevention of dementia (17).

Reducing dementia will reduce the financial impact on our island's health and community services, and ultimately on our economy. Further to this there is now also unmistakable evidence that if people with dementia follow the same risk reduction advice post-diagnosis, the symptoms they experience may have a lesser impact, and the progress of the condition may be slowed, thus helping them to live well and independently for longer (5).

We know from research, evidence, and from our engagement with islanders, that many people do not have a good understanding of what dementia is, and its possible symptoms. We have learnt that people do not know where and when to get the help and advice they need, and that dementia is often misunderstood as being a mental health condition, or just a normal part of ageing. This needs to change so that islanders are well informed and know when and where to get the help they need.

We also know that stigma still exists around dementia. However, we believe that if people are better informed, this should become a thing of the past as people with dementia will be better understood and be able to maintain their positive engagement in society.

We are committed to addressing these issues by taking the following actions:

	Action	Phase
1.1	Ensure prevention initiatives that aim to reduce long-term conditions include advice and services to improve brain health.	1-3
1.2	Work in partnership to raise awareness of brain health and dementia across Jersey, including within schools, workplaces, and businesses.	1-3
1.3	Improve awareness and understanding of dementia for public-facing government employees.	1-3

As an islander:

- I will know what I can do to reduce my risk of dementia, and the actions I can take to stay healthy and support the health of my brain.
- I will recognise symptoms linked with possible dementia and know where to go for information, advice, or assessment, for myself or for others.

Priority 2: Diagnosing well

We are committed to ensuring that all islanders have equal and timely access to quality diagnosis and post diagnostic support, regardless of age, stage of dementia, ethnicity, other health conditions, or where they live.

Although we know that getting a timely diagnosis is important, we know that many people do not recognise the early symptoms of dementia, and therefore will not always recognise that they need help. Inequalities in accessing a diagnosis have been widely reported and include age, stage of dementia, ethnicity, other health conditions, and where they live (52; 53; 54). The extent of these inequalities in Jersey are difficult to quantify without developing more robust data sets.

There is clear evidence that most people affected by dementia see clear benefits to getting a diagnosis (55) and that a diagnosis can help people to plan for the future, access the treatment and support they need, help them to understand their symptoms, and gain access to financial support for their care needs.

We have heard from some islanders however, that when they have raised concerns about symptoms, these have been considered unimportant or part of normal ageing by some health professionals. Such challenges have resulted in some people being diagnosed only at the point of crisis, or when admitted to hospital. Long waiting times for assessment, and difficulties in accessing information, advice, and support whilst waiting for diagnosis has been identified as having an adverse impact.

We are committed to addressing these issues by taking the following actions.

	Action	Phase
2.1	Work collaboratively to reduce the incidence of undiagnosed dementia within Jersey.	1-3
2.2	Develop and implement an integrated dementia diagnosis, care and support pathway incorporating standards of care and clear outcome measures.	1
2.3	Review and revise the information available to people with dementia and families, including development of a service directory.	1
2.4	Develop and implement a post-diagnostic support package for islanders.	1-2

As an islander:

- I will have access to a timely diagnosis, in a place and way that considers any health challenges or restrictions I might have.
- I will be offered support and advice at the point of diagnosis to help me and my family come to terms with my diagnosis and plan my next steps.
- I will know where to seek help, information, and support, and who to talk to about how to access support services.

Priority 3: Supporting people with a dementia and their families

We are committed to ensuring that people with dementia and their families have their rights respected, their voices heard, and they receive the help, care, and support they need to live well in Jersey.

Dementia is usually progressive with limited treatment options, and so the help and support that people with dementia and their families receive is essential for their health and wellbeing (56). We want people with dementia and their families to be treated with dignity and respect and have access to the care and support they need. We believe that this should be in line with best practice and the highest standards that we expect for any health condition, whether a person is being cared for in the community, at home, in hospital or in a care home.

Islanders have voiced their difficulties in accessing information, advice, support, follow-up care, therapies, and the therapeutic activities they need. Others have found that the community, domiciliary, residential, and palliative care they need has not been available, that some standards of care are limited, care costs excessive, and that funding mechanisms are too complicated and often not understood by professionals. People with dementia in hospital experience longer stays and delayed discharge, and too often care is not tailored to their needs (49).

Family carers have described how they are struggling, feeling burdened by the emotional, practical, and financial costs of caring, and need more support and skills to help them manage. Some family members have given up their careers to take on caring roles for which they feel unequipped. Options and availability for respite and short breaks were described by many carers as inadequate to meet their needs, with many saying that they rarely have a break from their caring role.

We are committed to addressing these issues by taking the following actions:

	Action	Phase
3.1	Develop and implement an approach to service delivery within HCS that embeds continuity of support from diagnosis to end of life and responds in a timely way to evolving needs.	1-2
3.2	Develop and implement a training support offer for family carers.	1
3.3	Work in partnership across government, and care providers to develop affordable options of community-based support and care for islanders.	1-2
3.4	Improve the range of, and access to, carer breaks and day support for people with dementia.	2-3
3.5	Work with independent and government providers to meet demand for domiciliary care and specialist care home placements for people with complex needs.	1-3
3.6	Develop and implement standards of care for people with dementia in hospital inpatient settings.	1
3.7	Work collaboratively with the end-of-life partnership group, to ensure the needs of people with dementia are included.	1-2

As a person with dementia:

- I will be treated with dignity and .
- I will know what I can do to help myself, and who else can help me.
- I will have the information, and the support I need to enable me to make decisions and choices about my goals and my future.
- I will receive considerate support, care, and treatment that is evidence-based, properly funded, and meets my needs, wherever I live.
- I will know that my family and those who help me have the support they need.
- I will be confident that my end-of-life wishes will be respected.

As a carer:

- I will be recognised as an important partner in care.
- I will have access to the information, advice and training I need to support me in my care-giving role.
- I will have my own emotional, psychological, and social needs regularly assessed and supported.
- I will feel confident that the care and support my relative receives is compassionate, person-centred, and safeguards their dignity.

Priority 4: Developing, valuing, and supporting the workforce

We are committed to developing a resilient workforce that feels valued, and has the skills, knowledge, resources, support, and leadership needed to deliver high standards of support and care.

Much has been written about the lived experiences and the needs of staff working with people with dementia, and the link between the health and wellbeing of staff and provision of compassionate, person-centred care. (29; 57; 58). Furthermore, positive staff wellbeing has been shown to improve patient safety and satisfaction, care quality, staff productivity, and the financial performance and sustainability of health and care services (59).

Tackling the underlying factors that lead to excessive workloads, pressure in the workplace, and improving training and development are recognised as factors that enable staff to succeed and thrive (60). Opportunities for staff to shape the culture of their workplace and influence decisions, together with ensuring that there are systems to support reflection, mentorship, supervision, and compassionate leadership, will also help.

All of these topics have been raised consistently throughout our engagement with islanders. Carers raised concerns that at times the number of staff working was inadequate to deliver good standards of care, and that some staff did not have the knowledge or expertise needed to support people with dementia. Staff at times described feeling physically and emotionally stretched to their limits, and being ill-equipped with the information, knowledge, experience, skills, and support they needed to care for people with dementia appropriately. The impact of staff shortages, cost of living, housing availability, were all identified as contributing to making working and living in Jersey more challenging.

We are committed to addressing these issues by taking the following actions:

	Action:	Phase
4.1	Develop an island-wide dementia training and mentoring standards framework, aligned to local legislation and policy.	1-2
4.2	Seek opportunities to support initiatives that promote recruitment and retention of the dementia workforce.	1-3
4.3	Develop resources that support the health and care workforce to deliver support and care to people with dementia from diverse communities.	2
4.4	Provide information about the services staff can access to support their physical and emotional wellbeing.	1

As a person with dementia:

- I will feel confident that the people supporting and caring for me and my family are skilled and compassionate, and that they understand me, and the impact dementia has on me.

As a member of staff:

- I will be supported by my employer to develop my knowledge, skills, and confidence in supporting people with dementia.
- I will understand my role in supporting the rights and voice of people with dementia, and the important role of carers.
- I will know where I can go to access the emotional and wellbeing support I need.
- I will feel valued and supported within my team and organisation.

Priority 5: Supporting Jersey to become a dementia-friendly and inclusive island

We are committed to making Jersey a dementia-friendly and inclusive island where people with dementia can maintain their engagement and participation in their local community, and where their voice and experiences are valued and respected.

Dementia affects us all either directly or indirectly in Jersey. Many of us have, or will have had, a family member, friend, or colleague with dementia, or have been a patient in hospital alongside people with dementia.

Dementia is common, but for people with dementia and their families to feel included, supported, respected, and valued as part our society, our current culture needs to change (29). This will mean building on the range of services and activities currently available to people with dementia, and improving access to other ‘whole community’ groups including, sports, education, social, spiritual, and cultural activities and events.

Islanders have told us that they would value opportunities for engagement that enable them to share what matters to them. They have also said that if the public understanding of dementia and its impact was better, and if public services, buildings, and community spaces, including access to them, was improved, this would make a positive difference. They have also told us that a renewed focus on wellness and living well with dementia, and attention to a person’s ability rather than disability, would be helpful. This would enable them to enjoy the things of life that matter to them, and to remain in their home for longer. There would also be a direct benefit to service costs, as the costs of a person’s care while living at home are often considerably less than the care costs associated with hospital or long-term residential or nursing care.

We know that all these changes will take time, however we are committed to building on the foundations that we already have, on what islanders have told us, current research and evidence, and what other jurisdictions have found to be helpful in achieving dementia-friendly status (61).

We are committed to addressing these issues by taking the following actions:

	Action:	Phase
5.1	Increase the proportion of people with dementia who are able to live well and longer within their own home, community, and familiar surroundings.	2-3
5.2	Collaborate across government, business, and the wider community to build on and develop initiatives that support people living with dementia to access local services and amenities.	1-3
5.3	Develop inclusive community initiatives that provide social, arts, cultural, spiritual, and sporting opportunities for people with dementia.	1-2
5.4	Support the inclusion of dementia-friendly design in planning and development across the island.	2
5.5	Promote the use of assistive technology to increase the ability of people with dementia to maintain independence and safety, and to maintain and develop social connections.	1-2

As an islander with dementia:

- I will feel confident that I will be supported to live in my own home for as long as possible.
- I will feel safe, comfortable, valued, and connected with my friends, social networks, and my community.
- I will feel included as part of society.
- I will be able to live well and enjoy the things that are important to me, with accessible public services, activities, buildings, and community spaces.

Enablers

In order that our commitments can be fulfilled, there are a number of overarching factors on which success will be dependent, and that will enable us to achieve our aims.

	Action	Phase
E.1	Identify and establish the necessary resources to develop, lead, coordinate and deliver a cross-governmental implementation plan for the strategy.	1-2
E.2	Establish / identify a strategic oversight group with the authority and responsibility of monitoring progress against commitments made within the strategy, and of implementation plans developed by key action owners.	1
E.3	Identify the core data needed to develop an improved understanding of the impact of dementia in Jersey, and that enables health and care systems to evidence outcomes for people with dementia and their carer(s).	1-2
E.4	Ensure value for money when allocating public resources to support the implementation of the dementia strategy, ensuring that funding decisions support the approach outlined within the strategy, are joined-up, and are based on evidence and measurable person-centred outcomes.	1-2
E.5	Develop performance indicators to measure progress in implementing the strategy.	1
E.6	Apply a partnership approach to the delivery of commitments, working collaboratively across government departments, and with external partners, providers, and community leaders, who are able to reach out in ways the government cannot.	1-2
E.7	Embed principles and approaches of co-production, consultation, or engagement as appropriate, when developing strategic initiatives.	1-2
E.8	Identify resources for a mid-term review of the strategy, and to develop plans for further work incorporating new evidence and evolving approaches.	2

References

1. **Alzheimer Europe.** 2019 Alzheimer Europe report: Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research. [Online] 2019. [Cited: 11 July 2023.] https://www.alzheimer-europe.org/resources/publications/2019-alzheimer-europe-report-overcoming-ethical-challenges-affecting.

2. —. Glasgow Declaration 2014. *Alzheimer Europe.* [Online] 2021-2023. [Cited: 11 July 2023.] https://www.alzheimer-europe.org/policy/campaign/glasgow-declaration-2014#:~:text=The%20Glasgow%20Declaration%20called%20for,global%20action%20plan%20on%20dementia..

3. **McCormack, Brendan and McCance, Tanya.** *Person-centred practice in nursing and healthcare: theory and practice.* Oxford : John Wiley & Sons, 2016.

4. *Tell me, how do you define person-centredness.* **Dewing, Jan and McCormack, Brendan.** 17-18, 2017, Journal of Clinical Nursing, Vol. 26, pp. 2509-2510.

5. **World Health Organization.** Dementia. *World Health Organization.* [Online] 2023. [Cited: 28 February 2023.] https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Dementia%20is%20a%20syndrome%20in,an%20inevitable%20consequence%20of%20ageing..

6. **Alzheimer's Disease International.** *World Alzheimer Report 2023. Reducing dementia risk: never too early, never too late.* London : Alzheimer's Disease International, 2023.

7. **Alzheimer's Research UK.** The economic cost of dementia. *Alzheimer's Research UK. Dementia Statistics Hub.* [Online] Alzheimer's Research UK, 2023. [Cited: 04 February 2023.] https://dementiastatistics.org/statistics/the-economic-impact-of-dementia/.

8. **World Health Organization.** Global action plan on the public health response to dementia 2017-2025. *World Health Organization.* [Online] 2017. [Cited: 30 June 2023.] https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025.

9. —. Dementia. *World Health Organization.* [Online] 2023 . [Cited: 16 March 2023.] https://www.who.int/news-room/fact-sheets/detail/dementia.

10. **Alzheimer's Disease International.** World Alzheimer Report 2021 Chapter 01. *Alzheimer's Disease International.* [Online] 2021. [Cited: 27 April 2023.] https://www.alzint.org/u/World-Alzheimer-Report-2021-Chapter-01.pdf.

11. **Dementia UK.** What is dementia? *Dementia UK.* [Online] 2023. [Cited: 23 June 2023.] https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/.

12. **Alzheimer's Research UK.** Dementia Statistics Hub - Subtypes of dementia. [Online] 2022. [Cited: 10 July 2023.] https://dementiastatistics.org/about-dementia/subtypes/.

13. **National Institute for Health and Care Excellence.** When should I suspect dementia? *National Institute for Health and Clinical Excellence.* [Online] 2022. [Cited: 24 July 2023.] https://cks.nice.org.uk/topics/dementia/diagnosis/clinical-features/#:~:text=Impairment%20of%20executive%20function%2C%20such%20as%20difficulties%20with,out%20coordinated%20movements%2C%20such%20as%20dressing.%20More%20items.

14. **Alzheimer's Research UK.** Reducing your risk of dementia. *Alzheimer's Research UK - for a cure.* [Online] 2021. [Cited: 26 June 2023.] https://www.alzheimersresearchuk.org/dementia-information/reducing-your-risk/.

15. **National Institute for Health and Care Excellence.** National Institute for Health and Care Excellence. *What are the risk factors?* [Online] 2022. [Cited: 24 July 2023.] https://cks.nice.org.uk/topics/dementia/background-information/risk-factors/.

16. **Livingston, Gill, et al.** Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet.* [Online] 8 August 2020. [Cited: 27 June 2023.] https://www.thelancet.com/action/showPdf?pii=S0140-6736%2820%2930367-6.

17. **World Health Organsization.** Global action plan on the public health response to dementia 2017-2025. *World Health Organization.* [Online] 2017. [Cited: 30 June 2023.] https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025.

18. **National Institute of Health and Care Excellence.** Dementia: assessment, management and support for people living with dementia and their carers NG97. *National Institute of Health and Care Excellence.* [Online] 2018. [Cited: 28 June 2023.] https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#diagnosis.

19. **Alzheimer's Research UK.** *Dementia Attitudes Monitor. Wave 3.* Cambridge : Alzheimer's Research UK, 2023.

20. **Dementia UK.** The emotional imact of a dementia diagnosis. [Online] 2023. [Cited: 16 August 2023.] https://www.dementiauk.org/get-support/understanding-changes-in-dementia/emotional-impact-of-the-diagnosis/#impact.

21. **Alzheimer's Society.** 91% of people affected by dementia see clear benefits to getting a diagnosis. *Alzheimer's Society.* [Online] May 2022. https://www.alzheimers.org.uk/news/2022-05-16/91-people-affected-dementia-see-clear-benefits-getting-diagnosis.

22. **National Institute for Health and Care Excellence.** Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's

disease. *National Institute for Health and Care Excellence.* [Online] 2018. [Cited: 14 August 2023.] https://www.nice.org.uk/guidance/ta217.

23. **Yorkshire and the Humber Clinical Network and London Clinical Network NHS England.** Appropriate prescribing of antipshycotic medication in dementia. *NHS England.* [Online] 2022. [Cited: 14 08 2023.] https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/10/Antipsychotic-Prescribing-Toolkit-for-Dementia.pdf.

24. *Alzheimer's disease drug development pipeline: 2023.* **Cummings, J, et al.** 2, 2023, Alzheimer's and Dementia: Translational Research and Clinical Interventions, Vol. 9, p. n/a.

25. **Mayo Clinic.** Alzheimer's treatments: What's on the horizon? *Mayo Clinic.* [Online] Mayo Foundation for Medical Education and Research, July 2023. [Cited: 14 08 2023.] https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers-treatments/art-20047780.

26. *Use of patient characteristics to determine non pharmacological interventions for behavioural and psychological symptoms of dementia.* **Cohen-Mansfield, Jiska.** Suppl 1, 2000, International Psychogeriatrics, Vol. 12, pp. 373-380.

27. **Alzheimer's Society.** Talking Therapies for people with dementia and carers. [Online] 2018. [Cited: 11 September 2023.] https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/talking-therapies#:~:text=There%20is%20evidence%20that%20having,of%20communication%2C%20understanding%20and%20memory..

28. **National Health Service.** Living with dementia. *NHS.* [Online] NHS, 2021. [Cited: 25 July 2023.] https://www.nhs.uk/conditions/dementia/living-with-dementia/activities/.

29. **Kitwood, Tom.** *Dementia reconsidered: The person comes first.* Buckingham : Open University Press, 1997.

30. **Alzheimer's Research UK.** *Dementia in the Family. The impact on carers.* Cambridge : Alzheimer's Research UK, 2019.

31. *Informal dementia care: The carer's lived experience at the divides between policy and practice.* **Britton, Anthony and Zimmermann, Martina.** 7, s.l. : DementIa, 2022, Vol. 21.

32. **Dementia Carers Count.** *Dementia Carers Count. Survey 2022.* London : Dementia Carers Count, 2022.

33. **Alzheimer's Disease International.** *Women and Dementia. A global research review.* London : Alzheimer's Disease International, 2015.

34. **Alzheimer's Society.** 4 out of 5 unpaid dementia carer take on the bulk of caring responsibilities. *Alzheimer's Society.* [Online] August 2023. [Cited: 27 September 2023.]

35. *Dementia and caregiver burden: A three-year longitudinal study.* **Connors, Michael, et al.** 2, s.l. : International Journal of Geriatric Psychiatry, 2020, Vol. 35.

36. **Alzheimer's Society.** Your health and wellbeing as a carer for a person with dementia. *Alzheimer's Society.* [Online] Alzheimer's Society, 2023. [Cited: 25 October 2023.] https://www.alzheimers.org.uk/get-support/help-dementia-care/caring-for-person-dementia#:~:text=Caring%20for%20a%20person%20with,a%20wide%20range%20of%20emotions..

37. **World Health Organization.** A blueprint for dementia research. *World Health Organization.* [Online] 2022. [Cited: 22 November 2023.] https://iris.who.int/bitstream/handle/10665/363341/9789240058248-eng.pdf?sequence=1.

38. **Alzheimer's Research UK.** The economic value of dementia research. *Alzheimer's Research UK. For a cure.* [Online] July 2023. [Cited: 22 November 2023.] https://www.alzheimersresearchuk.org/wp-content/uploads/2023/07/Economic-Value-of-Dementia-Research-July-2023.pdf.

39. **Alzheimer's Reserach UK.** Alzheimer's Research UK's Five Year Research Strategy. *Alzheimer's Research UK. For a cure.* [Online] 2022. [Cited: 22 November 2023.] https://www.alzheimersresearchuk.org/wp-content/uploads/2022/10/Alzheimers-Research-UK-Research-Strategy-2022.pdf.

40. **Alzheimer's Research UK.** Translating Science into Breakthroughs: The future of late-stage dementia clinical trials. *Alzheimer's Research UK. For a cure.* [Online] May 2021. [Cited: 22 November 2023.] https://www.alzheimersresearchuk.org/wp-content/uploads/2021/05/FUTURE-OF-CLINICAL-TRIALS-FINAL.pdf.

41. **Statistics Jersey.** Report on the 2021 Jersey Census. *gov.je.* [Online] 2022. [Cited: 17 April 2023.] https://www.gov.je/StatisticsPerformance/Population/pages/census2021results.aspx.

42. **Public Health Intelligence.** Jersey Health profile 2022. *gov.je.* [Online] 2023. [Cited: 10 July 2023.] https://www.gov.je/Government/Pages/StatesReports.aspx?ReportID=5654.

43. —. Strategic Policy, Planning anf Performance report: Multi-morbidity 2022. *gov.je.* [Online] 18 May 2023. [Cited: 11 July 2023.] https://www.gov.je/Government/Pages/StatesReports.aspx?ReportID=5677.

44. **London School of Economics and Political Science.** Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040. [Online] 2019. [Cited: 12 July 2023.]

https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf.

45. *Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia.* **Parker, Michelle, et al.** 5, s.l. : International Psychogeriatrics, 2020, International Psychogeriatrics, Vol. 32.

46. **NHS Digital.** Primary Care Dementia Data, December 2022. *NHS Digital.* [Online] 31 01 2023. [Cited: 05 10 2023.] https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2022.

47. **Royal College of Psychiatrists.** Quality Standards for Memory Services 8th Edition. *Royal College of Psychiatrists.* [Online] 2022. [Cited: 27 09 2023.] https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2.

48. —. *National Audit of Dementia care in general hospitals 2018-2019: Round Four audit report.* London : Royal College of Psychiatrists, 2019.

49. **National Institute for Health and Care Excellence.** Hospital Care. *National Institute for Health and Care Excellence.* [Online] 2023. [Cited: 13 July 2023.] https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch3-hospital-care#:~:text=At%20any%20one%20time%201,delirium%20for%20someone%20with%20dementia..

50. *Hospital outcomes of older people with cognitive impairment: An integrative review.* **Fogg, Carole, et al.** 9, 2018, International Journal of Geriatric Psychiatry, Vol. 33, pp. 1177-1197.

51. **World Health Organization.** Global Dementia Observatory (GDO). *World Health Organization.* [Online] 2016. [Cited: 07 03 2023.] https://apps.who.int/gho/data/node.dementia.

52. **Alzheimers Society.** *Reginal variation. Increasing access to a dementia diagnosis.* London : Alzheimer's Society, 2021.

53. **Alzheimer's Society.** *Ethnic minority communities. Increasing access to a dementia diagnosis.* London : Allzheimer's Society, 2021.

54. —. *Hospitals and care homes. Increasing access to a dementia diagnosis.* London : Alzheimer's Society, 2021.

55. —. 91% of people affected by dementia see clear benefits to getting a diagnosis. *Alzheimer's Society.* [Online] 05 2022. https://www.alzheimers.org.uk/news/2022-05-16/91-people-affected-dementia-see-clear-benefits-getting-diagnosis.

56. —. Your health and wellbeing as a carer for a person with dementia. *Alzheimer's Society.* [Online] Alzheimers Society, 2023. [Cited: 25 10 2023.] https://www.alzheimers.org.uk/get-support/help-dementia-care/caring-for-

person-dementia#:~:text=Caring%20for%20a%20person%20with,a%20wide%20range%20of%20emotions..

57. **Brooker, Dawn.** *Person-Centred Dementia Care. Making Services Better 2nd edition.* London : Jessica Kingsley Publishers, 2015.

58. **Wareing-Jones, Sian.** *Whispers and song: a phenomenological inquiry to discover nurses' lived experience of person-centred acre.* Edinburgh : Queen Margaret Univeersity, 2016.

59. **West, Michael and Coia, Denise.** *Caring for doctors, Caring for patients. How to transform UK jealthcare environments to support doctors and medical students to care for patients.* s.l. : General Medical Council, 2019.

60. **The King's Fund.** *The courage of compassion: Supporting nurses and midwives to deliver high-quality care.* s.l. : The King's Fund, 2020.

61. *Creating Dementia-Friendl Communities for Social Inclusion: A Scoping Review.* **Hung, Lillian, et al.** s.l. : Gerentology and Geriatric Medicine, 2021, Vol. 7.

Appendix 1 – Glossary

Term / Abbreviation	Definition
ADRT	Advanced decision to refuse treatment – part of the Capacity and Self-Determination (Jersey) Law 2016.
Alzheimer's disease	The most common cause of dementia. It is progressive and can affect multiple brain functions.
Ambiguous grief	A profound sense of loss and sadness without a death.
Anticipatory grief	Feelings of grief or loss that are felt before a loss happens.
Brain CT	Computed Tomography scan of the brain – non-invasive imaging procedure that provides information about brain tissue and structures.
Biomarkers	Measurable indicators that have a clinical role in narrowing or guiding diagnosis and treatment decisions.
Care home	A residential or nursing home where people may live permanently, or temporarily for respite care.
Carer	An unpaid family member or friend who helps support a person with dementia.
CLS	Customer and Local Services – a Government Department
Cognition	The processes that take place in the brain including, thinking, learning, remembering, and using judgement and language.
Cognitive reserve	The reserve of thinking abilities developed throughout life that helps protect against losses that occur through ageing or disease.
Cognitive testing	Tests to check how well the brain is functioning. These tests help to identify where there are problems with cognition but are not enough on their own to diagnose dementia.
CST	Cognitive Stimulation Therapy. A therapy group for people with dementia to assist cognition.
Delerium	An acute and usually sudden (developing over hours or days) decline in attention, focus, perception, and cognition.
Dementia	An umbrella term given to a group of symptoms caused by various diseases or damage to the brain.
Domiciliary care	Care provided by professionals for people in their own homes.
ED	Emergency Department (also called A&E).
EMIS	An electronic patient record system.
Engagement session	A scheduled meeting for attendees to recount their lived experiences.
FNHC	Family Nursing and Home Care.
GP	General Practitioner (also called a family doctor).
H&CS	Health and Community Services – Government of Jersey provider of health and social care services.
Incidence	The frequency of occurrence of new cases of a health condition in a population during a specific period.
Intermediate care	Time-limited rehabilitation, support and care for people who have been in hospital and require additional support before returning to their usual place of residence.
JGH	Jersey General Hospital.

Term / Abbreviation	Definition
Lasting Power of Attorney	A legal document that allows you to choose one or more people to make decisions on your behalf if you lack capacity to do so yourself in the future (also called LPA).
Long Term Care Scheme	Government of Jersey scheme to provide financial support to Jersey residents who have long-term care needs (also called LTCS).
LPA	Lasting Power of Attorney.
LTCS	Long Term Care Scheme.
MAS	Memory Assessment Service.
Neurological assessment	Assessments and tests to evaluate brain and nervous system function. May include scans, assessment of cognitive status, reflexes, and movement.
Neuro-psychological assessment	Comprehensive test of a wide range of cognitive functions including reading, language, attention, learning, processing speed, reasoning, remembering, problem-solving, mood, and personality.
Non-pharmacological interventions	Any type of health intervention which is not primarily based on medication. These include, diet, exercise, sleep improvement techniques, talking therapies etc.
OACMHT	Older Adult Community Mental Health Team.
Outcomes	A result or situation that exists at the end of an activity or process.
Palliative care	Care that improves the quality of life for people and their families associated with life-threatening or life-limiting illness.
Person centred practice	An approach to practice established through healthful relationships between care providers, service users and their families, that respects people's values and preferences.
PET scan	Scan that produces 3D images that can help reveal irregularities in the function of tissues and organs.
Prevalence	The proportion of the population who have a specific health condition or disease in a given time period.
Primary care	Care, support, or treatment usually received from a GP.
Professional	Any health professional who works with people with dementia or their family carers, including, but not limited to, doctors, nurses, health care assistants, and other physical and psychological therapists.
Professional carer	A carer who is, or whose employer is, registered with the Jersey Care Commission and receives payment for services delivered.
Psychotropic medications	Medications including antidepressants, antipsychotics, mood stabilizers and anti-epileptic drugs to treat the symptoms of mental disorders, reduce disability and prevent relapse.
Social care	The non-medical help and support people receive when living at home.
Vascular dementia	The second most common type of dementia resulting from conditions that affect the blood vessels in the brain.
Wellbeing	A sense of feeling comfortable, healthy, or content about yourself, and not necessarily the absence of illness.

Appendix 2 – Local services provided for people with dementia and carers

Service / Team name	Self-Referral	Availability	Summary of service offered
Adult Social Care Team	✓	M-F 9-5	Social care assessment and care coordination for complex care
Age Concern	✓	M-F	Social support and activities for 55ys+
Ambulance Service	✓	24/7	Emergency health response and patient transport services.
Hearing Resource Centre (Overdale)	✓	M-F	Screening and assessment of hearing and hearing aid repairs
Capacity & Liberty Assessment Team	✗		Assessment and education for significant restriction of liberty (SRoL) under Jersey legislation
Care homes, inc. residential and nursing	✓	24/7	Provision of residential and nursing care, including respite and convalescence.
Churches / other religious groups	✓		Spiritual and pastoral care
Citizen's Advice Jersey	✓	M-F	Advice and signposting to services and sources of support
Counsellors/ Psychotherapists (private practice)	✓		One to one and/or family counselling, online and in-person
MH Crisis and Emergency Response Team	✓	24/7	Urgent mental health assessment and support at time of mental health crisis
Customer and Local Services (CLS)	✓	M-F 9-5	Information and advice on benefits, tax, employment, and social security
Day Care Services (HCS)	✗	M-S	Social activities and day-time short breaks including provision for people with dementia
Dementia Jersey	✓	M-F	Social and therapeutic activities for people with dementia, carer support, advice, and counselling
Dietetic Service	✗	M-F	Nutritional assessment and advice; prescription of dietary supplements
Domiciliary Care Agencies	✓	24/7	Home care and assistance with personal care, medications, and meal preparation
DriveAbility Jersey	✓		Driving advice, assessment and testing for people with disabilities

Service / Team name	Self-Referral	Availability	Summary of service offered
Emergency Department (ED)	✓	24/7	Urgent and emergency health assessment and treatment
Eyecan	✓	M-F	Advice, support, and activities for people with registered sight impairment
Family Nursing & Home Care / Rapid Response & Reablement	✗	24/7	Short term packages of care to support hospital avoidance and discharge. District nursing, personal, and home care
Good Companions	✓	M-F	Support, meals, activities, and transport
GP Practices	✓	24/7	First point of contact by patients with a health care professional for physical and mental health concerns
HCS24 Single Point of Referral (SPOR)	✗	M-F	Processes referrals for most community-based services within HCS
HCS24 Telecare Service	✓	M-F	Monitored community telecare service
Hospital Chaplaincy	✓	24/7	Multi-faith, spiritual support and guidance for patients, visitors, and staff
MH Hospital Liaison Service	✓	24/7	Psychiatric support, treatment, and advice within JGH for patients with mental health or dementia
Hospital wards	✗	24/7	Inpatient medical and surgical assessment, care, and treatment
Jersey Care Commission	✓	M-F	Independent regulation and inspection of services for adults and children provided by government, private and voluntary sector.
Jersey Hospice Care	✗	24/7	Specialist care and support for people with life-limiting illness within in-patient, home, day-care and community settings. Emotional and bereavement support for adults and young people (self-referral).
Jersey Talking Therapies (JTT)	✓	M-F	Assessment and therapy services, in-person, on-line, guided self-help, and groups.
Judicial Greffe and Viscount's Office	✓	M-F	Information about Capacity and Self-Determination Law, registration of LPA, appointment of Delegates and ADRTs

Service / Team name	Self-Referral	Availability	Summary of service offered
Learning Disabilities Service	✓	M-F	Home assessments, support and advice, general health checks and referrals to other services
Les Amis	✓	24/7	Domiciliary, day-centre, and residential care, support, and advice
Listening Lounge	✓	M-Sun 10-10	In person, online and group support and counselling
Meals on Wheels (Age Concern)	✓	Tues-F	Delivery of hot meals
Memory Assessment Service (MAS)	✗	M-F	Assessment, diagnosis, prescribing, advice and information, post-diagnostic follow-up and programme of cognitive stimulation therapy groups
Mind Jersey	✓	M-F	Support, advice, and counselling, 1-1 and groups work, online, phone or in-person
My Voice	✓	M-F	Help and support for people to resolve problems as a direct result of their mental health or capacity issues
Neurology Department	✗	M-F	Assessments, diagnosis, treatment for patients with complex neurological disorders.
Occupational Therapy	✓	M-F	Assessments, and help with practical tasks for people with physical impairment, medical conditions, mental health problems and learning disabilities
Older Adult Community Mental Health Team (OACMHT)	✗	M-F	Multi-disciplinary team providing professional assessment, treatment, and support to over 65yr olds with needs relating to mental ill health or dementia
Older Adult Mental Health inpatient unit	✗	24/7	Inpatient assessment, treatment, and step-down care for people with dementia.
Outpatient Department	✗	M-F	Outpatient assessment, diagnostic tests, treatment, and care, and hospital follow up across a wide range of services.
Parish Community Support Teams	✓		Advice, support, social groups, activities, transport, and outings

Service / Team name	Self-Referral	Availability	Summary of service offered
Patient Transport Service	✗	M-F	Transport for hospital inpatient services and for outpatient appointments and day care centres
Pharmacies (Community)	✓	24/7	Advice, dispensing of medications, screening, sale of other medications, toiletries and mobility and other aids.
Pharmacy Department (Hospital)	✗	M-Sun	Provision of pharmacy services to the general hospital, and prescriptions from hospital and hospital out-patient departments.
Physiotherapy (HCS)	✗	M-F	Advice, assessment, treatment and rehabilitation by movement, exercise and manual therapy within inpatient, outpatient, and community settings.
Podiatry Services (HCS)	✓	M-F	Advice, diagnosis, and treatment of conditions of feet and lower limbs in inpatient, outpatient, and community settings.
Police	✓	24/7	General policing services plus searching for missing people, support for families and referrals to SPOR
Psychological Assessment and Therapy Service (PATS)	✗	M-F	Advice, 1-1 support for people with complex psychological needs, courses, and referrals (do not provide crisis intervention)
Speech and Language Therapy (SALT)	✓	M-F	Advice, support, speech therapy, assistance with communication and swallowing and referrals within inpatient, outpatient, and community settings
St John Ambulance	✓	M-F	Advice, friendship, support, outings, activities, support groups, and carer training courses
Travel Office (for appointments in Guernsey and UK hospitals)	✗	M-F	Assistance with travel arrangements and accommodation costs for hospitals in Guernsey and UK for specialist tests and treatment

Appendix 3 – Workforce roles

Workforce category	Roles	
Clinical	Allied Health Professional Ambulance Technician Audiologist Dietician Medical staff - Consultant, Associate Specialist, Middle and Junior grade, Medical Student, GP Nurses – Hospital, Community, General, Mental Health, Primary Care, Student, Clinical Nurse	Nurse Prescriber Occupational Therapist Optician Paramedic Pharmacist Physiotherapist Psychiatrist Social Worker Speech and Language Therapist
Clinical support	Activities Co-ordinator Care Support Worker Dementia Advisor Health Care Assistant Mental Health Patient Advocate	Peer Support Worker Support Worker Translator and Interpreter
Emotional and psychological	Complimentary Therapist Counsellor Mental Health First Aider	Psychologist Psychotherapist Wellbeing Practitioner
Spiritual	Hospital Chaplain	Other Religious Leaders
Financial	Fundraiser	Retail Staff
Service and administration	Administrator Ambulance Control Centre Staff Cleaner/Housekeeper/Laundry Staff Cook/Caterer Data Administrator	Driver IT Specialist Porter Receptionist Secretary Travel Officer
Leadership and Management	Board/Committee Member CEO Director	Manager Trustee
Other	Police Teacher/ Trainer/ Educator/ Lecturer	Volunteer