

Isle of Wight

Dementia Strategy



2022 to 2025

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Opening Statements

From System Leaders

We are delighted to launch this strategy which sets out our joint vision for improving dementia services and making the Isle of Wight a place where people with dementia can live safe and fulfilling lives.

Dementia is fast becoming the UK's largest health and social care challenge. It is likely that at some point dementia will touch the lives of each and every one of us in some way and that experience will be lasting, as it is for each and every person in our local community. Dementia is a condition that has a significant impact not only on our local people but on the services delivered by health, social care and the community and voluntary sector as evidenced by the IW Dementia Stocktake undertaken in 2019 as part of the development work for this strategy.

There are currently an estimated 2655 people over the age of 65 living with dementia on the Island and due to our ageing population and increasing life expectancy this number is estimated to increase to 3920 by 2030 (*source: LSE Projections and Alzheimer Society Local Dementia Profile 2021*). As health and social care leaders we have agreed that it must be one of our top priorities to identify and invest in the changes that are necessary to ensure that people are supported to live well with dementia on the Island.

In addition to the number of people living with dementia there are approximately 15,000 (*source: 2011 Census*) unpaid family and friends who care for people on the Island, 32.5% of which report caring for someone with dementia (*source: Alzheimer Society Local Dementia Profile 2021*). To better support carers we need to recognise and listen to them, to ensure that they have the support they need to carry out this important role.

We know that people affected by dementia have been severely impacted by the COVID-19 pandemic, experiencing increased social isolation and a deterioration in both mental and physical health. The pandemic has also created greater demands on unpaid carers.

We recognise that there is still a long way to go to improve the care and support that people with dementia and their family and carers receive within health and care settings and also in our communities. In 2019 we invited partners from the community and voluntary sector on the Island to work in partnership with us and to lead on the development of this new strategy. Age UK Isle of Wight, Alzheimer Café IOW, Carers IW and Healthwatch Isle of Wight have worked tirelessly to ensure that the voices and views of people with lived experience are central to this strategy. We thank them for providing their ongoing input and support with this piece of work.

We believe that the more we engage and plan together with those who need our support, the better quality of life will be achieved for them. We would therefore like to thank the many contributors to this strategy and in particular those who have shared their personal experiences to help improve services and outcomes for others.

Laura Gaudion

Interim Director of Adult Social Care and Housing Needs, Isle of Wight Council

Dr Lesley Stevens

Director of Community, Mental Health and Learning Disabilities, NHS

Alison Smith

Managing Director, Hampshire and Isle of Wight CCG Partnership



From Voluntary Sector Partners

As voluntary sectors partners on the Isle of Wight, we are committed to ensuring that the voice of people with dementia and that of their families, friends and carers, is heard and valued. We are indebted to the many people who shared their experiences with us to enable the development of this new Isle of Wight Dementia Strategy.

We believe that every person with dementia, has the right to receive the support they need to live happy fulfilling lives within their local community. We also believe that nothing can be achieved in isolation. We look forward to supporting and monitoring the implementation of this strategy and the subsequent action plan that will ensure that all people living with dementia and their carers will be able to access the right service for them at the right time ensuring a good quality of life.



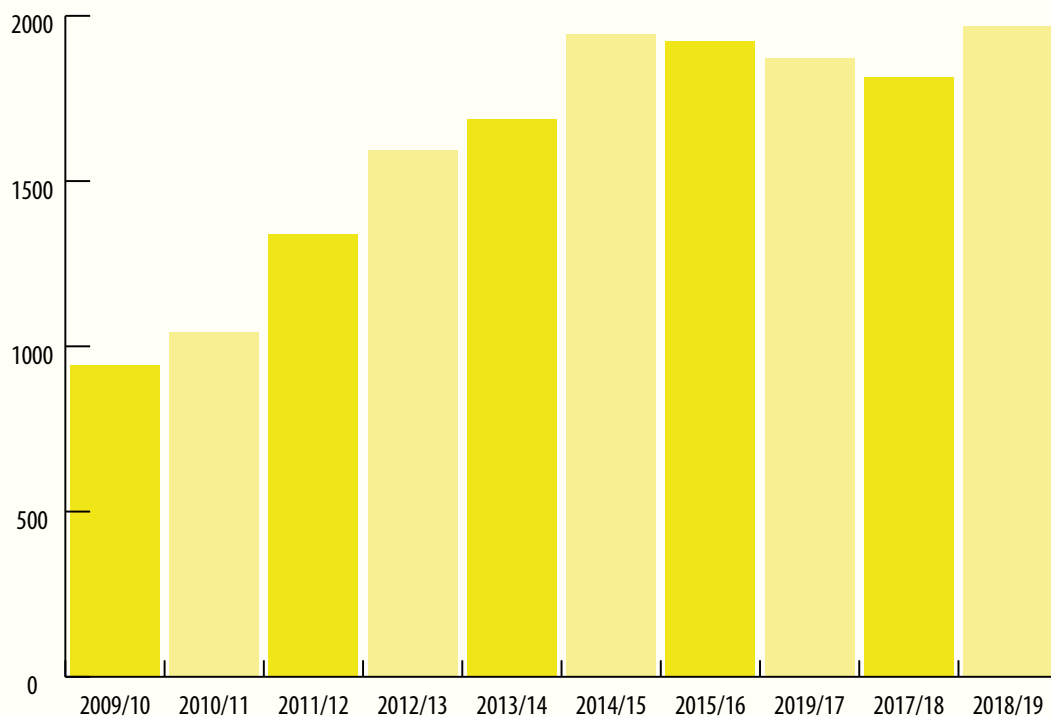
The following organisations are thanked for their support and input into the development of this Isle of Wight Dementia Strategy:

- Independent Arts
- Alzheimer's Society
- Mountbatten Hospice

Introduction

It is important to recognise the life changing impact of dementia on both the affected person and their family. Dementia impacts on a person's day to day life and will require the person, their family and carers to adapt how they do things in order to maintain a sense of normality for as long as possible. Many people will struggle to cope with the emotional losses attached to loss of independence, and their ability to communicate and make decisions and will be frightened about the future.

Dementia prevalence on the Isle of Wight is high and expected to rise with a predicted increase of 24% in the population of over 85 year olds in the next 10 years. Dementia is a condition that has a significant impact on services delivered by health, social care and the community and voluntary sector as evidenced by the IW Dementia Stocktake undertaken as part of the development work for this strategy. The impact can be particularly seen in secondary care at the IW NHS Trust where a high proportion of patients across the hospital at any one time have a diagnosis of dementia.



Graph 1: Dementia prevalence trends (all ages)

- Dementia prevalence in terms of diagnosis rates in primary care, has been steadily increasing over the last ten years.
- When compared to our peer group the Isle of Wight has one of the highest prevalence's of dementia for all ages and for those over 65 when age adjusted.
- In Sept 2021 on the Isle of Wight it is estimated that 2655 people over the age of 65 have dementia this number is estimated to increase to 3920 by 2030.

The Isle of Wight will see a significant increase in the number of people with dementia linked to the ageing population and increase in life expectancy, and this strategy has been developed to ensure the Island is able to develop services and communities that support this need.

How has this strategy been developed?

In May 2019 partners from the IWC, IW Trust and IW CCG approached the voluntary and community sector and asked them to lead on the development of a system-wide IW dementia strategy. It was recognised that they are often the people that are working most closely with people with dementia (diagnosed and un-diagnosed) and their families and would therefore be best placed to lead on meaningful public engagement to help us understand what people need. Age UK Isle of Wight, Alzheimer Café IOW, Carers IW and Healthwatch Isle of Wight have led this piece of work assisted by many other local organisations including Mountbatten Hospice, Independent Arts and the Alzheimer Society.

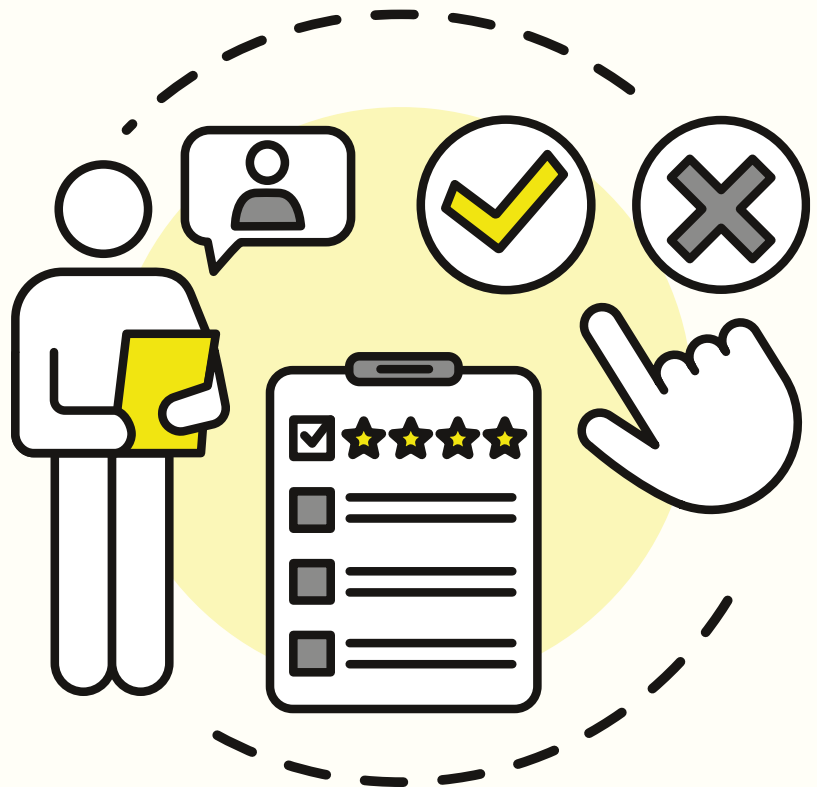
To support the development of the Isle of Wight Dementia Strategy a survey was developed which invited Island residents to tell us about their experiences of dementia care on the Island including the initial diagnosis, and the provision of information and advice and support within the community. The survey also asked people with dementia, their family and carers to tell us how services and support could be changed or improved to better meet their needs.

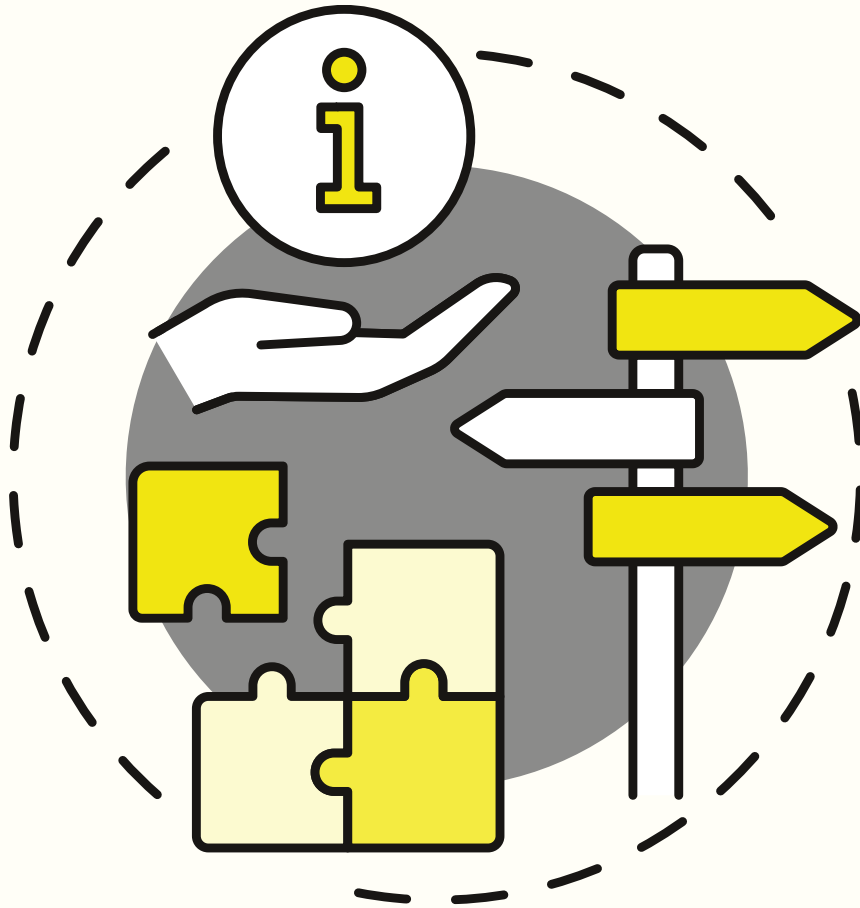
To ensure that we heard the views of as many people as possible we undertook a programme of public consultation and engagement, which included talking to local organisations that support people with dementia and holding public events across the Island where people were able to drop in and speak to us face to face. Focus groups were also held with carers and people who regularly attend the various Alzheimer Cafes, these forums gave people the opportunity to speak openly about their experiences.

Alongside our conversations with the public and professionals a detailed stocktake was completed to understand the current picture of dementia services on the Isle of Wight, this included looking at the number of people who currently have dementia on the island and how many we expect to be diagnosed in the future, availability of services and quality of services.

Feedback from all of these sources has been used to develop this strategy.

Reports have been published alongside this strategy which evidence the information gathered from public consultation and the detailed stocktake.





What are the current challenges?

A stocktake review of dementia services and feedback from extensive public consultation has highlighted a number of key challenges:

- Diagnosis rates on the Island have fallen below the national targets
- There are significant delays in the pathway for dementia diagnosis
- The length of hospital stay for a person with dementia is high in all areas of the IW Trust which is impacting on hospital capacity
- There has been an increase in overdue social work reviews for people with dementia
- Waiting times for support from Admiral Nurses have increased
- Feedback from patients and their carers suggests that there is a lack of coordination and information following diagnosis and during times of crisis
- Family and other unpaid carers are often overwhelmed by the nature of the caring role, and need better access to respite and day care services to enable them to take a break and focus on their own wellbeing
- Communication between and from health and social care agencies needs to improve and must ensure that family and carer are not excluded
- There is a need for improved dementia awareness and training across all areas of health, social care, and independent care providers

Preventing Well

There is no clear evidence that it is possible to prevent all types of dementia and research into how the disease develops is still in its early stages, however there is some evidence that a healthy lifestyle can help to reduce your risk of developing dementia when you are older. A healthy lifestyle can also help to prevent cardiovascular diseases such as stroke and heart attacks which are themselves risk factors for Alzheimer's disease and vascular dementia two of the most common forms of dementia.

What do we mean by preventing well?

We mean the risk of dementia is reduced as people have a better understanding of the impact of their lifestyle choices on their health in later life including memory issues.

What are the challenges?

- There are challenges nationally in supporting the public to take action to improve their general health, reduce the risk of dementia and live full and active later lives
- Raising awareness of the potential impact of lifestyle choices on the likelihood of developing dementia in later life
- Messages in the media and advertising conflicting with healthy lifestyles

How will dementia support be different?

- People will receive information and advice on the best ways that might reduce the likelihood of memory issues related to ageing
- People with mild cognitive impairment (MCI) will have access to early diagnosis and education to support better understanding of what could slow down the progression of their condition towards dementia
- People will receive clear public health messaging about living a healthy life and how this could reduce the risk of dementia
- People will understand the need to have regular hearing tests and the link between hearing loss and increased incidence of dementia
- Professionals will have access to improved resources that support them to discuss memory concerns and make appropriate referrals





What will we do to better support people?

Partnership Working

Through this strategy we will:

- Monitor Public Health data on preventative factors for the Island, and identify if there are any gaps that can be improved
- Support wider Island strategies that focus on prevention issues
- Work in partnership across the Island to spread risk reduction messages making sure that these are clear, honest and accessible for all
- Work with partners to 'Make every contact count', sharing prevention advice and information where relevant and linking into prevention services that promote healthy living
- Continue to treat people living with dementia and their carers as experts by experience; seeking their wealth of knowledge to inform and develop services

Advice and information

Through this strategy we will:

- Ensure that people have information about dementia and are aware of ways in which they can reduce their risk of developing dementia
- Implement a broader dementia awareness and information programme
- Work with alcohol detox programmes to raise awareness of the impact of drinking alcohol on dementia
- Support those delivering annual health checks to have awareness and information regarding dementia, and ensure memory questions are included where appropriate
- Provide people with a diagnosis of mild cognitive impairment (MCI) with information that can support them to stay healthier for longer

Diagnosing Well

What do we mean by diagnosing well?

We mean timely accurate diagnosis, personalised care planning and review. From the time you contact your GP about any concerns you may have around memory, to when you get a formal diagnosis from the memory service and the support provided in the first year following a diagnosis.

What are the challenges?

- People have told us that they have struggled to get a diagnosis, with the process taking a long time
- People with dementia, their family and carers felt that the dementia diagnosis had sometimes been delivered in an insensitive and unsupportive way
- Follow on support to help people understand and come to terms with the diagnosis is limited, and does not meet peoples needs
- People find it difficult to get to speak to appropriate health staff following diagnosis

“No constructive help was given at the point of diagnosis; I didn’t know what to do next and I remember crying and feeling helpless?”

“Because the GP would not refer him, I was so alone for over a year, struggling with the fact my husband had an illness, but I had nothing but worries and no one to share it with, I felt so alone.”

“Little information was given at the time of diagnosis. The family did not know where to go to get support or what support was even available.”

“My step-dad went to see his GP about his concerns several years before his diagnosis and was told it was nothing to worry about.”

Source: Public consultation 2019

How will dementia support be different?

- People with dementia will receive a timely diagnosis, and have an improved experience of receiving their diagnosis from staff
- People will receive the information they need at the right time
- People will feel better supported following a diagnosis and have a named point of contact
- People will have a better understanding of support available before and after receiving a diagnosis

What will we do to better support people?

Referrals

Through this strategy we will:

- Support GPs to have an understanding of the importance of early diagnosis and signposting to wider support

- Ensure information on support is provided at the earliest opportunity by professionals
- Make it simpler and easier to access the Memory Service
- Respond to referrals in a timely way meeting national targets
- Improve understanding of symptoms of dementia and the process to get a diagnosis

Making a diagnosis

Through this strategy we will:

- Complete a review of who the appropriate clinician is for diagnosis for people in all settings
- Provide information on support services at diagnosis
- Support diagnosis to be delivered in a sensitive person centred and consistent manner by all clinicians
- Ensure key contacts are identified when providing diagnosis including carers where appropriate
- Strive to meet national target rates for dementia diagnosis

Post diagnostic support

Through this strategy we will:

- Strive to increase the number of people diagnosed with dementia who start treatment within six weeks of referral
- Provide services, from the point of referral (and ongoing) that deliver access to a safe care pathway, timely support, focus on planning for the future, and providing a virtual support hub
- Proactively monitor people who do not yet meet the eligibility criteria of the Memory service, and provide preventative information

Support for carers

Through this strategy we will:

- Signpost family and carers to relevant dementia training as soon as possible
- Ensure all partners work together to create a network of support for any carers identified at the point of a diagnosis
- Develop an appropriate route for families and carers to access advice and information when they are concerned that the person they care for may have dementia and they are refusing support



Supporting Well

What do we mean by supporting well?

We mean that people living with dementia and their carers will be supported to have access to safe and high quality health and social care following a dementia diagnosis.

What are the challenges?

- People have told us that they feel abandoned post-diagnosis, and only find out about the support that is available by speaking to others
- Poor communication between statutory organisations is placing a burden on family and carers to ensure that important information is shared quickly and accurately
- People feel let down by a system that does not provide continuity of support from statutory services or from the care they receive in the community
- Currently there is no dedicated inpatient bed provision for dementia crisis support on the Isle of Wight, requiring some patients to be cared for on the mainland

"I felt alone, isolated and was watching my partner deteriorate daily, now the medical people were deserting us."

"It's sad he ended up in residential care sooner than he had to – so many different carers (five agencies) turned up at different times of day and could not get to know him, which led to him getting agitated and aggressive."

"I need a single, seamless support network. There is far too much repetition of details required to access statutory services."

"My wife needs to be with me, she didn't mean to hurt me, when can she come home? I haven't seen her for months, I may as well kill myself if she stays on the mainland. We have been together for 55 years; I know she would get better if she was with me."

Source: Public consultation 2019

How will dementia support be different?

- People with dementia their family and carers will have better access to education and information about dementia
- People with dementia will be better supported in hospital settings, with access to specialist tailored support to meet their needs
- People with dementia their family and carers will only have to tell their story once, and have better access to dementia services including those delivered by the voluntary and community sector
- People with dementia will receive improved services, as staff will be educated to provide appropriate and caring support
- Carers of people with dementia will feel better supported in their caring role, and empowered to influence services

What will we do to better support people?

Post Diagnostic Support

Through this strategy we will:

- Ensure that people are connected to a named worker to support them with information, advice and guidance
- Improve access to voluntary and community sector support services
- Improve the way that health and care staff share information and decision making with people living with dementia, their carers and each other
- Develop programmes of dementia education to meet the needs of people living with dementia, and their carers
- People with diagnosed or suspected dementia will be referred to audiology for a hearing assessment as recommended by National Institute of Health and Care Excellence (NICE).

Support in hospital

Through this strategy we will:

- Promote the use of the existing *This is Me* plan and Butterfly Scheme and develop more effective tools to replace these
- Provide staff within the Hospital who deliver non-clinical support to patients with dementia and their families throughout their hospital stay
- Improve the way that health and care staff work together to meet the needs of people living with dementia, particularly where the person also has other health conditions
- Complete a review of NHS funded dementia bed provision to reduce the need for anyone to be cared for off the Island

Support in the community

Through this strategy we will:

- Develop health and social care systems that provide continuity of support , minimising the need for people with dementia or their carers to repeatedly tell their story
- Work in partnership to make systems easier to navigate, and help people understand their options for health, care and support, by bringing services together in the same location where possible
- Improve the offer and uptake of assistive technology for people with dementia to support independence
- Ensure appropriate education programmes are available to the health and social care workforce in all sectors, working with independent providers of domiciliary and residential to ensure staff are trained to deliver quality services that maintain people's wellbeing and safety

Support for carers

Through this strategy we will:

- Listen more to family carers, and promote and respect their role
- Ensure that people who care for a person with dementia are connected to a named worker who will provide support and guidance
- Identify people who are undertaking a caring role and ensure they are offered a carer's needs assessment



Living Well

What do we mean by living well?

We mean that people with dementia and those who care for them are able to live full and active lives in safe and accepting communities, which enables independence and provides support where needed.

What are the challenges?

- People told us that they face stigma in their communities around dementia due to a lack of awareness and understanding of the condition
- Public spaces and environments are not planned with consideration for the needs of people with dementia
- Transport options are limited and costly which restricts peoples ability to stay active in their community
- People told us that they would like to remain in their own homes for as long as possible and when the time came, be given a choice of alternative accommodation options
- Respite care is highly valued but currently hard to find and too inflexible
- Follow up from health and care services is often unreliable

“It feels like you are very alone, admiral nurses closed us, but luckily Carers IW and Age UK have helped us.”

“Who of you books and looks forward to a holiday? Have you tried to prebook overnight respite – social workers made me feel like it’s a crime and some carers I know have had to cancel their holiday at the last minute as the overnight respite can’t be found! I feel broken, bone tired and just wonder is it worth it?”

“The Island needs a dementia hub where we can go when we want support, information, activity sessions, company, stimulation, friendship.”

“My whole life is now caring for my husband, I cannot visit family and rarely meet friends. I can no longer contribute to voluntary work and take part in keep fit etc. There is no financial help.”

Source: Public consultation 2019

How will dementia support be different?

- People with dementia will have up to date, person centred care plans and reviews, which identify their strengths and abilities and provide care and support which enhances this
- People with dementia and their carers will be able to access support and services which promote their independence and support them to remain in their communities
- The needs of people living with dementia will be included in the planning of public spaces in their communities through engagement and consultation

- Respite opportunities will be available and will be flexible to meet the needs of people with dementia and their carers
- People with dementia will have a variety of appropriate housing and accommodation options

What will we do to better support people?

Promoting Independence

Through this strategy we will:

- Provide consistent and timely care plan reviews, and access to a recognised source of advice and information when it is required
- Provide support that meets more than a person's physical needs and enables people to remain active in their communities and maintain friendships
- Increase co-production of services, ensuring that people with lived experience and their carers are involved in designing and reviewing services

Dementia Friendly Communities

Through this strategy we will:

- Identify existing initiatives such as Age Friendly Island and seek to expand on these while ensuring that the needs of people with dementia are central to all future developments
- Work with IW Council Regeneration Team to develop dementia friendly community spaces
- Work with community leaders, town and parish councils to ensure that people with dementia are considered in local plans
- Work with local businesses including transport providers to ensure that they are meeting the needs of people living with dementia and seek to develop local community initiatives such as Dementia Safe Places.

Housing Options

Through this strategy we will:

- Provide continued investment in extra care housing and accommodation options which meet the needs of people living with dementia
- Work in partnership with independent providers of residential care to ensure that staff are trained to deliver safe and high quality services that maintain people's wellbeing
- Work with landlords to develop appropriate support to maintain tenancies
- Strengthen links with Occupational Therapy and Housing Teams to maximise the opportunities provided by Disabled Facilities Grants and ensure that the needs of people with dementia are given the same consideration as those with physical needs

Support for carers

Through this strategy we will:

- Commit to undertaking a comprehensive review of respite provision for people with dementia
- Engage with carers to understand what is essential when developing any new respite offer
- Engage with the independent residential care sector to ensure that respite services are developed in a sustainable and flexible way



Dying Well

What do we mean by dying well?

We mean end of life services that support people with dementia to die with dignity in a place of their choosing, and support for family and carers before, during and after a person with dementia dies.

What are the challenges?

- People have told us that they are unclear of the services and support available from the local hospice for people with dementia, their family and carers
- Poor communication between providers around end of life care plans, especially when people with dementia move from one setting to another
- People in their own home are less likely to have support to develop an end of life plan than those who are in a care home setting
- People find it difficult to have conversations around decisions and options around end of life, in the early stages of dementia while they still have capacity to make these choices

“111 told me to give him Calpol, the care home did not know, luckily Carers IW referred us the Share my Care and he got the pain relief he needed.”

“Wherever someone is dying, at home, in a care home or a hospital bed, we need to have access to people who understand good pain relief or palliative care.”

Source: Public consultation 2019

How will dementia support be different?

- People with dementia their family and carers will have better access to end of life care plans, and only have to explain their wishes once
- People with dementia will have better access to pain relief medication at end of life
- Health and social care staff will have a better understanding of available end of life services for people with dementia their family and carers
- Carers of people with dementia will have improved support before, during and after a person with dementia dies

What will we do to better support people?

Improved communications between organisations

Through this strategy we will:

- Ensure that any advanced care plans are identified and shared in all decision making environments.
- Improve links between all dementia services and our local hospice
- Ensure the best and most sensitive method of communication are used at end of life in all settings.

Sharing good End of Life practices

Through this strategy we will:

- Support the roll out of end of life training to care homes to support people with dementia at the end

of their life

- Embed advance care planning for people with dementia in all settings
- Increase the number of people dying with dementia in the place of their choice
- Support carers and care homes to recognise the early signs of end of life to ensure early access to appropriate services
- Review GP procedures at end of life to reduce the need for coroner involvement

Dementia End of Life support

Through this strategy we will:

- Have local data on the number of people with dementia who are at or near end of life to ensure these people are known to end of life care services.
- Review end of life and bereavement services that support people with dementia, their family and carers, and identify any gaps

Support for carers

Through this strategy we will:

- Provide training to health and care staff around end of life to support families and carers
- Empower carers to feel confident and supported in their role
- Offer end of life care training to carers to minimise fear and enhance confidence if their cared for person wishes to die at home.
- Ensure carers have a named contact to help them to navigate end of life services



Next steps

Developing the strategy has highlighted that a lot of activity is already taking place. In addition to this, to meet the outcomes of this strategy, we will develop an action plan to identify what we need, who will do it and by when. This will cover the commitments identified under preventing, diagnosing, living, supporting and dying well chapters of the strategy.

The action plan will be led by Isle of Wight Council, Hampshire and Isle of Wight Clinical Commissioning Group and the Isle of Wight NHS Trust and will be delivered in partnership with the local organisations who supported the development of the strategy and other relevant partners.

We will publish regular updates against progress, as well as all the reports produced to inform the strategy, including the Dementia Stocktake, and consultation reports making these available via websites. This will provide evidence to support decision making by commissioners and service providers about dementia support services. It will also provide the evidence needed for additional grant funding opportunities.

Governance and Monitoring

The Dementia Strategy Steering Group will continue to oversee the implementation of the strategy. The group will meet regularly so they have the opportunity to address any issues highlighted and monitor progress. The steering group will provide twice yearly updates to the Health and Wellbeing Board and Integrated Care Partnership.

The success of the delivery of the dementia strategy will be measured by a set of indicators that will be used to create a dashboard to monitor effectiveness of the strategy. We know that to really meet the needs of the individual, it is important to listen to them, their families and carers. We will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

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