Living Well With Dementia on the Isle of Wight 2014–2019

A partnership approach to the development of services on the Isle of Wight for people living with Dementia.
6. Action plan

6.1 To improve awareness and prevention we will:

6.2 To improve diagnosis and post diagnostic support we will:

6.3 To improve care at home we will:

6.4 To improve specialist care we will:

7. Governance
Foreword

Dementia is becoming the UK’s largest health and social care challenge. It is likely, at some point in our lifetime, it will impact us directly or due to a family member or close friend. It is the aspiration of the My Life A Full Life Programme for the Island to become dementia friendly, allowing people to live well with dementia on the Isle of Wight.

This is the Isle of Wight’s second Dementia Strategy; the first was published in 2009 and focused on improving the number of people being diagnosed with dementia and the post diagnostic support they received afterwards. It began the process of the transformation of care across all the sectors in anticipation of the growing number of people with dementia.

Nationally, there is a call to action by the Prime Minister to improve dementia care, and for improvements to take place at a far greater pace. There is an increasing emphasis on enabling families and communities to look after themselves – supporting carers to care, and helping our local communities become more dementia friendly. We need to ensure that the money currently spent in dementia care is being invested in the most effective ways, traditionally spent on residential or hospital care, with little investment left for support earlier on in the ‘dementia journey’.

The engagement for this strategy has highlighted some of the excellent work carried out on the Island that is improving people’s quality of life. However we still have some way to go. There are just under 3000 people estimated to live with dementia on the Island and due to our elderly population and increasing life expectancy the number of people living with dementia is estimated to increase to 3651 by 2024. This means that ensuring people are supported to live well with dementia on the Island is one of our top priorities.

Addressing loneliness and isolation is a priority for the My Life A Full Life Programme and the State of the Nation report12 highlights this in particular for people living with Dementia. We would like people and their carers to have the confidence and support from their communities to carry out meaningful activities, to have aspirations and a good quality of life. We are delighted that this year saw the launch of Ryde as our first dementia friendly town and look forward to expanding this to other communities on the Island.
We have achieved 60 percent of the estimated dementia population to be diagnosed. Diagnosis is a gateway to making informed personal choices, providing access to a full range of post diagnostic support and services, ensuring people live well with dementia and delaying the time for more intensive packages of care. By March 2015 we aim to reach over 67% of the dementia population to have a diagnosis and access to post diagnostic support.

There have been some excellent examples of partnership working with the formation of the Dementia Alliance that has been delivering the Dementia Challenge Fund programme and the NHS Trust and care homes on the Island delivering the Dementia Friendly Environment programme which are both contributing to improving the quality of lives of people living with dementia on the Island.

It is important that CCGs, Local Authorities, local partner organisations and communities continue to work in partnership to break down the stigma, promote timely diagnosis and post diagnostic support services. This will help people and their carers feel supported by their communities to live well with dementia. The commitment of the Island’s organisations has been reflected in the contribution to this strategy and from the partners translating this strategy into actions. We would 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.

Dr John Rivers,
IoW CCG Executive Chair & Clinical Lead

Cllr Steve Stubbings,
Isle of Wight Council
Executive summary – The scale of the challenge

The vision
The Isle of Wight is to be a place where communities encourage people with dementia and their carers to seek help and feel supported to go about their daily lives safely and free from stigma. Where people are empowered to have high aspirations and have the confidence to participate in meaningful activities. A place where people and their carers receive high quality compassionate care, whether at home, in hospital, or in a care home.

About dementia
Dementia is an umbrella term describing a serious deterioration in mental functions, such as memory, language, orientation and judgement which impacts upon the person’s ability to carry out everyday tasks. There are many types of dementia with Alzheimer’s disease being the most common one accounting for approximately 62 percent, 17 percent are estimated to have vascular dementia and many have a mixture of the two. Most forms of Dementia, are progressive and so the symptoms gradually get worse and the condition is currently incurable. Medicines and other interventions can lessen symptoms and people may live with dementia for 7–12 years in which their health and social care needs change throughout this period.

Age is the most significant known risk factor for dementia. After the age of 65, the risk of developing Alzheimer’s disease doubles approximately every five years. With 1 in 14 people over 65 and 1 in 6 over 80 having some form of dementia.

The impact of dementia
The Department of Health ‘State of the Nation’ report on dementia care and support in England (DOH, 2013) Highlighted some key facts regarding the impact dementia has:

  **Mortality** – Of the top 25 causes of years of life lost in the UK due to premature mortality between 1990 to 2010, a study found Alzheimer’s disease and other dementias had risen from 24th place to 10th, accounting for 2.6 percent of total years of life lost across the top 25 causes.

  **Diagnosis** – Currently 60 percent of the estimated number of people to be living with dementia on the Island have a diagnosis and access to post diagnostic support, higher than the national average of 50 percent.
**Hospital care** – 70% of acute hospital beds are currently occupied by people over the age of 65 and half of these may have a cognitive impairment including dementia\(^\text{11}\). Hospitals are particularly challenging environments for people with dementia and they experience worse outcomes in terms of length of stay, mortality and institutionalisation compared with those without dementia for comparable illnesses, this is estimated to cost £6 million per year.

**Care homes and care at home** – An estimated one third of people with dementia live in residential care with two thirds living at home. Based on the Island's estimated prevalence of dementia, 724 people live with dementia in a care home on the Island. If our proportion of people living in care homes remains the same, by 2024 this will have increased to 894.

**Economy** – Dementia costs the UK society an estimated £23 billion a year, more than the costs of cancer, heart disease or stroke.

**Carers** – An estimated 21 million people in our country know a close friend or family member with dementia – that is 42 percent of the population. There are around 550,000 carers of people with dementia in the England. It is estimated that one in three people will care for a person with dementia in their lifetime.

**Fear** – People fear dementia more than any other disease. 39 percent of over 55s fear getting Alzheimer's the most, compared to 25 percent who worry most about cancer.

### The prevalence of dementia

The Island has the highest recorded prevalence of dementia in the UK for 2011/12 mainly due to the higher than average elderly population. In January 2014, 1768 people on the Island were diagnosed to be living with dementia, there were estimated to be an additional 1186 people living with dementia that do not have a diagnosis and therefore without access to post diagnostic support services.

Due to our ageing population the prevalence of dementia is predicted to continue to increase by 23 percent by 2024 which equates to an additional 697 people on the Island living with dementia.
Achievements

The Isle of Wight has developed a Memory Service Nationally Accredited Programme MSNAP, an integrated care pathway that includes, NHS Trust, Local Authority and third sector organisations, there has been training to improve diagnosis rates and reduce anti-psychotic prescribing for dementia, the formation of the Dementia Alliance, Dementia Friendly Communities and Dementia Friendly Environment work are to name a few of the projects that are improving peoples quality of life. This work has been recognised nationally and used as an example of best practice.

Priority areas for action

This is an Island wide strategy involving all stakeholder organisations on how we will continue to drive for improvements over the next 5 years enabling people to live well with dementia on the Isle of Wight.

This strategy refresh has been an opportunity to engage with the Island residents and organisations to understand what is working well and where the challenges remain. This involved a consultation with 106 people attending the engagement event on 15th October 2013, a number of focus groups and interviews with stakeholders. The following priority areas for action were highlighted from the consultation:

1. Dementia friendly communities that contribute to greater awareness of dementia and reduce stigma.
2. Timely accurate diagnosis of dementia.
4. People with dementia, their families and carers being involved in the care planning of their illness throughout the journey.
5. More people with dementia living a good quality of life at home for longer.
6. People with dementia in hospitals or other care settings to have improved quality of care and be treated with dignity and respect.
The Dementia Steering Group and Island organisations have explored these six priority areas and developed associated action plans. The strategy recommends:

1. The six priority areas for action are ratified and action plans are agreed with the relevant lead organisations.

2. The organisations will report to the Dementia Steering Group on the implementation and delivery of the action plans.

3. The Dementia Steering Group report on the progress of the implementation through six monthly reports.
1. Introduction

Dementia is predicted to become the biggest health and social care challenge of this generation. In the UK there are over 800,000 people living with dementia. With an ageing population the number is predicted to continue to increase by 17% by 2020.

Dementia is a huge cost to the local health economy and to the hearts of local communities. It is estimated to cost the UK economy £23 billion a year, more than cancer and heart disease combined. Figure 1 illustrates the split in the costs for dementia.

Figure 1: Distribution of Dementia Service Costs

The impact of dementia on the individual and their families is profound, family carers are often frail older people themselves with high levels of depression, physical illness and a diminished quality of life.
Dementia is an umbrella term describing a progressive decline in mental functions, such as memory, language, orientation and judgement. This can impact the ability to carry out daily activities. The symptoms gradually get worse over time and the condition is currently incurable, interventions can lessen the symptoms and people may live with dementia for a long period of time after diagnosis.

Approximately 62 percent of people with dementia have Alzheimer’s disease and 17 percent have vascular dementia, many others have a mixture of the two or some less common forms as illustrated in Figure 2.

Age is the most significant known risk factor for dementia. After the age of 65, the risk of developing Alzheimer’s disease doubles approximately every 5 years. With 1 in 14 people over 65 and 1 in 6 over 80 having some form of dementia.
There is no particular measure to prevent dementia at this point in time. There is evidence that healthy living behaviours such as better diet and physical activity can reduce the risk to a person of developing dementia or delay its onset. In December 2013 at the G8 Dementia Summit, leading nations committed to developing a cure or treatment for dementia by 2025. To meet this challenge, the UK government aims to increase its annual research funding to £132million by 2025.

On the Isle of Wight we have the highest percentage of the population living with dementia compared to the rest of the UK, mainly due to our higher than average elderly population. It is estimated that in 2013 there were 2954 people living with dementia, this is predicted to increase by 23 percent to 3651 by 2024. This increase in dementia prevalence is due to people living longer as a consequence of better healthcare and improved standards of living. This presents a number of challenges, directly for those people who develop dementia and their families and carers, and indirectly for the statutory and voluntary sector services that provide care and support.

Ensuring people live well with dementia on the Isle of Wight is a priority for everyone and reflected by the number of organisations involved in developing this Island wide strategy. This strategy has a two year action plan that will be reviewed by the Dementia Steering Group, which includes representatives from stakeholder organisations on the Island including; Isle of Wight Clinical Commissioning Group, Isle of Wight NHS Trust, Public Health, Local Authority, Police, Ambulance, voluntary organisations, private sector organisations, carers and service users.

The Dementia Steering Group is responsible for reporting the development and delivery of the action plan.

This strategy has three aims:

- Improve awareness and prevention.
- Ensure people receive a timely diagnosis and appropriate post diagnostic treatment and support.
- Create dementia friendly communities.
2. Policy context

2.1 Outcomes frameworks

Outcome frameworks are national documents published by the Department of Health that provide a vision for what we want to achieve and a mechanism for measuring outcomes linked to that vision.

There are three outcome frameworks that have been referred to for this Island wide strategy:

- NHS Outcomes Framework
- Public Health Outcomes Framework
- Adult Social Care Outcomes Framework

The Department of Health has commissioned a research team to investigate the potential for a routine Person-Reported Outcome Measure for dementia to be included in Domain 2 – *Enhancing quality of life for people with long-term conditions* in the NHS Outcomes framework 2015/16. This will measure the effectiveness of post-diagnosis care in sustaining independence and improving quality of life for people with dementia.

2.2 National & local policies

There are a number of national and local policies that inform this strategy including those from, Prime Ministers Challenge on Dementia, (2012), State of the Nation Report on dementia care and support in England, (DOH, 2013), NHS Outcomes Framework (DOH, 2013), National End of Life Care Strategy (DOH 2008), Caring for our future; Reforming Care and Support (DOH, 2012), Carers Strategy (DOH, 2011), and the Isle of Wight Carers Strategy (IWC, 2013). With particular focus on the Living Well With Dementia: A National Strategy (DOH, 2009) which aims is to ensure significant improvements are made to dementia services across three key areas:

- Improved awareness & prevention
- Early diagnosis and intervention
- Higher Quality of care

It aims to achieve this by identifying 17 key objectives. Further details about these reports can be found in Appendix One.
3. Dementia on the Isle of Wight

3.1 Local context

The Island had the highest recorded prevalence of dementia in the UK during 2011/12. In January 2014, 1768 people on the Island were diagnosed to be living with dementia, there was estimated to be an additional 1186 people living with dementia without a diagnosis and therefore do not have access to post diagnostic support services.

Table 1 illustrates the increase in diagnosis rates since 2007 and the predicted increase in the number of people living with dementia over the next 10 years.

![Graph showing increase in diagnosis rates and estimated population of people living with dementia.]

Table 1: The number of people on Isle the Wight with a dementia diagnosis and the estimated population of people living with dementia.

There is predicted to be a 23 percent increase in the number of people living with dementia by 2024 which equates to an additional 697 people on the Island with dementia. Table 2 illustrates the largest prevalence increase is in the 70–74 years old age group with a rise of 33% from 2013 to 2020 followed by the 90+ age group with a rise of 32%.
Table 2: Isle of Wight: Estimated Prevalence of Dementia: Number of People Age 65+ – Persons by Age and Year

The increase by gender from 2012 – 2020 is predicted to be larger in males with a 32% increase compared to females with a 16% increase as illustrated in Table 3.

Table 3: Isle of Wight: Estimated Prevalence of Dementia: Number of People Age 65+ – by Gender
Memory clinics
The memory service on the Island had 921 people on its case load in February 2014 and receives on average 88 referrals per month.

Comorbidities
Table 4 below shows the distribution of the number of chronic conditions, those with dementia and those without. On the Isle of Wight, 91% of people with dementia have one or more other chronic conditions.

Table 4: The number of people with a specified chronic condition. ACG June 2014

Care homes
There are 64 homes for older people on the Isle of Wight, 53 residential homes, 11 nursing homes. In 2011 there was 1,798 people aged 65 and over resident in a care home. In March 2014 there were 377 residents with a primary need of dementia supported by the local authority to live in care homes.
Of the estimated prevalence of people that have dementia on the Island, using the CAPITA Dementia Toolkit, it is estimated that 724 people live with dementia in care homes. In Table 5 this is broken down into the severity of mild, moderate and severe needs of care. Over the next 10 years this is predicted to increase by 23 percent.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people with Dementia</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Total Dementia population in a care home</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>Diagnosed</td>
<td>1772</td>
<td>55</td>
<td>133</td>
<td>234</td>
</tr>
<tr>
<td></td>
<td>Estimated Prevalence</td>
<td>2954</td>
<td>92</td>
<td>222</td>
<td>390</td>
</tr>
<tr>
<td>2024</td>
<td>Estimated to be Diagnosed</td>
<td>2811</td>
<td>87</td>
<td>211</td>
<td>371</td>
</tr>
<tr>
<td></td>
<td>Estimated Prevalence</td>
<td>3651</td>
<td>113</td>
<td>274</td>
<td>482</td>
</tr>
</tbody>
</table>

Table 5: The number of people estimated to live in care homes on the Isle of Wight

3.2 Population sub groups

Certain populations of people with dementia will have needs that are different from the general population. Some groups also have a higher risk of developing dementia.

Young people with dementia

Projections for early onset dementia suggest that between 40 and 50 people aged 30 to 64 will have dementia in any one year on the Isle of Wight.

The needs of younger people with dementia may be different due to their financial commitments and dependent children or family. The post diagnostic support services and accommodation are focused towards older people; therefore activities and interests often do not meet their needs.

People with learning disabilities

People with learning disabilities have an increased risk of developing dementia compared to other groups. Nationally, 50% of people with Down’s Syndrome aged 60–69 and 22% of those over 60 with other learning disabilities are recognised to be at risk of dementia³.
People from black and minority ethnic groups
People from all ethnic groups are affected by dementia. Early onset dementia is more common among black and minority ethnic populations, accounting for 6.1 percent of dementias in this group, compared with only 2.2 per cent for the UK population as a whole. People from minority ethnic backgrounds may require specifically tailored approaches to treatment and care e.g. due to language or cultural differences 4.

People with alcohol related dementia
It is estimated that up to 10 percent of dementias are related to alcohol. Services to support people with alcohol-related dementia frequently fall between standard dementia services and alcohol services 11. Younger people with behavioural problems due to alcohol related dementia are usually placed off-Island in specialist placements.

3.3 Achievements
The Isle of Wight dementia services Joint Commissioning Strategy 2009 – 2013 was published in March 2010 to drive improvements in dementia care locally. The action plan for the implementation of this dementia strategy has resulted in the delivery of a number of successful projects that have improved the level of care and support people receive on the Island. Some of these programmes are:

Accredited Memory Service
The Memory Service was set up in 2009 and is 1 of 77 of the memory services national accredited programmes (MSNAP) in the UK. The services receive just under 100 referrals per month from GPs and the Dementia Liaison Team in St. Mary’s Hospital.

Dementia pathway
A New Integrated Care Pathway for people newly diagnosed with dementia has been agreed and consulted upon. This ensures newly diagnosed people have access to intensive Cognitive Stimulation Therapy (CST) for 8 weeks and thereafter, maintenance CST. This pathway is illustrated in Figure 3.
**Dementia Care Pathway (Cluster 18/19)**

**Suspected Dementia/Re-referral to Memory Service**
(or End of Pathway as discharged back to GP)

Referral from:
- GP/Hospital Screening
- Other Primary/Secondary professional
- Self referral
- From carer or relative
- Local Authority or Voluntary Sector

*With GP and/or patient consent

**Assessment and Diagnosis of Dementia**
Memory Service: IW NHS Trust

Triage and Assessment
- Recognition, Investigation & Sub-Type

**Post Diagnosis Support**
Memory Service: IW NHS Trust

- Individual or Group sessions (subject to level of need but to encompass as below)
  - To encompass (aligned to Care Plan*) (not exhaustive)
    - Signs & symptoms of dementia; Course & prognosis of the condition; Carers support services;
    - Treatments; Local care and support services; Support groups; Mediation review;
    - Sources of financial and legal advice, and advocacy; Medico-legal issues, including driving
    - Local information sources, including libraries and voluntary organisations

* NICE guidance (for Information)

**Cognitive Stimulation Therapy (CST)**
Interventions for cognitive symptoms
Memory Service: IW NHS Trust

- 16 group sessions x 2 hours
- Up to 8 people per group

During this period: Discharge planning, Care Plans reviewed, Contingency Plan and List of Support Networks

**Interventions for maintenance of function**: Maintenance CST
Community Memory Groups: AGE (UK) IW

Long term CST support subject to eligibility

**Transition**
Refer to specialist intervention/GP if dementia deteriorates e.g. moves to Cluster 20/21

**Discharge**
If deceased/exit service

**Other Services**
e.g. Adelaide/Goulding Day Care, Carers Support Service, Riverside, Stroke Club, Friendships Groups, AGE (UK) IW, Alzheimer’s Society, Quay Carers Support, Sing About

- NICE guidance (for Information)

**CARE PLAN**: Care plans should be based on an assessment of a person’s life history, social & family circumstance, and preferences, as well as their physical and mental health needs and current level of functioning and abilities.

**COORDINATED HEALTH & SOCIAL CARE (HSC)**: Services for people with dementia should be delivered in a coordinated manner and involve:
- A combined care plan agreed by HSC; Assignment of named health and/or social care staff to operate the care plan; Endorsement of the care plan by the person with dementia and/or carers and Formal review of the care plan at an agreed frequency.

Figure 3: The Isle of Wight Integrated Care Pathway, 2013.
Increase in diagnosis rate

The number of people estimated to be living with dementia who have a diagnosis is 60 percent on the Isle of Wight. A number of initiatives have been introduced to increase the awareness and value of diagnosis of dementia. Amongst these is a GP training programme to support Primary Care in identifying people to be referred to the memory service for assessment. This rate has consistently increased over the last three years as demonstrated in Table 1.

Reduction in anti-psychotic prescribing

The Prime Ministers Challenge for dementia laid out a two thirds reduction in the use of anti-psychotic prescribing. On the Island this been reduced from 17 percent in 2006 to 3 percent of people with dementia being prescribed anti-psychotics as illustrated in Table 6.

Dementia friendly hospital

The Acute Matron Dementia Champion and Dementia Liaison Team have developed and delivered a number of initiatives to make St. Mary’s Hospital a dementia friendly hospital. Some of which include:

The Environment:

- Way finding: accent colours, clear signage with pictures and text, identification of bays.
• Orientation: Large face clocks with date and time, photographs of local scenes, clear signage of ward name, visible staff.
• Legibility: Even lighting, matt flooring, uncluttered spaces, discreet security measures.
• Meaningful activity: snack trolley, memorabilia, social spaces.
• Familiarity: distinct crockery, memory boxes.

Developing the workforce and changing culture:
• Dementia champions
• Competency pack
• Resource pack, Understanding dementia
• E learning package
• External course Level 2
• Development training days
• Protective mealtimes
• Developing and including the ward volunteers
• “Butterfly Scheme”
• “This is Me” leaflet
• Dementia awareness days

Assessment and referral:
The National Dementia CQUIN introduced in April 2012 has three elements focused on identifying unmet need in the acute physical hospital setting. It was based on the methodology of find, assess and refer.
• All patients aged 65 years and over are asked the “memory question” within 72 hours of admission.
• Refer patients with a AMT of 8 or below to the memory services.
• Monitor the use of anti-psychotic medication.
Supporting patients on discharge:

- Follow on referral from the memory services.
- Carers information leaflet.

**Move to Shackleton Ward**

The dementia inpatient unit was moved on 3rd June 2013 from its premises in Ryde to a new interim ward on St. Mary’s Hospital site. The new interim Shackleton Ward provides 7 beds, modern well-appointed facilities and the principles of the dementia friendly environment have been followed when designing the ward. The outcome quality measures are reported and monitored at the Dementia Officer Level Steering Group.

The care pathway for specialist inpatient assessment and treatment can be found in Appendix Two.

**Dementia Intensive Treatment Service (DITS)**

This team supports and educates residential homes, nursing homes, families and carers with people who have problematic symptoms of dementia, displaying challenging behaviour, or other complex presentations and whose placements are at risk. By supporting staff and carers at times when behaviour becomes challenging it is evidenced to prevent the escalation to crisis and reduce the number of placement breakdowns or hospital admissions.

**Dementia Alliance: Dementia challenge fund**

The IoW Clinical Commissioning Group (CCG) led the formation of the Dementia Alliance which was awarded monies from the NHS South of England Dementia Challenge Fund and CCG. The fund enabled local communities to identify and implement practical solutions to the problems faced by people living with dementia. This included the following projects on the island:

- Dementia Community Cafés
- Alzheimer Cafés
- Dementia Awareness Training Lighting (DARC)
- St. Mary’s Hospital – The butterfly scheme
- Raise awareness of dementia and increase information and support
- Dementia Advisory Service
- Circles of Support
- Community Memory Groups – Age UK IW
Dementia friendly communities

The Isle of Wight Clinical Commissioning Group (CCG) with the Department of Health investment, has commissioned Age UK IW to pilot a project to develop dementia friendly communities on the Island. This is in response to the Prime Minsters dementia challenge launched in 2012.

The Prime Ministers dementia challenge involved 20 cities, towns and villages signing up to becoming more dementia friendly. A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them⁵. Ryde Business Association and Town Council are leading the work for Ryde to become the first Dementia Friendly Community on the Isle of Wight. The Mayor of Ryde is championing this. Further information about this can be found in Appendix Three.

Dementia friendly environment

In the Prime Ministers Challenge in 2012 key commitment 3 was an innovation challenge prize of £1 million pounds which the Isle of Wight NHS Trust was awarded with support from the Isle of Wight Clinical Commissioning Group, Isle of Wight Local Council and Care homes.

The project is a step towards a dementia friendly Island, by providing some of the most vulnerable people with dementia with an environment which is standardised and harmonised across different care settings, reducing the distress caused by transitions of care and improving the quality of life and safety in each care environment.

The project focuses on these key areas:

- Safety – reducing falls and enhancing orientation by good lighting, signage and decor. Where possible these initiatives will be standardised across the care homes and hospital settings – for example flooring and decoration will have the same colour schemes. The person with dementia who needs admission from a care home to hospital will have their distress reduced by the familiarity of similar decor in hospital to their home.

- Encouraging outdoor recreation by improving access to gardens, enhancing garden areas by use of raised beds and sensory garden planting, and making areas safe.

- Provision of specialist equipment to encourage meaningful personalised activity.
My Life A Full Life

The My Life A Full Life programme is a collaboration between the Isle of Wight Clinical Commissioning Group, Isle of Wight NHS Trust, the Isle of Wight Council and third sector organisations. The initiative works in partnership with local people, voluntary organisations and the private sector to deliver a more coordinated approach to the delivery of health and social care services for older people and people with long term conditions on the Island. Dementia is being included in this programme to support integrated working across organisations to deliver effective and sustainable services that will improve the patient experience and outcomes.

Better care fund

The fund is being developed for 2015/16 and aims to support the integration of health and social care. The fund is an opportunity for local services to transform and improve the lives of the people that need it most.
4. Consultation

The development of this strategy was supported by a two month consultation period which involved a workshop delivered by the Dementia Steering Group. 106 people attended the workshop on 15th October 2013, including staff from the IW NHS Trust, Local Authority, Public Health, residential and care homes, third sector organisations, carers and service users.

People with dementia, their families and carers shared what they felt was working well, what challenges they faced and what they felt is needed to ensure people live well with dementia on the Isle of Wight. They said they wanted to receive an early diagnosis and timely, good quality information that will help them make informed choices about their care, they want to be involved in the care plan and their families and carers if appropriate.

The consultation draws on the concept of the “Dementia Journey”, designed by Dementia Partnerships UK. It helped to focus the thinking on the way dementia affects individuals at the various stages and how support needs to vary from stage to stage:

| Phase 1 | •When memory problems have prompted me, and/or my carer/family to seek help |
| Phase 2 | •Learning that the condition is dementia |
| Phase 3 | •Learning more about the disease, how to manage, options for treatment and care, and support for me and my carers/families |
| Phase 4 | •Getting the right help at the right time to live well with dementia, prevent crises, and manage together |
| Phase 5 | •Managing at more difficult times (including if it is not possible to manage at home) |
| Phase 6 | •Receiving care, compassion and support at the end of life |
Challenges

It was identified that there are still a number of challenges that we need to address to ensure people live well with dementia on the island:

- A timely diagnosis
- Reducing stigma and discrimination
- Addressing isolation and loneliness
- Knowing what your choices are
- Keeping people at home for longer and managing their challenging behaviour
- People in the hospital setting being treated with dignity and respect
- Care planning including end of life care planning
- Support for carers
- Understanding personal budgets

Priorities

The following areas were highlighted as priorities for the next five years from the consultation:

- Dementia friendly communities that contribute to greater awareness of dementia and reduce stigma
- Timely accurate diagnosis of dementia
- Better post diagnostic support for people with dementia and their families
- People with dementia, their families and carers are involved in the care planning of their illness throughout the journey
- More people with dementia living a good quality of life at home for longer
- People with dementia in hospitals or other care settings being treated with dignity and respect

A common theme throughout the consultation was the importance of supporting carers. The consultation report can be found in Appendix Four.
5. Priority areas for action

The priority areas for action have been broken down into the four stages:

1. Awareness and prevention
2. Diagnosis and post diagnostic support
3. Care at Home
4. Specialist Care

With priority areas highlighted under each that will inform the action plan.

5.1 Awareness and prevention

Prevention

There is evidence that healthy living behaviours such as better diet and physical activity can reduce the risk to a person of developing dementia or delay its onset. 17 percent of people with dementia have vascular dementia which may be prevented through healthy living behaviours and 10 percent of people have both vascular dementia and Alzheimer’s. It is estimated that up to 10 percent of dementias are alcohol related.

Awareness and education is important in promoting healthy living behaviours especially in vulnerable groups.

Dementia friendly communities that contribute to greater awareness of dementia and reduce stigma

Many people with dementia have reported feeling unsupported and not part of their community; they are not able to take part in activities that they enjoyed before they developed the condition. The DFC survey highlighted that 42 percent of people felt their area was not geared up to help people live with dementia.

35 percent of people with dementia said that they only go out once a week or less and 10 percent said once a month or less. While people face barriers in engaging with their community, it is possible to make changes that can make their day to day lives much better.
A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. The Alzheimer’s society has laid out ten key areas communities should focus on, these areas are described in Appendix Three.

A priority for the Island is to increase the number of dementia friendly towns where organisations in local communities are being supported to attend training and improve their understanding about dementia and how to assist and direct people to the appropriate support. By improving the public’s understanding and increasing their confidence in engaging and supporting people with dementia, it ensures people can live safely and confidently within their communities for longer.
Age UK IW is leading on developing Ryde as our first dementia friendly town on the Island. The Alzheimer’s Society ‘Building dementia-friendly communities: A priority for everyone’ report highlighted that a year living in the community with dementia (excluding the initial memory services assessment) is estimated to cost £24,128. This includes the cost of an integrated health and social care package, together with respite, therapies and medication. A year in residential care costs an average of £35,424. Therefore, for every person who is able to live at home rather than in residential care there is a saving of £11,296 per year or £941 per month. If just 5% of admissions to residential care were to be delayed for one year as a result of dementia-friendly communities, there would be a net saving of £55 million per annum across England, Wales and Northern Ireland.

A Dementia Friendly Communities Steering Group has been formed to explore how to expand the dementia friendly communities’ programme on the Island.

5.2 Diagnosis and post diagnostic support

Timely accurate diagnosis of dementia

There is a great deal that can be done to help people to live well with dementia. When people are diagnosed early enough and receive the appropriate support in the early stage, it can have a significant impact on the degree to which someone is able to manage the condition over time and live independently for longer.

People with dementia currently wait up to three years before reporting symptoms to their doctor. It is estimated that 40 percent of the people on the Isle of Wight that live with dementia have not been diagnosed and do not have access to post diagnostic support.

Having an early diagnosis can ensure people plan for the future, make informed choices about how they would like to be cared for and prevent future crisis resulting in a delay on the need for intensive care support.

Historically healthcare professionals did not see the value in giving someone a diagnosis of dementia. Evidence has demonstrated the impact that early diagnosis and access to post diagnostic support can have for both the person living with dementia and their carer. The Isle of Wight has invested, over the past three years, in raising awareness, educating the public and providing training to GPs and hospital staff around dementia. There is evidence that early diagnosis and intervention services are cost effective once they are established.

By 2015 the Department of Health will be asking that two thirds of people with dementia have a diagnosis.
Ensuring that the time between referral and assessment is as minimal as possible is important in achieving access to the appropriate support and information for the person and their carer.

**Better post diagnostic support for people with dementia and their families**

There is currently no national measure of the provision of post diagnostic support or understanding of what good post diagnostic support looks like. The Isle of Wight Clinical Commissioning Group, NHS Trust, Local Authority and Dementia Alliance have developed an integrated dementia care pathway for people on the Island (Figure 3). This care pathway has been shared nationally in the State of the Nation report\(^\text{12}\) and used as an example of good practice by many areas when developing their own pathway.

In 2015 the Isle of Wight Clinical Commissioning Group will be reviewing this pathway to understand the patient and carer outcomes achieved and how to ensure the future demands are met with people feeling supported to live safe independent lives in the community.

With 91% of people living with dementia having at least one other chronic condition the CCG will be scoping the possibility of integrating older persons physical health care community services with older persons mental health services to address the needs of this group within one integrated care pathway.

**5.3 Care at home**

**Care planning**

It is important that people with dementia, their families and carers are involved in the care planning of their illness throughout the journey.

A care plan is an agreement between the person, the healthcare professional, and / or social services and the carer about how to manage the person’s health day to day and in the future. It is important that people and their carers are clear on the options available to them and involved in the planning of their care throughout the journey and anticipatory of the future. Care planning can prevent someone from escalating into crisis and reduce unplanned hospital stays.

Advanced care planning ensures people are involved in the planning earlier enough that they have mental capacity to make informed decisions about their wishes for the future. This could include the use of lasting powers of attorney, advance decisions and advance statements.

From April 1\(^{\text{st}}\) 2014 GPs will have a Directed Enhanced Service (DES) for personalised care plans for people that are at risk of unplanned admissions to hospital or have complex medical problems.
The process for care planning at the different stages and the support required will be reviewed as part of the dementia pathway review. People who do not enter the post diagnostic support pathway also need to be considered in terms of how they are reached out to and supported as their needs change.

**Supported to live at home**

The Alzheimer’s Society ‘Support Stay Save’ report found that 83 percent of people with dementia want to stay in their own home. One in ten thousand respondents said the person was admitted into care because they were not receiving support in the community. It is felt with adequate support in the community, admission into hospitals and care homes would be greatly reduced.

Two thirds of all people with dementia live in their own homes in the community. Throughout the different phases of dementia a person’s needs will change from information and transport for example, to needing help maintaining their homes, gardens, physical health and peer support networks.

In 2013 thirty percent of people that attended the Long Stay Memory Clinics on the Isle of Wight lived alone. In a national survey it was found that 62 percent of people that live with dementia on their own are lonely and it can sometimes be hard for them to access services which only adds to the possibility of social isolation⁹.

Evidence suggests:

- **Early provision of support at home can decrease institutionalisation by 22%**.
- **Even in complex cases, and where the control group is served by a highly skilled mental health team, case management can reduce admission to care homes by 6%**.
- **Older peoples’ mental health services can help with behavioural disturbance, hallucinations and depression in dementia, reducing the need for institutional care**.
- **Carer support and counselling at diagnosis can reduce care home placements by 28%**¹⁰.

The role of telecare and assistive technology has developed a wealth of evidence for keeping people safe at home for longer and supports in managing any co-morbidities a person may have.
The Isle of Wight Clinical Commissioning Group is piloting a crisis response team which put a package of care around a person for 72 hours. The outcome of this pilot will be monitored and reported on in April 2015.

Supporting carers

Carers are the most valuable resource we have on the Island and are vital in enabling people to live well with dementia at home. Research shows that carers of people with dementia experience greater strain and stress than carers of other older people and are at risk of depression and physical health problems.

Carers are estimated to save the nation £7 billion a year. It is a statutory legal obligation of the Local Authority to support carers by offering carers assessments to ensure that they are willing and able to continue caring. Care managers and community support staff offer carers assessments together with a support plan, advice on benefits, carers services, carers therapies, support groups, sitting services and respite care schemes.

This strategy supports the implementation of The Isle of Wight Carers Strategy which was published in 2013 by the Isle of Wight Council.

5.4 Specialist care

It is part of the Prime Ministers challenge to ensure that people with dementia in hospitals or other care settings have improved quality of care and be treated with dignity and respect.

Care homes

At least two thirds of people in care homes live with dementia\(^1\). There are 64 homes for older people on the Isle of Wight, 53 residential homes, 11 nursing homes, all of which accept people with dementia depending on their level of need, with some homes taking more dementia patients than others.

A group of care homes bid for funds from the Dementia Environment Programme to support them in delivering therapeutic activities that enable positive environments where the individuality of the resident is respected. There are a number of training programmes along with the Dementia Intensive Treatment Service (DITS) that support staff in developing their knowledge and skills to enable people living with dementia to lead as fulfilling a life as possible.
Hospital care

70% of acute hospital beds are currently occupied by people over the age of 65 and half of these may have a cognitive impairment including dementia. Hospitals are particularly challenging environments for people with dementia and they experience worse outcomes in terms of length of stay, mortality and institutionalisation compared with those without dementia for comparable illnesses, this is estimated to cost £6 million per year.

End of life care

People with dementia do not receive the same level of end of life care as those that are cognitively intact. Dementia can impair a person’s ability to make themselves understood and quite often aggressive behaviour can be a result of pain. It has been reported that people with dementia receive less analgesia than other people of a given illness.

The Department of Health State of the Nation Report (2013) highlighted that too many people with dementia are not supported to have early discussions and make plans for their end of life care. Findings from the National Survey of Bereaved People, of which one fifth of the responses were related to dementia found that 1 in 10 of the bereaved rated their loved ones end of life care as poor.

The Isle of Wight Clinical Commissioning Group is reviewing the end of life care pathway to support an integrated model and will report on this in April 2014.

It is good practice that everyone in a care homes have an advanced care plan that is developed with their carer.
6. Action plan

The Action Plan is split into four sections:

1. Awareness and prevention
2. Diagnosis and post diagnostic support
3. Care at Home
4. Specialist Care

Stakeholder organisations are invited to contribute to the action plan and will be invited to report their activities to the Dementia Steering Group which meet bi-monthly.

The Dementia Steering Group include representation from the Isle of Wight Clinical Commissioning Group, Isle of Wight NHS Trust, Isle of Wight Council, Dementia Alliance (including IW Age UK, Alzheimer’s Society, Alzheimer’s café) Public Health, Residential and Care Homes Representatives, Service Users and Carers.

The action plan can be found in Appendix Seven, below is a summary of what the Islands organisations plan to do to ensure people live well with dementia:

6.1 To improve awareness and prevention we will:
- Produce a ‘Dementia Roadmap’ which informs people, carers and staff of national and local resources and services available.
- Health lifestyle message are promoted to the over 55’s by GP practices to reduce the risk of vascular dementia.
- Expansion of the dementia friendly communities programme on the Isle of Wight.
- Training programmes provided to local businesses and front line care staff.

6.2 To improve diagnosis and post diagnostic support we will:
- Increase the number of people diagnosed with dementia and having access to post diagnostic support to 67% of the estimated population living with dementia by March 2015.
- We will review the dementia care pathway to ensure it supports people to live well with dementia.
• All newly diagnosed people will be referred to a dementia support worker.
• All the agencies have a shared register of people with a diagnosis of dementia.
• We will deliver Health Education England foundation level dementia training programme to all relevant patient facing staff in the NHS by 2018.
• Maintain the MSNAP accreditation for Isle of Wight Memory Service.

6.3 To improve care at home we will:
• Ensure all people at risk of having an unplanned admission to hospital in the next twelve months have a personalised care plan.
• Identify hard to reach groups to ensure they are aware of the support and tools available to live safely.
• Increase the access to dementia training for the police.
• Pilot technologies to ensure people remain safe whilst maintaining their dignity and independence.
• Monitor the implementation of the Isle of Wight Carers Strategy.

6.4 To improve specialist care we will:
• Explore best practice in ensuring people admitted to hospital are assessed and supported appropriately if they have mental health problems.
• People over 75 admitted to hospital are screened for dementia.
• Dementia friendly environment principles will be shared with specialist care organisations on the Island.
• People with dementia and their carers are involved in end of life care planning whilst they have capacity.
7. Governance

The Isle of Wight Living Well With Dementia Strategy builds on the learning and requirements from the Department of Health State of The Nation Report, 2013 and Living Well With Dementia Strategy 2009 and has benefited from engagement with people with memory problems, carers, providers, clinicians, public sector and voluntary sector organisations.

It is recommended that the multi-agency Dementia Steering Group oversees the delivery of this strategy. The action plan and key performance indicators arising out of this strategy will be reported and monitored by the Dementia Steering Group.