Shetland Dementia Strategy

2015 - 2018

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NHS SHETLAND DOCUMENT DEVELOPMENT COVERSHEET*

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Shetland Mental Health Partnership	PFPI
CH&SC Operations Group	Dementia Services Partnership
Joint Acute/CH&SC Strategic Group	Senior Management Team
Area Clinical Forum	Joint Social Services/CHP Committee

DATE	VERSION	GROUP	REASON	OUTCOME
27/11/14	1	Shetland Mental Health Partnership	C/S	PRO
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19/03/15	3	Shetland Mental Health Partnership	C/S	MR
10/04/15	4	CH& SC Operations Group	C/S	MR
16/04/15	4	Area Clinical Forum	PO & C/S	PRO
28/04/15	5	Joint Acute/CH&SC Strategic Group	C/S	PRO
26/05/15	6	Strategy & Redesign Group	C/S	PRO
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Examples of reasons for presenting to the group	**Examples of outcomes following meeting**
• Professional input required re: content (PI)	• Significant changes to content required – refer to Executive Lead for guidance (SC)
• Professional opinion on content (PO)	• To amend content & re-submit to group (AC&R)
• General comments/suggestions (C/S)	• For minor revisions (e.g. format/layout) – no need to re-submit to group (MR)
• For information only (FIO)	• Recommend proceeding to next stage (PRO)
• For proofing/formatting (PF)	• For upload to Intranet (INT)

Please record details of any changes made to the document in the table below

DATE	CHANGES MADE TO DOCUMENT
14/01/15	Added more background narrative and reference to an Implementation Action Plan.
27/02/15	Restructuring of document in order to highlight local priorities.
06/04/15	Executive summary added and some minor changes made following suggestions from SMHP and Director of Health and Social Care.
07/04/15	Changes to layout and style.
20/04/15	Draft Action Plan added to Appendix 1.
26/05/15	Incorporated comments and suggestions made by Area Clinical Forum, Joint Acute/CH&SC Strategic Group and Strategy & Redesign Group.
26/06/15	Draft high level outcome measures added to Action Plan.

CONTENTS

1. Executive Summary

Since the publication of the first Dementia Strategy in 2010 a greater awareness of dementia has resulted in a greater number of people with a diagnosis. This has also resulted in an increased understanding within the general public of the importance of building dementia friendly communities that help keep people living with dementia engaged and supported within their community.

The second Dementia Strategy identified 17 National commitments highlighting key areas for improvement in care for people living with dementia and their families and carers. This local strategy develops a series of local priority actions that will support these commitments.

It is estimated that the number of people with a diagnosis of dementia will double in the next 25 years. In order to meet their needs we need to ensure that services are designed and developed to meet the needs of people living with dementia and their carers with the best possible care. We also need to ensure that the general public are educated to allow them to play their part in supporting people living with dementia to remain connected with their community.

It is estimated that in the next 25 years the population of people over 65 will increase at a greater rate than those of working age. There is already a population drift towards towns from more rural parts of Shetland. Taken together, we will have to identify ways of supporting people living with dementia to continue to live within their own communities for as long as possible with the best use of available resources. This strategy outlines the range of specialist services available to support people living with dementia and their families/carers provided by statutory and third sector agencies. However it is important to understand that the care of people living with dementia must be seen as integral within all services provided in Shetland.

There is a growing use of telecare/telehealth within Shetland and this document will outline a range of technology that is already being used to support people living with dementia to remain at home. It is intended that this will be further developed to also allow people to be better connected within their community, leading to less isolation.

This strategy links with the Older People's Strategy and as such public consultation on these strategies took place jointly in Shetland.

In developing this strategy it is essential to take account of the good progress and achievements that have already been made since service improvements were begun in 2009. Since then there has been the development of a specialist assessment and diagnosis service with support from Post Diagnosis Link Workers, support to Gilbert Bain Hospital and Care Centres from a Dementia Clinical Nurse Specialist, links to the National Dementia Nurse Consultant Group, new models of housing for people living with dementia and local support from Alzheimer Scotland.

Despite these developments there remain challenges that will be examined in more detail. Raising public awareness, knowledge and training across all parts of Shetland and with all levels of the population will be a target to aim for within this strategy as well as meeting the needs of people living with dementia as close to their own home as possible and without them having to leave Shetland.

In developing this strategy it was important to identify other key areas of work that are being progressed by the Scottish Government that will impact on people living with dementia and their carers. Some of these will be outlined in more detail. Although this Strategy has been written to reflect the National Dementia Strategy, it also acknowledges that there are a number of other general health and social policy documents and strategies that will impact on people living with dementia. As this strategy is written to address the development of care and support in the community for people living with dementia and their carers, it is not the intention of this strategy to address these areas specifically. It will be expected that these other documents will reflect the needs of the population as a whole and as such include people living with dementia.

A series of key outcomes were identified in the National Strategy and this strategy has taken account of these when identifying our local priorities. These priorities have then been developed into a series of actions that will outline how they will help to meet the 17 National commitments. Progress towards these actions will be tracked within an action plan that will indicate timescales and responsibilities for each one.

2. Overview

Scotland's first National Dementia Strategy was published in 2010 and focused on improving the quality of dementia services through more timely diagnosis and on better care and treatment, particularly in hospital settings. It began the process of the transformation of care across all sectors in anticipation of the growing number of people living with dementia.

This initiative led to an increase in diagnosis rates, with around 64% of people with dementia in Scotland now receiving a diagnosis.

Although a diagnosis of dementia has a huge impact on individuals and families, timely and sensitive diagnosis, backed by effective and holistic post-diagnostic support, is vital in helping people build their personal resilience and knowledge about dementia and enabling them to live a good quality of life at home for as long as possible. To help achieve this, the Scottish Government introduced a national commitment on post-diagnostic support for everyone diagnosed from 1 April 2013.

There are also huge challenges for us in ensuring that people with dementia are not admitted to hospital unnecessarily and that they get effective and dignified care while in hospital. A National Action Plan was developed to support NHS Boards in helping to make the required changes to our services and to maximise workforce initiatives such as the Alzheimer Scotland Dementia Nurse Consultants and the Dementia Champions.

The Scottish Government is also working closely with The Life Changes Trust as they begin to make funding available for initiatives across Scotland to build dementia-aware local communities – among other benefits, these will help tackle the isolation and depression often felt by people living with dementia and help them remain connected to their friends and neighbours.

All of this activity is to be aligned with the 2020 vision for health and care in Scotland, which will work to enable all people, including those living with dementia, to live well for longer at home or in a homely setting. This will be backed by an integrated health

and care system with a focus on areas like supported self-management and on ensuring community-based health treatment wherever and whenever possible.

3. National Commitments.

The national strategy describes 17 commitments that the Scottish Government has identified and these are listed below.

COMMITMENT 1: We will sustain and, where appropriate improve further, dementia diagnosis rates.

COMMITMENT 2: We will transform the availability, consistency and quality of post-diagnostic support by delivering the new post-diagnostic HEAT target.

COMMITMENT 3: We will implement the most effective means of providing integrated care and support on the basis of the 8 Pillars model, centred on a Dementia Practice Coordinator role.

COMMITMENT 4: Scottish Government will commission Alzheimer Scotland to produce an evidence based policy document outlining the contributions of AHPs to ensuring implementation of the 8-Pillar model.

COMMITMENT 5: We will take further action to support safe and supportive home environments and the importance of the use of adaptations and assistive technology, in maintaining the independence and quality of life of people with dementia and their carers

COMMITMENT 6: We will take further action to support and promote best practice in advance care planning, the assessment of capacity to consent to treatment and adherence to proper procedures for making decisions for people with dementia who lack capacity.

COMMITMENT 7: Scottish Government will publish a report on implementation of the dementia standards to date.

COMMITMENT 8: We will continue to improve staff skills and knowledge by working with NES and SSSC to take forward a second Promoting Excellence training plan across the period of this Strategy.

COMMITMENT 9: We will work with NES, SSSC, NHS Health Scotland, NHS 24 and Alzheimer Scotland to develop and launch an innovative digital platform for dementia, which will help inform and empower people with dementia and their families and carers in being equal partners in care.

COMMITMENT 10: We will develop and deliver a 3-year National Action Plan to improve care in acute general hospitals.

COMMITMENT 11: Scottish Government will set out plans for extending the work on quality of care in general hospitals to other hospitals and NHS settings.

COMMITMENT 12: We will work with national agencies (e.g. Scottish Care, SSSC, NES) and others to assess the need for, and take further action on, improving service response around care homes, care at home and adult day care services. This will include attention to staff training and support for the implementation of the post-diagnostic HEAT target and the commitment on reducing inappropriate prescribing of psychoactive medication for people diagnosed in care homes.

COMMITMENT 13: Scottish Government will finalise and implement a national commitment on the prescribing of psychoactive medications, as part of ensuring that such medication is used only where there is no appropriate alternative and where there is clear benefit to the person receiving the medication.

COMMITMENT 14: We will take account of the expectations and experience of people with dementia and their carers in taking forward the work on outcomes for the integration of health and social care.

COMMITMENT 15: Scottish Government will continue to support research through funding The Scottish Dementia Clinical Research Network and supporting the work of the new Scottish Dementia Research Consortium in its objective to bring together the range of dementia research interests in Scotland and maximise the impact of and funding opportunities for research capacity here.

COMMITMENT 16: Scottish Government will undertake a brief piece of work focusing on the care pathway for people with dementia in these groups, through diagnosis and support, through treatment and care, taking account of the particular challenges for carers and family members with the objective of identifying what further actions are required to ensure that each of the key improvement areas – diagnosis, post-diagnostic support, care co-ordination requires modification to take account of the needs of different groups.

COMMITMENT 17: Scottish Government will oversee and ensure progress on the dementia agenda and in implementing the National Strategy, it will carry over from the first Strategy an Implementation and Monitoring Group to co-ordinate, support and monitor progress on the commitments outlined in the Strategy.

This strategy will outline our local priorities and how they link to the national commitments.

4. Local context

Dementia is one of the foremost public health challenges worldwide. As a consequence of improved healthcare and better standards of living more people are living for longer. This means in Scotland that the number of people with dementia is expected to double between 2011 and 2031. This presents a number of challenges, most directly for the people who develop dementia and their families and carers, but also for the statutory and voluntary sector services who provide care and support.
For Shetland, we could expect to see a rise in the number of people with a diagnosis of dementia from 189 today to 368 in 2031. (Estimated number based on EuroCode prevalence rates and population projections)
Over time we expect that a greater proportion of health and social care expenditure will focus on dementia, and there is evidence of that change already.
This document sets out the actions that we will take to make progress toward achieving our vision of providing the very best of dementia care in Shetland.

It is our vision that both professionals and the general public must work together to create a Dementia Friendly community.
There will be a greater awareness of dementia in order to reduce the stigma associated with the illness and encouragement to communities to support people living with dementia to be able to remain connected with their community, living within their own home for as long as possible.

There is no particular measure which can prevent dementia. The interplay between the benefits of a healthy lifestyle and the increasing risk of developing dementia with age is complex and difficult to assess. There is evidence that healthy living behaviours, such as better diet or physical activity, may reduce the risk of a person developing dementia, or delay its onset. At the same time, the increase in life expectancy, also a consequence of healthy living behaviours is the main factor behind the increasing number of people with dementia. More work is needed to understand these interactions at a population level, though the benefits to the individual of healthy living are clear.
Although not exclusively a condition affecting older adults, dementias are predominantly a feature of an aging population. Dementia is an umbrella term for a

range of illnesses and disease symptoms, which primarily or secondarily affect the brain. Alzheimer's disease and vascular dementia are the most frequently occurring illnesses.

Nationally, as our population ages, the number of people living with dementia will increase and it is expected that the number will double over the next 25 years. Prevalence of dementia increases with age; around 1.5% of the 65 to 69-year-old population are affected, increasing to about one in three of the 90-plus age groups. Dementia is a key health issue facing Shetland in the coming decades. As our population ages there is a projected 50% increase in the number of those affected by the disease. Dementia is a major cause of disability in people aged 60 and over. It contributes 11.2% of all years lived with disability, which is more than stroke (9%), musculoskeletal disorders (9.8%), cardiovascular disease (5%) and all forms of cancer (2.4%). (***The Dementia Epidemic****- where Scotland is now and the challenge ahead, Alzheimer Scotland, June 2007*)

Therefore, to ensure effective delivery of services and most efficient use of resources this strategy has been developed in harmony with Shetland's Older People's Strategy. The following section on Demography has been shared with that strategy.

5. Demography

Total population size

There are different ways of measuring the total size of the population. According to the 2011 Census there were 23,167 people living in Shetland on census day. Of these, 3,777 were aged 65 or older (16%).

In Shetland, we can also use GP registrations as a good indicator of population size because we know that most people are registered with a GP. This can give us much more up to date information compared to the census which was done three years ago. According to GP registration on 1st April 2014, there were 22,886 people registered with a GP in Shetland and of these, 4,184 people were aged 65 or over.

Age structure

The table below shows the number of people in each age band in Shetland according to the Census and GP registration data. The age bands are not equal: they are based on how we tend to group people by age for purposes of statistics or service delivery for example.

	'Pre-school'	**'School age'**	**'Young people'**	**'Working age adults'**		**'Older people'**		
	0-4	**5-14**	**15-24**	**25-44**	**45-64**	**65-74**	**75-84**	**85+**
2011 Census (% of total population)	1389 (6%)	2776 (12%)	2746 (12%)	5859 (25%)	6620 (29%)	2143 (9%)	1178 (5%)	456 (2%)
2014 GP registrations (% of total population)	1303 (6%)	2592 (11%)	2615 (11%)	5659 (25%)	6533 (29%)	2454 (11%)	1256 (5%)	474 (2%)

Sources: *Scotland's Census 2011 website (www.scotlandscensus.gov.uk/r1-downloadable-files). Local GP data.*

The table above shows that there are slight differences in the percentages of people in each age grouping between the GP registration and the census data. There is a slightly higher proportion of people in the 65-74 age group, and a slightly lower proportion in the school age and young people groups in the 2014 GP registration data compare to 2011 Census data. This could reflect that there is a higher proportion of older people registered with a GP compared to young people (although we would expect a high registration amongst school age children) and / or that the proportions have shifted in the past three years.

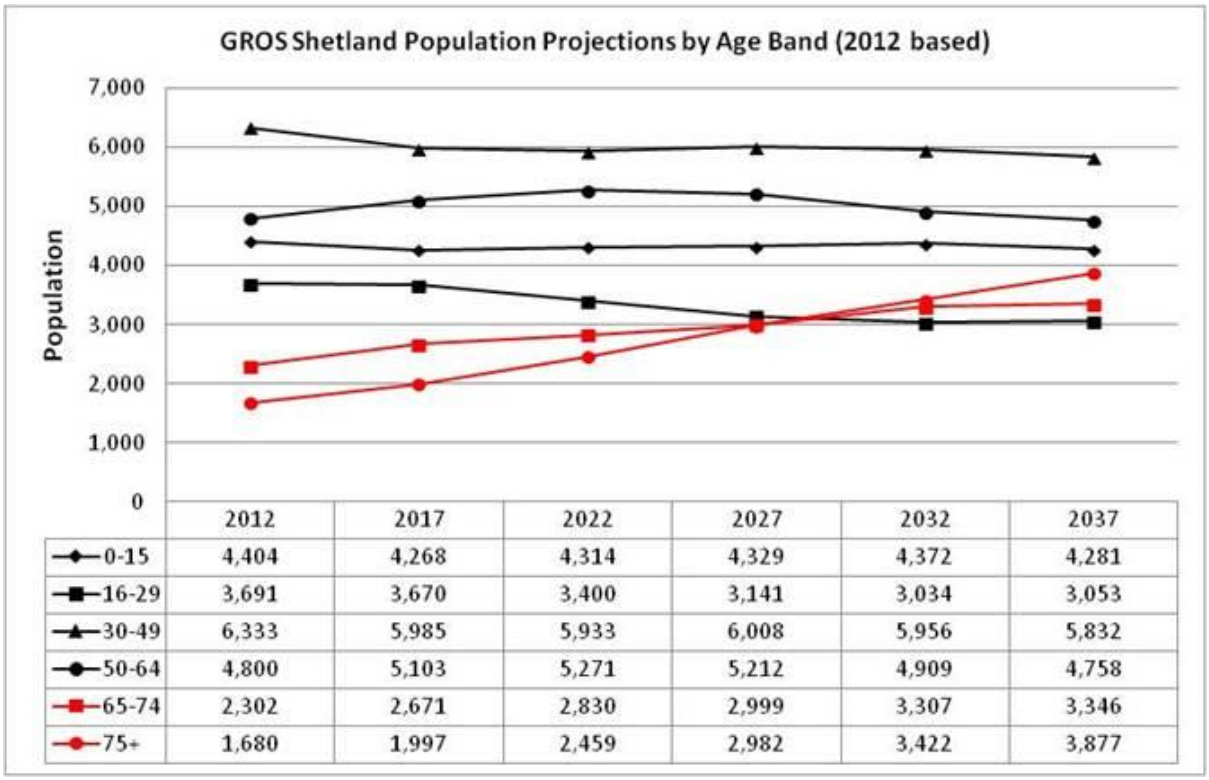
Population projections

Looking at current or recent figures for population size can help in understanding what health and social care needs are now for the current population, and would be useful for future service planning if the population profile remained static. However, we know that the 'shape' of the population has changed over time, with an increasingly aging population because people are generally living longer. It is predicted that this trend will continue. Therefore we can use 'population projections'

to understand what the population is likely to look like in the future, and therefore help to understand what the future needs are likely to be.

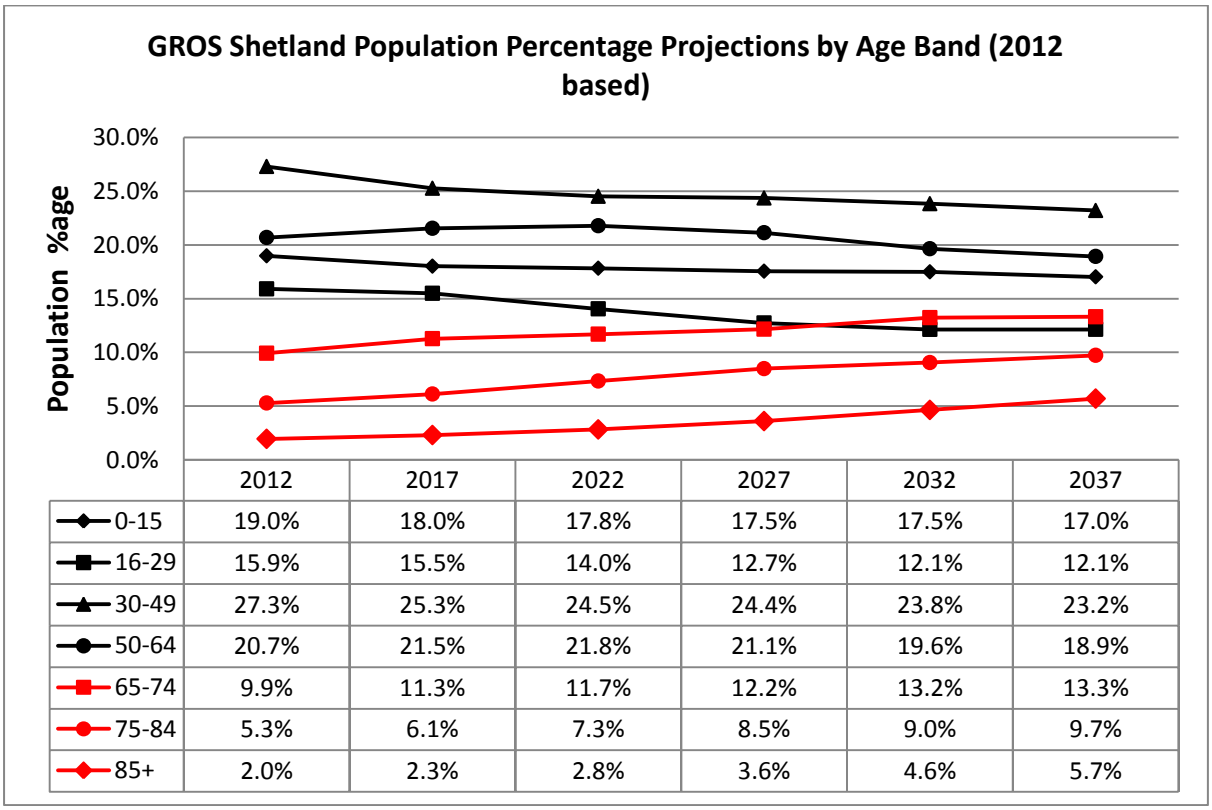
However, projections should be interpreted cautiously because they are estimated figures based on a set of underlying assumptions. They use past trends to predict what will happen in the future. There are four basic factors that dictate population size: births, deaths, immigration into the population and emigration out of the population. So population projections take into account the predicted numbers of births, deaths, immigrants and emigrants in a population based on past experience. They do not take into account the impact of significant behavioural or policy changes in the population or any unexpected variations in the birth, death, immigration and emigration rates. This caution is particularly required where the population is already small, such as in Shetland.

It can be seen, that for the over 65 age group, there is a predicted increase in both the total number of people and the percentage of the overall population. For the group aged 65 to 74, it is predicted that there will be an increase from 2302 people in 2012 to 3346 in 2037. And for the 75 and over age group, an increase from 1680 to 3877, more than double. Overall that is an increase of just over 3200 people aged 65 and over in the next 20 years, an 80% increase.

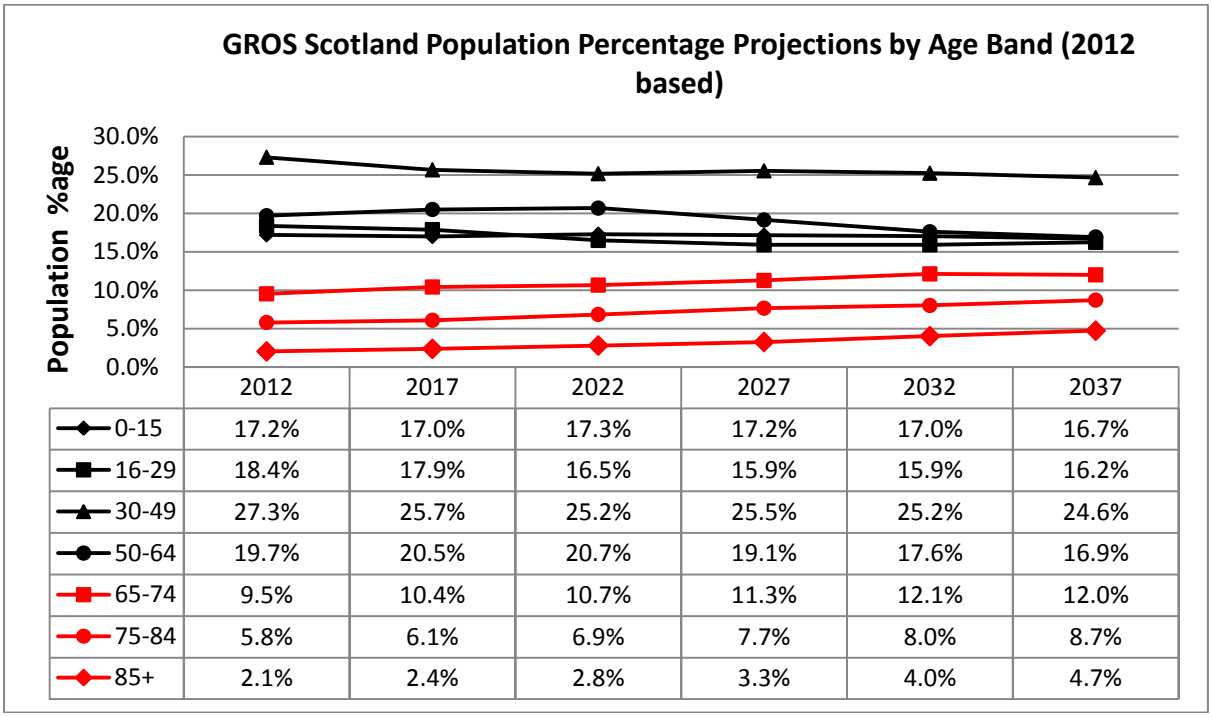


	2012	2017	2022	2027	2032	2037
0-15	4,404	4,268	4,314	4,329	4,372	4,281
16-29	3,691	3,670	3,400	3,141	3,034	3,053
30-49	6,333	5,985	5,933	6,008	5,956	5,832
50-64	4,800	5,103	5,271	5,212	4,909	4,758
65-74	2,302	2,671	2,830	2,999	3,307	3,346
75+	1,680	1,997	2,459	2,982	3,422	3,877

The charts below show that as well an absolute increase in the number of older people, they will also make up a bigger percentage of the Shetland population. The percentage of older people in Shetland compared to the rest of Scotland will also increase.



	2012	2017	2022	2027	2032	2037
0-15	19.0%	18.0%	17.8%	17.5%	17.5%	17.0%
16-29	15.9%	15.5%	14.0%	12.7%	12.1%	12.1%
30-49	27.3%	25.3%	24.5%	24.4%	23.8%	23.2%
50-64	20.7%	21.5%	21.8%	21.1%	19.6%	18.9%
65-74	9.9%	11.3%	11.7%	12.2%	13.2%	13.3%
75-84	5.3%	6.1%	7.3%	8.5%	9.0%	9.7%
85+	2.0%	2.3%	2.8%	3.6%	4.6%	5.7%



	2012	2017	2022	2027	2032	2037
0-15	17.2%	17.0%	17.3%	17.2%	17.0%	16.7%
16-29	18.4%	17.9%	16.5%	15.9%	15.9%	16.2%
30-49	27.3%	25.7%	25.2%	25.5%	25.2%	24.6%
50-64	19.7%	20.5%	20.7%	19.1%	17.6%	16.9%
65-74	9.5%	10.4%	10.7%	11.3%	12.1%	12.0%
75-84	5.8%	6.1%	6.9%	7.7%	8.0%	8.7%
85+	2.1%	2.4%	2.8%	3.3%	4.0%	4.7%

Gender

The number of men and women aged 65 to 74 is similar, but there are more women than men across the older age groups, which is the same pattern across Scotland. However, it is predicted that over the next 20 years, the number of older men (aged 70+) is projected to increase more rapidly than the number of older women, especially among the very oldest groups.

The difference in the number of men and women is significant because they may have different health needs (for example breast and gynaecological cancers which affect women and become more common with age). And their care and support needs may also be different: for example a preference for same sex care workers.

Gender breakdown of the older age groups in Shetland

	65 - 74	75-84	85 -94	95 and over
Male	1051	508	139	7
Female	1092	670	181	29

Source: *Scotland's Census 2011 website www.scotlandscensus.gov.uk*

Geographical variation in population ageing

There are differences in the age profile of different communities across Shetland. This can be demonstrated using the practice population data. The table below shows that four practices, including the largest in Lerwick, have an over 65 population of around 18%. Brae and Scalloway have younger populations; there are known to be more younger families and a larger working age population in Brae and Scalloway. The three island practices of Unst, Yell and Whalsay along with Walls on the Westside have the highest percentage populations of older people: around a quarter, and nearly 30% in Unst. This clearly has implications for service provision in these areas.

Shetland GP practice populations by age group (April 2014)

Practice	Total	Age under 65	65-74	75-84	85 and over	% aged over 65
Lerwick	9005	7383	930	497	195	18.0%
Scalloway	3296	2815	275	144	62	14.6%
Levenwick	2685	2188	296	156	45	18.5%
Brae	2486	2107	248	97	34	15.2%
Whalsay	1144	881	149	84	30	22.9%
Bixter	1143	935	123	68	17	18.2%
Yell	1073	810	151	91	21	24.5%
Hillswick	754	614	80	37	23	18.6%
Walls	722	561	94	41	26	22.3%
Unst	578	408	108	41	21	29.4%

Source : Local GP data

Ethnicity

According to the 2011 census; 23,167 people living in Shetland, 22,813 (98.4%) described themselves as white. Of the 3777 people aged 65 and over, 3762 (99.6%) described themselves as white as did every person aged 75 and over. This means that at the present time, there are very few older people within minority ethnic groups. However, as the under 65s grow older, then the percentage of older people within minority ethnic groups will increase (albeit still small numbers in Shetland). We may also need to look at language and communication needs of the older white, non-British population – there are currently 64 people in this category over the age of 65.

	0-15	16-24	25-64	65 and older	Total
White British	4262	2316	11691	3716	21985
White non-British	119	80	583	46	828
Asian	52	21	153	8	234
African	2	8	10	3	23
Caribbean /black	0	3	4	1	8
Other Ethnic group	2	3	10	2	17
Mixed / multiple ethnic group	34	9	28	1	72
	4471	2440	12479	3777	23167

Source: *Scotland's Census 2011 website www.scotlandscensus.gov.uk*

6. Current Service Provision

Dementia Services Partnership

The Dementia Services Partnership (DSP) consists of a range of professionals working within health, social care and the third sector. This partnership was developed to ensure a collaborative holistic approach to the treatment, care and support of individuals with a diagnosis of dementia and their carers. The group meets fortnightly and provides a Single Point of Referral for all people with a diagnosis of dementia. The aim is to ensure that people are in receipt of appropriate services and that they continue to be followed up as necessary.
The DSP is designed to meet the needs of clients of any age who have a diagnosis of dementia as well as supporting their carers.

The vision of the Dementia Services Partnership is to provide an integrated service to support individuals living with dementia, their families and other carers. We aim to do this by:

- Supporting people to remain independent.

- Providing a person-centred service to individuals with a diagnosis of dementia and their carers.
- Promoting positive risk taking.
- Offering ongoing and crisis support to avoid hospital admissions.
- Playing an active role in hospital discharge to support carers and other professionals.
- Ensuring individual's health and social care needs are being met.
- Encouraging each person living with dementia to participate in care planning and to play an active role in their own treatment.
- Encouraging and assisting individuals to remain part of the local community.
- Working alongside carers to develop a holistic and flexible treatment plan.
- Providing health promotion and education.
- Promoting the practice of evidence-based care.
- Offering people living with dementia a single point of access to a range of specialist services.

Dementia Assessment Service

The Dementia Assessment Service (DAS) has been developed as a partnership initiative between NHS Shetland and Alzheimer Scotland. The service is led by the Dementia Service Manager who also fulfils the function of the Alzheimer Scotland Dementia Nurse Consultant and has links with the National Nurse and AHP Consultant Group. The nurse led DAS is delivered by the following staff:

- Dementia Services Manager (DSM)
- Dementia Clinical Nurse Specialist (DCNS) (Alzheimer Scotland funded)
- Consultant Psychiatrist (weekly video conference service)

Referrals to the service for those suspected of having a dementia are received from GPs, the Community Mental Health Team and Gilbert Bain Hospital Consultants. The following services are provided:

1. Specialist dementia assessment is delivered with the support of two sessions weekly of Old Age Psychiatry input from NHS Grampian. Referrals of people suspected of having dementia are discussed with the psychiatrist, at a weekly clinic via videoconference. They are then assessed, usually in their own home, by one of the nurses. The referral is discussed in the weekly VC clinic and, where appropriate, a diagnosis can be made. If further assessment is required from the psychiatrist the person can be seen by them via videoconference.

2. Support to staff in the Gilbert Bain Hospital and Care Centres to assist in the assessment and management of people with dementia

3. Support to the Dementia Services Partnership (DSP). All people who are diagnosed with dementia are discussed in the DSP meeting ensuring that any support needs can be addressed.

4. Supporting the Alzheimer Scotland Dementia Advisor and Activities Coordinator (DAAC). In partnership with NHS and SIC staff the DAAC provides access to a wide range of specialist support, advice, activities and raises awareness of dementia issues.

5. Support to the Directorate's learning disabilities services as part of an ongoing commitment to provide care and support to people with learning disabilities who subsequently develop a dementia (NB some learning disability diagnoses are linked to early on-set dementia).

Community Dementia Support Service

This is provided by:

- Service Manager
- Senior Social Care Workers
- Social Care Workers

The service is based at Annsbrae House and delivers a range of community support services for people who have a new diagnosis of dementia and/or complex dementia needs and is proactive in seeking and promoting the views of all those who access the service.

Referrals to the service are primarily received through the Dementia Services Partnership. The services provided include:

1. Supported Accommodation
2. Outreach service
3. Post Diagnostic Link Workers
4. Short break/respite service
5. Duty Service
6. On call Service

There is one shared supported tenancy at King Erik House for up to three people living with complex dementia conditions who would otherwise require residential care.

The Outreach Service provides support to people with complex dementia in their own homes. This service is tailored to individual needs supporting people to live as

independently as possible. Support may be provided with a variety of life and social skills, such as cooking, shopping, budgeting and personal care.

Everyone who is newly diagnosed with dementia is offered the support of a Post Diagnostic Link Worker (PDLW) who will help support the person with dementia and their family for the first year following diagnosis.

A short break/respite service is available to provide family or carers' breaks for those who support individuals living in their own homes with complex dementia.

Annsbrae House, Duty Service offers access to advice or support on any aspect of social care for those with dementia needs and their family. This is provided by telephone, face-to-face, and where feasible, outreach contact.

Where physical frailty is the main presenting problem, a person living with dementia is more likely to receive care from one of the care services in their locality (e.g. Edward Thomason House, Overtonlea etc).

Alzheimer Scotland Services

Alzheimer Scotland provides a Dementia Advisor and Activities Coordinator. They are based in a Resource Centre where people can meet in private or as a group to get advice and support. The resource centre also has a range of information available for people to access.

They provide support to people living with dementia and carers on any aspects of dementia and coping with it.

They also raise awareness about dementia through talks, media involvement and training in order to help make the community more dementia friendly.

They also provide a range of activities which include,

- Four dementia cafes; Lerwick, Levenwick, Brae and Walls
- Art group
- Music and singing group

- Dancing
- Knitting group
- Sports group
- Reminiscence group
- Carers support group
- Sons and daughters support group

Housing and Telecare Services

SIC Housing has made many adaptations to social housing in order to make the person's house more dementia friendly. This is done in conjunction with the Telecare Manager who can advise on a range of assistive technology that can be used to help maintain a person living with dementia safely in their own home for as long as possible.

Simple devices such as door sensors to alert carers if someone goes out their house at unusual times of the day and doesn't return within a given time has proven to be very helpful. These can be linked to a community alarm which will alert a named carer or can alert someone else in the house.

We also have been using monitoring devices such as the Buddi tracking device which can help to identify where someone is if they go out and can be used to communicate with the person if required.

A very successful system that has provided reassurance for carers where the person with dementia lives alone is the Just Checking system. This provides movement sensors in different parts of the house that relays real time information via the internet that can be monitored online by anyone with permission to access it. This allows family to be able to check at any time where the person is in the house and can monitor their movements over a longer period to pick up any issues regarding night time activity if it is suspected the person is active during the night.

Non-Specialist Services

Most people living with dementia and their carers can also be supported by a wide range of non-specialist services and often only get support from the specialist services at the point of diagnosis, for the first year following diagnosis and later in the illness when their care needs may become more complex.

Mostly their support will come from their GP, Practice and Community Nurses, Care at Home staff, Housing support Workers as well as other mainstream services that would be accessed by the general public.

7. Preparation of this Strategy

The second national strategy and Shetland's first Dementia Strategy has been produced on the basis of participation and dialogue at a national and local level.

It was agreed that as an Older Person's Strategy was being developed alongside this Dementia Strategy that there would be a degree of duplication and as such this strategy should be read in conjunction with the Older People's one for additional generic information.

8. Progress and Achievements

The Scottish Government made dementia a national priority in 2007, set a national target on improving diagnosis rates in 2008 and published an initial 3-year National Dementia Strategy in 2010, underpinned by a rights-based approach to care, treatment and support. The work over the last three years has been based on strong collaboration in developing and implementing the strategy in a coordinated way.

In 2011 the Scottish Government published the Standards of Care for Dementia in Scotland and the Promoting Excellence framework, which supports the health and social services workforce to meet the standards.

In 2009, NHS Shetland developed the Dementia Assessment Service, outlined in the Current Service Provision section above in order to improve the quality of assessment and increase the number of people with a diagnosis. The 3-year diagnosis target was achieved locally and nationally and the Alzheimer Society's second annual dementia map – published in January 2013 – showed that at March 2012, in Scotland around 64% of those with dementia were being diagnosed. This was significantly higher than England and Wales and shows what can be achieved by clinicians and statutory and voluntary organisations working together.

From April 2013, a further target was introduced which guarantees that everyone newly diagnosed with dementia will be entitled to at least a year's worth of post-diagnostic support, coordinated by a named Link Worker. Locally we took the decision to develop Social Care Staff within the Community Dementia Support Service to fulfil the role of the Link Worker.

Since 2011 the Chief Nursing Officer has led an improvement programme with NHS Boards on the care of older people in hospitals. Alzheimer Scotland Dementia Nurse Consultants have been appointed to Boards across Scotland and 300 Dementia Champions were in place by March 2013.

NHS Shetland took the decision to develop the role of the Dementia Services Nurse Manager to fulfil the Dementia Nurse Consultant role and he participates in the National Dementia Nurse Consultant Group. This post is supported by the Alzheimer Scotland funded post of Dementia Clinical Nurse Specialist who takes the lead in providing support to the Gilbert Bain Hospital as well as all Care Centres in Shetland. Currently there are 7 Dementia Champions in place locally with 1 further one about to be trained.

Locally we have seen several developments in care for people and their families developed since 2010.

- We achieved our three year diagnosis target and have maintained it, continuing to increase the number of people being diagnosed with dementia.
- We are offering support following diagnosis for a year from a named person

- We are developing new models of housing support as well as adapting people's own homes to be more dementia friendly
- We are providing support for hospital and care centre staff to better support people with dementia and manage behaviour that may challenge them without resorting to pharmacological methods where possible
- We are supporting earlier, more appropriate discharge from hospital for people living with dementia
- We are developing Anticipatory Care Plans to better support a person living with dementia if they have to go into hospital or care
- We have established a local Alzheimer Scotland presence in Shetland with the development of a Dementia Advisor, Activities Coordinator, Resource Centre and a local branch of Alzheimer Scotland along with the associated support and activities they provide

9. Challenges

Over the next period of time there are three main challenges that we must address.

First, we must offer care and support to people living with dementia and their families and carers in a way which promotes wellbeing and quality of life, protects their rights and respects their humanity. This is a moral imperative and it is unacceptable that too often the experience of people does not meet this standard.

Second, we must continue to improve services and support from when someone presents for diagnosis, and throughout the course of the illness, including the support needs of carers. This support must be truly person centred, and should understand care and support from their perspective, not the perspective of service managers or clinicians.

Third, we must recognise that with increased life expectancy the challenge of providing high quality care and support to people living with dementia and their carers will increase over time. We must embrace the process of redesign and

transformation of services to ensure that we deliver services effectively and efficiently.

Locally, it has been acknowledged that there are particular challenges in delivering aspects of the National Strategy in the context of a remote and rural island group. Some of these challenges are as follows.

1. There is a need to embed dementia care within non-specialist health & social care providers whilst acknowledging that the same group of staff is required to work across many diverse areas of knowledge/skill (e.g. mental health, learning disability, palliative care, all long term conditions).

2. We must ensure co-ordination of service delivery across all health & social care providers.

   In Shetland current community capacity supporting people living with dementia is complex and often hidden.

3. Diseconomies of scale when providing facilities that are appropriate for managing behaviour that others experience as very challenging. This behaviour in people living with dementia is usually temporary and exacerbated by inexperienced responses from staff and families and poor design of facilities and care processes.

   Transferring the person to mainland Scotland will not prevent reoccurrence of the behaviour when the person is returned home after stabilisation.

10. Policy Context

The work on dementia is one strand of the wider work that Scottish Government is taking forward to transform and improve health and social care services. Other key strands of that work include:

Integration of Health and Social Care: the Scottish Government has enacted legislation to allow for the local integration of adult and older people's health and social care services in Scotland; the need to improve the response to dementia is one of the key policy drivers for this work and health boards, local authorities and the voluntary sector are involved in this process.

Reshaping Care for Older People/Change Fund: the Scottish Government is investing £300 million to facilitate changes in the way services are designed and care is delivered, including services for people living with dementia.

Health and Social Care Partnerships will set out their intentions for the future delivery of care for people living with dementia and their carers in their respective planning documents and have the ability to develop plans together through joint commissioning processes.

Carers Strategies: Caring Together: The Carers Strategy for Scotland 2010-15, which is underpinned by £98 million of investment between 2008 and 2015, recognises that carers must be seen as equal partners in the delivery of care as their support enables people living with dementia to live at home and in their own communities safely, independently and with dignity.

Self-directed Support: self-directed support is a major reform to the way in which social care and some healthcare services are delivered and gives greater choice and control to those who receive support; the Alzheimer Scotland pilot on self-directed support in Ayrshire showed that self-directed support offers benefits to people living with dementia.

Housing: older people, including those living with dementia, consistently tell us that they want to live in their own homes for as long as possible, rather than in hospitals and care homes. Age, Home and Community: A Strategy for Housing for Scotland's Older People: 2012 – 2021 emphasises the role of housing and housing-related

support in ‘shifting the balance of care’ towards independent living in the community and reducing the use of institutional care settings.

Palliative Care: Living and Dying Well; a National Action Plan for Palliative and End of Life Care (2008) and Living and Dying Well: Building on Progress. Work (2011) promote the provision of palliative and end of life care to all, regardless of diagnosis, and is consistent with, and highly supportive of, improvements in care for people living with dementia and their families.

11. Key Outcomes for Shetland

The key outcomes from this Strategy, which emerged from the National Dementia Dialogue as priorities, and were reflected in our local consultation and engagement processes, were:

- more people living with dementia living a good quality life at home for longer.

- dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma.

- timely, accurate diagnosis of dementia.

- better post-diagnostic support for people living with dementia and their families.

- more people living with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness.

- better respect and promotion of rights in all settings, together with improved compliance with the legal requirements in respect of treatment.

- people living with dementia in hospitals or other institutional settings always being treated with dignity and respect.

A local Implementation Action Plan will be developed in partnership with local and national partners. The plan will be subject to regular monitoring and review.

12. Local Priority Actions

This Strategy will identify our local priorities that we will develop in order to meet the 17 National Commitments that the Scottish Government has made in order to achieve the outcomes listed above.

These priorities are as follows:

- ***Further develop the Dementia Assessment Service***

People can be reluctant to go to the doctor when they are worried that they may have dementia because the benefits of diagnosis for them are not clear. There are challenges around diagnosis and we recognise that accurate diagnosis in the earlier stage of the illness can be difficult. But we also know that appropriate support in the early stages can have a very significant impact on the degree to which someone is able to manage the condition over time and live independently.

Effective diagnosis – including how it is imparted and how people are supported immediately after diagnosis – can mean that the traumatic aspects of receiving a diagnosis can be counterbalanced. Timely diagnosis enables people to plan ahead

while they still have capacity to do so and means they can get early and effective access to drug and other interventions which can sustain their cognition, mental wellbeing and quality of life. Current medications available for some forms of dementia can help to slow the symptoms and sometimes improve symptoms in the short term, although they do not treat the underlying disease; the main form of treatment is human intervention. Too often in the past diagnosis has been late, well after the condition is having a significant impact on daily life, causing confusion and distress to the individual and family around future planning.

The current nurse led service was developed on the islands supported by input remotely through video link from a consultant in old age psychiatry based in Royal Cornhill Hospital in Aberdeen. At present this service is able to provide assessment of people suspected of having dementia and if confirmed deliver and discuss diagnosis with the person and their family. The nurses can then review those prescribed medication for up to 6 months and then hand the care back to the GP to continue to review. Those not on medications are passed back to the GP for follow up at point of diagnosis.

Although input from a Post Diagnostic Link Worker is offered at point of diagnosis, not everyone wants this and so the uptake rate at present is around 60%.

There are a number of people living with dementia that would benefit from some further post diagnostic nursing input, which at present, due to service capacity, is difficult to meet.

It has been identified that building additional nursing capacity within this team is essential to meet their needs.

Meeting this priority would contribute to National Commitments 1, 2 & 3.

- ***Embed the role of Post Diagnostic Link Worker within all Care at Home Teams.***

Supporting people living with dementia and their families and carers (commonly known as post-diagnostic support) was one of the key change areas in the first Dementia Strategy. Better post-diagnostic support helps people to adjust to the diagnosis and its likely impact – both practical and emotional – and help them plan for future care, including through advanced care planning for the delivery of preferred end of life care. It can help services work better with people's "natural" family supports during this important stage of the illness. It can contribute to people with dementia living a better quality of life and living as independently as possible and as part of their community as for as long as possible.

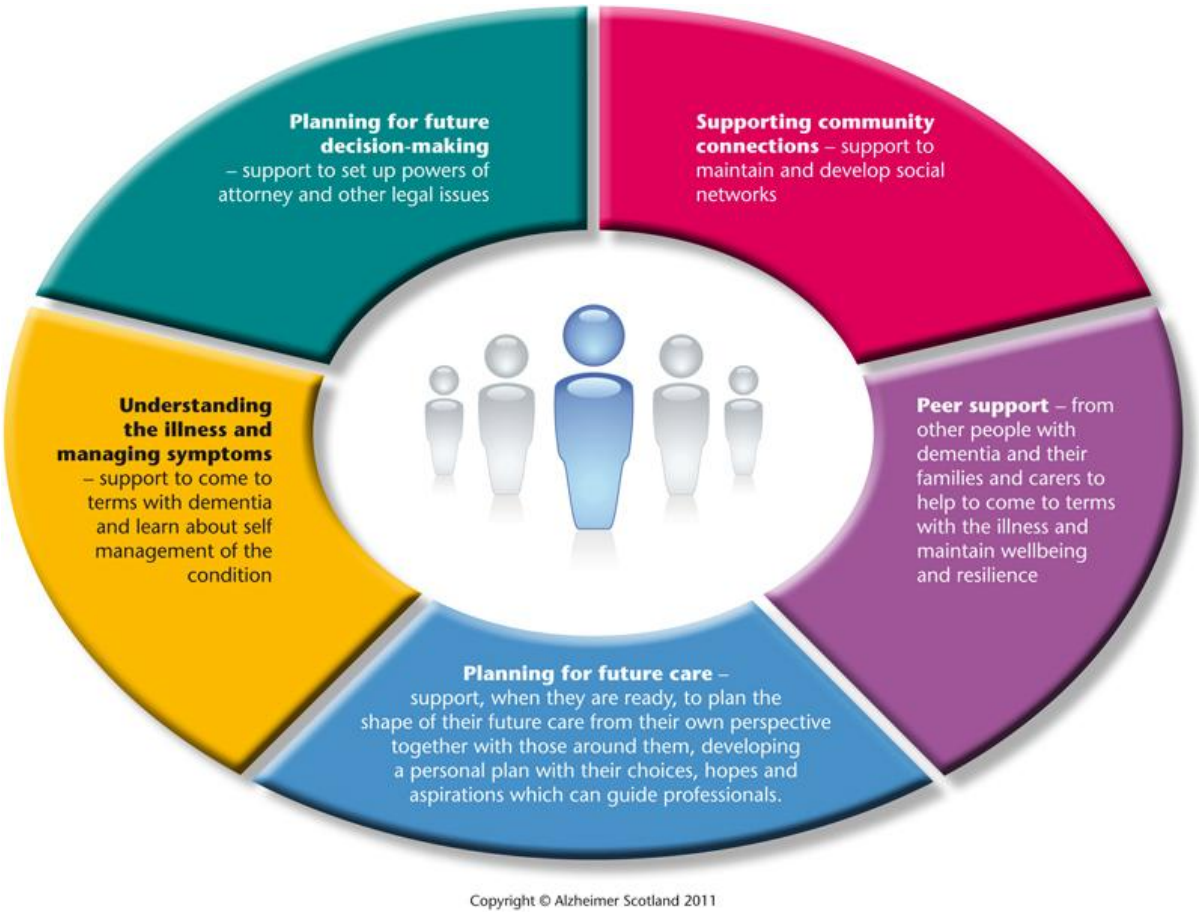
The Scottish Government HEAT target states that,

'To deliver expected rates of dementia diagnosis and by 2015/16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a Link Worker, including the building of a person-centred support plan'

The post-diagnostic target is designed to give people time and space to access services and receive high quality support in a way that meets their individual needs over the course of a year. It recognises that a diagnosis of dementia can have a huge impact on individuals, carers and families and that coming to terms with a diagnosis and what it will mean for an individual and their loved ones can take time and expert support.

While the target is primarily designed to support people in the earlier stages of the illness, it applies equally to everyone diagnosed from 1 April 2013 and in every care setting, including care homes and hospitals.

The post-diagnostic HEAT target is informed by Alzheimer Scotland's "5 Pillars" model of post-diagnostic support shown below



The 5 Pillars highlight key areas of activity for post-diagnostic support and each person's needs are assessed against each of the 5 pillars. The Link Worker operates at a minimum of 'Enhanced' level on the *Promoting Excellence* framework and has had specific training in post-diagnostic support and in the 5 Pillars model before undertaking this role.

The Link Worker works flexibly with each person living with dementia, and with the person's family and natural support networks, introducing each of the 5 pillars in a personalised and holistic way and at the appropriate time for the person.

Recognising the key roles of carers and families is essential in helping design and implement a person-centred support plan.

Although everyone diagnosed from 1 April 2013 will be allocated a Link Worker, some individuals may not want support right away, or may decide they do not want support further down the line before the end of the 12 months. There may be some people who do not want any support at all during the 12 month period. The Link

Worker keeps in regular contact with every individual on their caseload (as appropriate) and the post-diagnostic support is available for the individual to access in a manner of their choosing and which suits their individual needs and circumstances.

At the end of the 12 month period, each individual's support needs are assessed. At this point most people in the earlier stages of the illness are assessed as being able to move to self-management, drawing on support when needed; other people need more time-limited support while others with complex needs may require longer term support and treatment.

Locally the Post Diagnostic Link Worker is one of the Social Care Workers within the Community Dementia Support Service based in Lerwick. These workers have received additional training to take them to Enhanced Level within the Promoting Excellence framework but as they are based in Lerwick it means that they are supporting people living with dementia in all parts of Shetland which requires them to travel fairly lengthy distances with associated travelling time and costs.

In order to address this it is essential that this role is developed within existing locality care teams.

Meeting this priority would contribute to National Commitments 2 & 8.

- ***Develop Occupational Therapy (OT) support for people with dementia***

It is recognised that the role of the OT can be crucial in supporting active non-pharmacological interventions for people living with dementia as well as contributing to maintaining the independence of the person living with dementia to enable them to live at home for as long as possible.

People with dementia can benefit from timely health and social care supports, to enable them to live a good quality life at home for as long as possible as the illness progresses. Historically, interventions have tended to occur at a stage when the person with dementia's physical and mental capability and resilience has

deteriorated. In line with key principles underlying the integration of health and social care, we need to move more towards a system of care which maximises and promotes resilience and independence and which supports and promotes the capabilities of the person living with dementia at home during the moderate to severe stages of the illness, as they move from self-managing the illness with support to needing more intensive support.

The Standards of Care for Dementia recognise the importance of people living with dementia being enabled not only to stay at home and in their community. They should also be, as much as possible, visible, connected and active participants in their local communities – including in social events, the arts, and religious and community groups. Nurturing and supporting dementia-aware and dementia-friendly local communities is important in creating and sustaining a society where people living with dementia and their families and carers feel included and at the heart of the community.

While the post-diagnostic commitment for everyone diagnosed on or after 1 April 2013 will also help drive wider changes in dementia services, we know that there are a large number of people who have been living with dementia who are at the stage of the illness when they require more intensive support.

Alzheimer Scotland's policy paper *Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support* proposes an integrated care model to address these issues.

This 8 Pillar model focuses specifically on that stage of the illness where more intensive community services are needed to enable people to stay living well and as independently as possible at home for as long as possible. The model is based on a coordinated, holistic approach which also aims to provide continuity of care in the form of that key contact point for people living with dementia and their carers.

The 8 Pillars Model is shown below and the pillars are:

Pillar 1: The Dementia Practice Coordinator (to coordinate the 8 Pillars)

Pillar 2: Therapeutic interventions to tackle the symptoms of the illness

Pillar 3: General health care and treatment

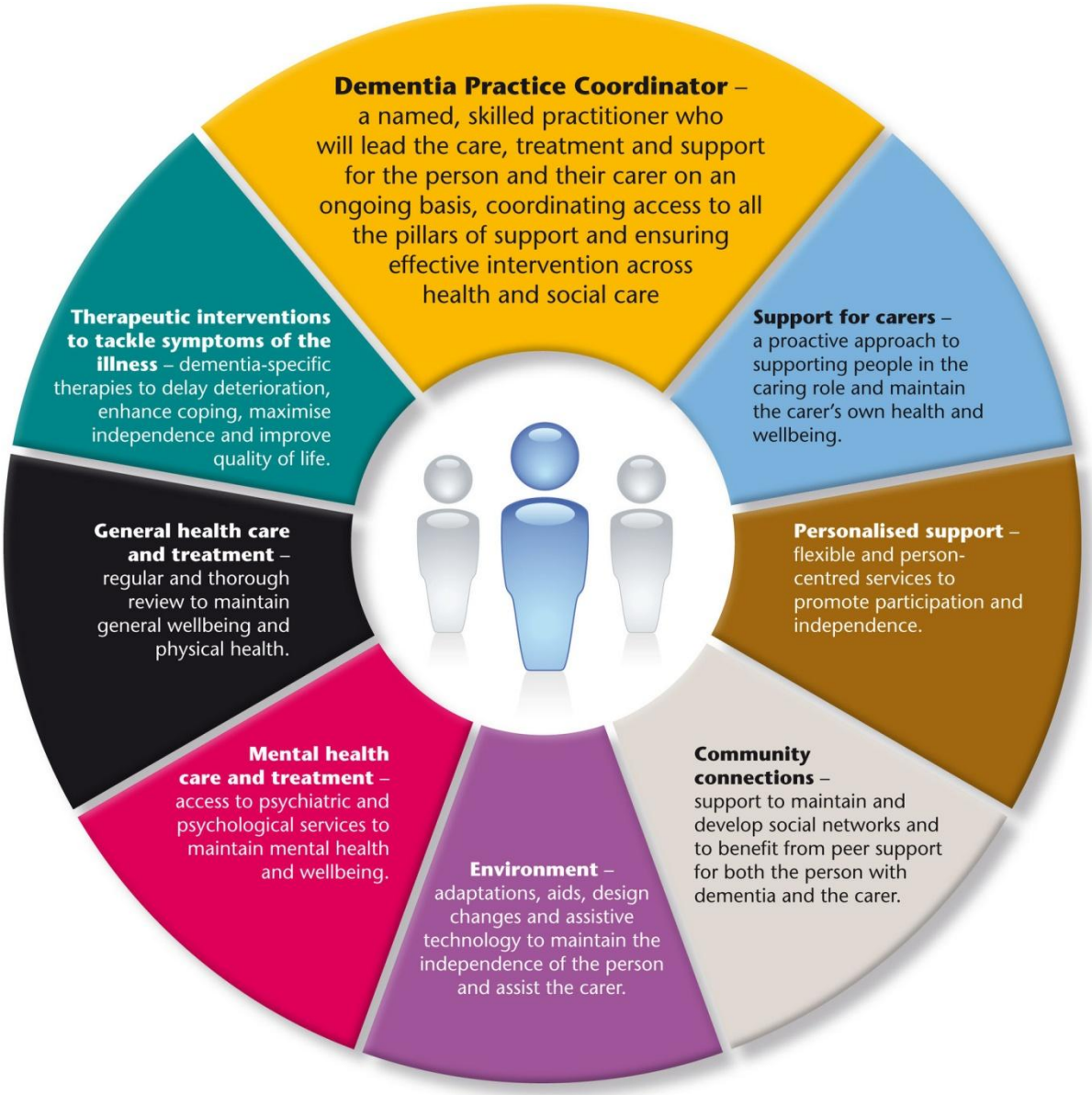
Pillar 4: Mental health care and treatment

Pillar 5: Personalised support

Pillar 6: Support for carers

Pillar 7: Environment

Pillar 8: Community connections



National testing and evaluation of a range of approaches based on the 8 Pillars Model is in progress in Demonstrator Sites across Scotland and the outcomes of this pilot will inform Shetland's service development.

It is likely that it will be essential to develop the role of Dementia Practice Coordinator locally and it would be sensible to consider this being an OT.

Meeting this priority would contribute to National Commitments 3, 4 12 & 16.

- ***Develop housing design support and interventions***

As people age, their housing needs change and some people, such as those living with dementia and mobility problems, will also need specialised housing-related support services. If these needs are not met, it may be more difficult for people to remain in their own homes.

A familiar home environment is particularly important to people living with dementia. Most people living with dementia live in their own homes in the community but in homes that were not built to today's standards of accessibility. Well-designed housing is particularly important to people living with dementia and can extend the amount of time that they are able to remain living at home, by reducing accidents and delaying the need for residential care.

Since most people living with dementia live in ordinary housing, the housing services that support them to remain in this environment are key, with housing adaptations, handypersons, small repairs and housing support services of particular importance. These services are generally provided by social landlords (local authorities and housing associations) for their tenants, and by Care and Repair services for people living in private sector housing.

The frontline housing officers and technical staff, who deliver these housing-related services, may often be working with people who have dementia, most likely in the early (sometimes undiagnosed) stages. Many staff would benefit from an increased understanding of what dementia is, how to identify the signs and what to do next to help support people living with dementia.

We will work closely with SIC Housing and Hjatland Housing Association to ensure that by becoming more understanding of the needs of people living with dementia they will consider these needs when making adaptations to existing housing as well as when designing new build.

Meeting this priority would contribute to National Commitments 5 & 8.

- ***Further trial and develop assistive technology***

Shetland has a good track record in the use of innovative new technologies and is committed to implementing telehealth and telecare solutions where these are proven to be of benefit. We will promote knowledge and awareness of these resources within the local community.

We have an excellent resource in the Independent Living Centre where there is a wide range of resources available for people to access and consider what would work for them.

Through the Northern Periphery Partnership we have participated in the RemoDem project in partnership with Norway, Sweden, Faroe Islands, Western Isles and Greenland to identify and test innovative ICT solutions and models of care to support older people living with dementia in rural areas to access professional health and care services based in larger towns and cities without having to travel or leave their homes, to maintain social contact with friends and family who may not live nearby, and to continue to feel and to be a part of the communities in which they live.

From this we have been working closely with colleagues in the Western Isles in a joint trial of innovative new technology to assist people to remain independent in their own homes.

A second project with the original RemoDem partners has been approved to further develop these models of care which will begin in 2015 and run for three years.

We will ensure that an awareness of what is available in the way of assistive technology that can keep people independent is developed in order that other alternatives to residential care are considered for older people in general and in particular, those living with dementia.

Meeting this priority would contribute to National Commitments 3, 4, 5, 15 & 16.

- ***Develop local expertise in rights based care***

In the first Dementia Strategy, the Standards of Care for Dementia in Scotland were developed**,** based on the Charter of Rights developed by the Parliamentary Cross Party Group on Alzheimer's disease**.** The dementia standards are based on six overarching statements of individual rights:

- I have the right to a diagnosis
- I have the right to be regarded as a unique individual and to be treated with dignity and respect
- I have the right to access a range of treatment and supports
- I have the right to be as independent as possible and be included in my community
- I have the right to have carers who are well supported and educated about dementia
- I have the right to end of life care that respects my wishes.

The standards are designed to inform care providers of their responsibilities and to help them self-audit services and to empower people living with dementia and their carers. A guide to the standards is available from Alzheimer Scotland. In conjunction with *Promoting Excellence*, they form a crucial part of work to improve knowledge and practice. Rights-based training has been developed for care home staff.

We will take more action specifically in relation to dignity and respect, including attention to human rights and the principles and requirements of mental health and incapacity legislation, including:-

- earlier identification of people with palliative care needs, to promote advance care planning, to facilitate the sharing of key information across settings through the development and roll out of the Electronic Palliative Care Summary

- promoting best practice in advance care planning based on the wishes of the individual and taking account of carers' views in accordance with the principles of incapacity legislation

- promoting best practice in assessing capacity and providing care and treatment in line with the law.

- in particular, promoting best practice on Do Not Attempt Cardiopulmonary Resuscitation decision-making and communication and supporting, with greater awareness of proper procedures for making decisions for people living with dementia who lack capacity.

- ensure that environments, especially in hospital, are sufficiently enabling for people living with dementia and that individual care planning based on the individual's life story is in place. The introduction of 'Getting to Know Me' has allowed for increased input from carers and people with dementia into their care. The introduction of person centred care will further this aim.

We have identified individuals from CMHT/Health/MHO who will be developed to become local "experts" and be available to provide advice and support to those required to carry out capacity assessments.

Meeting this priority would contribute to National Commitments 6, 7, 8, 10, 12 & 14.

❖ ***Continue to develop workforce skills and competencies***

Promoting Excellence: *a framework for all staff working with people with dementia, their families and carers* was launched in June 2011, together with the Standards of Care for Dementia in Scotland. Between 2011 and 13, NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) have undertaken a programme of work to support workforce development against the *Promoting Excellence* Framework, including the development of a number of educational

resources, the roll out of a number training programmes, and establishing infrastructures to ensure spread and sustainability of this work.

We have been developing the workforce locally in line with this and some aspects of *Promoting Excellence* has become embedded in both the SIC and NHS Shetland's staff development. Details of local education and training will be identified and recorded to ensure we maintain and develop the knowledge and skills of people working with those who are living with dementia.

We are also currently in negotiations with NES to further develop our workforce to better deliver post diagnostic support by delivering the *Promoting excellence in supporting people through a diagnosis of dementia* training locally.

Training will be delivered through a range of mediums including facilitated teaching, self directed, remotely through video links and online.

We will continue to improve staff skills and knowledge by working with NES and SSSC to take forward a second Promoting Excellence training plan across the period of this Strategy.

Meeting this priority would contribute to National Commitments 2, 8, 9, 10, 11 & 12.

- ***We will contribute to and deliver on the 3-year National Action Plan to improve care in acute general hospitals***

Our objective is to do two things: to make the current system of care in hospital work better for people living with dementia in ensuring better quality of care; and to begin to look at how we remodel the wider system of care, including care in hospital, to address how we best provide acute health care for people living with dementia in a way which keeps them at home wherever possible and which ensures they are discharged from hospital safely and timeously. The wider context for this work is the integration of health and social care.

A **10-Point National Action Plan** has been developed by an expert Dementia Standards in Hospitals Implementation and Monitoring Group (IMG), chaired by the Chief Nursing Officer and including representation from key partners such as Alzheimer Scotland, Healthcare Improvement Scotland, the Mental Welfare Commission, clinicians and healthcare services, to support implementation of the Standards of Care for Dementia in acute care to make sure the current system of hospital care is working and to maximise the impact of the investment over the last 2 years in the capability and capacity of staff operating in those settings. It will support service transformation and support strategic ownership of this agenda at an NHS Board level. The Action Plan will help focus and coordinate a range of initiatives taken forward over the last two years.

The Action Plan's 10 headline areas have been developed over recent months by the National Dementia Standards in Hospitals Implementation and Monitoring group.

The 10 Actions are listed in the table below:

1. Identify a leadership structure within NHS Boards to drive and monitor improvements
2. Develop the workforce against the *Promoting Excellence* KSF
3. Plan and prepare for admission and discharge
4. Develop and embed person-centred assessment and care planning
5. Promote a rights-based and anti-discriminatory culture
6. Develop a safe and therapeutic environment
7. Use evidence-based screening and assessment tools for diagnosis
8. Work as equal partners with families, friends and carers
9. Minimise and respond appropriately to stress and distress
10. Evidence the impact of changes against patient experience and outcomes

We will contribute to a detailed delivery plan with the intention that the 10-point Dementia Care Action Plan is implemented over the next 3 years. The implementation plan will identify key deliverables, action leads and improvement support. It will align and integrate where possible with other existing national programmes and initiatives, such as the Person Centred Health and Care Programme.

We will continue to develop integrated partnership working with all areas in the Gilbert Bain Hospital in order to support staff there in the implementation of the 10 Care Actions. We will further develop the principals of the 10 care actions within Care Centres.

Meeting this priority would contribute to National Commitments 3, 8, 9, 10, 11, 12, 13, 14 & 16.

- ***Develop a model of involving people living with dementia and their carers in deciding on future service direction***

It is recognised that the views of people living with dementia and their carers is essential when developing services for them. At present there are a small number of people living with dementia, carers, ex-carers and interested members of the public who have been actively involved in raising awareness about dementia.

It is important that their voices are heard when it comes to influencing local policies and as such developing a forum to take this forward should be one of our priorities in this strategy.

We will work in partnership with people living with dementia and their carers to develop a Dementia Working Group to contribute to helping to improve services for people living with dementia and to improve attitudes towards people living with dementia.

Meeting this priority would contribute to National Commitments 3, 9, 14 & 16.

- ***Develop Shetland as a Dementia Friendly Community***

It was identified in the Deep Dive Report commissioned from Dementia Services Development Centre at Stirling University that one of the underpinning issues to improving care for people living with dementia is to engage with the public in Shetland to obtain a commitment to becoming Dementia Friendly.

There are many examples of models to follow to develop a dementia friendly community and this will be a long-term commitment as it will involve engaging with a wide range of organizations and individuals. The intention will be to work with a few interested communities initially to pilot approaches and see what works well and what doesn't.

Work has already been carried out in Bigton with the Community Shop having had an audit carried out and action taken to make the shop more dementia friendly. Training was also carried out with staff. It is intended that further work will be undertaken in the community to build on this.

Some work has also been started in the Mossbank area, raising awareness in the local shop and pub which has been well received.

Enquiries have been made in Whalsay and it is likely that this will be the next area to engage with to work toward them becoming the first Dementia Friendly island and this will commence this summer.

We are aware that people with dementia are supported by a wide range of services and individuals and not just within Health and Social Care. The statutory agencies will need to adopt a more inclusive approach to capacity development, helping the public understand that they themselves are as critically important to dementia support as professional services have been.

As such, we need to focus on where financial resources are currently deployed with a view to challenging these deployments in terms of value and impact in supporting a fully functioning dementia-friendly island.

We will continue to build on the work that has been carried out in raising awareness of the importance of Dementia Friendly Communities and enlist further support throughout Shetland to make this a priority for everyone.

Meeting this priority would contribute to National Commitments 1, 5, 8, 9, & 14.

- ***Develop expertise and environment to manage behavior that is challenging within Shetland***

It was identified in the Deep Dive assessment that there were particular challenges for Shetland in managing certain types of more challenging behavior in a small number of individuals. There was a perception that only staff who were more experienced could manage these people and that there were occasions when the person could only be managed in off-island placements. There was also the perception that Shetland did not have an appropriate space where someone who is challenging for others to manage can be maintained safely during such episodes

Such behaviour in people with dementia is usually temporary and can often be a result of inexperienced responses from staff and families and poor design of facilities and care processes. As such it is likely that with the right response from carers and families and the right environment it is possible to minimise such behaviour.

This assessment also indicated that it should be possible to develop a small unit that can be staffed with appropriated experienced staff when required.

We will further develop the necessary skills to manage behaviour that is challenging and will develop an appropriately designed space that can be used, when necessary, to manage the person during this phase.

Meeting this priority would contribute to National Commitments 3, 5, 8, 9, 11, 12, 13, & 14.

13. Summary

This strategy aims to highlight the importance of effective forward planning to address the challenges involved in meeting the needs of the growing number of people who will be diagnosed with dementia.

To meet the challenge we need to work with those professionals who assist people living with dementia and the general public in Shetland to raise awareness of our community responsibilities.

To do this we need to ensure that dementia is kept firmly on the agenda when decisions that affect older people are being made. Dementia also needs to be kept in the public consciousness through ongoing awareness raising within the local media.

By striving towards the goal of creating a Dementia Friendly community we will ensure that people living with dementia and their carers will feel less stigmatised and will be able to live well with their diagnosis, remaining integrated, within their community, and where possible, within their own home for the rest of their lives.

Dementia Strategy Action Plan
2015 - 2018

The following outcomes are taken from the Scottish Government's National Health and Wellbeing Outcomes. The three selected are the ones seen as having the greatest relevance to the work that will be developed from this strategy.

Aims and Objectives

Directorate Plan Aims	Dementia Specific Action
Outcome 2. People, including those with disabilities or long term conditions or who are frail are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	There will be ongoing public awareness raising of the importance of maintaining the independence of people living with dementia to allow them to live safely in their own home wherever possible. There will be further investment in development of models of housing such as those found in King Eric House and Brucehall Terrace. There will be further investment in assistive technology that allows people to live safely and independently in their own homes wherever possible.
Outcome 3. People who use health and social care services have positive experiences of those services, and have their dignity respected.	All people in receipt of care from health and social care services can expect the same quality of service from all health and social care staff regardless of where they live. There will be ongoing training of all health and social care staff in the care of people living with dementia.
Outcome 4. Health and social care services are	People living with dementia and their carers can expect to be able to access a

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Directorate Plan Aims	Dementia Specific Action
centred on helping to maintain or improve the quality of life of people who use those services.	range of services provided in partnership between health, social care and the third sector that will maintain and improve the quality of their lives. We will focus on developing support to improve resilience and quality of life of people living with dementia by enabling them to remain connected to the communities in which they live.

Service Aims/Priorities	Objectives/Actions
Ensuring people can access information on the assessment, care and treatment of dementia	Develop information in electronic and paper version on services and initiatives for people living with dementia and their carers.
Promoting resilience and independence in people living with dementia	Work with communities to identify local supporters to assist in maintaining the involvement of people living with dementia in their communities. Develop methods of improving the quality of life of people living with dementia. Continue to promote the concept of reablement of people living with dementia to maintain and develop skills and abilities that promote their independence.
Early recognition and treatment of dementia	Continue to raise awareness of the importance of seeking early diagnosis of

Service Aims/Priorities	Objectives/Actions
	dementia.
Providing person centred care which can only be achieved through well integrated services focussing on an individual's needs including their carers and families	Further development of the role of the Post Diagnostic Link Workers in all localities in Shetland will ensure consistency of approach to person centred care and will include the development of robust personal care plans for all people living with dementia.
Ensuring people living with dementia are at the centre of care and treatment	All people living with dementia will be consulted about their care at key points in the care process. Treatment and planned care will only be agreed following consultation with them and with their agreement. In the event of them having lost capacity to make decisions, care will be agreed with their Power of Attorney.
Effective engagement of families and carers to support care and treatment	Family members and carers will be invited to take part in all assessments and care planning and will be encouraged to participate in the care of the person living with dementia.
Embedding the concept of risk enablement in the care of people living with dementia.	Care providers will work with people living with dementia and their carers to ensure that they are encouraged to remain independent and, in all cases, that they balance risk of harm to the person living with dementia with potential benefits to the emotional and physical wellbeing of them. In doing so the

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Service Aims/Priorities	Objectives/Actions
	person living with dementia will be able to experience a better quality of life.
Redesign of the Dementia Assessment Service in line with service demands.	Identify permanent funding for the Dementia Clinical Nurse Specialist role. Develop the Dementia Assessment Service to become an Old Age Psychiatry service including the assessment and treatment of older people with functional mental health problems.

Title/Heading	Start	End	Output	Expected Outcome/Supported Aims/Objectives
Review clinical workforce within the Dementia Assessment Service to build a stable and sustainable service structure, and move towards an Old Age Psychiatry Service.	July 2015	March 2016	Recruitment of additional staff that can provide a wider range of care and skills for people with functional mental health problems as well as dementia.	Better patient outcomes with additional nursing support.

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Title/Heading	Start	End	Output	Expected Outcome/Supported Aims/Objectives
			Development of an Old Age Psychiatry Service covering all aspects of mental health needs.	
Develop existing staff to have in depth knowledge of the assessment of capacity to act as “expert advisors” to support those carrying out assessments of capacity	September 2015	March 2016	Support to those carrying out assessments of capacity to ensure greater clarity and consistent approaches and decisions when required.	Availability of access to someone with knowledge of assessing capacity.
We will develop staff providing care for people living with dementia and their carers to adopt a personal outcome focussed approach to delivery of care	September 2015	March 2016	Information about current and potential future care needs for the person living	All people living with dementia will have individual personal support plans in place. They will also have an Anticipatory Care Plan

Title/Heading	Start	End	Output	Expected Outcome/Supported Aims/Objectives
needs.			with dementia and their carer will be gathered and will ensure that their wishes will be reflected in any care requirements.	developed which will be shared with staff in the Gilbert Bain Hospital.
A project focussing on the North Isles will pilot innovative ways to involve the community as a whole in supporting people living with dementia to remain integrated within their communities.	May 2015	April 2018	A trial of the use of different types of technology in supporting this group to assess its suitability. Involvement of people living in these areas in the support of people	People living with dementia in these areas will have an improvement in the quality of their life by feeling they are able to continue to be part of their community.

Title/Heading	Start	End	Output	Expected Outcome/Supported Aims/Objectives
			living with dementia.	

Dementia Strategy Implementation Plan
2015 - 2018

Action	Descriptor	What needs to be done	Responsibility	Date due	Progress
Develop the Dementia Assessment Service	Capacity to deliver ongoing nursing input beyond assessment and diagnosis is very limited within the Dementia Assessment Service	Review of current service provision and capacity to determine future needs	Dementia Services Nurse Manager Service Manager, Mental Health	January 2016	
Embed the role of Post Diagnostic Link Worker (PDLW) within all Care at Home Teams	Post diagnostic support requires to be provided throughout all parts of Shetland in an efficient and cost effective manner	Review the current model of the Post Diagnostic Link Worker to ensure that it meets the Scottish Government HEAT target requirements and determine if this is the best model for Shetland. Identify key individuals in each locality team have the required experience and training to deliver post diagnostic support and provide further training to become PDLWs	Dementia Services Nurse Manager Executive Manager, Community Care Resources	December 2015 April 2016	
Develop Occupational Therapy (OT) support for	Implementation of the 8 Pillar Model requires a Practice	Review current capacity within OT service to identify ways that this role could be developed prior to the implementation of	Executive Manager, Occupational Therapy	April 2016	

people with dementia	Coordinator. Support for people with dementia to remain as independent as possible, as the condition advances, requires the skills associated with an OT	the 8 Pillars Model once it has been evaluated in the test sites.			
Develop housing design support and interventions	Design of housing that meets the needs of people living with dementia is essential to support them to live safely at home and delay the need for residential care	Continue to develop current social housing stock to be more dementia friendly Consider the needs of people living with dementia when building new social housing stock Invest in developing further models of housing such as those found in King Eric House and Brucehall Terrace	Team Leader, SIC Housing Support Hjatland Housing representative	Ongoing	
Further trial and develop assistive technology	People living with dementia have a right to remain as independent,	Building on from the experience of participating in the RemoDem project in partnership with Norway, Sweden, Faroe Islands and Greenland, we will further	Telecare/telehealth Manager Dementia Services Nurse Manager	May 2018	

	living safely in their own home for as long as possible. They also have a right to remain integrated within their own community	identify and test innovative ICT solutions to support people living with dementia living in rural areas. We will trial ways that will allow people to access professional health and care services based in larger towns and cities without having to travel or leave their homes. We will use assistive technology to trial ways of allowing people living with dementia to maintain social contact with friends and family who may not live nearby, and to continue to feel and to be a part of the communities in which they live.			
Develop local expertise in rights based care	Identify people with palliative care needs, to promote advance care planning	Deliver Training in palliative care to a range of staff Further develop Anticipatory Care Plans for people with dementia	Dementia Clinical Nurse Specialist Dementia Services Nurse Manager Chief Nurse, Directorate of Community Health and Social Care	Ongoing April 2016	

	Capacity assessments and provision of care and treatment must reflect best practice Provision of person centred care must be central in all care settings	Develop “expert advisors” skilled in supporting those carrying out assessments of capacity Develop shared person centred care plans for SIC and NHS staff to use for people living with dementia	Dementia Services Nurse Manager Service Manager, Mental Health Dementia Services Nurse Manager Team Leader, Annsbrae Community Support Services	December 2015 December 2015	
Continue to develop workforce skills and competencies	Everyone who is in contact with people living with dementia requires to be educated to the appropriate level of need within the Promoting Excellence	LearnPro and Brightwave training modules for Promoting Excellence will be further promoted to encourage all NHS and SIC staff to complete. Training needs analysis to be carried out for NHS and SIC staff to determine levels of training required	Training Manager, SIC Staff Development Manager, NHS	Ongoing April 2016	

	framework	A learning event will be facilitated for hospital nurses to commence progression of Promoting Excellence, Skilled Level. This will be further developed for community nurses	Dementia Services Nurse Manager Dementia Clinical Nurse Specialist	December 2015	
Contribute to and deliver on the 3-year National Action Plan to improve care in acute general hospitals	The 10 Care Actions in Hospital is a Scottish Government priority and as such must be delivered	Continue to develop the local dementia nurse champions network Identify and implement projects to meet the identified Care Actions ensuring that these fit in with wider improvement work at ward/departmental level	Dementia Clinical Nurse Specialist Senior Nurses, GBH Director of Nursing & Acute Services	Ongoing April 2016	
Involve people living with dementia and their carers in deciding on future service direction	Establish a group of appropriate people living with dementia (PLWD) and carers to take forward the Strategy. Ensure the views of PLWD and carers are widely	Engage with PWD and carers to develop a focus group and invite to an initial meeting. Set up regular meetings and invite further members as appropriate.	Dementia Services Nurse Manager. Alzheimer Scotland Dementia Advisor	September 2015	

	represented.				
Develop Shetland as a Dementia Friendly Community	Dementia Friendly Communities are defined by the Alzheimer's Society as 'villages, towns, cities and organisations that meet set criteria to show a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and individuals and communities know about dementia to be able to help someone with the condition' (Alzheimer's	Develop an initial pilot in the North Isles, as part of the RemoAge project, to engage with the public through a series of events, meetings and workshops. Identify Community Leaders to assist with this task and agree most appropriate means of engagement. Use the data gathered in this project to further develop in other areas of Shetland Continue to work with and further develop dementia awareness in community businesses. Build on and develop community resources for PLWD and carers.	Dementia Services Nurse Manager. Telehealth/telecare Manager Dementia Services Nurse Manager Alzheimer Scotland Dementia Advisor	April 2016 Ongoing Ongoing	

	Society 2012)				
Develop expertise and environment to manage behavior that is challenging within Shetland	There needs to be a resource on-island to support people presenting with disturbing behaviour who need short-term time out from the environment that is likely to be causing the behaviour.	Develop a small unit that can be made operational at short notice when required. This would be staffed by specially trained staff who would work in other roles when not required. It is being considered that this could be developed as a resource that would also meet the needs of people with a mental illness requiring short-stay treatment that does not necessitate admission to hospital off island as well as a designated “place of safety” for people awaiting transfer to a psychiatric hospital, whether with a diagnosis of dementia or other mental illness. Various options are being explored at present to determine the best one to proceed with. Once a unit is identified, agree on and provide training and support for staff from colleagues in NHS Grampian.	Service Manager, Mental Health Head of Estates and Facilities Interim Executive Manager, Mental Health and Community Care Dementia Services Nurse Manager Team Leader, Annsbrae Community Support Services	April 2016	