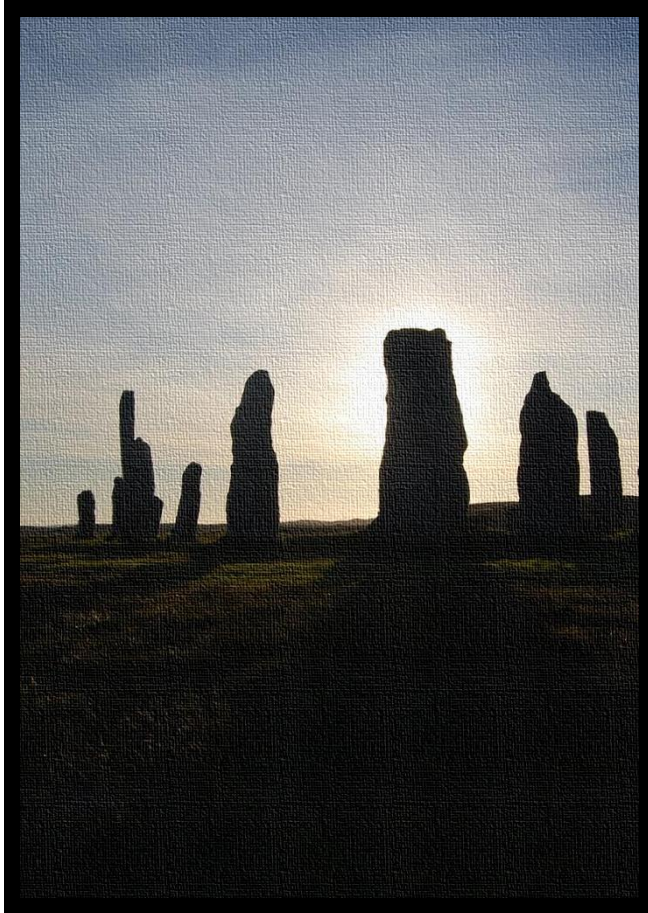


BOARD MEETING 27.06.18

Agenda Item: 7.2

Purpose: For Assurance



CÙRAM IS SLÀINTE NAN EILEAN SIAR

**WESTERN ISLES HEALTH AND SOCIAL CARE
PARTNERSHIP**

DEMENTIA STRATEGY: 2017-2020

1. Introduction

Every person with dementia is entitled to be treated with dignity and respect. In the Western Isles, by adopting a human rights based approach, we will ensure that the care and support we offer is responsive to individual need. This means that we must change the way that our services and communities think and act on dementia and ensure that the views and experiences of people with dementia, their families and carers, underpin our own policy development.

While no treatments are currently available to cure or even alter the progressive course of dementia, there is much that can be offered to support and improve the lives of people with dementia, their care-givers and families. The principal goals for dementia care are:

- Early diagnosis;
- Optimising physical health, cognition, activity and well-being;
- Detecting and treating behavioural and psychological symptoms;
- Providing information and long-term support to caregivers.

The prospect of developing dementia is a concern for many people, especially as they age. The Western Isles has the highest prevalence of diagnosed dementia in Scotland and we recognise that the majority of people with dementia wish to be supported and cared for in familiar, homely environments in their own community.

Given the profile of our ageing population, increasing levels of frailty,

rising demand for services and the challenging financial climate, there is a need for continuing improvements in order to ensure service efficiency and improved outcomes for the people we serve. In order to do this, Western Isles Health and Social care Partnership has embraced a local strategy that is capable of delivering targeted and achievable improvements, looking at the actions we can take to support people at different stages, from risk reduction through diagnosis, treatment, assistance to living well with dementia and provision for end of life care.



2. Legislative and Policy Context

The [Public Bodies \(Joint Working\) \(Scotland\) Act 2014](#) provides the legislative framework for the integration of health and social care services in Scotland. It required local authorities and health boards to integrate adult health and social care services – including some hospital services. It provides a new opportunity to design and deliver integrated care to people with dementia.

Other legislation also supports people with dementia and their carers, including:

- The [Carers \(Scotland\) Act \(2016\)](#) sets out the entitlement of carers to assessment and care planning, with support options for people who meet eligibility criteria.
- The [Social Work \(Self Directed Support\) Scotland Act \(2013\)](#) confers upon people with assessed social care needs the right to exercise choice and control over how their care package is put together.
- The [Adults with Incapacity \(Scotland\) Act 2000](#) safeguards the interests of persons who lack capacity to make some or all decisions for themselves. It enables carers or others to have legal powers to make welfare, health care and financial decisions on their behalf.

Policy Context

Since 2007, dementia has been identified by the Scottish Government as a national priority. The [National Dementia Strategy](#), updated in 2013, sets out 17 commitments to support the transformation of services and to improve and maintain high quality dementia care. This included a new national health target in relation to dementia diagnosis. A new three-year national dementia strategy is being developed and is expected to be released in November 2019. The [Standards of Care for Dementia](#) describe the range of rights people with dementia and their carers, and provides guidance to care providers in the standards to be met by all professionals involved in the care of people with dementia. These are:

- 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, care and supports
- I have the right to be as independent as possible, and to 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.

These rights are central to the aims and values of the Western Isles Dementia Strategy.

3. Our Vision and Values

Our overall vision is that by 2020 the people of the Western Isles will be living longer, healthier lives at home, or in a homely setting.

For people affected by dementia, our vision is that by building on a person's abilities, we will deliver high quality, person-centred care to enhance independence and wellbeing in their own communities

Our Values

Western Isles Health and Social Care Partnership abides by the values of partnership, collaboration and cooperation across NHS Western Isles, Comhairle Nan Eilean Siar, the third and private sectors. We subscribe to a set of values based on the human rights of the people who use our services, including:

- Respect for the inherent dignity and worth of all individuals.
- Promotion of individual autonomy including the freedom and support to make one's own choices.
- Support to ensure full and effective participation and inclusion in society.
- Respect for difference and a desire to respond to individual needs.
- Equal access to resources, services, information and opportunity.

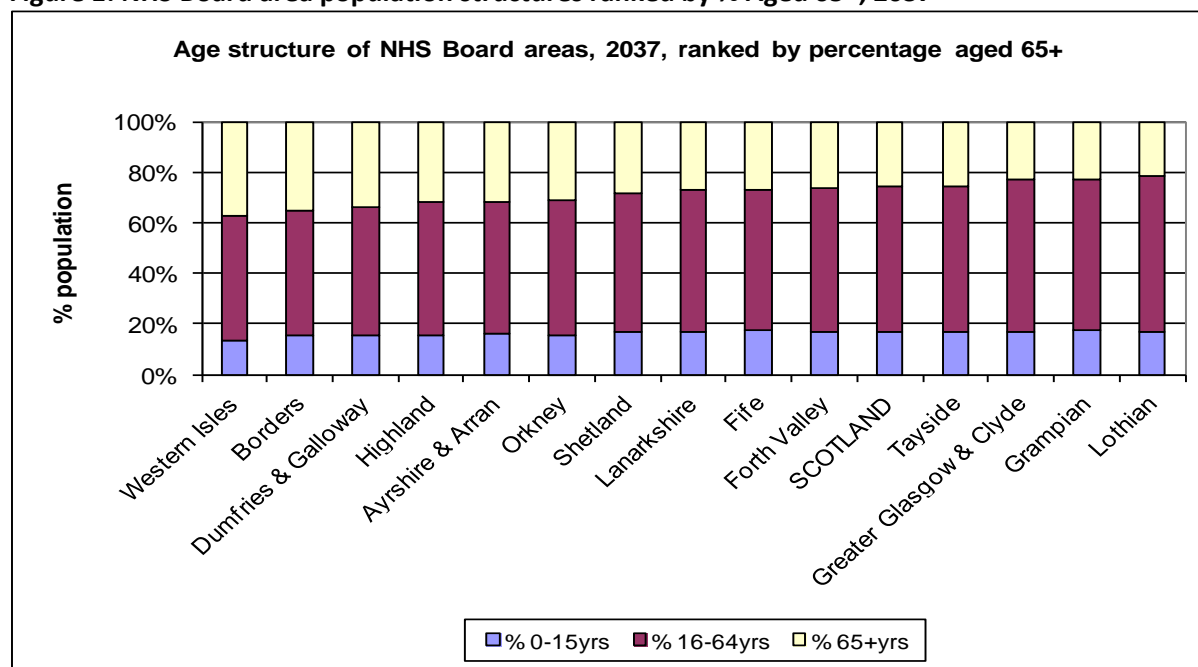


4. Our Changing Population

The population of the Western Isles is changing. Over the next 15 years, the Western Isles population is predicted to decrease in size while the proportion of older people and the number of those with complex long-term conditions is expected to increase. This puts an obligation on us to redesign services to meet the changing needs of our communities.

The older adult proportion of the population is projected to increase for all of Scotland areas but is greatest in the Western Isles, with 37.1% of the population predicted to be aged 65+ by 2037.

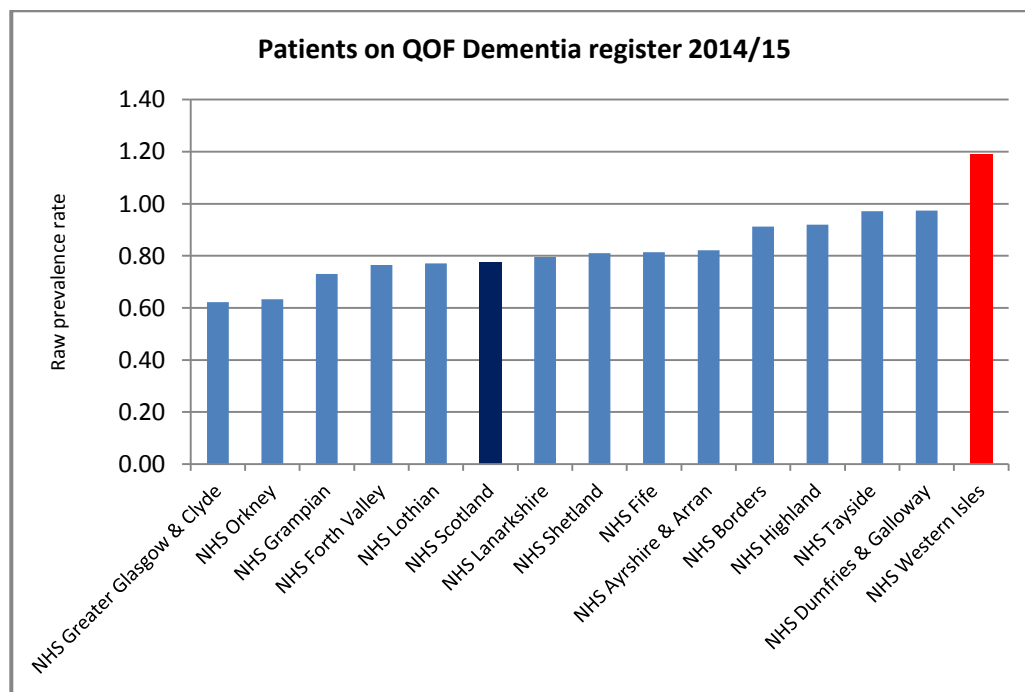
Figure 1: NHS Board area population structures ranked by % Aged 65+, 2037



The impact of depopulation and an ageing society is that there will potentially be a smaller available workforce for health and social services, and fewer unpaid family carers. This presents a challenging circumstance and opportunities to support our citizens into the future.

The latest census estimates suggest that the Western Isles already has the greatest proportion of lone pensioner households in Scotland – and this is likely to increase into the future. Living alone has strong associations with social isolation and loneliness, which both increase risks to health. Indeed, evidence is now emerging that the health impact of loneliness on mortality is equivalent to that of smoking and greater than that of obesity. Western Isles tends to have high levels of such conditions relative to the rest of Scotland, which in part reflects the older population profile. Over the next 20 years, it is projected that there will also be a 73% increase in people with dementia.

The Western Isles has a high level of dementia prevalence and diagnosis rates, as indicated by the GP held dementia registers and we perform well for rates of diagnosis in Scotland.



Western Isles Historic Dementia Diagnosis Figures

2009/10	2010/11	2011/12	2012/13	2013/14	2014/15	2015/16
233	262	274	267	313	322	316

Most people are diagnosed in later stage dementia with around only 11% in early stages in 2013/15. As in any disease, early diagnosis gives the benefit of access to information, advice, interventions and support.

Despite this good performance we are only achieving 60% of the Scottish Government target for diagnosing people with dementia.

Using age related risk factors, Alzheimer Scotland predicts local numbers to be almost double those we currently have diagnosed.

Alzheimer Scotland Estimates for Dementia Rates, 2016

Area	Males	Females	Total
SCOTLAND	31,282	59,402	90,684
Western Isles	208	422	630

The International Picture

- Dementia is one of the major causes of disability accounting for 11.9% of years lived with a disability due to a non communicable disease and it is the leading cause of dependency among older people.
- WHO estimates 15% of people over the age of 60 in Scotland have a dependency.
- In high-income countries, informal care (45%) and formal social care (40%) account for the majority of costs, while the proportionate contribution of direct medical costs (15%) is much lower.
- Evidence from lower to middle income countries suggests that home-based support for caregivers of persons with dementia, emphasizing the use of locally-available low-cost human resources, is feasible, acceptable and leads to significant improvements in caregiver mental health and in the burden of caring
- An average five year delay in the age of onset would tend to reduce population prevalence by 50%, hence greatly reducing its impact in the general population.
- 7 modifiable factors identified for risk reduction are diabetes, midlife hypertension, obesity, depression, physical inactivity, smoking and low education.

Source: DEMENTIA: A Public Health Priority. World Health organisation & Alzheimer Disease International, 2012

Western Isles Picture

- 70% of the residents in long term care facilities have a formal or informal diagnosis of dementia.
- 1 in 5 people with dementia, who are admitted to hospital, do not return home and are discharged into a long term residential unit.
- The average length of stay in hospital for a person with dementia is 29 days in comparison to 18 days for those who do not have dementia - this is the longest length of stay in Scotland and carries the often under estimated risk of hospital acquired infections.
- The length of stay in Western Isles old age psychiatric ward (1809 days) is 6 times the average length of stay in Scotland
- Despite the considerable evidence that the use of antipsychotic drugs is associated with significant harm in older people with dementia, local prescribing of these drugs continues to be higher than the Scottish average
- Dedicated community mental health nursing services are limited to a half time post in Lewis and Harris only

Source: Western Isles Dementia Benchmarking Toolkit, 2016

So What Does the Data Tell us?

1. We will need to respond to a growth in the long-term conditions associated with older age – and dementia in particular
2. We will need to take account of the falling numbers of adults who will be able to provide unpaid care for family members
3. We need to address the growing number of people living alone and who might experience social isolation
4. Integrated health and social care teams will be critical in delivering anticipatory care and self-management approaches
5. Our record in keeping people out of hospital is reasonable but we are not good at supporting discharge

5. Our Current Service Provision

Across the Western Isles, our health and social care teams work hard every single day of the year to provide high quality and person-centred care.

Over the last few years, we have sought to develop our services and respond to the challenges of growing demand and tighter resources. We are seeking to apply the stepped model of care, as highlighted in the graphic on page 12. This promotes tailored interventions, according to complexity of need.

Older People's Care

The delivery of care and support to older people relies on a network of linked professionals across the NHS, Comhairle, third and independent sectors, who provide medical, nursing, and therapeutic interventions, day care, home care and residential care.

Our balance of care remains positive, with the majority of older people with assessed care needs being supported at home by our combined services. This involves care and support for people in their own home to help them with personal and other essential tasks. It is a key service in supporting older people to remain at home.

Care at Home Services

The Comhairle is the largest provider of care at home services in the Western Isles. The level of care at home provision had been declining steadily in Scotland over the last 10 years. However, the level of care at home provided by the Comhairle had remained consistently higher than the national average. In 2013-2014, the level of care at home provided by Western Isles Comhairle was 70 per 1,000 older people compared with 53 per 1,000 older people for Scotland.

Following the introduction of the Self Direct Support legislation, individuals have the opportunity have more choice in how they wish to have their support services arranged. The 4 options range from the individual accessing the budget to have full control and management of the services they receive through to the local authority managing and delivering the service.

We face significant challenges in meeting the assessed need and demand for care at home services. A number of older people are waiting for a care at home package. This is a problem across the islands, but is most acute in some of the most remote and rural areas and is exacerbated by care at home staff having to travel very large distances to visit older people. In light of these challenges, we are carrying out a significant redesign exercise in respect of our care at home services.

NHS Community Nursing

There are 85 community nurses, 24 within specialist roles and 61 within geographical teams. Five Community nursing teams exist within NHS WI; they are geographically based and aligned with GP practices. The Community Nursing service is primarily aimed at patients who are housebound and it is recognised that patients should not be disadvantaged by their remote and rural location. However, strict referral criteria have been developed to encourage self-management and ownership of health needs. From the 2015 community nursing consultation, it was apparent that the care of older adults should be the focus of district nursing services. The increasing number of older people with multiple co-morbidities, long term conditions, polypharmacy and complex social care needs emphasised the importance of community nurses' case management and specialised clinical skills. Discussions highlighted the need for community nurses to proactively manage care by promoting health, anticipating health needs, enabling and supporting self-care and providing support and supervision to the well elderly.

Learning Disabilities

There are 170 people with a learning disability, all of whom will have an increased risk for developing dementia. People with Down's Syndrome are particularly at risk for Alzheimer's disease. Studies have estimated that 1 in 50 people with Down's syndrome

develop dementia in their 30s, rising sharply to more than half of those who live to 60 or over. Studies have shown that by the age of about 40, almost all people with Down's syndrome develop changes in the brain associated with Alzheimer's disease, although not all go on to develop clinical symptoms of dementia. The Learning Disabilities Nursing Service consists of 2 full time posts.

Community Psychiatric Nursing (CPNs) service

There are 7 CPNs who provide a generic mental health service to the people of the Western Isles. One CPN has a part-time 'dementia liaison' remit for Lewis and Harris, and dementia care in the Uists and Barra is subsumed into the generic CPN profile.

Psychiatry and Psychology

The Western Isles has one consultant psychiatrist and one locum psychiatrist who provide a service to hospital wards, care facilities and people living in their own homes.

A new Psychology Service has recently been developed in the Western Isles, with two 0.5 FTE consultant psychologists. One will specialise in older age psychology.

Hospital Dementia In-Patient services

Clisham ward currently has 10 beds for people with dementia. People who present with behaviour that is perceived as challenging can be admitted to Clisham ward for assessment. Most of the

patients in Clisham no longer need to be in hospital and represent a group of people with dementia whose length of stay is prolonged in hospital rather than being cared for in a more homely environment.

Allied Health Professionals (AHPs):

AHPs provide a range of services that help older people with dementia to continue to live independently and safely at home.

These services focus on self management, prevention, rehabilitation and re-ablement. An AHP can assist with falls prevention, swallowing assessments, nutritional support, pulmonary and cardiac rehabilitation, provision of aids and adaptations, pain management and fatigue management.

People living with dementia can access any of the AHP services and expect the same level of assessment and support regardless of which part of the service they access.

AHPs have a role in supporting both formal and informal /family carers by giving them the knowledge and skills required to meet the needs of the person living with dementia. This takes the form of delivering training both formally and informally and will include topics such as eating and drinking support, communication support, foot-care training and keeping people active.

End of Life

The proportion of older people in the Western Isles who spend the last 6 months of their life at home or in a community setting is increasing. By 2012-2013, this was higher than the proportion for Scotland as a whole. We have systems to support palliative care, with community and unscheduled care nurses and the community equipment store making a strong contribution. This approach helps to avoid calls to NHS 24 or presentation at hospital, and helps to minimise stress for the older people and families concerned.

Technology

The use of technology to support personal independence is also improving. Over 800 people in the Western Isles have a community alarm or other telecare service: usage is higher per capita than the national average. We are committed to expanding the number of community alarms by 15% each year until we reach the point where everyone over the age of 75 years, assessed as benefitting from having an alarm, has one. We recognise, however, that our success will depend on informal support from unpaid carers.

Residential Care

There are seven care homes and two nursing homes in the Western Isles, providing a total of 209 places for older adults incorporating respite beds: four in Stornoway, two in Harris, two in the Uists and one in Barra. The two nursing homes and one care home in Harris

are operated independently of the local authority. The care homes range from older establishments - Dun Berisay in Stornoway was built in the 1960s - to the very new - Harris House has 16 beds and was opened in 2014. Capital investment is being sought to a new health and social care hub in Barra, which will incorporate extra-care housing to replace the St Brendan's Care Home. This will provide older people with individual tenancies, while retaining the high-level care input of traditional residential care. This is a model of care at the heart of the plan to replace the two care homes in Stornoway with a view to expanding personalisation and capacity to meet the needs of those requiring access to 24/7 care. The high level of people who have a delayed discharge are predominantly due to the lack of capacity to meet the needs of those requiring this level of care.

In respect of the care and support we offer to people with a dementia diagnosis, we recognise that we have more to do. We are keen to ensure early diagnosis with post diagnostic support and will liaise with Alzheimer Scotland, service users and carers on how to improve our overall service offer.

Day care and respite Services

Alzheimer Scotland (Western Isles) provides advice and support for people with a diagnosis of Dementia and their carers/families. This includes individualised support services and peer support groups in Lewis and Harris to promote independence and well-being. Solas

Day centre in Stornoway is open 6 days a week and they have a part time Dementia Advisor. The Dementia Resource Centre serves the whole of the Western Isles as a hub to provide advice and information with added opportunities for support by phone, email and skype

In the Uists, Tagasa Uist provide some individual support at home and there are plans to expand to provide more dementia specific services if funding is secured from Life Changes Trust.

The Barra Day Centre supported by the Comhairle includes a community learning centre and garden and provides generic support including the older person, and Cobhair Bharrigh provides care and support to people with dementia.

Respite services are provided through the provision of points of care delivered within the home, residential care respite services and the allocation of a personal budget to enable the individual to commission their own arrangements within their own, through specialist providers or in the form of a short break.

Support for Carers

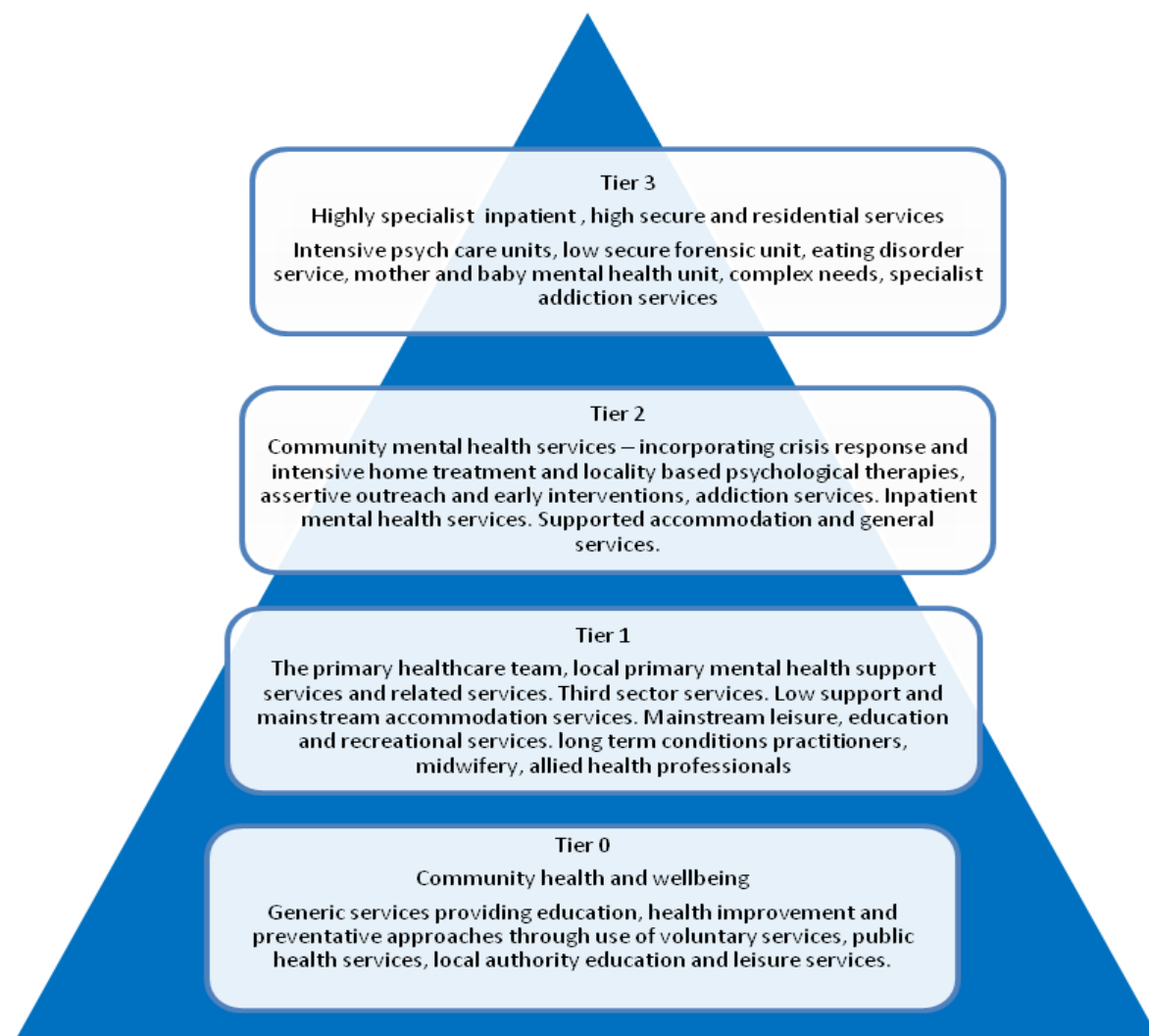
Most carers tell us they feel supported with their own healthcare needs and this has enabled them to continue in their caring role.

The third sector has an active and hugely important role in providing support to carers. Nonetheless, the support we provide to unpaid carers will be even more important into the future

We continue to face challenges in identifying carers and in trying to ensure that they received the right help and support to enable them to continue in their caring role. We have picked up on the reluctance of some carers to accept help and support, which is something we will keep working at.

Western Isles Community Care Forum

The Western Isles Community Care Forum maintains a register of people who are carers and this is kept up to date by liaising with GPs and the local community to encourage carers to register. They administer projects that support carers in various ways.



6. Our Resources

The financial outlook for the next three years is very challenging. The Integration Joint Board will have an outline budget of £58million for 2016/17, which will still require us to make significant efficiency savings. We are looking to find savings of £5million over three years.

In accordance with the Western Isles Integration Scheme, the IJB is required to approve a balanced budget on the basis of funding delegated by NHS Western Isles and Comhairle nan Eilean Siar (CnES). This has been a challenging process with both of the IJB's parent bodies experiencing significant financial pressure. NHS Western Isles has experienced a real terms reduction in funding and is carrying a funding gap of 6.1% against its baseline funding, while CnES has experienced a cash reduction of 4.5% and produced a balanced budget only as a result of difficult political choices.

The IJB budget for 2016/17 is therefore composed as follows:

	£m
Health board (Community)	32,431
Local authority	19,698
Health Board (Hospital Set-aside budget)	5,445
Total	57,574

In terms of how our budget has been allocated across services, the following arrangements have been made:

£m	2016-17
Hospital	5,445
Community healthcare	18,643
Family health services & prescribing	13,788
Social care	19,698
Total	57,574

In addition, there are a number of specific funds that have been delegated to the IJB for the purposes of meeting core pressures and supporting service redesign:-

- The Integrated Care Fund – £640k funding to support the implementation of the strategic plan.
- Delayed Discharge Fund - £192k of funding to address delayed discharge by delivering quality care and supporting people at home or in a homely setting.
- Primary Care Transformation Fund - £20k to support dementia diagnoses within primary care settings

Expenditure on Dementia

Dementia care is often wrapped up in wider service provision, so it is not always possible to identify the exact cost per capita. However, the following outline is illustrative of the levels of investment in the Western Isles for people with Dementia:

<u>Service</u>	<u>2016/17</u>
Hospital Based Care (Clisham)	£1,034,364
Residential	£4,272,000
Homecare	£4,815,000

In addition, we are investing resources into the third sector to better support dementia care:

Alzheimer Scotland Grant Funded Services £118, 000

Finally, we are investing resources into specific dementia-specialist roles:

Post Diagnostic Support Workers £30,000

Dementia Nurse Consultant £50,000

Western Isles has a very high level of delayed discharges with our dementia specific resources heavily focused on care within institutions. As the numbers of people affected and the demand for services increase, it is unlikely that full coverage of dementia healthcare services can be attained or afforded using the current care model (WHO report 2016, Appendix 5) A future model of stepped care needs to address a wider population need.

7. Our Strategic Priorities

The IJB's strategic plan sets out 12 priority areas for action in pursuit of our vision of high quality, sustainable and integrated care.

For each of these domains there will be 12 priority areas for action, often building on existing work and all requiring focused attention and acceleration. These areas include integrated care, safe care, personalised care, supporting recovery, primary care, housing and community capacity, self-management, unpaid carers, the early years, reducing variation, technology and use of assets, and finally workforce planning. Many of these are relevant to the support we provide to people with dementia. The strategic plan can be found on the IJB website at: <http://www.ijbwesternisles.scot>

However, there is one specific deliverable focused directly on supporting people with dementia:

We will develop a strategy and service model that supports people who have dementia to live at home for as long as possible. This will include the delivery of post diagnostic support for people who have received a diagnosis of dementia.

This dementia strategy has been developed in partnership with service users and third sector partners and is focused on supporting people to live more independently in the community.

Dementia is everybody's business so we are seeking to redesign existing services to shift the balance of care away from a medical and institutional-based model, which includes using long-stay psychiatric inpatient care, over to generic community provision, where people are supported in their own home environments for as long as possible. This strategy aligns with other improvement work aimed at supporting the older person to remain well, independent and living at home. We have appointed an Alzheimer Scotland Consultant Nurse for Older Adults and Dementia to lead this work and to develop the post diagnostic delivery model.

In pursuit of these broad aims, we have set out a strategic framework to guide activity. More specifically, we have sought to identify how we will improve our services at different stages of the disease: risk reduction, diagnosis, supported needs and end of life care. The full action plan is set out in detail at page 17.

**In the Western Isles, Dementia is
everybody's business**

8. Measuring Improvements and Communicating Change

It is extremely important that we understand the impact of our strategy on the outcomes that people with dementia experience.

We will therefore put arrangements in place to oversee this process. These include:-

- The continuation of a Dementia Managed Clinical Network to take forward changes in clinical practice
- Bi-monthly meetings of the dementia strategy working group, which will focus on implementation of agreed actions
- Quarterly reporting to the IJB's Strategic Planning Group on the implementation of the Strategy

Communicating Change

Good communication with staff, stakeholders and communities will be fundamental to the process as we change our service and support arrangements over the next few years.

To that extent, we are committed to:-

- Providing regular updates, newsletters, media articles and blogs that can be disseminated to inform people about our work
- Hosting regular staff meetings to allow for feedback about the changes we're introducing, including engagement with service users
- Update reports to Comhairle committees and the NHS Board to ensure that both parent organisations are kept up-to-date with the implementation of the strategy
- Contributing to Locality Planning Groups and to public engagement sessions about programmes of change

Diagnosis and Post-diagnostic Support	Objective	Actions	Lead	Timescale	Impact
	Continue improvement for dementia diagnosis rates to facilitate earlier diagnosis and uptake of post diagnostic support	<p>Introduce Primary Care diagnostic service based on accredited assessment tools which meets target time of 4 weeks for first appointment</p> <p>Utilise the Primary Care Transformation Fund to pilot change of model.</p> <p>Support team approach to community diagnostic service across localities in primary care</p> <p>Embed diagnosis within Primary care supported by diagnostic practitioners with link to psychiatrist and psychologist</p> <p>Raise awareness of benefits of early diagnosis to encourage assessment</p>	<p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia/Associate Director of Mental Health and Learning Disabilities</p> <p>Associate Director of Mental Health and Learning Disabilities</p> <p>Nurse Consultant Older people and dementia.</p>	TBA	<p>Reduce barriers to access for memory assessment and reduce anxiety about process of diagnosis</p> <p>Strengthens primary care interface with people affected by cognitive impairment</p> <p>Equality of access to all localities</p> <p>Promote inclusion</p> <p>Earlier diagnosis for service planning and people supported to self manage in all localities</p>

	Objective	Actions	Lead	Timescale	Impact
Diagnosis and Post-diagnostic Support	Ensure quality and consistency of post-diagnostic support for every person diagnosed with dementia	<p>Use waiting times and post diagnostic support (PDS) criteria to identify the provision of post-diagnostic services</p> <p>Align post-diagnostic services to Primary Care</p> <p>Embed specialist drug treatments for dementia in Primary Care</p> <p>Introduction and embedding of Alzheimer Scotland 5 pillar model for PDS (Appendix 1) across localities, ensuring Power of Attorney is considered by every person with dementia who retains capacity</p> <p>Post-diagnostic support will be available for every individual until they are no longer able to self manage</p>	<p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia/Associate Medical Director</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p>	TBA	<p>Ensures complete compliance with best practise in promoting independence</p> <p>Getting a diagnosis and accessing post-diagnostic support is easier and less daunting</p> <p>Treatment and care of people with dementia is focused in primary care</p> <p>Ensures consistency of service for benchmarking and ongoing delivery, Reduces need for Guardianship applications</p> <p>Continuity of care and reduced crisis presentations</p>

	Objective	Actions	Lead	Timescale	Impact
Diagnosis and Post-diagnostic Support	Ensure quality and consistency of post-diagnostic support for every person diagnosed with dementia	<p>Use waiting times and post diagnostic support (PDS) criteria to identify the provision of post-diagnostic services</p> <p>Align post-diagnostic services to Primary Care</p> <p>Embed specialist drug treatments for dementia in Primary Care</p> <p>Introduction and embedding of Alzheimer Scotland 5 pillar model for PDS (Appendix 1) across localities, ensuring Power of Attorney is considered by every person with dementia who retains capacity</p> <p>Post-diagnostic support will be available for every individual until they are no longer able to self manage</p>	<p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia/Associate Medical Director</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p>	TBA	<p>Ensures complete compliance with best practise in promoting independence</p> <p>Getting a diagnosis and accessing post-diagnostic support is easier and less daunting</p> <p>Treatment and care of people with dementia is focused in primary care</p> <p>Ensures consistency of service for benchmarking and ongoing delivery, Reduces need for Guardianship applications</p> <p>Continuity of care and reduced crisis presentations</p>

People with dementia will be supported fully to remain at home and be fully involved in their communities

Develop a range of intermediate care to respond to health changes which maximises resilience and promotes independence

Engage statutory services in using the Alzheimer Scotland's "8 Pillars" model via agreement on ICP (see appendix 2 for 8 Pillars)

Embed anticipatory care planning for people with dementia who live at home with a range of other conditions

Encourage communities to develop local response to reduce social isolation

Provision of day care as a community support embeds individual assessments of the impact of travel

Ensure access to a wide range of psychological therapies for people affected by dementia as per the NES Matrix for Older people

Integrated Joint Board Senior Management Team

Nurse Consultant Older people and dementia.

Lead Nurse

Integrated Joint Board Senior Management Team

Integrated Joint Board Senior Management Team

NHS Head of Planning and development

TBA

Reduction in avoidable admissions to the acute hospital settings and delays in discharge

Coordinated holistic care for people in a more advanced stage of the disease supports care at home

Strong community and primary care responses to the health needs of people with dementia

Communities strengthened

Reduced social inclusion

Increased well being of people with dementia and carers

	Objective	Action	Lead	Outcome	Impact
Care and Support	Home environments will be safe and supportive with the maximisation of adaptations and assistive technology	<p>Plan in partnership with people affected by dementia, their broader housing and accommodation needs.</p> <p>In partnership with housing providers, agree prioritisation of adaptations as detailed in the online guide <i>Improving the Design of Housing to assist People with Dementia</i>.</p> <p>Promote telecare, aids and adaptations for people with dementia by embedding in PDS.</p> <p>Post diagnostic support for early diagnosis includes future permissions for the range of assistive aids that could be used to help with safety such as GPS trackers</p> <p>Promote the therapeutic and enabling role of Allied Health Professionals in community settings</p>	<p>Health and Social care Senior Management Team</p> <p>Health and Social care Senior Management Team</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p> <p>Director of Nursing</p>	TBA	<p>Most people with Dementia can stay at home and be involved in their communities.</p> <p>Maintain the independence and quality of life of people with dementia and their carers.</p> <p>Cost-effective adaptation of housing for people with dementia</p> <p>Assistive aids that help with safety are fully in line with individual consent.</p> <p>Multi-disciplinary approach to care at home</p>

	Objective	Actions	Lead	Timescale	Impact
Care and Support	Provide integrated care and support on the basis of the 8 Pillars model	<p>Develop case management options within community Health and Social Care teams for people who can no longer self manage their condition.</p> <p>Formalise local Integrated Care Pathway and disseminate widely</p>	<p>Health and Social care Senior Management Team</p> <p>Nurse Consultant Older people and dementia.</p>	TBA	<p>Individuals and carers have adequate and identified support through all stages of the disease</p> <p>Raised awareness and service planning structure identified</p>
Care and Support	Respond to Stress and Distress with psychological support	<p>Benchmark level of antipsychotic prescribing across all sectors</p> <p>Introduce risk assessment and review protocol for initiation of antipsychotics for people with dementia for all prescribers</p> <p>Develop reporting tool for prescribers to identify numbers and patterns for use of antipsychotics</p> <p>Provide minimum of yearly training in functional assessments for stress and distress to front line staff across all sectors</p>	<p>Associate Medical Director</p> <p>Nurse Consultant Older people and dementia.</p> <p>Associate Medical Director</p> <p>Nurse Consultant Older people and dementia.</p>	TBA	<p>Meet national strategy guidelines on reduction of use</p> <p>Manage patient safety effectively</p> <p>Ensure overview of prescribing activity and promotion of alternatives</p> <p>Wide range of staff trained to use non pharmacological interventions for S&D</p>

Objective	Actions	Lead	Timescale	Impact
Continue improvement in acute and specialist dementia health and social care settings	<p>Use programme of inspections into older people's care in acute hospitals by Healthcare Improvement Scotland to effectively drive change and prioritise action areas</p> <p>Benchmark against the 10 Point National Action Plan and develop detailed plan to meet all standards by 2020 (Appendix 4)</p> <p>Effective discharge is fully supported by the required range of community services within a maximum of 72 hours of being fit for discharge</p> <p>Develop Alzheimer Scotland Allied Health professional role to support Alzheimer Scotland Advanced practice model</p>	<p>Health and Social care Clinical Governance Committee</p> <p>Director of Nursing</p> <p>Health and Social care Senior Management Team</p> <p>Health and Social care Senior Management Team</p>	<p>TBA</p>	<p>Standards of Care for Dementia in Scotland are met</p> <p>When admission to hospital is unavoidable for people with dementia, the care experience is safe, coordinated, dignified and person-centred.</p> <p>Discharges from hospital are safe and timeous</p> <p>Increased leadership in dementia at expertise level</p>

	Objective	Actions	Lead	Timescale	Impact
Care and Support	Identify and promote the specific issues and needs of the dementia client group in residential care	<p>Introduce and embed routine screening of admissions and at annual reviews of people living in care settings</p> <p>Introduce case management in residential units with identified responsible professional</p> <p>Include multi-disciplinary approaches to dementia in residential care within the Integrated Care Pathway</p>	<p>Head of Social and Partnership Services</p> <p>Head of Social and Partnership Services</p> <p>Nurse Consultant Older people and dementia</p>	TBA	<p>Diagnosis of dementia and optimisation of interventions</p> <p>Equity of case management provision</p> <p>Increase knowledge of response to stress and distress in care homes and elsewhere</p>

	Objective	Actions	Lead	Timescale	Impact
Care and Support	Implement and extend <i>Promoting Excellence</i> dementia health and social services training and embed dementia in the education plan for all employees and volunteers	<p>Workforce development plans for all employees of statutory services identifies the level of Promoting Excellence that the post requires.</p> <p>Employees who require to be trained to Enhanced level of Promoting Excellence are prioritised for training.</p> <p>Percentage employees trained to Enhanced level of Promoting Excellence will be set annually within departmental training projections.</p> <p>Agree recognition of alternative trainings that meet the requirements of skills and knowledge to the appropriate level</p> <p>Provision of <i>Promoting Excellence</i> training and awareness raising in other areas of public life includes schools and community groups</p>	<p>Heads of Service</p> <p>Heads of Service</p> <p>Heads of Service</p> <p>Nurse Consultant Older people and dementia.</p> <p>Nurse Consultant Older people and dementia.</p>		<p>All staff have adequate skills and knowledge to support people.</p> <p>Staff are more confident and less reliant on specialist advise.</p> <p>Baseline knowledge and skills are embedded in our staff communities</p> <p>Reduces staff frustration and promotes engagement.</p> <p>Reduction of stigma supports early assessment and ongoing support in communities</p>

	Objective	Actions	Lead		Impact
Palliative care	Respond proactively to the overall palliative and end of life care needs of people with dementia	<p>Promote advance care planning based on the wishes of the individual and taking account of carers' views</p> <p>Provide an electronic communication system that supports planned and emergency care</p> <p>Develop a care pathway for palliative and end of life care that effectively supports the individual to a good life and a good death</p> <p>Introduce and embed policies and procedures to promote best practice in end of life care with capacity assessments and Do Not Attempt Cardiopulmonary Resuscitation decisions</p> <p>Develop a workforce skilled in end of life care by use of national improvement programmes</p> <p>Develop a specialist dementia workforce to support Alzheimer Scotland Advanced Care service model with obligate network if required to enhance provision (Appendix 3)</p>	<p>Lead Nurse</p> <p>Associate Medical Director</p> <p>Health and Social care Senior Management Team</p> <p>Lead Nurse</p> <p>Health and Social care Senior Management Team</p> <p>Health and Social care Senior Management Team</p>		<p>Ensures compliance with incapacity legislation</p> <p>Key information is shared across settings</p> <p>Reduced variation for all conditions in remote settings</p> <p>Greater awareness of proper procedures for making decisions for people with dementia who lack capacity</p> <p>Generalist palliative skills are available across all localities</p> <p>Specialist and generalist palliative skills are available across all localities</p>

Appendix 1

Getting Post Diagnostic Support (PDS) right for people with dementia

There is clear evidence that high quality post diagnostic support, provided over an extended period, is essential in order to equip people with dementia and their families and carers with the tools, connections, resources and plans they need to live as well as possible with dementia. The positive effect which this kind of support can have on people's lives has been demonstrated in the post diagnostic support pilot funded by the Scottish Government and delivered by Alzheimer Scotland, and international evidence shows the long term impact in reducing and delaying the need for care services. There are five key pillars which are recognised as essential to supporting people after their diagnosis, outlined in the diagram opposite. Post diagnostic support will be provided for a minimum of one year, by a named person who has the flexibility to work alongside the person, their partner and family and ensure that over that 12 month period each person is given help and support to work through the five pillars. By the end of the year it is expected that some individuals might require ongoing professional support; however the purpose of the post diagnostic support is to enable the individual and their family to develop a robust personal plan that utilises all their own natural supports, that maintains newly developed peer support mechanisms alongside existing and new community connections and that will support each person to live well and independently with dementia for as long as possible



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Appendix 2

8 Pillars Overview

The 8 Pillars Model of Community Support provides an integrated and comprehensive approach to the support of people with dementia, their families and carers. This will help to enable people with dementia to remain at home for as long as possible with moderate to severe dementia. At a time of demographic change, it delivers a coherent approach in response to increasing dementia prevalence. This model builds on key developments in relation to post-diagnostic support and will ensure the impact of the investment in early intervention is not lost. By tackling the full range of factors that influence the experience of the illness in a coordinated way, it takes a therapeutic approach to enhancing the resilience of people with dementia and their families and carers: equipping and supporting them to cope with the symptoms of the moderate to severe stages of the illness.

The move towards community capacity building and proportionately fewer resources for institutional care requires a coordinated approach to support people with dementia in the community, which is provided by the 8 Pillars Model.

Adopting this model must be a priority for the integration agenda; it will empower families, make effective use of the full range and depth of interventions, provide a coordinated approach to engage with all partners and use their resources and skills to the fullest effect.



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Appendix 3

Advanced care model

The Advanced Dementia Practice Model provides the response to this most complex phase of dementia.

When a person requires the Advanced Dementia Practice Model there will be a range of people already involved in their care and support – this is the 8 Pillars Team. They will be coordinated by the Dementia Practice Coordinator and determined by the person's experience of dementia and underlying health. For younger people with dementia there may be continued involvement from the neurology team. People with learning disabilities are likely to continue to be supported by specialist LD services. There should also be close links between the Dementia Practice Coordinator and medical disciplines related to the person's co-morbid conditions.

The decision to refer the person for assessment by the Advanced Dementia Specialist Team will be initiated by the Dementia Practice Coordinator. This will follow from discussion and agreement between the Dementia Practice Coordinator and the 8 Pillars Team. The entry point to the Advanced Dementia Practice Model is determined by the level of complexity of need requiring substantive health care as assessed by the Advanced Dementia Specialist Team. The range of factors necessitating this approach will be specific to each individual but likely to be determined by the progressed physical experience of dementia and inter-play of co-morbid illness. Access to this approach is based on the principle of equality and determined by need as opposed to prognosis.



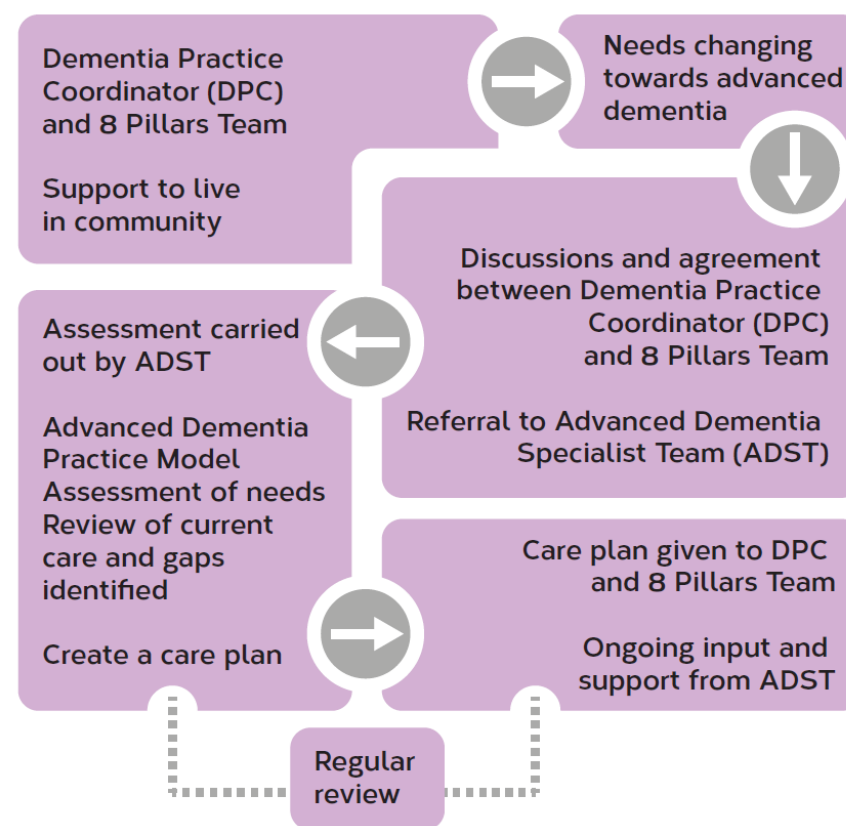
Once the person has been assessed as requiring the Advanced Dementia Practice Model the Advanced Dementia Specialist Team will review their current care and identify gaps. A care plan will be created outlining the responses to the person's physical, psychological and social care needs. The diagram opposite outlines the operation of the Advanced Dementia Practice Model.

The care plan will build a strategy to support the person through advanced dementia and end of life. It will identify the practitioners required to support the person's care — bringing in specialist support where this is not already being provided by the 8 Pillars Team. The Advanced Dementia Specialist Team will enhance the support provided by the 8 Pillars Team and provide advice through the Dementia Practice Coordinator.

The care plan will be held by the Dementia Practice Coordinator and 8 Pillars Team. Crucially, there will be regular review of the care plan and ongoing input from the Advanced Dementia Specialist Team.

People may experience the advanced dementia phase for months or years. The intensity of health care input required is likely to fluctuate along with the level of involvement from the Dementia Practice Coordinator. The input from the Dementia Practice Coordinator and the Advanced Dementia Specialist Team may be less intensive for periods if the person has relatively stable needs and support is in place to meet these.

Whilst the entry point to this Model is determined by the level and complexity of health care needs, responding to the social and emotional experience of advanced illness and end of life is of equal importance.



Appendix 4

NHS the 10 National Actions are:-

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

Appendix 5

World Alzheimer report 2016 Improving healthcare for people living with dementia.

Summary of review findings: Models of healthcare delivery

Healthcare is at the core of the system of treatment and support for people with dementia and their carers. Healthcare professionals, and services have important roles to play across the course of the condition; promoting brain health; providing a timely diagnosis with post-diagnostic information and support; signposting community support services; initiating treatments where appropriate; optimising physical health and managing comorbidities; assessing and managing behavioural and psychological symptoms.

Dementia is not just another diagnosis on the lengthening list of comorbidities that most of us face as we age. It changes everything, not least future expectations of life, and independence. It impairs one's ability to recognise and report new symptoms, seek help, and manage one's own health conditions. Therefore, it has profound implications for the management of all health issues for the person with dementia, and the way that healthcare needs to be planned and delivered for people with dementia in general.

Healthcare for people with dementia needs to be

- continuous; treatment options, care plans and needs for support need to be monitored and reviewed as the condition evolves and progresses
- holistic; treating the whole person, not single conditions, organs or systems, mindful of that person's unique context, values and preferences
- integrated; across providers, levels of care, and health and social care systems

Currently, healthcare systems struggle to provide adequate coverage of diagnostic services, and care is too often fragmented, uncoordinated, and unresponsive to the needs of people with dementia and their families at the time when they arise. In high income countries, dementia healthcare systems tend to be highly specialised, from diagnosis onwards, with very little formal recognition of the role of primary care services, or allocation of tasks to this sector.

This is probably also true for low and middle income countries, where diagnostic coverage is low, but such services as are available are provided by a very limited number of specialists.

As the numbers of people affected and the demand for services increase, it is unlikely that full coverage of dementia healthcare services can be attained or afforded using the current specialist care model. There are other limitations too. Seamless and continuing care goes beyond the capacity and reach of specialist services working in isolation. The specialist model of dementia care does not facilitate holistic management of or care-coordination for, complex multimorbidities. These are core functions of primary healthcare.

Task-shifting and task-sharing, including but not limited to increasing the role and competencies of primary healthcare services within the system, will be the core strategies for increasing the coverage of diagnosis and continuing care. Collaborative or shared-care models distribute tasks between primary and secondary care services in a structured and organised fashion. Case management may be an important strategy for increasing treatment coverage, and improving integration and coordination of care. More research is needed to clarify the best ways of delivering this promising intervention. Evidence to date suggests that case management needs to be adequately resourced by skilled staff with manageable caseloads, and implemented such that case managers have the authority to work with all stakeholders and providers. The introduction of evidence-based care pathways, linked to process and outcome indicators, should help to improve adherence to healthcare quality standards, and allow transparent monitoring of treatment coverage and effective treatment coverage.

For the full report <https://www.alz.co.uk/research/WorldAlzheimerReport2016.pdf>