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Consultation Document

Together for a Dementia Friendly Wales **2017-22**

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Action required: Responses by 3 April 2017

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

Overview Draft strategy - '*Together for a Dementia Friendly Wales*' 2017-22

How to respond Electronic responses should be submitted by 3 April 2017 to:

mentalhealthandvulnerablegroups@wales.gsi.gov.uk

Alternatively you can send a hard copy response to:

Mental Health and Vulnerable Groups Division

Health and Social Services

4th Floor, (North Core)

Welsh Government

Cathays Park

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CF10 3NQ

Further information and related documents Large print, Braille and alternative language versions of this document are available on request.

Contact details If you have any queries relating to this consultation, please email:

mentalhealthandvulnerablegroups@wales.gsi.gov.uk

**Data
protection**

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about. It may also be seen by other Welsh Government staff to help them plan future consultations.

The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tell us this in writing when you send your response. We will then blank them out.

Names or addresses we blank out might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

Question 1

The strategy follows the following themes:

- Risk reduction and health promotion.
- Recognition and identification.
- Assessment and diagnosis.
- Living as well as possible for as long as possible with dementia.
- The need for increased support in the community.
- More specialist care and support
- Supporting the plan:
 - Education and training
 - Research.

Do you feel there should be any additional themes included?

Please tick the appropriate box below.

Yes	No	Partly
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Where you have ticked 'Yes' or 'Partly', please explain what the additional themes should be.

Question 2

Within each theme we have identified a number of proposed key actions. Do you feel these are the right ones? Please tick the appropriate box below.

Yes

No

Partly

Where you have ticked 'No' or 'Partly', please provide an explanation and any alternative suggested wording below. Please state which theme you are commenting on.

Question 3

The strategy describes what services should be available for people and their families and carers to live well in the community for as long as possible.

What do you think are the key features of this type of service?

Question 4

Within the final *Together for a Dementia Friendly Wales* we would like to include examples of notable practice. If you have any which you would like to highlight, please do so here.

Please explain why you think it is an area of good practice e.g. an evidence base, an achieved accreditation award.

Question 5

Within the document we have highlighted the advantages of using telehealth, telecare and assistive technologies to help people live more independently and safely within their own home.

What do you think the challenges and barriers are in making this happen and how could you overcome these?

Question 6

Do you think the key actions will provide a positive impact for people based on the following protected characteristics:-

- Disability
- Race
- Gender and gender reassignment
- Age
- Religion and belief and non-belief
- Sexual orientation
- Human Rights
- Children and young people

Yes

No

Partly

Where you have ticked 'No' or 'Partly', please explain why.

Question 7

Do you think the key actions will provide a positive impact on the opportunities for use of the Welsh language?

Yes

No

Partly

Where you have ticked 'No' or 'Partly', please explain how you feel the opportunities for using Welsh could be strengthened to ensure it is treated no less favourably than English.

8. Additional Comments

We have asked a number of specific questions. If you have any related issues which we have not addressed, please use the space below to comment.

9. Sources of information

The final document will include a list of useful sources of information. If there is anything you feel should be included, please state in the space below:

Draft: Together for a Dementia Friendly Wales

Introduction

The Welsh Government is committed to creating a dementia friendly nation. We have come a long way but we have more to do. The Glasgow Declaration¹, which the Welsh Government signed in 2015, commits us to promoting the rights, dignity and autonomy of people living with dementia. By signing this declaration we affirmed that every person living with dementia has:

- *The right to a timely diagnosis.*
- *The right to access quality post diagnostic support.*
- *The right to person centred, co-ordinated, quality care throughout their illness.*
- *The right to equitable access to treatments and therapeutic interventions.*
- *The right to be respected as an individual in their community.*

This national strategic plan for Wales has been developed to deliver these commitments and builds on the work being undertaken as part of the delivery of *Together for Mental Health*; the Alzheimer's Society and Welsh Government's 2011 '*National Dementia Vision for Wales*' and '*Wales: a Dementia-Friendly Nation*', launched in April 2015.

What is Dementia?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. It often starts with memory problems but goes on to affect many other parts of the brain, producing symptoms including:

- Difficulty coping with day-to-day tasks.
- Difficulty communicating.

¹ <http://www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014>

- Changes in mood, judgment or personality.

Dementia is not a natural part of the ageing process but it is much more common in older people. It can also run in families, although this is rare. Dementia can affect anyone, irrespective of gender, ethnicity or class.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's, or a series of strokes or other illnesses. Dementia is progressive, which means the symptoms will gradually get worse.

Around 60-70% of people with dementia have Alzheimer's disease, the most common form of dementia. Around 10-20% have vascular dementia, which results from an interrupted blood supply to the brain. Some people may have a mixture of the two conditions. There are many other less common forms of dementia, such as frontotemporal dementia and dementia with Lewy bodies, often associated with Parkinson's disease. Throughout this document 'dementia' is used as shorthand for this broad range of conditions.

It is also recognised that dementia is more common in people with learning disabilities and Down's syndrome.

The challenge of Dementia

As our population ages, dementia is one of the most significant health and social care issues we face. Figures suggest that dementia is already costing our society in Wales up to £1.4bn a year².

The statistics tell us that 1 in 16 people aged 65 or over, and 1 in 6 aged 80 or over, will be affected by dementia and this will affect more women than men. Improved life expectancy means that as more people are living longer, more people are developing dementia.

² https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3051

It is estimated that between 40,000-50,000 people in Wales are currently living with dementia³. This includes more than 2,200 people in Wales with young onset dementia⁴ (dementia which starts before the age of 65). Clearly the impact of dementia in society is much wider when we consider carers and family members.

Dementia shortens life expectancy and many people will die of dementia, but also many will have other life-limiting illnesses at the same time. The Office for National Statistics⁵ suggests dementia is now the leading cause of death in England and Wales, with 11.6% of deaths attributable to dementia with proportionately more women than men dying with the illness.

Meeting the needs of dementia

No two people with dementia or those that support them will have identical needs. We know from talking to people with dementia and carers that services need to be values driven, tailored to the individual and flexible to provide for different needs at different stages of the condition.

We know that people with dementia need assessment and care to be available in their preferred language. Dementia assessment and care, need to be accessible through the medium of Welsh and in other languages, to meet the needs of a diverse population.

Providing health and social care to dispersed populations within both rural and urban settings also needs to be considered. We expect health boards and local authorities to robustly assess the needs of their own populations and deliver services that are appropriate to their areas.

What progress have we made in recent years?

Since 2010, the Welsh Government has worked with key partner organisations to develop and deliver a range of actions under the

³ <http://gov.wales/docs/statistics/2016/161019-general-medical-services-contract-quality-outcomes-framework-2015-16-en.pdf>

⁴ https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323

⁵ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015>

'National Dementia Vision for Wales', the 'Wales a Dementia Friendly Nation' initiative and *Together for Mental Health*. Actions include:

In the community

- Building public awareness and support through the Dementia Friends/Dementia Supportive Communities campaigns.
- Publishing 'Dementia: reduce your risk' guidance, which sets out the lifestyle choices people can take which could lower the risk of developing some types of dementia.
- Actions to improve dementia diagnosis rates – including the provision of primary care link nurses to provide training for residential and nursing homes staff about how to identify dementia, provide post-diagnosis support, link up with local GP services and advise how to make buildings more dementia-friendly.
- Providing a further £1m this year to improve timely access to memory assessment services.
- Providing £800,000 a year for new support workers across Wales to help people who have received a dementia diagnosis, in addition to £1m in 2010 for similar posts.
- Launching a dementia helpline and website which offers emotional support and advice to anyone who has been diagnosed with dementia and their families and carers.
- Expanding the Book Prescription Wales scheme to ensure books are available for people with dementia and their carers in every library in Wales. The *Book of You*⁶ has been translated into Welsh and made available in libraries.
- Funding dementia information packs for people diagnosed with dementia, developed by the Alzheimer's Society.

⁶ <http://www.bookofyou.co.uk/>

- Establishing additional dedicated dementia posts within older persons community mental health teams across Wales.
- Developing young onset dementia support services across Wales.
- Implementing a series of intelligent targets⁷ for dementia care.

In hospital settings

- Investing over £130m in new older person's mental health facilities across Wales.
- Providing an extra £4m a year to develop general hospital liaison teams.
- Providing additional training, to ensure NHS Wales staff have the knowledge and skills to provide the best care for people with dementia.
- Providing an extra £500,000 a year for occupational therapy support workers to be in every older person's mental health ward in Wales, ensuring people are engaged in meaningful and stimulating activities.
- Providing £2.3m a year to develop flexible resource teams in hospitals to provide extra support for people with complex needs, including dementia.

⁷ <http://www.1000livesplus.wales.nhs.uk/mh-dementia>

Developing the strategic action plan

Engagement with people with dementia, their families and carers has been central to drafting this strategy, to ensure we focus on what is needed to make a real difference to the lives of people affected by dementia. It has also been informed by:

- Stakeholder events held in both North and South Wales.
- Events held in conjunction with Alzheimer's Society and DEEP with people personally affected by dementia.
- Consultation on the *Together for Mental Health 2016-19* delivery plan and reviewing other UK relevant dementia strategies.
- National Institute of Health and Clinical Excellence (NICE) guidance.
- Key reports such as the Older People's Commissioner for Wales' report '*Dementia – more than just memory loss*'⁸, '*My Language, My Health: The Welsh Language Commissioner's Inquiry into the Welsh Language in Primary Care*'⁹, the Alzheimer's Society report '*Dementia in rural Wales*'¹⁰ and the DEEP report '*Dementia Words Matter*'¹¹.

Structure of the plan

The plan outlines the key themes which we propose need further action over the next five years. It will be reviewed and refreshed after three years to ensure it remains relevant and appropriately targeted.

Overwhelming feedback from the stakeholders to date is that they want support and services to be delivered with 'a rights based approach' and that action considers all parts of a pathway, starting from whole population awareness of dementia. The plan therefore follows a pathway approach.

⁸ [Dementia: more than just memory loss](#)

⁹ [My Language, My Health: The Welsh Language Commissioner's Inquiry into the Welsh Language in Primary Care](#)

¹⁰ [Dementia in rural Wales](#)

¹¹ <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

Monitoring Delivery

Progress with delivery of this strategic plan will be overseen by the Older Persons' Delivery Assurance Group (DAG), which includes key stakeholders, and is a sub group of the National Mental Health Partnership Board. This will ensure alignment with the oversight arrangements for the wider *Together for Mental Health* Strategy. The membership of the older persons' DAG will be reviewed and refreshed, if required, during the consultation period on this document to ensure it can undertake this function effectively.

Wider strategic context

This strategic action plan is aligned with the ambitions of the ***Well-being of Future Generations (Wales) Act 2015***¹². The Act requires public bodies to:

- Think more about the long-term.
- Work better with people and communities and each other.
- Look to prevent problems and take a more joined-up approach.

It also seeks to further embed the requirements of the ***Social Services and Well-being (Wales) Act 2014***¹³, namely to:

- Improve well-being and outcomes for people.
- Transform the way social services are delivered, promoting people's independence to give them a stronger voice and more control.
- Partnership working across health, social care, third and independent sectors to deliver integrated services, care and support.
- Promote equality, improve the quality of services and the provision of information people receive.
- Encourage a renewed focus on prevention and early intervention.

¹²<http://gov.wales/topics/people-and-communities/people/future-generations-act/?skip=1&lang=en>

¹³<http://gov.wales/topics/health/socialcare/act/?lang=en>

In addition, the plan has also been underpinned by the principles of ***Prudent Health and Care***¹⁴. This plan aims to strengthen that approach through a greater emphasis on co-production, prevention, integration and long term sustainability.

As part of the development of this plan, we have also undertaken a series of impact assessments to ensure the actions outlined in the plan will have a positive impact on people with protected characteristics (please see glossary), as set out in the Equality Act 2010. This plan has also considered the articles contained within the United Nations Convention on the Rights of the Child (UNCRC) and the impact of delivery in settings which are more dispersed (i.e. rural areas). The objectives of *'More than just words follow on strategic framework'*¹⁵ for Welsh language services in health and social care have also been embedded into actions throughout the plan.

¹⁴ www.prudenthealthcare.org.uk

¹⁵ <http://gov.wales/topics/health/publications/health/guidance/words/?lang=en>

Risk reduction and delaying dementia onset

As recent evidence shows, there are steps people can take across the life course to reduce their risk of developing dementia, to delay its onset or slow deterioration following diagnosis.

In Wales, a study in Caerphilly¹⁶ looked at the health behaviours of over 2,000 men aged 45–59. It found that people could reduce their risk of developing dementia by up to 60% by simply living a healthier lifestyle. This study supports the view of the Alzheimer's Society that regular physical exercise can reduce your risk of developing Alzheimer's disease significantly, and can also slow further deterioration in those who have already started to develop cognitive problems

We published new guidance on dementia risk reduction in 2015-16 which set out six simple steps to ACT NOW to reduce people's risk or to delay the onset of dementia. The six steps are:

Active (physically and socially),
Check your health regularly,
Try new things,
No to smoking,
Only drink alcohol within the recommended guidelines, if at all,
Watch your weight.

As the evidence continues to evolve, we need to take every opportunity to promote the steps people can take to reduce their risk of developing dementia. We will therefore be running further public information campaigns to raise awareness of the steps required to reduce risk.

¹⁶ <http://medicine.cf.ac.uk/news/benefit-healthy-lifestyle/>

Proposed key actions:

- Raise awareness of the steps required to reduce risk of dementia through public information campaigns.
- Develop and deliver general and targeted education programmes to raise awareness of the signs and symptoms and risk factors associated with Alcohol Related Brain Damage (ARBD).

Raising Awareness and understanding

If we are to achieve our vision of a dementia friendly Wales, we need individuals and communities to understand that dementia is a physical illness that is usually associated with ageing, but is not a normal part of the ageing process and, although rare, it can occur in younger people.

Tackling stigma and discrimination is vital, as it can lead to unwillingness to seek help and advice when the early signs of dementia arise. Many individuals have told us that the diagnosis of dementia can make them feel excluded and less welcome in the everyday places and activities they used to enjoy, even within their family, or when dealing with healthcare providers. There is also anecdotal evidence that some communities such as Welsh language or BAME communities, may be less likely to talk about dementia.

Overcoming these issues will require more public education initiatives and awareness training designed to explain the challenges faced by people with dementia. This includes schools and other educational settings working to help young people better understand dementia, and how it can impact both family and community.

Notable practice example: Ageing Well in Wales is a national partnership programme to improve the wellbeing of people aged 50+ in Wales. One of the key strands of this work is to make Wales a nation of dementia supportive communities¹⁷. A dementia supportive community shows a high level of public awareness, understanding and direct action to support people living with dementia and carers based on what matters to them. For example, businesses and shops can identify specific quiet shopping slots, cinemas can identify slots for screenings (such as the Chapter Arts Centre in Cardiff) when people with dementia and other older people know their needs will be catered for.

The dementia friends and dementia friendly communities in Wales are a big step forward in this respect and Wales already has 59,000 friends and 40 communities who are either 'dementia friendly' or working towards being so.

Proposed key actions:

- Increase the number of people in Wales who are able to recognise dementia and understand where to access additional support through the expansion of dementia friends and dementia supportive communities / organisations.
- Publicise and actively encourage educational settings to use the "Creating a Dementia Friendly Generation" resources developed by the Alzheimer's Society.

¹⁷ <https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200436>

Recognition and Identification

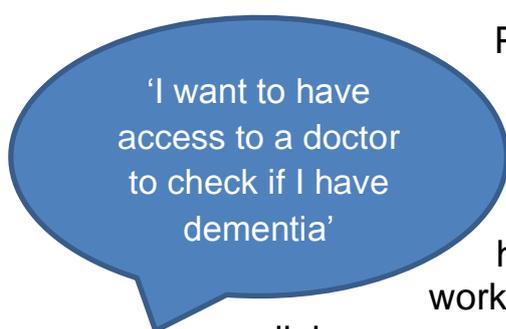
The benefits of recognising dementia

We know that people can be reluctant to go to the doctor when they are worried that they may have dementia, despite the benefits of getting a diagnosis. Similarly, professionals can be reluctant to refer people for a formal diagnosis if they believe there are limited options for treatment or support. However, undiagnosed dementia makes people vulnerable and has risks, for example, they may not remember to take medication regularly or unknowingly put their safety at risk. Therefore, primary care teams need to have a better understanding of the benefits of a timely diagnosis.

While a diagnosis of dementia can be difficult news, an explanation of the problem and what support is available can help an individual to feel empowered and reduce some of the worry caused by uncertainty.

Work in North Wales suggests that most people do in fact want to have the diagnosis, at their own pace, and then have the opportunity to consider issues such as where and how they want to live in the future, or whether they may wish to move home to be closer to family members or not.

Recognition and referral



clinics.

Primary care services are important in identifying when a referral needs to be made to specialist services such as memory clinics. However, there are other professionals who may have this first contact, a social care worker, for example, or staff in frailty

A key to delivery of this plan is ensuring Wales has an informed and skilled professional workforce, which is able and confident to identify and respond appropriately with any person presenting with

symptoms of possible dementia. We need to ensure professionals across all sectors including health, social care, other emergency services and agencies are able to identify the early signs and symptoms of dementia, and have clear information about where and how to refer on appropriately.

Many people presenting with dementia related symptoms will be referred to memory clinics to consider whether there are other causes of memory loss. However, not everyone with symptoms will need to be. Other clinicians will have the necessary competencies at different stages in the illness to diagnose and then, if appropriate, to refer into dementia services. For example, individuals who have a well documented and progressed dementia living in a care home, their GP may be well placed to confirm the diagnosis. Similarly care of the older person's physicians and neurologists will have the competency to diagnose appropriate cases.

Local services should not insist that a memory clinic diagnosis of dementia is the only pathway into care and support; it is the diagnosis of dementia by a suitably competent clinician that is necessary. To ensure everyone can access appropriate and timely assessment and diagnosis, each local area must have agreed clinical pathways in place, which are adapted appropriately depending on need.

Proposed key actions:

- Health boards to develop a consistent and evidenced based local referral pathway to enable people to receive an appropriate, proportionate and comprehensive assessment for a diagnosis.
- Health boards and local authorities to ensure there is appropriate 'case finding' (see glossary) for dementia.
- Increase the number of primary care practices in Wales that are dementia supportive.

Specific risk factors

While dementia may occur in working age adults, it is also the case that risk increases for everyone as people age, with over a third of people who live to over 90 developing dementia symptoms. In

particular we know that some groups have higher risks of dementia, including those:

- Aged over 35 with Down's syndrome, as they are at higher risk of Alzheimer's disease.
- Over 50 with a learning disability.
- With a history of drinking alcohol heavily, especially if their diet is poor.
- With known genetic/family history.
- With cardiovascular disease, high blood pressure, type 2 diabetes and Parkinson's disease.
- From Black African-Caribbean and South Asian UK populations.

Professionals in specialties that work with people at higher risk of dementia, including cardiology, stroke services, learning disabilities and prisons and those working with alcohol and homelessness services, also need to be engaged and have access to tools and referral pathways and learning and support opportunities.

Mild cognitive impairment

People diagnosed with mild cognitive impairment should be offered an explanation of their problem and provided with health promotion information and advice on memory strategies.

Proposed key actions:

- Staff within areas which are likely to come into contact with people who may have dementia, (such as learning disabilities, substance misuse services, police and prison staff) to be able to access high quality learning and support opportunities.
- Health boards to ensure that clear clinical pathways including case identification/screening questions are in place to identify people on admission to an acute hospital as potentially having dementia.
- Welsh Government to review population assessments, required by the Social Services and Well-being (Wales) Act, to ensure they include the care and support needs of older people with complex needs (including dementia) and those that care for them.

Assessment and diagnosis

Improving timely diagnosis rates of dementia allows those affected to take the right steps to manage their condition, plan ahead and to access the right information, advice, care and support. In Wales, currently around 51% of individuals with dementia have a diagnosis and therefore the opportunity to begin to consider their future. It is vital that we take steps to increase the diagnosis rate to support them.

Getting the right assessment and diagnosis at the right time needs to be straightforward and offered in a sympathetic manner. Professionals must be sensitive to how much an individual and their carer/family want to know at any point in time.

Dementia is not a single condition – it refers to difficulties with thinking and memory that may be caused by over a hundred different underlying diseases. This is one reason why not everyone with dementia experiences the same problems. Recognising that there is a problem and discovering the underlying causes of dementia is important. This will help guide the choice of treatments and services.

Some causes of memory loss and other symptoms are treatable and fully or partially reversible, depending on the nature of the problem. Treating them can prevent further damage and problems. Getting an early diagnosis relies on professionals being able to recognise symptoms. However, identification for some people can be complicated by cultural interpretations or complexities due to comorbid problems such as a learning difficulty.

Importance of language in diagnosis

Tools to assess for dementia need to be in the right language and we expect all memory clinics to use the appropriate tools, such as that developed by Bangor University¹⁸, and assessors who speak Welsh to assess Welsh speaking individuals. In our *'More than just words follow on framework'* we also expect staff in health boards, social services and the social care sector to ensure people have the choice to be treated through the medium of Welsh without needing to ask, through the active offer commitment. Services also need to source language appropriate tools and assessors when required.

Those working in more specialist services including memory clinics need to use appropriate validated tools such as the Addenbrooke's Cognitive Examination (ACE-111) and a number of other tests and investigations to support their holistic assessment of need, and to either confirm the diagnosis of dementia or provide an alternative diagnosis. Getting a diagnosis is a process and not a result of a single test. There should be information and support available for the individual who is being diagnosed and for their carers and/or families over this time.

Young onset dementia

People with dementia whose symptoms started before they were 65 are often described as having young onset dementia. Young onset dementia is generally caused by broadly similar diseases to dementia in older people but there are some important differences. Younger people are more likely to present with atypical symptoms, to be diagnosed with a rarer form of dementia and more likely to have a genetically inherited form of dementia than older people. The prevalence rates for younger onset dementia in black, asian and ethnic minorities are also higher than in the population as a whole.

¹⁸ www.micym.org

Key proposed actions:

- Health boards to increase diagnosis rates.
- Health boards to ensure access to Welsh language diagnostic tools and care – recognising this as a clinical need for Welsh speakers living with dementia.
- Welsh Government to engage with researchers to ensure there is a clinically validated dementia assessment tool for use in the Welsh language.

Early support and treatment for people with dementia and carers/families following diagnosis

Getting the right support at these early stages can have a significant impact on the degree to which someone is able to manage the condition over time and live independently.

The process of making a diagnosis may take considerable time, where a person has been referred at an early stage of illness and it is necessary for a 'watch and wait' approach to be taken in order to ensure a confident diagnosis. However, undue delays are often complained of by people, and a presumptive/working diagnosis of dementia, subject to a final confirmation may be helpful.

At the point of first diagnosis of dementia, all individuals should be offered access to a dementia support worker, or equivalent, to talk to about the diagnosis, what it means to them, and to be signposted to appropriate information and local facilities. At a minimum they will require advice and support to minimise the risks of further cognitive decline, a contact number for a support worker within the Memory Assessment Service to ring if they wish, and an agreed plan specifying how their condition will be monitored.

Dementia support workers are available for all newly diagnosed individuals in every primary care cluster in Wales. The Welsh Government's dementia helpline¹⁹ is also there for early advice and

¹⁹ Helpline is available on 0808 808 2235 or <http://www.callhelpline.org.uk/Dementia-Helpline.asp>

support, and we will continue to promote its use and link to other media resources.

Individuals newly diagnosed with dementia should be offered treatment in line with NICE guidance where indicated. If drug treatment is initiated, primary care and specialist services should work together to ensure that the medication is prescribed conveniently for the individual.

A diagnosis of dementia is also a good time to ensure that medications for other conditions are also reviewed, in case they are having a negative effect on concentration or memory.

Wider health needs

Early in the illness, individuals can and should be supported to manage their dementia as well as their wider health - as for most people this early, mild phase of dementia will last for many years. They must have equal access to health promoting activities, and aim to keep as well as possible for as long as possible.

For people living with dementia who also have conditions such as obesity, diabetes, cardiovascular disease or those who are drinking heavily, the risks to their health and benefits of better health management need to be explained and behaviour change supported.

It is also important to actively treat any identified health problems as many will contribute to vascular dementia, and may make any form of dementia worse.

People newly diagnosed with dementia should have access to a range of medical-psychological-social treatments that have a strong evidence base, indicating that they can slow the rate of deterioration in memory and other cognitive abilities.

Recognising the needs of carers

Carers will also want to understand what support they can expect and what they can do in practical terms to support the individual

with dementia. Under the Social Services and Well-being (Wales) Act, carers should also be offered an assessment of their own emotional, physical and social needs. If the assessment confirms they have 'eligible needs', the carer is entitled to their own support plan which sets out what the local authority will do to meet the identified needs. Local authorities must also make accessible information and advice available to carers.

Opportunities for carers' education about dementia should also be taken which may be via formal courses run by organisations such as the Carers Trust, Crossroads or Alzheimer's society. Many carers will also find peer support very helpful, both from the education sessions and through groups such as dementia cafes.

Key proposed actions:

- All people with dementia to have access to evidence based pharmacological and psychosocial interventions.
- Memory assessment services to continue to contribute to the national audit supported by Public Health Wales 1000 lives+ and work towards complying with their recommendations.
- Health boards to ensure every newly diagnosed person with dementia receives an information pack in an accessible format, including digital options and is offered access to a dementia support worker or equivalent.
- Health boards / local authorities to facilitate access to carer education and support.

Living as well as possible for as long as possible with dementia

People with dementia and their carers have the right to be able to influence and have personal choice over the care and support that is received. This support should be:

- Available within the community for as long as possible.
- Services should wrap around individual need and be flexible, wherever possible, rather than individuals having to adapt to what services exist.
- Services individualised with a focus on what can be done, rather than on what can no longer be done.

Dementia support that should be available on diagnosis includes information on what help is available at home or in the community for example:

- Signposting to advice regarding financial affairs and what financial benefits and support maybe available.
- Information and support groups for dementia and links through 111 and Dewis Cymru information and advice website, as well as books on dementia available in every public library in Wales, through the Book Prescription Wales scheme.

Support for specific groups

Provision of services should be equitable and sensitive to particular needs, for example, those who have a sensory loss or a learning disability, BAME or lesbian, gay, bisexual and transgender (LGBT+) people.

Services must be sensitive to people with a range of abilities, cultures and backgrounds and from different age-groups. Services should take steps to address this locally to improve equity, such as developing different information resources and/or appointing outreach workers.

Proposed key actions:

- Health boards and local authorities to develop specific actions to increase access for individuals who have protected characteristics.

Support for young onset dementia

The symptoms of dementia may be similar regardless of a person's age, but younger people often have different needs. Younger people and their partners are more likely:

- To be in work at the time of the diagnosis and to have financial commitments.
- To have caring responsibilities for children and their own parents.
- To be more active, stronger and fitter than much older people.

Young onset leads should be in place across Wales and work in collaboration with appropriate specialist diagnostic services, including neurology and genetics. Age sensitive day/respite care as well as support for carers and children should be made available.

Alcohol related dementia/brain damage (ARBD)

Health boards and local authorities should ensure timely diagnosis is available for people suspected of having alcohol related dementia/brain damage.

There should be clear and agreed care pathways, to specialist assessment, prompt treatment to halt illness progression as well as rehabilitation services. This can be provided with the support of the identified lead ARBD clinician present within each health board area in Wales.

All areas must ensure individual need is met by appropriate services whether in mental health or substance misuse provision. Services must work together to address the differing components e.g. for those who continue to misuse alcohol, or need to access dementia services.

Living in rural settings

There are aspects of living in a rural community which can be helpful, for instance, established community networks. However challenges faced by people living with dementia in rural areas include accessing dispersed healthcare and support services, and dispersed transport links.

Services need to be adaptable in delivering support, and consider the role that assistive technologies can play in delivering care and support to those with a dementia, particularly those who live in rural and isolated settings. Rural areas need to develop networks that consider carefully transport links and opportunities, so that people with dementia can access similar services to non rural areas.

Support for education and training of staff

A number of reports published in Wales emphasise how important it is to ensure staff are aware of how best to work with people who have dementia, as well as how best to support families and carers. Further information on education and training is on page 47.

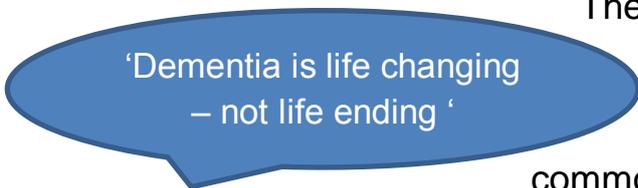
Proposed key actions:

- Health boards to meet Welsh Government targets for training of front line staff to an appropriate level.
- Social Care Wales to develop learning opportunities for the health and social care workforce, including the third sector based on *Good Work*.

The importance of the wider community

People with dementia, their families and carers continue to be a valuable part of our communities and should be respected as such. Therefore, there needs to be a range of support outside of statutory services to maintain quality of life and help people live as usual and prevent individuals and their carers becoming withdrawn, isolated and lonely.

Communities need to be encouraged to support those living with dementia. For example, libraries, leisure centres and faith buildings are often community hubs that can empower and support local people making them feel less isolated.



‘Dementia is life changing
– not life ending ‘

These do not always need to be ‘dementia specific’ but activities which can adapt to individual as well as common needs. While some

activities such as dementia cafes and dementia choirs are important, general activities such as tea dances or walking groups are good for physical and emotional health, they can offer peer support and volunteering opportunities for everyone, irrespective of age.

Training and support from statutory and third sector bodies will be needed for groups keen to open their activities to people who have dementia.

Proposed key actions:

- Health boards and local authorities to regularly map and publish available services for dementia including area service directories.
- Local authorities and health boards to work with local communities and third sector organisations to encourage them to open up their services so that people with dementia, their families and carers can participate.

Planning for the future

Each person and situation is different, and their needs will change over time, so it is important the person and family have a contact point in the months and years following a diagnosis and that care and support are flexible. This means that there needs to be a clear agreed dementia care pathway which can be individualised for each person’s specific requirements.

Services should recognise that different people with dementia, (and their carers) will have different ways of coping with and adjusting to the changes being experienced, and 'one size will not fit all'.

Support offered following diagnosis should include consideration of the need for support for:

- Adjustment, including psychological interventions²⁰ and opportunities for peer support for both people with dementia **and** carers, as well as interactive education sessions.
- Planning for the future, including signposting as to how to ensure lasting powers of attorney²¹ and advanced decisions²² are made.
- Developing a life story book (paper or digital) or similar so that the person with dementia is able to readily share important information about themselves.
- Maintaining independent living, for example' through use of memory aids, adaptations and assistive technology.
- People with dementia who have protected characteristics. Staff should receive training on how to give culturally acceptable care and support, for example to BAME, LGBT+ or Gypsy and Traveller people living with dementia.

Proposed key actions:

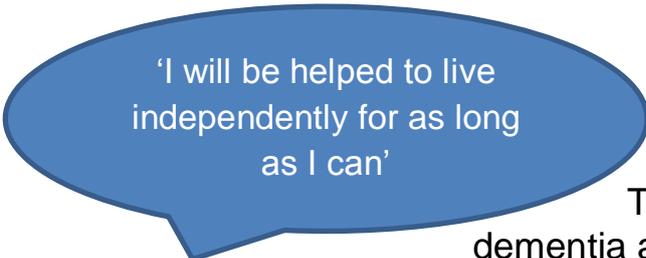
- Health boards to ensure a range of treatment options, including evidence based psychological therapies.
- People with dementia to be able to create their own life diary/story (such as 'Book of you' or 'This is me') and be involved in ongoing care planning and anticipatory decision making and care planning

²⁰ [https://www.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20\(FPoP\)/public/clinical_psychology_in_early_stage_dementia_care_pathway.pdf](https://www.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20(FPoP)/public/clinical_psychology_in_early_stage_dementia_care_pathway.pdf)

²¹ <https://www.gov.uk/power-of-attorney>

²² <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

Support to stay safe and secure in the home and community



'I will be helped to live independently for as long as I can'

Practical support is critical to being able to live independently for as long and as well as possible.

This is what most people with dementia ask for and expect. This support may be environmental for the home or relate to financial or personal care.

The physical home environment may have hazards that can be identified by an assessment from appropriate staff. In 2015 the fire service in Wales completed 63,027 safety checks, many of which were for people with dementia. In future years fire services plan to address a wider range of domestic safety risks for vulnerable groups, which will further support safety in the home for people with dementia.

Notable practice examples: The Care and Repair scheme which operates in every local authority in Wales helps older people who are homeowners or private tenants to repair, adapt and maintain their homes. They visit to discuss what repairs or adaptations are required, the possible solutions, the likely costs and sources of funding.

In some areas, police forces have worked with health services to provide cards with key phone numbers that can be carried by individuals with dementia, so that they are to hand should the person become lost.

Practical support may require a needs assessment being undertaken by a social worker or other team member. Home support services for both personal care and/or day to day tasks such as shopping and cooking will need to be assessed by social services, and the need for nursing support if required through the NHS assessment for continuing healthcare. Support in ensuring medication is taken as prescribed is an important factor in maintaining independence.



'I do not want to repeat my needs over and over again'

What is important is that assessments by health and social care are joined up and that both have a role in identifying other specialist support services to meet people's needs in a flexible way, focussing on what matters to individuals and the outcomes they want from support.

Local authorities must also ensure carers are offered an assessment of their own support needs – and for those with 'eligible needs' to have their own support plan, which sets out what the local authority will do to meet these needs.

Local authorities and health boards are also expected to involve people living with dementia, their families and carers in the design and planning of services. Involving people as much as possible in their care, support and treatment is central to the provision of effective, safe, respectful and dignified services.

Proposed key actions:

- Local authorities and health boards to develop a 'team around the individual approach' - assisting people with dementia and their families and carers to access information, advice and support to maintain their independence and quality of life.
- Welsh Government to ensure Regional Partnership Boards (required through the Social Services and Well-being (Wales) Act), to specifically consider as a priority area, ways to integrate services, care and support for older people with complex needs, including dementia

Role of technology

Telecare, telehealth and assistive technology can also help people live independently, with more confidence, for example:

- Movement sensors can help detect potential emergency situations, and alert devices can summon help through a local authority alarm call system.
- Devices to support and remind people to take medication.

- Adaptive aids that can help e.g. phones with photos next to a one button call system, or aids for bathing.

Occupational therapy and physiotherapy provision can ensure the right assessment to determine what specific adaptations and support will best meet any particular individual's needs. This may include reablement services to support the person with dementia and their carers.

Proposed key actions:

- Explore options to expand the use of telehealth, telecare and assistive technology.
- Ensure access to services such as occupational therapy to ensure appropriate aids and appliances are in place.

Safeguarding

Many of the symptoms that are often a part of having dementia can increase vulnerability. Sometimes people are taken advantage of or hurt by strangers, but the largest proportion of abuse and neglect happens within the home. This may occur when the carer or family is under stress.

Neglect and abuse can come in a variety of forms - financial, emotional, physical and sexual abuse as well as withdrawing or not supplying adequate food, drink, warmth, physical protection or cleanliness.

It may be difficult for people to express their concerns if they are reliant on others to provide their care, especially if they are fearful of being moved from their home, or physically hurt.

People with dementia and carers should be able to get help as soon as they have any concerns. Understanding the illness, advice on how best to communicate and how to avoid some of the common pitfalls can make a significant difference. Sometimes meeting together as a family can help to make plans that keep everyone safe.

Raising concerns

Each NHS organisation, NHS-funded provider and local authority should follow all-Wales policies and procedures. For NHS organisations, an all Wales procedure for staff to raise concerns within NHS Wales was issued in February 2015²³.

To ensure protection for all, staff should be encouraged and supported to raise concerns about poor care in accordance with these policies and procedures, and these concerns should be listened to and, where appropriate, acted upon.

The Social Services and Well-being (Wales) Act 2014 required local authorities to establish a Safeguarding Board. The Safeguarding Boards' function is to protect adults in its area who have needs for care and support, (whether or not the local authority is meeting any of those needs directly), and are experiencing, or are at risk of, abuse or neglect.

Anyone with concerns about an adult's safety should contact the local authority or police in line with all-Wales policies.

Prompt problem management

Some people with dementia have times when they become so distressed, fearful, angry or frustrated that those seeking to provide care and support find it difficult to calm the situation or know how best to respond. These situations may develop in the person's home, in hospitals or care homes. Not all people with dementia experience these levels of distress, but when they occur they affect the quality of life of both the person with dementia and those supporting them.

The specific causes of these experiences vary between individuals, and may be different for the same person at different times. The

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[http://www2.nphs.wales.nhs.uk:8080/PHWPapersDocs.nsf/\(\\$All\)/22491CF0DD9F797380257E2A0057FD45/\\$File/38%2010%20All%20Wales%20Procedure%20of%20NHS%20Staff%20to%20Raise%20Concerns.pdf?OpenElement](http://www2.nphs.wales.nhs.uk:8080/PHWPapersDocs.nsf/($All)/22491CF0DD9F797380257E2A0057FD45/$File/38%2010%20All%20Wales%20Procedure%20of%20NHS%20Staff%20to%20Raise%20Concerns.pdf?OpenElement)

trigger is sometimes a physical health problem or it can be a reaction to something in the person's environment that is perceived as a danger or a threat. Identifying the cause is the first stage in resolving the problem.

Problems can sometimes be prevented, by maintaining familiar routines avoiding situations or places likely to cause upset, or avoiding confrontations and arguments arising from 'correcting' the person.

Where the distress is extremely severe, and/or there is a danger of harm, good practice NICE guidance includes the use of medication, such as certain major tranquillisers or 'antipsychotic medication'. These should only be used in the short-term and be reviewed regularly, in view of the serious side effects associated with them. This requires careful audit and monitoring of antipsychotic use. Psychosocial approaches, including engaging in personalised social activities should always be implemented first or in emergency situations alongside medication.

Care staff and family carers will often require support from specialists, such as community mental health nurses and clinical psychologists, in identifying creative strategies to respond to these difficult situations effectively.

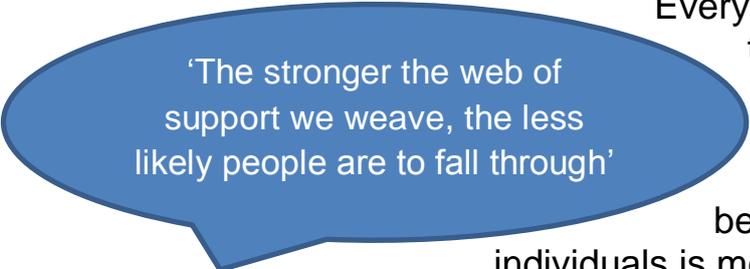
Proposed key actions:

- Reduction in percentage of people with diagnosis of dementia receiving inappropriate anti-psychotic medications and reduction in duration, particularly in care homes.
- Social Care Wales to explore the development of specialist roles and to deliver outcomes focused care and support.

The need for increased support in the community

As the illness progresses the needs of people with dementia and their families and carers will change. Some individuals with dementia will be diagnosed and may not need to receive more than support and advice from their GP and third sector organisations/dementia support workers. However for many others, there will be points in the illness where there is a need to access more support whether in the community, residential care or in hospital.

Increasing needs for care and support in the individual's home



'The stronger the web of support we weave, the less likely people are to fall through'

Everyone has the right to care that is effectively planned and reviewed to ensure that the support and treatment being offered to individuals is meeting their needs.

Local services will need to be flexible and 'wrap around' the individual where ever they live.

If someone with dementia chooses to live in their own home for as long as possible, local services need to recognise and support that choice. To do this effectively, there needs to be integrated working across health, local authorities, the independent and third sectors. This support may take a variety of forms including personal care or the provision of home respite support for carers to have breaks.

Where individuals have carers, taking a team around the carer supportive approach, with carers as part of the team, is desirable. They will want access to advice and support to learn how to better manage the changing behavioral needs and psychological symptoms of dementia in the person they care for.

Services need to respond quickly when challenges or crises occur and avoid carer breakdown or hospital admission. This can lead to

further problems and reduces the chances of an individual maintaining an independent life in their own home. This response may require specialist intensive support from social services and/or mental health staff with training and experience in the resolution of such problems, for a limited period.

Some people may wish to consider moving into a supported living community, in order to maintain their independence for as long as possible, and again this choice must be respected and supported. Housing providers and local authorities should review the demand for such provision locally and respond appropriately.

As care needs increase, there will also be a need for primary care providers, including for example, dentists and opticians, to consider the adjustments that they need to make to their services to enable their patients living with dementia to access them.

Proposed key actions:

- Ensure access to services which are non-specialist but can support people with dementia access other assistance needed e.g. financial advice.
- Health boards /local authorities to ensure that there are processes in place to undertake 'satisfaction surveys' for both people with dementia and their family and carers.
- Welsh Government to examine a national approach to respite care.

Addressing workforce training needs

The whole public-facing workforce needs to have appropriate knowledge and skills to meet the needs of people with dementia. This applies across health, social care, independent and third sector organisations. Further information on education and training is on page 47.

Key proposed action:

- Public services, domiciliary care agencies and care homes to shape their workforce development plans in line with '*Good Work: Dementia Learning and Development Framework*' to ensure that staff have an appropriate level of training in relation to dementia.

Good care in hospitals

The average age of people being treated in the general hospital population has increased. One in four patients in district general hospital beds now has dementia. This impacts on nearly every ward as well as in community hospitals and health boards must plan their services accordingly, so that wards are dementia friendly and responsive to the needs of their patients.

Hospitals must embed a clear values based approach to ensure that the right of people living with dementia to be treated with dignity and respect at all times is assured. The Trusted to Care²⁴ report provided clear recommendations about how to best care for people with dementia in general hospitals. Guidance has been issued on how clinical settings in Wales should become more suitable for older people and those with dementia.²⁵ For example toilet doors painted in a contrasting colour (normally yellow), large picture signs and having a calm environment at night with dimmed lighting levels. There are many models for adapting care settings, (including primary care settings) to better suit the needs of people with dementia such as the King's Fund²⁶ and the University of Stirling²⁷ work.

Hospital wards in Wales are also expected to be able to clearly demonstrate the benefits of initiatives such as 'This is me'²⁸, which are designed to ensure that individual needs of people with dementia are identified.

Key proposed action:

- Increase the number of hospital settings in Wales that are dementia supportive and can demonstrate that their working practices reflect the needs of people living with dementia and their carers, such as use of 'This is me'.

Acute admissions

²⁴ <http://gov.wales/docs/dhss/publications/140512trustedtocareen.pdf>

²⁵ [NHS Wales: Infrastructure guidance](https://www.nhs.uk/infrastructure-guidance/)

²⁶ <https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia>

²⁷ <http://dementia.stir.ac.uk/>

²⁸ https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290

There is a growing range of evidence highlighting the risk of people with dementia losing independent living skills as a consequence of an acute hospital admission. This risk should be considered as part of the care planning and management of people with dementia, with the aim of either preventing the admission from A&E or reducing length of stay. Individuals assessed as having mental capacity have the right to decide to return to their home after an illness, even if staff judge there to be risks to that choice.

Psychiatric Liaison services provide a single point of contact, enabling early detection of an individual's problem to enable rapid and appropriate intervention, such as additional support for their stay from new flexible resource teams, or continuity of care for people already known to services. They will also offer general advice and support and help with discharge planning to assist in providing a better inpatient experience.

Proposed key actions:

- Older people being admitted to acute hospital should have screening for dementia and delirium and be able to access comprehensive geriatric assessment to support the implementation of a personalised care plan.
- Acute hospital pathways should reflect the growing proportion of people with dementia accessing acute care.

More specialist care and support

The aim of older persons community mental health teams (OP CMHTs) is to support people with complex mental health needs, including dementia, to live independently as long as possible. Individuals have a right to mutually agreed care and treatment plans as required under the Mental Health (Wales) Measure 2010²⁹ and this plan seeks to prevent crises before they happen.

OP CMHTs and memory assessment services will need to be multidisciplinary with a range of staff with expertise in the assessment, care and treatment of mental health conditions commonly occurring for older people including dementia. They

²⁹ <http://gov.wales/topics/health/nhswales/mental-health-services/law/measure/?lang=en>

should support care homes to better understand and manage individuals' needs as well as having a role in monitoring medication and discussing with the individuals GP if changes should or could be made. They will also be able to support training and understanding of staff in the homes following *the 'Good Work: Dementia Learning and Development Framework'* and encourage care homes to deliver a range of therapeutic activities. They can also offer direct advice to care home settings when required if an individual's behaviour changes.

Learning disability specialist teams should interact and support individuals in their homes and care homes if they develop dementia. The Welsh Government is developing a learning disabilities action plan which will also consider what support is required in this area.

Older person's mental health inpatient units

These highly specialist units must be expert in providing a person-centred, holistic and respectful care culture.

Welsh Government guidance states that units are more dementia centred through proper signage, contrasting coloured toilet doors and by ensuring dietary needs and wishes are catered for. People with dementia and families or carers should be encouraged to provide materials such as photographs for their rooms to create a familiar environment

The reasons why any sedative or anti-psychotic medication has been prescribed should be recorded, along with duration, in line with NICE guidance. Wards should also ensure the provision of effective and regular pharmacy input into all multidisciplinary teams.

Units should, where possible, be flexible to fit in with a person with dementia's needs and not just fit around staff routines. This can include flexibility around meal time or letting people sleep and wake at their own pace. Allowing visiting times to be more flexible is important especially in areas where transport links are poor.

Wards should be open, welcoming and places which can facilitate family carers to continue to support a person with dementia whilst they are in hospital if they wish. Relatives and carers should be valued by services as they provide an irreplaceable source of information as well as potential support and care for the person with dementia.

It is important to ensure that people can access daily activities which are enjoyable, meaningful and support feelings of self worth. This will include working with occupational therapists but also with the wider community being invited in for specific activities.

The delivery of care needs to be both 'person centred' and coordinated between the numbers of professionals who will need to input into an individual's care over a period of time. A community of practice for older person's mental health wards has been established in Wales, to ensure clinicians share good practice and how to learn from and emulate best practice.

There must be parity between physical and mental health care. Older person's mental health liaison teams can provide support and advice in physical health care settings, and similarly support and advice must be available from physical healthcare teams on older person's mental health wards.

Proposed key action:

- All older person mental health units to have agreed care pathways for accessing regular physical healthcare.

Capacity for decision making

The Mental Capacity Act (2005) assumes all people have the capacity to make their own choices and decisions, even if others consider them unwise. One of the key aims of the Social Services and Well-being (Wales) Act is for individuals to be at the centre of decisions about them and to be supported to have choice and control over their lives.

All efforts must be made to enable people to make and communicate their decisions for as long as possible. If the capacity to make some decision is lost, a best interest decision may need to be made on the person's behalf, especially if personal circumstances change. These must always be the least restrictive and least intrusive needed to make sure the person gets the care they need.

Individuals without the capacity to agree to their care and treatment in hospital may also be subject to the Deprivation of Liberty Safeguards (DoLS). DoLS provides assurance that the care and treatment a person is receiving is in their best interests and is the least restrictive needed.

Advocacy arrangements

Access to advocacy is important as this empowers and supports people living with dementia to express their views, wishes and concerns, to support them in their choices and securing entitlements.

When admitted to any hospital, individuals with dementia should have access to effective non-instructed advocacy or an Independent Mental Capacity Advocate (IMCA) and Independent Mental Health Advocate (IMHA) in the most appropriate manner depending on individual circumstances.

Key proposed action:

- Health boards /local authorities have clear processes in place to ensure that all people living with dementia who are eligible for an independent advocate are able to do so.

Care Homes

While the aim is usually to support people to remain in their own home for as long as possible, there will always be occasions when people's preference is to live in a care home, or when the risk or demand on carers would be too great for them to remain in their own home. There are also circumstances where care homes are

commissioned to provide residential respite care to enable carers and family members to have a break.

A significant number of people in care homes will have dementia, due in part to the age profile of residents. Care homes need to be considered as an individual's home and all the principles of living well with dignity and respect and having as healthy a lifestyle as possible still apply.

Staff working in care homes need to be supported to recognise and work well with people with dementia. They should understand how to help people with dementia understand their surroundings better, for example where their bedroom is by using a familiar photograph next to the door, or at night giving cues that it is bed time by lowering light and noise levels or even staff wearing pyjamas can be helpful. Similarly if people have good routine and they have opportunities for stimulation they will be more settled – all of which is important in creating the right homely, but therapeutic care home environment.

There needs to be clear governance and commissioning arrangements for all individually and state funded placements. The Welsh Government is in the process of finalising a 'Directed Enhanced Service' (DES) for care homes and as part of the specification will ensure that there is a comprehensive review of physical and mental health for all residents when they move into a care home. This will include a review of medication, including antipsychotic prescribing.

Care homes should also work closely with carers so that if they wish to they can continue to be part of the care team involved in day to day care. Ensuring older people and their families or carers have a positive experience whilst in a care home is crucial.

Key proposed action:

- Health boards to ensure implementation of care homes Direct Enhanced Service.

End of Life care

Dementia is a long term condition and accounted for 15% of female deaths in 2015, which was the leading cause of death, and it was the second highest cause of death for men at 11%. Many more people will die of another condition alongside dementia.

Options and access to palliative care at the end of life should be the same for a person living with dementia as for any other individual in our community.

In 2015 the Alzheimer's Society Wales and Marie Curie published a report entitled 'Living and Dying with dementia in Wales: Barriers to Care'³⁰. The report highlights that dementia is often not recognised as a terminal diagnosis, which can lead to poor access to care, inconsistent quality of care and inadequate pain management

The explicit wish of most people, with dementia and without, is to die at home, yet hospital often ends up being the 'default' option for many people. Understanding that people and families have the right to choose where to end their lives is important.

Services should be designed to provide comfort and care to both the person with dementia, their families and carers. This needs to be done sensitively and opportunities to discuss the importance of making advance decisions need to be taken early in the illness course. These discussions should include where people would prefer to die.

It is important that such discussions are held while the individual has the capacity to make meaningful choices for themselves in discussion with carers/family. As with any life limiting condition conversations should be held sensitively but openly. This requires appropriate staff in dementia services to be trained to hold such conversations. Staff in dementia care should be taught how to use their skills to identify needs for care in the individual and palliative care staff being trained to better understand and manage advanced

³⁰ <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf>

dementia symptoms in all settings including the home, hospices and care homes.

An agreed palliative care pathway should be in place, so a dignified death at home is integral to care. Where this is a care home, health professionals should support them in enabling end of life care.

The *Together for Health - Delivering End of Life Care* delivery plan is currently being refreshed to cover the period 2017-2020. This document will set out the expectations of the NHS in Wales to deliver high quality end of life care, regardless of diagnosis, circumstance or place of residence in Wales.

Proposed key actions:

- Health boards, local authorities, primary care clusters and third sector providers should:
 - Support people who have been diagnosed with dementia and their families to better plan ahead for their end of life care.
 - Identify professionals who would benefit from training in initiating serious illness conversations, and provide such training.
 - Work with bereavement services to recognise the differing needs of families and carers of those with dementia.
- All relevant health and social care professionals, including care home workers, should be trained and supported to help people and their family/carer think about end of life care and develop care plans.

Supporting the plan

Education and Training

The *'Good Work: A Dementia Learning and Development Framework for Wales'*³¹ has been developed by the Care Council for Wales in collaboration with partners. *'Good Work'* describes a value based approach to dementia education and training.

Staff need to be able to demonstrate appropriate learning opportunities as identified in the Older People's Commissioner report *'Dementia: more than just memory loss'*. The *Good Work: Learning and Development Framework* looks to ensure the expectations and standards are the same across care home and health sectors.

The framework provides a benchmark for learning that ranges from a basic awareness of dementia to the more in-depth knowledge and skills that people need when they directly work with people with dementia, their families and carers. It also describes the areas of learning needed for people who influence service provision, such as senior managers or commissioners. Improving services and outcomes for people with dementia will also be one of the priorities for the newly established Social Care Wales³².

Health boards have been set an initial target that all staff will have appropriate training, and meet the requirements of the 'informed' level of Good Work; there is a similar expectation for other sectors. Staff who deliver direct care to people with dementia will be expected to meet the competencies in the 'skilled' level and those who have managerial, leadership and responsibility for service development will be expected to meet the 'influencer' level of Good Work.

³¹ <http://www.ccwales.org.uk/dementia-care/>

³² Care Council will be changing into Social Care Wales from April 2017 - See more at: <http://www.ccwales.org.uk/we-are-changing/>

Research

Continued research will allow us to better understand the causes and management of dementia, which will enable the development of new treatment and care approaches. It will also help us to understand what matters to people living with dementia, and how we can best work together to enable people to live full and healthy lives for as long as possible.

Research which is based on the principle of people living with dementia, including families and carers being co-researchers, should be encouraged and developed to consider ways of addressing inequalities experienced by people with dementia. All research should include equality statistics.

Wales has been at the forefront of dementia research for some years. The Welsh Government is committed to developing policy and supporting health and social care research in Wales and invests £43m annually in health and social care research through Health and Care Research Wales; including over £0.5m in the Centre for Ageing and Dementia Research.

Notable research

Researchers at Swansea lead the Health and Care Research Wales Centre for Ageing and Dementia Research, who is addressing key internationally important questions in ageing and dementia. The Centre integrates multi-disciplinary activity and develops areas of expertise from biological, through psycho-social and environmental, to social policy in ageing and dementia.

Cardiff and Swansea are two of ten universities involved in the Medical Research Council's (MRCs) UK Dementias Research Platform (UKDP), which aims to take new approaches in the detection, treatment and prevention of dementia. The project is a £16m public-private partnership.

Bangor University's Dementia Services Development Centre are leading the way in providing research and practical advice about new ways to support people who have dementia, and their families

and carers in order to enrich their lives. The Centre also coordinates Welsh involvement in the Join Dementia Research platform³³ which works towards bringing together people who are interested in taking part in research.

Bangor's work also includes leading the ESRC funded Cognitive Function and Ageing Study – Wales (CFAS-Wales) looking at how people maintain function and well-being in later life. The Welsh project will follow 5,000 older people aged over 65 across two points in time to investigate stability and change over time.

The work of care and support services, in conjunction with the Health and Care Research Wales workforce and leading centres of dementia research in Wales, is aiming to provide more opportunities for people affected by dementia and their carers and families to participate in health and social care research wherever they live in Wales.

The Involving People Network³⁴ of Health and Care Research Wales provides opportunities for members of the public to influence the research agenda. Increasingly, people with dementia and carers are working with research teams in Wales to help design, conduct and disseminate research, helping to ensure that it is carried out 'with' rather than 'on' or 'for' them.

³³ <https://www.joindementiaresearch.nihr.ac.uk>

³⁴ <https://www.healthandcareresearch.gov.wales/involving-people-network/>

Key actions:

- Welsh Government and NHS to work with Health and Care Research Wales to support dementia related research studies undertaken in Wales.
- Put in place mechanisms for uptake of best practice and service change to improve clinical practice and individual outcomes.
- Social Care Wales to work with research partners to identify interpret and share lessons from research to support service improvement and practice development.
- Welsh Government to consider with Public Health Wales (PHW) supporting a dementia mapping project across Wales.
- Memory clinics to ensure that all people with dementia and their carers are informed of opportunities to be involved in research if they wish to, including as co-researchers.
- To develop research that uses public health approaches to consider ways of addressing inequalities experienced by people with dementia.

How we will know – High Level Performance Measures
Increase the number of dementia friends and dementia communities in Wales. Source: Alzheimer’s Society Cymru (Annually)
Increase in the number of corporate / public bodies who are participating in dementia friends training or working towards ‘dementia friendly status’. Source: Alzheimer’s Society Cymru (Annually)
Increased number of primary care settings, hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting. Source: Health boards (Annually)
Increase in the take up rate of the dementia helpline. Source: Welsh Government/Dementia helpline call rate (Annually)
Percentage of NHS employed staff who come into contact with the public who are trained in an appropriate level of dementia care (as specified in - ‘ <i>Good work – Dementia Learning and Development Framework</i> ’). Target: 75% by end of 2019. Source: Health boards (Annually)
Population assessments required by the Social Services and Well-being (Wales) Act to include the care and support needs of older people with complex needs (dementia) and this information is used to publish local area plans. Source: Health boards / local authorities
Numbers / % of carers offered an assessment and for those with ‘eligible needs’ to be offered a support plan. Source: Local authorities (Annually)
Clear evidence based care pathway in place and published for each health board – this pathway to include access to ‘wraparound’ support. Source: Health boards (return to local mental health partnership boards (LMPHB) by December 2017)
Increase the number of people formally diagnosed with dementia from 51% in 2016, increasing 3 percentage points annually i.e. 54% by December 2017, 57% by December 2018, 60% by December 2019, 63% by December 2020 and 66% by December 2021. Source: Welsh Health Stats Quality and Outcomes Framework (QOF) Data

All memory services to involve people with dementia and carers in feedback and service development. Source: Health boards
Every person referred for an assessment of dementia receives a first assessment by 28 days and a working/preliminary diagnosis within 12 weeks (when it is clinically possible to do so). Source: Health boards
All newly diagnosed people with dementia to be offered access to a support worker depending on need after diagnosis. Source: Health boards
Reduction in the percentage of people with a diagnosis of dementia prescribed antipsychotic medications and a reduction in duration of treatment. Source: Health boards local audit report to LMHPB by June 2018
District General Hospitals have psychiatric liaison service / support worker team in place. Source: Health boards

GLOSSARY OF TERMS

1000 lives+	1000 Lives Improvement is the national improvement service for NHS Wales delivered by Public Health Wales. Its aim is to support the NHS to improve outcomes for people using services in Wales.
ACE	Addenbrooke's Cognitive Examination (tool)
CALL	Community Advice & Listening Line (helpline)
Carer	A carer is anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who needs care and support.
Case finding	Is a strategy for targeting resources at individuals or groups who are suspected to be at risk for a particular disease. It involves actively searching systematically for at risk people, rather than waiting for them to present with symptoms or signs of active disease.
CCW	Care Council Wales
DEEP	Dementia Engagement and Empowerment Project
Dementia	The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes.
DES	Directed Enhanced Service
DOLS	Deprivation of Liberty Safeguards
IMCA	Independent Mental Capacity Advocate
IMHA	Independent Mental Health Advocate
IMTP	Integrated Medium Term Plans
MCA	Mental Capacity Act
MCI	Mild Cognitive Impairment: is a clinical state where people have impairment of cognition that is not significant enough to be diagnosed as dementia.
NICE	National Institute for Health and Care Excellence

OP CMHT	Older Person Community Mental Health Team
PHW	Public Health Wales NHS Trust
Protected Characteristics	<p>Protected characteristics are as follows:</p> <ul style="list-style-type: none"> • gender • race • faith or belief • sexual orientation • age • pregnancy and maternity • being married or in a civil partnership • being a disabled person • being transgender. <p>As defined by the Equalities and Human Rights Commission: more information at: https://www.equalityhumanrights.com/en/equality-act/protected-characteristics</p>
Prudent Health and Care	<p>The public sector faces the dual challenges of rising costs and increasing demand, while continuing to improve the quality of care. Since the publication of the strategy, the Welsh Government has developed a number of principles of Prudent Health and Care which it expects services, or individuals providing a service, to adhere to. These are to:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Achieve health and well-being, with the public, patients and professionals equal partners through co-production. <input type="checkbox"/> Care for those with the greatest health need first, making the most effective use of all skills and resources. <input type="checkbox"/> Do only what is needed, no more, no less; and do no harm. <input type="checkbox"/> Reduce inappropriate variation using evidence based practices consistently and transparently. <p>Further examples of this approach can be found via the Welsh Government's prudent</p>

	healthcare resource www.prudenthealthcare.org.uk .
UNCRC	United Nations Convention on the Rights of the Child.
QOF	Quality and Outcomes Framework
SCI	Subjective Cognitive Impairment: is a clinical state where the individual experiences problems with their memory but cognitive testing is normal.
Screening	The primary purpose of screening tests is to detect early disease or risk factors for disease in large numbers of apparently healthy individuals.