



Llywodraeth Cymru
Welsh Government

Dementia Action Plan for Wales

2018-2022



Taking Wales Forward

Contents

- 7 **Chapter 1**
Risk reduction and delaying onset
- 9 **Chapter 2**
Raising awareness and understanding
- 12 **Chapter 3**
Recognition and identification
- 15 **Chapter 4**
Assessment and diagnosis
- 18 **Chapter 5**
Living as well as possible, for as long as possible with dementia
- 23 **Chapter 6**
The need for increased support
- 28 **Chapter 7**
Supporting the implementation
- 31 **Annex 1**
Meeting the needs of specific groups
- 33 **Annex 2**
Detailed action Plan
- 43 **Annex 3**
How we will know – High Level Performance Measures

Ministerial Foreword

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Cabinet Secretary for Health and Social Services

We have a clear vision for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities.



We want to create a society without stigma – where people living with dementia continue to go about their day to day life with the wider public who are understanding and know how to provide support.

This is not something that health and social services can do alone.

Achieving a dementia friendly nation requires a cross-Government, multi-agency and society wide response. Our national strategy, Prosperity for All, challenges us to work differently, not just across portfolios within Government, but also with our partners and stakeholders.

We recognise that dementia is a significant health and social care issue which impacts not only on those living with dementia, but on their families, friends and carers too. We also recognise that whilst dementia is more common in older people, we also need to support those with young onset dementia.

This plan positively responds to this challenge; setting out the range of stakeholders who can support this agenda and the actions required to make a real change. It has been developed with those who know most about what needs to be done to improve truly person-centred dementia services – those with lived experience of dementia, their families and carers and service providers.

As a signatory to the Glasgow Declaration¹ the Welsh Government has previously committed to promote the rights, dignity and autonomy of people living with dementia. Through our engagement with stakeholders we heard about the positive work of Dementia Action Alliance in developing a series of statements with people living with dementia and their carers².

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

² Further information can be found at: <https://www.dementiaaction.org.uk/nationaldementiadeclaration>

These are:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause cure and care for dementia and be supported to take part.

We have adopted the principles of these dementia statements which not only underpin our plan, but will be considered in the implementation of all its actions.

We have a strong platform to build on. In the last few years we have provided additional funding to support improvements in dementia care. This includes the introduction of dementia support workers, occupational therapy support in older people mental health units, and teams working within our district hospitals to support

people with dementia. We have also supported closer working between primary care and residential homes through our link nurses. In response to the most recent evidence we have shifted a focus to risk reduction to raise awareness of the steps a person can take to reduce the risk, or delay onset, of certain dementias.

This document responds to what we have been told through the extensive engagement and consultation process and emphasises the right of people living with dementia to person-centred, coordinated and quality care. From this engagement we know that services need to be adaptable to meet the individual needs of people with dementia – for instance those with young onset dementia and those with other conditions where dementia is more common. The quotes embedded throughout the document are taken directly from our consultation and represent the expectations of those affected by dementia.

Our service and community response needs to be equitable – whether you live in a rural or remote area or in a town, and it needs to meet diverse needs, for instance people with protected characteristics who may be living with dementia and people who may be able to understand only their first language as their condition progresses. These principles of equitable access will underpin each of the actions set out in the plan. Please see further information in annex 1.

As a result of views expressed in our consultation and engagement processes we have structured this action plan around outcomes which follow a pathway approach to dementia care.

These outcomes are:

- Individuals will understand the steps they can take to reduce their risk, or delay the onset, of dementia.
- The wider population understands the challenges faced by people living with dementia and are aware of the actions they can take to support them.
- People are aware of the early signs of dementia; the importance of a timely diagnosis; and know where to go to get help.
- More people are diagnosed earlier, enabling them to plan for the future and access early support and care if needed.
- Those diagnosed with dementia and their carers and families are able to receive person-centred care and support which is flexible.
- Research is supported to help us better understand the causes and management of dementia and enables people living with dementia, including families and carers, to be co-researchers.
- Staff have the skills to help them identify people with dementia and to feel confident and competent in supporting individual's needs post-diagnosis.

To support the delivery of our vision we are investing an additional **£10 million a year** from 2018/19 to support the delivery of key actions in this document, which include

- Developing 'teams around the individual' to provide additional support for people with dementia and their families/carers.
- Reviewing and standardising the role of dementia support workers – increasing their numbers as required.
- Development of an All Wales Dementia Allied Health Practitioner Consultant post which will give advice and support to health boards and local authorities to drive forward service improvements.
- Increasing the rate and timeliness of dementia diagnosis.
- Strengthening collaborative working between social care and housing to enable people to stay in their homes longer.
- The roll out of the 'Good work – Dementia Learning and Development Framework' to enable people who work with those living with dementia to have the skills to recognise symptoms earlier and help them feel confident and competent in caring for and supporting those living with dementia.
- Introducing the principles of 'John's Campaign' across all health boards and trusts.

Alongside this document we will also publish a compendium of notable practice to assist service planners and commissioners in the implementation of this plan.

We will also ensure that we have mechanisms in place to continue to engage and listen to the experts by experience.

The action plan, a result of working with and listening to a wide range of stakeholders, is ambitious and person-centred. This co-productive approach will continue throughout its implementation and will involve people living with dementia, their families and carers being equal partners.

How will we measure progress?

Progress against delivery of the plan will be overseen by a Dementia Delivery Assurance and Implementation Group (DDAIG). Membership of this group will include people living with dementia and their carers and families. Progress against this plan will also be a key vehicle for demonstrating achievements and areas for improvement outlined within the Health and Care Standards for Wales.

The actions in this plan are summarised in Annex 2 to assist with monitoring progress. These will be formally reviewed after three years to ensure they remain ambitious and relevant. It is also recognised that through the implementation of any plan things do change and in certain areas we have detailed that further work is needed.

This will be reflected in the work of the DDAIG.

Risk reduction and delaying onset

There is increasing evidence that there are steps people can take to reduce their risk of developing certain dementias or to delay their onset^{3,4} In 2014 we signed up to the Blackfriars Consensus⁵

in recognition of the importance of improving awareness that simple changes to lifestyle can reduce the risk of dementia.



‘I can make informed choices about my lifestyle...’

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

4 <https://www.scie.org.uk/dementia/symptoms/diagnosis/risk-factors.asp>

5 http://nhfshare.heartforum.org.uk/RMAssets/Reports/Blackfriars%20consensus%20%20_V18.pdf

Since then we have published guidance on dementia risk reduction and we have launched national campaigns to increase awareness that it is never too early or too late to make changes to your lifestyle, by following **six simple steps**.

These are:

- 1 Be physically active
- 2 Maintain a healthy weight
- 3 Be socially active
- 4 Avoid drinking too much alcohol
- 5 Stop Smoking
- 6 Commit to review your health

Healthy lifestyle choices remain beneficial following a diagnosis and can help people to feel better, improve wellbeing and help maintain mobility.

We shall continue to respond to the emerging research to ensure that people can access evidenced based advice and information to lower their risk of dementia. We will need to make this information available across all the different groups in Wales.

We will:

- Ensure that risk reduction messages are included in relevant public health policies and programmes.
- Promote action across the six steps to support people to change behaviours and reduce their risk of dementia.
- Ensure that people living with dementia receive advice about the changes they could be supported to make to increase their general health and wellbeing.

What will be different:

People understand the steps they can take to reduce their risk, or delay the onset of certain dementias.

“ *Nothing about us without ALL of us – how can we feel valued if we are not included from the very beginning* ”

Raising awareness and understanding

Our consultation has told us that stigma and discrimination can result in a fear and reluctance to seek help and advice when the early signs of dementia arise.

We have also been told that a diagnosis of dementia can make people feel excluded and less welcome in everyday activities they used to enjoy, leading to feelings of loneliness and isolation.



‘I feel included and valued in my community...’



Some people also reported a lack of understanding from family members, and among health professionals, including their GPs.

We will:

- Work with the third sector and people with lived experience to increase the number of people in Wales who are able to recognise dementia through expanding initiatives such as dementia friends and dementia supportive communities / organisations.
- Local authorities and health boards to work with local communities and third sector organisations to encourage them to open their services so that people with dementia, their families and carers can participate.
- Publicise and actively encourage educational settings to use the “Creating a Dementia Friendly Generation” resources developed by the Alzheimer’s Society to build inter-generational understanding and awareness.
- Ensure NHS-employed staff who come into contact with the public (including porters, receptionists and medical / support staff) receive an appropriate level of dementia care training (as specified in – ‘Good work – Dementia Learning and Development Framework’⁶).

Lower levels of awareness about dementia and the existence of stigma within some minority ethnic communities in Wales can also result in these groups being under-represented in dementia services⁷.

We need to make sure that all sections of our population have the same opportunities.

Overcoming these issues will require continued public education initiatives and awareness training so that more individuals, communities, businesses and public authorities have a better understanding of dementia.

This will enable people to understand the challenges faced by those living with dementia and how they can make small changes that could help.

Those that are involved in the planning and designing of public spaces such as shops, parks and transport systems, will be encouraged to have processes in place to consider and involve people living with dementia in their design and audit processes in order to understand their needs.

“Wales should be a place where people with dementia feel understood, engaged, included and valued”

⁶ <https://socialcare.wales/resources/good-work-dementia-learning-and-development-framework?record-language-choice=en-cy>

⁷ <https://www.scie.org.uk/publications/briefings/briefing35/>

We will:

- Work with local authorities, local health boards and Public Health Wales so the needs of people living with dementia are considered as part of planning processes.
- Ensure that transport planners / operators consider the needs of people living with dementia in the development of their services including major contracts such as the 'metro' and the rail franchise, to improve access to passenger transport information, enabling people to plan and undertake journeys on the public transport network.
- Develop and undertake training designed to raise awareness amongst transport workers of the barriers that are encountered by those with dementia when using public transport.

What will be different:

People understand the challenges faced by people living with dementia and are aware of the actions they can take to support them.



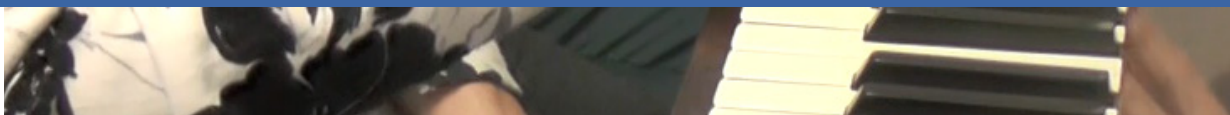
Recognition and identification

We understand that people may be reluctant to go to the doctor when they are worried that they may have dementia. We need to ensure people are aware of the benefits of a timely diagnosis.

We also want professionals to know what options are available for treatment and support if they refer people for a formal diagnosis.



‘I am aware of the signs and symptoms of dementia and I know where to go to seek help if I am worried...’



Many people are worried about dementia as they grow older, but some symptoms similar to those of dementia can occur for other reasons, such as depression, infections, or as side effects of medication. An early assessment is important to identify other conditions which may be treatable.

We will:

- Encourage GPs to take up the dementia component in the mental health Directed Enhanced Service (DES) introduced in 2017.
- Review and update, as needed, the dementia awareness DVD for GPs.
- Ensure that primary care practices are able to evidence that they are dementia supportive⁸.
- Work with stakeholders to deliver the most effective ways to increase awareness of dementia to ensure timely diagnosis.

People have the right to a timely diagnosis and our consultation told us that more needs to be done to ensure this happens. To enable people to seek help earlier, more non-specialist professionals across the statutory and third / independent sectors need to be trained to identify those who might have the early signs and symptoms of dementia, and have clear information about where and how to refer on appropriately. The roll out of the 'Good Work' framework will be an integral part of dementia learning and training programmes.

“ The stronger the web of support we weave, the less likely people will fall through ”

We will:

- Ensure workforce plans are in line with the principles of 'Good Work'⁹ to enable key front line staff to recognise the early signs of dementia.
- Ensure training for staff who work with people who have a higher risk of developing dementia (such those working in learning disabilities, substance misuse, ambulance and prison services).

A consistent pathway will be developed to enable people to get a timely diagnosis and care and support. This will include closer relationships with GPs and other health professionals working in the community to promote case finding and appropriate assessment (for example reviewing medication and identification of other conditions) before referral to memory services.

The pathway will also focus on those outcomes which matter to the individual, and cover the steps needed to ensure that people with dementia are able to see the right professional with the right skills and at the right time – this includes access to advice on issues such as finance and employment.

Those who are diagnosed with a cognitive impairment other than dementia, as well as those diagnosed with dementia, must be offered an explanation of the difficulties they may experience and be provided with health information and advice on memory strategies.

A person with dementia may also have other symptoms such as sensory loss, perception or communication difficulties – therefore a variety of strategies will need to be considered and offered.

⁸ http://www.olderpeoplewales.com/Libraries/Uploads/Dementia_Supportive_A_Checklist_of_Actions_for_Public_Services.sflb.ashx

⁹ <https://socialcare.wales/resources/good-work-dementia-learning-and-development-framework> – more information on Good Work is available in the 'learning and development' section.

We will:

- Develop a consistent clearly understood diagnosis, care and support pathway which incorporates standards of care and outcome measures.
- Agree a common approach to cognitive impairment (other than dementia) assessment and intervention, with support offered to primary care by specialist memory assessment services where required.

What will be different:

People are aware of the early signs of dementia; the importance of a timely diagnosis; and know where to go to get help.



Assessment and diagnosis

We know that a timely diagnosis of dementia allows those affected to take the right steps to plan ahead and access information, care and support. We also know that accessing practical

and emotional support at an early stage can have a significant impact on the way someone is able to manage their condition over time and live independently.



‘I have a timely diagnosis which enables me to make decisions about my care and support...’

“ I want to have access to a doctor to check if I have dementia ”

However, despite small increases in recent years, currently only around 53%¹⁰ of individuals in Wales with dementia have a diagnosis. It is vital therefore that we take action to improve the rate of increase in diagnosis rates.

Our consultation has told us that people want the diagnosis process to be handled in an empathic manner, and one which leads to the provision of an appropriate level of support in the right place at the right time. They also want the process to be consistent and timely, accessed close to home and responsive to the needs of their carers and families.

We recognise that dementia is not a single condition and receiving a diagnosis can be complicated, for instance by cultural and language interpretations, or other complexities such as sensory loss or a learning disability. We need to work with our partners and stakeholders to remove these barriers to support and care.

As a first step we need to ensure that health professionals are well supported to ensure that they have the right knowledge and skills to make an appropriate diagnosis. They also need to be made aware of the help and support that is available post diagnosis so they can be more confident that a diagnosis will lead to an individual and their family feeling better supported.

Furthermore, diagnostic tools must be available in a variety of languages, which are culturally appropriate, and in various formats to ensure that health boards can meet the needs of their population.

We will:

- Continue to implement the recommendations from the memory assessment service national audit and set targets for health boards to increase diagnosis rates by at least 3% a year.
- Work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary.
- Scope access to, and provision of, memory assessment services to those with learning disabilities.
- Ensure compliance with the Welsh Government's All-Wales Standards for Accessible Communication and Information for People with Sensory Loss.
- Scope a programme of work that will capture, record, share and flag the communication needs of service users with sensory loss.

“ Dementia is life changing – not life ending ”

The consultation also told us that people with a diagnosis and their families and carers want someone to talk to about it, and what it means to them. They want help to adjust to the diagnosis, plan for the future and to be pointed to the right information and support. In response, we will review and promote our dementia helpline¹¹.

As part of this review we will ensure that we are able to sign post to the relevant services whether statutory, third sector or peer support.

¹⁰ <http://gov.wales/statistics-and-research/general-medical-services-contract>

¹¹ Helpline offers information, support and agency signposting for anyone living with dementia or their supporters. They can be contacted on Freephone 0808 808 2235 or text 'help' on 81066

We will also review the role of dementia support workers alongside the development of the 'teams around the individual' (please see page 15 and 16 for more information) to ensure that a person living with dementia has a key point of contact to provide appropriate tailored information and support as well as sign-posting.

This should include making sure that people are connected to local support networks that are available, including peer support options and enabling access to other financial and practical support. People living with dementia also need to be provided with information on what adjustments could be made to their lifestyle or environment to help them remain as fit and healthy as possible.

This needs to be made equally accessible for those in remote, rural and urban areas, and provided in a way that meets language and cultural needs.

Opportunities for peer support for both people living with dementia and their carers also need to be considered as part of this work.

Getting a diagnosis of dementia is usually a process and not the result of a single test. This can take time if a person is referred at an early stage of the condition and a 'watch and wait' approach may be necessary to make a confident diagnosis.

A working diagnosis of dementia, subject to a final confirmation, can be helpful so that individuals can access information and support at the earliest opportunity.

We will:

- Review and promote the all-Wales dementia helpline as a key source of information.
- Review the capacity and role of dementia support workers to ensure all individuals with dementia living in the community have a dedicated support worker working to agreed occupational standards.
- Ensure every diagnosed person with dementia receives a tailored information pack in an accessible format including, as needed, digital options, and is offered access to a dementia support worker or equivalent.
- Ensure that carers will be offered an assessment of their own needs and, if eligible, a support plan will be developed with them to identify appropriate support (in line with the Social Services and Well-being (Wales) Act 2014).

What will be different:

More people are diagnosed earlier, enabling them to plan for the future and to access early support and care if needed.

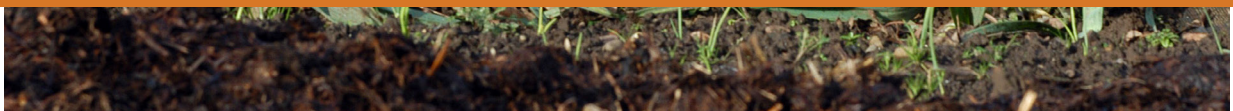
Living as well as possible, for as long as possible with dementia

We have listened carefully to the lived experiences of those with dementia, as well as families and carers, and heard

how individuals have different ways of coping with and adjusting to the changes experienced.



‘My support worker helps me and my carer access a range of support for me to remain in my community...’



Universally we have heard that we need to develop a support system that is:

- Available within the community to support people to remain in their homes for as long as possible.
- Flexible – with services able to respond to an individual’s needs rather than expect people to adapt to what exists already.
- Individualised – with a focus on what can be done, rather than what can no longer be done.
- Able to respond to the needs of carers.
- Able to respond to the language and cultural needs of their population.
- Able to meet specific needs such as those resulting from sensory loss, learning disabilities, or young onset dementia.
- Supporting people in the early stages of dementia to ensure they have the information and opportunity to make decisions about their own future care and support. This should consider lasting powers of attorney¹² and advanced decisions¹³. For further information please see section on ‘capacity for decision making’.
- Enabling access to cognitive stimulation programmes, such as teaching and practising memory strategies, which can improve both cognitive function and quality of life.
- Ensuring access to allied health professionals (such as physiotherapists and occupational therapists) and re-ablement / rehabilitation services to delay loss of skills and maintenance of life roles for longer.
- Enabling access to assistive technology and / or equipment and making adaptations to the environment to maintain or improve a person’s independence, safety and wellbeing.
- Provision of flexible, enabling and personalised respite support.
- Ensuring access to advocacy support.

This means that ‘one size will not fit all’ and we need to develop an approach which builds upon the support that is provided by dementia support workers. These should be in the form of multi-disciplinary teams who are able to adapt what is required as a person’s needs change.

The team will flex to meet individual needs but their roles will include:

- Developing individual care plans
- Maximising physical well-being for example advice and support to keep active, eat well or prevent falls.
- Communication support, such as speech and language therapy.
- Counselling support.
- Introduction to palliative care interventions. These will include the management of pain and other symptoms with a goal of achieving the best quality of life.

“ I will be helped to live independently for as long as I can ”

The underpinning approach for these teams is that people have the right to individualised and person-centred care. We will continue working with key stakeholders, including people living with dementia and their carers, to ensure that this happens.

¹² www.gov.uk/power-of-attorney

¹³ www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx

We will:

- Develop multidisciplinary ‘teams around the individual’ which provide person-centred and co-ordinated care, support and treatment as needed.
- Develop an All Wales Dementia Allied Health Practitioner Consultant post who will give advice and support to health boards and local authorities to drive forward service improvements.
- Ensure that Regional Partnership Boards (as required through the Social Services and Well-being (Wales) Act 2014), prioritise ways to integrate services, care, and support, for people with dementia.

Support to stay safe and secure in the home

Housing partners and care and repair agencies are also key to helping people with dementia live independently and in a way that provides a good quality of life.

This independence can be achieved through the provision of a range of housing choices such as supported housing or extra care facilities and access to physical adaptations in existing homes.

Housing staff (including those in extra care and sheltered accommodation) should have access to training to enable them to support people with dementia to live well.

We will:

- Work with social care, health services and housing providers and involve people with dementia, their families and carers to strengthen collaboration on a strategic approach to housing to enable people to stay in their homes.
- Enable housing staff to access to training to assist them to support people with dementia.
- Consider the relevant recommendations of the “Expert Group on Housing an Ageing Population” to inform future housing development.
- Review the Housing Aids and Adaptations Programmes to ensure that people are able to access appropriate and timely support (April 2019)

Advocacy arrangements

At the heart of rights-based and person-centred support and care, is ensuring that the voice of the person remains at the centre of any actions or decisions. Throughout the course of a person’s lived experience of dementia, the type of support they might need to express their views, to make decisions and to access entitlements will vary.

It is acknowledged that the term “advocacy” can be used to mean different things for different people. For some, acting as an “advocate” can be considered to be part of a friendship or a family relationship with the person or in the course of a more general support worker role.

For others, part of their professional role will be to advocate for the people they support. In some situations the role of an advocate can only be taken by a person who is totally independent from the person's personal circumstances and any decisions or actions that need to be taken. This is known as an 'independent advocate'.

Sometimes the involvement of an advocate is required by law and there are particular or specialists areas of advocacy, undertaken by specialist independent advocates.

“ Talk to me about my life, and give me the support I need to keep living the life I choose ”

Other than when the appointment of an advocate is required by law, it is not the intention of this plan to prescribe the type of advocacy or provider of advocacy at different stages.

However, the potential value of the role of independent advocacy as “the voice of the citizen” should be recognised at all stages of a person's lived experience of dementia, explained and actively offered as a rights based approach to service delivery.

Capacity for decision making

The Mental Capacity Act (2005) provides a statutory framework for people who lack the capacity to make specific decisions, at certain points of time, for themselves. The Act also makes provisions for when people who have capacity want to make preparations for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations and how they should go about this.

The Act is intended to be enabling and supportive of people who lack capacity and aims to maximise their ability to make decisions or to participate in decision-making as far as they are able to do so.

One of the key aims of the Social Services and Well-being (Wales) Act 2014 is for individuals to be at the centre of decisions about them and to be supported to have choice and control over their lives.

Safeguarding

It is important to recognise that people with dementia may be at risk of abuse and neglect. The Social Services and Well-being (Wales) Act 2014 (Part 7) strengthens existing safeguarding arrangements for relevant partners (such as NHS, Police or Probation) to have a duty to report to the local authority someone suspected to be an adult at risk of abuse or neglect.

This is supplemented by a new duty for the local authority to make enquiries to determine whether any action is required to safeguard adults at risk.

The Act includes the establishment of a National Independent Safeguarding Board and Regional Safeguarding Boards. The national board is responsible for reviewing the effectiveness of safeguarding arrangements in Wales and makes recommendations to the Welsh Ministers as to how those arrangements could be improved.

The Act also reaffirms the importance of advocacy during the safeguarding process.

We will:

- Ensure that relevant recommendations received from the National Independent Safeguarding Board are considered and embedded into policy development across Government and integrated into operational practice.

Responding to people with dementia experiencing strong feelings

Some people with dementia have times when they become distressed, fearful or frustrated. These symptoms of dementia often represent attempts to communicate a need that has not been met.

An explanation for the behaviour needs to be developed from information gathered about the person, taking into consideration their physical health, medication, recognising triggers of the behaviour and social and physical environment.

This information is used to develop a plan to address the person's needs, reducing behaviours that challenge, improving understanding of their needs and their quality of life. This also helps the people around the person with dementia to know how best to respond. In line with NICE guidelines psychosocial interventions should always be tried first.

Where a person's level of distress is extremely severe or there is an immediate risk of harm to themselves or others it may be appropriate to use medication such as certain major tranquillizers, or 'anti-psychotic medication'. This should be seen as a short term intervention and will need careful audit and monitoring to ensure that the use of such medication meets guidelines published by NICE and is not overused.

We will:

- Ensure health boards provide access to evidence-based psychosocial and pharmacological interventions in line with *Matrics Cymru*¹⁴ and other relevant guidance.
- Respond to the recommendations of the Health, Social Care and Sport Committee's Inquiry into the use of anti-psychotic medication.

What will be different:

People with dementia and their carers and families are able to receive person-centred care and support which is flexible.

The need for increased support

Care and support in the individual's home for increasing needs

We understand the importance for people with dementia to remain in their own home for as long as possible. Hospital admissions, particularly lengthy ones, increase the risk of a person with

dementia losing independent living skills. The new 'teams around the individual' will need to be able to respond quickly when challenges or crises occur.



'I am reassured to know that my carer is able to access support too...'



This may also require specialist intensive support for a limited period of time, for example from social services, learning disability teams and/or community mental health teams with training and experience in crisis resolution support and meeting complex needs.

Both the 'teams around the individual' and other specialist teams will need to work together to ensure support complements each other.

We will:

- Ensure health (including Wales Ambulance Service Trust – WAST) and social services have pathways in place to ensure the responsiveness of community assessment and ongoing management services.

Support for families and carers including personalised respite

The ability of individuals with dementia to live at home for as long as possible is often dependent on the support of families and carers. A very strong message from our consultation was that support for the carer can help to prevent crisis and help maintain their own physical and mental well-being as well as that of the person they are caring for. We are firmly committed to ensuring the rights of all unpaid carers are enhanced and protected.

The Social Services and Well-being (Wales) Act, provides carers with an equal right to have a needs assessment. For carers that have eligible needs, the local authority has a duty to meet those needs through a carers support plan.

All carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring. We also heard that respite provision needs to be flexible as the person with dementia, their family and carers, will all have different needs, expectations and preferences.

Therefore we need to ensure there are different options for respite care which can be provided within the home or outside the home and be relevant to different age groups as well as providing opportunities for people living with dementia to sustain and maintain their physical, intellectual, emotional and social abilities. Additional funding has been awarded to local authorities across Wales in order to develop new approaches to respite care which are based on the needs of carers and those being cared for. We will also ensure that we learn from the Older People's Commissioner's Rethinking Respite research following its publication in 2018.

We will:

- Ensure that the new 'teams around the individual' enable families and carers to access respite care that is able to meet the needs of the carer as well as those of the person living with dementia.
- Monitor the use of funding provided to local authorities for respite provision to identify best practice in supporting the needs of the carer and the person who is cared for and ensure this practice is shared.

“ *The carers need to be looked after as well – they have their own needs* ”

Care home settings

We recognise that it will not always be possible for people to remain in their own homes, even with enhanced support. Living in a care home may be as a result of personal choice or because of the risks of harm to the individual if they remain at home. Care homes may also provide respite care to enable family and carer members to have a break. Whatever the circumstances, care homes need to be considered as an individual's home as people have the right to 'live well' and be treated with dignity and respect.

We need to further develop the links between care homes and community services and will expect the dementia 'teams around the individual' to provide specialist and regular in-reach support to care homes. We are also encouraging GP practices to offer a new enhanced service for residential and nursing care in Wales. This will ensure a comprehensive review of physical and mental health for all residents when they move into a care home, including a review of medication and antipsychotic prescribing.

We will:

- Further develop use of the new directed enhanced service for residential and nursing care homes.

The need for hospital admission

We understand that when a person with dementia is accessing urgent and emergency care they are often at their most vulnerable.

It is vital that health and social care professionals work together and consider risk as part of the care planning and management of people with dementia in order to prevent admissions from A&E, or reduce length of stay when an admission is unavoidable.

We expect health boards to ensure that their hospitals embed a clear rights-based approach to ensure that people living with dementia are treated with dignity and respect at all times. The 'Trusted to Care' report provides clear recommendations on how best to care for people with dementia in general hospitals¹⁵. The 1000i Lives team has also developed a series of tools to assist in providing person-centred care and dementia supportive hospital environments.

We have already introduced psychiatric liaison teams in district general hospitals. These teams look at the interaction of a person's physical health and how that can impact on someone's mental health. Liaison psychiatry team members work together, using their different skills and expertise to help people.

They also work closely with other doctors and healthcare workers to ensure that physical and mental health care is as joined up as possible. Additional support for a person's stay in hospital can also be provided from the newly established 'flexible resource teams'.

“ I do not want to repeat my needs over and over again ”

During our consultation, we heard a lot about how we should better accommodate the needs of a person with dementia when they are in hospital. Family members and carers also told us that there should be flexibility to allow them to support a person whilst in hospital if they wish.

Hospitals need to consider this in the delivery of their care, for example:

- Flexibility around meal times.
- Letting people sleep and wake at their own pace.
- Allowing flexible visiting times.
- Offering activities which are enjoyable and support feelings of self worth.
- Facilitating families and carers to continue to support a person with dementia whilst they are in hospital if they wish.
- Adapting environments so they are more 'dementia supportive' such as considering the layout and signage.
- Ensuring that broader physical health care needs are considered as well as the presenting medical problem and symptoms of living with dementia.
- Ensuring that people are screened to identify delirium, which is common in people living with dementia, so it can be appropriately treated.

Some health boards are already responding to the need to involve family and carers members by adopting the principles of 'John's Campaign' in a number of their wards. We need to ensure that all health boards adopt this approach.

We will:

- Monitor the implementation of the recommendations from the 'Trusted to Care' report.
- Ensure that psychiatric liaison services are available to all general hospitals in Wales.
- Ensure that the recommendations from the Royal College of Psychiatrists' National audit of dementia in general hospitals are implemented, including instructing health boards and trusts to adopt the principles of 'John's Campaign'.

Inpatient care for older people within mental health services

Sometimes people will be admitted to an older person's mental health inpatient unit to get the care that they need. As with any setting this needs to be delivered in a person-centred, holistic and respectful way. A community of practice for older person's mental health units has been established in Wales so good practice can be shared.

Access to advocacy in hospital

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.

Practitioners are required¹⁶ to help people access advocacy, when this is needed, to determine their well-being outcomes and express their wishes and feelings.

We will:

- Expand the use of Dementia Care Mapping™ as an established approach to achieving and embedding person-centred care for people with dementia and ensure health boards implement ‘Driver Diagram – Mental Health Inpatient Environments for people with dementia’.
- Ensure older person mental health units have agreed care pathways for accessing regular physical healthcare.
- Ensure that access to advocacy services and support is available to enable individuals to engage and participate when local authorities are exercising their statutory duties under the Social Services and Well-being (Wales) Act 2014.

End of life care

Dementia is a long term condition and in 2015 was the leading cause of death, accounting for 11.6% of all deaths¹⁷. Many more people will die of another condition alongside dementia.

In 2015 the Alzheimer’s Society Wales and Marie Curie published a report entitled ‘Living and Dying with dementia in Wales: Barriers to Care’¹⁸.

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.

Everyone has the right to good end of life care where they are treated as an individual, with dignity and respect, without pain and other symptoms, in familiar surroundings and with their close family and friends. We need to ensure that the options and access to palliative care and end of life care is the same for a person living with dementia as it is for anybody else.

We will:

- Ensure the ‘teams around the individual’ discuss the importance of making advance decisions and ensure an agreed palliative care pathway is in place.
- Identify professionals who would benefit from training in initiating serious illness conversations, and provide such training.
- Review the capacity of existing bereavement services and settings in which they are delivered to ensure that the differing needs of families and carers of those with dementia are being met.

What will be different:

People with dementia, their families and carers, receive person-centred care and support that adapts as the needs of an individual increases.

¹⁶ Legislation laid down in the Social Services and Well-being (Wales) Act 2014, The Mental Health Act 1983 and the Mental Health (Wales) Measure 2010.

¹⁷ www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregisteredinenglandandwalesseriesdr/2015

¹⁸ www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf

Supporting the implementation

Learning and development

People with dementia, their families and carers, have the right to be supported and cared for by a workforce, whether it is at a GP surgery, hospital or a care

home, which has the knowledge and skills to offer high quality dementia care and support.



'I am supported by people who are both skilled and compassionate and who understand me and the impact that having dementia has on me...'



Families and carers should also have access to training which enables them to support people with dementia to live well and which provides information and advice about looking after themselves. The provision of dementia related education and training across the sectors should be developed with people with lived experience, families and carers.

Professionals working with people who are at a higher risk of developing dementia also need to be engaged, suitably trained and involved in the development of pathways. This will include professionals working across a number of areas such as cardiology, stroke services, learning disabilities services, prisons, substance misuse services and homelessness / housing services.

To help deliver this, Good Work: A Dementia Learning and Development Framework for Wales¹⁹ has been developed. The Framework aims to support people to address their own specific learning and development needs within the context of their lives and circumstances.

“ *It’s only when you’re informed yourself can you then look after someone to the best of your capacity* ”

We will:

- Ensure people with dementia, their carers and families are involved in the development and delivery of dementia education and training.
- Improve access to training for carers and families through the implementation of the ‘Good Work’ framework.
- Ensure that the principles of ‘Good Work’ are embedded in the new vocational qualifications for social care and health.
- Develop learning resources for the health and social care workforce, including the third sector, based on ‘Good Work’.
- Ensure all NHS employed staff who come into contact with the public receive an appropriate level of dementia care training (as specified in – ‘Good work’).
- Ensure training for health and social care staff includes awareness-raising about the role of carers and how to involve them appropriately in the care process.

What will be different:

Staff have the skills to help them identify people with dementia and to feel confident and competent in supporting individual’s needs post-diagnosis.

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.

Wales has been involved in dementia research for some years. This includes work undertaken through Health and Care Research Wales' Centre for Ageing and Dementia Research, the Dementia Services Development Centre and the recently created UK Dementia Research Institute.

The Welsh Government remains committed to developing policy and supporting health and social care research in Wales.

“ I am aware that I can be involved in dementia research and will be supported to participate if I want ”

We will:

- Fund an independent evaluation of ‘teams around the individual’ to inform the continued development of the approach.
- Work with NHS and social care and research teams to support and promote more dementia related research studies to Wales. Supporting the role of research in delivering good quality care in a flexible and responsive fashion.
- Create more opportunities for people with and affected by dementia across Wales to participate, be involved and engaged in research activity.
- Encourage research that uses public health approaches to consider ways of addressing inequalities experienced by people with dementia.
- Ensure there are regular opportunities to identify innovative service models and areas of evidence-based practice, to ensure research findings are implemented in services across Wales and to inform research partners of areas where further research could usefully inform practice.

What will be different:

People living with dementia, including families and carers have the opportunity to be involved in research that looks at cause, cure and care for dementia.

Annex 1: Meeting the needs of specific groups

To ensure the different needs of our population in Wales are fully understood, and in recognition that ‘one size does not fit all’, the following themes and actions have been identified as areas to be considered across the pathway.

Young onset dementia

Younger people living with dementia often have different needs. They and their partners are more likely to:

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

Services must address the specific needs of younger people with dementia and their families and ensure that they are aware of the help that is available. Employers should have access to the right information in order to be able to support employees. They must be able to demonstrate how they are providing local age-appropriate and meaningful support, whether that is in a person’s home or through day, respite or residential care.

Welsh language provision

For Welsh speakers living with dementia receiving care and support in their first or preferred language is a matter of clinical need. As their condition progresses, people with dementia may understand or be able to communicate in their first language only.

Our ‘More than just words follow on framework’ expects staff in health boards, social services and the social care sector to actively offer services through the medium of Welsh language, rather than expect patients to have to ask for them. The ‘Active Offer’ commitment will be strengthened when the Welsh Language Standards for the health sector are introduced in 2018.

Learning disabilities and dementia

People with learning disabilities have a higher risk of developing dementia compared to the rest of the general population. For people with Down’s syndrome, it is predicted that 1 in 3 people over the age of 50 will develop dementia. If people already have difficulties in processing information or short term memory problems this can make diagnosis more difficult. Symptoms affecting personality, emotion or behaviour may show before any change in language ability or memory²⁰. Communication difficulties, and an increased potential for sensory impairment, may make it more difficult for a person with learning disabilities to describe their experience of symptoms.

Sensory impairment and dementia

A number of people with dementia will have some form of sensory impairment (such as sight loss, hearing loss or both). As this can create additional difficulties with communication, service design across the pathway should allow equal access for people with a sensory impairment to all dementia related services and support.

The Welsh Government introduced the All-Wales Standards for Accessible Communication and Information for People with Sensory Loss in December 2013. The aim of this document is to set out the standards of service delivery that people with sensory loss should expect when they access healthcare in Wales. A key part of the Standards is the requirement that every service user who requires communication support should have this need met.

People with dementia from Black, Asian and Minority Ethnic (BAME) and Gypsy, Roma, and Traveller (GRT) communities:

We need to ensure that people from BAME and GRT communities can access appropriate services easily. There is known stigma connected with dementia and diagnosis in some cultures and communities that can lead to reluctance to access services. Equally, services that are not designed to meet cultural or religious needs can unintentionally exclude people and their families and carers from accessing support.

The language needs of people living with dementia may change as the condition progresses, and services need to be aware of and able to respond to a person's language and communication needs.

Services should ensure that care, support and treatment provided is culturally acceptable and that staff are appropriately trained. Steps should be taken to ensure that a person is asked about their individual culture during contact and that equity of access is improved, by, for example, developing different information resources and/or appointing outreach workers.

Lesbian, gay, bisexual or transgender (LGBT) people with dementia

Older LGBT people are more likely to be single and to live on their own, and are less likely to have children or regular family support.

Some LGBT people feel that services are not sensitive to their needs and individuals can sometimes feel out of place in traditional support groups.

Dementia UK (2007) reported that many older transgender people (aged 60 and over) are concerned that they may develop dementia and need intimate care, which may result in being treated in ways not fitting with their gender identity²¹.

Services should ensure that staff are aware and appropriately trained to deliver care and support that is sensitive and acceptable to a person's sexuality and gender identity.

Dementia in rural and remote areas

Living in a rural / remote community can offer well-being benefits such as established community networks and availability of green spaces. However, those who have moved into such areas may find it more difficult to build networks. Other challenges faced by people to living with dementia in some of our remote communities include accessing support services which might not be available locally.

Local transport, health and social care services should be co-designed in line with the needs of local populations and it is expected that Regional Partnership Boards (required through the Social Services and Well-being (Wales) 2014 Act), will play a role in facilitating joined-up working to provide accessible services more locally.

Annex 2: detailed action plan

Key actions – What will we do and by when	Who will be involved in delivery
Theme 1 – Risk reduction and delaying onset	
Ensure that risk reduction messages are included in relevant public health policies and programmes (by September 2018 and annual review).	Welsh Government, Public Health Wales, health boards and third sector.
Promote action across the six steps to support people to change behaviours and reduce their risk of dementia (by September 2018 and annual review).	Welsh Government, Public Health Wales, health boards and third sector.
Ensure that people living with dementia receive advice about the changes that they could be supported to make to increase their general health and wellbeing. (by September 2018 and annual review).	Health boards and third sector.
Theme 2 – Raising awareness and understanding	
Work with the third sector and people with lived experience to increase the number of people in Wales who are able to recognise dementia through expanding initiatives such as dementia friends and dementia supportive communities / organisations (baseline number: September 2017 and six monthly review thereafter).	Welsh Government, public sector and third sector organisations.
Work with local communities and third sector organisations to encourage them to open their services so that people with dementia, their families and carers. Can participate (April 2019 and annual review).	Local authorities and health boards.

Publicise and actively encourage educational settings to use the “Creating a Dementia Friendly Generation” resources developed by the Alzheimer’s Society to build intergenerational understanding and awareness (baseline number: September 2017 and annual review thereafter).

Welsh Government, educational settings and Alzheimer’s Society.

Ensure all NHS employed staff who come into contact with the public (including porters, receptionists and medical / support staff) receive an appropriate level of dementia care training (as specified in – ‘Good work – Dementia Learning and Development Framework’) (April 2018 and annual review thereafter).

Health boards.

Work with local authorities, health boards and Public Health Wales so the needs of people living with dementia are considered as part of the planning process (ongoing).

Welsh Government, local authorities, Public Health Wales, health boards, Public Service Boards.

Ensure that transport planners / operators consider the needs of people living with dementia in the development of their services, including major contracts such as the ‘metro’ and the rail franchise, to improve access to passenger transport information, enabling people to plan and undertake journeys on the public transport network (ongoing).

Welsh Government, transport planners / operators.

Develop and undertake training designed to raise awareness amongst transport workers of the barriers that are encountered by those with dementia when using public transport (ongoing).

Welsh Government, transport planners / operators.

Theme 3 – Recognition and identification

Encourage GPs to take up the dementia component of the mental health Directed Enhanced Service (DES) introduced in 2017 (September 2018 and annual review).

Welsh Government and health boards.

Review and update, as needed, the dementia awareness DVD for GPs (September 2018).

Welsh Government.

Ensure that primary care practices are able to evidence that they are dementia supportive (baseline April 2018 and six monthly review thereafter)²².

Welsh Government, primary care practices.

Work with stakeholders to deliver the most effective ways to increase awareness of dementia to ensure timely diagnosis (ongoing).

Welsh Government.

Ensure workforce plans are in line with the principles of 'Good Work' to enable key front line staff to recognise the early signs of dementia (ongoing).

Welsh Government, health boards, Social Care Wales, third sector, public sector.

Ensure access to training for staff who work with people who may have a higher risk of developing dementia (such those working in learning disabilities, substance misuse, ambulance (April 2019) and prison services (April 2020).

Welsh Government, health boards, Social Care Wales, third sector, public sector.

Develop a consistent, clearly understood, diagnosis, care and support pathway, which incorporates standards or care and outcome measures (April 2019).

Welsh Government, health boards, local authorities, Public Health Wales 1000i lives.

Agree a common approach to Cognitive Impairment (other than dementia) assessment and intervention, with support offered to primary care by specialist memory assessment services where required (April 2019).

Welsh Government, Public Health Wales 1000i lives.

Theme 4 – Assessment and diagnosis

Continue to implement the recommendations from the memory assessment service national audit and set targets for health boards to increase diagnosis rates by at least 3% a year. (September 2018 and annual review).

Welsh Government,
Public Health Wales 1000i lives and
Memory Assessment Services.

To work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary. (September 2018).

Welsh Government and health boards.

Scope the access to and provision of memory assessment services to those with learning disabilities (June 2018).

Public Health Wales 1000i lives.

Ensure compliance with the Welsh Government's All Wales Standards for Accessible Communication and Information for People with Sensory Loss (ongoing).

Health boards,
local authorities,
third sector.

Scope a programme of work that will capture, record, share and flag the communication needs of service users with sensory loss (March 2018).

Welsh Government working in collaboration with the NHS Centre for Equality and Human Rights (NHS CEHR), health boards and health professionals and third sector.

Review and promote the All-Wales dementia helpline as a key source of information (Review to be undertaken by September 2018).

Welsh Government.

Review the capacity and role of dementia support workers to ensure all individuals with dementia living in the community have a dedicated support worker working to agreed occupational standards. (June 2018).

Welsh Government,
Public Health Wales 1000i lives,
statutory / third sector providers.

Ensure every diagnosed person with dementia receives a tailored information pack in an accessible format, including, as needed, digital options, and is offered access to a dementia support worker or equivalent (ongoing).

Health boards.

Ensure that carers will be offered an assessment of their own needs and, if eligible, a support plan will be developed with them to identify appropriate support (in line with the Social Services and Well-being (Wales) Act 2014). (Ongoing).

Health boards,
local authorities,
third sector.

Theme 5 – Living as well as possible for as long as possible with dementia

Develop multidisciplinary ‘teams around the individual’ which provide person-centred and co-ordinated care, support and treatment as needed. (April 2019). and six monthly review of implementation thereafter).

Health boards,
local authorities,
third sector.

Develop an All Wales Dementia Allied Health Practitioner Consultant post who will give advice and support to health boards and local authorities to enable the delivery of person-centred care and drive forward service improvements. (April 2018).

Welsh Government,
Allied Health Professionals,
health boards.

Ensure that Regional Partnership Boards (as required through the Social Services and Well-being (Wales) Act), prioritise ways to integrate services, care, and support, for people with dementia. (Ongoing).

Welsh Government,
Regional Partnership Boards.

Work with Social Care, health services and housing providers and involve people with dementia, their families and carers to strengthen collaboration on a strategic approach to housing to enable people to stay in their homes. (March 2019).

Welsh Government,
Regional Partnership Boards.

Enable housing staff to have access to training to assist them to support people with dementia. (Ongoing).

Welsh Government.

Consider the relevant recommendations of the “Expert Group on Housing and Ageing Population” to inform future housing development. (September 2018).

Welsh Government, local authorities and registered social landlords.

Review the Housing Aids and Adaptations Programmes to ensure that people are able to access appropriate and timely support. (April 2019).

Welsh Government.

Ensure that relevant recommendations received from the National Independent Safeguarding Board are considered and embedded into policy development across Government and integrated into operational practice. (Ongoing).

Welsh Government,
health boards and local authorities.

Ensure health boards provide access to evidence-based pharmacological and psychosocial interventions in line with Matrics Cymru and other relevant guidance. (September 2018 and six monthly review thereafter).

Health boards.

Respond to the recommendations of the Health, Social Care and Sport Committee's inquiry into the use of anti-psychotic medication. (Ongoing).

Welsh Government.

Theme 6 – The need for increased support

Ensure health (including Wales Ambulance Service Trust – WAST) and social services have pathways in place to ensure the responsiveness of community assessment and ongoing management services. (Ongoing).

Health boards and Trusts.

Ensure that the new "teams around the individual" enable families and carers to access respite care that is able to meet the needs of the person living with dementia. (April 2018).

Welsh Government,
health boards,
local authorities and third sector.

Monitor the use of funding provided to local authorities for respite provision to identify best practice in supporting the needs of the carer and the person who is cared for and ensure this practice is shared. (September 2018 and six monthly review thereafter).

Welsh Government and local authorities.

<p>Further develop use of the new directed enhanced service for residential and nursing care homes. (Baseline April 2018 and annual review thereafter).</p>	<p>Health boards and GP practices.</p>
<p>Monitor the implementation of the recommendations from the Trusted to Care report. (Ongoing).</p>	<p>Welsh Government.</p>
<p>Ensure that psychiatric liaison services are available to all general hospitals in Wales. (Ongoing).</p>	<p>Health Boards and Trusts.</p>
<p>Ensure that the recommendations from the Royal College of Psychiatrists National Audit of Dementia in general hospitals are implemented including instructing health boards and trusts adoption the principles of the 'John's Campaign'. (September 2018).</p>	<p>Health boards and Trusts.</p>
<p>Expand the use of Dementia Care Mapping™ as an established approach to achieving and embedding person-centred care for people with dementia and ensure health boards implement 'Driver Diagram – Mental Health Inpatient Environments for people with dementia (September 2018) (baseline April 2018 and annual review thereafter).</p>	<p>Welsh Government, Public Health Wales 1000i lives and health boards.</p>
<p>Ensure older person mental health units have agreed care pathways for accessing regular physical healthcare (September 2018).</p>	<p>Health boards.</p>
<p>Ensure that access to advocacy services and support is available to enable individuals to engage and participate when local authorities are exercising their statutory duties under the Social Services and Wellbeing (Wales) Act 2014. (Ongoing).</p>	<p>Health boards.</p>

Ensure the 'teams around the individual' discuss the importance of making advance decisions and ensure an agreed palliative care pathway is in place. (Ongoing).

Health boards and local authorities.

Identify professionals who would benefit from training in initiating serious illness conversations, and provide such training. (March 2019).

National End of Life Care Board.

Review the capacity of existing bereavement services and settings in which they are delivered to ensure that the differing needs of families and carers of those with dementia are being met. (September 2018).

National End of Life Care Board.

Theme 7 – Supporting the implementation of the Plan

Ensure people with dementia, their carers and families are involved in the development of dementia education and training. (September 2019).

Health boards and local authorities.

Improve access to training for carers and families through Good Work rollout. (September 2019).

Health boards and local authorities.

Ensure that the principles of 'Good Work– Dementia Learning and Development Framework' are embedded in the new vocational qualifications for social care and health. (September 2018).

Social Care Wales.

Develop learning resources for the health and social care workforce, including the third sector, based on 'Good Work'. (September 2018 and annual review).

Social Care Wales.

Ensure NHS employed staff who come into contact with the public receive an appropriate level of dementia care training (as specified in – 'Good work'). (December 2019).

Health boards and Trusts.

Ensure training for health and social care staff includes awareness raising about the role of carers and how to involve them appropriately in the care process. (Ongoing).

Social Care Wales,
Local Authorities and Health Boards.

Fund an independent evaluation of 'teams around the individual' to inform the continued development of the approach (timing to be confirmed).

Welsh Government.

Work with NHS and social care and research teams to support and promote more dementia related research studies to Wales. Supporting the role of research in delivering good quality care in a flexible and responsive fashion. (Ongoing).

Health and Care Research Wales.

Create more opportunities for people with and affected by dementia across Wales to participate, be involved and engaged in research activity. (Ongoing).

Health and Care Research Wales.

Encourage research that uses public health approaches to consider ways of addressing inequalities experienced by people with dementia. (Ongoing).

Health and Care Research Wales.

Ensure there are regular opportunities to identify innovative service models and areas of evidence-based practice, to ensure research findings are implemented in services across Wales and to inform research partners of areas where further research could usefully inform practice. (Ongoing).

NHS Wales and 'research teams'.

Annex 3

How we will know – High Level Performance Measures

Increase reporting of people who follow ‘good healthy lifestyle behaviours’
Source: National Survey for Wales (annually).

Increase the number of dementia friends and dementia friendly/ supportive communities and organisations in Wales. Source: Third Sector (six monthly).

Increase the number of GPs who undertake training in the early identification, effective management, advice and support for people with dementia and their carers.
Source: NHS outcomes framework.

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.

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 Government; Quality and Outcomes Framework (QOF) Data.

Percentage of people who rate the care and support they have received as excellent or good Source: National Survey for Wales (annually).

Delaying care home and / or hospital admission. Source: Team around the individual monitoring / evaluation reports.

Population assessments required by the Social Services and Well-being (Wales) Act to include the care and support needs of those with dementia and this information is used to publish local area plans. Source: Health boards / local authorities.

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.

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 by June 2018.

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 – ‘Good work – Dementia Learning and Development Framework’). Target: 75% by end of 2019. Source: Health boards (Annually).