



**Alzheimer's Society Cymru
consultation response:
*Together for a Dementia
Friendly Wales 2017-22***

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1. Executive summary

Wales' first dementia strategy is an historic step forward and an enormous opportunity to drastically improve the wellbeing of people affected by dementia in Wales. We have come a very long way in developing such a strong and comprehensive draft strategy, and Alzheimer's Society Cymru welcomes both the progress made to date and the ambition of the Welsh Government to create a dementia friendly Wales.

About us

Dementia can devastate lives. For someone with the condition, as well as their family and friends, dementia means the plans you made, and the future you thought you had, will not be so.

Alzheimer's Society Cymru has a simple vision: a world without dementia. We know that moment will come. Today, too many people with dementia struggle. They cannot access information, help and support. Everyday things people take for granted become difficult.

Our mission is to transform the landscape of dementia forever. Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.

How we have developed this consultation response

The chapters that follow provide a detailed analysis of the content of the draft dementia strategy, as well as recommendations for where the strategy must go further. This has been based on our own technical analysis of the draft strategy, but also on the significant involvement of people affected by dementia, and their voices are prominent throughout the document. As part of the development of our draft response, we have:

- Jointly facilitated 10 consultation events for people affected by dementia across Wales¹;
- Run an online survey, eliciting nearly 550 responses (predominantly from carers and family members of people with dementia) on the draft strategy's proposals, including a mixture of both quantitative and qualitative data;
- Held specific consultation sessions with underrepresented communities;
- Supported two meetings of the Senedd's Cross-Party Group on Dementia which saw attendance from a range of people living with dementia from across Wales and allowed them an opportunity to contribute their thoughts on the proposals;
- Supported six people affected by dementia to give evidence and share their stories with the National Assembly for Wales' Health, Social Care and Sport Committee during their inquiry into the draft Dementia Strategy.

¹ Alzheimer's Society Cymru and DEEP will be submitting a separate analysis of the comments and themes raised at the consultation events. However, the points raised have informed and shaped Alzheimer's Society Cymru's response in this document.

- Had detailed discussions within our own Service User Review Panels [SURP] across Wales and incorporated comments from many of our own service users, their family and friends, and our staff.

In addition, we also consulted extensively with a wide range of partner organisations, and set out key areas where there was consensus that the strategy should aim to drive change.

These can be read online at alzheimers.org.uk/walesstrategy17

Throughout the consultation process, we have listened to the voices of people affected by dementia – people with dementia, carers, family, friends, loved ones, wider support networks, professionals, and the general public. Throughout this document, we have included direct anonymous quotes from these individuals in **dark blue text boxes** – such as below. The only individuals named are those for whom the quote is in the public domain.

Priority areas

The full response in the pages that follow gives a comprehensive guide to Alzheimer's Society Cymru's view on the Welsh Government's proposals. However, we believe that the following points are particularly fundamental and must be addressed if Wales is to have a strategy that will truly deliver a Dementia Friendly nation:

- **Diagnosis rates:** A diagnosis is of vital importance to people with dementia, as it is the key to unlocking the vital support and treatment to which people have a right. Lack of a diagnosis can leave people unaware of the steps they can take to manage their condition, unable to plan for the future, and distanced from support and care. It is precisely for this reason that the Glasgow Declaration² recognises the right to a timely diagnosis. Furthermore, people affected by dementia were unequivocal during the consultation events and in responding to our survey that improving diagnosis rates should be a key component of the dementia strategy.

“You wouldn’t tolerate a 51% diagnosis rate for cancer.”

For this reason, **we recommend** that the final version of the strategy should set out clear and more ambitious targets for increasing dementia diagnosis rates in Wales. While a commitment to increasing diagnosis rates by 3% is a good first step, we are concerned that it will take until the end of the strategy's lifetime for Wales to catch up to Northern Ireland – this is clearly not sufficient. **We urge** the Welsh Government to consider increasing the target – possibly setting a target which rises over time (for example, 3% for Year 1, 3.5% for Year 2, 4% for Year 3 and so on) in order that procedures and practices can be put in place at the start of the strategy's lifetime which can escalate the diagnosis rate in later years. This also allows time for the development of high-quality support services for pre-and post-diagnosis to go hand-in-hand with the increasing diagnosis rates. Such support services are vital to ensure that people get the support they need following a diagnosis.
- **Access to Dementia Support Workers:** We strongly welcome the strategy's target for “all newly diagnosed people with dementia to be offered access to a support

² Alzheimer Europe (2014) [Glasgow Declaration 2014](http://alzheimers.org.uk/walesstrategy17), date accessed 30/03/2017.

worker depending on need after diagnosis”. We know that a support worker is a valued and important first point of contact who can signpost and support people with dementia, as well as their family/carers. This multi-skilled and multi-role individual should be able to address both health and social care issues, signposting as needed, co-ordinating communication between providers, and be capable of acting as an advocate when appropriate.

We are, however, **concerned** that this proposal will not support individuals with an existing diagnosis who may need support, particularly given the nature of dementia as a condition that progresses over time. People affected by dementia may require the support of a DSW throughout the dementia journey, not just at the start, and this needs to be reflected. **We recommend** that the pledge to improve access to a DSW should be offered to all people affected by dementia, regardless of need, and it should be possible to access a DSW later in an individual’s journey with dementia if they need support at a later stage. We believe that this access to a DSW should, at the latest, be in place by the end of the strategy’s lifetime.

“All I want is for someone to talk to, someone to listen.”

Alzheimer’s Society Cymru wants to see funding provided to ensure enough support workers to meet demand. Currently, the Welsh Government funds 32 Dementia Support Workers as part of Wales’ GP clusters – but with 20,000 people with a dementia diagnosis and an aspiration to increase this number, we will need significantly more of these support workers. To do this, we would like to better-understand the rationale behind the target of one Dementia Support Workers per two GP clusters target and what the evidence base is for this to be the appropriate level, especially in rural areas. In particular, we would like to understand what workload the Welsh Government is assuming each DSW to have. There may be necessity, in order to enable support workers to be able to provide high-quality person-centred support, to set a recommended case load or limit for case work, as is done for social workers via Social Care Wales.

- **Training of health and social care professionals:** The strategy proposes that, by 2019, 75% of NHS employed staff who come into contact with the public should be trained in an appropriate level of dementia care (as specified in *Good Work: dementia learning and development framework*).

Whilst we welcome this aspiration, **we would also strongly recommend** that commissioned staff should also be included in targets for training, not just those employed by the NHS. This could be achieved through commissioning arrangements.

We also recommend that people with dementia should be involved with delivering and developing training wherever possible, as they are the true experts on dementia. This will maximise the opportunity for staff to learn how to respond to people’s needs in an appropriate and sensitive manner that protects their dignity and minimises distress. Staff must also feel able to ask for more support, and feel valued through training.

- **Young onset dementia:** Dementia is not just an older person’s condition. A dementia diagnosis is complex and difficult to deal with at any age, but many of the

complexities of being diagnosed under the age of 65 mean that access to specialist services is vital. People affected by young onset dementia may present with atypical symptoms, be diagnosed with rarer forms of dementia, and are more likely than older people to be diagnosed with a genetically inherited form of dementia. As a result, younger people with dementia often struggle to access appropriate care and support because dementia services are often designed to meet the needs of older people.

Both in our online survey and at the consultation events, a recurring theme was the lack of services for people affected by young onset dementia. We estimate there are around 2-3,000 people with young onset dementia in Wales, and it must be recognised that this group has different and specific needs.

Alzheimer's Society Cymru remain concerned that the Welsh Government's decision to move from the DELPHI consensus to CFAS when calculating prevalence of dementia in diagnosis rates does not properly reflect the number of under-65s affected by dementia. **We recommend that**, in order to offset this lack of consideration, Welsh Government should collect more accurate figures and establish the number of people with young onset dementia in each local health board and of the variants of dementia with which people are being diagnosed.

"What about young-onset? How it affects all the family, work and money. We nearly lost our house, my husband had to go part-time and I lost my job. I only got a social worker because I broke my leg – not because I had dementia."

Furthermore, the plan for the strategy to be monitored by the Older Persons' Delivery Assurance Group (DAG) leaves open the possibility that the needs of younger people with dementia could be ignored. **We therefore recommend** that the terms of reference for the DAG should explicitly reflect the needs of people with younger onset dementia in its work.

We also recommend that the Welsh Government ensures GPs are properly aware of the need for people with young onset dementia to get a diagnosis, and to be aware of it when diagnosing. GPs are likely to turn to other answers before dementia – leading to significant under-diagnosis. Worryingly, the lack of awareness amongst health care professionals and young onset dementia means that many people are often misdiagnosed with a differential diagnosis of depression. In some instances, women are being delayed a referral for dementia because of the similarity of symptoms with the menopause. **We also believe** that there is a need to develop a network of specialist Dementia Support Workers (at least one per LHB) with knowledge and experience of younger people with dementia and the specific challenges they face.

- **Cross-cutting themes:** We welcome that the strategy has been structured to reflect the 'life course' of dementia from prevention through diagnosis and support through to end of life care. This was a strong theme that came out of the consultation sessions, as something that people affected by dementia wanted to see. However, whilst this structure is helpful in many ways, it does risk a range of cross-cutting issues not being tackled in the strategy as fully as they should be, precisely because they are present throughout the dementia life course and, as such, require consideration in the round.

We therefore suggest that a further section is added to the strategy in order that these cross-cutting themes can be fully explored. These themes include, but are not limited to, the following groups:

- First-language Welsh speakers: We strongly welcome the fact that language is recognised in the draft strategy as a clinical need. Alzheimer's Society Cymru wants to see more detail on how proposals to support Welsh language speakers will be taken forward, and **we recommend** that steps are taken to ensure that diagnosis and support in Welsh language are available.
- People with dementia in rural areas: Our Dementia in Rural Wales project³ has opened a dialogue about rural dementia. We want to work with the Welsh Government and other stakeholders to unite against dementia and make sure services meet the needs of people affected by dementia in rural Wales. We estimate that at least 17,000 people affected by dementia live in rural Wales, and the figure is likely higher – it is only likely to increase, given Wales' ageing population. **We recommend** the Welsh Government invest in research so that we can better understand the extent of the problem.
- People with dementia from LGBT groups: Lesbian, gay, bisexual and transgender (LGBT) people with dementia, and their carers, partners, friends and relatives, face additional and specific challenges. **We recommend** that services should promote diversity inclusion and that there is board-level support for doing this. We also call for better information to be collected on the impact of dementia on LGBT communities.
- People with dementia from BAME and GRT communities: Black, Asian and Minority Ethnic (BAME) and Gypsy, Roma, and Traveller (GRT) communities are more likely to be diagnosed late and less likely to be diagnosed or use dementia services. There are substantial health inequalities that face these communities and high barriers to accessing services. Families may be reluctant to use services that do not meet cultural or religious needs and try to carry on alone. **We recommend** the provision of culturally appropriate services and raising awareness of dementia among minority ethnic communities. Work should also be done to hear the voices of BAME and GRT communities to increase awareness of dementia and to design culturally sensitive services.
- People with disabilities and sensory loss: In particular, we have undertaken specific consultation work with people who are deaf, hard of hearing, or have sight loss or impairment. This community has unequal opportunity to access dementia education, information and support. **We recommend** that all of the key actions and high level performance measures should be reviewed to ensure that they are inclusive of people with disabilities and make sure that they have fair access to dementia awareness, diagnosis and post diagnostic support. Local work between health, social care and third sector needs to be established so resources that can support people who are deaf and/or blind can be shared.
- People with dementia living alone: Around a third of all people with dementia live on their own. Whilst Alzheimer's Society Cymru fully supports the notion that that people with dementia who want to remain in their own homes should

³ Alzheimer's Society (2016) [Dementia in Rural Wales: the three challenges](#), Cardiff: Alzheimer's Society.

be supported to do so for as long as possible, evidence shows that people who have dementia and live alone are at greater risk of social isolation and loneliness. Our research has found that 62% of people with dementia who live alone feel lonely compared to 38% of all people with dementia.⁴ **We recommend** that all of the strategy's key actions should be sensitive to the needs of people with dementia living alone.

Furthermore, a recurring theme of the consultation events, the submissions from members of our SURPs, and engagement with other stakeholders was that the draft strategy draws too much from the 'medical model' of dementia. We strongly welcome the publication of *Good Work: a dementia learning and development framework for Wales* - this is an excellent project that people affected by dementia had the opportunity to feed in to, and we believe the dementia strategy could usefully borrow from its use of language in reflecting the wider social needs of people living with dementia, not simply the narrow medical approach. More broadly, there needs to be a better understanding by providers of the social model.⁵

Finally, **we believe** that the "high level performance measures" listed in the strategy need to have SMART targets attached to them, and that this should include detail of what additional resources will be made available to support the strategy's implementation. Spending on improving dementia care is an investment, and careful investment can transform the lives of individuals, communities, and society.

Next steps

We look forward to working further with the Welsh Government and other partners – in particular, people affected by dementia – as part of any group overseeing the strategy's implementation and delivery. We also believe that there is a huge opportunity during the next three years prior to the strategy's refresh for a wider conversation to happen with people from across Wales affected by dementia to feedback on the strategy's impact on the ground. The consultation events which helped to inform the strategy demonstrated that there is a largely untapped resource of experts across the country who have strong and constructive views on how support and services could be improved. We must listen to them.

⁴ Alzheimer's Society (2017) [People with dementia living alone](#), London: Alzheimer's Society, date accessed 30/03/2017.

⁵ Royal College of Psychiatrists and the British Psychological Society (2007) [Dementia: The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care](#), date accessed 14/03/2017.

2. Hearing the voices of people affected by dementia

The true experts on dementia are people who are living with and caring for people with the condition every day. Alzheimer's Society Cymru firmly believes in the importance of putting the voices of people affected by dementia at the centre of the strategy to meaningfully influence its development and direction. This is why we developed a series of engagement and consultation mechanisms to elicit the views of people affected by dementia.

We welcomed the Cabinet Secretary's statement⁶ on the launch of the draft Dementia Strategic Action Plan which recognised the importance of engaging people affected by dementia during the development of the strategy. We are committed to working with the Welsh Government to ensure this involvement continues during the strategy's lifetime.

The Welsh Government commissioned Alzheimer's Society Cymru and DEEP (Dementia Engagement and Empowerment Project) to collaboratively facilitate a series of consultation events with the aim of involving as many people as possible affected by dementia from Wales in the development of Wales' first dementia strategy. Phase one of the consultation was held between October – December, 2016 and allowed people affected by dementia to share their experiences and generate priority points that needed to be included in the Wales Dementia Strategic Action Plan. The views of people affected by dementia across Wales were summarised into a report for Welsh Government, which was then used to inform the development of this first draft of the dementia strategy which was published in January, 2017. Phase two of the consultation, which occurred between January – April 2017, created an opportunity for people affected by dementia to read the first draft of the Dementia Strategic Action Plan and comment on its key actions.

Alzheimer's Society Cymru has also facilitated additional engagement opportunities, both to broaden our understanding and to ensure the involvement of people affected by dementia who were underrepresented during the consultation period. We have facilitated consultation events with BAME communities; with the Deaf community and people who are hard of hearing; with people who are blind or have visual impairments; people who are affected by dementia and end of life care, with Marie Curie; around bereavement and counselling for people affected by dementia with Cruse Bereavement Care, along with interviews with individuals. Alzheimer's Society Cymru also designed and delivered a national survey to ensure people affected by dementia, the general public and professionals had an opportunity to share their views on the dementia strategy; this alone has gathered the views of over 500 people affected by dementia across Wales.

We have also supported people affected by dementia to share their stories with the National Assembly for Wales' Health, Social Care and Sport Committee during their inquiry into the draft dementia strategy and during two meetings of the Senedd's Cross-Party Group on Dementia, to inform responses to this consultation. Through this, a range of people affected by dementia from across Wales had an opportunity to contribute their views on the proposals and we hope both of these groups will have benefited from hearing first-hand the experiences of people affected by dementia, and will use this to inform their scrutiny of the dementia strategy.

⁶ Gething AM, Vaughan (2017) [Statement: Consultation on the Draft Dementia Strategic Action Plan for Wales](#), Record of Proceedings, National Assembly for Wales, 10th January 2017, date accessed 30/03/2017.

Consultation and engagement

The Welsh Government will have been provided with a full copy of the report on our consultation and engagement sessions, which highlights the needs and priorities of people affected by dementia in their own words.

The involvement of people affected by dementia in a range of settings has been invaluable. We have often been told that, at last, it feels like something concrete is happening to support people affected by dementia in Wales. It is important to recognise that, we hope, many of the people affected by dementia in Wales will turn to the Dementia Strategic Action Plan to see what care, support, and services they can expect to receive. **We recommend that** the final document should be drafted with this in mind and that the voices of people affected by dementia remain at the centre of Wales' first dementia strategy.

Consultation sessions

A number of key recommendations have emerged from the consultation sessions facilitated by Alzheimer's Society Cymru and DEEP that were not answered in the draft strategy. People affected by dementia felt these are priority areas and ask that the Welsh Government consider developing actions to ensure these are supported.

- A key point of contact to provide appropriate and tailored information and support for people affected by dementia from the point of being referred for diagnosis.
- Support services for people affected by dementia to be open to people going through the diagnostic pathway, to prevent crisis situations when a diagnosis is received, including pre and post diagnostic counselling for all people affected by dementia.
- People affected by dementia should be aware of their rights as an individual and how these rights can support any needs that may arise in relation to finances, respite, and employment.
- Peer support groups and user involvement opportunities should be recognised as valuable forms of support for people affected by dementia and for them to be resourced and sustained across Wales.
- A roll out of information and support hubs, to ensure engagement and support for the general public and people affected by dementia in both urban and rural areas.
- Carers and wider family support networks to be recognised in their own right and for their needs to be assessed and supported by adopting a person-centred approach.
- Respite services for people affected by dementia, including their carers and wider family support networks to be flexible and not limited to residential care. They should consider an age specific or ability based approach, where respite is relevant to the age and abilities of the individual.
- A holistic support plan, where support is informed and given by therapies such as speech and language, nutritionists, occupational therapists and psychologists.
- Dementia awareness, support and information to be inclusive of people from the BAME, LGBT, and other underrepresented communities, including better engagement to understand their needs and priorities.
- A palliative care and end of life care pathway to be established for people affected by dementia. Palliative care should be offered, explained and given to people affected by dementia at point of diagnosis.

Consultation with underrepresented communities

It was identified that various communities were under represented at the consultation events. As a result, other engagement activities were planned and facilitated to seek wider consultation and understanding of the needs of people affected by dementia in Wales. This included three consultation meetings with deaf clubs across Wales, one consultation meeting with a hard of hearing club in Cardiff, and a Black, Minority and Ethnic (BAME) consultation group in Cardiff. We have included the results of this work in Chapter 6 on support for specific communities, as most of the feedback was qualitative or recommendations for proposals, and not quantitative.

Palliative Care and End of Life

We are conducting ongoing engagement with people affected by dementia around end of life care in collaboration with Marie Curie. Focus groups have been planned to understand further the needs of people affected by dementia at this point. These engagement sessions have been developed based on the feedback gathered from the consultation groups as part of the dementia strategy, where palliative and end of life care was a priority. The subsequent findings will be shared with the Welsh Government, but current emerging themes include:

'When you get a diagnosis, no one checks to see whether or not you understand that dementia is a palliative condition, there is no palliative care pathway for people with dementia, yet dementia is so complex'

'No one wants to have the conversation with you, or we aren't supported or encourage to have the conversation with ourselves. I'd rather decide whilst I can the advanced decisions I can make and how I ensure these are met; we need to know about advanced directives and planning for end of life care at the earliest point – don't make it a taboo'

'I felt so guilty that she had to spend her last days in care, if I had known this is what she wanted and we'd been encouraged to have that discussion earlier on in her diagnosis I wouldn't be living with the constant sense of guilt and that I failed her'

Dementia in Rural Wales

Rurality often creates additional barriers for people affected by dementia. From our engagement work with people affected by dementia in rural Wales, we've found that, of the 237 people surveyed at the Royal Welsh Show in 2016 (69% of whom self-defined as living in a rural area):

- 46% of people knew of someone with dementia in their local area, and 29% had cared or were caring for a person affected by dementia. This potentially highlights the need for support from friends and family in rural areas. Only 4% had only 'heard of' dementia or knew nothing about dementia.
- 77% of people from rural areas would attend their GP as the first point of contact if they were worried about their memory and/or if they had a diagnosis for information and support. Only 4% would contact a memory clinic – interviews highlighted that most within rural areas found that memory clinics were far away and difficult to access.

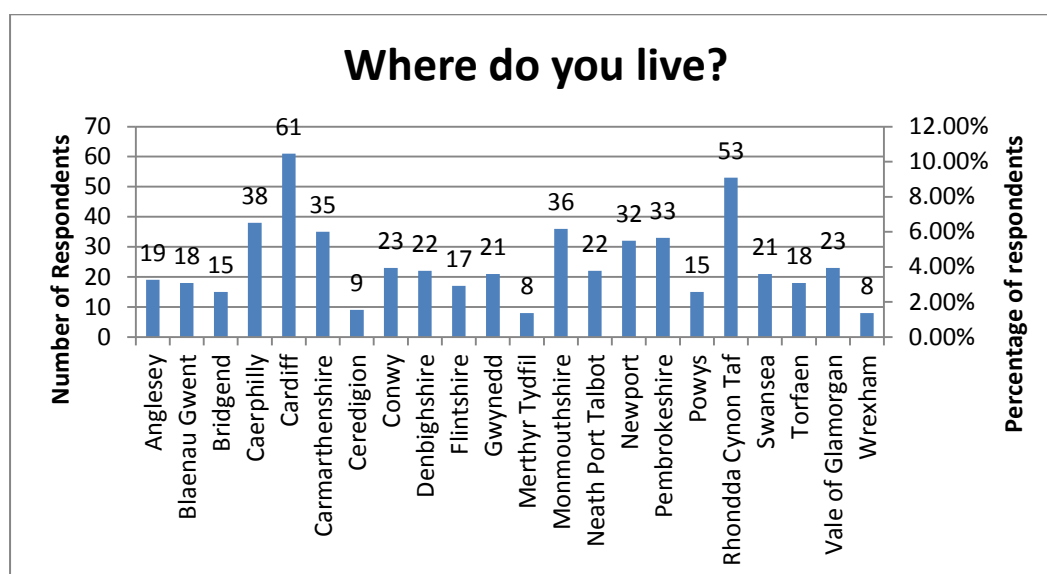
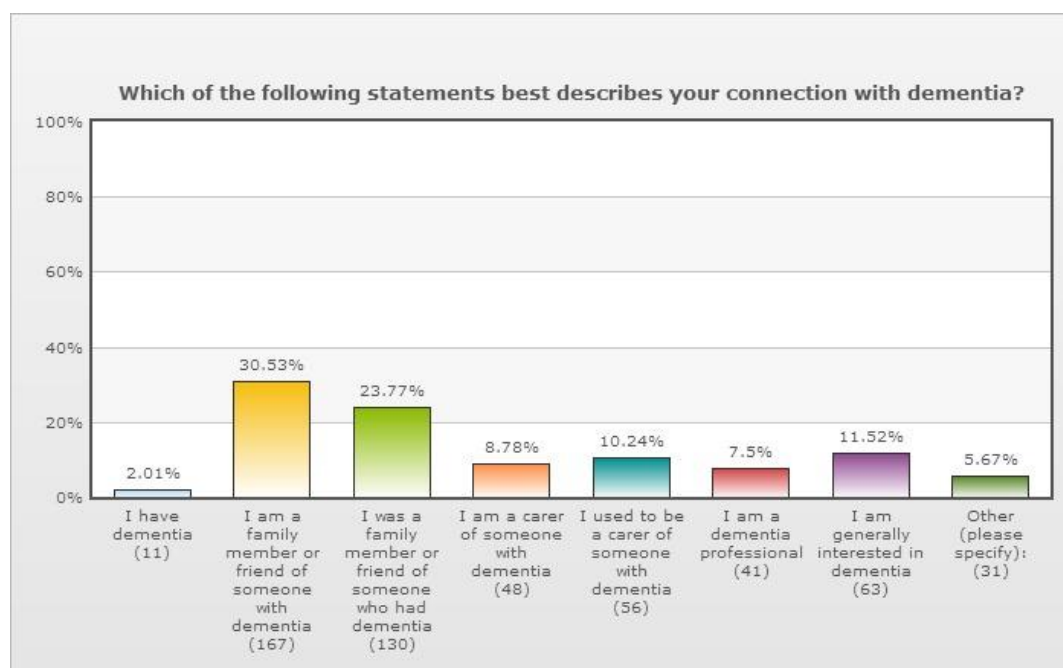
- 50% of people in rural areas said that the main enabler of people affected by dementia living well with dementia in their local area would be support services in the community.
- The highest (31%) barrier to living well with dementia in rural areas was lack of support services.
- People felt that community based support services would look like 'peer support', 'dementia networks', 'carer support' and 'information specific about dementia'.
- The second highest scoring barrier of living well with dementia in a rural area was lack of understanding of dementia – stigma was the most commonly used word to describe this.
- Transport was ranked as a barrier by 16% of people in rural areas, versus 6% in urban communities. Given this survey was undertaken at the Royal Welsh Show, we could assume that this group may be unrepresentative on transport – given people would need to have access to transport to Builth Wells in the first place.



Online Survey

It was important to expand our engagement methods, as many people affected by dementia across Wales who manage the demands of living with dementia or care for a person affected by dementia may find it difficult to also attend group consultations, or arrange appointments for one to one consultation. Alzheimer's Society Cymru developed an online survey that was open to people affected by dementia, as well as the general public and professionals, to complete to ensure they had the opportunity to contribute with to the dementia strategy. The survey was open from January until March 2017, and had 547 completed responses, broken down below:

"We need to deal with this issue now, before we ourselves have dementia and there are no services to help us."



We asked respondents to rate how much they agreed with the 12 proposed key actions in the draft dementia strategy, results are listed below - whether they agreed strongly, agreed but would like the proposal to go further, were neutral, disagreed because the proposal was going in the wrong direction, or strongly disagreed because the strategy should not focus on that issue. Some notable results included:

- The proposal with the highest number of respondents who agreed strongly was regarding a clear pathway for accessing care and support. It is clear that this must be a priority for the Dementia Strategic Action Plan.
- A number of measures achieved a higher than 70% of respondents that “strongly agree”.
- The measure most respondents wanted to “go further” was the diagnosis rate target, with 36%. Qualitative responses indicated this was due to a mix of wanting to see a higher target and wanting to ensure that support services pre- and post-diagnosis were supported and available.
- The second highest target that respondents wanted “to go further” was the 75% target for training staff in dementia care by 2019, with 25% giving this response.
- The proposal that had the highest number of people responding neutrally or disagreeing because “they shouldn’t focus on that” was on proposals for Welsh language – with 32.54%. This may be due to a number of respondents who do not have exposure to the Welsh language not fully appreciating the clinical need that the Welsh language represents for first language Welsh speakers.
- The second highest neutral responses was on antipsychotics –qualitative responses indicated that people did not feel they had enough experience of the issue to comment, or appreciating that in some, very limited, cases that antipsychotics were appropriate.

“Brilliant if it is actioned”

Below are the key proposals which respondents could offer their feedback on, followed by the breakdown of results.

Increase the number of people formally diagnosed with dementia by 3% annually, from 51% today.

36% of the respondents agreed with the proposal, with 36% agreeing but would like proposal to go further. Only 5% of people disagreed or strongly disagreed, with 23% remaining neutral.

Offer access to a support worker to all people newly diagnosed with dementia.

80% of the respondents strongly agreed to the proposal, with 17% of the respondents asking for the proposal to go further. Only 0.4% of people disagreed or strongly disagreed with the proposal and 1.5% remained neutral.

Increase the number of Dementia Friends and Dementia Friendly Communities in Wales.

79% of the respondents strongly agreed to the proposal, with 14% of the respondents asking for the proposal to go further. Only 0.6% of people disagreed or strongly disagreed with the proposal and 6% remained neutral.

Introduce waiting times for memory clinics, with every person referred for an assessment of dementia receiving a first assessment within 4 weeks and a preliminary diagnosis within 12 weeks.

75% of the respondents strongly agreed to the proposal, with 20% of the respondents asking for the proposal to go further. Only 2% of people disagreed or strongly disagreed with the proposal and 4% remained neutral.

Increase the number of hospitals and care homes that are dementia friendly.

83% of the respondents strongly agreed to the proposal, with 15% of the respondents asking for the proposal to go further. Only 0.2% of people disagreed or strongly disagreed with the proposal and 1% remained neutral.

Ensure 75% of NHS staff who come into contact with the public are trained in dementia care by 2019.

72% of the respondents strongly agreed to the proposal, with 25% of the respondents asking for the proposal to go further. 1% of people disagreed or strongly disagreed with the proposal and 2% remained neutral.

Make sure every local health board sets out a clear pathway for people to access care and support.

84% of the respondents strongly agreed to the proposal, with 15% of the respondents asking for the proposal to go further. Only 0.2% of people disagreed or strongly disagreed with the proposal and 1% remained neutral.

Offer all carers an assessment to get them support that is tailored to their individual needs and situation.

82% of the respondents strongly agreed to the proposal, with 15% of the respondents asking for the proposal to go further. Only 0.4% of people disagreed or strongly disagreed with the proposal and 2% remained neutral.

Ensure all memory services involve people with dementia and carers in feedback and service development.

82% of the respondents strongly agreed to the proposal, with 14% of the respondents asking for the proposal to go further. Only 0.4% of people disagreed or strongly disagreed with the proposal and 3% remained neutral.

Reduce the number of prescriptions for antipsychotic medicine to people with dementia, and reduce the duration of treatment with antipsychotics.

46% of the respondents strongly agreed to the proposal, with 20% of the respondents asking for the proposal to go further. 6% of people disagreed or strongly disagreed with the proposal and 29% remained neutral.

Ensure all district hospitals have a psychiatric liaison service in place.

78% of the respondents strongly agreed to the proposal, with 14% of the respondents asking for the proposal to go further. Only 0.4% of people disagreed or strongly disagreed with the proposal and 7% remained neutral.

Ensure health boards improve access to diagnosis and care in the Welsh language.

49% of the respondents strongly agreed to the proposal, with 10% of the respondents asking for the proposal to go further. Only 8% of people disagreed or strongly disagreed with the proposal and 32% remained neutral.

“All of the above are excellent targets and we should work to achieve these to the highest possible levels.”

“I wholeheartedly agree with the proposed key actions and hope that they can be implemented as soon as possible.”

As well as the challenges highlighted during the consultation events, we wanted to develop our understanding of the challenges faced by people affected by dementia across Wales. We asked 'please tell us about the biggest challenges that you've faced that you want the dementia strategy to address. Some of the key themes that emerged were:

- Training for staff across all sectors that will come into direct contact with people affected by dementia. An overwhelming number of respondents commented on the lack of empathy and understanding from staff.
- Lack of dementia specific services, that includes: respite, care homes and information and support services as the most frequently mentioned services that are required by people affected by dementia.
- Services are not tailored to support people affected by dementia that have additional needs such as: physical disabilities, hearing and/or visual impairments.
- Lack of services for people affected by young onset dementia that includes information and support services for the person living with dementia and the carer.
- More support needed to enable people affected by dementia to remain into employment.
- Dementia awareness needs to improve.
- Co-ordination and communication break downs between professionals involved in supporting people affected by dementia.
- Difficult to access diagnostic pathways, with a reluctance to diagnose because of the lack of support available for people affected by dementia in the local area.
- Support for people affected by dementia as they transition into care/residential settings.
- Carer specific support is rarely available or is not practical enough to support the day to day demands of caring for a person with dementia. It needs to be accessible for all ages and respectful of generational differences. Help is needed to support carers of people living with dementia who decline support.



Continued engagement of people affected by dementia in implementation & monitoring

We hope that people affected by dementia who have been involved with the consultation so far, and others who have not, will continue to engage with the process as implementation rolls out.

We believe that public bodies such as Local Health Boards and strategic planning boards must ensure they have in place robust and effective mechanisms to continually listen to people affected by dementia as they implement the Dementia Strategic Action Plan, to learn what is working and not working, and must be able to evidence that they have used this feedback to drive continuous improvement.

Once the strategy is agreed, implementation is going to be key. ⁷

We recommend that there should be firm guidelines on involving people affected by dementia in the implementation of the strategy itself. We have a wide base of expertise and knowledge to support this from a dementia-specific point of view and would be glad to work with Welsh Government to enable this to take place.

“Engagement and involvement [can’t be] treated as tick-box – need to be accountable, mandatory and not open to interpretation”

Notable practice: Cardiff and the Vale UHB recently held a workshop to develop the next dementia strategy for the area, and discuss the key themes. In order to develop a co-produced strategy, informed by the needs of people affected by dementia locally, people affected by dementia were invited to attend and take an active role in the discussions, alongside a range of organisations that support people with dementia.



⁷ Phelps, Sue (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.4).

3. Response to the text of the Draft Strategic Action Plan

Overview

We welcome the Welsh Government's vision of creating a dementia friendly Wales. Alzheimer's Society Cymru wants the draft strategy to be ambitious in its goals for dementia care, support and services in Wales, but also for it to be achievable – something towards which all sections of Welsh public services can work. The dementia strategy is a huge opportunity for Wales to set clear, ambitious targets to improve life for the 45,000 people in Wales living with dementia and the carers, loved ones and wider support networks who support people living with dementia. There is a great deal in the strategy which we strongly welcome, and it is heartening to see dementia being recognised as “*one of the most significant health and social care issues we face*”⁸, costing Wales in the region of £1.4bn per year⁹.

“People with [a] diagnosis suffer – but we are not sufferers – we live with it, and it's about how we live with it.”

We welcome that the Welsh Government is a signatory to the Glasgow Declaration with its call for governments to “*[d]evelop comprehensive national dementia strategies with allocated funding and a clear monitoring and evaluation process*”.¹⁰ We also welcome the rights-based approach taken in the document; it is important that people affected by dementia and service providers are aware of the rights people affected by dementia are entitled to. Wales needs a major effort to make rights into a reality for many people living with dementia – this was a strong call from people affected by dementia during our consultation work.

“We are one side of the same coin” - *person living with dementia talking about himself and his wife.*

We welcome the commitment to review and refresh the strategy after three years – this is important to make sure the strategy is relevant and delivering for people affected by dementia. We recommend that there is ongoing discussion with stakeholders in the years ahead to ensure that the refresh process is robust and inclusive.

We recommend that:

- The strategy recognises that dementia is a progressive condition, from which there is no cure and where symptoms gradually get worse over time¹¹. All people who develop dementia will have dementia at the end of their lives, either as the condition from which they die or as a factor which may complicate the care of a different condition.
- The strategy should set out a vision of what is meant by a *Dementia Friendly Wales*. Key actions and high level performance measures should then be judged by how well they align with this vision. This vision should be developed in partnership with people affected by dementia, and potentially be based on the national well-being outcomes

⁸ Welsh Government (2017) [Together for a Dementia Friendly Wales 2017-22: consultation document](#), Wales: Welsh Government, p.9.

⁹ Alzheimer's Society (2015) [The Hidden Cost of Dementia in Wales](#), Cardiff: Alzheimer's Society.

¹⁰ Alzheimer Europe (2014) [Glasgow Declaration 2014](#), date accessed 30/03/2017.

¹¹ Alzheimer's Society (2013) [End of life care: Dementia as a terminal illness](#), London: Alzheimer's Society, date accessed 30/03/2017.

and national outcome indicators of the Social Services and Well-being (Wales) Act 2014¹² or the refreshed National Dementia Declaration, which was co-produced with people with dementia and which will be launched in May 2017.

- The high-level performance measures associated with the Dementia Strategic Action Plan consist of SMART targets so progress can be monitored and reviewed (see Chapter 4).
- The strategy recognises that the impact of dementia is on everyone in Wales – nearly everyone knows someone who is affected by dementia. We need to be united against dementia and take a whole society approach.
- The strategy embeds a rights-based approach throughout. While initial references are welcome, there needs to be an effort to reflect those rights *throughout* the strategy. The approach of the Scottish Government to dementia care, support and services may provide notable practice as Scottish Dementia Strategies are also underpinned by the *Charter of Rights for People with Dementia and their Carers in Scotland*.¹³ The Charter “*is guided by a human rights-based approach (known as the “PANEL” approach, endorsed by the United Nations). It emphasises the rights of everyone to:*
 - Participate in decisions which affect their human rights.
 - Accountability of those responsible for the respect, protection and fulfilment of human rights.
 - Non-discrimination and equality.
 - Empowerment to know their rights and how to claim them.
 - Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.”
- This strategy better reflects the many cross-cutting themes which have an impact on the lives of people affected by dementia throughout the dementia journey. The concerns of people affected by dementia under the age of 65, those in rural Wales, those whose first language is Welsh or a language other than English, the needs of those in the BAME or the LGBT community, and more all require particular attention throughout the dementia pathway. There is a risk that by taking the pathway approach, these are not given sufficient priority within the strategy. Chapter 5 of our response makes specific suggestions as to how these issues could be addressed.
- The strategy should better reflect the needs of people with dementia who may be in the later stages of their journey. It is good that the strategy takes the approach of the patient journey, but risks too great a focus on the health sector – in reality, many people’s main involvement with public services after an initial diagnosis and introduction to support services will be in other areas such as social care, transport, and housing. This is where people will receive most of their services. There is also a period of time when someone is at a more advanced stage of the condition but are not at the end of life – the sections on end of life focus on people for whom death may be imminent, but many people will be at an advanced stage for many years without death being an imminent factor. People in this stage will need far greater support, as will their carers, family and wider support network, than those in earlier

¹² Welsh Government (2016) [Social Services: The national outcomes framework for people who need care and support and carer who need support](#), Cardiff: Welsh Government.

¹³ Alzheimer’s Scotland (2009) [Charter of Rights for People with Dementia and their Carers in Scotland](#), date accessed 21/03/2017.

stages. This is a cohort who will need better engagement throughout the implementation of the strategy.

We note that the Dementia Strategic Action Plan for Wales must be driven forward by a range of Welsh Government legislative drivers, strategies and action plans. **We therefore further recommend that:**

- The strategy should take forward the Welsh Declaration of Rights for Older People, ensuring that people with dementia have a sense of security, continuity, belonging, purpose, achievement and significance.¹⁴
- The strategy should build on the National Outcomes Framework, ensuring people with dementia feel healthy and active, safe, happy and can do the things that matter to them.¹⁵
- Public Services Boards (PSBs) should include a target in their Local Wellbeing Plans to increase the number of people with dementia supported to live well in their communities.
- The strategy should complement the Local Wellbeing Plans produced by the Public Services Boards and the Ageing Well plans produced by the Local Authorities.¹⁶
- Regional Partnership Boards should consult people affected by dementia to shape and influence their decision making, especially in regard to the implementation of the Dementia Strategy.
- The Welsh Government should provide greater detail and information on the impact assessments which it has undertaken to ensure the actions outlined in the plan will have a positive impact on people with protected characteristics.
- Regulations for the Nurse Staffing Levels (Wales) Act 2016 should explicitly reference dementia. People with dementia may well need a higher level of direct care than other patients which will reflect on required staffing levels on a given ward.¹⁷
- The dementia strategy should look to the National Audit of Dementia¹⁸ to monitor progress and ensure all hospitals participate.

“Biggest challenge [was] getting any service at all other than Alzheimer’s Society. Diagnosis took months then nothing but annual review at memory clinic since diagnosis 5/6 years ago. Although we disengaged and went to go for review last year. The clinic only undertook demoralising memory tests in a really poor building and environment nothing practical so couldn’t see the point.”

¹⁴ Welsh Government (2014) [Declaration of Rights for Older People in Wales](#), Cardiff: Welsh Government, date accessed 06/03/2017.

¹⁵ Welsh Government (2016) [Social Services: The national outcomes framework for people who need care and support and carer who need support](#), Cardiff: Welsh Government.

¹⁶ Ageing Well in Wales (2017), [Local Ageing Well Plans](#), date accessed 30/03/2017.

¹⁷ Our response to this consultation is available on request.

¹⁸ Royal College of Psychiatrists (2017) [What is the National Audit of Dementia?](#), date accessed 20/03/2017.

Monitoring delivery

Alzheimer's Society Cymru believes it is essential to involve the voices of people affected by dementia in the ongoing monitoring of the strategy. We welcome the Cabinet Secretary's commitment at the Cross-Party Group on Dementia's meeting in February 2017, that it "*would be useful to have those voices from people affected by dementia around the table*" at the Older Persons' Delivery Assurance Group (DAG).

We recommend that:

- The DAG should be responsible for ensuring people affected by dementia across government can access services, as a variety of portfolios outside health and social care such as housing, transport, leisure and cultural facilities, local government, and more play a huge role in the wellbeing of people affected by dementia.
- The DAG should have clear terms of reference published, and a clear requirement to report back.
- The DAG should consider how best to make its own processes dementia friendly and accessible to people affected by dementia as a priority as soon as it is reconvened.
- The DAG should explicitly reflect the needs of people with young onset dementia in its work – otherwise, there is a risk that the issue may not be within the purview of the Older Persons' DAG.
- The membership of the DAG is refreshed to include more representation from the third sector.
- All local health boards and organisations should develop ongoing engagement with people affected by dementia to inform the implementation of the strategy.
- There should be ongoing consultation on a broad basis with people affected by dementia. Following the *Prime Minister's Challenge* in England, the Department of Health launched a listening programme "to find out more about the experiences of people with dementia and their carers"¹⁹ including an online survey²⁰ and discussion by local groups with accompanying guidance for consultation with people affected by dementia.²¹ The feedback, data and information that is gathered will inform the formal review of the Implementation Plan in 2018. This could provide a potential model for use in Wales.
- Every local health board and organisation with key actions assigned to it within the dementia strategy should make sure that there is a named person responsible for leading on implementing and monitoring the strategy, in order to ensure accountability.

¹⁹ Department of Health (2016) [Listening to people with dementia and their carers](#), date accessed 27/02/2017.

²⁰ Department of Health (2016) [Dementia: care, support awareness](#), date accessed 27/02/2017.

²¹ Department of Health (2016) [Talking to people about the government's work on dementia](#), date accessed 27/02/2017.

Risk reduction and health promotion

Risk reduction and delaying dementia onset

The WHO recently acknowledged that *"the global health community has recognised the need for action and to place dementia on the public health agenda."*²² At present, there is no cure and limited treatments for dementia – but evidence shows that a healthy diet, regular physical exercise, managing conditions like Type 2 diabetes and high blood pressure, and avoiding smoking and excessive drinking can help reduce risk of developing some forms of dementia including Alzheimer's and vascular dementia.²³ Alzheimer's Society believes public health has five broad roles in relation to dementia:

- Informing people how to reduce their risk of developing dementia
- Diagnosing dementia early
- Supporting people to live well with the condition
- Enabling dementia friendly communities
- Monitoring and managing data.²⁴

"Health promotion is good – but all the health promotion ideas are the ideas that should be followed, whether or not you get dementia. Is this a good use of the strategy for this section?"

We believe it is important to measure any public health campaigns against these objectives.

We believe that public health information campaigns should be designed and delivered sensitively. Where possible, they should involve people affected by dementia in their development in order to ensure this.

We welcome the Welsh Government's commitment to the ACT NOW campaign. Public health campaigns are a vital element of building a dementia friendly Wales. A clear message of 'What's good for your heart is good for your head' is needed to encourage people to take steps to reduce their risk of developing dementia.

We recommend that:

- There should be a wider campaign to boost public understanding of dementia and its symptoms. This would help make society more dementia friendly and combat stigma.
- Public health campaigns should focus not only on lowering risk but on helping people understand the benefits of getting a timely diagnosis and how to live well with dementia. This is necessary to enable people with dementia to access support.
- Public health messages encourage life-long learning given the evidence showing that building up cognitive reserves can reduce the chance of developing dementia.²⁵
- General health promotion campaigns should be accessible to people affected by dementia.
- Health promotion *post-diagnosis* should also be considered. Following a diagnosis of dementia, people have often felt they have had to stop physical exercise or habits associated with a healthy lifestyle because of their dementia.

²² World Health Organisation (2012) [Dementia: a public health priority](#), Geneva: WHO.

²³ Alzheimer's Society (2014) [Public health, prevention and dementia](#), London: Alzheimer's Society, date accessed 22/02/2017.

²⁴ Alzheimer's Society (2014) [Public health, prevention and dementia](#), London: Alzheimer's Society, date accessed 22/02/2017.

²⁵ Alzheimer's Society (2014) [Public health, prevention and dementia](#), London: Alzheimer's Society, date accessed 22/02/2017.

- Specific campaigns should be run for Welsh Language and BAME communities in Wales. Diagnosis rates are traditionally lower in these communities and there are also higher correlations with some behaviours that ACT NOW focuses on reducing. As the draft strategy notes, there is anecdotal evidence that Welsh language and BAME communities “may be less likely to talk about dementia”. Our *Diagnose and Disempower* report²⁶ cited anecdotal evidence we have collected that Welsh language communities were less likely to talk about dementia, and that describing symptoms through the medium of Welsh was a particular challenge.

“How can you raise awareness amongst BME communities if you don’t even know what the issues are that you need to raise awareness on – whoever has ever sat at the table with us?”

Raising awareness and understanding

We welcome that the Welsh Government is aiming to create a Dementia Friendly nation. Alzheimer’s Society Cymru wants to see all of Wales united against dementia, building on the 60,000 Dementia Friends²⁷ created since 2014, and Wales’ 34 certified Dementia Friendly Communities.^{28,29}

“Important to raise awareness so my family can understand why I am doing funny things – now we know my family can now cope better.”

We note that communities that register for the dementia-friendly recognition process will be working towards meeting the foundation criteria³⁰ and should develop a strong local voice for people living with dementia in the community, to make sure their plan focuses on areas people with dementia feel are most important. The local community is in the driving seat of becoming more dementia friendly – the local community and its Steering Group are responsible for setting its own objectives, and providing evidence to show the work it has undertaken. It is essential that the voices of people affected by dementia are heard in that process.

We welcome the key action to increase the number of people in Wales who can recognise dementia, know how to support people affected by dementia, and access more information about dementia. We hope to work with Welsh Government to develop ambitious and achievable targets for spreading this awareness.

²⁶ Alzheimer’s Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer’s Society.

²⁷ A Dementia Friend is someone who has learnt a little bit more about what it’s like to live with dementia and then turns that understanding into action. Anyone of any age can be a Dementia Friend either by attending a face-to-face Dementia Friends Information Session or watching an online video. For more information, see: www.dementiafriends.org.uk

²⁸ Dementia Friendly Communities is a programme which facilitates the creation of dementia-friendly communities across the UK. Everyone, from state services, health boards to the local corner shop and hairdresser, share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community. They also develop a strong local voice for people living with dementia in the community, to make sure their plan focuses on areas people with dementia feel are most important. Communities also decide on 1-3 areas on which to focus for the first 12 months taken from [PAS standards](#). These can include: arts, culture, leisure, recreation, businesses / shops, children & young people, voluntary / faith groups, emergency services, health / social care, housing and transport.

For more information, see: Alzheimer’s Society and Dementia Action Alliance, [Foundation criteria for the dementia-friendly communities recognition process](#), Alzheimer’s Society: London.

²⁹ A list is available on request.

³⁰ Alzheimer’s Society and Dementia Action Alliance, [Foundation criteria for the dementia-friendly communities recognition process](#), Alzheimer’s Society: London.

We welcome that the strategy recognises the value of the [educational resources for learners in Wales](#) developed by Alzheimer's Society and Welsh Government.

We recommend that:

- Awareness and understanding is recognised as a theme in and of itself, distinct from risk reduction. Dementia friendliness is about ensuring that people with dementia feel understood, valued and able to contribute to their community, not specifically about reducing individuals' risk of developing dementia.
- Welsh Government commit to making all government departments dementia friendly and induct all new staff as Dementia Friends, and that government departments are reminded of their role in supporting dementia friendly communities.

“Children have to realise that this is normal and that people live with this. It’s nothing to be ashamed of or anything like that.”

Notable practice: Brecon Dementia Friendly Community - a community-led steering group was established in 2013, made up of carers, interested individuals, health and social care professionals and a range of community and voluntary organisations, to explore the opportunity to become a Dementia Friendly Community. Brecon Dementia Action Alliance was established to bring together regional and local members, including Brecon Medical Practice, Brecon Library Service, Dyfed-Powys Police, Brecon Mountain Rescue, Brecon Beacons National Park Authority, Barclays, Lloyds Bank, Brecon Theatre and more. They were awarded ‘working towards dementia friendly’ status from Alzheimer’s Society and won an award for their work in 2016.³¹

“I would like to see positive images of people with dementia.”

³¹ Dementia Friendly Brecon (2017) [Dementia Friendly Brecon](#), date accessed 15/03/2017.

Recognition, identification, assessment and diagnosis

“On the strategy’s aims to increase the numbers of people who have a diagnosis, there is a target of 3 per cent, annually, as an increase. Is that enough?”

- Rhun ap Iorweth AM

“Well, we have to support that because it’s better than it is now. But, no, it’s not enough, and if you look at the other national averages, it’s well below.”

-Nigel Hullah, person with dementia.³²

Several factors have led to low diagnosis rates, including historical lack of diagnosis, lack of understanding by the public and healthcare professionals, and an attitude among some healthcare professionals that there is little benefit in diagnosing dementia.³³ We need this to change. The Glasgow Declaration³⁴ recognises the right to a timely diagnosis. A diagnosis is of vital importance to individuals as it can help get the support people with dementia have a right to. Lack of a diagnosis can leave people unaware of the steps they can take to manage their condition, plan for the future, and access support and care. A diagnosis can unlock access to medicines which can help manage their condition.

In our consultation events, the majority of people affected by dementia agreed with the Welsh Government’s proposal to increase diagnosis rates. In our online survey, there was a strong feeling that the action on diagnosis was correct but did not go far enough, than for any other area covered. At the same time, there have been concerns expressed around the level of support available to support the increase of people diagnosed with dementia, including their family, friends and support network. In addition to increasing diagnosis rates, a framework of support needs to be developed, funded and firmly in place where people are effectively supported. Whilst progress is welcome, there is clearly a feeling amongst people affected by dementia that the target for improving diagnosis rates is not sufficiently ambitious and there also needs to be improvement on support, pre- and post- diagnosis.

Increasing the diagnosis rate would help the health and social care system with advance planning and improving clinical management in order to reduce future in-patient admissions.³⁵ Indeed, if the diagnosis reflects the actual prevalence of dementia in the population, then local authorities, health boards and other providers are more likely to commission specific services for people affected by dementia.

We believe there could be mileage in setting a target which rises over time (for example, 3% for Year 1, 3.5% for Year 2, 4% for Year 3 and so on) in order that procedures and practices can be put in place at the start of the strategy’s lifetime which can escalate the diagnosis rate in later years. This also allows time for the development of high-quality support services for pre-and-post diagnosis to go hand-in-hand with the increasing diagnosis rates.

“If I’d have known what I know now, I would have gone for a diagnosis years ago.”

We welcome proposals for “a consistent and evidence based local referral pathway to enable people to receive an appropriate, proportionate and comprehensive assessment for a diagnosis.” People with dementia clearly told us that they want to know,

³² ap Iorweth, Rhun & Hullah, Nigel (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 9th March 2017 (para.259-261)

³³ Alzheimer’s Society (2014) [Public health, prevention and dementia](#), London: Alzheimer’s Society, date accessed 30/03/2017.

³⁴ Alzheimer Europe (2014) [Glasgow Declaration 2014](#), date accessed 30/03/2017.

³⁵ Alzheimer’s Society (2014) [Diagnosis and Assessment](#), London: Alzheimer’s Society, date accessed 01/03/2017.

without difficulty, where they can turn for more information and support when they are ready for it. This was a priority area in our consultation sessions. However, they felt there should be a recommended gold standard pathway for Wales to ensure a consistent approach. We need to see a consistent, integrated, seamless, straightforward approach to making sure that people can get the support they want and need. This requires investment, joint working across health and social care, clear communication, and leadership at both local and national levels.

We welcome actions for primary care settings to become dementia friendly. GPs will often be the first place that people affected by dementia turn for support. We welcome Welsh Government's commitment that "*primary care teams need to have a better understanding of the benefits of a timely diagnosis*"; we have heard many stories of people not being given a proper diagnosis by their GP, ignoring their right to know and better understand their condition. We have been told of several barriers GPs may face that prevent them from giving diagnoses themselves:

- There is a lack of general diagnostic test for any type of dementia³⁶ which means GPs feel more comfortable referring to specialists.
- GPs feeling that giving a diagnosis of dementia is "pointless" without support services.³⁷
- GPs may be concerned about paying for medication and support for an individual out of their own limited budget if they are the ones to make a diagnosis.
- Stigma can play a huge role, and not wanting to impact on a patient's wellbeing.
- GPs may look to refer to specialist services as, supposedly, the target for referrals focuses on *avoiding errors* instead of *appropriate* referrals and diagnoses – creating a risk averse culture.

"When I visited the GP, he spent more time discussing the bad points of having diagnosis, he asked me if this was something I really wanted and recommended that there was no win win with the diagnosis as there was no support out there for me anyway. I didn't get a referral, but I did go back a year later when things were becoming too difficult. A year wasted."

In some places this leads to GPs refusing to give a diagnosis of dementia or potentially giving an improper diagnosis of mild cognitive impairment (MCI). From anecdotal information from our consultation and engagement sessions, some clinicians who potentially may not appreciate the importance of a timely diagnoses or appreciate an individual's right to know³⁸ may give a 'lesser' diagnosis of MCI in order to not scare a patient. An incorrect diagnosis can lead to people not getting the care and support that they have a right to access. We need to make sure GPs can accurately identify and diagnose dementia, in order to help people access appropriate services and medications.

"Sometimes a person is diagnosed with mild cognitive impairment. They are called back regularly for re-tests, but the memory tests don't take into account behaviour and personality changes. These people need support too even though they don't have formal diagnosis of dementia."

³⁶ Marie Curie (2015) [Living and dying with dementia in Wales: Barriers to care](#), Cardiff: Marie Curie, p.8.

³⁷ Rimmer, Abi (2016) [BMA meeting: Early dementia diagnosis is pointless without support services](#), British Medical Journal, 2016;353:i3505, date accessed 30/03/2017.

³⁸ Alzheimer's Society (2017) [Right to Know campaign – diagnosis and support](#), London: Alzheimer's Society date accessed 30/03/2017.

We recommend that:

- The strategy should set out clear and ambitious targets for increasing dementia diagnosis rates in Wales. While a commitment to increasing diagnosis rates by 3% is a good first step, we fear that it will take until the end of the strategy's lifetime for Wales to catch up to Northern Ireland – this is not sufficient. We must ensure that there are adequate post-diagnostic support services to support an increased number of people with a diagnosis of dementia, in order to support people after a diagnosis.
- Welsh Government should develop a series of Patient Reported Outcome Measures to monitor progress. Individuals should be able to receive an early diagnosis, if they so wish, that is delivered in a compassionate and sensitive manner.
- People should receive a comprehensive assessment of mental and physical health as part of the diagnostic process and at regular intervals subsequently.
- Local health boards should be routinely recording the number of people newly-diagnosed with dementia. Freedom of information requests in May 2016 suggested this wasn't being done. The Second Welsh National Audit Report into Memory Clinic and Memory Assessment Services recommended there "should be a requirement for every service to report basic activity data (for example the number of new referrals, time from referral to diagnosis, number with new dementia diagnosis and its severity, total number of patients actively being managed) every quarter."
- People with dementia should be able to receive an annual review in primary care. At present, the quality and outcomes framework provides for a review for people within a 15 month timeframe. This should be offered to all people affected by dementia.
- Public health campaigns promote the importance of a diagnosis.
- Welsh Government work with GPs and other health professionals to ensure everyone is aware of the benefits and importance of a dementia diagnosis. The 'WaMH in PC' programme³⁹ is a good example of notable practice in this field. In England, an online forum is being developed following the Prime Minister's Challenge for sharing information and best practice.
- A national pathway should be developed by Welsh Government in order to improve consistency, following a single model, with appropriate flexibility to represent local needs of people affected by dementia need at the LHB level.
- The national pathway should integrate and align with the work of third sector organisations wherever possible.⁴⁰
- Welsh Government should work with GPs and clinicians, the British Medical Association, the Royal College of GPs and others to better understand what prevents them from making these diagnoses, and overcoming those barriers. This should include explaining the importance of giving a diagnosis to GPs and other clinicians.
- Post diagnostic services must be available and well-advertised; including signposting to dementia support workers, pre- and post-diagnostic counselling, cognitive stimulation, speech and language support from therapists, occupational therapy and more.⁴¹

"The biggest issues for my parents following my mother's diagnosis of early onset dementia has been the absence of a clear plan for support and access to respite."

³⁹ WaMH in PC (2011) [Managing Dementia in Primary Care – Training Package](#), date accessed 30/03/2017.

⁴⁰ Wood, Dr Suzanne (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 2nd February 2017 (para.409).

⁴¹ Rudd, Dr Les (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.371).

- Welsh Government should clarify, as a priority, the standards that primary care, hospital and care homes will need to be to be “dementia supportive.”
- Welsh Government invest in “more GP-led clinic[...], more outreach to in-patient nursing homes, community care homes—particularly by both the GPs and the memory assessment services that can outreach.”⁴²
- Welsh Government should collect better data on diagnoses of MCI to allow us to better understand how widespread misdiagnosis is as an issue.
- Welsh Government should clarify what is meant by a “suitably competent clinician” as, theoretically, almost any clinician should be suitably confident in making a diagnosis. We want to see an increase in the diagnosis rate but this will only come through making sure GPs are confident in recognising the symptoms of dementia.
- Welsh Government should examine the potential for one uniform coding system across Wales. One of the challenges we have heard about anecdotally in diagnosing dementia is coding – seemingly, different coding systems are being used by different areas of the health system, ICD10 by hospitals and memory clinics, but READ codes for GPs. This can lead to confusion, even when someone has been referred as, for example, mild vascular MCI might get coded as mild vascular dementia due to lack of option in READ, even though they are far from the same thing.
- The highest standards for quality in memory clinics should be ensured, such as by joining the Memory Services National Accreditation Programme (MSNAP). We believe an independent review to establish the effectiveness of the programme, and explore other options for quality assurance for clinics with fewer staff, would be beneficial.⁴³ The ‘hub and spoke’ model has been used by some areas in order to lower cost of accreditation.

“Carers are the experts in that patients’ condition and how they present, really important to engage with that carer.”

Notable practice: Dementia Friendly GP Practices – GPs act as a gatekeeper for key aspects of care for people with dementia, however people with dementia can struggle to remember GP appointments, and may have trouble navigating the physical space of the GP practice. It is therefore hugely beneficial for a GP practice to become dementia friendly to raise the awareness of staff, train them in how best to support people with dementia, and even reduce the number of missed appointments. The Alzheimer’s Society provides training and resources for GP practices to become dementia friendly.⁴⁴

Cardiff and the Vale UHB – The Health Board has “commenced GP diagnostic clinics, funded through intermediate care fund moneys, to ensure that GPs are more skilled up and aware of dementia and they can make the diagnosis, with the supervision of the memory team” through utilising Addenbrooke’s cognitive examination III diagnostic tool.⁴⁵

⁴² Rudd, Dr Les (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.387)

⁴³ Alzheimer’s Society (2014) [Diagnosis and Assessment](#), London: Alzheimer’s Society date accessed 01/03/2017.

⁴⁴ Alzheimer’s Society (2017) [Dementia friendly GP practices](#), London: Alzheimer’s Society, date accessed 29/03/2017.

⁴⁵ Wood, Dr Suzanne (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 2nd February 2017 (para.374).

People affected by dementia in our consultation sessions offered examples of what they defined as a “**dementia supportive**” **primary care practice**, which included:

- Being able to access the same GP
- GPs being aware of how and where to access dementia-specific information
- All practice staff being aware of local services that can support people affected by dementia.
- The carer being seen as a person in their own right who may have health needs which require support

People affected by dementia should be involved to help the practice work towards becoming dementia supportive.

[Alzheimer's Society](#) has developed a toolkit to make GP surgeries more dementia friendly. The evaluation report concludes:

- A significant number of changes require little in the way of resource but can really have a big effect and can indeed be adopted by GP practices.
- Information sessions focusing on applying awareness of Dementia Friends to General Practice are instrumental in getting staff to be interested and enthusiastic.
- Putting these changes into practice could help many other sets of patients as well, not just those with dementia.

We welcome that specific risk factors have been acknowledged within the strategy. It is important that professionals in specialities that work with people at a higher risk of dementia – whether typically members of the health and social care professions or not – have appropriate and tailored training and support opportunities relevant to the sector in which they work, to improve their understanding and awareness of dementia.

One aspect not recognised is those in prisons. Individuals who are in prison may be at a higher risk of dementia than the general population, while less likely to be able to access services. Our work in The Prison Project⁴⁶ in HMP Wandsworth, HMP Wormwood Scrubs and HMP Pentonville found:

- The level of awareness of dementia among prison officers and prisoners is very low and symptoms are not identified or misdiagnosed due to pre-existing conditions.
- A very rigid regime means that no allowances are made, and so healthcare appointments tend to last no more than 10 minutes, which is insufficient for an assessment.

Notable Practice: HMP Parc opened an Assisted Living Unit to support older prisoners with dementia and other complex and clinical needs. They pioneered the use of Supported Living Plans and aimed to create an environment that is proactive and socially inclusive.

⁴⁶ Sindano, Natasha (2016) '[The Prison Project: Raising awareness of dementia in prisons](#)', Alzheimer's Society Blog, 15/11/2016, date accessed 29/03/2017.

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

People with dementia were unequivocal that accessing services should be based on need rather than being able to demonstrate proof of a formal diagnosis – particularly given that dementia is occasionally difficult to diagnose to a specific condition (out of over a hundred different forms).

We welcome that Welsh Government is proposing a high level performance measure (HLPMP) for every person referred for an assessment of dementia to receive a first assessment within 28 days and a working/preliminary diagnosis within 12 weeks (when it is clinically possible to do so). Diagnoses can take a long time – but wherever clinically possible, diagnoses should be timely. We would encourage the Welsh Government to explore the potential for using ‘provisional diagnoses’ to enable people to access support and information while the ‘wait and see’ process is ongoing. From the survey and focus group responses in our *Diagnose and Disempower* report⁴⁷ it is clear that for those who did experience a delay in their diagnosis it was most likely to occur in trying to get a referral to a memory clinic. According to the second Memory Assessment Services Audit⁴⁸ there has been “*little increase in diagnostic capacity of existing memory clinics over the past two years*” which has led to increased waiting times as diagnosis rates have increased. At present, only one health board delivered an average diagnosis time of less than 12 weeks. **We recognise** there may be clinical reasons why this process takes longer than 12 weeks and would not wish for diagnoses to be rushed to meet an inappropriate target – however we would not tolerate people being forced to wait for a diagnosis due to lack of capacity or other non-clinical factors. The Welsh Government should invest in order to make waiting for a diagnosis a thing of the past. **We highly recommend** that the Welsh Government should urgently provide greater resourcing to these clinics to aid diagnosis. **We also recommend** that the Welsh Government investigate opening up the process of referral to memory clinics – potentially to self-referral or referral by other ‘competent clinicians’.⁴⁹

Too often, it is pot luck that people get to hear about the services Alzheimer’s Society Cymru and other third sector organisations provide. We must also ensure that third sector partners are seen as equals within the care pathway, and value the role that specialist services bring. There needs to be greater integrated working across health, local authorities, and the independent and third sector. Social Services often act as gatekeeper to people accessing third sector services through referrals. There should be greater cooperation between social services and third sector, in order to be able to provide a fuller range of appropriate support. Increasingly, dementia-specific service contracts are being given to general care providers, which fails to recognise some of the complex and specific needs of people with dementia that require specialist knowledge and training.

“People often access our services at crisis point... because they’ve not known what support is out there.”
- Alzheimer’s Society Cymru staff

⁴⁷ Alzheimer’s Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer’s Society.

⁴⁸ 1000 Lives (2016) *Second Welsh National Audit Report Memory Clinic and Memory Assessment Services*, 100 Lives: Cardiff.

⁴⁹ Johnson, Nick (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 2nd February 2017 (para.377).

Information packs are welcome to help consistency and increase awareness of support services. However, it is also not sufficient to just receive an information pack – someone should always be available to go through the options and be there to design a tailored support package. An information pack is a useful tool to deliver person-centred support but not a solution in and of itself and cannot replace direct support and information. **We recommend** that GPs refer people newly diagnosed with dementia to the cluster's DSW service in order to go through this information in a more person-centred approach.

The Dementia Helpline is a welcome introduction in Wales, but our online survey shows that 77.15% of people with dementia, carers, family members, and professionals surveyed are not aware of this facility. Work should be done by the Welsh Government to promote the facilities that exist, such as the Dementia Helpline and Alzheimer's Society's own helpline.⁵⁰

"I haven't used the helpline because I know that the call takers are following a script and have no knowledge of dementia."

We agree that all people should be offered access to a dementia support worker, dementia adviser, or equivalent post, when diagnosed. This is a very welcome proposal, as we know that a support worker is a valued and important first point of contact who can signpost and support people with dementia, as well as their family/carers. This multi-skilled and multi-role individual should be able to address both health and social care issues, signposting as needed, co-ordinating communication between providers, and be capable of acting as an advocate when appropriate.⁵¹ Alzheimer's Society Cymru wants to see funding provided to ensure enough support workers to meet demand. According to one evaluation, the role of DSWs⁵² is "*required*" and offers potential cost savings to ensure "*that provision is cost-neutral after 4 years from implementation*". Currently, Welsh Government funds 32 Dementia Support Workers as part of Wales' GP Clusters – but with 20,000 people with a dementia diagnosis and an aspiration to increase this number, we will need significantly more of these support workers. To do this, we would like to better-understand the rationale behind the target of one Dementia Support Workers per two GP clusters target and what the evidence base is for this to be the appropriate level, especially in rural areas. In particular, we would like to understand what workload the Welsh Government is assuming each DSW to have. It may be necessary, in order to enable support workers to be able to provide high-quality person-centred support, to set a recommended case load or limit for case work, as is done for social workers via SCW. It would also be useful to better understand how the £1 million in 2010 and the £800,000 in 2016 build on each other, and whether lessons were learnt from the initial investment decision. We would encourage the Welsh Government to consider the case instead for a target of a number of DSWs per individuals diagnosed or by prevalence estimate in an area, instead of by GP cluster – as there may be substantial difference in diagnosis rate between cluster areas.

⁵⁰ Our National Dementia Helpline is at 0300 222 11 22. Our helpline advisors are available Mon-Weds 9am-8pm, Thursday and Friday 9am to 5pm and on Saturday and Sunday between 10am and 4pm. All calls are confidential. Calls to the Helpline cost no more than the national call rate. They count towards any inclusive minutes in a phone contract. This applies to mobiles, BT or other fixed lines or payphones. Confidential interpreters can be provided for many languages, and Text Relay is available for people with speech or hearing difficulties or who have a textphone or an adapted computer. We also offer online advice and help by e-mail.

More information can be found at: www.alzheimers.org.uk/info/20012/helpline

⁵¹ 1000 Lives (2016) *Second Welsh National Audit Report Memory Clinic and Memory Assessment Services*, 100 Lives: Cardiff.

⁵² South West Dementia Partnership (2011) *An evaluation of dementia support worker roles*, Bridgwater: South West Dementia Partnership.

We are concerned that this proposal does not seem to support all those individuals with an existing diagnosis who may also need support, particularly given the nature of dementia as a condition that progresses over time. People affected by dementia may require the support of a DSW throughout the dementia journey, not just at the start, and this needs to be reflected. We believe that the offer of access to a DSW should be offered to all people affected by dementia, regardless of need, and it should be possible to access a DSW later in an individual's journey with dementia if they need support at a later stage. **We believe** that this access to a DSW should, at the latest, be in place by the end of the strategy's lifetime.

It is important that the strategy recognise the high level of qualifications of Dementia Specialist Nurses and believe that DSNs, DSWs, and or other AHPs with expertise in dementia care have a role to play in providing support for people affected by dementia.

We would also like to highlight concerns that our DSW services are facing inappropriate referrals for people with medical needs who may be at crisis point. There is a strong need for DSWs to be involved in supporting people affected by dementia early, at an appropriate point. Often, support from a community mental health team would be more appropriate due to heightened need for monitoring and safeguarding of the person with dementia. Partially, this may have been an unintended consequence of the Social Services and Well-Being Act, where statutory providers are over referring. There needs to be a better understanding by statutory providers of dementia support services and the social model.⁵³

We recommend that:

- DSWs should provide people with dementia with annual follow-ups to ensure that individuals do not fall off the radar. These follow-up contacts should also include the offer of a health and wellbeing assessment being organised on behalf of carers.
- DSWs should be responsible for organising a health and wellbeing assessment on behalf of carers for people with dementia if one has not already been undertaken.
- DSWs should be available to follow up on all people newly diagnosed with dementia, whether or not they choose to receive the information pack.
- A single, unified job description for DSWs should be provided to health boards to prevent inconsistencies between the type of support being provided. We have heard of very varying standards of provision offered by LHB DSWs in different parts of Wales.

“After my diagnosis of vascular dementia aged 60 years there was no follow up at all I felt lost, lonely and tearful with many unanswered questions until I plucked up the courage to contact the Alzheimer’s Society who have subsequently been of great help.”

⁵³ Royal College of Psychiatrists and the British Psychological Society (2007) [*Dementia: The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care*](#), date accessed 14/03/2017.

Wider health needs

Individuals should be supported throughout their journey as best as possible. Proper support can improve their wellbeing and even help slow the progression of some symptoms.

The dementia strategy must take into account the fact that people living with dementia often have comorbidities with other conditions. It is estimated that 72% of people living with dementia also have another medical condition or disability. Often these conditions are chronic, and may be related to sensory loss, which will result in specific needs when accessing diagnosis, care and support. It is therefore essential that everyone living with dementia is able to access multi-disciplinary care and support capable of addressing the totality of a person's health needs.

We believe that AHPs have a unique spectrum of professional skills which are crucial in helping people with dementia to have an improved quality of life. At present the strategy misses a crucial opportunity to set out a new vision for how care could be delivered differently by enhancing a multi-disciplinary approach to care at home and in care homes, pre- and post-diagnosis, and promoting an enablement and reablement approach. It is clear that these skills are in demand – a strong theme from our consultation work has been that people affected by dementia felt that Allied Health Professions, in particular Occupational Therapists, could play a much larger role in terms of adapting activities and coping strategies, more than just equipment and technology. **We recommend** that:

- Dementia support post-diagnosis should include access to multi-disciplinary support from a range of therapists to adapt and cope with a dementia diagnosis as well as to promote independence and support people to develop the skills they will require in the later stages of dementia.
- The strategy should include a more explicit section focusing on enabling people with dementia to maximise their own wellbeing and build resilience and skills to support them throughout their journey, particularly with regard to prevention and early intervention. To support this, the strategy needs to ensure that eligibility criteria for support are not too high, so as to ensure people affected by dementia can access services when they need them and avoid the risks of waiting until crisis before they can access an intervention, in line with the principles of the Social Services and Well-being Act (Wales) 2014.
- The Welsh Government should consider the Scottish approach where AHPs are reflected as a key pillar within the post diagnostic stage and are explicitly highlighted within the 2013 strategy and its refresh. This includes key actions of:
 - working collaboratively with the new Integrated Joint Boards to support locality planning and re-design of dementia services;
 - enhancing a multi-disciplinary approach to care at home;
 - the promotion of therapeutic and enabling role of AHPs for people with dementia.

“[My mother] was also struggling with depression herself, which I didn’t realise. So, I think it’s also very important, when somebody is diagnosed with dementia or when they are continuing in the process of it, for healthcare professionals to just keep an eye, at best, that they might also be struggling with other illnesses. Dementia is not the end of it.”
- Emily Jones, Young carer⁵⁴

People with dementia often live with other conditions and illnesses. Some conditions, such as obesity, diabetes, or cardiovascular diseases are linked to developing dementia themselves. It is important that people are considered holistically, and all their health needs are met. Additionally, dementia can be linked to exacerbating other health needs. There may be the possibility of the person with dementia or carers or loved ones already having, or developing over time, illnesses such as anxiety and depression. There must also be a recognition that the person living with dementia may also be a carer for loved ones with other health needs.

We welcome proposals that all people with dementia should “*have access to evidence based pharmacological and psychosocial interventions.*” However, we caution that this is at present too vague, and should consider specific interventions and how they can best be delivered. The strategy should distinguish between pharmacological and psychosocial interventions and acknowledge the benefits of the interventions separately, in order to provide the biopsychosocial support. People affected by dementia explained that this was the most effective intervention in enabling them to live well with dementia.

It is often most effective when pharmacological and psychosocial interventions are combined. However, not everyone is able to access pharmacological interventions (due to the type of dementia, or additional health conditions). Pharmacological interventions are often only used when people receive an early diagnosis – further reinforcing the importance of an early and timely diagnosis.

“As little support as there is out there, it needs to start early, to have as much support as possible.”

There is scant reference to the importance of communication, swallowing, and eating, nutrition and hydration, or the role of speech and language therapy in supporting people affected by dementia. Communication problems often occur for people with dementia and can become increasingly challenging. Communication difficulty is one of the most frequent and hardest to cope with experiences for family members and can be exhausting for the person with dementia and affects their identity and relationships. Additionally, dysphagia is a recognised challenge for people with dementia, particularly in the later stages of the condition. As a minimum, we would expect these needs to be highlighted within key sections of the document including: support to stay safe and secure in the home and community, safeguarding, addressing workforce training needs and care homes.

We also believe that the strategy needs to recognise the role of group activities, peer support, and influencing groups as a valuable support mechanism for people affected by dementia, which help build confidence, give new skills and prove that it is possible to live well with dementia. We know that the best people to offer support to people affected by dementia are other people affected by dementia, who understand their experiences and can

⁵⁴ Jones, Emily (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 9th March 2017 (para.291)

offer support from their own life story – Welsh Government should work to enable this wherever possible.

We recommend that:

- There should be a specific key action around psychosocial interventions, with explicit mention of peer support groups and activity based groups as forms of support that are most valuable and effective.
- The strategy should include greater detail on communication needs given its strong link with behavioural symptoms, maintaining relationships, and safeguarding issues and consent. Proposed actions should include access to communication support for people with dementia and their families.
- Health workers should be trained in understanding signs of anxiety and should be able to offer support/services if necessary.

“I’ve always wanted to talk to someone who’s got the same problem as me – because of data protection, they can’t help set up meetings.”

Notable Practice: The British Psychological Society has released a guide which was co-produced with people affected by dementia, which informs and describes psychosocial interventions for people affected by dementia.⁵⁵

“The biggest challenge initially was finding things we could do together. The Forget Me Not Chorus gave us just what we needed as it was stimulating, fun, something we could do together and we had a huge amount of support from the people who run it and people from other 3rd sector agencies who were asked along to support us. We also had amazing support from others who were in a similar situation to us. I now go along, since my husband died, to support other [people affected by dementia].”

⁵⁵ The British Psychological Society (2013) [*Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia*](#). London: BPS.

Recognising the needs of carers

Family, friends and wider support networks are pivotal in enabling a person to live well with dementia. They will often require support to fulfil the role of carer. We must recognise and value the carer's journey and ensure a commitment to adequate respite, support, and training for carers.

“Caring for someone with dementia is so isolating and the lack of public awareness of the condition does not help.”

We recommend that the strategy recognises:

- Four out of five carers in Wales first encounter a statutory service in a community health-based setting – more can be done to raise awareness in community health settings to actively offer support and advice to carers.⁵⁶
- Information must be made available at the right time, and the right place. Directly after receiving a life-changing diagnosis may not be the best place to get further information – follow up meetings are important and should be consistently offered to better support carers & people with dementia.
- Often the ‘person to turn to’ is not standardised, and is simply someone who the carer has built up a relationship with – while this can be an important relationship to have, lack of a standard means some carers simply don't have anyone to whom they can talk.
- The range of information a carer can require, which may include understanding the causes of memory loss & where and how to get help; continence issues; legal issues – for example, what is a Lasting Power of Attorney, capacity for decision-making, wills and home ownership issues; managing medications; mobility issues; creating environments at home to support memory loss; issues around sexual health and consent; managing behaviour; signs to look out for; emotional support; when to see your GP; decisions relating to residential care and end of life. There are a great many issues that are currently poorly represented in carer support and training.

We welcome proposals for carers' education and access to carers' assessments, but feel that the strategy should go further. Alzheimer's Society Cymru wants to see firmer targets for carers' assessments. We must ensure that carers' assessments reflect the realities of living with dementia – for example, that dementia is a progressive condition and the needs of a carer may vary over the course of a person's condition. As such, a carer's assessment should be the start of the conversation, not just the end. The need to avoid carer breakdown is generally well-recognised but we are concerned that the eligibility criteria for carers assessments are too high. At present, there is a risk to people's wellbeing in only assessing them as having ‘eligible need’ when they are already close to breakdown. Carers assessments need to be focused on support to prevent breakdown, not on helping when a carer is already in crisis. When someone presents in hospital with a loved one, a carer's assessment should be a priority at this crisis point.

⁵⁶ Rees, Kieron (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.145)

We welcome the Welsh Government's commitment to examine a national approach to respite care. Alzheimer's Society Cymru wants to see a proper plan for respite care, to avoid this important area falling between different aspects of Welsh Government's ongoing policy development work. People living with dementia and carers must have timely access to a range of flexible befriending and respite services that are appropriate and meet their specific needs and interests. The range of respite care options offered must reflect what carers themselves identify as being most impactful. Consistency is important. The value of breaks to carers is well documented and can be valued as part of a preventative intervention to avoid carer breakdown and maintain carer health and well-being. Welsh Labour committed to "*investigate the benefits of establishing a national carers respite scheme in Wales*" ahead of the election.⁵⁷ Any such scheme should ensure access to specialist dementia respite care.

"[The biggest challenge] as a carer, the feeling of loneliness. People say you must look after yourself, and I agree but this is very difficult to achieve. The most, realistically, is a few hours to do shopping or whatever, even when paying for extra services, that is if you are in a close relationship and want only the best for the person with the illness."

We recommend:

- Introducing a national approach to involving carers in the treatment of those with dementia, including training for health and care home staff in identifying, supporting and involving carers of people with dementia. [Best Interest meetings](#) should always involve carers.⁵⁸ The strategy should explicitly set out that people with dementia and their carers should be involved as equal partners in care, supported by a multi-disciplinary team around the individual with professionals from different specialities. Health care services should meet the [Triangle of Care](#) standard, which is a "*therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing*"⁵⁹.
- All healthcare professionals should be able to access information on a patient's carer, in order to provide support, particularly in cases where the carer is not necessarily the formal next of kin or an individual with power of attorney. This may be particularly true in the older LGBT community.
- Providing carers' education that, where possible, should be co-developed and co-delivered by carers. This would increase the opportunities for peer support. Courses should include practical elements such as washing, dressing and feeding and be accessible to the carer from point of diagnosis.
- That Welsh Government, local authorities, health boards and other key statutory agencies work together to develop good practice on how the new duties in the Social Services & Wellbeing (Wales) Act can promote tailored advice and information to carers.

⁵⁷ Welsh Labour (2016) [Welsh Labour Manifesto 2016: Healthy & Active](#), Cardiff: Welsh Labour, date accessed 30/03/2017.

⁵⁸ Social Care Institute for Excellence (2015), [Making decisions in a person's best interests: How best interest decisions must be made](#), London: SCIE, date accessed 30/03/2017.

⁵⁹ Carers Trust (2013) [The Triangle of Care - Carers Included: A Guide to Best Practice in Mental Health Care in England](#), 2nd edition, London: Carers Trust, p.3.

Notable practice: CRISP - Alzheimer's Society's Carer Information and Support Programme (CrISP) provides support and up-to-date, relevant information in a group environment, where carers can share experiences and find out about local and national services that can offer support. The programme is run in a series of sessions which offer carers the opportunity to share experiences in a confidential and friendly environment with others in a similar situation. Trained staff and volunteers run the sessions to ensure carers get the most out of the programme and can provide further information and support.⁶⁰

Side-By-Side Alzheimer's Society has recently launched our innovative Side By Side⁶¹ befriending service, in a bid to reconnect people with dementia with their communities and favourite pastimes. Launched in response to the loneliness and isolation so many people with dementia report experiencing, the service has been piloted since 2014, and now has a waiting list of almost two thousand people with dementia across England, Wales and Northern Ireland.

The **Dementia and Imagination** research project explores how art can improve life for people with dementia and their carers.⁶²



⁶⁰ Alzheimer's Society (2017) [Carer Information and Support Programme](#), London: Alzheimer's Society date accessed 29/03/2017.

⁶¹ Alzheimer's Society (2017) [Side By Side](#), London: Alzheimer's Society, date accessed 29/03/2017.

⁶² Dementia and Imagination (2017) [About the project](#), date accessed 29/03/2017.

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

Everyone in Wales' diverse communities must unite against dementia and build a Dementia Friendly Wales. People living with dementia have the right to feel understood, valued and able to contribute to their community. Communities can provide vital support – but equally, if someone feels isolated from their community, it can have strong negative effects on their wellbeing. 39% of people with dementia said they felt lonely, rising to 62% of people with dementia who live on their own. Difficulties in maintaining social relationships and other features of dementia contributed to this, with 35% of people with dementia saying they'd lost friends after a diagnosis.⁶³

“My life is still being lived it's not over – as long as it's not just about what I've done and not what I'm going to do. I'm still here.”

We welcome the Welsh Government's intention to develop a national strategy to tackle loneliness and isolation.⁶⁴ Given the link between dementia and loneliness, we believe that, any loneliness and isolation strategy should include a discrete section on dementia.

We also welcome the strategy's suggestion that people should be able to use *Book Of You* as a reminiscence tool. **We recommend** that the strategy set out who would be responsible over implementing this, and how. Additionally, the strategy should recognise that *This Is Me* is different to reminiscence and exists to support professionals in delivering person-centred care and understanding immediate needs.

We recommend that post-diagnostic support should include:

- Tailored information about the condition, including where appropriate specialist information regarding less common dementias or atypical problems. This is of particular importance to those with rarer forms of dementia or individuals under 65 who develop dementia.
- Access to bereavement services, to help people cope with the loss of family members.
- Advice on memory strategies and access to cognitive stimulation programmes, group or individual, which have been shown to lead to improvements in both cognitive function and quality of life.
- Communication support through speech and language therapy.
- Opportunities for engagement in valued and enjoyed activities, which maintain engagement in the wider community. These would include creative activities (for example, visual arts, music, gallery and museum visits), intergenerational activities and exercise programmes in a social context.
- Support with planning for the future.
- Support that recognises the needs of families & care-givers, in terms of information, peer support, education and psychological therapies where appropriate. Some families will require skilled support where difficulties in communication or conflict arise, as the experience of dementia can be very stressful for some couples and families.

⁶³ Alzheimer's Society (2013) [Dementia 2013: The hidden voice of loneliness](#), London: Alzheimer's Society.

⁶⁴ Welsh Labour (2016), [Tackling Loneliness and Isolation in our Welsh Communities](#), date accessed 24/03/2017.

We recommend that the strategy explicitly recognises the duty to consider advocacy (particularly when being assessed or considering services) for people who have been diagnosed with dementia.

We recommend that there should be pre-and post- diagnostic counselling available. This is a strong recommendation from our engagement sessions with people affected by dementia. This can prevent help crisis situations which have a negative impact on an individual's ability to live well with dementia.

We welcome the acknowledgement that "*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*". This is vital to ensuring the provision of effective, safe, respectful and dignified services that meets the needs of people living with dementia.

Assistive Technology has the potential to offer benefits to people with dementia and their carers in specific circumstances. There should be a greater role to support maintaining independent functioning through the use of memory aids, adaptations, structured cognitive rehabilitation programmes, assistive technology and occupational therapy input. However, there are practical and ethical issues that must be understood and addressed with respect.⁶⁵

Whilst most people affected by dementia view assistive technology positively, they are concerned that assistive technology may compensate for direct face to face support. People affected by dementia in our consultation sessions largely felt that the use of telehealth, telecare and assistive technology should be optional and not be used in place of more meaningful support.

"With the GPS tracking device, I can now relax when he goes out for his walk and he can relax because he knows I'm not worrying about him."

We recommend that:

- People affected by dementia receive an assessment for evidence based assistive technology and/ or necessary personal 'reasonable adjustments' shortly after diagnosis and on request at other times. This should take into account issues around sensory loss.
- People with dementia are included, wherever possible, in decisions about assistive technology. People with dementia will not be able to fully benefit unless they are diagnosed earlier and able to access services.
- Awareness by health and social care professionals is raised about the potential for assistive technology.
- Assistive technology is personalised to the individual and not part of a 'set menu'. Assuming that every individual with dementia requires or will benefit from the same piece of assistive technology is unhelpful.
- Assistive technology and telecare is supported by access to services such as occupational therapy.

⁶⁵ Alzheimer's Society (2013) [Assistive technology](#). London: Alzheimer's Society, date accessed 30/03/2017.

Notable practice:

The Raglan Project in Monmouthshire is piloting relationship-based care as opposed to task-based care. It increases flexibility and tailors care provided around the individual. It has been hugely successful, with people with complex needs staying at home rather than moving to permanent residential care or hospital, and people with dementia being supported back to independence and re-engagement with their local community. Staff have better morale, job satisfaction and sickness remained at 0% for 18 months.⁶⁶

“Named support workers for person with dementia and carer. More support for Carers by way of respite, care services, health, financial. Patient centred model for care team like the ‘Raglan Project’.”

Cruse Bereavement Care and **Alzheimer’s Society Cymru** have built a partnership, supported by Welsh Government, to support people with dementia who have been bereaved and people who have lost someone who had dementia.⁶⁷ Cruse have “recognised from attending the support group, they saw the grief when they came in, they’ve gone and arranged meetings and they’re looking at dementia as a definite grieving process, they’re training staff to go through the grieving process with people when someone is still alive, still has a heartbeat, but isn’t the person they were anymore” [quote from Newtown consultation event].

The Herbert Protocol can be a useful tool to support people with dementia and their carers. The Protocol is a form that contains vital information about a person with dementia, including favourite places, medication and routines. This information can be utilised by the police if that person goes missing. When a person is reported missing, the police need a vast amount of information from people who are likely to be in a heightened state of anxiety. Extracting that information takes time and may not always be accurate, particularly when it relates to historic information which can be important when searching for a person with dementia.⁶⁸

The Llantrisant Support (Dementia) Group Model was established through cooperation between the Memory Assessment Service for the Taf/Rhondda areas and the Vicar and Parish of Llantrisant (Church in Wales) and Hospital Chaplaincy. The Llantrisant (Dementia) Support Group was established in April 2015 - the group provides peer, community and professional support outside of hospitals, and other clinical settings to help regain/maintain a feeling of identity and self-worth by being part of, and active members of the group and community.

⁶⁶ Monmouthshire County Council (2015) [Raglan Project takes prize for transforming lives](#), date accessed 28/03/2017.

⁶⁷ Cruse Bereavement Care (2016) [Cruse Bereavement Care Cymru and Alzheimer’s Society in Wales working together](#), date accessed 27/03/2017.

⁶⁸ North Yorkshire Police (2017) [Dementia and the Herbert Protocol](#), date accessed 28/03/2017.

Safeguarding and raising concerns

The mistreatment and abuse of people with dementia is always unacceptable. The risk of abuse can be reduced through the provision of adequate support, training, ongoing supervision and legal protection. Wales has the highest prevalence of elder abuse in the UK, with a rate of 6%, compared with 4.3% in Scotland, 3.9% in England and 3% in Northern Ireland.⁶⁹

People with dementia are at higher risk of elder abuse⁷⁰ and can be more vulnerable to abuse as they may struggle to discuss their feelings and experiences or remember what happened to them. Common reactions to abuse, such as withdrawal from communication, can also be symptoms of dementia.

We welcome the new role Safeguarding Boards have in protecting adults who have needs for care and support.

We recommend that there must be:

- Improved dementia training for staff in care homes and hospitals in particular. Lack of training is an important cause of poor-quality care. Staff may be unable to communicate effectively with people with dementia, involve people with dementia in decision-making following the principles of the Mental Capacity Act and care for people with dementia who experience behavioural and psychological symptoms. This can mean that people with dementia do not receive person-centred care, are deprived of their legal rights and receive inappropriate treatments, such as physical restraint and anti-psychotic drugs, that can exacerbate symptoms.
- Effective and robust enforcement. Abuse and mistreatment are too serious to be considered as part of a general complaints procedure. Alzheimer's Society Cymru believes that regulators, not providers, should deal with such complaints.
- Dementia training and support for carers. People with dementia who experience behavioural and psychological symptoms can behave aggressively. Such behaviour can be highly stressful for carers. Carers who lack support may manage this behaviour inappropriately, for instance by physically restraining a person with dementia. This kind of abuse, despite the fact that it is unintentional, is as unacceptable as intentional abuse. People with dementia can also abuse their carer. This is usually as a result of the behavioural and psychological symptoms of dementia. To prevent abuse, carers must receive support.
- Signposting to advocacy to support people raising concerns and ensuring the duty to consider advocacy for all people with dementia for whom there are safeguarding concerns.

⁶⁹ Stevens, R. (2012) "[We can 'Rule Out Abuse' in Wales](#)", Cardiff: Age Cymru.

⁷⁰ Claudia Cooper, Amber Selwood and Gill Livingstone (2008), [The Prevalence of Elder Abuse and Neglect: A systematic review](#), *Age and Ageing*, 37, pp.151-160.

Prompt problem management

We recommend changing the title of this section. People living with dementia are never a ‘problem’ to be managed, and whilst we are sure this was not the intention of the authors of the draft strategy, we would suggest titling the section as “Medicines Management and Antipsychotics” or similar, taking into account polypharmacy (discussed below).

Behavioural and psychological symptoms of dementia are often a reaction to distress, unfamiliarity with the environment, or lack of ability to communicate. All of these can be addressed by avoiding situations likely to cause upset, avoiding confrontations arising from attempting to ‘correct’ the person with dementia, and by ensuring care is person-centred from staff who have the time and skills to support people with dementia, not by use of “medical clubbers”⁷¹.

“Lack of suitable homes. Many we saw fell far below the standards we expected. Staff were often blasé and sedated patients for a quiet life. Stimuli were in short supply and communication left much to be desired. This needs to be improved.”

We are deeply concerned about the over-use and inappropriate use of anti-psychotics in Wales, and strongly believe that these drugs should only ever be the last resort. Antipsychotic drugs can be used to reduce psychotic experiences such as delusions and hallucinations. However, use of antipsychotics should be limited, due to only moderate benefit, not addressing underlying causes of behavioural and psychological symptoms (BPSD)⁷², and links to serious side effects. The use of antipsychotics results in a number of side effects, such as drowsiness, nausea and constipation. The longer term use of antipsychotics increases the risk of fatal conditions such as stroke (though there is some debate over this in recent evidence⁷³).

Within the National Dementia Vision for Wales, there were commitments to ensure appropriate use of antipsychotic drugs, and it is important to build on this example.⁷⁴ We agree with recent campaigns by the Older People’s Commissioner for Wales, the Royal College of Psychiatrists Wales, and the Royal Pharmaceutical Society Wales to ensure antipsychotics should not be routinely prescribed to treat behavioural and psychological symptoms of dementia. When antipsychotics are necessary, as per NICE guidelines, only the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled pharmacist as part of a multidisciplinary team.^{75,76} This is a particular issue for dementia – according to a 2009 report by Professor Sube Banerjee, *The use of antipsychotic medication for people with dementia*, of 180,000 prescriptions for people with dementia, 140,000 were inappropriate.

We welcome the Welsh Government’s proposal to reduce the percentage of people with dementia prescribed antipsychotics but want to see more information on how this will be

⁷¹ Fenton-May, Dr Jane (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.241)

⁷² Alzheimer’s Society (2014) [Antipsychotic drugs](#), London: Alzheimer’s Society, date accessed 30/03/2017.

⁷³ Howard. R. (2016) [Baseline characteristics and treatment-emergent risk factors associated with cerebrovascular event and death with risperidone in dementia patients](#), *British Journal of Psychiatry*, 209/3.

⁷⁴ Alzheimer’s Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer’s Society.

⁷⁵ Royal Pharmaceutical Society Wales (2016) [Improving Medicines use for Care Home Residents](#), Cardiff: RPSW.

⁷⁶ Older People’s Commissioner for Wales (2014) [A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales](#), Cardiff: OPCW.

implemented and what will be reported to local mental health partnership boards by June 2018.

Behavioural and psychological symptoms can often be managed without medication through person-centred care. People with dementia should have the opportunity to participate in meaningful activities. This involves tailoring the person's care to their interests, abilities, history and personality to make sure they are comfortable and engaged. It is important to give them the chance to take part in one-to-one conversation and activities that interest them.⁷⁷ Positive interactions and supportive contexts can help to mitigate the impact of particular difficulties or symptoms.⁷⁸

People affected by dementia need to be aware of their rights when it comes to deciding to take medication; their individual choice should be supported.

We recommend that the Welsh Government:

- End routine prescribing and work towards a reduction in the time and dosage where antipsychotics are required.
- Ensure people have a full explanation of the medication they may be prescribed and choice in their treatment. We should ensure that people with dementia prescribed antipsychotics have support from carers, loved ones, or advocates.
- Ensure that multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics. Reviews and reductions of antipsychotics are most effective when nonpharmacological interventions were available to replace antipsychotics.⁷⁹ Non-pharmacological interventions could include OT, sensory, gardening, talking, arts, exercise and more.
- Institute a cycle of national and local audits of prescribing antipsychotics in care homes to patients with dementia to improve clinical practice.
- Ensure health boards work with pharmacists and other medical professionals who deliver enhanced support for care homes to reduce the use of antipsychotics in care homes through ensuring MDT support is available to go into care homes to deliver medication reviews on arrival and at regular intervals (for example every six months).

Support in ensuring medication is taken as prescribed is an important factor in maintaining independence for as long as possible. Medication reviews and the importance of informed consent were a strong theme of our consultation events - a number of people with dementia and their carers told us they weren't aware of the name of their medication or why they were taking it. This is of great concern. We also have concerns over polypharmacy, whereby four or more medicines are prescribed for an individual. The proportion of patients receiving 10 or more medicines has increased from 1.9% in 1995 to 5.8% in 2010.⁸⁰ Medicines should be reviewed regularly for people with dementia; for many patients, dealing with multiple medicines can be

⁷⁷ Alzheimer's Society, [Treating behavioural and psychological symptoms of dementia](#), London: Alzheimer's Society, date accessed 21/03/2017.

⁷⁸ British Psychological Society (2016) [Psychological dimensions of dementia: Putting the person at the centre of care](#). BPS: London.

⁷⁹ Ballard C (2016) [Impact of Antipsychotic Review and Nonpharmacological Intervention on Antipsychotic Use, Neuropsychiatric Symptoms, and Mortality in People With Dementia Living in Nursing Homes: A Factorial Cluster-Randomized Controlled Trial by the Well-Being and Health for People With Dementia \(WHELD\) Program](#), *American Journal of Psychiatry*, 173(3), pp.252-62.

⁸⁰ Duerden M, Avery T, Payne R. (2013) [Polypharmacy and medicines optimisation: Making it safe and sound](#). London: The King's Fund.

confusing, and this is of particular concern for people living with cognitive impairment such as dementia. Research⁸¹ has shown that between 30% and 50% of other patients fail to take their medicines correctly or are otherwise noncompliant with their prescribed medicines regime.

We recommend:

- It may be appropriate for individuals to receive weekly prescriptions, to have carers support medication taking or to receive medication aids.
- As part of a multidisciplinary review, all care home residents should receive a review of their medication by a pharmacist when they first move into a care home in order to optimise their medication regimen.
- Residents of care homes should receive a minimum of one annual medication review from a pharmacist, with additional support for significant medication changes. For patients with complex medication regimens, this review should increase to every 3-6 months.
- With patient consent, all pharmacists directly involved in patient care should have full read and write access to the patient health record in the interest of high quality, safe and effective patient care.
- The Welsh Government must ensure that people have a full explanation of the medication they may be prescribed and be enabled to make an informed choice about their treatment and medication.

Notable practice: There is a great deal of excellent work being carried out in Wales regarding improving the use of antipsychotics for people with dementia. This includes research at **Swansea University** regarding structured scrutiny by nurses⁸² which has “*led to improvements in prescribing practice and pain management and greater awareness of adverse side effects*”, as well as the **STOPP/START toolkit** developed by Dr Victor Aziz of the Royal College of Psychiatrists⁸³, both of which demonstrate interesting routes for further inquiry and best practice development.

⁸¹ Royal Pharmaceutical Society (2013) [Medicines Optimisation: The evidence in practice](#). London: RPS.

⁸² Swansea University (2015) [Structured scrutiny could reduce drug side effects for people with dementia](#), Swansea: Swansea University.

⁸³ Aziz, V. (2015) [Potentially Inappropriate Medications for older people: the STOPP/START tool](#), Cardiff: Royal College of Psychiatrists in Wales.

The need for increased support in the community

Good care in hospitals

Memory loss for patients with dementia can worsen the longer they stay in hospital and the transition from ward to home becomes increasingly difficult. A prudent mental healthcare approach would encourage shortened admission times and rapid discharge where appropriate.⁸⁴

We welcome proposals to increase the number of primary care settings, hospitals and care homes that are dementia friendly. We look forward to seeing more detail in due course on how these aspirations will be met.

We welcome the recent investment in liaison services. 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.

Research shows that the number of registered nurses and healthcare support workers in a team, as well as the skill mix of team, make a real difference to patients' experience of care. It is essential in all settings therefore to ensure that healthcare teams are made up of the right numbers and the right skill mix to provide appropriate and sensitive patient care.

We recommend that:

- By the end of the strategy, all hospital and primary care settings should achieve dementia friendly status.
- All hospitals should publish an annual statement of dementia care, including:
 - satisfaction levels among patients with dementia and their carers;
 - figures showing the number of falls;
 - the number of inappropriate discharges, including those between 11pm and 6am, with less than 24 hours' notice or with significant delays;
 - the number of emergency readmissions within 30 days;
 - the number of people who receive an appropriate assessment of health and wellbeing on arrival;
 - levels of staff and board dementia awareness and training;
 - the number of people with dementia being prescribed antipsychotic drugs;
 - examples of how care is being personalised (for example, use of Alzheimer's Society's "This is Me" tool to understand a person's needs and preferences); and
 - examples of integrated care (for example, employing dementia support workers).⁸⁵

This should be monitored through the implementation of the strategy, and be used by hospitals as part of their risk assessment framework to identify and take action where dementia care is inadequate.

"Access to specialist day centres is so very important e.g. Oldwell Court in Cardiff. We need more like this NOT generic oap day centres which are just not suitable. The government needs to ensure that councils do not close valuable dementia trained centres."

⁸⁴ Lloyd, Keith Prof. (2016) [Making prudent decisions in mental health services](#), Cardiff: Welsh Government, date accessed 30/03/2017.

⁸⁵ Alzheimer's Society (2016) [Fix Dementia Care: Hospitals](#), London: Alzheimer's Society.

- Healthcare Inspectorate Wales should appoint a specialist dementia adviser and include dementia care indicators as part of its monitoring work to improve regulation of dementia services in hospital.
- Liaison services in hospitals should be age-appropriate. Generic services often don't meet the needs of older people. Liaison psychiatry services are extremely effective at supporting patients, reducing admissions and risk. It should also have an understanding of the distinct requirements of individuals with younger onset dementia. The pattern of substance misuse in older people, a key indicator and cause of some forms of dementia, can also be different in older people than in younger adults.⁸⁶ This would fit with the 2015/16 roll out of services which was accompanied by £4m in Welsh Government funding – we want to see all further services meet this standard, at a minimum.
- Older person's mental health wards can support evidence based therapeutic daily activities such as through occupational therapy teams.
- All hospitals should develop a dedicated team as the 'go to' people on dementia, in order to ensure everyone knows where to turn to better understand how to support people affected by dementia. This should include involvement from dementia support worker type posts, and provide access to a suitable room and activities for people with dementia.
- To achieve dementia friendly emergency departments we need better flow through the emergency department. Services such as frailty teams should be located alongside emergency departments to help tackle the increasing rate of Type 1 A&E attendances – which has increased by nearly two million in a decade. The Royal College of Emergency Medicine's [Hub Campaign](#) has shown that patients present throughout the 24 hour period and services need to be tailored to this demand.

“Regular meetings take place with staff from Ward B2 and Alzheimer’s Society Cymru to discuss ideas on how to improve the Ward to make it more dementia friendly and most importantly, to discuss best person centred approaches. We refer cases to Alzheimer’s Society Cymru for those affected by dementia to receive on-going support by having an assigned Dementia Support Worker. We value their input, ideas and support given not only to us in Ward B2 but also to those affected by dementia; to continue living well within their communities and home. Our working relationship has strengthened and will continue as we go forward in providing the best possible dementia care for staff and for those affected by dementia.”

- Sharon Stanley, Staff Nurse (B2), Ysbyty Cwm Rhondda.⁸⁷

Notable practice

- John’s Campaign is an excellent example of notable practice. A person with dementia’s need for access to their loved ones doesn’t end with visiting hours. **We recommend that**, as soon as practicably possible, all health boards should follow the lead of [Betsi Cadwaladr LHB](#) by signing up to [John’s Campaign](#) and giving carers the right to stay with people with dementia in hospital. In England, the NHS have developed a local CQUIN to incentivise acute trusts to adopt John’s campaign.
- Other projects such as the [Butterfly Scheme](#) and the “[This is Me](#)” leaflets should be adopted in all settings, and evidence provided that they are being implemented and used appropriately. Some feedback from our consultation work was that this is not

⁸⁶ Connelly, P. & Perera, N. (2013) [Developing an ideal old age service](#), London: Royal College of Psychiatrists.

⁸⁷ Social media contribution from Sharon Stanley, Staff Nurse (B2), Ysbyty Cwm Rhondda.

being used in the proper way to make them meaningful for people affected by dementia – too often, “This is Me” leaflets are being filled out and then ignored, and not used to facilitate person-centred care. Some care homes have produced similar files themselves.

- The King’s Fund has produced a range of resources to enable care homes, health centres and hospital wards become more dementia friendly.⁸⁸
- The Welsh Ambulance Services NHS Trust has become a Dementia Friendly Community and was nominated for an award for *Dementia Friendly Organisation of the Year*. WAST has distributed a ‘Message in a Bottle’ containing a ‘This is Me’ document - the form is contained in a plastic bottle which is placed in the patient’s refrigerator and a sticker is placed on the inside of the main house door to highlight to the Emergency Services that the patient has a MIAB pot. WAST also began a referral pathway pilot for paramedics who, when attending a patient, identify signs of cognitive impairment.⁸⁹ They have been engaging with groups and forums for people affected by dementia to gather experiences and stories – this will hopefully result in learning resources for their control staff.
- Neath Port Talbot Hospital was recently named the Best Dementia Friendly Hospital in the UK, at the National Dementia Care Awards. Their collaborative approach was commended, which has seen clinical teams including nurses, doctors, occupational therapists, physiotherapists and pharmacists working together to improve care.⁹⁰
- Ward B2, Ysbyty Cwm Rhondda has worked collaboratively with Alzheimer’s Society Cymru to improve dementia care and ensure that those affected by dementia receive the right level of support, information and guidance (see quote on previous page).
- Sycamore Ward, St Woolos Hospital in Aneurin Bevan UHB is Dementia Friendly and has produced a video discussing some of the changes they’ve made, including orientation information, sensory activities, reminiscence and a bar.
- Suite 4, Tonna Hospital, Neath, has worked to integrate OTs within the team, and has seen a decrease in ward staff sickness and patient falls, while having a positive impact on patients – providing an enhanced mood, engagement in meaningful activities at the right cognitive level, increased enjoyment/ relaxation levels, patients being mentally stimulated and maintaining patients skills and abilities. There is an Activity Coordinator in place to implement therapies and activities. Patients have even been transferred to other wards due to decreases in behavioural symptoms.
- Cardiff and the Vale UHB has made Dementia Friends sessions mandatory for 100% of their staff.
- Health Building Note 08-02 sets out some key principles for dementia-friendly Health and Social Care Environments.⁹¹
- The Welsh Ambulance Service NHS Trust has developed a Pre Hospital Communication Guide in booklet and app form, to help people who may have difficulties with communication. This could be of great benefit to people affected by

“People in hospitals need to be supported as people, not bed number 6.”
- Alzheimer’s Society Cymru Advocate

⁸⁸ The King’s Fund (2017) [Developing supportive design for people with dementia](#), date accessed 13/03/2017.

⁸⁹ Alzheimer’s Society (2016) [‘Dementia Friendly Awards 2016: Meet the finalists for Dementia Friendly Organisation of the Year’](#), 11/11/2016, date accessed 27/03/2017.

⁹⁰ Health in Wales (2015) [Neath Port Talbot named Best Dementia Friendly Hospital in UK](#), date accessed 27/03/2017.

⁹¹ Department of Health (2015) [Health Building Note 08-02: Dementia-friendly Health and Social Care Environments](#), London: Department of Health.

dementia: “A person may use a mixture of speech, gesture and pictures to communicate”. The App uses images and a small amount of text to help you find out important information about someone or what has happened if they have had an accident.”⁹²

- Bradford Royal Infirmary refurbished two wards, including cinema-style seating for people to watch archive films, a reminiscence café and memory boxes.
- Birmingham Heartlands Hospitals set up a new team – Rapid Assessment, Interface and Discharge (RAID)⁹³ including psychiatrists, psychologists and nurses who provide a strong presence within the hospital, created to see patients from A&E within an hour, within four hours from the medical assessment unit – where people are assessed to see if they need to be admitted – and within 24 hours from the wards. They also provide training to hospital staff, including two days’ training in the “Four Ds” – dementia, delirium, depression and dignity.
- Crisis resolution and home treatment teams such as the one in Swansea are designed to offer crisis support, alternatives to admission, and to facilitate early discharge by offering additional support where needed.
- Heath Hospital A&E has used volunteers to make hospital environments dementia friendly.
- The Norfolk and Suffolk Dementia Alliance introduced Dementia Intensive Support teams to speed up transfer of care & funds a senior nurse to co-ordinate dementia care in each hospital.
- More information can be found from [Dementia Action Alliance](#)⁹⁴, the [University of Stirling's DSDC Virtual Hospital](#), and [Bangor University's Dementia Services Development Centre](#).

⁹² Betsi Cadwaladr University Health Board (2016) [Pre Hospital Communication Guide](#), date accessed 17/03/2017.

⁹³ Royal College of Psychiatrists (2016) [Inquiry into winter preparedness 2016/17 - Consultation Response](#).

⁹⁴ The goal of this work was that by March 2013 every hospital in England would have committed to becoming a dementia friendly hospital, working in partnership with their local Dementia Action Alliance. 164 acute and non-acute trusts made that commitment, with 88 submitting action plans and joining the Dementia Action Alliance. The Dementia Friendly Hospital Charter is the second phase of the Right Care initiative, now called Dementia Friendly Hospitals. Hospitals are being encouraged to sign up to the Charter.

Advocacy and decision making

People with dementia must always, where possible, be at the centre of decisions about them. This may require other methods of communication to be supported. If and when that becomes no longer possible, then they should have an advocate to support their interests.

All too often, we find statutory services assuming lack of capacity – the Mental Capacity Act is firm that capacity should always be assumed, unless ascertained otherwise.

We must remember that a third of people affected by dementia in Wales live alone, without family or loved ones to support them; the dementia strategy must provide for this group as well. All health and social care organisations should establish clear and transparent pathways for people with dementia who do not have a carer with them in any given situation. For example, where an individual living with dementia is admitted to hospital and does not have a carer, the hospital must ensure that they have access to effective non-instructed advocacy in the most appropriate form, for example, independent mental capacity advocate, independent mental health advocate, independent advocate. Individuals with dementia when admitted to hospital should have access to effective non-instructed advocacy or Independent Mental Capacity Advocate (IMCA) and Independent Mental Health Advocate (IMHA) in the most appropriate manner depending on individual circumstances. This also applies to specialist mental health care.

We welcome proposals for 'satisfaction surveys' but would like clarity on its role. It would be useful to clarify how and when it would be utilised and how the results of such surveys will be used to inform changes within services. This method of engagement would also need to be flexible for those with communication needs, such as being blind, deaf or having a physical need. It is important that an independent advocate would be involved in this process, particularly to safeguard vulnerable people who may be afraid of repercussions.

We note that referral to advocacy services is still patchy across Wales – some local authorities clearly prioritise the important support a non-instructed advocate can provide, and involve advocates early in the process. But too many of our advocates are called when a person with dementia is at crisis point.

We recommend that:

- The number and proportion of people accessing independent advocates in different settings should be monitored.
- The key action for advocacy should not be for people to be able to access these services but should be facilitated to do so.
- The strategy should recognise that people affected by dementia may require access to an advocate in circumstances which may not meet the criteria under the Mental Capacity Act (2005). This is often too narrow a definition as it fails to provide for people with fluctuating mental capacity or slightly impaired capacity – both of which are common users of our services.
- The strategy should reflect the legality of access to Independent Professional Advocacy. It is not simply a 'should' but a 'must' that advocacy be considered when someone is undergoing assessment, care planning, care review or safeguarding.

“The biggest challenge is to ensure that the person with dementia has access to a specialised independent advocates who can support a person with dementia to make informed decisions which affect their future. It is important that the person with dementia's voice is heard when professionals, family and other services are making decisions with regard to their life.”

End of life care

We welcome proposals for improved coverage for end of life care and the recognition that dementia is a terminal diagnosis “*which can lead to poor care, inconsistent quality of care and inadequate pain management*” (as highlighted in *Living and Dying with Dementia in Wales*⁹⁵).

We recommend that more detail is added to this section. It should potentially even form its own theme within the strategy – this is a difficult time for many people affected by dementia, and dedicated support and attention is necessary. Dementia is now recognised as the leading cause of death in England and Wales⁹⁶. End of Life Care, Palliative Care, Advance Care Planning, and advanced decisions play an increasingly important role in empowering people to clarify their own wishes and preferences. It is about more than where someone dies – people affected by dementia and professionals need to have an understanding of the needs a person with dementia has at the end of life, and this affects the care they need. End of life care needs to be recognised as a significant part of dementia care, not simply as an add-on at the end.

People affected by dementia who we consulted with have called for a palliative and end of life care pathway. This should include providing information to people about their options to plan for a loss of capacity under the Mental Capacity Act 2005, by making an Advance Decision to Refuse Treatment or Lasting Powers of Attorney for Health and Welfare and Property and Financial Affairs – accessible information and support should be available to people to help them do this. Professionals involved in the care of people with dementia should also have an understanding of these options and receive training to have conversations with people about their preferences if they lack capacity, including at the end of life. Problems with capacity and communication can contribute to undignified treatment and the under treatment of pain in people with dementia at the end of their lives. Significant, co-ordinated and holistic support is needed to ensure that all people with dementia end their lives with dignity, free from pain and in the place of their choosing. Advanced directives and advanced decision making should be discussed as early on as possible after the diagnosis with people affected by dementia, where appropriate – this was a clear feeling from our consultation sessions, that people affected by dementia wanted to have these conversations when they knew about them. This should involve health professionals being honest and informing people about the progressive nature of dementia and not being afraid to define it as a terminal illness. If conversations like this are initiated as early as possible, people affected by dementia can be identified where they may need additional support (for example from psychology services) which can help support health and wellbeing.

Often it is the explicit wish of most people – with dementia and without – to die at home, yet hospital often ends up being the ‘default’ option. But every individual is different, and planning should facilitate the person with dementia’s preferences for their end of life care – including, but not limited to their place of death, wherever they may want that to be.

We recommend that the strategy recognises the distinctions between palliative and end of life care. Palliative care aims to treat or manage pain and physical symptoms. There is a particular emphasis on actively doing things to relieve (palliate) discomfort or distress

⁹⁵ Alzheimer’s Society and Marie Curie (2015) [Living and Dying with Dementia in Wales: barriers to care](#), Penarth: Marie Curie.

⁹⁶ Office of National Statistics (2016) [Deaths registered in England and Wales \(Series DR\): 2015](#), date accessed 01/04/2017.

(whatever the cause), rather than on curing the underlying illness. End of life care is an important part of palliative care that aims to support someone with an advanced incurable disease to live as well as possible until they die. It also aims to support family and carers during this time and after the person dies. It supports the person to die naturally and with dignity when the time comes. It covers all aspects of wellbeing: physical, psychological, social and spiritual.⁹⁷

End of life or 'just in case'⁹⁸ boxes can be a vital form of anticipatory or pre-emptive prescribing, but anecdotal evidence suggests that they are either not being discussed or provided far too late – often, we find that these conversations happen 2-3 weeks in advance of an individual's death, whereas it would be better to do so months in advance. Particularly given the nature of dementia to affect communication and capacity, delaying such conversations can mean they cannot happen at all.

We recommend:

- A national review of the current provision of palliative care and end of life services and medication for care home residents as part of steps to develop all Wales standards for anticipatory prescribing in care homes.⁹⁹
- All relevant health and social care professionals, including care home workers, should be trained and supported to help people think about their care and develop advanced care plans. This process will empower people to make important decisions about their care and how they want to live as they approach the end of their lives.¹⁰⁰
- Better dementia training should be available for hospice staff. As Marie Curie have said *"one key message that we need to send out is that hospices are open and available for people with dementia and that staff and volunteers have the training and skills needed to deliver services to people with dementia."*¹⁰¹
- All such conversations should include the people with dementia, as well as their family, wherever possible.
- There should be improved data about dementia and end-of-life care and a [bereavement survey for Wales](#) should be established to give us a better understanding of these issues.
- The importance of people with dementia getting access to information and choices about palliative and end of life care is recognised in the strategy. This should be done in an integrated manner, rather than at the crisis point of end of life or a hospital admission.
- That the importance of continuity of care at the end of life should be recognised. Many people move from care home to psychiatric ward to medical ward, and then between the last two multiple times over the last few weeks of their life. There needs to be better recognition of end of life and multi-disciplinary team working, so that people can be supported in the one most appropriate setting.

⁹⁷ Alzheimer's Society (2013) [End of life care: End of life and palliative care](#), London: Alzheimer's Society, date accessed 30/03/2017.

⁹⁸ Palliative Drugs (2016) [Pre-Emptive Prescribing in the Community](#), date accessed 31/03/2017.

⁹⁹ Royal Pharmaceutical Society Cymru (2016) [Improving Medicines Use for Care Home Residents](#), Cardiff: RPSW.

¹⁰⁰ Wynne, Natasha (2016) [Using prudent healthcare to design a system for people approaching the end of their lives](#), date accessed 30/03/2017.

¹⁰¹ Marie Curie (2015) [Living and dying with dementia in Wales: Barriers to care](#), Penarth: Marie Curie, p.13

Notable practice:

The Challenge Project in Blaenau Gwent has combined the specialist knowledge of the Hospice of the Valleys and Alzheimer's Society Cymru. Clinical Nurse Specialists and Dementia Support Workers combine their expertise to support the palliative and end of life care needs of people living with dementia, including by exchanging training information and raising awareness. Families have a single point of contact for information and support.¹⁰²

SPice—the Swansea Palliative Intermediate Care Team – involves the local authority, third sector and health working together to support people with advice on managing symptoms, psychological support for patients and families, and information and education support for patients and families. Care is delivered with a multi-disciplinary team of doctors, nurses, physiotherapists, occupational therapists, social workers, chaplaincy service, administration and volunteer staff, in partnership with GPs, district nurses, and hospital based doctors and nurses.¹⁰³

¹⁰² Hospice of the Valleys (2016) [Challenge Project features in Alzheimer's Society Magazine](#), date accessed 27/03/2017.

¹⁰³ Tŷ Olwen (2017) [Our Services](#), date accessed 28/03/2017.

Supporting the plan

We welcome the development of the 'Good Work: A Dementia Learning and Development Framework for Wales'. This is an excellent project, and we look forward to see it being embedded throughout the NHS. As outlined in 'Good Work', all health staff will understand what dementia is, how it affects a person living with a dementia and those around them, and how to provide appropriate support. We also welcome the recognition of Tom Kitwood's work on maintaining a sense of personhood. The concept of Person-Directed/Centred Care Approach for people with dementia developed by Kitwood is in line with the values and principles held in the Social Services Well-being (Wales) Act 2014.

We welcome that *"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.

Training must ensure staff have adequate skills and understanding of dementia to respond to people's needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress. Training should also recognise the importance of mental, physical and sensory aspects of dementia and other health concerns of people living with dementia. We want to ensure that staff feel able to ask for more support, and feel valued through training.

The strategy should explicitly include a requirement that everyone with dementia receives the highest level of care from health care professionals who are trained to a level whereby they can appropriately and sensitively meet their needs i.e. if they require specialist dementia care then they receive care from a dementia specialist nurse (or someone with an equivalent level of specialist dementia training). At present, there is too much variation between the level of training that is actually available for staff who support those with dementia, and this the case in hospitals, in the community and in the independent and care home sectors.

Higher levels of training for all staff working in environments where people with dementia receive care is required, and this includes practice nurses, community nurses and nurses working in the independent sector, social workers, social care workers, domiciliary care staff, and others who are working within environments where people with dementia receive care, treatment or support. There must be distinctions between formal training routes and dementia awareness which, while useful in order to increase understanding and empathy, is not intended as a replacement for in-depth training for health and social care professionals.

Health and social care staff who have been part of the consultation groups have discussed how they have gained a lot of knowledge and understanding from meeting people affected by dementia and listening to their experiences; real life experiences should be included in training. **We recommend that** people affected by dementia should be enabled to co-produce and co-deliver training wherever possible.

"Learning opportunities should include more than sitting in front of a desk completing a 20 minute online module – go out and meet people living with dementia, their family, friends. Visit a group, speak to a person with dementia – learnt what it's like in the real world and what we need from you – no book or module can teach you that."

"Specifically trained health care visitors ...who understand the changing phases of dementia."

We recommend that particular attention is paid to:

- Nursing professions. Nursing staff make up a huge proportion of the health care workforce in Wales – across adult, children, mental health and learning disability specialities and across primary, acute, independent (care home) and community settings. There is a need to upskill the nursing workforce in all settings to feel competent in supporting people with dementia, and ensure nurses can access CPD.
- Emergency Department Staff: Patient experience surveys consistently describe a poor patient experience in emergency departments but a supportive environment in emergency departments can prevent clinical problems or anxiety escalating. All clinical staff need to be trained how to respond compassionately and knowledgeably to people affected by dementia.
- Speech and Language Therapy. Dementia can result in a range of difficulties including with communication, unsafe eating, drinking and swallowing. Speech and Language Therapists (SLTs) support people with dementia and carers by assessing needs and delivering interventions to support communication and safe eating, drinking and swallowing. The strategy should recognise that people with dementia have communication, eating, drinking and swallowing needs and ensure people with dementia have access to SLT services they need in hospitals, care homes and their own homes. Data suggests 19% of hospital admissions of people with dementia could be prevented by interventions from an SLT.¹⁰⁴ 68% of people with dementia in care homes have dysphagia (difficulty swallowing).

We further recommend:

- Dementia awareness training should be taken up in all settings. By 2018, all clinical and care staff (including domiciliary care staff) working within environments where people with dementia receive care, treatment or support must have the skills to ensure they have sufficient knowledge and understanding of dementia to respond to their needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress.
- Any training needs to be value-driven so that it kick-starts cultural change, rather than being a tick-box exercise.
- Commissioned staff should also be included in targets for training, not just NHS employed staff - this could be achieved through commissioning arrangements.
- Inductions for staff to clinical environments and care homes should include dementia awareness sessions, and leaflets and materials should be consistently available.
- All public services in Wales should shape their workforce development plans in line with the *Good Work Framework* to ensure that their staff understand that many of the people that they will come into contact with may have a form of dementia or be a carer – this should extend far beyond the health and social care sector.
- Undergraduate health and social care courses should include dementia awareness and formal training pathways. Welsh Government should conduct a mapping exercise with Higher and Further Education sector to understand current provision.
- People with dementia should be involved with training and developing training, wherever possible, as the true experts on dementia.

“Staff don’t communicate very well - they use jargon which you have to pull them up on and ask all the time what does that stand for etc. Everything is very fluffy and vague.”

¹⁰⁴ Inpatient Hospital Episode Statistics, Health & Social Care Information Centre, Public Health England, 2015.

- Welsh Government should work with Royal Colleges and trade unions to explore the potential for incentivising prompt take-up of training - such as through offering CPD points.
- Staff training and CPD on dementia should include training on carers' awareness issues.
- Embedding the principles of the Mental Capacity Act and capacity assessment into staff development.
- Training should incorporate an understanding of speech, language and communication issues, and provide education, support and training, and set the highest standards, for health professionals, care home and agency staff to understand the communication difficulties experienced by people with dementia and identify the early signs of eating, drinking and swallowing difficulties to ensure people's nutritional needs are met.

We would like to better understand what is the role of NHS Wales Shared Partnership Services¹⁰⁵ in driving forward training, how the All Wales collaborative dementia benchmark project will work following the development of the *Good Work Framework*, and whether training could be recognised in the Knowledge and Skills Framework (via Agenda for Change) in order to link it to goals, job descriptions and promotions.

Notable practice

Good practice already exists - for example the '**Dementia Care Matters – Being a Star Programme**' which aims to improve self-awareness among care staff.¹⁰⁶

The **Welsh Ambulance Service** worked in partnership with Swansea Dementia Friendly Community to raise awareness among locality staff, and piloting a patient referral pathway so that if ambulance staff think a person may have dementia but is undiagnosed, they can refer that patient to the health board's Acute Clinical Response Service for further assessment.¹⁰⁷

We welcome that memory clinics should 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. Currently less than 4% of people with a diagnosis of dementia are involved in a clinical research study (Department of Health, 2012a¹⁰⁸).

We recommend that to help achieve this, the opportunity to participate in research should be one of the conditions for accreditation of memory services through the Memory Services National Accreditation Programme (MSNAP).

Notable practice: Centre for Excellence in Rural Health Research – the new Research Centre will see Aberystwyth University work closely with the Mid Wales Healthcare Collaborative and Hywel Dda University Health Board to address some of the unique challenges of delivering healthcare in a rural area such as mid Wales.¹⁰⁹

¹⁰⁵ NHS Wales (2016) [Workforce, Education and Development Services](#), date accessed 30/03/2017.

¹⁰⁶ Older People's Commissioner for Wales (2014) [A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales](#), Cardiff: OPCW.

¹⁰⁷ Welsh Ambulance Services NHS Trust (2016) [Welsh Ambulance Service makes final of Alzheimer's Society's Dementia Friendly Awards](#), date accessed 30/03/2017.

¹⁰⁸ Department of Health (2013) [The Prime Minister's Challenge on Dementia](#), London: Department of Health.

¹⁰⁹ Mid Wales Healthcare Collaborative (2016) [Centre for Excellence in Rural Health and Social Care](#), date accessed 30/03/2017.

4. Public services uniting against dementia

This has to be a strategy for all of government to unite behind. At present, the draft strategy focuses deeply on the health and social care system. But much of a person's experience of the public sector will be in other areas of life. **We believe** the strategy should also reach outside of health and social care into other policy areas. This would be consistent the aims of the Social Services and Wellbeing Act and the Wellbeing of Future Generations Act.

We know that, for example, transport is vital to consider when designing dementia services. If people affected by dementia in rural communities can't access services, their wellbeing may be impacted. This is why Dementia Friendly Communities look at arts, culture, leisure, and recreation; businesses and shops; housing; and transport, amongst others, when developing their local plans – all of these areas of public policy can support someone to live well with dementia. The Standards for DFCs contain a number of useful examples of actions.

We believe there should be a strategic approach to developing a Dementia Friendly Nation. This is a cross-cutting issue for all levels of government. Amongst others, Local Authorities can help deliver Dementia Friendly Communities by working differently and in partnership with community organisations, across the whole of their areas of responsibility. For example:

- Planning officers can involve people with dementia in advising on new developments and make others aware of the issues that people with dementia face in accessing the built environment.
- Housing departments can make sure that housing staff understand how adaptations can enable people with dementia to stay independent in their own homes for longer.
- Transport providers can consider the needs of people living with dementia in the development of their services, so that they have the confidence to travel and can ask for help when required.¹¹⁰

There is a strong lack of understanding of the importance, value and benefits of enabling continued engagement in occupations. Welsh Government should work with major employers to enable more people affected by dementia to continue in employment, if appropriate.

We recommend that:

- There should be more key actions for housing, transport and culture sectors. There are some references at present that could be developed into key actions.
- There should be a theme regarding how such portfolios can work to make Wales a Dementia Friendly Nation.
- The Delivery Assurance Group should involve and have responsibility across Governmental portfolios.
- Welsh Government and Local Authorities should ensure that people affected by dementia are involved in steering groups that influence transport plans in Wales.

¹¹⁰ LGA and ID (2015) [Dementia Friendly communities: Guidance for councils](#), London: Local Government Association.

Notable Practice :

Alzheimer's Society has produced a **dementia-friendly housing charter**, on how housing, its design and supporting services can help improve and maintain the wellbeing of people affected by dementia.¹¹¹

The King's Fund has produced resources for use in extra care housing, retirement communities, and sheltered housing in order to improve dementia friendliness.¹¹²

The Royal Town Planning Institute has produced a guide to *Dementia and Town Planning*, which discusses good urban and housing design principles to support people living with dementia.¹¹³

¹¹¹ Alzheimer's Society (2017) [Dementia-friendly housing charter](#). London: Alzheimer's Society

¹¹² The King's Fund (2017) [Developing supportive design for people with dementia](#).

¹¹³ Royal Town Planning Institute (2017) [Dementia and Town Planning: Creating better environments for people living with dementia](#). London: RTPI.

5. How will we know? High level performance measures

We must make sure that the action plan has clear and measurable outcomes, and a consistent data dashboard. We want the High Level Performance Measures to be measurable, accountable and time-limited in order that the impact of the strategy can be effectively measured.

We recommend the following steps in order to improve data collection:

- By 2018, NHS Wales should publish an annual statement on the quality of dementia care in hospitals including emergency admissions, length of stay, falls, emergency re-admissions, timely & efficient discharge, and levels of staff dementia training. Much of this information is already available (for example, through annual quality statements and hospital episode statistics), but producing it collectively will allow comparisons to be made more easily to assess performance. The Patient Episode Database for Wales ([PEDW](#)) contains some of this data, but is not very user friendly - it was implemented in April 1991. The Royal College of Psychiatrists collected some of this data in their [Dementia Audit 2012-13](#).
- All hospitals should publish an annual statement of dementia care.
- Population needs assessments should be collected in GP Clusters. This is a more holistic approach than looking solely at disease needs.

We recommend collecting and publishing data on:

- Dementia diagnoses by age, by gender, for those with protected characteristics, and by comorbidity.
- Prescription of anti-Alzheimer's drugs.
- Delayed transfers of care, broken down by reasons for delay.
- The proportion of people with dementia who go through safeguarding process which receive an active offer of an IPA.
- Referral rates to advocacy.
- Length of wait in hospital for an appropriate bed.
- Proportion of people with dementia with an advanced statement/directive.
- Place of death for people with dementia, broken down by care home, hospital or home. At a minimum, deaths in hospital due to dementia should be recorded.

Notable Practice:

England has recently introduced the [Dementia Atlas](#) - this would be an important step forward in transparency, provided consistency on IT systems between Wales' LHBs. Data collected should be consistent across Wales.

Public Health England produces the National Dementia Intelligence Network Dementia Data Catalogue, to provide a list of indicators and datasets around *prevalence; preventing well; diagnosing well; living well; supporting well; and dying well*.¹¹⁴

Greater Manchester's Dementia United project has published a draft set of standards intended as a tool for making progress on Dementia United pledges. It aims to build a holistic measure of the lived experience of people affected by dementia which asks those people what it is like for them to live with dementia, to "monitor the lived experience and use the findings to co-produce and redesign the system in a way which is meaningful and required."¹¹⁵

Aneurin Bevan UHB is trying to develop an "outcome measures plan" with a multi-agency dementia board with carer representation and involving people with dementia on the board.¹¹⁶ This utilises proxy measures to get an idea of local dementia-friendly initiatives and staff training levels.

¹¹⁴ Public Health England (2016) [National Mental Health Dementia and Neurology Intelligence Network: Dementia profile and data catalogue](#), date accessed 21/03/2017.

¹¹⁵ Dementia United (2017) [GM Draft Standards](#), date accessed 21/03/2017.

¹¹⁶ Slater, Lin (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 2nd February 2017 (para.468).

Proposed High Level Performance Measures	Alzheimer's Society Cymru comments
Increase the number of dementia friends and dementia communities in Wales. Source: Alzheimer's Society Cymru (Annually)	We support these, and would appreciate the opportunity to work with Welsh Government to develop SMART targets.
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)	Setting out the 'agreed criteria' would be essential to this performance measure.
Increase in the take up rate of the dementia helpline. Source: Welsh Government/Dementia helpline call rate (Annually)	This could benefit from including information on current take up in order to assess increases.
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)	We would like to understand how "comes into contact with the public" is defined. We would also strongly recommend including commissioned staff in this target.
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	People affected by dementia should be involved in the development of the population assessments and local area plans. This needs to better reflect the needs of people with young onset dementia, who may not be covered within the 'older people' parts of population assessments.
Numbers / % of carers offered an assessment and for those with 'eligible needs' to be offered a support plan. Source: local authorities (Annually)	Given the statutory duty on local authorities to offer assessments under the Social Services and Wellbeing (Wales) Act 2014, we would anticipate that this target is 100%. This HLPM also needs to record the number of assessments carried out after being offered to carers, how many of those are found to have eligible needs, and how well those support plans are being implemented.
Clear evidence based care pathway in place and published for each health board – this pathway to include access to 'wraparound' support such as financial services. Source: health boards (return to local mental health partnership boards (LMPHB) by December 2017.	We welcome the inclusion of a pathway approach – this is something people with dementia have strongly told us they want to see. We would recommend a national approach, with flexibility for local needs for health boards.

<p>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.</p>	<p>We welcome proposals to increase diagnosis rates, but believe 3% is still unambitious – particularly given the recent move to CFAS which excludes people with young onset dementia. It would take until the end of this Assembly to reach where Northern Ireland is today. We believe there could be mileage in setting a target which rises over time (for example, 3% for Year 1, 3.5% for Year 2, 4% for Year 3 and so on) in order that procedures and practices can be put in place at the start of the strategy's lifetime which can escalate the diagnosis rate in later years. This also allows time for the development of high-quality support services for pre-and-post diagnosis to go hand-in-hand with the increasing diagnosis rates.</p>
<p>All memory services to involve people with dementia and carers in feedback and service development. Source: health boards</p>	<p>We welcome both these measures.</p>
<p>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 appropriate to do so). Source: health boards.</p>	
<p>All newly diagnosed people with dementia to be offered access to a support worker depending on need after diagnosis. Source: health boards</p>	<p>This will need more work to understand how many support worker positions are required in Wales, particularly given increases in diagnosis rates. We would also reiterate the need to ensure that people with a current diagnosis are not 'left behind'. This should be offered to all people with a diagnosis of dementia, regardless of need.</p>
<p>Reduction in the percentage of people with a diagnosis of dementia receiving antipsychotic medications and a reduction in duration of treatment. Source: health boards local audit report to LMHPB by June 2018</p>	<p>This is welcome but will require a greater understanding of current baseline figures and improved guidance for staff, in order that the target can be made SMART.</p>
<p>District General Hospitals have psychiatric liaison service / support worker team in place. Source: health boards</p>	<p>These services should be age-appropriate and link in to Accident and Emergency teams in order to help triage.</p>

6. Support for specific communities and cross-cutting themes

Wales has diverse communities and cultures, all of which may have distinct requirements for dementia care which need to be addressed. The approach taken by the strategy to examine dementia through the prism of the patient journey is helpful – but in doing so, it unintentionally downplays some of the many cross-cutting themes relevant to specific communities.

We have heard concerns from people affected by dementia under the age of 65, those in rural Wales, those whose first language is Welsh or languages other than English, those in the Black, Asian and Minority Ethnic (BAME), those in the LGBT community, individuals with disabilities or sensory loss, and more. All of these aspects of people's lives mean that they have specific needs that require particular attention throughout the dementia pathway.

We recommend that specific chapters/sections are required which give a broad overview of the challenges affecting these communities. Suggestions for what those chapters/sections contain are outlined below. We would recommend that actions and sections are developed through proactive and direct consultation and engagement with people from these groups, giving examples of specific issues that have faced them and the outcomes for people with dementia, their families and loved ones, and carers when services are inaccessible or blocked.

We welcome that Welsh Government recognises the specific needs for individuals with dementia who may have protected characteristics – notably the BAME, LGBT and disabled community. But the strategy needs to go into more depth. Alzheimer's Society Cymru wants to see more specific actions that Welsh Government expects health boards and local authorities to meet. The 'key action' for health boards and local authorities "*to develop specific actions to increase access for individuals who have protected characteristics*" should be supplemented by specific actions that Welsh Government may require, may be able to complete or facilitate itself on an all-Wales basis, or may propose for local authorities and health boards to develop further.

As the final strategy will not be able to reflect the vast array of issues people affected by dementia may encounter during their journey, the emphasis should be on meeting the needs unique to each individual and not trying to fit the person to a service instead of the other way around. This will help tailor services to the individual needs of people who have a protected characteristic. **We recommend** close monitoring of how successful each service is in doing this and the overall success of the strategy, with on-going regular discussions with communities taking place. This could, in part, be achieved by reaching out to already existing groups.

We recommend that Welsh Government publish their equality impact assessments on the draft dementia strategy.

Some groups are defined as “seldom heard” – these groups are often under-represented in being involved in activities to develop services.¹¹⁷ There is merit in the Welsh Government seeking to hold further, additional dialogue with specific groups as part of the development of the strategy and its implementation. This is particularly true of groups where there has been limited engagement so far, such as BAME, GRT, and LGBT communities. **We recommend** that Welsh Government plan and facilitate wider involvement with these communities to better understand their needs and to shape information and services.

People affected by dementia who identify as having protected characteristics feel that there should be a national call to implement projects across Wales which specifically focus on ensuring that people who fall under one or more of these characteristics are able to access support and information, including the development or implementation of specific roles that work within diverse communities.

An option for more detailed guidance might be providing practical examples in Codes of Practice for different services. The Equality and Human Rights Commission Codes are a good example of this as they provide specific advice on how to follow the 2010 Act by the use of straight forward examples.



¹¹⁷ Community Care (2008) [Proven Practice: Hard-to-reach/seldom-heard groups](#), date accessed 30/03/2017.

Young onset dementia

Dementia is not just an older people's condition. A dementia diagnosis is always complex, but many of the complexities of being diagnosed under the age of 65 mean that access to specialist services is vital. People affected by young onset dementia may present with atypical symptoms, be diagnosed with rarer forms of dementia, and are more likely than older people to be diagnosed with a genetically inherited form of dementia. Younger people with dementia often struggle to access appropriate care and support because dementia services are often designed to meet the needs of older people. There are many specific non-medical concerns that are more likely to confront people with young onset dementia – they are more likely to have a young family at home, risk losing their job, or face financial difficulties such as paying the mortgage. People with young onset dementia and carers can both face difficulties at work – despite requirements under the Equality Act (2010) for employers to make reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace and the Flexible Working Regulations (2006) obliging employers to consider requests for flexible working from carers. It can be more difficult to stop driving at a younger age. People with young onset dementia may face being ineligible for much of social care provision because they are not old enough. They may also encounter a lack of understanding, skills and knowledge amongst professionals.

“In one weekend we had the case where we had to decide how to proceed as they had told my husband that he could not work. Huge strain on all the family and the business.”

We recommend that the Welsh Government ensures that GPs are properly aware of the need for people with young onset dementia to get a diagnosis, and to be aware of it when diagnosing. GPs are likely to turn to other answers before dementia – leading to significant under-diagnosis. Worryingly, the lack of awareness amongst health care professionals about young onset dementia means that many people are often misdiagnosed with a differential diagnosis of depression. In some instances, women are being delayed a referral for dementia because of the similarity of symptoms with the menopause.

We welcome the aims of the Welsh Government to support people with young onset dementia and the additional £500,00 in funding since 2010 – but this sadly risks being undone by the move to CFAS. Welsh Government's decision to move from the DELPHI consensus to CFAS when calculating prevalence of dementia in diagnosis rates does not properly reflect the number of under-65s affected by dementia. We estimate there are around 2-3,000 people with young onset dementia in Wales.

We recommend that, in order to offset this lack of consideration, Welsh Government should collect more accurate figures and establish the number of people with young onset dementia in each local health board and of the variants of dementia with which people are being diagnosed. This will feed in to designing better services for people with young onset dementia. It may be that in order to get the right economies of scale and space for specialist services to be developed, a national approach would work best for young onset dementia services.

We welcome that Welsh Government states *“young onset leads should be in place across Wales and work in collaboration with appropriate specialist diagnostic services.”*

We recommend that named leads in local health boards for young onset dementia should be enabled or even required to collaborate on an all-Wales basis in order to ensure consistency of care and sharing of best practice. This may make it more possible to provide age sensitive day/respite care and support for carers and children.

“I was a career for a younger person with dementia (under the age of 50) there are no services that cater for this. Lack of knowledge of people with genetic / younger dementia, with health professionals which led to a very delayed diagnosis.”

We recommend that Welsh Government should:

- Develop a national assessment, diagnostic and support service for Wales, including genetic testing services. There are limited services that are able to best treat this cohort of people and patients are often inappropriately referred to Old Age services. Such services are often too specialised to deliver in each LHB.
- Establish a consistent approach for supporting people with young onset dementia - people are often left in limbo between Older Person or Adult mental health teams.
- Ensure access to age appropriate groups and full time care settings, in addition to day and respite care.
- Make sure every local authority has a young onset dementia lead.
- Develop a network of specialist Dementia Support Workers (at least one per LHB) with knowledge and experience of younger people with dementia and the specific challenges they face. This support is especially important for people with young onset dementia as they may require different signposting (for example for support with financial issues) – this is combined with an assumption often made by clinicians that because a person is younger, they are more ‘capable’. This is often incorrect, and means people are left to cope alone.
- Recognise in the strategy that the need for advocacy may be higher for people with young onset dementia, reflecting the different types of public services that they may need support to deal with (such as welfare, housing, or employment services).
- Work to raise awareness of employees’ rights and employers’ responsibilities to support people affected by dementia and engage in longer-term planning for an ageing society.¹¹⁸

Notable Practice: Gwent has led the way in Wales on providing support services for younger people with dementia, including a dementia café, art group, singing group and specialist care and support.¹¹⁹¹²⁰¹²¹

¹¹⁸ Alzheimer’s Society (2017) [Employment and dementia](#). London: Alzheimer’s Society, date accessed, 30/03/2017.

¹¹⁹ Which? (2017) [Dementia Support Blaenau Gwent Younger People](#), date accessed 30/03/2017.

¹²⁰ Alzheimer’s Society (2017) [Dementia Café Torfaen Younger People](#), date accessed 30/03/2017.

¹²¹ Alzheimer’s Society (2017) [Younger People Singing for Fun](#), date accessed 30/03/2017.

Welsh language communities

We welcome the fact that language is recognised in the draft strategy as a clinical need. Alzheimer's Society Cymru wants to see more detail on how proposals to support Welsh language speakers will be taken forward.

"I want to be able to communicate in the language I want to communicate in – but I have been told that it is difficult to get the right level of qualified professionals who can assess and work with people in the Welsh language."

The second Memory Assessment Service report by Dr Les Rudd and Public Health Wales found that, while most clinics can provide for diagnosis in Welsh, *"in a majority of cases this requires involvement of Welsh speaking staff from other services or sometimes a booked interpreter"*. This risks losing the quality of the test in the translation. A [previous academic study](#) (from 2003) suggested adopting the practice of doing the test in English and Welsh and using the highest score as the right way of making an accurate diagnosis. As raised by Dr Rudd at the Health, Social Care and Sport Committee inquiry:

*"we've got these tools, but we haven't had the research to validate them in their Welsh language versions. We don't know what the norms are. So, we can use a Welsh language translated tool, and we use English normative data to validate the tool. There's some good evidence that being bilingual or multilingual is a protective factor, so I think it's really important. So, research please; helpful research is a priority to validate some of the very good existing tools we've got."*¹²²

We welcome the Welsh Government's proposal *"to engage with researchers to ensure there is a clinically validated dementia assessment tool for use"* in Welsh.

We recommend that:

- Only qualified assessors are involved in diagnosis.
- When there are no assessors who speak a given language, steps should be taken to train speakers of different languages in diagnosing dementia.

A more proactive approach to language need and choice is needed to mainstream the 'Active Offer' principle into dementia services as they are designed and implemented and to address the challenge of the shortage of Welsh speaking staff. Access to services in the Welsh Language is an "integral element in the care and support of many Welsh speakers" but "some groups have greater need to receive their services in Welsh. *For these groups, the Welsh language should be viewed as an even more fundamental element of service provision. These groups [include] Dementia services [our emphasis].*"¹²³

In particular, respite and befriending services would benefit from improved Welsh language provision, in order to reduce social isolation.

There is a need for better data on dementia in Welsh language communities in Wales, so there can be a better understanding of the relationship between dementia and the Welsh language.

Notable practice

Cwm Taf has a Welsh language ward that is of great benefit to people affected by dementia.

¹²² Rudd, Dr Les (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.392)

¹²³ Welsh Government (2016) [More than just words...Follow-on strategic framework for Welsh language services in health, social services and social care](#). Cardiff: Welsh Government.

BAME and GRT communities

“If you don’t understand, you are going to misperceive a lot of things.”

- Dr Victor Aziz, Royal College of Psychiatrists¹²⁴

BAME communities are more likely to be diagnosed late and less likely to be diagnosed¹²⁵ or use dementia services overall. Families may be reluctant to use services that do not meet cultural or religious needs and try to carry on alone. This means that BAME communities need specific actions to support individuals affected by dementia. Sometimes, only

small adjustments are necessary to make sure services are more accessible and welcoming – such as providing for diverse dietary needs that some communities may have, such as halal or kosher diets.

We recommend that services should be co-designed with locally prevalent BAME communities and families should be involved in delivering and designing care. The “Triangle of Care” approach is particularly relevant here, to ensure that providers involve family members who may better understand the cultural background. The strategy should also recognise the value of peer-led networks and lived experience – both as a support for individuals supported by those who understand their situation best and as a sounding board to advise on service delivery and policy.¹²⁶

BAME communities in Wales may share many similar concerns to the Welsh Language community – specific concerns over language as a clinical need (not preference) for diagnosis, support and care are just as valid for this community. There may be areas where the Welsh Government can engage with the UK Government; for example, to ensure there is provision for diagnostic tools in different languages.

Within the BAME community, there are different cultural representations of dementia which have negative connotations and thus influence family dynamics when a person receives a diagnosis. In some languages, there is no definition of the word ‘dementia’, meaning diagnosis, awareness, and public health campaigns have to reach out hard and make the extra effort necessary to make sure that they are going into those communities and raising awareness. There needs to be research into the cultural understandings of dementia within different communities and for this to be applied within services and to professionals to ensure they have the basic understanding of the needs of a person affected by dementia.

People from the BAME community have highlighted the lack of day services open to them as well as the difficulties in accessing Dementia Cafes, for example because of lack of transport or fear of going out especially at particular times of the day.

Similar concerns can apply to Wales’ gypsy, roma and traveller (GRT) community, as aspects of different cultures may make diagnosis and care more complex. This community has long been one of the most disenfranchised and marginalised groups in society and is particularly seldom heard. There is much ill-health in the community “caused by cardiovascular disease and depression, [which] potentially increases the risk of dementia. Social factors related to the lifestyle and experience of Travelling people also increase the risk and make it difficult for people with memory loss to cope with the condition. These

¹²⁴ Aziz, Dr Victor (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.244)

¹²⁵ Social Care Institute for Excellence (2014) [SCIE Research briefing 35: Black and minority ethnic people with dementia and their access to support and services](#), date accessed 30/03/2017.

¹²⁶ National Care Forum (2016) [Dementia care and LGBT communities: A good practice paper](#), Coventry: NCF.

matters also impact on the ability of family and community to cope, although their willingness and skill to do so is strong.”¹²⁷

We recommend:

- The provision of culturally appropriate services and works to raise awareness of dementia among Black, Asian and minority ethnic communities.
- Work should be done to hear the voices of BAME communities to increase awareness of dementia and to design culturally sensitive services.
- Services should work to lower barriers to the gypsy, roma and traveller community accessing services.
- A person's culture and/or religion needs to be identified sensitively - people from BAME communities have expressed in our consultation that they are happy to disclose this information if they know that it is being used to support them rather than it only being used to evidence demographic data for a specific service. A person's culture and/or religion needs to be considered as part of their support and care plan, with resources in place to support any needs. Professionals need to tailor their support to meet the needs of people affected by dementia from the BAME community.
- Health boards should ensure they have diverse staff membership.
- Specific BAME workers should be provided to offer information and support to people affected by dementia from these communities. Where this is not possible, there should be collaborative working with organisations like Diverse Cymru and local BAME community groups to ensure that services are developed to support appropriate and relevant needs.
- Dementia Awareness amongst the BAME community is a priority need to help reduce stigma – work should be done to listen to the BAME community to identify methods in which dementia awareness can be provided, including local radio stations and meetings. Within BAME communities, there are pre-existing peer support or social groups that would benefit from support to become dementia friendly - rather than having dementia specific groups, well attended supportive groups become more inclusive of those affected by dementia.
- Dementia awareness initiatives, including dementia friendly communities, need to involve key pillars from different communities who can act as a point of contact between the community and organisations to engage people affected by dementia and to increase awareness and break down stigma.
- Joint working for health boards to support linguistic communities that may cross boundaries.
- Services and diagnosing GPs should be aware of and signpost to the information and resources available in other languages, particularly those provided by Alzheimer's Society.¹²⁸
- Ensuring that diagnostic tools are available in a variety of languages for use by clinicians.

“He went to a day care centre and I found out he hadn't eaten for three days his lunch, why? Because the food they made he couldn't eat for religious reasons but he felt too bad to say, is that the inclusive community and support we dream of?”

¹²⁷ Tilki, Dr Mary (2016) [*Dementia in Gypsies and Travellers: a brief guide for commissioners and providers*](#), Leeds: Leeds GATE.

¹²⁸ Rayson, Rebecca (2017) '[*Dementia doesn't discriminate – making our national services more inclusive*](#)', *Alzheimer's Society Blog*, 03/03/2017, date accessed 27/03/2017.

- Gathering specific data on the impact of dementia on BAME and GRT communities.
- Services should work to lower barriers to GRT community accessing services, which has long been one of the most disenfranchised and marginalised groups in society. Equality should be ensured across all key actions for the GRT community.
- Conducting research into how dementia impacts on the GRT community, including prevalence, in order to develop key actions and high level performance measures that are specific to the GRT community as a reflection of the well documented inequalities they experience.

Notable Practice:

The **Faith in Health** project works in partnership with the local health authority and other organisations and services, offering a range of events and initiatives to create awareness amongst different faith communities of health services available to them. The project trained Imams to go into their communities and talk about dementia to raise awareness among families of people living with dementia.¹²⁹

Communities First BRG (Butetown, Riverside and Grangetown) are working to become a Dementia Friendly Community.¹³⁰ They hold dementia friendly cafés and memory cafés to provide support and information for people affected by dementia. The area has a high proportion of ethnic diversity, and therefore aims to be inclusive in terms of staff employment and volunteers, language provision and meeting cultural and religious needs.¹³¹



¹²⁹ East London Mosque & London Muslim Centre (2017) [Faith in Health](#), date accessed 28/03/2017.

¹³⁰ BRG Cardiff (2016) [Dementia and Communities](#), date accessed 27/08/2017.

¹³¹ SRCDC (2017) [South Riverside Community Development Centre](#), date accessed 29/03/2017.

LGBT communities

Lesbian, gay, bisexual and transgender (LGBT) people with dementia, and their carers, partners, friends and relatives, may face additional challenges.¹³² Older LGBT people with dementia may experience disadvantage, discrimination and prejudice that impacts on their health and wellbeing, leading to health inequalities and unmet needs. As per Sermlyen:

Their age, their gender/sexual identity and their cognitive impairment bring a triple marginalization to this group. For example, older LGBT people may feel out of place in traditional support groups and may be anxious about accessing services due to fears of homophobia or of not having their specific needs met. What is already difficult is made worse as health and social care professionals frequently reinforce this by assuming everyone in care is heterosexual. In fact, many care providers and carers report never encountering anyone with dementia who is LGBT. This risks further silencing LGBT people and makes it more difficult for them to feel able to come out. Clinical services must be sensitive to people with a range of abilities, cultures and backgrounds and from different age-groups. Services are less accessible for people from black and minority ethnic groups, who are under-represented in memory clinics. Services should take steps to address this locally to improve equity.

Older LGBT people are also more likely to be isolated and less likely to have younger support networks – they may be estranged from their families and they are less likely to have had children who could be caregivers so are more likely to need access to dementia care services. LGBT people will often not only have to repeat their story but have to “come out” each time they access services - and they are always determining when it is safe to do so. This can be especially difficult for people with dementia who may have lost their capacity to assess whether it is safe to disclose their sexual/gender identity. Alternatively, by not disclosing and remaining silent, LGBT people with dementia are more likely to have unmet long term care needs – moreover they may choose to not use services at all. Knowing there are others there or knowing that the care services are LGBT friendly will provide a safe environment for LGBT people to seek care and help when needed and feel safe to come out and stay out.

We recommend that:

- Services should aim to be proactively friendly towards the LGBT community, and promote diversity inclusion and present the environment as non-discriminatory. Services could clearly display their equality policy or have LGBT material clearly showing or use images that represent people from LGBT community. This should be supported from the board-level.¹³³
- Support such as reminiscence activities should be designed sensitively, “to avoid returning people to a challenging period in their sexuality or gender identity”.¹³⁴
- Awareness of diverse sexual and gender identities (and the diversity within those) should be present throughout health and social care training, and should ensure staffs do not make assumptions about sexuality and gender identity. Training is key in addressing behaviours and attitudes that stem from a lack of knowledge, lack of

¹³² Dementia Action Alliance & Sermlyen, Dr Joanne (2016) [Dementia and the lesbian, gay, bisexual and trans \(LGBT\) population](#), date accessed 29/03/2017.

¹³³ National Care Forum (2016) [Dementia care and LGBT communities: A good practice paper](#), Coventry: NCF.

¹³⁴ National Care Forum (2016) [Dementia care and LGBT communities: A good practice paper](#), Coventry: NCF.

awareness and thus important in preventing discriminatory practice and resultant health inequalities. However this training needs to be integrated within all dementia training and not provided merely as a token session on diversity.

- Better information should be collected on the impact of dementia on LGB+ communities. There needs to be more research capturing the LGB+ experience of having for dementia, more funding explicitly for LGBT research, and, where appropriate, better collection of sexual orientation and gender identity monitoring data in order to better shape services.

Dementia and disabilities

Having conditions such as additional learning needs, hearing or sight impairment, or a range of others can have a distinct impact on an individual's wellbeing and complicate their needs for care from dementia services.

We know that certain conditions mean an individual has a higher chance of developing dementia – such as those with Down's Syndrome, over 50% of whom will develop Alzheimer's by their 60s. Services need to be designed to take this into account. Learning Disability services also need to be aware of this when addressing the needs of their older service users. Just as with all of us, people with Down's syndrome will typically know when something is wrong. However, we are less likely to talk about the diagnosis with someone we think may not understand. It is important to remember that the words we use to talk about being ill are pitched so that they are understood and have meaning for each individual – this may, or may not, include the word dementia in the conversation.¹³⁵

We have been told that, while individuals with moderate or severe learning disabilities are more likely to be given support by existing Learning Disability services, those with milder learning disabilities can be poorly served by existing services. They are usually cared for by loved ones or in the community – but if, over time, they either develop dementia or their learning disability leads to a cognitive degeneration, then they can find themselves confronted with services which will easily misdiagnose them. Services could misdiagnose dementia symptoms as part of their LD, or think deteriorating LD must be dementia related – this is because services will not understand their case history or baseline cognition as they do not have a relationship with that individual. Without contact over time with LD services, clinicians wouldn't recognise their baseline cognition in order to properly diagnose them at a later state which may be dementia-related. Older Person's Mental Health services may not have the background of that individual's baseline cognition. We need better coordination between such services.

"The professionals didn't want to contact me. They were contacting my brother or my daughter, and it was not appropriate. She's a young woman. Why were they only contacting my daughter because she is hearing? It was just easier for them. They don't realise the impact."
- Michelle Fowler, carer for father with dementia and member of the deaf community¹³⁶

We attended a number of sessions, in particular with the deaf and hard of hearing community, asking what can be done to increase awareness of dementia within the deaf and hard of hearing community; how can we support the needs of people who are deaf or hard of hearing and have a diagnosis of dementia; and how can we best support the needs of informal carers who are deaf who care for people living with dementia. We learnt that members of these communities often have many of the same concerns around dementia care, support, and services, but barriers to access are often much higher, and many of their individual needs are not met by services.

¹³⁵ Watchman, Dr Karen (2017) '[Mythbusting guide to Down's syndrome and dementia](#)', Alzheimer's Society Blog, 21/03/2017, date accessed 24/03/2017.

¹³⁶ Fowler, Michelle (2017) '[Health, Social Care and Sport Committee](#)', National Assembly for Wales, 9th March 2017 (para.249)

It is important that Welsh Government recognise that the deaf community are a linguistic minority who use British Sign Language according to the British Deaf Association and that all of the same concerns – losing use of a language, being unable to communicate with services, inappropriate diagnosis – for speakers of Welsh or BAME languages also exist for this community. BSL use represents a clinical need for many people. Alzheimer’s Society has produced our *Dementia Guide*, an introduction to dementia, in BSL and promoting this through the Welsh Government’s engagement with the deaf and hard of hearing community may be useful to increase awareness.¹³⁷

We recommend that:

- All information on dementia should be developed in a range of accessible formats. We have discussed the importance of language at length – but it is important that, for example, members of the deaf community whose language is British Sign Language can also access the same support.
- The diagnosis process, support and services are made accessible to members of the deaf and hard of hearing community, who may require use of British Sign Language, and individuals who are blind or with sight impairments.

“I think the way you can [increase awareness] is by visiting deaf people, by going to the clubs for deaf people like the hard of hearing community here.”

Memory tests are often not suitable for people in the BSL community. As explained by carer who is deaf explained at the Health, Social Care and Sport Committee:

*“For example, if you asked them maybe who the Prime Minister was a few years ago, they would struggle to know the name, because they’ve had such a poor education that they struggle with their literacy skills, so they don’t read very well. Most of them left school with a reading age of 8, so just basic news and general knowledge they would really struggle with, and in a memory test they might never have known that information, so it’s not that they’ve forgotten it.”*¹³⁸

- All care environments need to be accessible for people who have dementia and sensory loss such as sight or hearing impairments.
- People with sensory loss are always involved in decisions about their care. One person in our consultation sessions with the deaf community talked about a family member having been frightened and upset by staff trying to give an injection to him, without first getting someone to communicate what was to happen in BSL. Such examples are unacceptable. Where dementia is a factor, it is possible the person may react by struggling or hitting out, which may mean they are labelled as aggressive or violent.
- Welsh Government do work to reach out to these communities in order to co-produce further key actions to support them.
- Welsh Government should reach out to the UCL Deafness Cognition and Language Research Centre (DCAL) to better understand the issue.¹³⁹

¹³⁷ Alzheimer’s Society (2017) [The dementia guide in other languages](#), date accessed 30/03/2017.

¹³⁸ Fowler, Michelle (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 9th March 2017 (para.216).

¹³⁹ UCL (2017) [UCL Deafness Cognition and Language Research Centre](#), date accessed 30/03/2017.

Notable Practice:

Alzheimer's Society has funded research from **Dr Karen Watchman, Dr Kate Matthews, and co-researchers who have a learning disability**, to test non-drug therapies to support people with a learning disability who have developed dementia. The therapies will be meaningful to the person and may include music, reminiscence, environmental adaptation or technology.¹⁴⁰

For over 50 years, **Easthill Home for Deaf People** on the Isle of Wight has provided a home offering residential care and support to deaf adults. Easthill is a "culturally and linguistically deaf environment where British Sign Language is the first language".¹⁴¹ It provides specialist dementia care and received an overall "Good" rating from the Care Quality Commission.¹⁴²

"It would be a utopia, even if you just had a dementia centre it would be great, they have mental health in Manchester, why can't we have dementia in Wales, that would be fair."

¹⁴⁰ Alzheimer's Society (2017) [Care and Cure Magazine – Spring 2017](#), date accessed 30/03/2017.

¹⁴¹ NHS Choices (2014) [Easthill Home for Deaf People](#), date accessed 29/03/2017.

¹⁴² CQC (2015) [Easthill Home for Deaf People](#), date accessed 29/03/2017.

Dementia in rural Wales

Our [*Dementia in Rural Wales*](#) project has opened a dialogue about rural dementia.¹⁴³ We want to work with the Welsh Government and other stakeholders to unite against dementia and make sure services meet the needs of people affected by dementia in rural Wales. We estimate that at least 17,000 people affected by dementia live in rural Wales, and the figure is likely higher – it is only likely to increase, given Wales' ageing population.

While many rural areas have strong community ties and networks, they can be isolating places to live – with dispersed support services and poor transport links. Many people retire into rural communities in Wales from urban Wales or England, and may lack the community or family ties commonly associated with rural communities.

We welcome that there is an acknowledgement that rural areas face specific challenges in delivering dementia care – now we need to answer those challenges. We want the final strategy to include a more detailed section on dementia in rural Wales, setting out how Welsh Government will develop a better understanding of the extent, impact and growth of dementia in rural Wales. We must ensure current services are accessible to people in rural areas and are co-produced in line with the needs of people affected by dementia who live in rural areas across Wales, and that those responsible for designing services are accountable for this. **We believe** there should also be a commitment to work with the Rural Dementia Taskforce to further identify policy challenges and potential solutions in the years ahead.

We recommend the Welsh Government:

- Invest in research to understand the extent of the problem. Academic and research bodies in Wales should be encouraged (and, if necessary, commissioned) to develop a robust, evidence base and statistical data so that we can better understand the extent, impact and potential growth of dementia in rural Wales. As a bare minimum, the Welsh Government should commit to working with the Wales Rural Observatory to establish reliable baseline figures,
- Identify good practice examples from across the UK and Europe. A detailed review of research and other literature that already exists around the impact of dementia in rural areas should be commissioned to inform future policy decisions. This should either be from Wales specifically, or identify good practice from other nations which could be applied to a Welsh context.
- Address dementia in a new Rural Health Plan. Welsh Government should, when updating the Rural Health Plan, include a specific dementia component, as well as examining the wider health and wellbeing implications of rurality on people affected by dementia.

“Rural communities struggle purely because of their geographic locations, what is being done to support these people and carers?”

¹⁴³ Alzheimer's Society (2016) [*Dementia in Rural Wales: the three challenges*](#), Cardiff: Alzheimer's Society.



The background of the entire page is a dark blue color. Overlaid on this background is a large, stylized graphic in a lighter blue shade. The graphic depicts a human brain, with its characteristic folds and sulci. Two hands are shown, one on the left and one on the right, with their fingers gently cupping the sides of the brain. The hands are rendered in a simple, almost cartoonish style, with the fingers slightly spread. The overall composition suggests a theme of care, support, and understanding of the brain, which is central to the topic of dementia.

United against dementia

Read about our work at www.alzheimers.org.uk/walesstrategy17 and follow @AlzSocCymru for updates.

Please contact Morgan Griffith-David (Policy Officer) at M.Griffith-David@alzheimers.org.uk for more information.