

Cabinet Secretary for Health, Wellbeing & Sport,
Welsh Government,
Tŷ Hywel,
Cardiff, CF99 1NA
Correspondence.Vaughan.Gething@gov.wales

3rd April 2017

Dear Cabinet Secretary,

We welcome the publication of Wales' first ever Dementia Strategy, and would like to take this opportunity to respond to the consultation. Our organisations represent and support a wide spectrum of society including people living with dementia, carers, loved ones, and their wider support network, as well as health and social care professionals. We want to see a Dementia Strategy that is ambitious and achievable, and are uniting against dementia for this and we call on the Welsh Government, Local Health Boards, Local Authorities and other providers to do the same.

Since our letter in December 2016, the draft Dementia Strategic Action Plan has been published for consultation, and there has been a continuation of wide spread, meaningful engagement with people affected by dementia. This letter is informed by the draft Strategy and the voices of people affected by dementia, who contributed through the work of our individual organisations.

We believe that the Dementia Strategy should:

- 1) **Set out clear aims and targets.** We are concerned that the aims of the strategy are not spelled out in detail. All of the key actions and high level performance measures need to be SMART in order that the impact of the strategy can be effectively measured. We want to ensure that the Older Persons' Delivery Assurance Group has proper involvement from people affected by dementia in this process, in particular during the refresh in three years. We must ensure the Older Persons' DAG properly reflects the needs of people with younger onset dementia (dementia developed younger than age 65) in its work. The Dementia Strategy should look to the National Audit of Dementiaⁱ to monitor progress and ensure all hospitals participate.
- 2) **A Strategy across Government.** We believe that a number of themes are not well represented at present within the strategy. The strategy should also reach outside of health and social care into other policy areas. We believe this would be consistent with the aims of the Social Services and Wellbeing Act and the Wellbeing of Future Generations Act. There is a strong lack of understanding of the importance, value and benefits of enabling continued engagement in occupations, roles and society. We recommend that the strategy should include a more explicit section focusing on enabling people with dementia and their carers 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. People need support to maintain relationships, roles, work and occupation. Awareness and understanding should be 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. The Dementia Strategy needs to make strategic and policy links with Housing, Transport and Culture, all of which can have an impact on an individual's wellbeing and their ability to access services. For example, there is a current Expert Group report on meeting the housing needs of an ageing population, to which Dementia Strategy should be linked.

- 3) **Ensure that dementia services meet the needs of Welsh language speakers.** We welcome that there is a recognition in the draft strategy that Welsh language represents a clinical need, not simply a preference for many people. We believe that the Dementia Strategy should work to spread best practice and ensure action is taken to mainstream the "Active Offer" principle into dementia services as they are designed and implemented. A more proactive approach to language need and choice is needed, with responsibility placed on providers to offer their services in Welsh thereby eliminating the unfair burden on patients to request services in Welsh. There is also a need for data on dementia in Welsh language communities in Wales, so there can be a better understanding of the relationship between dementia and Welsh language as well as data on the numbers of Welsh speakers living with dementia in each health Board as a basis for the planning of Welsh language services.
- 4) **Ensure that dementia services meet the needs of seldom heard and marginalised groups such as the BAME, LGBT+, and other minority communities.** Wales has diverse communities and cultures, all of which may have distinct requirements for dementia care which need to be addressed. We welcome that Welsh Government recognises that individuals with dementia who may have protected characteristics may have individual needs but the strategy needs to go into more depth with specific actions that Welsh Government expect health boards and local authorities to meet. We would recommend that these 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. As a starting point, we would recommend:
 - Services need to be co-designed with locally prevalent communities.
 - Families should be involved in delivering and designing care.
 - Work should be done to reach out to 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 (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.

- Services should be aim to be proactively friendly towards the LGBT+ community, and promote diversity inclusion and present the environment as non-discriminatory.
- Awareness of diverse sexual and gender identities (and the diversity within those) should be present throughout health and social care training.
- Staff should not make assumptions about sexuality and gender identity.
- Ensuring that diagnosis process, support and services are 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. All care environments need to be accessible for people who have dementia and sensory loss such as sight or hearing impairments.

5) **Meet the challenges of living with dementia in rural Wales.** Too often, services are designed for urban areas, and the needs of those in rural Wales are forgotten. Lack of access to appropriate services, lack of awareness of dementia, and attitudes to dementia are particular problems for people living with dementia in rural areas. The Welsh Government should develop a better understanding of the extent, impact and potential growth of dementia in rural Wales and commit to working with the Rural Dementia Taskforce and other stakeholders to address these challenges.

6) **Set out clear and ambitious targets for increasing dementia diagnosis rates in Wales.** We welcome proposals for a national minimum waiting time standard for time from referral to first contact of 4 weeks and from referral to diagnosis of 12 weeks for all memory clinic services (when clinically appropriate) – a timely diagnosis is a human right for people affected by dementia guaranteed by the Glasgow Declaration. Timely diagnoses are vital to help people access services early in the dementia journey. We want to see a more ambitious target for dementia diagnosis. 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 also 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. We firmly believe that a multidisciplinary and joined-up approach between health and social care is needed to achieve these targets. Health and social care professionals should have access to advanced training in dementia to support their relevant practice to fully contribute to improving diagnosis rates and supporting individuals and their carers throughout the care pathway. It is crucial that the results of these assessments and services are communicated effectively to the teams in primary and secondary care. Information technology systems need to be robust across health and social care sectors.

7) **Ensure access for all people with a diagnosis of dementia to excellent support.** We welcome proposals to ensure that all newly diagnosed people with dementia should be offered access to a support worker - we know that a Dementia Support Worker (DSW) is a valued and important first point of contact who can signpost and support people with dementia, as well as their family and carers. However, with 20,000 people with a dementia

diagnosis and an aspiration to increase this number, we will need significantly more of these support workers - this pledge also does not seem to support all those individuals with an existing diagnosis who also need access to DSWs. 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. It is important that the strategy recognises that people affected by dementia can benefit from the support and signposting offered by a DSW. We believe that this access to a DSW should, at the latest, be in place by the end of the strategy's lifetime. We recommend that there should be consistency for key worker provision and a single, unified job description for DSWs should be provided to health boards. It is important that the strategy recognise the high level of qualifications of Dementia Specialist Nurses and believe that DSNs, DSWs, AHPs and other health professionals with expertise in dementia care have a role to play in providing support for people affected by dementia. 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 offer support from their own life story – Welsh Government should work to enable this wherever possible.

- 8) **Ensure that all primary care settings, hospitals and care homes achieve dementia friendly status**— there are currently welcome proposals in the draft and we look forward to seeing more detail on when it will be achieved by and what standard will be expected. This should be supported by spreading accepted notable practice such as John's Campaign and the Butterfly Scheme to all Local Health Boards – there are too many stories of these not being adopted or being misused, when we know the benefits they bring when done and done well. “This is Me” should be mandated in all settings. To achieve dementia friendly emergency departments we need better flow through the emergency department - the overcrowding which results from ‘Exit Block’ⁱⁱ severely limits facilities to provide dedicated calm environments for patients with dementia in emergency departments. Work on flow through the acute hospitals, community hospitals and social care must be included in the strategy. There are many models for adapting care settings to better suit the needs of people with dementia, which we will provide in individual responses. 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.ⁱⁱⁱ 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.
- 9) **Ensure appropriate dementia training and dementia awareness is taken up in all settings.** We welcome the initial goal that 75% of NHS employed staff who come into contact with the public will be trained in an appropriate level of dementia care, according to the *Good Work Framework*. We would like to better understand the definition of ‘coming into contact with the public’ and recommend that, wherever possible, this goal should include NHS contractors and other commissioned staff. 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 is the case in hospitals, the community and 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. Training must recognise the importance of mental and physical aspects of dementia, recognise other health concerns of people living with dementia, and make sure staff 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. Where possible, people affected by dementia should be involved in co-designing and co-delivering training, as staff have told us that it is highly impactful and delivers quality learning outcomes. Training should demonstrate cultural competence and be reflective of the community they serve. There should be specific training in outcome focused/what matters conversations also available for staff. We believe that all undergraduate health and social care courses include dementia awareness and more formal training pathways, including on delirium, and Welsh Government should look to work with the higher and further education sectors to map current provision. There should be a focus on expanding dementia awareness and training to other sectors of the public and private sector, reflecting the large numbers of front line workers who will have daily contact with people affected by dementia.

- 10) **Support carers, family, and the wider support network of people with dementia.** We welcome proposals for carers' education and access to carers' assessments, but feel that the strategy should go further. We want to see firmer targets for carers' assessments and a proper plan for respite care. We must ensure that carers' assessments reflect the realities of living with dementia – for example, that dementia is a terminal condition that is degenerative, and may need regular review. We believe that 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 – this should be supported by implementing the Triangle of Care in Dementia^{iv}, and introducing a national approach to involving carers, including training for health and care home staff in identifying, supporting and involving carers of people with dementia. We must recognise and value the carers journey and ensure a commitment to adequate respite, support, and training for carers. All healthcare professionals should be able to access information on a patient's carer in order to provide support. At the same time, the strategy must recognise 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 actions should establish clear pathways for people with dementia who do not have a carer with them in such a situation.

11) Ensure the skills of Allied Health Professionals are used to meet the needs of people

affected by dementia: 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, following diagnosis, and promoting an enablement and reablement approach. Dementia support post diagnosis should include access to multi-disciplinary support from a range of therapists (including occupational therapists, physiotherapists, speech and language therapists, dietitians and art music and drama therapists) to promote independence and support people to develop the skills they will require in the later stages of dementia. This should include sensory needs, nutrition, hydration and more. 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 proposals for the 2017 strategy may provide a basis. This includes a key action of working collaboratively with the new Integrated Joint Boards to support locality planning and re-design of dementia services and 'enhancing a multi-disciplinary approach to care at home, including the promotion of therapeutic and enabling role of AHPs for people with dementia. In particular, references to occupational therapy are poor and only limited to adaptations and equipment. Occupations are referenced but not acknowledged as fundamental to a person's health and wellbeing. Occupational therapists are able to act as a catalyst in establishing an enabling ethos to help a person achieve personalised goals. Advice from an occupational therapist can address how to undertake daily living activities, teaching techniques and advising on assistive technology, equipment and adaptations. This has the overall aim of enabling a person to retain independence, minimise care costs and remain safe in their home. This also helps to reduce the levels of stress experienced by carers

12) Support people with communication, swallowing, and eating needs: There is scant reference to the importance of communication and the role of speech and language therapy. Communication problems often occur for people with dementia and 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. We strongly believe that 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. In addition, it is concerning there are no references to swallowing, eating and drinking difficulties and associated actions within the strategy. Dysphagia and dysphasia are recognised challenges 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, care homes.

- 13) **Support people with dementia with wider health needs.** 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, 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.
- 14) **Support people with their medicines and prevent inappropriate use of antipsychotics,** We want to see more information on how this will be implemented and what will be reported to local mental health partnership boards by June 2018. The Welsh Government must ensure that people have access to a pharmacist for appropriate medication support ensuring they have a full explanation of the medication they may be prescribed and be enabled to make informed choices about their medication and treatment options and medication. The Dementia Strategy should ensure that carers, loved ones or advocates of people with dementia who are prescribed antipsychotics are fully informed about the impact of those medicines and are able to provide appropriate support in all care settings. Antipsychotic medicines should not be routinely prescribed to treat behavioural and psychological symptoms of dementia. In line with NICE guidance, when an antipsychotic medicine is required, the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled pharmacist as part of the multidisciplinary team. Multidisciplinary support and regular medicines reviews from a pharmacist should be available to all people with dementia, including those living in care homes, to help optimise individual medication regimes and reduce inappropriate use of antipsychotics. With patient consent, all pharmacists directly involved in care should have full read and write access to a patient's health record in the interest of high quality, safe and effective care.
- 15) **Support people living with dementia right to the end of life.** Dementia is now recognised as the leading cause of death in England and Wales. We welcome that this is referenced in the Strategy, but more detail is necessary. We welcome proposals for all relevant health and social care staff to be trained and supported to help people with dementia develop care plans. Given the importance of the end of life care, it should potentially form its own theme within the dementia strategy. We recommend that the strategy recognises the distinctions between palliative care, which focuses on treating and managing pain and physical symptoms, and end of life care, which aims to support people to live as well as possible until they die. We recommend that the strategy establishes a national review of the current provision of palliative and end of life care, and ensures that better dementia training is available for hospice staff. Families of people with dementia may also require a different bereavement support to those dying of other conditions - the carers, loved ones and families of people with dementia may experience different stages of loss as the condition progresses, for example when the person with dementia no longer recognises them.^v People living with dementia may experience a range of emotions when bereaved and for people affected by dementia, they may be coping with some added and unique challenges as a consequence of the condition. Cruse Bereavement Care and Alzheimer's Society Cymru "Bereaved by

Dementia” project is working to address the meet the complex needs of people with dementia, their carers and families who are faced with a bereavement.^{vi}

We would be very happy to discuss these points with you further if it would be helpful to do so. We will also, of course, be submitting individual consultation responses on behalf of our own individual organisations.

Yours sincerely,



Full list of signatory organisations:

1. Age Alliance Wales
2. Age Cymru
3. Alzheimer's Society Cymru
4. BASW Cymru
5. British Geriatric Society in Wales
6. British Red Cross
7. Care & Repair Cymru
8. Carers Trust Wales
9. Chartered Society of Physiotherapy
10. College of Occupational Therapists
11. Cruse Bereavement Care
12. Diverse Cymru
13. Leonard Cheshire Disability Wales
14. Marie Curie
15. Motor Neurone Disease Association
16. Royal College of Emergency Medicine
17. Royal College of Nursing
18. Royal College of Physicians
19. Royal College of Psychiatrists
20. Royal College of Speech and Language Therapists
21. Royal Pharmaceutical Society Wales
22. Welsh Language Commissioner

-
- ⁱ Royal College of Psychiatrists (2016) *What is the National Audit of Dementia?* Available online at www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/dementia/nationalauditofdementia.aspx
- ⁱⁱ Royal College of Emergency Medicine (2015) *Tackling Emergency Department Crowding*. London: RCEM. Available at: [www.rcem.ac.uk/docs/College%20Guidelines/5z23.%20ED%20crowding%20overview%20and%20toolkit%20\(Dec%202015\).pdf](http://www.rcem.ac.uk/docs/College%20Guidelines/5z23.%20ED%20crowding%20overview%20and%20toolkit%20(Dec%202015).pdf)
- ⁱⁱⁱ Rafferty, A. M., Clarke, S., Coles, J. et al (2007) Outcomes of variation in hospital nurse staffing in English hospitals: Cross-sectional analysis of survey data and discharge records. *International Journal of Nursing Studies*, February 2007, 44(2), pp.175-182, available online at www.ncbi.nlm.nih.gov/pmc/articles/PMC2894580
- ^{iv} Carer's Trust and Royal College of Nursing (2016) *Triangle of Care for Dementia*, London: RCN. Available online at <https://professionals.carers.org/triangle-care-dementia>
- ^v Marie Curie and Alzheimer's Society (2015) *Living and dying with dementia in Wales: Barriers to care*. London: Marie Curie. Available online at <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-wales.pdf>
- ^{vi} Cruse Bereavement Care (2016) *Cruse Bereavement Care Cymru and Alzheimer's Society in Wales working together*, available online at <http://www.cruse.org.uk/news/dementiaproject>