

Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
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	The Welsh NHS Confederation response to the Health, Social Care and Sport Committee inquiry into the Welsh Government: Together for a Dementia Friendly Wales (2017-22).
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Introduction

1. We welcome the opportunity to contribute to the Health, Social Care and Sport Committee inquiry into the Welsh Government: Together for a Dementia Friendly Wales (2017-22). Providing person-centred support and services to people living with dementia and their carers is a priority for the NHS in Wales.
2. The Welsh NHS Confederation represents the seven Health Boards and three NHS Trusts in Wales. The Welsh NHS Confederation supports our members to improve health and well-being by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.
3. While we are pleased to be able to respond to such an important inquiry we would like to highlight our disappointment with the very tight timeframes that the Committee has set. The Welsh NHS Confederation and our members have been given less than a week to provide a written response to the inquiry. While we appreciate that the Welsh Government delayed publishing the draft 'Dementia Strategy' it is very difficult for the NHS to provide a substantive, evidence based, response in such short timeframes, especially on such an important area where there is significant work being done across the NHS to support people affected by dementia. We hope that the Committee considers our concerns when launching future inquiries. Our members will be providing comprehensive responses to the Welsh Government consultation and they will share these with the Committee by the 3rd of April.

Overview

4. Providing person-centred support to people affected by dementia (people living with dementia, their family and carers) is a priority for the NHS. As our population ages, dementia is one of the most significant health and social care issues we face. The statistics presently tell us that 1 in 16 people aged 65 or over, and 1 in 6 aged 80 or over, will be affected by dementia.ⁱ Improved life expectancy means that as more people are living longer more people are developing dementia.
5. It is estimated that between 40,000 - 50,000 people in Wales are currently living with dementia.ⁱⁱ Dementia shortens life expectancy and many people will die of dementia, but also many will have other life-limiting and complex illnesses at the same time. The Office for National Statisticsⁱⁱⁱ has recently suggested that dementia is now the leading cause of death in England and Wales, with 11.6% of deaths attributable to dementia. Dementia presents a significant public health concern; overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years, are attributable to it. Dementia prevalence roughly doubles every 5 years from the age of 65 onwards.^{iv} Population projections estimate an increase of 68% in the number of people with dementia in Wales between 2011-2030 (specifically 88% for males, and 57% for females).^v Alongside this, people's health and well-being needs are becoming more complex, with many

people having multiple long-term conditions that require different levels of intervention and support.

6. As well as the human cost, it has recently been estimated that dementia costs the UK £23 billion a year.^{vi} Most of this cost, £12.4 billion per year, is met by unpaid carers, with the rest made up of social care costs (£9 billion), health care (£1.2 billion) and productivity losses (£29 million).
7. With the number of people living with dementia increasing the health and social care sector is working to provide person-centred support and services to people affected by dementia. As the draft 'Dementia Strategy' highlights, there has been significant progress and investment in dementia awareness and services, including:
 - a. Increased public awareness and support through the Dementia Friends/ Dementia Supportive Communities campaigns;
 - b. Investment in hospital settings and the community;
 - c. Increased numbers of memory clinics; and
 - d. Additional training to give NHS and social care staff the knowledge and skills to provide the best care for people living with dementia.
8. There is no doubt that Wales has the skills, the capacity and the ability to meet the demanding targets in the Welsh Government's 'Dementia Strategy'. The Welsh NHS will continue to work in partnership with social care and other public and third sectors to support people living with and affected by dementia.

Our general views on the draft 'Dementia Strategy'?

9. We welcome the development of this Strategy as a means of providing clarity over the future direction of dementia care in Wales. The draft Strategy provides a framework on which we can build on in future years. We are pleased that the Welsh Government, when drafting the Strategy, has engaged with people living with dementia, their families and carers, as well as organisations supporting people living with dementia. This engagement, and future engagement as the Welsh Government consultation develops, ensures that the focus is on what is needed to make a real difference to the lives of people affected by dementia.
10. The draft Strategy is comprehensive, especially from a prevention, health promotion, treatment and support point of view which is welcomed as it raises the profile of dementia within the health and care settings. This is important as people living with dementia constitute about a quarter of all general inpatient hospital stays, and they often have an increased length of stay due to their condition.
11. While we support and welcome the draft Strategy, we think it would benefit from more specificity regarding delivery, especially in relation to who will be delivering; what they will be delivering; and what the expected outcomes would be. The setting of key deadlines for implementation would also be beneficial to ensure delivery is accelerated in line with likely population need.
12. Given the expected increase in dementia cases in the next period, delivery of the Strategy will be heavily dependent on the Welsh Government ensuring sufficient resources are made available to both the NHS and social care to enable the development and delivery of the integrated, person-centred services designed to enable those living with dementia to live as well as possible for as long as possible. It is essential that services and resources are aligned to deliver a person-centred care approach rather than a strict medical model of care.

13. It will also be important that there is equity of access to support and services for people living with and affected by dementia, which suggests that we will need a universal set of standards to be achieved across health and social care, notwithstanding the need for more locally nuanced services in response to individual community need. This will involve consideration of environment (e.g. housing and geography) language preference, and protected characteristics.
14. Beyond these general points, we would offer the following observations:

Public health and awareness

15. We are pleased that the draft Strategy recognises the importance of healthy behaviours. It has been estimated that by promoting and adopting healthy lifestyles in middle age, an individual's risk of developing dementia could be reduced by approximately 20%.^{vii} Risk factors that may impact on the risk of dementia include: obesity, raised cholesterol levels, social isolation, smoking, alcohol and physical inactivity. An awareness raising campaign for those in middle-age, to address the lack of knowledge on dementia prevention would be advantageous. In addition, greater public awareness is required to support the general understanding about the normal ageing process, particularly with regards to memory loss, to support early advice seeking.
16. As well as public awareness campaigns, it is important that the Government and public bodies support the population to adopt healthy lifestyles, particularly in middle age. As the Welsh NHS Confederation Policy Forum 'One workforce': Ten actions to support the health and social care workforce in Wales^{viii} document highlights the *"whole workforce should be ambassadors for healthy living, making mental and physical public health and well-being a priority and working collaboratively to create the right conditions to support everyone to make healthier lifestyle choices"*. Public health plays a key role in ensuring that we reduce demand and empower people to take control of their health and well-being.
17. As part of public health and awareness we must continue to drive a mass shift in public thinking. In relation to people in poor health, the NHS and social care sectors need to communicate with people and ensure that they are aware of the choices and decisions that they are making and how they are impacting on their health and well-being. In terms of how services are used, the re-education of the public is vital and we need to support people to participate in planning, designing their care with health and social care professionals.
18. Furthermore communities need to become more dementia-aware and supportive to assist in the process of increasing diagnosis levels: this is not purely within the gift of the Health Boards.

Early intervention and diagnosis

19. We are really pleased that the draft Strategy highlights the importance of early intervention and diagnosis. Evidence clearly highlights the value of early intervention and diagnosis (including access to services, risk reduction, planning for the future and greater autonomy). Early intervention, both pharmacological and non-pharmacological, can help to slow the progress of dementia and its symptoms. It can also help to better prepare individuals and their families for the future of living with the condition. However, early diagnosis does carry ethical implications, and consideration needs to be given to ability to consent and the potential benefit and harm for each individual case.

Carers

20. We support the recognition in the draft Strategy of the crucial role of carers in supporting and caring for those living with dementia. We know that the services that carers and family members

provide are invaluable, for both those that they care for, and the public purse. The health and social care system needs to provide information and support to carers to equip them with the skills and tools they need to care for someone living with the disease. As the impact of dementia grows over the coming years, family members will have an increasingly important role to play in dementia prevention and early intervention. A key function to consider in the dementia prevention and early intervention agenda is providing support for carers. If carer breakdown occurs, or family members are not prepared for a caring role and all the life changes that are implicit with it, outcomes for individuals with dementia are inevitably worsened and usually involve admission to a care setting. Effective care giving has a major impact on the quality of life of someone living with dementia, helping them to live well and stay independent for longer. As such, investment in the skills, capacity and well-being of carers should be prioritised and seen as investing to save.

Primary Care

21. It is helpful that the draft Strategy acknowledges the need for primary care teams to understand the value of early diagnosis. In parts of the UK where a primary care led approach to dementia care has been advocated, diagnostic rates have been seen to improve significantly. A clearer expectation and responsibility for primary care to identify people who have dementia would be welcomed. While the financial incentivising of dementia diagnosis in primary care has been seen to lead to an increase in the likelihood of misdiagnosis, it would be useful to consider a mechanism to ensure that the responsibility of primary care was more explicit.

Does the Strategy covers the right areas?

The number of people diagnosed with dementia

22. There is a need to improve dementia diagnosis rates and to understand the demographic composition of the data so that we can more effectively plan to meet the current and future demand for information, support and care at the right time and in the right place. The current data regarding the number of people diagnosed with dementia needs to be more transparent, especially in relation to how diagnostic rates are calculated.
23. Currently data regarding numbers of people with dementia are collected only once a year (in March) via GP Quality and Outcomes Framework (QOF) reporting. Consequently routine monitoring of changes in diagnosis rates is challenging and Health Boards need more regular measurement to support effective service improvements locally.
24. Furthermore in relation to diagnosis rates, the method of calculating diagnostic rate presently is through comparison of age related estimated prevalence compared with the numbers of people on the primary care register. This calculation isn't always transparent via QOF. The method and methodology for calculating diagnostic rates is to be modified from the calculation achieved as a result of a Dementia Delphi Consensus Study to the dementia diagnostic rate, indicated through the Cognitive Function and Ageing Study II (CFAS II).^{ix} CFAS II only considers people who are over 65 and not those under 65 who are diagnosed with dementia. Consequently the change in the method of calculation will automatically improve diagnostic rates. It would be helpful if the algorithm for calculating diagnostic was transparent so that the diagnostic rate could be utilised in an informed way to achieve service improvement e.g. to illustrate, the Dementia Delphi Consensus Study algorithm is: 30-34yrs 0.0094%, 35-39yrs 0.0077%, 40-44yrs 0.014%, 45-49yrs 0.0304%, 50-54yrs 0.0583%, 55-59yrs 0.1368%, 60-64yrs 0.9%, 65-69yrs 1.7%, 70-74yrs 3.0%, 75-79yrs 6.0%, 80-84yrs 11.1%, 85-89yrs 18.3%, 90-94yrs 29.9%, 95yrs+ 41.1%. This would be fine if

the dementia register was split into over and under 65 so that diagnostic rate could be calculated accordingly. The register currently isn't age defined.

Supporting people in crisis

25. It is positive that the draft Strategy focuses on keeping people with dementia in their familiar home environment and preventing deterioration where possible. It also recommends that NHS organisations have teams and resources dedicated to managing people with dementia in the community, which is likely to mean a realignment of existing resources to support new models of care and health and social care-wide system support for dementia patients and their carers/families.
26. The Strategy also needs to recognise what is needed to manage crisis situations, which is when the Welsh Ambulance Service NHS Trust (WAST) is most likely to receive a 999 call. Individuals with dementia do not benefit from being taken to a busy Emergency Department and it is important that the health and care system has pathways in place (preferably 24/7) so that community assessment and ongoing management services are available and responsive.
27. The role of Unscheduled Care Services could be strengthened in this strategic direction. Given developments within WAST, the changing role of their clinical staff and the changing nature of their case mix, it is important that the contribution of WAST is reflected in the Strategy.

Implementation

28. The key actions within the draft Strategy are in some places not directed. Some of the proposed actions could be more explicit, for example '*increase the number of primary care practices in Wales that are dementia supportive*' on p 20 of the draft Strategy. To demonstrate this it might be helpful to identify the percentage of practices, where staff have received an appropriate level of awareness /training and efforts have been made to provide a dementia friendly service and environment. Health Boards will need to build on this year on year with expectation of eventual 100% compliance. The 'Good Work: A Dementia Learning and Development Framework for Wales'^x will be instrumental in achieving this cultural shift.

Specific areas where the chapters within the Strategy could be improved

29. As well as the specific areas highlighted by Public Health Wales NHS Trust in their written response to the Committee, which we support, the following areas could improve the Strategy:

a. The title

30. The current title of the Strategy may need to be revised to describe it as a 'Dementia' Strategy. The reference to 'friendly Wales' confuses the overarching nature of the Strategy with the more specific elements focused on Dementia Friendly Communities.

b. Introduction

31. Page 12 states that "*£130m to be invested in new older persons mental health facilities and £500,000 a year for Occupational Therapy Support Workers to be in every older person's mental health ward in Wales*". We would ask that consideration should be given to the fact that the vast majority of people living with dementia are treated within the acute hospital setting. The issues is whether this money (£130m and £500k) would be more prudently invested in improving environments and activity participation for those wards located in the acute settings.

32. In addition, it is unclear from the Strategy what is required to ensure that general health services are dementia aware and friendly and how can the NHS build this into their estates design and facilities provision.

c. Risk reduction and health promotion

33. In relation to page 20 a clear working definition is needed of what constitutes a 'suitably competent clinician' in terms of the diagnostic process. The Strategy should clarify that an official and *registered* diagnosis is needed to enable individuals and families/carers to access post diagnostic services.
34. In relation to memory clinics, referrals to memory clinics should not be the sole reserve of Doctors, GPs and Consultants. Referrals should be open to other qualified health professionals such as Nurses, Occupational Therapists and Physiotherapists. The current system causes extended delays in securing memory clinic appointments. To counteract the argument that this will lead to a huge number of inappropriate referrals, clinics should consider developing robust triage processes. Furthermore we would recommend the addition of the utilisation of 'Making Every Contact Count' within NHS healthcare settings by all staff with patients in the Strategy.

d. Recognition and Identification

35. Regional integrated 'dementia pathways', jointly developed and owned by health and social care, would be helpful in describing what support and services should look like across the range of services and would assist in driving up best practice. This could support in determining regional performance measures and in identifying local solutions to local difficulties. This may also support stakeholder involvement, particularly in the development of dementia friendly communities and helpful in signposting to appropriate services.

e. Assessment and diagnosis

36. While we are supportive of the annual targets set out on page 51 of the draft Strategy, it has not been made explicit within the draft Strategy that a diagnosis percentage of 51% (compared with those expected to have the condition) is the lowest percentage in the UK, far lower than Northern Ireland and Scotland (c 90%). Subsequently there should be a commitment to specific annual targets to improve the percentage of case identification and diagnosis. To achieve this additional resources to Memory Clinics will be needed to ensure dementia is diagnosed in a timely manner.
37. As highlighted in the previous page, there needs to be a greater emphasis within this section of the Strategy on the role that all health professionals (GPs, pharmacists, general hospital staff, geriatricians and physicians etc) must play in diagnosing, treating, monitoring and caring for people with dementia. There is also an opportunity to establish an explicit recommendation to establish a diagnostic pathway as a feature of acute hospital admission initiated by cognitive screening and the elimination of delirium diagnosis, which is already in place in England. Alongside this there needs to be clear recognition of the need to increase and expand the availability of, and access to, both Memory Service specialist dementia services and the number of consultant of Old Age psychiatrists across Wales.

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

38. There needs to be more clarity within the Strategy in regards to meeting the challenge of providing equitable support to all people living with and affected by dementia irrespective of where they live, what language they speak and whether they have protected characteristics. The draft Strategy does not clearly state how the challenge of supporting people with dementia in a rural community will be met. Specifically who will explore the options around telehealth, telecare and assistive technology and ensure access to Occupational Therapy? Nor does it explain how the

needs of Welsh speakers will be met. In addition the Strategy would benefit from consideration of the extra resources that may be required for people with sensory loss, BAME communities and LGBT+. Support for carers also needs to include consideration of same sex couples, who are often disadvantaged and disempowered.

39. It would be helpful if the Strategy gave greater consideration to the impact of environment, including housing, education and employment as well as that potential for reablement services to support the person with dementia to establish compensatory strategies. Addressing environmental factors and providing access to reablement services supports people to carry out essential daily living activities for longer. In this context it would be appropriate to include a recommendation that this type of service was available as part of the key actions.
40. The action within the Strategy that a *“reduction in the percentage of people with a diagnosis of dementia receiving inappropriate anti-psychotic medications and a reduction in duration, particularly in care homes”* is welcomed. However, it does not go far enough in terms of Welsh Government support. To optimise this firstly Care and Social Services Inspectorate Wales (CSSIW) could be engaged in ensuring that non-pharmacological methods should be used where possible in care homes for behaviour that challenges staff and secondly, further resource could be invested in the data extraction and education of GP practices in anti-psychotic prescribing where needed.
41. This Strategy should make the connection to other Welsh Government Strategies that relate to the treatment and care of people with chronic conditions and also sensory impairment as the demographics around this are clear.

g. The need for increased support in the community

42. In relation to the ‘In the More Specialised Care and Support’ section it almost entirely refers to Community Mental Health Teams (CMHTs) as the teams responsible for offering support. This is directly at odds with the fact that dementia is not a mental health condition and is a physical disease. It is felt that this section contradicts that view, we feel that all community teams should have the skills required to provide support to people living with dementia and who regularly come into professional contact with people living with dementia. Many CMHTs are not multidisciplinary and do not have specialist skills to deal with needs of people living with dementia. Should this area of work be seen as the responsibility of CMHTs we feel that individuals may be referred onto these services which could very quickly be overwhelmed. We would suggest that if staff need to be trained and educated in line with the ‘Good Work – Training Framework’, then all community staff will have the skills to provide timely, evidenced based care whatever the clinical setting.
43. Within the End of Life Care section of the Strategy there is a need to clearly define the difference between ‘Palliative Care’ and ‘End of Life Care’ because these terms are not interchangeable. ‘Palliative Care at End of Life’ is a different definition again. Palliative Care is a process that should commence at a point after diagnosis that enables forward planning and discussion around Advanced Care Plans, Power of Attorney and Advanced Directives. Palliative Care practices should accept that dementia is a progressive disease that will ultimately lead to End of Life. End of Life Care should be defined as a process that occurs when people are actively dying. If the Palliative Care process has been stringent and efficient, it should inform decision making when that person is entering their last days of life. Without considering the need for Palliative Care post diagnosis there is a distinct likelihood that decisions made at End of Life could be made from a crisis management perspective, many official reports have shown that such an approach leads to a distressing end of life experience for people.

44. We would recommend a specific emphasis within the Strategy on utilisation of the Intermediate Care Fund to support people living with dementia.
45. Finally, it is also important that people living with dementia have all of their drugs reviewed regularly. It must also be remembered that in some cases the clinical view is that medication to relieve severe anxiety may be in a person's best interests, but this must be part of a regularly reviewed clinical care plan.

h. Supporting the Plan

46. In relation to training, while some specialist training is required, this generally involves enhancing the skills for those providing personal care and treatment and may apply equally to carers at home as staff in a hospital or other care settings. What is important is ensuring the right care approach is provided depending on what the individual requires and that this is understood and communicated to others so that this is delivered with the skills and consistency to avoid distress and agitation. Another key issue relating to training that needs to be considered is that there is no reference around the need for staff to receive regular specialist training in how to reduce distress and aggression in older people's services generally, and inpatient services & nursing homes specifically. Dementia services consistently have the highest incidence of aggressive incidents of any clinical population and there is a wealth of clinical evidence about reducing challenging behaviour in dementia that is specific to this condition.
47. With regard to research within the Strategy, the International Consortium for Health Outcomes Measurement (ICHOM) work is worth referencing. This brings together patient representative, clinician leaders and relevant others from across the globe to develop standard sets focussing on patient outcomes and quality of life.

Conclusion

48. As highlighted in our response to the inquiry providing person-centred support to people living with dementia is a priority for the NHS. There is significant work already being done across the health and social care sector to support people affected by dementia but this Strategy provides further clarity over the future direction of dementia care in Wales.

ⁱ Alzheimer's Society, November 2014. Key stats on older people, ageing and Age UK.

ⁱⁱ Welsh Government/ Statics for Wales, October 2016. General Medical Services contract: Quality and Outcomes Framework statistics for Wales, 2015-16

ⁱⁱⁱ Office for National Statistics, November 2016. Deaths registered in England and Wales (Series DR): 2015

^{iv} Williams J W, Plassman B L, Burke J, Holsinger T, Benjamin S. 2010. Preventing Alzheimer's Disease and Cognitive Decline. Report No.: Number 193.

^v Public Health Wales, August 2010. Public Health Wales Future Dementia Estimates (2011). 11 A.D. Aug 23.

^{vi} Luengo-Fernandez R, Leal J, Gray A. Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom.

^{vii} Russ T C, Starr J M. Clinical Evidence Editorial : Could early intervention be the key in preventing dementia? BMJ Group.

^{viii} Welsh NHS Confederation Policy Forum, September 2016. 'One workforce': Ten actions to support the health and social care workforce in Wales.

^{ix} Cognitive Function and Ageing Study <http://www.cfes.ac.uk/cfas-ii/>

^x Care Council for Wales, NHS Wales, Public Health Wales and the Welsh Government, November 2016. Good Work: A Dementia Learning and Development Framework for Wales