



## **Royal College of Psychiatrists**

### **Consultation Response**

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**DATE:** 16 January 2017

**RESPONSE OF:** THE ROYAL COLLEGE OF PSYCHIATRISTS in WALES

**RESPONSE TO:** Dementia Strategy

The Royal College of Psychiatrists is the professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in the United Kingdom.

The College aims to improve the outcomes of people with mental illness, and the mental health of individuals, their families and communities. In order to achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

RCPsych in Wales is an arm of the Central College, representing over 550 Consultant and Trainee Psychiatrists working in Wales.

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## **The Health, Social Care and Sports Committee Work on Welsh Government's draft Dementia Strategic Action Plan**

The Royal College of Psychiatrists welcomes the Committee's work on the draft Dementia Strategy and is pleased to be invited to respond. We were happy to learn at the beginning of last year Welsh Government had plans to introduce a Strategy, which was then set out in the *Together for Mental Health Delivery Plan 2016 – 2019*. Unlike Scotland and England, there is currently no Dementia Strategy for Wales. The driver for improvements in dementia services has come from *The Dementia Vision* report that was published in 2011, which is a laudable document, however lacks specific targets. The College feels that a strategy is long overdue.

1. The Strategy is an important document that requires a significant amount of time and expertise to develop. We are concerned that the initial deadline for completion by end of 2016 was unrealistically short. The extended deadline of end April 2017 is welcomed but we still feel that more time should have been afforded to this important piece of work. This document must be able to meet the challenges we face now and into the future.
2. We think the title of the strategy document 'Together for a Dementia Friendly Wales' is misleading and actually does not reflect the content. The title could be revised to 'Together for Dementia'.
3. The consultation strategy meets most of the areas in a joint signed letter sent to the Health Secretary (attached) apart from meeting the needs of living with dementia in rural settings. We are also concerned about the strategy meeting the needs of minority groups residing in Wales.
4. The Strategy is a national pathway from diagnosis to end of life care. It covers the area of: 1. recognition and identification; and 2. assessment and diagnosis of dementia, which are clinical components that cannot be avoided since dementia is caused by disease. An overarching clinical strategy and management of dementia plan would complement the dementia strategy.
5. To ensure workable dementia strategy in Wales robust integration of health and social care will need to be implemented first.
6. We are pleased that the document stresses the importance of *timely diagnosis*. What *is* crucial is the provision of support services once a diagnosis has been made. This is addressed in the strategy.
7. The Strategy is fairly generic with no specific outcomes. The Actions at this stage are ambiguous. We must wait until a delivery or implementation plan is developed to see if outcomes are SMART. The College would be most willing to participate in this.
8. The English and Scottish Strategies could have been modified to fit the Welsh Context. We are cross referencing these strategies against the Wales consultation documents. We need to learn lessons from the other devolved Nations that already have dementia strategies in place.

9. We are concerned that more emphasis should be placed on the following areas:

- Young/early onset
- LD and cognitive impairment
- Palliative care
- Traumatic brain injury
- Alcohol
- Sensory impairment
- BME community.
- Prison population
- Supporting primary care services

## Appendix

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

8<sup>th</sup> December 2016

Dear Cabinet Secretary,

As organisations representing a wide spectrum of people living with dementia, as well as carers and health & social care professions, we welcome the Welsh Government's work to date on developing Wales' first Dementia Strategy.

We want to ensure that the vision for dementia care for Wales is ambitious and achievable, and as such are writing to you to make ten recommendations which we believe must be included if the Strategy is to be seen as sufficiently ambitious for people living in Wales with dementia.

We are aware that the Welsh Government has commissioned a series of engagement and consultation events to involve people affected by dementia in the development of the Dementia Strategy. The voices of those affected by dementia should always be central in Welsh Government's concerns, and we hope that those meetings are fruitful and give the Welsh Government a strong steer for the direction of Wales' first Dementia Strategy. The proposals below are the views of a range of organisations which work with people affected by dementia in a variety of capacities.

We believe that the Dementia Strategy should:

1. **Set out clear targets for increasing dementia diagnosis rates in Wales.** We believe that by 2021, each Local Health Board (LHB) should attain a diagnosis rate of at least 75%. As an interim measure, by 2019 we believe Wales should learn from good practice to match the diagnosis rate in Northern Ireland (currently 64%). As a step towards this, LHBs should immediately commence routinely recording the number of people newly-diagnosed with dementia. Welsh Government should also aim to ensure early and timely diagnoses. 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 should be introduced.
2. **Ensure that by the end of the Strategy's lifetime, every person with dementia can access support from a Dementia Support Worker.** A DSW can provide vital support and signposting to people with dementia, and can help support follow-up with people with dementia, and vastly improve an individual's well-being. We recognise the high level of qualifications of Dementia Specialist Nurses and believe that both DSNs and DSWs have a role to play in providing support for people affected by dementia. Evaluations of a variety of Dementia Support Worker and Dementia Adviser roles have found there is scope to ensure provision is cost-neutral after just four years.
3. **Ensure that all hospitals and primary care settings achieve dementia friendly status by 2021** – this should be supported by spreading accepted best practice such as John's Campaign, the Butterfly Scheme, and "This is Me" type leaflets to all Local Health Boards. There are many models for adapting care settings to better suit the needs of people with dementia.

4. **Ensure appropriate dementia training and dementia awareness is taken up in all settings.** By 2018, there must be higher levels of training for NHS and care staff including all nursing staff in particular practice 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. This training must ensure 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. The *Good Work* Framework should form the basis of this training, complimented by specific training in outcome focused/what matters conversations. Training should recognise the importance of mental and physical aspects of dementia and other health concerns of people living with dementia. This should include NHS employed staff and, wherever possible, commissioned staff. It should also ensure that all undergraduate health and social care courses include dementia awareness and more formal training pathways.
5. **Support carers and family of people with dementia,** including by ensuring appropriate information is available at the right time and the right place including at diagnosis, ensuring access to a carers assessment, and ensuring people with dementia and their carers are involved with clinical professionals as equal partners in care supported by a multi-disciplinary team with professionals from different specialities. All healthcare professionals should be able to access information on a patient's carer in order to provide support. There should be better recognition for and involvement of carers, supported by implementing the Triangle of Care in Dementia, 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.
6. **Prevent the over-use and inappropriate use of antipsychotics, and support people with prescriptions.** Antipsychotics should not be routinely prescribed to treat behavioural and psychological symptoms of dementia, and when necessary only the lowest dose should be prescribed for the shortest time. Multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics. People with dementia may need more support with their prescriptions such as receiving weekly prescriptions - care home residents should receive regular reviews to optimise their medication regimen. 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.
7. **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 is a particular problem 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.
8. **Support people living with dementia right to the end of life,** including by establishing a national review of the current provision of palliative and end of life care. The explicit wish of most people – with dementia and without – is to die at home, yet hospital often ends up being the “default option” for many people. Where possible and desired, people should be enabled to die at their place of residence with support from professionals such as community nurses. As people live longer, they die with more complex and often multiple conditions. Statistics show that more and more people are dying with dementia. Welsh Government should ensure that better dementia training is available for hospice staff, and all relevant health and social care staff are trained and supported to help people with dementia develop advanced care plans.
9. **Ensure that dementia services meet the needs of Welsh language speakers.** For many Welsh speakers, language is an integral element of their care – as dementia progresses, they may lose use of their second

language. The Dementia Strategy should work to spread best practice. Action is needed 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 rural dementia and Welsh language, as well as data on the numbers of Welsh speakers suffering dementia in each health Board as a basis for the planning of Welsh language services.

- 10. Ensure that dementia services meet the needs of 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. Families are reluctant to use services that do not meet cultural or religious needs and try to carry on alone. Services need to be co-designed with locally prevalent communities and 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 and traveller community accessing services. 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, and should ensure staff do not make assumptions about sexuality and gender identity.

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,

*Signatories*

