

***Together for a Dementia Friendly Wales (2017-22)* written report
from RCGP Wales to Health, Social Care and Sports Committee
from RCGP Wales**

1. RCGP Wales represents GPs and doctors training to be GPs from across Wales. We welcome the opportunity to provide written comments to the Health, Social Care and Sports Committee on the new Strategy Together for Dementia Friendly Wales (2017-22).
2. We welcome the fact that The Welsh Government is committed to creating a dementia friendly nation and their signing of the Glasgow Declaration in 2015, committing to promoting the rights, dignity and autonomy of people living with dementia. In addition, this affirmed that every person living with dementia in Wales has:
 - *The right to a timely diagnosis.*
 - *The right to access quality post diagnostic support.*
 - *The right to person centred, co-ordinated, quality care throughout their illness.*
 - *The right to equitable access to treatments and therapeutic interventions.*
 - *The right to be respected as an individual in their community.*
3. We also welcome the launch in 2015 of '*Wales: a Dementia-Friendly Nation*'.
4. We welcome the systematic approach of the strategy in the form of a comprehensive pathway. We welcome the drive to improve the aim of the Nation with a view to reduce the onset of dementia in our aging population. We particularly welcome the inclusion of public education and specific training for public sector workers at all levels in support and recognition of dementia. Research and end of life are appropriately included and we are pleased to see that these are included.
5. We are concerned that there may however be inappropriate expectations on an increased workload in general practice, which is currently suffering from excess workload and recruitment problems.
6. The prevalence of affected people in Wales is increasing as people live longer as the incidence increases with age. Older people are more likely to have other health conditions and this means that their care is more complex. Adding dementia to the multimorbid conditions in one person makes management more complex and particularly in the early stages when patient's dignity and independence is being maintained. Progress of the deterioration

and prognosis of dementia is very varied. Care and support for those affected by dementia need to be tailored to the needs of the individual and their carers and reviews must be provided at regular intervals as needs change. Family carers may themselves be elderly and suffer from poor health requiring care and support themselves.

7. Those in rural areas may have difficulty reaching or receiving services but for the elderly travel in urban areas may be difficult and even some short journeys may be difficult without adequate public transport. This is worse in rural areas where bus services are often no longer supported or very infrequent.
8. We welcome the recognition that assessments and care should be available in the patient's preferred language, including Welsh. GPs use phone translations services to support consultations with patients. This may be more difficult for home visits or when patients are in care or nursing homes. Dementia assessment and care need to be accessible through the medium of Welsh. Providing assessments and support may be particularly challenging to those from minority ethnic groups, who may never have learnt English or Welsh or who may as part of their dementia forget their second language. Encouraging the development of more link workers who can translate as well as understand the local culture of the ethnic group is extremely helpful for doctors and patients with dementia both in general practice and memory clinics. A good example of this are the health link workers based in Butetown Health Centre, who support the Somali and other ethnic groups. Sadly, due to demand from the wider health service, they are often not available to GPs in the local surgeries and seldom for home assessments. There are a few carers or care home staff who speak the languages of the ethnic minorities making them very isolated
9. We welcome the need for increased public awareness of dementia to help the people of Wales to improve their wellbeing and adopted healthy life styles to reduce their risk of developing dementia. GPs are well placed to encourage this in their own patients, but there is scope for wider education of the general public on prevention, recognition and support. Other public sector workers may benefit from education such as teachers and school staff who may have contact with children of affected parents or grandparents. The children may be young carers. School staff may also be able to raise health concerns of children's relatives or support their interaction with the school children.
10. GP may be reluctant to diagnose dementia without support of memory clinics and access to these across Wales may be varied in different parts of Wales, even for those in the advanced stages due to concern about potential misdiagnosis of treatable conditions. Access to memory clinics in some areas of Wales may take several months and the support provided and time to final

diagnosis is varied. Patients in the early stages of dementia may be reluctant to accept a referral to such a clinic and may need time to adjust to the possible diagnosis. For some it may be helpful to get support and specialist advice prior to the diagnosis to enable them to adjust to their memory deterioration prior to formal diagnosis.

11. We welcome the potential of improving occupational therapy input to older people in hospital. We would welcome if this included those in their own homes with the provision of supportive equipment to help those with dementia to maintain independence where possible and to help those in care homes to have the best possible wellbeing. We also welcome the increase in training planned for care home staff. We hope that this will help reduce the numbers of patients who are prescribed anti psychotics to manage behaviour problems and minimise the length of time they are used, when required.
12. As the strategy does not have details of the potential care home enhanced service we are unable to welcome this. We would however support the funding of the additional work that is required for all those in care homes as these patients represent additional work load for doctors and this would enable GPs and their staff to provide additional services to those in care homes. These patients generally have multiple medical problems and require longer than normal consultation times. In addition time is required to visit the patients in the homes, to consult with relatives and the staff on the patients' management.
13. We welcome the development of awareness and training of dementia support staff in end of life care. In parts of ANB LHB there has been good development of this work by linking palliative nurse specialists with frailty teams.
14. The document talks about improving telemedicine but as currently there are areas of Wales which have poor broad band connectivity this needs to be considered as part of long term planning. Transfers of care need to be improved as and when patients move from home to hospital to care home, medical records often do not move smoothly with them. Any moves must be kept to a minimum as they increase anxiety and cause increased memory loss. It is particularly important not to diagnosis dementia based on such agitated forgetfulness compounded by acute ill health.
15. In particular we are concerned that there is still in this document a need to increase the rate of dementia diagnosis as if this a target , which has limited basis and no actual figures or facts attached.