



Research Briefing **A Global and National Perspective on Dementia**

Author: Dr Catrin Hedd Jones, Bangor University

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National Assembly for Wales
Research Service

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Author: **Dr Catrin Hedd Jones, Bangor University**

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Contact Us

Research Service
National Assembly for Wales
Tŷ Hywel
Cardiff Bay
Cardiff
CF99 1NA

 : 0300 200 6304

 : Stephen.Boyce@Assembly.Wales

 : senedresearch.blog

 : [@SeneddResearch](https://twitter.com/SeneddResearch)

 : Assembly.Wales/Research

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Research Briefing

A Global and National Perspective on Dementia

This paper is published as part of the Assembly's pilot Academic Fellowship Scheme, which enables academics to work at the Assembly on a specific project, for the mutual benefit of the academic and the Assembly.

As Wales enters a new phase in tackling dementia this paper outlines examples of innovative work in Wales, the UK and internationally set in the context of the WHO Global Plan of Action on the Public Health Response to Dementia 2017- 2025.



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1. Introduction

This paper provides an international perspective on dementia, including some of the issues facing other nations and the approaches taken to address these matters affecting the 50 million people worldwide living with dementia. The paper is structured around the principles of the WHO Global Action Plan on the public health response to dementia (2017-2025)¹, with examples of good practice that meet these national targets.

Recent studies estimate that there are between 38,444 (CFAS)² and 55,829 people living with dementia in Wales (Western Europe Delphi)³. The consultation on the first Dementia Strategy for Wales in 2017 generated a great deal of discussion on what needs to be in place to fulfil the vision of a Dementia Supportive Nation.

The World Health Organization (WHO) also recognises dementia as a public health priority and in May 2017 the World Health Assembly endorsed the “Global Plan of Action on the Public Health Response to Dementia 2017- 2025”¹. The WHO Plan includes seven cross cutting principles to improve the lives of those living with dementia and their carers and reduce the impact of dementia on society.

The cross cutting principles within the WHO plan are:

- 01.** Human rights of people with dementia.
- 02.** Empowerment and engagement of People Living with Dementia and their carers.
- 03.** Evidence based dementia risk reduction and care.
- 04.** Multi-sectoral collaboration on the public health response to dementia.
- 05.** Universal health and social care coverage for dementia.
- 06.** Equity.
- 07.** Appropriate attention to dementia prevention, cure and care.

The WHO Action Plan on Dementia also involves seven actions and national targets, which form a framework for this briefing. Examples of innovative work in Wales, the UK and internationally are included, in line with the seven WHO Global action plan priorities.

2. Action area 1: Dementia as a public health priority

WHO Target: 75% of the countries to develop or update a policy/strategy/framework on dementia.

The introduction of the [Dementia Action Plan for Wales 2018-2022](#)⁵ is a positive move for the nation. However, a note of caution is provided by the experiences of countries such as Singapore (2009) and Indonesia (2013) where plans have been proposed but have not yet been implemented or have lacked ownership.

“Set up a focal point, unit or functional division responsible for dementia or a coordination mechanism within the entity responsible for non-communicable diseases, mental health or ageing within the health ministry (or equivalent body), in order to ensure sustainable funding, clear lines of responsibility for strategic planning, implementation, mechanisms for multisectoral collaboration, service evaluation, monitoring and reporting on dementia.”¹ (p11.)

The WHO Action Plan¹ recommends that people affected by dementia are involved in the design, planning and implementation of National Strategies to ensure accountability and allocation of sustainable financial resources to deliver the strategy. In Wales the evidence provided by people living with dementia (personally or as supporters) was a significant contribution to the consultation process, the Welsh Government's Task and Finish group included members living with dementia and the Action Plan (p.6) includes people living with dementia, their carers and families in the Dementia Delivery Assurance and Implementation Group (DDAIG).

Research⁶ conducted in eight European countries, including the UK, evaluated the enablers and barriers for informal carers accessing support in the middle stage of dementia. The findings included important recommendations based on enhancing access, and factors that enable and enhance the use of services to prevent a crisis. The role of a key contact person and access to staff that are knowledgeable in dementia was clear in these recommendations.

Link workers have been supporting people diagnosed with dementia in the first year after diagnosis in Scotland. The commissioning of Dementia Co-ordinators and Dementia Support Workers has improved the support provided after diagnosis but it is imperative that this remains a person centred support for the person receiving a diagnosis and their supporters/ carers.

3. Action area 2: Dementia Awareness and Friendliness

WHO Target- all countries to have a public awareness campaign to foster a dementia inclusive society and 50% of countries to have a dementia friendly initiative.

Dementia is an umbrella term for a complex condition affecting everyone differently according to the location of damage to the brain. As dementia may affect the person's ability to communicate it is important to ensure that health and social care staff make an Active Offer of Welsh Language services to patients that speak Welsh. Alzheimer's Disease International published the '10 warning signs of dementia'⁷ to increase public awareness. Merched y Wawr have agreed to distribute a Welsh translation of this poster to their members in 2018. An accompanying paper on bilingual resident's access to dementia services will be available through the Research Service.

Language is a significant factor in the way people are portrayed⁸. The term dementia, derived from 'out of mind' and can be stigmatising, which may prevent some people from seeking support. In 2004, the authorities changed the Japanese word to describe someone living with dementia from 'Foolish' to 'Dementia'; this has made a significant impact in Japan. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (2013) replaced the term Dementia with Mild and Major Neurocognitive disorders. This change reflects the negative use of the word dementia and may be a significant step forward in tackling fear and lack of engagement in support at an early phase of the condition.

A media campaign in the Netherlands highlighted how citizens can help people living with dementia live a full life in the community. In 2017 the Social Justice Department of Kerala State in India funded staged plays on the importance of care and the current environment for people living with dementia to feel included. Doctors gave talks in the morning to raise awareness followed by an afternoon play and an interactive session after the play. Theatre companies in Wales (Fran Wên and Re-Live) have performances linked to dementia touring in 2018. "Wŷ Chips a Nain" is a family play depicting the relationship between a grandparent and grandchild and Belonging/ Perthyn has included elements to educate care staff about the importance of being 'in the moment' with the person living with dementia' and how language can open channels of communication.

The benefits of engaging in visual arts sessions as part of the Dementia and Imagination⁹ research illustrated the importance of providing stimulating opportunities that allow people living with dementia to enjoy creative expression irrespective of their diagnosis.

Training of medical students in Cost Rica also increased their awareness and diagnosis of younger onset dementia. Training within GP surgeries funded by the Welsh Government reported to have resulted in only a 30% uptake in 2016¹⁰. The volunteer programme, Dementia RED, provides signposting services in GP practices in North Wales. Dementia RED will now expand to other information sites¹¹.

Peer support is a valued way of gaining information and providing support for both those that receive a diagnosis and their supporters/carers. The Dementia Engagement and Empowerment Project (DEEP) is a peer led group support for people living with dementia with over 80 active groups in the UK and a growing presence in Wales. **Bilingual Guides**, developed by DEEP members to support the involvement of people living with dementia, are available online. In North East Wales a pioneering voluntary initiative will offer people that receive a diagnosis of young-onset dementia the opportunity to meet and discuss issues with other individuals living with dementia. The 'Friendly Face' initiative supports individuals to engage with peers and support services after diagnosis. The Scottish Dementia Working Group published a booklet highlighting that dementia is about more than just memory¹². This work has been translated into four languages and has informed both the public and practitioners of the additional challenges people may face when living with dementia.

Dementia Friends have been very successful in raising awareness and supporting the movement to encourage more Dementia Friendly Communities with over two million taking part in England, Northern Ireland and Wales (correct on 26/6/17). Resources developed by the Alzheimer's Society as part of Dementia Friends and health board initiatives such as the arts-based projects Anti Glenda¹³ in Betsi Cadwaladr UHB should be promoted as best practice in tackling stigma and meeting important elements of the new curriculum in Key stage 1-2. The Dementia Friendly Communities movement led by the Alzheimer's Society also has the potential to normalise dementia within communities.

Intergenerational activities as seen in a recent TV series shown on S4C have the potential to raise awareness and reduce stigma. Research into the impact of shared care of preschool children and older adults developed at Bangor University is currently underway. Further work in Gwynedd with the support of Bangor University researchers will look at the potential to facilitate greater links between primary schools and care facilities in 2018.

4. Action area 3: Dementia risk reduction

WHO Target- global targets for prevention and control of non-communicable diseases 2013–2020 and any future revisions are achieved for risk reduction and reported.

Research suggests that a third of dementia cases are preventable by tackling recognised risk factors such as hypertension in over 45 year olds and other recognised interventions to reduce the risk of developing dementia¹⁴. The Welsh Government ACT NOW campaign (2017) provides advice on how to reduce the risks of developing some types of dementia. The campaign includes maintaining physical and social engagement, reducing obesity, avoiding excessive drinking of alcohol and smoking. Additional factors shown to reduce the risk of developing some dementias include improving childhood education, management of hearing loss, depression and diabetes¹⁴.

A thirty-year study of male health in Caerphilly shows that adopting healthy lifestyles has a positive impact on cognitive performance although actual uptake of healthy lifestyles is low¹⁵. Ongoing research into the effects of lifestyle changes in Finland¹⁶ will increase the potential to deliver interventions to reduce the risk of developing some types of dementia.

5. Action area 4: Dementia diagnosis, treatment, care and support

WHO target of a minimum 50% of the estimated people living with dementia to receive a diagnosis.

Data released by the Alzheimer's Society¹⁷ emphasised the importance of a timely diagnosis to support those affected to access the appropriate support and plan for the future.

The WHO recommends that a co-ordinated, person-centred care pathway from diagnosis to palliative care is required. This area needs significant progress through integrated awareness raising and an established clear pathway for GP surgeries to refer into services that are person-centred and equitable to all regardless of location.

The regional diversity and low diagnosis rates¹⁷ throughout Wales suggest that there is a risk that citizens receive a different experience of dementia based on the place that they live. Further work to investigate the results that Welsh speaking citizens engaged later with memory services¹⁸, explored in a separate briefing paper, presents ten recommendations based on consultations with practitioners, academics and healthcare managers.

Dementia is a life-changing diagnosis and there is currently no cure for dementia. Although some forms of dementia may respond to medication there is growing appreciation that non-pharmacological, ecopsychosocial¹⁹ support can enable those that receive a diagnosis to live a fulfilling and stimulating life. Research in Australia on the long-term use of antipsychotic medication showed that the demand for prescribing came mainly from nurses²⁰. Family members were resistant to de-prescribing but the majority of residents did not show behaviours that challenged the staff when they stopped administering antipsychotics.

6. Action area 5: Support for dementia carers

WHO target-Support and training for carers and families in 75% of the countries by 2025

Consultation meetings with carers in North West Wales led by TIDE (Together in Dementia Everyday-an organisation for carers of people diagnosed with dementia) highlighted the varied experiences of support offered to informal carers. Carers said that it was difficult to navigate the support system which was often was not fit for purpose. The Alzheimer's Society offer carers' information sessions over four weeks (CrISP programme) providing knowledge, information and coping strategies in a group setting. The Older People's Commissioner for Wales is currently examining respite provision in Wales.

Research on timely access to care services for people cared for in the community recently published recommendations⁶: The Action Plan for Wales⁵ state that "all individuals with dementia living in the community have a dedicated support worker" (p17). People with dementia and their informal carers should have access to psychoeducation at diagnosis and information about the available support throughout their journey with dementia.

7. Action area 6: Information systems for dementia

WHO Target- 50% of countries to routinely collect a core set of dementia indicators through national health and social information systems every two years to be used by the Global Dementia Observatory.

Greater co-ordination of dementia diagnosis type based on sex, age, language spoken and ethnicity is required to ensure that individuals receive adequate support throughout the dementia 'journey'. Data on the provision of the Active Offer is also of clinical importance in Wales.

8. Action area 7: Dementia research and innovation.

WHO Target-Output of global research on dementia doubles between 2017 and 2025.

Strengthen research capacity, translate what is known into action and promote equitable access for people living with dementia and their carers to be part of research that concerns them.

A report on the UK dementia research and workforce capacity²¹ commissioned by the Alzheimer's Society stated that only 62% of dementia PhD graduates remain in dementia research careers with the lack of a secure career path affecting the retention of graduates in the UK. The continued funding of the Centre for Ageing and Dementia Research (CADR) until 2020 by Welsh Government through the Health and Care Research Wales is a positive move for growing the research expertise in Wales. The funding supports a virtual centre led by Swansea University in partnership with Cardiff University and Bangor University.

*Join Dementia Research*²² launched in the UK in 2015 as an online and telephone service that helps people to take part in dementia research. The latest figures by the National Institute for Health Research show 36,112 volunteers have registered and 187 studies have used the service to recruit participants in the first two years (data on 5/2/18).

The North Wales Dementia Network aims to increase the impact of dementia research in practice and encourage greater collaboration between those affected by dementia and professionals. The series of face-to-face 'cross county' meetings, themed events and conferences encourage members to share best practice and increase collaboration across sectors. Membership of the Network continues to grow through social media platforms and a second collaborative national conference is planned for the 7th March, 2018 focusing on how Wales can become a dementia inclusive country. Networks in Australia and Japan have also shown to be effective in supporting the exchange of ideas and collaboration beyond traditional boundaries.

9. Conclusions

Wales is at a pivotal point in determining how we build a society that works together to tackle the issues facing people affected personally and professionally by dementia. The Global Plan of Action by the WHO's cross cutting principles and actions enable countries to set priorities in this fight against the disease. The inclusion of people with dementia on the Wales dementia strategy task force follows the example of other nations such as Scotland, as Kate Swaffer from Australia explains in this video "Nothing about us without all of us". Only by including all the experts (professional and personal) will we progress "together for a dementia friendly Wales"²³.

10. References

[All web links accessed 5 February 2018]

01. [Global action plan on the public health response to dementia 2017–2025](#). Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
02. [CFAS](#)
03. Ferri, C., et al. (2006). [Global prevalence of dementia: a Delphi consensus study](#) *The Lancet* 366, 9503 2112-2117
04. Matthews, F., et al. (2103). [A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing study 1 and 11](#). *The Lancet* 383, 9902, 1405-1412.
05. Welsh Government (2018). [Dementia Action Plan for Wales 2018-2022](#). Taking Wales Forward. (pdf 8MB) {WG31821}.
06. [Actifcare](#) (pdf 544KB)
07. [Poster on 10 symptoms of dementia by ADI](#)
08. [Language guide](#) (pdf 135KB)
09. Windle, G., Joling, K., Howson-Griffiths, T., Woods, B., Jones, C. H., van de Ven, P., Newman, A., Parkinson, C. (2017). The impact of a visual arts programme on quality of life, communication and well-being of people living with dementia: A mixed-methods longitudinal investigation. *International Psychogeriatrics*, 1-15. doi:10.1017/S1041610217002162
10. [GP training](#)
11. [Dementia RED](#)
12. [Dementia and Sensory challenges booklet](#) .
13. [You tube film of intergenerational work – Anti Glenda with English subtitles](#)
14. Livingston, G., et al., (2017). [Dementia prevention, intervention, and care](#). *The Lancet*, 390, 10113, 2673-2734
15. Elwood, P., et al. (2013). Healthy Lifestyles Reduce the Incidence of Chronic Diseases and Dementia: Evidence from the Caerphilly Cohort Study. *PloS one*. 8. e81877. 10.1371/journal.pone.0081877.
16. Ngandu, T. et al. (2015). [A 2-year multi domain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people \(FINGER\): a randomised controlled trial](#). *The Lancet*, 385, 9984, 2255–2263.
17. [Diagnose or disempower](#) (2015). (pdf 949KB) Report by Alzheimer’s Society.
18. Clare, L., et al. (2016). Bilingualism, executive control, and age at diagnosis among people with early-stage Alzheimer's disease in Wales. *J Neuropsychol*, 10: 163–185. doi:10.1111/jnp.12061
19. Zeisel, J., Reisberg, B., Whitehouse, P., Woods, R., & Ad Verheul. (2016). Ecopsychosocial interventions in cognitive decline and dementia. *American journal of Alzheimer’s disease and other dementias*. 31, 6, 502-507.

20. HALT study ADI presentation (2017) (pdf 519KB).

21. Mapping the UK's dementia research landscape and workforce capacity infographic

22. Join Dementia Research

23. Welsh Government (2107). Together for a Dementia Friendly Wales 2017-2022. Consultation document (pdf 708KB) {WG30441}.