

Policy Brief: An update on dementia care for Welsh speakers

Summary

- **Little progress has been made** regarding most of the recommendations made in the report published in 2018 by the Welsh Language Commissioner and Alzheimer's Society Cymru. **The momentum that once existed has stalled.**
- The following should be prioritised in order to provide new impetus:
 - The evaluation of the Dementia Action Plan for Wales **should gather the experiences of Welsh-speaking patients and carers**
 - **The Dementia and Welsh Language sub-group should be re-established**
 - **The Welsh language** should be a **core element** in the next dementia action plan for Wales
 - The Welsh Government should lead on a **specific implementation plan for the development of Welsh-medium dementia care pathways**, prioritising areas such as data collection, increasing language awareness, assessments and resources, and linguistic training
 - To drive all these recommendations, **a specific role should be created to lead on the Welsh language and dementia.**

Language is a matter of need rather than choice

If care is not available in Welsh, then that care is inadequate. Provision of services through one's first language is a basic clinical need for those living with dementia, and this is recognised as such in Welsh Government Policy.

Legislation and policy - the background

Legislation and policies are already in place to create favourable conditions for the provision of care through the medium of Welsh for people living with dementia. These include:

- More than Just Words: 5 Year Plan, 2022–27
- Social Services and Wellbeing Act (Wales) 2014

- Regulation and Inspection of Social Care (Wales) 2016
- Welsh Language Measure (Wales) 2011

Together, legislation and policies supporting the Welsh language in care are powerful.

The report by the Welsh Language Commissioner and Alzheimer's Society Cymru

In 2018 the Welsh Language Commissioner and Alzheimer's Society Cymru produced a report on '[Dementia Care for Welsh Speakers](#)'. This research was carried out because scores of stories had come to light revealing the experiences of people affected by dementia evidencing their inability to receive care provision through the medium of Welsh. These individual cases were obviously not

exceptions and examples of inadequate provision across the country emerged.

The report presented a mixed picture of the care received by Welsh speakers living with dementia. Although there were local examples of good practice and despite an awareness of the Welsh language and the proactive offer at a strategic level, the research revealed many gaps in the care provided at grass roots level. There were very few examples of Welsh speakers having all their needs met.

Although policy at a national level highlights the fact that receiving care in one's first language is a matter of clinical need rather than of choice, research revealed that a similar awareness and understanding has not permeated through to the grass roots. The research highlighted examples of the detrimental effect a lack of Welsh language services has on people, and at an all-Wales level dementia care for Welsh speakers is inadequate.

The report highlighted three main challenges in terms of the provision of Welsh-medium dementia care.

1. Workforce training and development:

Although some examples of good practice were observed, a lack of training and awareness of the effects of dementia on Welsh speakers was also noted. A lack of confidence amongst staff in their Welsh language skills posed a substantial challenge as did wider challenges in terms of recruitment.

2. Appropriate assessments and resources: the research highlighted inconsistency in the Welsh-medium diagnostic tests and assessment resources that are available and used for dementia.

3. Leading, commissioning and planning services: the research revealed that data on the linguistic skills of staff and those receiving a dementia diagnosis were not sufficiently collected or used and that this was impeding the planning of Welsh-medium dementia services.

The report made 15 recommendations so that work could begin on tackling these challenges.

The establishment of the Dementia and Welsh Language Group and the Dementia Action Plan for Wales 2018-22

At about the same time as the above report was published the [Wales Action Plan for Dementia](#) was developed. This plan recognises the importance of providing services in an individual's first language and that the provision of care through the medium of Welsh is a matter of clinical need for those living with dementia.

Following the publication of the action plan, the Welsh Language and Dementia sub-group was established to sit below the wider group responsible for the oversight of the Wales Action Plan for Dementia (DOIIG). This sub-group was intended to convene key stakeholders to advise and share information and to co-ordinate efforts to implement the recommendations made by the Commissioner and Alzheimer's Society Cymru within the context of the Wales Action Plan for Dementia.

Six years later: has there been any progress?

The momentum that existed following the publication of the report and the establishment of the sub-group has stalled substantially. The sub-group has not met for two years, and there has been no specific national action aimed at co-ordinating efforts to strengthen Welsh-medium dementia care.

The fact that the sub-group has not been active in recent years makes it more difficult to reach an informed opinion regarding progress made to date.

From the limited information available, it seems that little progress has been made on the majority of recommendations.

In 2020 the Social Care Inspectorate published a [National Review of Care Homes for people living with Dementia](#). A number of the conclusions in this review reflect the findings of research carried



out by the Commissioner and Alzheimer's Society Cymru two years previously. Although a number of Welsh speakers do receive care through the medium of Welsh, the report also refers to Welsh-speaking residents in homes where there were no Welsh-speaking members of staff or any Welsh language activities or resources available. Fewer than half of care homes were reported to be providing bilingual services and few homes kept a record of whether they had any Welsh-speaking residents.

Whilst acknowledging the risks of over-generalisation and also of disregarding efforts at a more local level, it seems that steps taken have been comparatively limited in terms of improving Welsh-medium dementia care. As is true of the wider care and health sector, the challenge is to move from a situation where the 'proactive offer' is accepted and discussed as a policy concept, to a situation where this has a practical impact upon the way care is planned, provided and funded.

Some positive developments

Placing dementia care within the wider health and care policy context, a number of significant strategic and statutory actions during recent years should be acknowledged.

Since the publication of the report by the Commissioner and Alzheimer's Society Cymru, the National Health Service's Health Boards and Trusts are obliged to comply with Welsh language standards. The standards place specific duties on organisations in terms of service provision, their operation, and consideration given to the Welsh language in policy making. More specifically it is crucial to consider the importance of standard 110 with which all health boards must comply. This means that they are required to publish plans every 5 years to indicate to what extent they are able to provide clinical consultations in Welsh and essentially, the steps they intend to take to improve their ability to do so.

In 2021 an [Evaluation of More than Just Words](#) was published. This is the Welsh Government's plan for

improving Welsh language services in the health and care sector. Following the evaluation, the government published its new plan: '[More than Just Words new version for the period 2022-27](#)'. The plan includes a substantial number of actions relating to matters such as workforce language training, raising awareness of the proactive offer, data collection and planning provision. The actions frequently reinforce the requirements of the Welsh language standards and together they set out a clear direction for the health and care sector in Wales.

As well as references to the health workforce in the Welsh language standards and in the 'More than Just Words' strategy, The Welsh Government published the [Health Workforce Strategy](#) jointly produced by Education and Health Improvement Wales and Social Care Wales. The strategy recognises the importance of the Welsh language as a clinical need and lists a number of actions relating to workforce development so that care can be provided through the medium of Welsh.

In 2021 Improvement Cymru published a document entitled [All Wales Dementia Care Pathway of Standards](#), which identifies the key areas for the provision of improved dementia care in Wales. The standards acknowledge the importance of Welsh language provision in order to meet the linguistic needs of individuals.

The next steps: reviving the momentum

The Welsh Government is currently evaluating The Dementia Action Plan for Wales 2018–22. It is timely therefore to evaluate progress made in terms of providing dementia care for Welsh speakers during the life of the plan. This is essential in order to ensure that the next dementia action plan fully considers the Welsh language and builds upon wider plans already in place to strengthen Welsh language provision within health and social care services.

In order to achieve this, we recommend that the following actions be considered:



1. To ensure that **the evaluation of the Dementia Action Plan for Wales gathers the experiences of Welsh-speaking patients and carers** and considers this evidence in the context of the plan's commitments regarding the Welsh language.
2. **The imminent re-establishment of the Dementia and Welsh Language sub-group.** In the short term, the group needs to support the above evaluation and play a key role in advising the Welsh Government as it prepares the next action plan.
3. To ensure that **the next Dementia Action Plan for Wales has the Welsh language at its core.** The plan should consider the recommendations of the 2018 report and should also build upon the More than Just Words strategy and the requirements of the Welsh language standards.
4. **Following the publication of the new dementia action plan, the constitution, remit, reporting arrangements, and accountability of the dementia and Welsh Language sub-group require consideration.** The sub-group should become an effective forum for scrutiny and for holding partners to account.
5. In partnership with the dementia and Welsh language sub-group, **the Welsh Government should draw up a specific implementation plan for the strengthening of Welsh-medium dementia care.** The implementation plan should build upon wider plans for dementia, care and health (including the More than Just Words strategy, the requirements of Welsh language standards, and those of the Social Services and Well-being Act (Wales) 2014) **setting out specific actions for the development of Welsh-medium pathways for dementia care.** The implementation plan should consider carefully the recommendations of previous reports, prioritising actions likely to have a real impact on the care provided to Welsh speakers living with dementia. As a starting point, we

would suggest that the plan should consider the following:

- The processes for collecting data on patients' language choice and their needs and how this information is used to plan care
 - The processes for collecting data on the Welsh language skills of the workforce and how this information is used to plan care
 - Language awareness and linguistic training for the dementia care workforce
 - Ensure that Welsh-medium dementia assessments are diagnostically accurate and increase their use by clinicians
 - The development of national and local fora to share resources and experiences of providing voluntary dementia care through the medium of Welsh
6. To drive all the above recommendations, we believe a **specific role should be created to lead on the Welsh Language and dementia.**