



Consultation Response

Inquiry into Hospital Care for People Living with Dementia

National Assembly for Wales Cross-Party Group on Dementia

April 2019

Introduction

Age Cymru is the leading charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We are pleased to respond to the Cross-Party Group on Dementia's inquiry into hospital care for people living with dementia.

Hospital care

One quarter of hospital beds are occupied by people with dementia¹. Outcomes for people with dementia who are admitted to hospital are markedly poorer than those without the condition. People with dementia stay longer in hospital than others who go for the same procedure. Longer stays are associated with worsening symptoms of dementia and poorer physical health, which means that discharge to a care home becomes more likely and that antipsychotic drugs are more likely to be used.

The misuse of anti-psychotic medication to 'manage' dementia has an impact upon the person with dementia and their carer(s), and places further financial pressures upon the NHS. NHS Wales should monitor the regularity of reviews of its use; the number of patients taken off the medication at three months (as recommended) and the overall level of use of such medication. Overall, we would like to see a marked reduction in the use of such medication in Wales.

Currently, specialist mental health beds in hospitals are often not equipped to support those with frailty and physical needs, whilst intermediate care services can be reluctant to admit people with dementia. As a result, discharge from hospital becomes extremely difficult, even when it is clear that hospitals cannot provide the most appropriate support for the person with dementia.

Improving the experience of the large number of people with dementia in hospitals is key to improving the NHS overall. If people with dementia were supported to leave hospital one week earlier than they currently do, significant savings might be achievable across the system as a whole. Much of the money currently spent on treating people with dementia in hospitals could be more effectively invested in

¹ Alzheimer's Society (2014): *Dementia 2014: Opportunity for change*, viii

appropriate community services outside hospitals, as well as workforce capacity and development.

Dementia Action Plan (DAP)

The DAP is an historic opportunity to improve life for people affected by dementia. However, we have concerns about: a lack of distinction between palliative care and end of life care; lack of consideration of links to care homes; lack of workforce planning; lack of consideration of ambulance and emergency departments being dementia friendly.

We believe Welsh Government should improve education and training for health and care staff on recognising, understanding and managing dementia-related conditions. All pre-registration nursing programmes should cover specific content on ageing including dementia. Information and support for those diagnosed with dementia and their carers and families still needs to be improved. All health and care staff should be able to provide appropriate information on and signposting to advice, advocacy and support services.

Welsh language

Dementia is a condition which affects linguistic ability. Not providing care in the Welsh language can lead to frustration and to losing dignity and respect. Even though national policies state that care through the medium of Welsh is a clinical need not a matter of choice, this is not reflected in the grassroots services available.²

Assessment and care in Welsh are often not available unless someone asks, which has a negative effect on Welsh speakers with dementia. One example of this was a patient (in a care home in this case) who did not speak at all as the staff were not aware that he spoke Welsh and he had lost his ability to speak English. One of the managers said a few words in Welsh and he started speaking straight away in fluent Welsh.

Today, there are more laws, policies and strategies than ever before which recognise the importance of providing services and care through the medium of Welsh. Welsh Government and NHS Wales should concentrate on putting the principles into action and ensuring that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

² Welsh Language Commissioner and Alzheimer's Society Cymru (2018): *Welsh Speakers' Dementia Care*

Palliative and End of Life Care

A 2015 Alzheimers Society and Marie Curie Report³ identified a growing number of deaths recorded with Alzheimer's, dementia and senility as the underlying cause. However, people with dementia are referred for expert end of life care in smaller numbers and at a later stage than people with a cancer diagnosis.⁴

Everyone who needs palliative care should have access to it, regardless of where they live, their age, medical condition or preference over place of death. Palliative and end of life care should be an integral part of care planning.

In no circumstances should a Do Not Attempt Resuscitation (DNAR)⁵,) order to be placed on a person's medical records without their knowledge or consultation, or that of an appropriate family member. If a DNAR is placed on a person's file, it should be regularly reviewed and removed if circumstances change. It is essential that staff receive training in how to communicate with the person and their family in a sensitive and professional manner during difficult circumstances.

Inappropriate transfers to hospital

Without external clinical support in care homes, a resident may end up being transferred to hospital to die. Although the latter may be appropriate in some situations, there continue to be inappropriate transfers to hospitals from care homes. The factors which can influence this process include a lack of forward planning, a lack of knowledge of the older person's preferences, poor links with GPs and a shortage of resources in the care home.

A National Audit Office report on end of life services⁶ showed that a significant proportion of people who die in hospital after being admitted from a care home could have died in the home with better support and advice for, and from, care home staff.

NHS Wales' Palliative and End of Life Care Delivery Plan⁷ envisages people being able to end their days in the location of their choice and to have access to high quality care wherever they live and die. It is unsustainable to continue to move patients reaching the end of their lives to hospital when they could be cared for outside.

³ Alzheimers Society and Marie Curie (2015): *Living and dying with dementia in Wales: Barriers to care*

⁴ Ibid.

⁵ Also known as Do Not Resuscitate (DNR) or Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

⁶ National Audit Office (2008): *End of Life Care*

⁷ NHS Wales (2017): *Palliative and End of Life Care Delivery Plan*