

## **Together for a Dementia Friendly Wales - 2017-22**

### **Consultation Response**

#### **Question 1**

The strategy follows the following themes:  Risk reduction and health promotion.  Recognition and identification.  Assessment and diagnosis.  Living as well as possible for as long as possible with dementia.  The need for increased support in the community.  More specialist care and support  Supporting the plan: - Education and training - Research.

Do you feel there should be any additional themes included?

Please tick the appropriate box below. Yes

Where you have ticked 'Yes' or 'Partly', please explain what the additional themes should be.

Whilst there is good coverage of living with dementia in hospitals and for specialist services, there is little mention about the large community of people with dementia in care homes and their quality of life

#### **Question 2**

Within each theme we have identified a number of proposed key actions. Do you feel these are the right ones? Please tick the appropriate box below.

Partly

Where you have ticked 'No' or 'Partly', please provide an explanation and any alternative suggested wording below. Please state which theme you are commenting on.

#### **Diagnosis of Dementia**

Coverage is needed about the assessment and diagnosis of dementia in Care Homes. There is anecdotal evidence that less than 20% of residents in care homes have a formal diagnosis of dementia with appropriate requirements for action in their care plans, whereas it is said that up to two-thirds of care home residents actually have some form of dementia. Bringing more residents into a formal assessment of their condition would have a number of benefits including an explicit accountability on the relevant Health Board for relevant care regimes and related resources to be enhanced in care homes. A key action on Health Boards would be to ensure comprehensive assessments for dementia of the existing care home cohort as well as those entering for the first time.

## **Quality of Life of People with Dementia**

In her report (November 2014) on the Quality of Life and Care in Care Homes in Wales, the Commissioner for Older People in Wales made a recommendation for a single outcomes framework of quality of life, and care, to be developed for use by all bodies involved in the provision, commissioning, regulation and inspection of care homes. It is recommended that the framework must include references to the following:

- 1) Independence
- 2) Control over daily life
- 3) Rights, relationships and positive interactions
- 4) Ambitions (to fulfil, maintain, learn and improve skills)
- 5) Health (to maintain and improve)
- 6) Safety and security (freedom from discrimination and harassment)
- 7) Dignity and respect
- 8) Protection from financial abuse
- 9) Receipt of high quality services

The need for a good quality of life should be regarded as a right for people with dementia in care homes – as far as is possible within their circumstances. The Dementia Strategy should reference the Commissioner's report and how the Welsh Government and others are responding to the recommendation.

One example of quality of life in care homes relate to the availability of arts and music experiences for dementia residents. There is ample research evidence about the therapeutic benefits of arts and music for residents in long term care, particularly those with dementia and that such activities help redefine staff attitudes towards residents and the caregiving role. The Social Care Institute for Excellence (2012) suggests that Arts approaches (such as dance, music and visual art) can improve wellbeing and quality of life of people with dementia in care homes. Other research contends that that engaging care home residents in meaningful activities can improve their physical and mental wellbeing and should be part of daily routine. There are award winning examples of how the arts and music benefit people with dementia in North Wales (Pendine Park Care Homes) but this is also prevalent in more enlightened care homes across Wales. The Strategy should encourage the development of this response in meeting the needs for a good quality of life in care homes whether you have dementia or not.

## **Care of People with Dementia**

Person Centred Care (PCC) has become a "flagship" concept in care over the last decade. The Strategy fails to mention the importance of Person Centred Care (PCC) for people with dementia except briefly in relation to Mental Health Units. This approach is supported by significant research evidence and whilst there are different approaches including the "Butterfly Model" it is becoming more common practice in good dementia care homes. It is also central to the "My Home Life" initiative for care homes funded by Welsh Government for a number of years. The prevalence of a "task based" approach to care in Nursing Homes as an economically efficient model of care in times of austerity, must be challenged by the principles of PCC and relational based care and its benefits to individuals. The Dementia Strategy could show leadership in this respect and encourage the further development and adoption of PCC.

## **Isolation and Loneliness**

Isolation and Loneliness is a particular risk for people with dementia living on their own or without regular contact. The Welsh Government is developing a Strategy for this problem and the National Assembly for Wales Health and Social Services Committee is undertaking an Inquiry into the matter. The Dementia Strategy should therefore acknowledge the on-going priority being given to isolation and loneliness and include a relevant key action to link up the policy thinking in these separate initiatives. Some practical approaches for public and voluntary sector bodies to adopt should be outlined.

### **Question 3**

The strategy describes what services should be available for people and their families and carers to live well in the community for as long as possible.

What do you think are the key features of this type of service?

The Strategy needs to be more explicit about the services that social services together with health boards should provide to meet the requirements of the Social Services and Well-being Act 2014 in respect of prevention and well-being services for people with dementia in the community. There is a general statement of intent but no specific requirements to develop a tailored action plan for those with dementia. Whilst it is possible to find reference in Council and LHB documents to particular support services planned or provided, this is not brought together in the Strategy to provide a coherent action plan to build on their population needs assessment.

### **Question 4**

Within the final Together for a Dementia Friendly Wales we would like to include examples of notable practice. If you have any which you would like to highlight, please do so here.

Please explain why you think it is an area of good practice e.g. an evidence base, an achieved accreditation award.

Whilst an English example, this is relevant because it highlights important general principles. A research project in York, England to determine how that City might become a more dementia-friendly describes dementia friendly communities as people with dementia being able find their way around and be safe; have access to the local facilities that they are used to and where they are known; and are able to maintain their social networks so they have a sense of continued belonging. The importance of green spaces, amenities, shops cafes, transport, housing, signage were all significant environmental and resource factors. Nevertheless, the most significant determinant of a dementia friendly community was how welcoming and understanding the people encountered in everyday life are. Peer group support and carer support were also seen as important. The conclusions of the project were to propose a model that covered the role and importance of people, places, networks and resources for analysing the suitability and helpfulness of existing arrangements

or features of a place or an organisation in order to realise a more dementia-friendly community. The limitations of this research were the difficulty in reaching people with dementia who had not yet been diagnosed, or those on the margins of society but the model produced provides a valuable contribution to the debate and in improving practice.

The Commissioner for Older People's Ageing Well initiative also has development of dementia friendly communities as one of its key aims and there are numerous examples from Wales that could be utilised.

### **Question 5**

Within the document we have highlighted the advantages of using telehealth, telecare and assistive technologies to help people live more independently and safely within their own home.

What do you think the challenges and barriers are in making this happen and how could you overcome these?

The Welsh Government has a long history of developing policy and providing significant grant funding for local authorities to develop telecare services. Much progress has been made in improving these services as reports from the Social Services Improvement Agency (2014) demonstrate. It should not be a case of just "exploring options to improve" as the Strategy suggests as a key action but a need to cross relate and build upon the work already done on telecare more generally to this Dementia Strategy and looking to develop it further and give it greater priority.

### **Question 6**

Do you think the key actions will provide a positive impact for people based on the following protected characteristics:-  Disability  Race  Gender and gender reassignment  Age  Religion and belief and non-belief  Sexual orientation  Human Rights  Children and young people

No

Where you have ticked 'No' or 'Partly', please explain why.

There is no Equality Impact Assessment in line with Welsh Government requirements to accompany the draft Strategy; one should be provided.

In relation to Human Rights of people with dementia the recent statement (December 2016) by the Commissioner for Older People in Wales about the need for Welsh Legislation on the human rights of older people is relevant. In that statement, it is said that the First Minister responded positively to this call for legislation and therefore this Strategy should acknowledge the debate about ensuring human rights of older people with dementia are protected in the delivery of services to them. At the very least mention should be made of the UN Principles for Older People that are enshrined already in Welsh Legislation – mention is made of the UN Children's

Rights Convention. Also, the Welsh Government's own Declaration of Rights of Older People should be mentioned in this context.

The Joseph Rowntree Foundation examined the social model of disability and its relevance to dementia. and suggest that "The impairments and impairment effects that are associated with dementia are viewed as foundations upon which social barriers are erected by the non-disabled – whether this is done purposively or entirely innocently and in good faith" The JRF findings describe the necessity of explaining the social barriers that the social model of disability highlights in the lives of people with dementia. *Since Welsh Government is already committed to the Social Model of Disability, then the Dementia Strategy should also include it as a key cornerstone.*

The World Health Organisation and Alzheimer's Disease International Report (2012). Dementia: A public health priority. (Retrieved from [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1) eport,) outlines a six stage process to achieve an "Acceptance of Dementia" model as the ultimate solution to the approaching dementia challenge is to create a society where dementia is normalized and accepted as a disability. This model should be adopted in Wales.

### **Question 7**

Do you think the key actions will provide a positive impact on the opportunities for use of the Welsh language?

Partly

Where you have ticked 'No' or 'Partly', please explain how you feel the opportunities for using Welsh could be strengthened to ensure it is treated no less favourably than English.

As people in later stages of dementia can revert to their first language, the specific references to the Welsh Language are welcomed but not cross referenced to the Welsh Language Standards that are published by the Welsh Language Commissioner

### **8. Additional Comments**

We have asked a number of specific questions. If you have any related issues which we have not addressed, please use the space below to comment.

The Commission on Dignity in Care for Older People in England (2013) undertook a comprehensive investigation into Dignity in Care Homes and produced 37 recommendations for action to secure improvements and achieve "a major cultural shift in the way the system thinks about dignity, to ensure that care is person-centred and not task-focused". The work completed on Dignity in Care for Welsh Government by Dr Win Tadd (Cardiff University) in 2012 as well as that report should therefore be utilised in the Dementia Strategy to set out how the concept of dignity should be interpreted and implemented in Wales. A position must be taken of accepting that older people with dementia in care homes want and must be treated

with dignity and that this is an important feature of the overall rights that residents can expect.

Caerphilly 50+ Forum

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