

DEM 06

Ymchwiliad i strategaeth genedlaethol ddrafft Llywodraeth Cymru ar ddementia

Inquiry into the Welsh Government's draft national dementia strategy

Gwybodaeth Ychwanegol gan: Cymdeithas Siartredig Ffisiotherapi, Coleg Brenhinol y

Therapyddion Lleferydd ac Iaith a Choleg y Therapyddion Galwedigaethol

Additional Information from: Chartered Society of Physiotherapy, Royal College of Speech and Language Therapists and College of Occupational Therapists

Dr Dai Lloyd AM

Chair, Health, Social Care and Sport Committee

National Assembly for Wales

Cardiff Bay

Cardiff,

CF99 1NA

13 March 2017

Dear Dr. Lloyd AM,

Re: Health, Social Care and Sport Committee Inquiry into Draft Dementia Strategy

The Royal College of Speech and Language Therapists (RCSLT), Chartered Society of Physiotherapy (CSP) and the College of Occupational Therapists (COT) welcome the Health, Social Care and Sport committee's decision to undertake a short inquiry into the draft Welsh Government dementia strategy. Allied Health professions (AHPs) have a key role to play in transforming dementia care and enabling people to live well with the condition. As organisations representing AHPs, we have a number of key concerns about the strategy in its current form and would be grateful if the committee could give consideration to the important issues which we raise.

COT, CSP and RCSLT welcome the Welsh Government's work to date on developing Wales' first Dementia Strategy. Our members want to ensure that the vision for dementia care for Wales is ambitious and delivers real change. We have listed below seven key improvements which we believe must be included if the strategy is to deliver on its commitment to create a dementia friendly nation.

We believe that the Dementia Strategy should:

1. **Include a separate theme on prevention and early intervention** with a focus on enabling people with dementia to maximise their own wellbeing and build resilience and skills to support them in later stages of the journey. This should include support to maintain relationships, roles, work and occupation. This would be consistent with the aims of both the Social Services and Wellbeing (Wales) Act 2014 and the Wellbeing of Future Generations (Wales) Act 2015, which are quoted within the document. Prevention also needs to be highlighted as a key theme in the section on living as well as possible with dementia.

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2. **Include separate themes for palliative care and end of life as key stages within the pathway.** There should be references within these themes to the proposed Welsh Government End of life Strategy but the prognosis for the disease necessitates a greater focus on this area within the strategy, with particular reference to legal issues such as power of attorney and overcoming barriers which may prevent people with dementia being able to die in their place of choice.
3. **Recognise the key role of AHPs in supporting people living with dementia** –AHPs have a unique spectrum of professional skills which are crucial in helping people with dementia to cope better and have an improved quality of life. We believe that the document, in its current form, misses a crucial opportunity to set out a new vision for how care could be delivered differently by enhancing a multi-disciplinary approach to care at home and in care homes, following diagnosis. In our view, dementia support post diagnosis should include access to multi-disciplinary support from a range of therapists to promote independence and support people to develop the skills they will require in the later stages of dementia. There is much we can learn from the Scottish approach where AHPs are regarded as a key pillar within the post diagnostic stage and are explicitly highlighted within the 2013 strategy and proposals for the 2017 strategy. For example, the proposals for Scotland's National Dementia Strategy has a key action of working collaboratively with the new Integrated Joint Boards to support locality planning and re-design of dementia services. This includes 'enhancing a multi-disciplinary approach to care at home, including the promotion of therapeutic and enabling role of AHPs for people with dementia'¹. A proposed key action added in **page 26** of the draft Welsh dementia strategy might be:

Health boards, local authorities, housing providers, primary care clusters and third sector providers should:
 - Support people who have been diagnosed with dementia and their families to access daily activities which are enjoyable, meaningful and support feelings of self-worth.
 - Teach people who have been diagnosed with dementia strategies and techniques to maintain their independence doing the daily activities that are important to them.
 - Ensure timely access to therapy services including occupational therapy, physiotherapy and speech and language therapy as routine.
4. **Recognise the importance of rehabilitation and reablement and enablement within the strategy document and include specific actions in this regard-** the document needs to highlight that enablement and reablement are important, not just for prevention and delay of onset but in the prevention and loss of skills and abilities. An enablement approach includes identifying the strengths and abilities of people with dementia. Dementia should not be used as a screening tool for excluding people from accessing the services they need.
5. **Recognise the importance of communication support and support for swallowing, eating and drinking difficulties within the strategy document** - We are very concerned about the scant references to communication within the document. Communication problems occur in all forms of dementia and in the later stages, these problems become increasingly challenging. Communication difficulty has been described as one of the most frequent and hardest to cope with experiences for family members² (Egan et al 2010) and can be exhausting for the person with dementia and affects their identity and relationships. We strongly

¹ Scottish Government (2016) *Proposal for Scotland's National Dementia Strategy*.
<http://www.gov.scot/Resource/0049/00497716.pdf>

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believe that the strategy should include greater detail on communication needs given its strong link with challenging behaviour, relationships, safeguarding issues and consent. Proposed actions should include access to communication support for people with dementia and their families. Speech and language therapists as experts in communication with the specialist knowledge and skills to directly assess and manage problems should be explicitly referenced within the document, as are other professions. In addition, it is concerning that no references to swallowing, eating and drinking difficulties and associated actions within the strategy. Dysphagia is a recognised challenge for people with dementia, particularly in the later stages of the disease. As a minimum, we would expect these needs to be highlighted within key sections of the document including – support to stay safe and secure in the home and community, safeguarding, addressing workforce training needs, care homes.

6. **Make changes to the safeguarding section of the document** to recognise the safeguarding issues for carers of people with dementia who may also be at risk.
7. **Reference the importance of AHPs with regard to 'silent harms'** – AHPs can ensure people with dementia remain active and are not prevented from activity by a risk averse approach.

We would be very happy to discuss these points with you further if it would be helpful to do so. We also include in **Annex A** a number of references to documents which may be of interest to the committee, including three joint documents produced by Alzheimer Scotland and the Scottish Government on the contribution of AHPs to dementia care.

Yours sincerely,

Ruth Crowder, Wales Policy Officer, College of Occupational Therapists

Philippa Ford MBE MCSP, Public Affairs and Policy Manager for Wales, Chartered Society of Physiotherapy

Dr. Caroline Walters, Wales Policy Officer, Royal College of Speech and Language Therapists



College of Occupational Therapists
Coleg Therapyddion Galwedigaethol



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Annex A – Links to documents of potential interest to the Health, Social Care and Sport committee

[Allied Health Professionals Dementia Champions - Agents of Change](#) features practice examples provided by some of the AHP Dementia Champions, illustrating how they are implementing new ideas and developing innovations in practice. It describes the impact that they are having as they work in partnership with healthcare support workers, paid carers in care homes, home care services, relatives, students, GPs and Alzheimer Scotland.

[Allied Health Professionals Delivering Post-Diagnostic Dementia Support](#) features the role AHPs can play, including best practice examples, in supporting people with dementia in the first year after diagnosis, based on Alzheimer Scotland's 5 Pillar model of Post-Diagnostic support and implemented by the Scottish Government through their Post-Diagnostic Support Guarantee. The work of AHPs, through early interventions and therapeutic approaches, can make a huge difference to how well someone can live with dementia.

[Allied Health Professionals Delivering Integrated Dementia Care](#) - AHPs have a vital role to play in the delivery of integrated care, support and treatment for people with dementia, and those who care for them, in Scotland's communities. In particular, AHPs have a unique spectrum of professional skills which are crucial in delivering a range of non-pharmacological therapeutic interventions which tackle the symptoms of dementia, help people cope better and improve their quality of life. This publication shows the work AHPs are already involved in at several test sites of Alzheimer Scotland's 8 Pillar Model of Community Support across Scotland. This is directly linked to Commitment 4 in [Scotland's current National Dementia Strategy](#).