**Consultation response form: *Together for a Dementia Friendly Wales* (2017-22)**

|  |  |
| --- | --- |
| **Overview** | **Proposed *Together for a Dementia Friendly Wales* (2017-22)** |
| **How to respond** | Responses should be submitted by 3 April 2017 to: [mentalhealthandvulnerablegroups@wales.gsi.gov.uk](mailto:mentalhealthandvulnerablegroups@wales.gsi.gov.uk)  Or post the completed form to:  Mental Health and Vulnerable Groups  Health and Social Services  4th Floor, North Core  Welsh Government  Cathays Park  Cardiff  CF10 3NQ |
| **Further information and related documents** | Large print, Braille and alternative language versions of this document are available on request. |
| **Contact details** | Queries on the consultation should be sent to:  [mentalhealthandvulnerablegroups@wales.gsi.gov.uk](mailto:mentalhealthandvulnerablegroups@wales.gsi.gov.uk) |
| **Data protection** | Responses will be seen in full by Welsh Government staff dealing with the issues included in this consultation. It may also be seen by other Welsh Government staff to help them plan future consultations.  The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tick the box further down this page.  Names or addresses we blank out might still get published later, though this does not happen often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone’s name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information. |

|  |  |
| --- | --- |
| Responses to consultations may be made public – on the internet or in a report. If you would prefer your response to be kept confidential, please tick here: |  |

1. **Contact Details**

|  |  |
| --- | --- |
| Your name: | **Dr Caroline Walters** |
| Organisation (if applicable): | **Royal College of Speech and Language Therapists** |
| Email address: | **Caroline.walters@rcslt.org** |
| Contact telephone number: | **029 2039 7729** |
| Your address: | **2nd Floor,**  **Transport House**  **1, Cathedral Road**  **Cardiff**  **CF11 9SD** |

1. **Are you responding as an individual or on behalf of an organisation?**

Please tick box.

|  |  |
| --- | --- |
| **Individual** | **On behalf of an organisation** (please tell us which organisation) |
|  | **Royal College of Speech and Language Therapists** |

**3. Structure of the document**

In the Welsh Government’s Programme for Government ‘Taking Wales Forward 2016-2021’ we confirmed we would take further action to make Wales a dementia friendly country through developing and implementing a national dementia plan. This commitment was also highlighted in the 2016-19 delivery plan supporting the Welsh Government’s 10 year ‘Together for Mental Health’ strategy aimed at improving mental health and well-being for the whole population.

This is the first dementia strategy for Wales but builds on previous work. Engagement with people with dementia, their families and carers has been central to drafting this strategy. Feedback from stakeholders has informed the layout of the strategy, including organising actions as part of a pathway and embedding a ‘rights based approach’ within the document.

**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: * Training * Research.   **Do you feel there should be any additional themes included? Please tick the appropriate box below.** | | |
| **Yes** | No | Partly |
| Where you have ticked ‘Yes’ or ‘Partly’, please explain what the additional themes should be. | | |
| The Royal College of Speech and Language Therapists (RCSLT) believes the strategy should include a more explicit section on prevention, 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 would be consistent with the aims of both the Social Services and Wellbeing Act and the Wellbeing of Future Generations Act, which are referenced within the document. Prevention also needs to be highlighted as a key theme in the section on living as well as possible with dementia.  We provide further detail on this theme in our response to question 2.  In addition, our members believe strongly that palliative and end of life care should be separate themes within the document, as key elements within the pathway given the numerous issues at play.  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, advanced care planning (eg around eating and drinking wishes), and overcoming barriers which may prevent people with dementia being able to die in their place of choice.  Our members also believe that there should be a greater focus on young onset dementia within the strategy given previous investment in services and the particular needs of this client group. For example, many of the language -based dementias tend to manifest at a younger age and therefore affect employment, family life (including young dependents) and financial circumstances. | | |

**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.** | | |
| Yes | **No** | 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. | | |
| As a general point, we are concerned that many of the actions within the plan are very broad and lack sufficient detail to enable the Older Persons’ Delivery Assurance Group to effectively measure progress. Actions focus on individual health boards rather than All Wales responses with good practice standards/minimum requirements which may increase inequity in services e.g. page 28 – ‘health board and local authorities to develop specific actions to increase action for individuals who have protected characteristics’.  We are very concerned at the scant references to changes to the communication abilities of people with dementia within key themes throughout the document. Changes to communication abilities occur in all forms of dementia and in the later stages, communication can become increasingly challenging. Difficulty communicating has been described as one of the most frequent and hardest to cope with experiences for family members (Egan et al 2010) and can be exhausting for the person with dementia and affects their identity and relationships. We strongly believe that the strategy should include greater detail on communication needs given its strong link with challenging behaviour, wellbeing, relationships, participation in activities, safeguarding issues, mental capacity and consent.  Proposed actions within the section ‘living well with dementia’ on page 31 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 develop management plans should be explicitly referenced, as are other professions.  We are pleased to see recognition of the ‘team around the family approach’ in the action points on page 33 but believe this needs to be expanded as a key driver for change in dementia services. In our view, the team around the family approach should include a multi-disciplinary approach to support. We discuss this in more detail in response to question 3.  We believe that communication should be explicitly mentioned within the safeguarding section on page 34. For example:  ‘Behaviour that challenges is often an attempt to make sense of the environment or communicate an unmet need. Through careful communication with the person, the caregiver can take steps to understand the hidden meaning concealed by the confusion and therefore take steps to reduce the incidence of behaviour that challenges.’ (RCSLT 2014).  We would also wish to see an action related to ‘ensuring access to communication support’ on page 36 to stress the point that all avenues with regard to understanding changes in behaviour have been explored before medication is prescribed.  We are disappointed to see 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. 68% of people in care homes with dementia have difficulties eating, drinking and swallowing (Steele et al, 1997). If dysphagia is untreated, the consequences are significant and can result in dehydration, malnutrition, and ultimately aspiration, choking, chronic chest infections and pneumonia. We believe the strategy should highlight these needs within key sections of the document including – good care in hospitals, care homes, prevention, end of life care and include relevant actions. Suggested wording might include;  ‘Staff should understand the communication difficulties experienced by people with dementia and identify the early signs of eating, drinking and swallowing difficulties to ensure people’s nutritional needs are met.’  In addition, specialist assessment and advice concerning swallowing and feeding in dementia should be available in keeping with NICE guidelines (2006).  There is a particular need to raise issues relating to eating, drinking and swallowing difficulties when considering the advanced stages of the dementia pathway when sensitive discussions about end of life decisions frequently involve these issues. Appropriate management of eating and swallowing is integral to a comprehensive end of life approach (Smith et al 2009) and the contribution of SLTs is vital to this process | | |

**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?** |
| On diagnosis, the strategy highlights the importance of access to a dementia supporter worker and evidence based pharmacological and psychosocial interventions. Allied Health Professionals (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, including speech and language therapists, to promote independence and support people to develop the skills they will require in the later stages of dementia.  In Scotland, AHPs are regarded as a key pillar within the post diagnostic approach and the dementia strategy 2013 includes several actions in relation to increasing the involvement of AHPs in dementia care. The evidence base is growing to support the AHP contribution to this area (Alzheimer Scotland/Scottish Government 2016)  Speech and language therapists have a key role to play within an integrated, multi-disciplinary service in solving issues at an early stage and supporting people to develop self-management strategies. Specialist advice and management for dysphagia increases independence, helps to maintain eating skills and can reduce the risks of undernutrition, dehydration, choking and aspiration. There is a growing body of evidence that SLT interventions with people who have dementia and their carers improves communication (Enderby et al, 2013) and supports ongoing interpersonal relationships between the person with dementia and their carers. Furthermore, it can increase participation in activities and enhance wellbeing.  In light of the important role of AHPs within dementia care discussed above ,we believe that a key proposed action on page 26 should include  Local 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. |
|  |

**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 notable practice e.g. an evidence base, an achieved accreditation award.** |
| We would like to highlight two particular examples of notable practice namely; the SLT role in Cardiff and Vale Memory Team, and an example from Scotland..  **The SLT role in Cardiff and Vale Memory Team**  There is currently 1 0.6 full time equivalent SLT role in the Cardiff and Vale Memory Team. The key aspects of this post are;   * assessment to support differential diagnosis * specialist assessment and advice on communication * specialist interventions to enhance communication, confidence and engagement * unpicking behaviour that may be challenging = a form of communication. * assessment and management of eating, drinking & swallowing difficulties * making communication accessible * education & training * working with 3rd sector organisations   Analysis of referrals in 2016 suggest 23% of referrals for diagnosis support, 23% feeding and swallowing and 54% communication support. The service is widely regarded as being a key element within the multi-disciplinary team. The two case studies attached at Annex A provide a snap shot of the impact the service is having on the lives of people living with dementia in Cardiff and the Vale.  **Example of taking dementia SLT expertise in the community from Royal Victoria Hospital, Dundee**  Please see page 20-21 from good practice document produced by Scottish Government/Alzheimer Scotland  [**Allied Health Professionals Dementia Champions - Agents of Change**](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4051528/AHP%20Dementia%20Champion.pdf) |

**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?** |
|  |

**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 | | |
| Yes | No | **Partly** |
| **Where you have ticked ‘No’ or ‘Partly’, please explain why.** | | |
| We have particular concerns as to whether the actions will provide a positive impact for people with disabilities and particularly those with speech, language and communication needs. Within the population with dementia, there is a group of people with specific communication difficulties (where changes to the language system is the dominant feature). In addition, the incidence of dementia in older adults with learning difficulties is significantly higher than in the general population and people with down’s syndrome have an increased risk of Alzheimer’s disease.  Communication difficulties can lead to barriers accessing and communicating with other professionals, social exclusion, increased level of dependence at an earlier stage and people being excluded from decision making and service planning.  We believe the strategy document should include specific actions around supporting communication. RCSLT believes that any person with a communication disorder or dysphagia has a right to access a professional with specialist expertise in these areas. | | |

**Question 7**

|  |  |  |
| --- | --- | --- |
| **Do you think the key actions will provide a positive impact on the opportunities for use of the Welsh language?** | | |
| Yes | No | **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. | | |
| We would also wish to highlight that language system/s are complex and dementia can result in changes to language systems differently in people who are multilingual; individuals with dementia may develop a preference for using a language that they developed during childhood, and this may be less impaired than their preferred language as an older adult (eg Welsh becoming the preferred/less impaired language over English). The specialist expertise of a Speech and Language Therapist may form an essential part of identifying preferred communication method. | | |

**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.

|  |
| --- |
| RCSLT raise below a number of other key issues which we believe the strategy should consider to achieve its ambition of delivering real change for people with dementia.   1. **Recognise the importance of 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 to maximise a person’s inclusion and support wellbeing. Dementia should not be used as a screening tool for excluding people from accessing the services they need. 2. **Make changes to the safeguarding section of the document** to recognise the safeguarding issues for care partners who may also be at risk. 3. **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. 4. **Greater focus on the needs of people with dementia who are admitted to general wards** – currently members have concerns that many hospital wards are inadequate to meet the needs of people living with dementia i.e. inappropriate environments, mixed gender wards, lack of interaction/day rooms/dining rooms/activities, staff with less specific dementia skills and that this these factors have an impact on length of stay, reablement, enablement, and service user experience. We would welcome detail on how this may be approached. |

**9. Sources of information**

The final document will include a list of useful sources of information. If there is anything you feel should be included, please state in the space below:

|  |
| --- |
| Royal College of Speech and Language Therapists (2014). *Speech and Language Therapy Provision for People with Dementia – RCSLT Position Paper*. RCSLT:London  The Alzheimer Scotland/Scottish Governent document - [**Allied Health Professionals Dementia Champions - Agents of Change**](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4051528/AHP%20Dementia%20Champion.pdf)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.  The Alzheimer Scotland/Scottish Government document - [**Allied Health Professionals Delivering Post-Diagnostic Dementia Support**](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4052050/02295%20AHP%20report%20on%20post-diagnostic%20support.pdf)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**](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/4056217/Integrated%20dementia%20care%20living%20well%20with%20community%20support.pdf) - 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](http://www.scotland.gov.uk/Resource/0042/00423472.pdf). |