

Response ID ANON-TTKE-XYMA-Q

Submitted to A national conversation to inform a new Dementia Strategy
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Questions

1 What does dementia mean to you and those around you?

Please use this text box to respond.:

As a membership organisation and the representative body for independent social care service providers across care homes, homecare, housing support and day services, the support of people living with dementia is a crucial part of shaping everyday care practice, considering the impact of policy, shaping workforce development, upholding social care values and directing the future design and resourcing of supports. This applies to Scottish Care, our members and their workforce. In Scotland, the independent social care sector across day care, care home, care at home and housing support services for adults contributes to:

- The employment of 100,590 people, which is over 48% of the total social services workforce, including over 4,000 nurses
- The provision of 90% of care home places for older people
- The delivery of over 55% of all home care support hours provided to adults.

In care homes across Scotland, the latest figures show that 64% of residents over the age of 65 and nearly 4,000 people supported in their own homes are living with dementia. It is also likely that these figures are even higher in reality.

In Scottish Care's regular engagement opportunities and research projects with our members, a consistent message is the increased number of people being supported with dementia, across a broad age range, and the higher complexity of care and support being delivered as people are supported at different stages of life and at various stages of progression right up to and including end of life care.

2 What supports work well for you?

Please use this text box to respond:

Throughout Scotland, there are innumerable examples of excellent care and support being provided on a daily basis with and for people living with dementia. We are also very encouraged and supportive of work being undertaken in the broader cultural space to support the wellbeing of people with dementia, to ensure communities and groups are inclusive and to enable choices to be available. We would particularly commend the work of Luminate, Scotland's creative ageing organisation, in supporting older people to access a range of creative opportunities including for instance the establishment of a Dementia Inclusive Singing Network.

Additionally, it has been positive to see the slow but growing recognition of some of the intersectional challenges facing many people living with dementia. There is still a long way to go in addressing these as they relate to gender, sexuality, poverty, race and many other factors. However Scottish Care is pleased to have been involved, with LGBT Health and Wellbeing, care providers, Alzheimer Scotland and the Care Inspectorate, in the development of a toolkit – Proud to Care – for health and social care staff to reflect on and develop their practice in working with lesbian, gay, bisexual and transgender (LGBT) people with dementia.

However, in the social care context, the challenges that exist in ensuring high quality care and support is sustainable undoubtedly threaten all forms of provision. As we begin to plan for the future of care and support in Scotland, it is therefore more important than ever that we recognise, value and invest in the distinctive contribution of social care in supporting wellbeing and enabling people to live a full and fulfilling life. If we lose this focus and prioritisation, undoubtedly the outcomes for people living with dementia will be substantially and harmfully impacted.

3 What challenges need to be addressed?

Please use this text box to respond.:

There are a significant number of challenges that need to be addressed, all of which relate predominantly to a considerable implementation gap as is common in many areas of policy relating to social care and older people in particular. Whilst many of the challenges have been recognised and potential solutions outlined through previous strategies and in other fora, the reality for those most impacted often remains steeped in difficulties and progress limited by systemic and practice barriers. Most of these have been further detrimentally affected by the experience of the pandemic and current pressures, not least economic and financial ones.

A core part of any new Strategy has to consistently recognise that equipping and skilling up the workforce is essential for the delivery of effective dementia support and care. Within social care, there is a distinct inadequacy of resource being allocated to the workforce – numbering over 130,000 across care homes, homecare and day care employers - which delivers the vast majority of support to people living with dementia in Scotland. Whilst many positive components of achieving this exist, including commendable learning programmes, the most significant challenge is the capacity of organisations to free up their staff to do the training and develop their practice. In particular care at home organisations are struggling in the face of rising costs and reductions in fees to equip their staff to achieve dementia excellence, because the very existence of these organisations is under such threat. We can never achieve a skilled dementia-confident workforce in social care unless we resource and support it properly.

Most palliative care and end of life support is delivered by social care staff. By 2040, depending on the method used, projections estimate that between 74% and 95% of people will die from a condition associated with palliative care needs. If current trends continue, deaths where dementia is the underlying or main cause will increase by 185%, and dementia will account for nearly 20,000 of all deaths by 2040. This has considerable implications for

the future of dementia support and social care support in Scotland and is one of many reasons why it is so important to be shaping the next iteration of a Dementia Strategy for Scotland with social care providers, their workforce and the people they support.

There also needs to be additional investment in more progressive models for care and support based in individuals' homes, in care homes, and in other community-based supports such as day opportunities. The existence of electronic call monitoring as a means of effectively tagging homecare workers and the reality of task-focused, time-limited visits, including of 15 minutes, do not represent treating people with dementia and those who support them with dignity and respect.

As outlined previously, nearly two thirds of older care home residents are living with dementia but that figure may be even higher. What we consistently hear is the continuing issue of an inequity of access to wider supports for care home residents, including post-diagnostic support commitments, and this requires renewed focus. Wider issues such as the inability of care home residents to access all Self-directed Support options in directing their care and support must also be borne in mind when considering how to meaningfully progress the rights of access and opportunity for people living with dementia in any new Strategy.

The steady erosion and even more dramatic loss since the pandemic of local day services and other community support opportunities to offer respite and rest to individuals, carers and loved ones has undoubtedly done untold harm. The results of a 2022 audit of adult day and respite services highlighted that only 48.7% of day services commissioned or run by health and social care partnerships or local authorities were fully open, with 38.4% operating at reduced capacity. 11.8% of day services and 14.1% of respite services remained closed. These services, mostly impacted by workforce shortages and pandemic restrictions, are vital to supporting wellbeing, maintaining community connection and in achieving a preventative and proactive approach to support.

In the context of technology and data, it is important that developments advance choice, enable greater control and promote independence for people living with dementia and their families. As progress in this area continues at pace, including for example in relation to citizen held data and Artificial Intelligence, it is crucial that approaches and initiatives that are developed with people and consider all aspects of choice, inclusivity and access are prioritised. This must also include how to equip, train and support for instance the social care workforce to utilise technologies tailored to individuals' needs, choices and preferences. What's more, at a time of severe financial, workforce and wider resource constraints, it will be more important than ever to ensure that technology is adopted as an enhancement, never as a replacement for human support. Scottish Care has developed a number of resources to support ethical decision making and human-rights based approaches to technology and data, which we recommend are built into future policies and strategies in this space.

Finally, it must be recognised that the reality of dementia support in Scotland is one of financial and resource discrimination, and is ultimately an issue of human rights. The treatment of a group of people within a population who have urgent health needs in a manner which is systemically and consistently less equal to others represents a breach of legislative frameworks and of the values which sit at the heart of so much of Scotland's health and social care policy. It is necessary to acknowledge that someone in advanced neurological decline has primarily health needs, even if these sit alongside social care requirements, and the disparity of treatment access and resource allocation related to current practice must be addressed with urgency in a time of wider debate and reform about shaping Scotland's support landscape to be fit for the future for all its citizens.

4 How would addressing these challenges change lives?

Please use this text box to respond.:

Care home, care at home and housing support providers remain committed to ensuring that Scotland is not only dementia friendly but dementia confident, delivering supports and services which enable people who live with dementia to achieve the fullest possible life to the very end. At present, that confidence is more shaken than ever by a perceived lack of value, inadequacy of resource and gap in sustainable, human rights based and innovative solutions to current challenges. By addressing the areas outlined above, this uncertainty and anxiety can be transformed into a positive and codesigned future for people living with dementia and those that support them in all capacities.

It is time to make Scotland a human rights society, and to give new life to dementia strategies that don't just pay lip service to human rights but embed, enact and let our rights flourish. We need to act to make human rights real for dementia. The treatment of people living with dementia is an issue of age discrimination and the time for action in removing discriminatory practice is now.

5 What do we need to build on/learn from what has been done before?

Please use this text box to respond.:

It will be important to build on solid progress made in the learning and development space, not least the Promoting Excellence framework. However, the very real issues of workforce capacity and resource require to be recognised and addressed in developing plans for building on dementia learning and development. Educational and experiential opportunities to develop skills and practice around dementia support must therefore reflect and be sensitive to the context of social care delivery, whilst also driving improvement and supporting career consolidation and progression.

Undoubtedly, the experience of the pandemic must also inform future plans for dementia support including how human rights, dignity, choice and access to essential health, care and wellbeing supports will be prioritised for older people and those living with dementia in all settings and circumstances.

6 What else would you like to tell us?

Please use this text box to respond.:

About you

What is your name?

Name:

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What is your email address?

Email:

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Care

Why are you interested in a new Dementia Strategy?

Please respond to this question in the text box below:

As outlined in our response, Scottish Care is a membership body and the representative organisation for independent sector social care providers who support a significant proportion of individuals in Scotland living with dementia. Scottish Care is committed to a high quality, sustainable and rights-based social care sector, which is also vital for the wellbeing and positive outcomes of people living with dementia and their loved ones.

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Please enter comments here.: