



Simon Thomas AM,
Finance Committee,
National Assembly for Wales,
Cardiff,
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30th January 2018

Dear Simon,

**Re: Finance Committee inquiry into the Cost of Caring for an Ageing Population:
Alzheimer's Society Cymru response**

- 1.1 I am pleased to respond on behalf of Alzheimer's Society Cymru to the [Finance Committee's consultation on the cost of caring for an ageing population](#).
- 1.2 Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.
- 1.3 Alzheimer's Society Cymru welcomes the Committee's interest in the financial impact of the cost of caring for an ageing population.

Overview

- There are 45,000 people with dementia in Wales, and this is forecast to rise to over 100,000. Around 60% of people in receipt of homecare have dementia, rising to 70% of people living in care homes. The social care crisis is a dementia crisis.
- People with dementia usually have to use costly means-tested social services, instead of free health care services because of the lack of a cure for dementia. They must pay more for support because of their condition. This is the dementia tax.
- Dementia costs Welsh society £1.4 billion every year, the majority (£622 million) is shouldered by unpaid carers. Dementia also has a huge social cost, with 61% of carers saying caring has had a negative impact on their own health.
- Dementia care can cost £100,000+ per person – it could take 125 years to save this.
- We welcome increased funding for social services, but are concerned that this funding will not keep pace with increasing demand in the future.
- We believe there should be a lifetime cap on care costs to protect vulnerable people.
- We are concerned that eligibility criteria for carer support are too high, and are driving people into needing expensive crisis care.
- We would like to work with Welsh Government to better understand their proposals for a social care levy, but any proposals need to be based on principles designed to deliver high quality social care.
- We believe that any reforms to social care finances need to share risk across society, to remove the burden of catastrophic costs on individuals and families.
- Over the long term, we believe the social care sector needs new funding sources or insurance based models of support.
- We welcome the Parliamentary Review's findings, provided there is sufficient funding and support for reform from people who are affected by dementia.

Alzheimer's Society Cymru and social care policy

- 2.1 Wales is at a crossroads on dementia policy. We have an older population than any of the other UK nations, and the lowest rates of dementia diagnosis; we have very few support workers to help people living with dementia, and there are challenges in ensuring access to diagnosis and services in rural areas.
- 2.2 Yet in the coming years, we can turn things around. The Welsh Government is developing Wales' first ever dementia action plan. We are already becoming a more dementia-friendly nation. And all the time, research is going on to find breakthroughs which can transform how we perceive and deal with dementia. Now, we believe that we have a historic opportunity to address catastrophic costs for social care that can impact on people affected by dementia.
- 2.3 Dementia devastates lives. There are currently 45,000 people living with dementia, yet half have not received a formal diagnosis. It is estimated that by 2055 there will be over 100,000 people living with dementia in Wales. Across the UK, we estimate that there will be two million people living with dementia by 2051.
- 2.4 Alzheimer's Society funds research into the cause, care, cure and prevention of all types of dementia and has committed to spend at least £150 million on research over the next decade. This includes investing in the UK's first dedicated Dementia Research Institute, including £13 million to establish a new dementia research centre at Cardiff University.¹ Until the day we find a cure, Alzheimer's Society will be here for anyone affected by dementia - wherever they are, whatever they're going through. Everything we do is informed and inspired by them.
- 2.5 The Welsh Government is in the process of developing their first ever dementia action plan. The strategy is likely to have a broad impact on the social care sector which we believe the committee should be aware of when inquiring into the area of funding. The proposals in the consultation on the strategy² include proposals that:
- Every newly-diagnosed person with dementia should be offered access to a Dementia Support Worker.
 - Introduce a joint health service/local authority "team around the family".
 - 75% of health care staff should be trained in "Good Work: Dementia Learning and Development Framework".
 - Population assessments should include care and support needs of older people with complex needs (dementia).
 - Monitoring carers being offered assessments and support plans.
 - Local Health Boards and Councils to facilitate access to carer education.
 - Ensure social care has pathways in place so that community assessment and ongoing management services are responsive.
 - Develop training and learning resources for the social care workforce based on the principles of the 'Good Work' framework.
 - All relevant health and social care professionals, including care home workers, should be trained and supported to help people and their family/carer think about end of life care and develop care plans.
 - Increasing numbers of Dementia Friends and Dementia Friendly Communities.

¹ Cardiff University (2017) [£13m dementia research centre](#), date accessed 26/01/2018.

² Welsh Government (2017) [Together for a Dementia Friendly Wales 2017-22: consultation document](#), Cardiff: Welsh Government.

- 2.6 There is a great deal in the draft strategy which we strongly welcome, and it is heartening to see dementia being recognised as “*one of the most significant health and social care issues we face*”³, costing Wales in the region of £1.4bn per year⁴. We also welcome the Committee’s inquiry into the issue of social care funding as one of the utmost importance for members of the “aging society” who are affected by dementia. However, as part of this inquiry we would urge the Finance Committee to recognise that we should welcome that people are living longer and recognise the contribution of older people and people with dementia to Welsh society. Older people bring value to Wales, enriching our worth as a nation. Negative stereotypes of older people and people with dementia demean and stigmatise people. Older people make important financial contributions to Welsh society - in 2010, over-65s made a net contribution of over £1 billion to the Welsh economy, equating to nearly £3 million every day⁵. This should not be forgotten as part of this inquiry and we concur with the Older People’s Commissioner on Wales’ comments on this issue.⁶
- 2.7 We have also supported people affected by dementia to share their stories with the National Assembly for Wales’ Health, Social Care and Sport Committee during their inquiry into the draft dementia strategy and during two meetings of the Senedd’s Cross-Party Group on Dementia, to inform responses to this consultation. Through this, a range of people affected by dementia from across Wales had an opportunity to contribute their views on the proposals and we hope both of these groups will have benefited from hearing first-hand the experiences of people affected by dementia, and will use this to inform their scrutiny of the dementia strategy. We would be happy to support Finance Committee on a similar evidence gathering exercise to hear from people affected by dementia what they would want to see in terms of social care funding reform.

³ Welsh Government (2017) [Together for a Dementia Friendly Wales 2017-22: consultation document](#), Cardiff: Welsh Government.

⁴ Alzheimer’s Society (2015) [The Hidden Cost of Dementia in Wales](#), Cardiff: Alzheimer’s Society.

⁵ WRVS (2011) [Gold Age Pensioners: valuing the socio-economic contribution of older people in the UK](#) (Welsh summary document), Cardiff: WRVS.

⁶ Older People’s Commissioner Wales (2017) [Commissioner: Disappointing that Committee Inquiry could reinforce ageist attitudes](#), date accessed 25/01/2018.

The current landscape of dementia and social care funding

- 3.1 There is an enormous injustice in the care system for people with dementia – the Dementia Tax. Dementia is currently a condition with no cure and people who develop it receive most of their support from the government from the social care system, not health care.
- 3.2 Dementia is a complex condition and the impact of symptoms can make it increasingly difficult to carry out the everyday tasks most of us take for granted, like washing, eating or using the toilet. Someone with dementia may require one to one support with nearly every aspect of life, either at home with a homecare worker or in a care home. This is classed as social care, rather than care provided free on the NHS. Social care is means-tested and therefore costly.
- 3.3 For many other long-term health conditions, such as cancer and heart disease, medical treatments are available for free on the NHS. However, these treatments don't yet exist for dementia, meaning that it is costly social care, as opposed to free treatments, that people with dementia are forced to pay for. It should not be the case that because you develop one condition over another, you can be left bankrupted by care costs. This is not a fair system and Alzheimer's Society has been calling for an end to this 'dementia tax' for the last ten years.⁷
- 3.4 Being diagnosed with any condition can be challenging and stressful, but in the current system people with dementia are facing the added worry of financing their care, which could cost thousands of pounds. We believe this system is unequal and needs overhaul. Regardless of the condition you have, you should have the same access to high quality and affordable care, including for people with dementia. People with dementia should not bear the sole responsibility for saving and paying for their care.
- 3.5 We believe that dementia can be the channel through which to achieve social care reform. We know that around two thirds of recipients of homecare or care home residents have dementia.⁸ This means social care crisis is therefore a dementia crisis. When the social care system is restricted or provides poor quality care, it can have a devastating impact on people and on the wider health system. We believe that building a social care system that is better for people with dementia will improve the system for everyone.

⁷ Alzheimer's Society (2017), [Dementia Tax](#), date accessed 20/01/2018.

⁸ Alzheimer's Society (2007), [Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes](#), London: Alzheimer's Society.

Patterns in demand for social care services for those of pension age, and the related costs of delivery of residential and non-residential care.

- 4.1 The social care crisis is a dementia crisis. Prevalence and diagnosis rates for dementia are increasing and with it, demand for social care services to support those people affected by dementia. The costs for people affected can be catastrophic, and informal carers are often relied upon to provide unpaid services. People with dementia depend on the costly social care system for essential support
- 4.2 We know that there is increasing demand for social care, in particular services for people with dementia. There are currently around 45,000 people living with dementia in Wales; this is estimated to increase to over 100,000 people by 2055.⁹
- 4.3 More and more people are developing dementia as Wales' population ages – age being a key, but not the only, risk factor for dementia. It is anticipated that by 2022-23, people aged 65 and over will account for over 22% of Wales' population - up from around 18% in 2009-10.¹⁰ Over the next 20 years, the percentage of people aged over 65 in Wales is set to increase to around 25% of the entire population. The population aged over 75 in Wales is also projected to increase from 9% of the population in 2014 to around 13% in 2030.¹¹ There is a projected increase in the number of people aged over 65 in Wales by almost 37% by 2041, while there is a projected increase in the number of people aged over 85 of 119% by 2035.¹² Wales has a higher proportion of people aged over 85 than the other UK nation.¹³
- 4.4 At present, the diagnosis rate for dementia in Wales is around 51% – the lowest of any UK nation – but the Welsh Government's Dementia Action Plan sets out an ambition to increase the rate by at least 3% annually, reaching 66% by 2021. With both prevalence and diagnosis increasing, it is clear that people affected by dementia will form an even larger proportion of people using social care services in the future.
- 4.5 Supporting people with dementia is further complicated by comorbidities - secondary or other conditions which people have at the same time as dementia. Some common comorbidities are depression, diabetes, hypertension, falls, fractured hips or hip replacements, urinary or chest infections, chronic obstructive pulmonary disorder, musculoskeletal disorders and chronic cardiac failure. People living with dementia who are over 65 have on average four comorbidities, while people without dementia have two on average.¹⁴ Research has shown that untreated comorbidities of people living with dementia cost UK health care at least £993m annually, covering three main comorbidities of £377m due to diabetes, £115.7m due to urinary infections and £501.7m due to depression.¹⁵ These co-morbidities mean even higher pressures on the health and social care system as “people with dementia and comorbidities are more likely to be hospitalised, have longer admissions, and incur higher expenditures for their comorbidities than people without dementia” because people with dementia are often “subject to an increased risk of serious delays in the recognition of new or

⁹ Alzheimer's Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer's Society.

¹⁰ Wales Public Services 2025 (2017) [The future funding of health and older adult social care in Wales](#), date accessed 25/01/2018.

¹¹ Wales Government Future trend report (May 2017) cited in Welsh Government (2017) [Consultation document: Mandatory Concessionary Fares Scheme in Wales](#), Cardiff: Welsh Government.

¹² Welsh Government, [National population projections](#), date accessed 26/01/2018.

¹³ Social Care Wales (2017) [Care and support in Wales: national population assessment report](#), Cardiff: SCW.

¹⁴ Poblador-Plou B et al (2014) “Comorbidity of dementia: a cross-sectional study of primary care older patients”, *BMC Psychiatry*, cited by [Dementia Statistics](#), date accessed 24/01/2018.

¹⁵ Scrutton, J and Brancati, CU (2016); *Dementia and comorbidities; Ensuring parity of care*, The International Longevity Centre supported by Pfizer, cited by [Dementia Statistics](#), date accessed 24/01/2018.

exacerbating symptoms.”¹⁶ This may be down to atypical symptoms, communication issues for the person with dementia, or a lack of adequate training for professionals.

- 4.6 These factors are likely to drive an increase in demand for social care services by people affected by dementia. Today, at least 60% of recipients of homecare have dementia¹⁷ and two-thirds of people living in care homes¹⁸ with some estimates as high as 80%.¹⁹ The number of people aged 65 and over receiving residential care services is projected to increase by 82% between 2015 and 2035, and the numbers receiving community based services to increase by 67% when 2015 population prevalence is uprated for forecast population growth in older people.²⁰
- 4.7 The costs of this social care provision can be enormous for people with dementia. We know dementia costs Wales £1.4billion per year. This represents an average cost of £31,300 per person per year. £622 million is contributed by the work of unpaid carers of people with dementia; social care costs alone amount to £535 million, whilst £196 million is spent on healthcare costs (of which around £4.6 million is spent on diagnoses).²¹ Assuming the breakdown of publicly and privately funded social care costs is the same in Wales as in the whole of the UK, of the £535 million spent on social care for people with dementia in Wales, £212 million is met through public expenditure, £298 million is borne by the individuals directly affected by dementia, and the remaining £24 million is the cost attributed to assessment and care management. £6 million is spent on other costs, including police costs of missing person enquiries, advocacy services and research.
- 4.8 We are also concerned that the impact on social care is being exacerbated by a shift of responsibility from health care services to social care. While people with dementia and carers will need far more social care services than people with many other conditions, people with dementia and their carers will also need access to healthcare services – yet we hear anecdotally all too often that health care services push responsibility for support away from health and towards social care services. This means that many people cannot access the support they need and instead are forced into more expensive social care, exacerbating the dementia tax and leading to worse health outcomes. This drives further costs for health, as individuals who do not receive appropriate health care services when they need them may then need to re-enter the health system to receive support such as expensive crisis care, and can lead to delayed transfers of care (DTOCs) which increase costs to health services.
- 4.9 It is not only a financial cost that is borne by unpaid carers of people with dementia. The human cost can be substantial as well – caring responsibilities can be difficult, physically and emotionally, and have a substantial effect on a carer’s health and well-being. Our *Turning Up the Volume*²² report found that:
- Around three in five carers (61%) say their health has been negatively affected by caring for someone with dementia
 - 27% of carers for people with dementia feel ‘cut-off from society

¹⁶ Fox, C et al (2014) “[The importance of detecting and managing comorbidities in people with dementia?](#)”, *Age and Ageing*, Volume 43, Issue 6, pp.741-743.

¹⁷ Alzheimer’s Society (2016) *Fix Dementia Care: Homecare*, London: Alzheimer’s Society, p.8.

¹⁸ Alzheimer’s Society (2007) *Home from home: A report highlighting opportunities for improving standards of dementia care in care homes*, London: Alzheimer’s Society, p.iv.

¹⁹ Alzheimer’s Society (2013). *Low Expectations: Attitudes on choice, care and community for people with dementia in care homes*, London: Alzheimer’s Society, p.9.

²⁰ Data sourced from the [Daffodil care data archive](#), cited in Ogle, J and Trickey, M (2017) *Can Wales fill the social care funding gap?*, IWA website, date accessed 18/01/2018.

²¹ Alzheimer’s Society (2015) *The Hidden Cost of Dementia in Wales*, Cardiff: Alzheimer’s Society.

²² Alzheimer’s Society (2017) *Turning up the Volume: unheard voices of people with dementia*, London: Alzheimer’s Society.

- 37% of people caring for someone with dementia that we spoke to report that doing so has affected their personal relationships and social life for the worse.
 - Just 17% agree with the statement ‘there is enough support available for those who care for people with dementia’. However almost two-thirds (65%) disagree, with 31% saying they strongly disagree.
- 4.10 The costs for an individual can be enormous and we know they worry people affected by dementia. People are largely unprepared for the challenges of meeting the hidden costs of care. Our research *Turning up the Volume*²³ found the following:
- We estimate typical dementia costs to be around £100,000 for a person throughout their journey, although can be as much as £500,000.
 - It would take someone around 125 years to save for their dementia care costs, if they saved at the same rate as their pension.²⁴
 - Nearly half (47%) of the UK adults aged between 16-75 years old questioned have not started saving for the care and support they might need in the future.
 - A third (37%) of the public agree that before being asked, they had not considered the cost of dementia care and support.
- 4.11 *Our online dementia tax survey, which was launched on the 6th June 2017 and sent to our supporters on social (which has 2,216 respondents to date), found:*
- 65% of respondents are worried about having to sell their or their family’s home to pay for dementia care.
 - 55% of respondents believe we should create a fair and balanced system between what the state and the individual pay towards their care, which takes into account their financial situation.
 - 79% believe you could face spending everything you have on dementia care.
- 4.12 Alzheimer’s Society undertook polling of the general public in June 2017 following the General Election and in October 2017. This showed overwhelming public support for reform:
- 75% of respondents support the need for an upper limit on care costs to ensure people no longer face catastrophic costs.
 - 68% of respondents agree that the government should pay for their care if they develop dementia, which increased 10% since the polling in June post-election (the percentage of people agreeing rose from 58% in the last round).
 - When asked about the possibility of losing their home to pay for social care if they developed dementia, 72% felt worried, angry or frightened – representing a rise of 9% since the June polling post-election.
 - When asked how they would feel if the Government does not address the issue of social care, 81% said they felt angry, worried or frightened.
 - 63% agreed they worry any savings they have could be spent on future care costs and they would have nothing to pass on to their children or loved ones.

²³ Alzheimer’s Society (2017) [Turning up the Volume: unheard voices of people with dementia](#), London: Alzheimer’s Society.

²⁴ This statistic has specifically been developed for England, but is likely to be similar for Wales, information available at Alzheimer’s Society (2017) [Impossible cost; dementia care bill would take 125 years to save for](#), date accessed 25/01/2018.

- 4.13 We know from IPPR/PwC research²⁵ that public awareness of social care provision is low. Their research highlights key areas of misunderstanding, such as:
- Funding: only 46% of people involved knew that social care is means-tested.
 - Lack of preparation and planning for care needs: only 22% are planning for their care needs.
 - Reluctance towards greater family responsibility: 52% believe they should not be compelled to pay for their family's care.
 - Support for a more collective, universal system: only 18% are in favour of the current means-testing system.
 - A strong will for more debate on the future of the care system: 69% do not feel informed enough about the care system.

4.14 Overall, the picture painted by our research is of a condition that is exacting a substantial human and economic cost in Wales. It is clear that between the £622 million contributed by unpaid carers and the £298 million borne by individuals directly affected by dementia, and the associated negative effect on wellbeing, the impact on an individual with dementia and their loved ones can be enormous. Unpaid care accounts for 74.8% of the total cost of people with dementia living in the community, and 45.7% of the total cost of the overall population of people with dementia in Wales. Our research found that people with dementia, carers and their families currently shoulder around two-thirds of the costs of dementia themselves. It is hoped these findings will concentrate the minds of all those who have responsibility for improving the lives of people with dementia, and that this focus will help to move Wales closer to the goal of becoming a truly dementia-friendly nation.

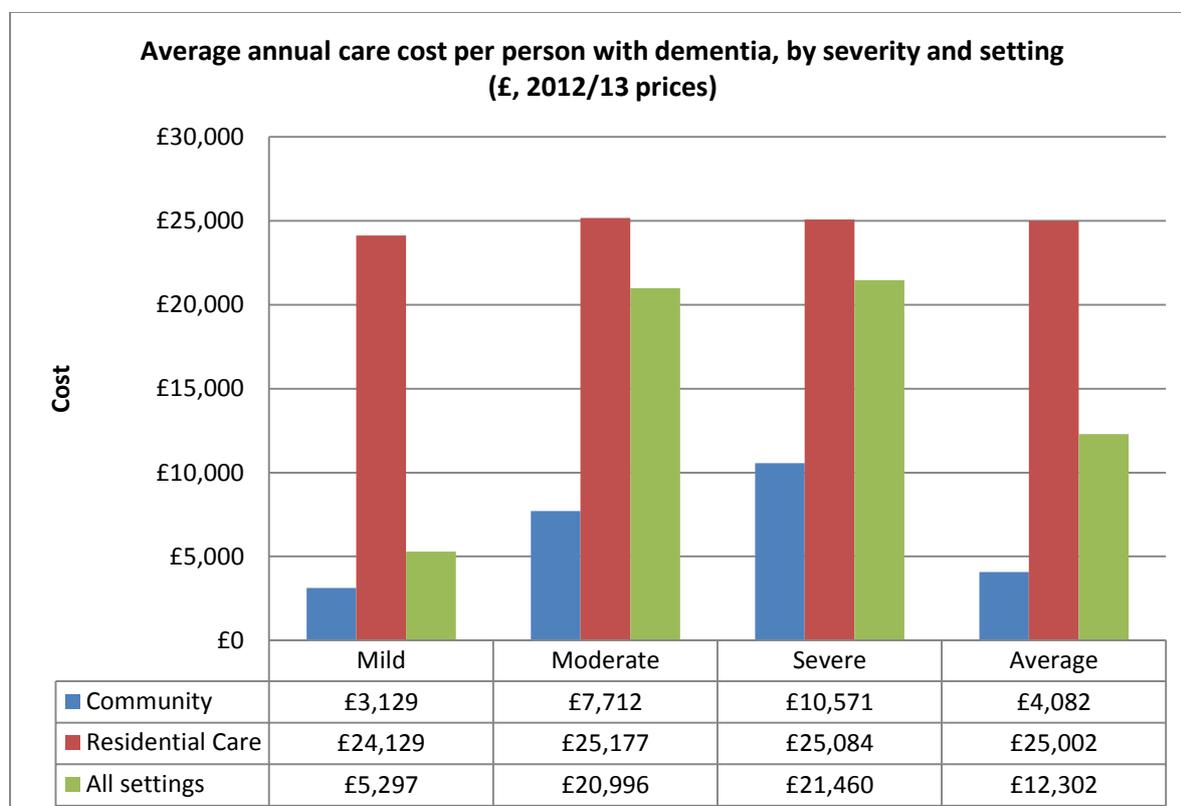


Figure 1 - Source: Alzheimer's Society (2015) [The Hidden Cost of Dementia in Wales](#), Cardiff: Alzheimer's Society.

²⁵ IPPR (2009) [Expectations & Aspirations: Public attitudes towards social care](#), London: IPPR.

Financial Pressures on the social care system

- 5.1 According to Social Care Wales, while 14,000 social care workers were recruited by care providers commissioned by Welsh local authorities in 2016, 11,000 staff also left commissioned care providers. This churn in the sector can result in a lack of consistency in service delivery, additional financial burden on providers to recruit and train new staff, and strain on other staff in covering vacant positions. Out of the 70% of leavers whose destinations were known, 32% left the sector and 5% retired.²⁶
- 5.2 There are a range of issues which affect staffing difficulties in social care, including staff recruitment and retention, such as low pay, lack of security in terms of contracts, well-being and support, workers' rights, and the lack of a proper career pathway. All these issues need taking into consideration when Welsh Government sets policy, and public services should address them when developing workforce planning.
- 5.3 Alzheimer's Society is concerned about the impact of Brexit on adult social care particularly on the workforce. We are concerned that any restrictions on the free movement of people between the UK and the rest of the EU and EEA, will exacerbate the current shortfalls in staffing in adult social care and make the option of working in adult social care in the UK an even more unattractive and uncertain profession.
- 5.4 As the UK prepares to leave the European Union, it is vital that negotiations feature dementia research and care at the centre of discussions. We believe that the Government must consider the impact of Brexit negotiations on the adult social care workforce. We must ensure that the resulting deal between the UK and the Union guarantees that the UK remains a centre of excellence in dementia care and research and that people with dementia are not disadvantaged, either now in the future, by the change in our membership. Leaving the European Union could present multiple challenges in relation to dementia, and one of the principle issues is that in many areas the full impact on people is still unknown. Negotiations to leave the European Union started in June 2017 but have not yet reached firm agreements on the areas that could impact people with dementia.
- 5.5 This specifically includes the impact of any changes to migration policy on the ability of EU and EEA nationals to work within the UK. Brexit could result in a shortage of nurses, given that 10,000 of the nurses arriving into the UK per year are from the European Economic Area. In the social care sector, research by Independent Age indicates that nearly 1 in 5 care workers was born outside the UK – around 266,000 people.²⁷ There are currently 144,000 people with EU nationality working in health and social care, approximately 80,000 of which are in adult social care. While specific data for Wales is often not available, the Welsh Government has claimed that as of September 2015 around 1,140 EU nationals were employed in NHS Wales, with 6% of doctors in Wales having trained in other parts of the EU.²⁸ The Government must act to ensure that adult social care is made an attractive career choice to address current shortfalls in recruitment and retention of staff.

²⁶ The Local Government Data Unit – Wales (2017) [Social Care Workforce Development Partnership \(SCWDP\) workforce data collection 2016: the findings](#), Cardiff: Local Government Data Unit – Wales.

²⁷ Independent Age (2015) [Moved to care: the impact of migration on the adult social care workforce](#), London: Independent Age.

²⁸ Welsh Government and Plaid Cymru (2017) [Securing Wales' Future: Transition from the European Union to a new relationship with Europe](#), Cardiff: Welsh Government.

Future social care needs and related costs

- 6.1 We know there is a projected increase in demand for social care by an increasingly large population of people with dementia. It is important that this demand is met by public, private and third sector organisations that are well equipped and properly funded to deliver high quality services. The picture in Wales is often thought to be better than England, as “social services spending has more or less been protected.”²⁹ Despite this, we are strongly concerned about a shortfall in funding for social care provision in the future.
- 6.2 We are glad that Welsh Government has “*prioritised social care as a sector of strategic national importance*” according to the Minister for Children and Social Care, Huw Irranca-Davies AM.³⁰ The Welsh Government has also taken concrete steps to support the social sector and underpin this commitment with additional funding, as “a total of £55 million of recurrent additional funding has been provided to local authorities for use in social services in 2017-18” and “£60 million for the delivery of integrated care across Wales” through the integrated care fund which “includes funding for reablement services, support for timely and effective discharges from hospital, and integrated care teams.”³¹ We also welcome the recent funding (November 2017) of £1 million to improve support available to carers by enabling access to breaks from caring, supporting identification of carers, and providing information and assistance.³²
- 6.3 This is welcome in order to support the existing system and services. However, we fear that it will not enable the social care sector to meet the challenges confronting Wales and Welsh public services in the future.
- 6.4 The Health Foundation have projected that cost pressures for adult social care in Wales will increase by 4.1% annually up to 2030-31 or by £1 billion, due to demography, chronic conditions (such as dementia), and rising costs.^{33 34} This would be a near doubling by 2030, and push spending up to £2.3 billion.³⁵
- 6.5 Spending will need to keep pace with this – meaning that by 2022-23, Wales would need to spend an extra £184 million per year in 2015-16 prices above and beyond what was already spent by local authorities in that year.³⁶ Research done by Wales Public Services (WPS) 2025 demonstrated that pressures in social services budgets drive 2.9% growth each year, which is around £43m annually up to 2019-20.³⁷
- 6.6 This would be to maintain existing standards. In order to maintain pre-austerity (2009-10) levels of per-capita, spending on older adult social care would require a

²⁹ Ogle, J and Trickey, M (2017) [Can Wales fill the social care funding gap?](#), IWA website, date accessed 18/01/2018.

³⁰ Irranca-Davies AM, Huw (2017) [Questions to the Cabinet Secretary for Health and Social Services— Postponed from 8 November](#), Record of Proceedings, National Assembly for Wales, 15th November 2017, date accessed 26/01/2018.

³¹ Irranca-Davies AM, Huw (2017) [Questions to the Cabinet Secretary for Health and Social Services— Postponed from 8 November](#), Record of Proceedings, National Assembly for Wales, 15th November 2017, date accessed 26/01/2018.

³² Welsh Government (2017) [Carers Rights Day: Welsh Government unveil new plans to improve the lives of carers](#), date accessed 26/01/2018.

³³ Watt & Roberts (2016), [The path to sustainability: Funding projections for the NHS in Wales to 2019/20 and 2030/31](#), London: The Health Foundation.

³⁴ WPS 2025 (2017) [The future funding of health and older adult social care in Wales](#), date accessed 18/01/2018.

³⁵ Ogle, J and Trickey, M (2017) [Can Wales fill the social care funding gap?](#), IWA website, date accessed 18/01/2018.

³⁶ WPS 2025 (2017) [The future funding of health and older adult social care in Wales](#), date accessed 18/01/2018.

³⁷ Jeffes, M (2013) [Future pressures on Welsh Public services](#), cited in WLGA (2016) [Submission to National Assembly Finance Committee Welsh Government Draft Budget 2017-18 scrutiny](#).

similar level of additional resource to the Health Foundation estimates above - around £168 million extra relative to 2015-16.³⁸

- 6.7 We know local authorities are under pressure. WPS 2025 estimates local authority spending per older person has declined over the last seven years by around 13% and that £134 million a year more would be needed by 2020-21 to get back to 2009-10 per-capita levels.³⁹ A survey of councils in England and Wales found 75% had little or no confidence in the sustainability of local government finances. In addition, more than 40% of all councils anticipated making “cuts in frontline services”.⁴⁰
- 6.8 Local authorities are increasingly looking to third sector organisations to provide for shortfalls in their own service provision. But there are growing examples that independent organisations providing residential and home care are struggling to remain viable, caught between squeezing local authority funding for care contracts, challenges in recruiting and retaining staff, and increasing workforce costs (for the national living wage, pensions, and national insurance employer contracts). 13 of Wales’ 22 local authorities told the BBC that they had had contracts handed back to them by providers unable to bid, a higher proportion than across the UK (59% in Wales compared to 48% average across the UK).⁴¹
- 6.9 This underfunding has negatively impacted the quality and volume of care that people with dementia receive. Inaction on social care reform has left thousands of people without the support they need. Too often we hear the consequences of inadequate care – our Fix Dementia Care investigation last year revealed people with dementia left in soiled sheets or being left for days without food.⁴²
- 6.10 Informal and unpaid carers are bearing the brunt of this funding shortfall for adult care services. Often carers and people with dementia will pay care fees which are actually higher than the cost of delivering the care they receive for support that is frequently disjointed and variable in quality. Sometimes these costs total hundreds of thousands of pounds, with Alzheimer’s Society’s latest estimates projecting it would take 125 years to save for the typical cost of dementia care. Additionally, even where people do meet the strict means test threshold for council funded care, people with dementia face having to pay top up fees and other unexpected costs. This can be anything from hotel costs to costs for dementia being a ‘complex’ condition.
- 6.11 We believe that this system is unfair, unsustainable and needs a long-term overhaul, to ensure that people with dementia receive affordable and high quality care as and when they need it. We require a system that encourages people with dementia to access care early enough to live well and reduce the need for more costly and stressful acute care further down the line. We call for the establishment of a care system that recognises the true cost of dementia care and ends the unfairness that currently exists between dementia and most other conditions. We know that there are major challenges to ensure that the right health and social care services are available in Wales and are sustainably funded. But it is only through this will we be able to ensure that people with dementia are not treated unfairly because of the condition they have and are able to access the same level of care as those with other physical conditions.

³⁸ WPS 2025 (2017) [The future funding of health and older adult social care in Wales](#), date accessed 18/01/2018.

³⁹ Ogle, J and Trickey, M (2017) [Can Wales fill the social care funding gap?](#), IWA website, date accessed 18/01/2018.

⁴⁰ Institute for Fiscal Studies (2017) [The local vantage: how views of local government finance vary across councils](#), IFS: London.

⁴¹ BBC (2017) [Home care firms in Wales facing ‘desperate’ pressures](#), date accessed 22/01/2018.

⁴² Alzheimer’s Society (2017) [Turning up the Volume: unheard voices of people with dementia](#), London: Alzheimer’s Society.

Financial Impact of current Welsh Government policies

- 7.1 The most noticeable financial impact of Welsh Government policies on people affected by dementia in Wales are charges for non-residential and residential care.
- 7.2 Non-residential care can be provided by local authorities or commissioned from private or third sector providers, such as Alzheimer's Society Cymru. Local authorities have discretion over whether to charge for these services, although all local authorities do charge. The scope of these charges are constrained by legislation, primarily the Social Services and Well-being (Wales) Act 2014 which provides for a maximum weekly charge for non-residential care services of £70 (2017-18).⁴³ People receiving services are entitled to retain a minimum income. A capital limit in the means test for non-residential care of £24,000 also applies. The capital limit determines whether a person pays for the full cost of their residential care, or whether they receive financial support towards the cost from their local authority.⁴⁴ Below the capital limit, individuals are not expected to contribute to the costs of their non-residential care from their capital.⁴⁵
- 7.3 In the Fifth Assembly, the Welsh Government has announced that this capital limit will be raised to £50,000, on a progressive basis. In October 2016, the Minister for Social Services and Public Health at that time Rebecca Evans AM, announced⁴⁶ that the Welsh Government would raise the capital threshold to £30,000 and introduce the War Disablement Pension disregard from April 2017 as a first step in implementing the reforms to charging for residential care. The Social Care Minister, Huw Irranca-Davies AM, has recently announced that this capital limit will increase to £40,000 in April 2018.⁴⁷
- 7.4 Alzheimer's Society Cymru welcomes this rise, but would advocate that in order to protect the majority of people, it should be set higher to ensure that those with fewer assets are protected by the State. A higher capital limit of "at least £100,000" was proposed by the Wales Stakeholder Advisory Group on Paying for Care in 2015.⁴⁸
- 7.5 Welsh Government is also proposing reforms to the maximum weekly charge for non-residential care services by raising it from £70 in 2017-18 to £100 in 2021.⁴⁹ We welcome the maximum weekly cost placed on homecare but would advocate that in order to protect people with dementia adequately there should be a limit on what people pay overall. Many individuals with dementia may have a need for long term non-residential care and thus have a significant cost over a lifetime. We agree that "a lifetime cap on care costs should be introduced for residential care. The cap should also be timebased to provide assurance over the length of time a person might have to pay charges" as proposed by the Wales Stakeholder Advisory Group on Paying for Care in 2015.⁵⁰
- 7.6 We are also concerned about the current impact of the system of carer's assessments on people affected by dementia. We are greatly concerned that the eligibility criteria for carer's assessments are too high to properly assist carers in need of support. At present,

⁴³ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

⁴⁴ Welsh Government (2017) [People in residential care to keep even more of their money](#), date accessed 23/01/2018.

⁴⁵ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

⁴⁶ Welsh Government (2016) [Written Statement – Implementation of Taking Wales Forward Commitments on Charging for Social Care](#), date accessed 24/01/2018.

⁴⁷ Welsh Government (2017) [People in residential care to keep even more of their money](#), date accessed 23/01/2018.

⁴⁸ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

⁴⁹ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

⁵⁰ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

too many carers are only assessed as having 'eligible need' for support when they are already close to breakdown. The need to avoid carer breakdown is generally well-recognised to support the carer's own wellbeing and health, and the knock-on effect on those for whom they provide care. Carers assessments need to be focused on support to prevent breakdown, not on helping when a carer is already in crisis. We are concerned that high eligibility criteria means that more carers are being driven to the point of breakdown unnecessarily.

7.7 This must be avoided in order to better help carers and those they support, and to reduce financial cost. It is important to support the health and well-being of carers and those they care for, particularly because the care required at a crisis is far more expensive to deliver. We are concerned that high criteria may save money in the short-term by enabling public services to provide fewer services to carers on an ongoing basis, but risks necessitating more expensive crisis care, as well as forcing vulnerable individuals into worse health outcomes.

7.8 Alzheimer's Society Cymru wants to see firmer targets for carers' assessments. We welcome the Welsh Government's commitment to examine a national approach to respite care. We must ensure that carers' assessments reflect the realities of living with dementia – for example, that dementia is a progressive condition and the needs of a carer may vary over the course of a person's condition. As such, a carer's assessment should be the start of the conversation, not just the end.

Fiscal levers available to the Welsh Government to reform the arrangements for funding social care

- 8.1 It is clear we need reform of the social care funding system if we are to meet the challenges of the future. Reform is long overdue — and given the controversy earlier in the year over plans for a “Dementia Tax” in England, it is time for Wales to lead the way by examining progressive models that could give us properly funded social care.
- 8.2 The General Election in 2017 showed us how salient the Dementia Tax was to many people. Though Wales has a devolved social care system and proposals from the election would not directly affect Wales, the Welsh Government is taking steps that could potentially address the underfunding of social care in Wales.

Social Care Levy

- 8.3 The Welsh Government has announced proposals to introduce a ‘social care levy’ to meet the longer-term challenges to finance social care. As we currently understand it from the Welsh Tax Policy Report⁵¹ the Welsh Government expects to propose a new tax to the UK Government in 2018, as per the powers to raise new taxes that Welsh Government has under the Wales Act 2014. The social care levy is one of four currently discussed potential taxes.⁵²
- 8.4 The Welsh Government has set out its tax policy principles in the paper for the development of new taxes. To test the mechanism, the Welsh Government expects to provide information to the UK Government on whether a new tax is within the competence of the National Assembly for Wales; whether a policy case exists for such a tax and whether it has harmful effects for UK macro-economic or fiscal policy. The Welsh Government has looked at the extent to which proposals address the priority areas in the Prosperity for All national strategy, analysed how they might meet our framework criteria, and conducted initial engagement with the relevant departments to select the new taxes with the most potential.
- 8.5 Welsh Government will explore “potential financial levers including taxation to support social care provision in Wales.”
- 8.6 Alzheimer’s Society Cymru will do all we can to work with the Welsh Government as they explore the practicalities of a social care levy. However, there are many ways such levers could be utilised and many ways to develop a levy for social care. We believe that any proposals – such as a hypothecated tax or social care levy; a cap on care; or insurance-based models such as are used in Germany and Japan – should meet a stringent set of criteria in order to meet the needs of people affected by dementia.

Principles for reform

- 8.7 We believe that any new fiscal levers or policy decisions on social care funding designed to better support people affected by dementia should:
- **Address the considerable inequity of support between dementia and other conditions.**
People with dementia should not receive less support, increased charges and costs nor face challenges accessing care based on their age or the increased need for social care as a result of having dementia.
 - **End catastrophic care costs for families.**
While some people with dementia may make some contribution towards the cost of their care, this is a fair amount which has a financial limit and does not

⁵¹ Welsh Government (2017) [Welsh Tax Policy Report](#), Cardiff: Welsh Government.

⁵² The other ideas being a “tourism tax”, a tax on non-recyclable cups, and a tax on vacant land.

impact on their wellbeing or ability to live a normal life. No individual should have to spend everything they have on care. In order to end catastrophic costs, any reforms to social care must have adequate funding in the long-term and we believe that in order to do so, the Government must commit to creating a new annual influx of funding for social care.

- **Ensure a better connection between the price paid for dementia care and the cost of providing this care.**

The cost of delivering high quality care provided by professionals who are both confident and competent must have a close and transparent connection to the price that people pay for their care, regardless of how that care is commissioned. As it stands in the current system, people with dementia are faced with paying top-ups for their care, the significant price of cross-subsidising and the system not taking into account the additional cost of dementia care. In addition, people are having to spend additional funds on hotel costs and are shouldering larger financial burdens as a result of years of underfunding of the system. It is vital that the Government prioritises immediate action in this area to ensure that there is a better connection between the price paid for care and the cost of providing this, to ensure that what people are paying is more fair and reflective.

- **Guarantee greater efficiency across health and care, providing preventative support in the appropriate setting.**

In addition to an adequately funded care system, it is absolutely vital that we ensure the health and social care systems are utilising the funding available in the most efficient way to minimise wastage on the one hand and direct the funding in ways that will ensure the wellbeing of people with dementia. For instance, great importance is currently being placed on reducing delayed transfers of care (DTOCs) by placing additional funding into healthcare. However, as an organisation we believe that a holistic and whole-system approach is needed to address these challenges. Therefore, we are calling for the Government to take a comprehensive view over where the funding is currently being spent, where the wastage currently occurs and how this can be spent differently to the benefit of people with dementia. Alzheimer's Society intends to put forward evidence that demonstrates the money wasted on avoidable admissions, DTOC and emergency readmissions for people with dementia. This will focus on and underline both the costs borne by the health system due to the failings of social care but also the terrible damage this can do to people with dementia and their families who have not been provided with the support they needed within the community. In order to fully understand this, the Government must place importance on ensuring evidence and data regarding the system as a whole is strengthened (specifically in relation to dementia).

- **Ensure better quality of care for people with dementia across health and social care.**

We know that there is poor care, insufficient training, and waste throughout the health and social care system – combined with concerning variation across Wales and lack of clear standards, this is a challenge that needs to be addressed. We are hopeful that the forthcoming Welsh Government dementia action plan will address these disparities in the quality of care. Our full response to the consultation on the draft dementia strategy can be found at: www.alzheimers.org.uk/walesstrategy17

8.8 These principles should guide reforms to social care funding. Any proposed reforms should be in the service of good quality care for vulnerable people with dementia, which must always be the core and most important goal. Good quality care should be

based on individual need, and focus on ensuring that there is appropriate training and understanding from care workers of the challenges that people affected by dementia face. We want to see homecare that provides continuity of familiar faces where possible, proper recording of care plans, minimal use of 15 minute visits, and care homes that are dementia friendly environments, have ways to keep people connected to the community and have appropriate staffing levels.

- 8.9 This should also feed into service commissioning. It is essential that commissioners understand the complex nature of dementia and provide services that meet those needs. The requirement in the Well-being of Future Generations (Wales) Act 2015 for Public Service Boards to produce Assessments of Local Well-being⁵³ will hopefully help commissioners better understand local prevalence of dementia and future projections, and commission services appropriately. We know that this is a challenging time for commissioners, with “a steady reduction in the number of both residential and nursing homes across Wales”⁵⁴ and commissioners saying they “need more extra care, EMI residential and nursing care and less residential care”⁵⁵. Commissioners need to ensure that appropriate fees are paid to providers to deliver quality care for people with dementia, including appropriate training and appropriate pay & conditions for staff.
- 8.10 We know that care work has a “particularly low social status, reflected by low pay, long working hours, poor working conditions and a lack of opportunities for professional development and career progression”.⁵⁶ This work is often “emotionally, mentally and physically challenging and demanding”⁵⁷ and current rates of pay are seen as “undervaluing the contribution made” by staff.⁵⁸ This can lead to low morale, high staff turnover, and a lack of consistent care – which has a detrimental impact on the quality of life and care of staff and people with dementia.^{59 60} It is a false economy for providers/operators to limit pay as staff should be incentivised and rewarded for maintaining high quality care and to avoid staff turnover.⁶¹
- 8.11 Additionally, it is important not only that people affected by dementia and their needs are at the centre of their care, but that they have a voice themselves in decisions regarding their care. People should have control over the outcomes that help them reach well-being. This is a key principle of the Social Services and Well-Being (Wales) Act 2014 and must be upheld to a greater degree by commissioners.⁶²

⁵³ Available at: <http://gov.wales/topics/improving-services/public-services-boards/?lang=en>

⁵⁴ Rattle, N. and Moultrie, K. (2015) *The Care Home Market in Wales: Mapping the Sector*, Cardiff: PPIW.

⁵⁵ Interview with local authority commissioner, low population density area, cited in Rattle, N. and Moultrie, K. (2015) *The Care Home Market in Wales: Mapping the Sector*, Cardiff: PPIW.

⁵⁶ Older People's Commissioner for Wales (2014) *A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales*, Cardiff: OPCW.

⁵⁷ Older People's Commissioner for Wales (2014) *A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales*, Cardiff: OPCW.

⁵⁸ Tadd W, Woods R, O'Neill M, et al (2011). *Promoting Excellence in all Care Homes (PEACH)*. PANICOA.

⁵⁹ Older People's Commissioner for Wales (2014) *A Place to Call Home? Literature Review*, Cardiff: OPCW.

⁶⁰ Colliers International (2013). *Care Homes Review*, London: Colliers International.

⁶¹ Colliers International (2013). *Care Homes Review*, London: Colliers International.

⁶² Social Care Wales (2017) *Overview: Social Services and Well-being (Wales) Act 2014*, date accessed 26/01/2018.

Our position on social care funding reform

- 8.12 Alzheimer's Society Cymru believes that any proposed reforms to social care funding need to address the needs of people affected by dementia. Given the demographic changes discussed earlier, it is clear that a greater proportion of those who are affected by social care funding will be people affected by dementia in the future.

Medium-term solutions

- 8.13 Alzheimer's Society supports the creation of a cap on care costs that works for people affected by dementia, which would prevent people from spending all they have on care. Establishing a cap on the care costs is essential to ending the catastrophic cost of care people with dementia face now, and is the first step to ending over all inequity people with dementia face as a result of the current health and care system compared to those with other conditions. Alzheimer's Society research showed that people with dementia are, on typically, spending £100,000 on their care over the course of their lifetime, highlighting the devastating cost they and their families face⁶³.
- 8.14 This must happen in conjunction with a rise in the means-test threshold to would protect people with modest means from having to pay for their care. Alzheimer's believes that in order to adequately protect the population, both elements should be implemented together. The implementation of a limit on overall care costs and increase in the means-test threshold would be a crucial first step towards ending the inequality that currently exists between dementia and other conditions. This would constitute a medium-term reform to the care system, as it would place a maximum cost on dementia care and therefore would put an end to spiralling costs for the first time.
- 8.15 Alzheimer's Society has commissioned LaingBuisson to determine and consider what level a cap should be set at in order to protect the majority of people affected by dementia from uncontrolled cost, using figures from England. As a starting point, this research⁶⁴ used the original £72,000 cap that was set out in the Care Act 2014 (the implementation of which has since been postponed) to project the number and proportion of service users with dementia who might benefit this cap. The latter demonstrates that if the cap was set at £72,000, 17% of eligible residents across England would have reached this in their lifetime. At a cap value of £120,000 the proportion would drop to 2% and at a cap value of £50,000 it would rise substantially to 38%, which highlights how redundant a cap becomes to people with dementia if it is set too high. Viewed from another angle, 20% penetration would require a cap of £68,000, 25% would require £63,000 and for a majority (51%) to benefit from the care cap would require it to be set at £41,000.

⁶³ Alzheimer's Society (2017) [Turning up the Volume: unheard voices of people with dementia](#), London: Alzheimer's Society.

⁶⁴ Alzheimer's Society (2017) [Laing Buisson proposes solution for funding social care – Alzheimer's Society comments](#), date accessed 15/01/2018.

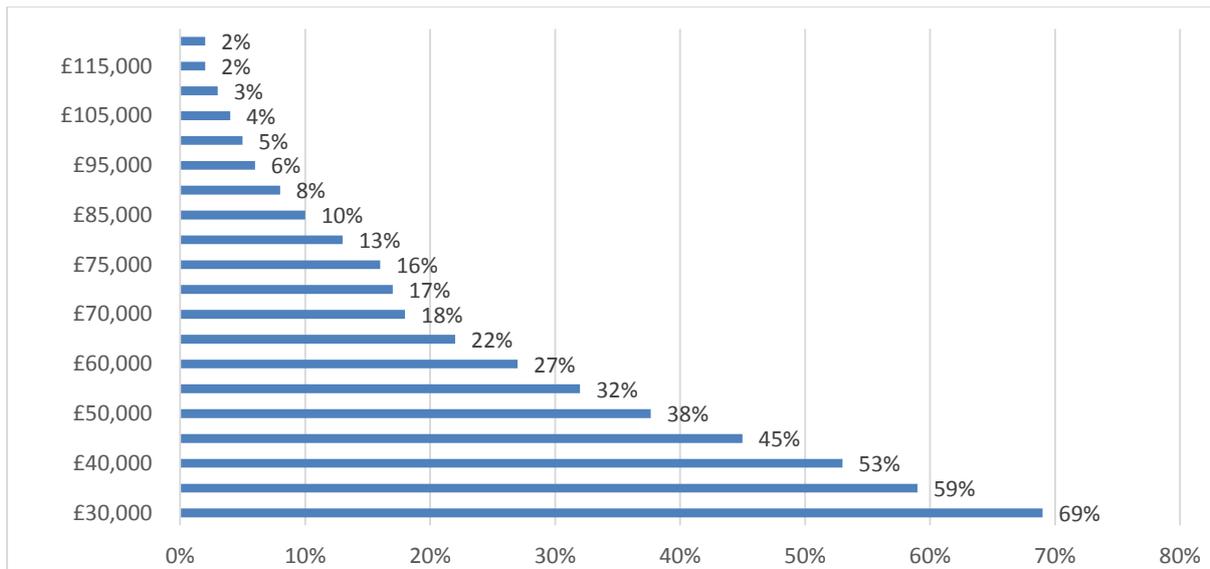


Figure 2: Share of eligible, older (65+) care service users with or without dementia who will have reached a lifetime care cost cap set at different levels at 'steady state' (in up to 10 years), England

- 8.16 If the means-test threshold was raised to £100,000, it would transfer a projected 27,900 older care home residents with dementia in England out of private pay and into council financial support. This would raise the proportion of people with dementia who have access to public funding, through councils or the NHS, from 54% to 66% across England. Significantly, however, this higher means test would not include the home as an asset for residential care, and would provide far less protection if this was the case.
- 8.17 Obviously with different current fees for care and a different means-testing regime with capital limits in Wales, appropriate figures will be different. However, this information may provide a useful starting point for future research to be commissioned.
- 8.18 Alzheimer's Society Cymru acknowledges that this in itself would not put an immediate end to the current inequity between conditions, as people with dementia would still face a significant financial responsibility for paying for their own care. It would, however, guarantee that many more people no longer have to spend everything they have and would ensure greater public understanding of the care system and the risks that people could face if they develop a care need.

Longer-term solutions

- 8.19 In the longer term, fiscal levers could be used to develop more radical solutions. In order to end catastrophic costs, any reforms to social care must have adequate funding in the long-term and we believe that in order to do so, the Government must commit to creating a new annual influx of funding for social care. In the longer-term, Alzheimer's Society supports the creation of a system that wholly pools the risk of dementia across society and ensures that people with dementia no longer have to face a disproportionate financial responsibility just because of the condition they have developed. No solution around a cap or increased asset floor will work unless this is the long-term goal.
- 8.20 We agree with the proposal of the Wales Stakeholder Advisory Group on Paying for Care that "[i]n the longer term, care and support should be paid for

through national insurance, or taxation, to pool risk.”⁶⁵ The Group also said there may be a role for tailored and reliable financial products, such as annuities to fund care.

8.21 To this end, a social care levy may be the appropriate method. However, we would need to better understand the details of the Welsh Government’s proposals to estimate the impact, positive or negative, that this reform could have on people affected by dementia in Wales. If this option is taken forward by Welsh Government, we would recommend the Welsh Treasury engages with people affected by dementia directly in order to understand their needs and experience of social care funding.

8.22 We believe that pooling risk is essential, and as such any distinct funding stream for social care should be Wales-wide. This will pool risk between areas which may have different levels of prevalence of dementia and different tax bases. For example, an area with a larger number of older people who have a small number of assets would need to spend larger amounts on dementia care, which exposes that local authority to far greater risk. While the Council Tax precept in England is welcome as a new source of funding for social care provision, it does not address the mismatch between the amount needed to fund acceptable care in an area and the amount the Local Authority has to spend on care in that area. It is likely that the business rates changes will encounter the same issue. There is no accepted cost for delivering care in an area. Whilst it is possible to see what Local Authorities pay for care, and what providers charge for care there remains no way for locally elected representatives, or the voters in an area, to see whether the amount that is being paid for care in that area is reasonable compared to the local cost factors and needs of the population. We suggest that in the long term the settlement which is provided to Local Authorities to pay for adult social care is more explicitly linked to the cost of providing an acceptable level of care in that area.

8.23 In addition to placing a maximum on the financial responsibility that people with dementia face and thereby re-balancing the responsibility between the individual and the state, Alzheimer’s Society also supports a cap as a way to stimulate an insurance market that will enable people to protect themselves against the risk associated with the cost of dementia. One way to do this would be to implement a compulsory social insurance system, similar to systems already implemented internationally such as Germany and Japan. Alzheimer’s Society would support this as it builds upon the cap on care/means-test threshold system in ending catastrophic costs and enabling the provision of high quality and affordable care in the future. It also ensures there is fairness between generations.

8.24 Private long-term care insurance allows people to take out individual products to help cover the cost of care. Specifically, in its current form it is intended to cover the cost of assistance for those who need help in performing the basic activities of daily life, such as getting out of bed, dressing, washing and going to the toilet.

8.25 There are two predominant types of long-term care plans; immediate needs annuities and pre-funded care plans. In the former, someone would pay a guaranteed income for life to help cover care fees in exchange for a one-off lump sum payment, if someone has immediate needs. The average price of an immediate care need annuity plan is £69,000.⁶⁶ While this may therefore not cover the entirety of someone’s dementia care, which currently stands at a typical cost of £100,000 across someone’s care journey, this would cover the majority of average dementia care costs. If a person chooses a pre-funded care plan, they will be able to insure against their future care needs before such a care need develops. Payment is usually in the form of a monthly payment and someone becomes eligible for the benefits

⁶⁵ Boyce, Stephen (2017) [Research briefing – Paying for adult social care in Wales: Debate and Reform](#), Cardiff: National Assembly for Wales Research Service.

⁶⁶ Forder, Julien (2011) [Immediate Needs Annuities in England](#), Canterbury: PSSRU.

after being classed as being 'chronically ill' (or similar). Although the definition of what this entails varies according to the country and company, someone will usually be assessed by a licensed health care professional and eligibility usually entails someone being unable to perform at least two Activities of Daily Living. These could include:

- Eating (whether someone can feed themselves)
- Bathing (whether someone is able to bathe themselves)
- Toilet (whether someone can use the bathroom by themselves)
- Dressing (whether someone can get dressed by themselves)
- Continence (whether someone is able to control their bladder and bowel function)
- Mobility (whether someone is able to get into or out of a bed, a chair or a wheelchair)

8.26 Although these products could in theory benefit people affected by dementia, they are not being used due to multiple and intertwining factors:

- In order for a market to be stimulated, there must be clarity about the system and what someone would end up paying for care if they needed it. There is a lack of awareness and understanding about the long-term insurance industry and how this works.
- There is an overriding lack of understanding relating to how the system currently operates and what people are entitled to. A major barrier is that people assume all care is free through at the point of use through the NHS and therefore are unaware of the risks associated with older age and specific condition, such as dementia.
- To make matters worse, the care system is currently very complex and lacks transparency, which further disempowers people from protecting themselves against the risks associated with conditions and their end of life care.
- People do not currently see the value in purchasing insurance for something that will statistically not happen to them – the stakes are too high.
- The premiums for such products are currently too high to be attractive to people.

8.27 While we believe private insurance is in principle beneficial to people affected by dementia, insurance must be set up in a way that supports and empowers people with dementia rather than taking advantage of people with dementia or disadvantaging people, such as:

- Ensuring that people with dementia are not disadvantaged because they already have a diagnosis, or a genetic predisposition for the condition, which is now available through DNA tests such as 23andme.
- Ensuring that the process and information is accessible to enable people with dementia to easily navigate the insurance product when they choose to take this out

8.28 The following countries have made significant strides in creating compulsory insurance models for care, which we as a country could draw upon when reforming our own care system:

8.29 **Germany:** The German social long-term care insurance is a compulsory pay as you go system with contribution based on salary, split between employee and employer. Initially, the contribution rate was 1% in 1995 and for the next financial

year (2017-2018) will be 2.55%. In addition, employees over 23 who do not have children pay an extra 0.25% of their salary (as they have an absence of support from their offspring and are more likely to need paid for support). 90% of the German population is covered by the scheme, including retired people and recipients of social welfare and unemployment benefit.

- 8.30 German long-term care insurance is not intended to cover all costs, but just basic needs. Recipients of long-term care are expected to make a contribution themselves or apply for means-tested welfare benefits. Anyone with a physical or mental illness or disability, who has made contributions for at least two years, can apply for benefits. Assessment is carried out by doctors and nurses mandated by medical review boards, with costs charged to the long-term care insurance fund.
- 8.31 **Japan:** Japan's compulsory public long-term care insurance covers the needs of the population aged 40 and over. Benefits are designed to cover the costs of care, minus a 10% co-payment. The intention is that social care services provide a substitute for informal care. The LTCI is primarily designed to cover the care needs of those aged 65 and over; for adults aged 40-64 the system only covers long-term care needs arising from age-related disease (such as dementia). Benefits cannot be taken as cash - they must be taken as formal services. Approximately 50% of revenue for the long-term care insurance scheme comes from general tax, 1/3 from premiums from people aged between 40-64 (in addition to 1/6th from people over 65). User co-payments account for the rest.
- 8.32 **The Netherlands:** The Netherlands has a universal social insurance scheme, AWBZ, which pays for the care of older and disabled people. This covers both home care and care provided in residential facilities, including accommodation costs. The extent of care provided is determined by a needs assessment and a complex set of cost-sharing arrangements apply. Patients have the option to receive services in kind or to receive a personal budget to pay for personal care, home care and support with daily activities. The budgets are calculated based on the number of hours of care needed and patients must top up their budget with income-related contributions to buy the level of care they are assessed to need (in reality most recipients use the money provided by the scheme and buy less care than their assessed need). The budget can be used to pay relatives for providing informal care. The compulsory social care social insurance scheme is administered by private insurance companies and paid for via an income-related premium deducted from the wages of all citizens aged 16 and over, and an employer contribution. Individuals who use services also have cost-sharing obligations that vary depending on their level of income, their family status and the location of care.
- 8.33 **Costa Rica:** Costa Rica, which is ranked in 69th position in terms of GDP per capita, is also ranked at a very high 35 on the Human Development Index. Due to its strong welfare state and provision of a compulsory social insurance (Caja Costarricense del Seguro Social). Costa Rica has the highest life expectancy for males and the second highest for females (of Latin American countries). According to the WHO, the success of the health system was in part due to a higher social public expenditure. Arguably, it was also a result of integration – as the health services and public institutions responsible for social care provision have been brought together.
- 8.34 The WHO has stated that the “relatively rapid growth of the elderly population as a result of improvements in their quality of life, are compelling policy-makers to consider a potential increase in the demand for long-term care over the next 25 years. Some efforts to provide increased LTC at the institutional level have been implemented, in particular through the reform of the health system and the law concerning integral care of the elderly.”

- 8.35 **Lithuania:** The country is administratively divided into ten districts, each of which is led by a centrally appointed district governor. These districts have certain responsibilities in the realms of health and social care. There have been significant changes to the way in which the system is operated, which has been prompted by two major events, including the establishment of a state health insurance system and new legislation, which redefined the status of health care institutions.
- 8.36 In Lithuania, the increase in life expectancy and the change towards an older demographic has contributed to a greater social care needs. So far, social care has predominantly taken the form of informal care but due to the change in the workforce this was no longer deemed feasible. Therefore, the country has laid the foundations for a social insurance system (through the Law on State Social Insurance), which has expanded over the last 20 years. In 1996, national state insurance became obligatory, which resulted in the creation of the State Social Insurance Agency that provides pension benefits, maternity and sick leave as well as being responsible for the collection of social insurance contributions. The social care system is funded through a levy of a certain percentage of personal income tax and payroll tax
- 8.37 Due to the fact that there is currently little active treatment and no cure for dementia, people with dementia rely predominantly on social care, as opposed to the NHS, which is free at the point of use. As such, they resultantly shoulder significant responsibility for paying for their own care due to the type of condition they have developed. As such, they could stand to benefit considerably through the establishment of a system that provides more protection against escalating costs and amounts to an important step in providing more equality between health conditions.

To consider the findings and conclusions of the Parliamentary Review.

- 9.1 Alzheimer's Society Cymru welcomes the publication of the Parliamentary Review into the Long Term Future of Health and Social Care in Wales. We welcome the statement by the Cabinet Secretary for Health and Social Services Vaughan Gething AM, that a long-term plan for health and social care will take into account these recommendations and be published in the spring.⁶⁷
- 9.2 We agree that there should be one seamless system for Wales which organises care around the individual "as close to home as possible" and which is "preventative with easy access and of high quality, in part enabled via digital technology, delivering what users and the wider public say really matters to them." However, goals of more care in the community, more digital technology access, and more preventative approaches, should not come at the expense of *high quality care* when and where it is necessary.
- 9.3 The primary focus should be to securing the right care for people affected by dementia based on their individual needs. For many people, this will be at home and within the community, for as long as possible. However, we are concerned that the recommendation regarding "new forms of prevention and home- rather than hospital-based care" (p.44) and "developing Primary Care services out of hospitals" (p.47) could be used for closures of wards that fulfil vital services. It is important to remember that for conditions such as dementia, which are progressive and terminal, hospital specialist care is ultimately necessary for many individuals and community care is not a sufficient alternative. It is critical that adequate resourcing and training of staff is made available to appropriately deliver high quality, specialised care at all stages of dementia - wherever it is located; in the community, in residential care or at hospital. Alzheimer's Society Cymru have long called for more integration between health and social care and hopes that this develops in the future, combined with the right resourcing and sustainable funding to meet the changing needs of people living with dementia and supports the needs of carers.
- 9.4 We welcome the recognition that "the public, voluntary and independent sectors all have a role to meet the needs of the population now and in the future." We must ensure that third sector partners are seen as equals within the care pathway, and value the role that specialist services bring. There needs to be greater integrated working across health, local authorities, and the independent and third sector. Social Services often act as gatekeeper to people accessing third sector services through referrals. There should be greater cooperation between social services and third sector, in order to be able to provide a fuller range of appropriate support. Increasingly, dementia-specific service contracts are being given to general care providers, which fails to recognise some of the complex and specific needs of people with dementia that require specialist knowledge and training.
- 9.5 In particular, we believe that engagement with the voluntary sector is essential to deliver the Cabinet Secretary's vision of a dementia friendly nation. The Dementia Friends and Dementia Friendly Communities are key to ensuring that Wales is a place that is welcoming and accessible to all people affected by dementia.
- 9.6 It is essential that we "put the people in control" and "strengthen individual and community involvement, through voice and control in health and care, and ensuring all ages and communities have equal involvement". We believe that the new plan from the Cabinet Secretary should ensure that the voices of people affected by dementia are heard through direct user involvement activity. These voices should be at the heart of any proposed service change consultation processes for it to truly reflect the needs of people affected by dementia.

⁶⁷ Welsh Government (2018) ["Different system of care needed to deliver for the people of Wales" says expert panel](#), date accessed 25/01/2018.

Conclusion

We welcome the Finance Committee's interest in the important topic of social care funding. The dementia tax has affected people in Wales for far too long – and it is time to tackle this head on. We believe that we have a historic opportunity for reform, with the new dementia action plan soon to be published, proposals for a social care levy in Wales being discussed, and a forthcoming new green paper on care and support for older people in England.⁶⁸

All of these areas of work need to include engagement with organisations in the third sector, the general public, and most importantly, with the people affected by any proposed changes themselves. We would be happy to facilitate consultation with people affected by dementia with Finance Committee in order to help Members better understand what people affected by dementia would want to see in any potential reforms. We know that the social care crisis is a dementia crisis and people affected by dementia should be at the heart of efforts to reform the system.

If you require any other information, please do not hesitate to contact me.

Yours sincerely,



Sue Phelps

Country Director, Alzheimer's Society Cymru

⁶⁸ UK Government (2017) [Government to set out proposals to reform care and support](#), date accessed 29/01/2018.