

# **Alzheimer Scotland**

## **Private Members Bill – Free Personal Care for Under-65s**

### **Introduction**

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally and through facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website ([www.alzscot.org](http://www.alzscot.org)) and our wide range of publications.

Alzheimer Scotland is pleased to be able to contribute to this consultation. Our response covers similar ground to our initial submission to the Scottish Government's Feasibility Study on expanding Free Personal Care to people under 65 earlier in 2017 and also speaks to some of the issues raised in their subsequent report in September 2017.

Alzheimer Scotland welcomes the statement from the First Minister as part of the Programme for Government, indicating that the Scottish Government would 'fully implement' free personal care for people under 65 in Scotland, following the campaigns of Amanda Kopel and others. We wish to see this commitment delivered in a timely and comprehensive manner.

### **General Comments**

In Scotland, we estimate that about 3,200 people under the age of 65 are living with some form of dementia. Whilst not everyone with early onset dementia will necessarily have a need for personal care, a significant number are faced with no provision of support from statutory services on the basis of their age.

The Scottish Government's announcement on the extension of Free Personal Care is an important development in improving the experience of people with dementia of people, their families and carers to ensure they receive the care and support which allows them to live well with the condition. However, there are a number of issues which may arise as a result of the change, some of which have been identified in the Scottish Government's Feasibility Study report, which will determine the effectiveness of the implementation of this policy change.

Whilst welcome, the proposed changes should not be considered as having 'fixed' the system of social care (and accordingly Free Personal Care). One such issues which is not addressed by the proposed change is the healthcare needs of people with advanced dementia, which are often met and charged through the social care system. In line with the recommendation in our Advanced Dementia Practice Model – that the care needs of people with advanced dementia should be recognised as healthcare needs and therefore not chargeable – we have been working with a panel who have specialist knowledge of

dementia, health economics and epidemiology to develop arguments to support the case for change and consider how this may be practically implemented. We will continue with this work over the coming months and will build on the campaigning work that has taken place to date. The panel is expected to publish its findings in 2018.

## **Opportunities and Benefits of Extension**

Alzheimer Scotland believes that as people over 65 receive Free Personal Care to assist them are supported to realise their rights and live well in society through the provision of various supports and provisions, it is iniquitous that people under 65 are excluded from the same level of support based solely on their age. Everyone should be able to live well and where possible be supported to live well in a home or homely setting where possible; Free Personal Care is a fundamental to realising this aim.

Extending Free Personal Care to people under 65 should not be viewed as an end in itself, rather it is one measure among many which provides support to allow people to continue to live well in their communities, delay or avoid the need for institutional care and alleviate some pressure and stress on familial carers.

The health and social care agenda in Scotland presents a good opportunity to transform the way in which people are supported, including the way in which they are able to exercise choice and control over the types of support they want. Similarly, the integration of health and social care has the potential to radically change the way in which statutory organisations work together to deliver services. Finally, the devolution of some social security benefits has the potential to more closely align benefits with the needs of people and complement the other forms of financial, social and health supports – though we appreciate that this is complicated by the reserved nature of working-age benefits.

Health and social care policy in Scotland has increasingly taken a rights based approach to the delivery of services and supports for people who need help with day-to-day living. Condition specific strategies such as Scotland's National Dementia Strategies, legislation such the Social Care (Self-Directed Support) (Scotland) Act 2013 and the new National Health and Social Care Standards, have all taken a rights based approach grounded in the PANEL (Participation, Accountability, Non-Discrimination, Empowerment and Legality) principles, seeking to uphold the rights of people and improve their overall health and wellbeing. The provision of free personal care is one of many supports which help people to realise their rights.

In addition to the improved quality of life experienced by the people supported and their carers, the provision of Free Personal Care is a good example of preventative spend which can reduce the likelihood of an unplanned admission to care, the need for crisis interventions and, where a person has a progressive degenerative condition, may delay the need for a person to move into a residential care setting. Whilst requiring significant initial investment, the cost savings from avoiding more costly interventions or supports have the potential to be effective preventative spend.

There is the potential for the development of indicators and measures to better understand the delivery of Free Personal Care in Scotland, including the benefits to individuals and how services can be improved. Whilst there is good data on quantitative and process measures, the quality of the service delivered and the outcomes for individuals is not well understood and widely recorded. Whilst done to some degree through the regulation of services and the National Care Standards, Free Personal Care should be subject to analysis not only to demonstrate its cost effectiveness, but also the outcomes it delivers for people.

### **Challenges for Implementation**

Alzheimer Scotland recognises the challenges and pressures on the social care sector in Scotland and the inevitable affect this has had on the way residential and non-residential care services are commissioned and delivered, as well as the quality of services and the outcomes for the people who use them.

The Scottish Government has given a commitment to fully implement the policy by April 2019, however, it is currently unclear how this is to be funded and whether there will be any additional resource allocated by the Scottish Government. In the context of a social care system which is experiencing significant financial pressures, it is difficult to envisage how, without investment from central government or council tax increases, this policy can be implemented. The current practice of increasing eligibility thresholds for other services or the introduction/increase of charges for non-residential services restricts access to these supports. This increasing stringency is an expression of the pressured circumstances of local authority funding. However, if this policy is implemented without sufficient resource behind it, free personal care risks being further restricted to only those with the most profound need, an approach which goes against the numerous policy drivers from the Scottish Government which advocate early interventions and preventative spend, especially for people with dementia. The Scottish Government's Feasibility Study acknowledged this issue, however, no proposed solution was identified.

Alzheimer Scotland believes that this policy should not be an end in itself and cannot solely be an extension of free personal care as it is offered at present. There is a significant risk that if adequate resource is not made available to local authorities/integrated joint boards, introducing this policy risks simply increasing the number of people eligible for free personal care, without addressing some of the key problems of the present, including 15 minute visits, time and task approaches and high staff turnover rates; this would likely result in expanded low quality provision which doesn't meaningfully support people.

Irrespective of the funding model used to implement this policy, local authorities/Integrated Joint Boards must make sufficient provision to ensure the sustainability of Free Personal Care provision long term. This must include inflationary increases in costs and increasing demand for provision, particularly in the context of an ageing population. If sustainability of these services is not addressed and guaranteed prior to the extension of provision, it will be subject to the existing problems faced by other services which are funded by temporary or short-term arrangements. The consequence of this is uncertainty for people using the service and the professionals responsible for delivery. This impacts on the ability of services

and practitioners to deliver consistent, high quality, coordinated care and support across health, social care and third sector provision, significantly hindering any ability to plan for longer term provision.

Another key challenge in the implementation of this policy is the use of the term 'Free Personal Care' itself and the wider public understanding about social care charging, including interactions with non-residential care charges. Non-personal care remains subject to charges. The amount that a person pays is determined by the income and capital they possess and not the level of service. Local authorities cannot however, charge more than the actual cost of the service. For example, where a financial assessment determines that a person should pay £60 per week and the actual cost of the care service is £50 per week then the person would be charged the lower amount. For some people who receive personal and non-personal care services, this can mean that the amount they are charged is no different to what it would have been if free personal care had never been introduced.

Whilst the Social Work (Scotland) Act 1968 makes provisions for Local Authorities to charge people in receipt of non-residential social care support, there is no national financial assessment, unlike the rules prescribing charging for residential accommodation. Despite guidance developed by Convention of Scottish Local Authorities (CoSLA), there remains significant variation across Scotland. This variation is created by a number of variable factors which include the treatment of income, capital thresholds, disability related expenditure, treatment of couples' resources and the level of taper, which varies from 15 percent to 100 percent. In addition local authority non-residential care charging policies are not easily found and on many local authority websites the charging policies appear to be several years out of date.

Financial assessments for care at home or care homes is one of the most common areas of concern for people with dementia and their families, often coming at times of crisis and frequently without any appropriate level of explanation or transparency. When this happens to people, it adds to an already difficult and emotionally distressing time for the person with dementia, their carers and family. The financial burden of charges is often a significant factor in people choosing to withdraw from or not to take up crucial social care support.

This lack of transparency makes it almost impossible for any individual to understand why they are asked to pay what they are and to benchmark their local authority charging policy against other Scottish local authorities.

### **National vs. Local Criteria and Delivery**

Alzheimer Scotland understands the importance of local authorities and integrated joint boards having the mechanisms available to deliver services in a way which responds to and meets local need; as part of this, services must be both viable and sustainable. As financial pressures continue to dominate decisions around the provision of services, social care has seen an increase in the scale, scope and levels of charges for non-residential services. However, whilst we understand the need for this local flexibility, there is considerable

variation across local authority areas in charging and delivery of care services, creating an inequity of access to services.

Alzheimer Scotland believes that recent policy developments in this area demonstrate that the implementation of this policy would be possible with agreement between national and local governments. The Scottish Government and the Convention on Scottish Local Authorities (CoSLA) have been able to come to agreement about raising the charging threshold in other contexts, including additional funding for veterans receiving social care and the abolition of charges for people in the last six months of life. However, as a caveat to this latter point, we note that the Scottish Government's Feasibility Study report does not acknowledge the use of the DWP's DS1500 criteria as the basis for approach in identifying person's in the last six months of life. Whilst the report notes that some feel that this time should be extended, Alzheimer Scotland suggests that for neurodegenerative conditions such as dementia, any timescale is unhelpful and progression of the condition is generally unpredictable.

We expect that both the Scottish Government and Local Authorities/Integrated Joint Boards will recognise the value and importance of this policy being implemented well and will work together to overcome the challenges identified.

## **Conclusion**

Alzheimer Scotland supports the Scottish Government's commitment to extending Free Personal Care to people under 65. However, we have a number of concerns as to how this may practically be done. If the problems of quality of provision and inequity in charging policies and eligibility criteria across different local authority areas in Scotland are not addressed, widening access to social care will increase the number of people who experience these problems in the system.

The considerations around the extension of this policy must not be solely considered in relation to financial terms alone. There must be an equal focus on the benefit to individuals who receive free personal care and how this improves their quality of life, as well as the wider context of transformative change in the health and social care system.

Alzheimer Scotland is happy for this submission to be made publicly available. A copy will also be placed on Alzheimer Scotland's website.

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Alzheimer Scotland  
10 October 2017**