

# Alzheimer Scotland

## Scottish Government – Personal Care Feasibility Study

### 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, including 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 welcomes the opportunity to contribute to the Scottish Government's call for evidence on extending free personal care to those aged under 65. Alzheimer Scotland does not propose to address all themes identified by the government but will consider some of the key elements of the policy and the potential impact on people with dementia and their carers.

### Background

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.

Alzheimer Scotland recognises that the Scottish Government's work in this area has been driven by the campaigning work of Amanda Kopel. Alzheimer Scotland has been supportive of the campaign to raise awareness of the needs of younger people with dementia, the difficulties younger people with dementia face in accessing supports and services, and the financial impact of paying for care. We support the introduction of free personal care for people under the age of 65. Alzheimer Scotland has also been developing a campaign which would build on the principles of Frank's Law, to ensure that people of any age who have advanced dementia do not have to pay any social care charges.

Alzheimer Scotland's campaign stems from the development and publication of our Advanced Dementia Practice Model which sets out a model for the delivery of care for people with advanced dementia. The report sets out the complex nature of advanced dementia and how these needs are recognised as health care needs and that accordingly, people with advanced dementia of any age should receive healthcare which is free at the point of delivery.

Over the past year we have been working to develop the arguments to support the case for change and we will continue with this throughout 2017. Over the coming months we are bringing together several experts in a commission to help us develop the case for ceasing care charges for people with advanced dementia and to consider how this may be implemented across Scotland. We have been working with Amanda Kopel to help develop our campaign to build on Franks Law and align these distinct but complementary campaigns.

## **Opportunities and benefits of Extension**

The proposal to extend free personal care to people under 65 should not be viewed as an end in itself, rather it should be recognised as one measure among many which provide support to people to allow them to continue to live well in their communities, (in some cases) delay or avoid in the need for institutionalised care and alleviate some of the pressure and stress on familial carers.

Alzheimer Scotland believes that the current context of health and social care policies, including the extent to which they have and are being delivered, must be considered within this feasibility study. 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 as 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 focus 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.

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.

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; this should be examined in more depth as part of the feasibility study.

If this policy is adopted, 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, the spread widening of access to free personal care presents a good opportunity, not only to demonstrate its cost effectiveness, but also the outcomes it delivers for people.

### **Challenges and Risks of Extension**

The challenges and pressures on the social care sector in Scotland are well-known and have inevitably affected the way in which both residential and non-residential care services are commissioned and delivered, the quality of services and the outcomes for the people who use them.

Alzheimer Scotland understands the financial challenges this policy presents and we are aware of the significant variation in estimates of the up-front cost of this policy in Scotland. In the context of a social care system which is experiencing significant financial pressures, it is difficult to envisage how, without a substantial investment from central government or council tax increases, this policy could be implemented. The current practice of increasingly strict eligibility criteria for other services or the introduction/increase of charges for non-residential services restricts access to these supports; if this policy is implemented without sufficient resource behind it, free personal care risks being 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.

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, in introducing this policy risks simply increase 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.

Free personal care interacts 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 so if 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.

The Social Work (Scotland) Act 1968 makes provisions for Local Authorities to charge people in receipt of non-residential social care support. However, 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 vary from 15 percent to 100 percent. In addition local authority non-residential care charging policies are not easily found. On many local authority websites the charging policies appear to be several years out of date.

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.

Financial assessments for care at home or in 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 not to take up, or withdraw from crucial social carer support.

### **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.

Whilst we understand the need for some degree of local flexibility, there is considerable variation across local authority areas in charging and delivery of care services, creating an inequity of access to services. Whilst the reasons for differences in charges are multifaceted, however, the confusion and poor understanding of care charging in Scotland is made by a lack of transparency and information about the way in which charges are calculated as explained above.

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. We would hope that both would recognise the value and importance of this policy to work through the challenges identified.

## **Conclusion**

Alzheimer Scotland supports the principles of removing personal care charging for 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.

However, the debate around this issue and the feasibility study must not make a determination based on 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. services delivered and the improved outcomes the delivery of free personal care deliver fir This work represents an excellent opportunity to set out what type of (health and) social care system we wish to see in Scotland and how we can ensure that people are able to live well in their communities.

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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