

Alzheimer Scotland

Response to petition PE1480

PE1480/B

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 the provision of specialist and personalised services. We also offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to respond to the Scottish Parliament Petition Committee regarding the issues raised by petition PE1480.

Response to the Scottish Parliament Petition Committee

What are your views on what the petition seeks and the discussions that took place at the meeting on 17 September?

In responding to this question we have considered both the petition and the record of the meeting held on the 17 September.

The petition raises several key issues, namely;

- The need to increase awareness of the impact of dementia on both the person with dementia and the partners, families and friends who care for them, particularly the issues faced by younger people with dementia who are under the age of 65
- The age inappropriate services available to younger people with dementia
- The challenges of getting help from a complex and bureaucratic social security system which lacks understanding of dementia, particularly when the claimant is a person with dementia who is still of working age
- The charging system for non-residential community care.

The petitioner has asked that free personal care be extended to people with dementia, under the age of 65, who require personal care. The petitioner argues that the current age limit discriminates against younger people with dementia who have equally complex personal care needs as those aged 65 or over.

Alzheimer Scotland supports the aims of the petitioner to increase awareness of the impact of dementia on younger people and the families, partners and friends who care for them. The petitioner provides a familiar account which highlights the very complex personal support needs of people with younger onset dementia.

We acknowledge and support the petitioners view that health and social care services for younger people with dementia often fail to meet the needs of younger people living with the illness. Younger people with dementia are too often referred to older people's health and social care services which often fail to provide age appropriate person centred care, treatment and support. The care treatment and support for people with dementia, of any age, should be person centred and meet the individual needs and outcomes of the person with dementia.

We also recognise the difficult experiences that people with dementia and their carers often have in obtaining information about social security benefits, and other sources of financial help, administered by the Department for Work and Pensions (DWP), Local Authorities and other agencies. Making a claim for social security benefits can be stressful and complex for anyone unfamiliar with the system. This is exacerbated for people with dementia and is particularly difficult for people of working age. This is not helped by the lack of understanding of how dementia impacts on the day to day lives of people with dementia among those responsible for the administration of social security benefits as well as those who carry out medical assessments. This lack of understanding of dementia often leads to poor decision making and ultimately to people being refused the benefits they are entitled to. In the petitioner's case, this resulted in the unnecessary additional stress of going through the lengthy and bureaucratic appeals process. This is an all too familiar story, particularly for younger people with dementia who are also subject to many of the UK Government's welfare reforms.

Younger people with dementia are more likely to face financial hardship. They will have given up work at a time when they may have ongoing financial commitments such as mortgages and other forms of credit. They may have families which include young dependents. The partners of younger people with dementia frequently often have to give up work or reduce hours of work so that they can provide care and support to the person with dementia. The increased fuel costs and the additional cost of living with an illness or disability also add further to this increasing financial burden.

Alzheimer Scotland also recognises the additional financial strain placed on people with dementia and their families from local authority charges for community care services. In recent years many local authorities have increased the scale and level of charges for community care services, in response to budget pressures. Financial assessments vary from one local authority to another. Financial assessments and charges lack consistency, transparency and often fail to recognise the additional financial burden on those people living with dementia. Younger people with dementia and their families therefore face, not only the challenge of living with a complex and progressive illness, but the added pressures of significant loss of incomes increased care costs associated with living with dementia.

Alzheimer Scotland acknowledges the petitioners demands to extend free personal care to people with dementia who are under the age of 65. However, in our view this would discriminate against those people, under the age of 65, living with other health conditions or disabilities and who need personal care and support. Any consideration of such a change would need to include all people under 65 who need personal care. Also, free personal care does not apply to all community care services, therefore those who have services which do not qualify as personal care or support may still be subject to charges. Extending free personal care to under 65's would reduce the charges for many people with dementia, however, many would continue to be subject to charges for the non - personal care and support services they receive and would see no reduction in the charges they pay.

Dementia is not simply a social care need: it is a complex illness with a challenging disease process. Human intervention is the main way we can tackle and treat dementia. This can only be provided by skilled staff who understand the complex nature of the illness and who can provide interventions that deal with symptoms and support people and their families. In cases of complex needs, such as those described by the petitioner, the support needed may actually be health care needs, rather than social care, and as such should be free of charge.

Alzheimer Scotland is committed to improving the lives of people with dementia and those who care for them. We support the aims of Scotland's national dementia strategy and continue work closely with other stakeholders and partners to ensure that the strategy delivers on the commitments it contains. We are also working with COSLA and other stakeholders to ensure fairness and transparency in care charges. However, despite the positive work that is taking place this petition highlights the substantial work that remains to be done to ensure that every person living with dementia in Scotland receives world class care, treatment and support.

Please contact me if the committee has further questions or needs any explanation of the points raised in this response.

Jim Pearson
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Alzheimer Scotland