PE1480/A

Directorate of Health and Social Care Integration
Integration and Reshaping Care
Room 2 E R
St Andrews House
Regent Road
Edinburgh
EH1 3DG

T: 0131-244 - 2242 F: 0131-244 - 5076

19 November 2013

PUBLIC PETITIONS COMMITTEE – PETITION PE1480

I am replying to your letter of 18 September regarding the regarding petition PE1480: "*Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of the daily issues suffered by people with Alzheimer's and dementia and to ensure that free personal care is made available for all sufferers of this illness regardless of age*." I apologise for not meeting your original deadline.

You asked for a response to the petition and in particular if there are plans to lower the age at which people with dementia are entitled to Free Personal and Nursing Care. You also asked about contact between the Scottish Government and the UK Government on developing information and advice for people with dementia. In reply to the latter I will set out the distinctive policy context in Scotland on dementia.

By way of a general introduction I would emphasise that, as part of our delivery of Scotland's 2013-16 National Dementia Strategy http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia/DementiaStrategy1316 (our second) we are considering carefully how we improve the care pathways available for people with early onset dementia.We recognise that people coming to terms with an illness like dementia may need to be signposted to a distinct range of information and support and have a reasonable expectation to receive care and support in age-appropriate settings. In addition, those with early onset are likely to have different needs in respect of post-diagnostic support. I will say more about this later.

FREE PERSONAL AND NURSING CARE

Addressing first the issue of lowering the eligibility age for Free Personal and Nursing Care, it is worth reiterating the overall context. Overall expenditure on Free Personal and Nursing Care rose from £219 million in 2003/4 to £458 million in

2011/12 – this is an increase of 109%, and continues to improve the lives of around 77,000 vulnerable people in Scotland. It is also a service which responds quickly to people's needs, with quarterly monitoring showing that more than 80% of people assessed as needing care get the service in under 2 weeks.

The definition of Free Personal Care covers physical assistance with care and help with the mental processes related to that care – for example helping someone to remember to wash. This still leaves the option for local authorities to levy a charge for non-personal care such as day care, lunch clubs, meals on wheels, community alarms and help with shopping and housework.

UNDER 65s AND CHARGING

The Scottish Government has no plans to lower the eligibility criteria for Free Personal and Nursing Care. The Free Personal and Nursing Care policy was introduced in 2002 to benefit people aged 65 and over, as this group were no longer eligible for working age benefits. For people under the age of 65, two forms of support were provided in 2002. Nursing care payments are available to care home residents who fully fund their care home costs; and people who have degenerative illness who require care, and who live in their own homes, could claim disability living allowance at that time (this will be replaced by Personal Independence Payments in the welfare reforms being brought in by the UK Government). People of pensionable age are not eligible to claim these benefits. It is also worth noting that those who receive Free Personal and Nursing Care are no longer eligible to claim Attendance Allowance under policy set out by the Department for Work and Pensions, which precludes anyone who is in receipt of financial help from their local authority for their care from receiving Attendance Allowance.

The majority of people under 65 have assets or income below the thresholds set by local authorities whereby a person becomes liable for a charge. In fact, less than 3% of the total expenditure by local authorities on social care services was recovered through charging in 2010-11. The charges set by local authorities rarely cover the costs of providing the services, and must not exceed the cost of providing the service.

The Scottish Government's position on the issue is that we want to ensure fair, consistent and transparent charging policies for community care services. In order to improve transparency, the charging policies of local authorities are now published on the CoSLA website at:

http://www.cosla.gov.uk/local-authority-non-residential-social-care

It is important that local authorities have the autonomy to set their own charges to take account of local priorities and needs, and we believe that legislating for consistent charging across all local authorities could lead to higher charges for all. The costs of providing services will naturally vary by local authority.

In addition, CoSLA is in the process of continuing work on a review of the Charging Guidance for Non-residential Social Care Services. This is being done in co-

production with a wide range of stakeholder organisations, including Alzheimer Scotland, Scottish local authorities and the Scottish Government.

CoSLA is committed to greater consistency in the development of charging policies and council leaders have agreed a policy to reduce unwarranted or inexplicable variation, while protecting some local differences where these are justified and appropriate. A number of improvements have already been made to the charging guidance, including the establishment of a national benchmarking group, the publication of councils' charging policies on the CoSLA website and the development of a rights-based approach to charging policies. In addition, the working group is exploring standard financial assessment processes and policies to assist with portability of care.

The CoSLA Charging Guidance also covers charging for services for adults under the age of 65. As in the case of England and Wales the charges for these 'non personal' care services are not subject to prescription through legislation and councils have the flexibility to set them according to local need and priority. The guidance does however recommend that a common income threshold at which charges would begin to apply should be adopted.

DEMENTIA POLICY

As I mentioned above, as part of the current 3-year National Dementia Strategy we are considering how we improve the care pathways available for people with early onset dementia. We know that of the 86,000 people currently living with dementia in Scotland, around 3,000 are under 65. There are specific challenges for this group. Rarer forms of dementia are more common in under 65s and can be more difficult to diagnose. In addition, under 65s have different post-diagnostic support needs, in areas such as maintaining their community connections and accessing peer support. They will often be in employment and may be the main provider for their household.

The 3 challenges which we are focussing on over the next 3 years have direct relevance for those with early onset dementia: offering services which promote wellbeing and quality of life of people with dementia and their families, which also protects their rights and respects their humanity; improving care pathways to ensure they are person-centred; and continuing to embrace the process of redesign and transformation of services to ensure that we deliver services effectively and efficiently.

As part of implementing the current National Dementia Strategy we will do more to identify what further actions are required so that key improvement areas – diagnosis, post-diagnostic support, care co-ordination - takes account of the needs of this group.

Our national post-diagnostic target
http://www.scotland.gov.uk/Topics/Health/Services/Mental-Health/Dementia -
underpinned by a commitment that everyone diagnosed from 1 April this year will receive a minimum of a year's worth of dedicated support, coordinated by a trained Link Worker and regardless of age - is based on Alzheimer Scotland's "5 Pillars" person centred support model and will help meet those needs. This person-centred

care model will help people with early onset dementia and their loved ones work with the Link Worker to build a care and support plan which is relevant to their particular needs – both practical and psychological - and circumstances.

On diagnosis, there has been encouraging progress made since we made dementia a national priority in 2007. We established a 3-year national diagnosis target in 2008, which was achieved nationally and contributed greatly to significant improvements in diagnosis rates. In terms of UK comparison on diagnosis, as at March 2012, in Scotland, around 64% of those with dementia were being diagnosed, a similar figure to Northern Ireland and significantly better than England and Wales. This is encouraging but we cannot be complacent and we will continue to focus on sustaining and further improving diagnosis rates.

We are also committed to working with Alzheimer Scotland and others to test and evaluate Alzheimer Scotland's "8 Pillars" model which is designed to help people with moderate to severe dementia live well at home for longer and avoid unnecessary admissions to hospitals and care homes. We know how vital it is that people have good quality and seamless care and support as their symptoms advance and they begin to need more intensive support. As the "8 Pillars" model illustrates, people not only need interventions to tackle the symptoms of dementia but also coordinated and holistic attention to their overall health, wellbeing, home environment and quality of life and that of their carers. People have their own individual experience and challenges but the "8 Pillars" can be a means by which all individuals are comprehensively assessed and supported as their dementia becomes but challenging. We have selected five sites to test this model over the course of the current National Dementia Strategy – Glasgow City, Highland, Midlothian, Moray and North Lanarkshire – and we will publish an evaluation of the model on completion of this testing process.

In terms of your question on advice and information available to people with early onset dementia and their families, we engage primarily with stakeholders in Scotland, rather than with our UK counterparts, to ensure that information and signposting is relevant to the Scottish context and contains information on national and local dementia services in Scotland. In addition to a number of free resources available by Health Scotland and Alzheimer Scotland, in October Health Scotland published the *Younger people with dementia: living well with your diagnosis* resource *http://www.healthscotland.com/topics/stages/healthy-ageing/dementia/younger-people-with-dementia.aspx* . Developed in partnership with Alzheimer Scotland, it provides a range of insights and information from younger people with dementia and their family carers in their own words about what helps to live well with the diagnosis.

WIDER WORK

Our work on dementia is of course one strand of the wider work that we are taking forward to transform and improve health and social care services. Other key strands of that work include legislating for the local integration of adult and older people's health and social care services in Scotland; the need to improve the response to dementia is one of the key policy drivers for this work. Furthermore, we are investing £300 million to facilitate changes in the way services are designed and care is delivered, including services for people with dementia. Health and Social Care

Partnerships set out their intentions for the future delivery of care for people with dementia and their carers in their respective planning documents and have the ability to develop plans together through joint commissioning processes.

On caring, *Caring Together: The Carers Strategy for Scotland 2010-15,* which is underpinned by £98 million of investment between 2008 and 2015, recognises that carers must be seen as equal partners in the delivery of care as their support enables people with dementia to live at home and in their own communities safely, independently and with dignity. Finally, self-directed support is the major reform to the way in which social care and some healthcare services are delivered and gives greater choice and control to those who receive support, and the Alzheimer Scotland pilot on self-directed support in Ayrshire showed that self-directed support offers benefits to people with dementia.

I hope this reply is useful in addressing the issues in the petition and in placing them in the wider context.

Yours faithfully

Kathleen Bessos