



## Briefing for the Public Petitions Committee

**Petition Number:** [PE1480](#)

**Main Petitioner:** Amanda Kopel

**Subject:** Alzheimer's and dementia awareness

Calls on the 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.

### Background

The petitioner raises two main issues for consideration. The first relates to raising awareness of the issues faced by those with Alzheimer's and dementia. The second is a call for free personal care to be extended to all those with dementia regardless of age.

#### *Alzheimer's disease and dementia in Scotland*

In its latest [statistical release](#)<sup>1</sup> for 2013, Alzheimer Scotland estimates that approximately 86,000 people have dementia in Scotland, of which 3,200 are under the age of 65. Other publications<sup>2</sup> by Alzheimer's Scotland note that whilst there are many different illnesses that cause dementia, Alzheimer's disease is the most common. It estimates that 55% of those who have dementia will have Alzheimer's disease.

The petitioner provides information related to the symptoms of Alzheimer's disease and details why they believe awareness levels need to be raised. Additional information on such issues is available on the Alzheimer Scotland website [here](#).

#### *Free personal care*

Free Personal and Nursing Care (FPNC) was introduced on 1 July 2002 through the Community Care and Health (Scotland) Act 2002 (the 2002 Act) and associated regulations, and is available for everyone aged 65 and over who have been assessed by the local authority as needing it. Prior to this date people could be charged for personal care services provided in their own

<sup>1</sup> Alzheimer Scotland (2013) [Statistics: Number of people with dementia in Scotland 2013](#). This statistical release also provides estimate by local authority area in Scotland.

<sup>2</sup> For example, Alzheimer Scotland (2003) [Alzheimer's disease](#). [Last updated October 2012].

home and many residents in care homes had to fully fund their care from their own income and savings.

Personal care refers to anything done for the individual that is of a personal nature, such as personal hygiene, continence management, and food and diet. The full list is available [here](#)<sup>3</sup>. If the care an individual is assessed as needing does not fall within the listed categories, they may be charged for it. Nursing care is anything which requires the knowledge and skills of a qualified nurse.

If an individual aged 65 or over requires personal care as part of a home care package, they will not be charged for it. Individuals aged 65 or over receiving personal and / or nursing care in a care home can receive a payment towards the care component of their fees. On 1 July 2002, the personal care payment was set at £145 per week and has risen to its current rate of £166 (as from 1 April 2013). The nursing payment was set at £65 per week from 1 July 2002, rising to the current rate of £75 (as at 1 April 2013).

In July 2013, the Scottish Government published its latest [statistical bulletin](#) on Free Personal and Nursing Care. For ease of reference the key findings are replicated in [Appendix 1](#).

The policy of FPNC stemmed from the Royal Commission on Long Term Care, chaired by Lord Sutherland. This was established by the then UK Government in March 1998 in response to concerns over the funding of care for an ageing population. The [report](#) was laid before the UK Parliament in March 1999. Its main conclusions included that personal care should be free in all settings and paid for through general taxation. However, it also stated that

“We think our recommendations can apply in general to all adults with disabilities who may need long-term care.”

Given that, soon after the report’s publication, competence over most aspects of social care was devolved to the Scottish Parliament, the then Scottish Executive produced its own response to the Commission’s report. It accepted many of the Commission’s recommendations, but, initially, not that concerning free personal care. However, following a number of reports<sup>4</sup> and debates within Parliament, the Scottish Executive committed itself to bringing forward the implementation of FPNC, though only for older people<sup>5</sup>. Whilst evidence was submitted criticising the fact that young adults with disabilities were not to be included in eligibility for FPNC, it was not a significant issue of debate during the passage of the Bill that led to the 2002 Act. The then Scottish Executive’s position was that more work was needed to analyse the needs of

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<sup>3</sup> Care Information Scotland (Online) [Personal and nursing care](#).

<sup>4</sup> These included the then Health and Community Care Committee’s [Inquiry into the Delivery of Community Care in Scotland](#) report of 2000, which considered that the Royal Commission’s recommendations on free personal care should be implemented.

<sup>5</sup> For a synopsis of the background to the policy, see Health and Community Care Committee (2001) [Stage 1 Report: Community Care and Health \(Scotland\) Bill](#).

younger people with disabilities and to consider how the policy worked for older people<sup>6</sup>.

## **Scottish Government Action**

### *Raising awareness of Alzheimer's disease and dementia*

The Scottish Government made dementia a national priority in 2007. It set a national target on improving diagnosis rates in 2008 and published an initial 3-year [National Dementia Strategy](#) in 2010. The strategy was based on the premise that people who have dementia, and those who care for them, are entitled to dignity and respect and should be able to access services that provide support, care and treatment in a way that meets their personal needs. Through the strategy, the Scottish Government, local government and the voluntary and private sectors, committed themselves to delivering high quality services by, amongst other actions:

- developing and implementing standards of care for dementia
- improving staff skills and knowledge in both health and social care settings
- continuing to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support

Alzheimer's Disease International [analysed](#)<sup>7</sup> the strategy against 18 policy areas identified by Alzheimer disease experts that they would like to be addressed through such strategies. It found that whilst the strategy did address a range of issues such as dementia training, diagnosis and care coordination, it did not cover other areas including awareness raising.

The Scottish Government<sup>8</sup> has advised that in 2008 it undertook a pilot in Dundee and Perth on awareness-raising on dementia and to encourage people to seek support if they were concerned about their memory. The evaluation showed that people were more likely to seek help if they knew that support and information would be available following a diagnosis, if indeed they did have the condition.

Following a period of engagement with stakeholders that began in 2012, the Scottish Government developed a [second strategy](#)<sup>9</sup>, published in 2013, which sought to build upon the first. The key commitments in the new strategy include:

- dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma.
- better post-diagnostic support for people with dementia and their families.
- more people with dementia and their families and carers being involved as equal partners in care throughout the journey of the illness.

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<sup>6</sup> See [S1W-13333](#) and answer to S1O-3050 (Scottish Parliament [Official Report](#), 8 March 2001, col 377-378)

<sup>7</sup> Alzheimer's Disease International (Online) [Scotland's National Dementia Strategy](#)

<sup>8</sup> Personal communication 26 August 2013

<sup>9</sup> Scottish Government (2013) [Scotland's National Dementia Strategy 2013-16](#)

The Scottish Government<sup>10</sup> has advised that the first strategy (2010-13) consolidated its work in supporting better diagnosis rates (for example, the 2008-11 diagnosis HEAT target was achieved nationally) and it is now building on this and addressing the need for better post-diagnostic support by taking forward a 3-year [post-diagnostic HEAT target](#) (2013-16). This target is: to deliver expected rates of dementia diagnosis and by 2015-16, all people newly diagnosed with dementia will have a minimum of a year's worth of post-diagnostic support coordinated by a link worker, including the building of a person-centred support plan.

#### *Free Personal Care for those aged under 65*

The most significant review of the FPNC policy that has been undertaken since the inception of the policy was that by Lord Sutherland, who [reported](#)<sup>11</sup> in April 2008. However, the focus of the review was to investigate the level and distribution of resources for the policy and to make recommendations on its long-term sustainability. It made no recommendations to extend the policy to other care groups.

The Scottish Government has advised<sup>12</sup> that it has no plans to extend the policy to other care groups.

### **Scottish Parliament Action**

#### *Raising awareness of Alzheimer's disease and dementia*

There has not been an inquiry undertaken by a Committee of the Parliament that has covered the precise issues raised by the petitioner in this regard.

#### *Free Personal Care for those aged under 65*

This issue was raised during the then Health Committee's Care Inquiry, which [reported](#)<sup>13</sup> in June 2006. The aim of the inquiry was to carry out post-legislative scrutiny on recent community care legislation, including the 2002 Act. One element of the enquiry relates to FPNC. As well as considering such issues as implementation, funding and sustainability it also considered the possibility of extending the policy to other groups, including those with Alzheimer's disease who were aged under 65<sup>14</sup>. Overall, the Committee concluded that there was a logical and ethical case for extending free personal care to those who required care who were under 65. However, it also recognised that such an extension would be financially difficult to achieve. Nevertheless, it recommended that the then Scottish Executive actively consider the extension of free personal care.

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<sup>10</sup> Personal communication 26 August 2013

<sup>11</sup> Lord Sutherland (2008) [Independent Review of Free Personal Care in Scotland](#).

<sup>12</sup> Personal communication, 22 August 2013.

<sup>13</sup> Scottish Parliament Health Committee (2006) [Care Inquiry Report](#).

<sup>14</sup> See para 77-82.

In its response<sup>15</sup>, the then Scottish Executive noted the Committee's comments, but also referred to a policy review that was to take place. The Scottish Government<sup>16</sup> has advised that an [Evaluation of the Operation and Impact of Free Personal Care](#) was commissioned by the then Scottish Executive, and was published in February 2007. There was no mention of extending the policy to other groups.

**Jude Payne**  
**Senior Research Specialist**  
**27 August 2013**

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<sup>15</sup> Online copy unavailable. However, paper copies are available from the Clerks.

<sup>16</sup> Personal communication 23 August 2013

## Appendix 1: Key statistics related to Free Personal and Nursing Care

### Care Homes

- The overall number of older people in care homes has reduced slightly over the years since the Free Personal and Nursing Care policy was introduced, from nearly 32 thousand people in 2003-04 to just under 31 thousand people in 2011-12.
- The number of people in Scotland receiving Free Personal Care and/or Free Nursing Care (FPNC) payments to help pay their Care Home fees increased steadily in the first few years of the policy and in 2011-12 there were nearly 9,700 people receiving Free Personal Care payments. These payments are available to self-funding care home residents who have assets (including property) worth more than £25,250 from April, 2013. Over the last 5 years to 2011-12, the number of people receiving Free Personal Care payments has levelled out at just over 30 per cent of all older people in Care Homes.
- Around two-thirds of people receiving the Free Personal Care payments also receive the Free Nursing Care payment (just over 6,000 residents in 2011-12).
- The remaining 70 per cent of residents in care homes are publicly funded. These residents contribute to their care home fees from their pensions and any other income they may have and the local authority funds the balance which will be greater than the free personal and/or nursing care payments received by self-funding residents.

### Home Care

- The number of older people receiving personal care services in their own homes has increased from 33 thousand people in 2003-04 to nearly 47 thousand people in 2010-11 and 2011-12. Since July 2002, Local Authorities in Scotland can no longer charge for these services.
- This large increase in people receiving services in their own homes reflects an increasing older population and a move away from long-term care in hospital and care homes toward providing care in a person's own home for as long as possible.
- People receiving personal care services at home received on average nearly 7 hours of care each week in 2003-04. This has risen steadily to over 8 hours of care each week in 2011-12, showing that people receiving care at home have increasing levels of need.
- In 2011-12, 91 per cent of all older people receiving Home care services received personal care services as part of their package of care. This has increased each year since 2003-04 when only 57 per cent of clients received personal care.

### Expenditure

- The amount of money spent by Local Authorities on Free Personal care and Free Nursing Care (FPNC) payments to self-funding residents in Care Homes has increased each year from £86 million in 2003-04 to £111 million in 2011-12. This increase reflects the increasing number of self-funders up until 2008-09 and the annual increases in the FPNC payments from April 2008. All of this is new money arising from the FPNC policy.
- The amount of money spent by Local Authorities on providing personal care services to older people in their own homes has risen from £133 million in 2003-04 to £347 million in 2011-12. This more than doubling of spend over the last 8 years reflects the fact that an increasing proportion of older people are cared for at home, rather than in hospital or care homes; that increasingly home care workers are providing personal care services rather than domestic services; and that people living at home have increasing levels of need. It should be noted that this is not all new spend arising from the FPNC policy, but prior to the policy Local Authorities could generate income by charging people for these services.

Source: Scottish Government (2013) [Free Personal and Nursing Care, Scotland, 2011-12](#).