

Dementia in Scotland



April 2021 – Issue 102

Fair Dementia Care special edition



Not Fair. Not Equal. Not Right.
Help achieve Fair Dementia Care



Worried about dementia?

24 HOUR
Dementia
Helpline

Freephone 0808 808 3000
Email helpline@alzscot.org



Making sure nobody faces dementia alone.



Welcome

I have great pleasure in introducing this very special edition of Dementia in Scotland magazine, which may look substantially different than what you would normally expect. This edition focuses on one key subject: achieving Fair Dementia Care.

As you may know, the Scottish General Election will be held on Thursday 6 May. Across the country, we will all be asked to vote for who we believe should lead Scotland for the next four years. For Alzheimer Scotland, the Election is the opportunity to ask candidates from all political parties to show support for one specific piece, or several different pieces, of work. This year we are calling on candidates to pledge their support for our Fair Dementia Care campaign, specifically around the assessment process and the charging policies in place. You can read our pledge in full on page 6.

Our Fair Dementia Care campaign was launched in 2019, as a result of the 'Delivering Fair Dementia Care For People With Advanced Dementia' report. It was, and remains, one of the most significant campaigns in Alzheimer Scotland's history. People with advanced dementia, and their families, are on the receiving end of substantial inequalities; something the coronavirus pandemic has only served to highlight. For many people with dementia and their families, the decision to move to a care home is one of the most difficult decisions that will ever be made. On top of having to make this decision, the processes, including a financial assessment, are often incredibly complex and vary depending on which Local Authority area you stay in. Just recently, one carer told us that his wife pays approximately £1200 a week for her care home. She has been admitted to hospital for a period of six weeks and, short of losing her space in the care home, these fees will need to be covered despite the fact she is not living in the care home at this time. This is just one experience of many. This is just not right.

There are apparent differences in the experience of someone with advanced dementia compared to someone with another life-limiting disease, such as cancer. It is simply not fair that people with advanced dementia are having to pay for their care, because their needs are not recognised as health care needs. The costs associated vary based on individual circumstances (you can find out more about this on page 5) but the fact of the matter is that they are paying for care which, should they have had another illness, they would receive free at the point of delivery through the NHS.

As Chief Executive of Scotland's leading dementia charity, I have never been surer that we must do all we can to end this inequity. There are chinks of light with the proposed 7.5% increase in the Free Personal and Nursing Care payment, as well as the Independent Review of Adult Social Care which is proposing a National Care Service, however people with advanced dementia right now do not have the time to wait for these to come to fruition. They need, and deserve, action now.

This is why we need your help. On P10-11 you can find out how you can support our campaign. Whether it's writing to your local candidates, sharing our communications on social media or telling your story – you can make a difference.

I hope you enjoy this special edition of Dementia in Scotland magazine. We'll be back with our traditional format next month, with news on our support and services across Scotland. In the meantime, your support for this campaign is greatly appreciated. Take good care and stay well.



Henry Simmons

Henry Simmons, Chief Executive

We would like to hear your thoughts on Dementia in Scotland magazine. If you have any questions or comments, get in touch with the Editor, Dawn Ferguson, by email: dferguson@alzscot.org or by phone: 0141 410 0108.

Alzheimer Scotland is a proud signatory of the Digital Participation Charter.

This means that we are committed to ensuring that people living with dementia and their families have access to digital support and expertise across Scotland.

**DIGITAL
PARTICIPATION
SIGNATORY**

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Fair Dementia Care: the story so far

By Jim Pearson, Director of Policy and Research, Alzheimer Scotland



In the two years since we published the 'Delivering Fair Dementia Care For People with Advanced Dementia' report, Alzheimer Scotland has continued to campaign to bring about change so that people with advanced dementia have equality of access to free health and nursing care on a par with people with other progressive life-limiting illnesses.

Dementia is caused by progressive and terminal neurological diseases such as Alzheimer's Disease. In advanced dementia, people experience complex physical and psychological symptoms which require specialist health and nursing care. Our current social care model means that people with advanced dementia do not always have access to the health and expert nursing care that they need in advanced illness, and are disproportionately subjected to social care charges for what are primarily health and nursing care needs.

To date, over 18,000 people have supported our Fair Dementia Care campaign. Members of the Scottish Parliament from across the political spectrum have also supported Fair Dementia Care.

The COVID-19 pandemic has further demonstrated the inequity experienced by people living with advanced dementia in Scotland. Tragically many have died during this pandemic, and those who live in care homes have been denied the comfort of having meaningful contact with their families and friends as a consequence of the public health measures in place to prevent the spread of the virus. There is irrefutable evidence of the direct and indirect harm of COVID-19, yet people with advanced dementia continue to face care home charges despite what are primarily health and nursing care needs.

Fair Dementia Care

However, since we launched the Fair Dementia Care Campaign there has been progress. The Scottish Government have recently proposed an above inflation increase in Free Personal and Nursing Care payments of 7.5%. This is a modest but positive step forward and demonstrates that Fair Dementia Care can be achieved within the existing legal framework providing the political will exists.

A further positive development has been the recently published Independent Review of Adult Social Care report, which sets out a transformational and positive vision for a new future for social care in Scotland, including the creation of a new National Care Service. The Scottish Government have committed to implementing the recommendations of the report in full. These include recommendations to end all non-residential social care charges (for social care provided in the community) and a substantial increase in the level of Free Personal and Nursing Care payments for people living in care homes.

We welcome those proposals. However, people living with advanced dementia today do not have time to wait several years for the type of transformation set out in the Independent Review to be implemented. Nor do we believe that the proposed increases in Free Personal and Nursing Care payments go far enough. While this is a substantial step in the right direction, Alzheimer Scotland are calling for every person with advanced dementia to have an individual assessment of their health and nursing care needs, and a corresponding increase in Free Personal and Nursing Care payments which reflects the actual cost of providing that care. Only then will people with advanced dementia be treated equally with those who have other progressive and life-limiting illnesses.

Did you know?

Social Care in a care home is not free. If you are assessed as needing care in a care home you will have to pay towards the costs.



How much you pay will be determined by a financial assessment process carried out by your Health and Social Care Partnership.



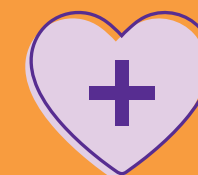
The financial assessment helps them decide whether you qualify for public funding towards the costs of the care (and how much) or if you should be self-funding.



Whether you are self-funding or entitled to public funding, you will normally be entitled to a free personal care contribution.

If you are assessed as requiring nursing care then you will also receive a nursing care contribution. The weekly rates from April 2021 are:

£193.50
for free personal care
£87.10
for nursing care



The financial assessment calculates how much income and capital you have.

Capital can include things like savings, cash, investments, or land and property that you own.



If you are the legal owner of your home and it is no longer occupied by a spouse or partner, relative aged 60 or over, or a child under 16 your home may count as part of your capital.



The standard rates for care homes run by private companies (or voluntary organisations) for 2020/21 are:

£740.00
a week for nursing care
£635.79
a week for residential care



Note – at the time of publishing, the rates for 2021/22 weren't available.

Note – The rates depend on whether you are assessed as requiring nursing or residential care
Note – these rates may be higher in care homes owned and managed by your Local Authority. Some Local Authorities may also set higher rates for people in private/voluntary sector care homes who have more complex needs.

Those who have a weekly income lower than the standard rate, or who have **savings under £28,750 (from 6 April 2021) will qualify for financial help** up to the level of the standard rate.



If you are assessed as having income above the standard rates or have **capital of over £28,750 (from 6 April 2021) you are considered self-funding.**



If you are self-funding the weekly care home fees are likely to range between **£740 and £1,800 per week.**

What we're calling for

People with advanced dementia continue to face care home charges for what are clearly health and nursing care needs.

During the Scottish Parliamentary Election campaign, we are asking our members and supporters to contact their candidates, and ask them to pledge to deliver Fair Dementia Care for people with advanced dementia.

Alzheimer Scotland is calling on candidates from all political parties to end this inequity and pledge to deliver Fair Dementia Care for people with advanced dementia by committing to:

- Ensuring that every person with advanced dementia, living in a care home, has an individual assessment of their health and nursing care needs.
- Support an increase in Free Personal and Nursing Care payments to a level which is equal to the actual cost of the care people with advanced dementia need.

Between
70% – 90%
of people living
in Scotland's care
homes are people
with dementia*.



We estimate that **35%**
of those are living with
advanced dementia
and because social
care is not free, they
are disproportionately
impacted by social care
charges*.



Fair Dementia Care is about
ensuring that those with
advanced dementia receive
free health and nursing care
on a par with those with other
progressive and life-limiting
illness.



*Alzheimer Scotland 'Delivering Fair Dementia Care for People with Advanced Dementia' report, 2019



Fair Dementia Care Election Pledge

I fully support Alzheimer Scotland's call for Fair Dementia Care for people with advanced dementia in Scotland.

If elected to the Scottish Parliament, I pledge to help deliver Fair Dementia Care by:

1. Working to ensure that every person with advanced dementia, living in a care home, has an individual assessment of their health and nursing care needs.
2. Supporting an increase in Free Personal and Nursing Care payments to a level which is equal to the actual cost of the care people with advanced dementia need.

To find out more visit

www.alzscot.org/fairdementiacarepledge



Action on Rights

Alzheimer Scotland's new Action on Rights team, funded by the Scottish Government, has been set up to help carers, families and friends of anyone living in Scotland's care homes. The team can support you:

- To have meaningful contact between those living in care homes and their families and friends; and where necessary and appropriate to liaise directly with care home staff responsible for visiting arrangements to facilitate visits (when permitted and within any relevant restrictions)
- To be better informed about care home visiting guidance, local public health restrictions and support available to you
- To make more informed decisions and have better dialogue with care homes around visiting
- To explore alternative ways for meaningful contact when restrictions result in the suspension of visits
- To have access to the range of support that Alzheimer Scotland provide
- To be supported to access the support of other agencies or organisations
- To obtain support to address the trauma and distress of the pandemic and restrictions.

Making sure nobody faces dementia alone.

The Action on Rights team are available Monday-Friday by calling our 24 hour Freephone Dementia Helpline on **0808 808 3000** or email actiononrights@alzscot.org

Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered in Scotland 149069. Recognised as a charity by the Office of the Scottish Charity Regulator, no. SC022315 160 Dundee Street, Edinburgh, EH11 1DQ. 0131 243 1453. www.alzscot.org

Our experience of paying for care

By Jim Nixon

I met Frances in 1982 when we were at university. She was beautiful, smart, sociable and had an absolutely wicked sense of humour. We married in 1986 and had two children who are now 26 and 23 – our pride and joy. Frances spent most of her working career in financial services and held senior positions before she accepted redundancy in 2009. She was so clever; and we were all so proud of her when she undertook an MBA which she achieved with distinction in 2010.

Frances started to notice a decline in her concentration and memory initially, which progressed after her MBA. She was applying for jobs and being invited to interview, and she noticed she was struggling to think of examples in answer to the interview questions. Frances accepted some senior level contracting work but eventually realised that she was just not able to continue with the positions anymore. It was so tough seeing my wife, the person I'd been with for over 30 years, start to change. It was gradual – starting with losing her confidence and wasn't the commanding figure she had once been.

Frances made the tough, but right, decision to look at jobs which she felt would be easier for her and she got a job in the clothing department of a high-street store. Initially she found this relatively ok however it became an increasing challenge. She was struggling to remember details; if customers asked her a question, she would need to write it down and then eventually she was finding it hard to recall the question even before she wrote it down. We knew then that it was time for her to retire.

By this point, we were both aware that there was something wrong but it was really difficult to get a diagnosis, mainly because of Frances's age. When she eventually received her Alzheimer's diagnosis, she was just 53. As I've heard is quite common, Frances's symptoms were put down to many things: depression, anxiety, menopause – everything except dementia. Whilst receiving this diagnosis was devastating, we used the label as the opportunity to get access to support and we both benefited vastly from Alzheimer Scotland's Edinburgh Services – both the Day Care and the one-to-one support. We also used the time we had to make more memories; we went on incredible holidays to Italy and travelled to see Frances's family down south. She was such a sociable person and the diagnosis didn't change that – we went to dementia-friendly art galleries and museums, we loved walking and went on hotel breaks which we both enjoyed so much.



As time progressed, we were beginning to struggle a bit more. I am a Modern Studies teacher and initially I was able to reduce my hours, however it got to a point where I had to retire to become Frances's full-time carer. For the first 6–9 months, this was ok – we remained sociable. I'm so glad that I have these memories to look back on, they were such treasured times. However, Frances's dementia progressed and I really began to struggle. There was a lack of respite for carers, which is common when the person who has dementia is younger.

In December 2019, Frances got a space in an Assessment Unit. This was initially for a period of 6 weeks, which I used to look at our options. As a family, we knew Frances would have to go into residential care which is one of the toughest decisions we will ever have to make. The full process of finding a suitable care home, knowing what our rights were and undergoing a financial assessment was so complex and you find yourself navigating this really difficult path whilst having to accept the circumstances you find yourself in. Frances's age also made the process much harder; most care homes won't accept you unless you're over 65 which just shows how dementia is still treated as an older person's illness and how there is a complete lack of understanding about the scale and complexities of the condition. The whole process was unnecessarily stressful – you find yourself asking questions and asking for help from people who should know the answers but don't.

Eventually I found Frances a care home close to where we stayed, and she moved in on Wednesday 11 March 2020 – two days before the care home shut down due to the pandemic. Having gone through the financial assessment, Frances's contribution was set at £840 a month. I cannot fault the staff at all, they were fantastic, however I still find it incredibly unfair that people with advanced dementia are subject to these charging policies.

We were both involved in the initial Alzheimer Scotland Fair Dementia Care campaign. Frances had a strong justice/injustice line. She didn't like people being treated unfairly – whether that was on tv, in work or at home. My sister had died in February 2019 of cancer and there are such distinctive differences in the way these two conditions are treated. There was no question of money; whether my sister could afford her care and nobody had to agonise over care homes for her. At that point, Frances and I felt it so

unfair that we were having to make provisions for her eventually going to a care home. We had no idea how long Frances had, what the costs of a care home would be, or whether she would get a space in a place that would be right for her. At a time where the focus should be creating memories and doing the best with the time you have left, the last thing you should do is have to worry about financial implications. My mum would say it was like Britain in the 1930s when people wouldn't go to the doctor for fear of affording it.

Frances died in December last year aged 57. After she went into the care home in March, I didn't get to see her again until July. There's no doubt in my mind that the pandemic sped up the progression of her dementia, however we were lucky in a sense that we could make use of the garden visits and then latterly, some indoor visits before the care home went back into lockdown. The staff in the care home really did their very best, but they weren't Frances's family. They didn't know her like we did, no matter how much they tried. We were the ones who knew her wishes, her likes and her dislikes. We also knew which names, stories, songs etc would generate a smile or a remark from Frances; smiles and remarks that were so special to us as a family.

If Frances had gone to a night out and there were only 20 people there, it was a quiet night. For her to have only 20 people at funeral was difficult, however our family have been overwhelmed at the outpouring of love shown. We knew it anyway, but it was so clear just how well thought-of she was. Colleagues from years ago got in touch and came along to the funeral – I'm so proud of my wife for being the supremely intelligent, witty, outgoing and kind person she was. The kids and I miss her every day but count our lucky stars that she was ours. **We are determined to do right by Frances and hope that by sharing our story, people will see just how unfairly people with advanced dementia are treated. We owe her that.**



Some of the details in this article have been changed to ensure anonymity.

How you can get involved

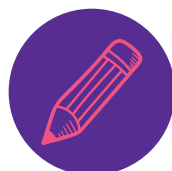
Alzheimer Scotland is wholeheartedly committed to ending the various inequities people with advanced dementia, their carers and families face every day in Scotland.

We need your support to do so, and here's how you can help:



You can write to your local candidates ahead of the Scottish Election on 6 May 2021.

- On page 11, we've drafted a letter you can copy and send to your candidates. This can be downloaded from our website (www.alzscot.org/fairdementiacarepledge) and printed off, or copied in to an email.
- If you're unsure who your candidates are, you can find out by visiting: <https://whocanivotefor.co.uk/>



If you are aware of any local hustings taking place, you could attend and ask your candidates to show support for the pledge.



If you have your own story to tell, we would love to hear from you. You can email us: info@alzscot.org or phone us: 0131 243 1453.



You can show your support on social media by sharing our campaign posts and asking your networks to support Fair Dementia Care. We will be launching a frame that you can put on your Facebook profile photo, which is a really easy way of raising awareness of Fair Dementia Care.

Follow us here:

 @alzheimerscotland

 @alzscot

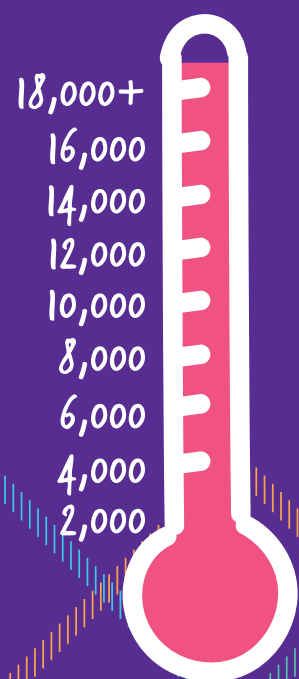
 @alzscot



Over 18,000 people have signed up to the Fair Dementia Care campaign so far

and thousands more have supported us in a variety of ways. By doing so, Alzheimer Scotland is one step closer to ending the inequities faced by people with dementia, their carers and families. You have made a difference.

Thank you



Dear (Candidate name)

I'm contacting you as a local resident to ask you to sign **Alzheimer Scotland's Fair Dementia Care pledge**.

People living with advanced dementia have complex physical and psychological symptoms. However, they do not always have equality of access to the specialist health and nursing care they need and are disproportionately impacted by social care charges. Alzheimer Scotland's Fair Dementia Care campaign seeks to address these inequities by ensuring that people with advanced dementia have equal access to free healthcare on a par with people who are living with other progressive and life-limiting illnesses.

Since launching the Fair Dementia Care campaign two years ago, more than **18,000** people have signed up to support it, including MSPs from across the political parties. The recommendations of the recent Independent Review of Adult Social Care in Scotland, including those to end non-residential social care charges and substantially increase Free Personal and Nursing Care payments for those in care homes, are positive but will take time to come to fruition.

Those with living today advanced dementia don't have the time to wait – they need and deserve action now.

That's why I'm supporting Alzheimer Scotland's call for candidates in the Scottish Parliament election to commit to the **Fair Dementia Care pledge**:

- Ensuring that every person with advanced dementia, living in a care home, has an individual assessment of their health and nursing care needs.
- Support an increase in Free Personal and Nursing Care payments to a level which is equal to the actual cost of the care people with advanced dementia need.

These two measures can be implemented quickly and within the existing legal framework.

I hope that you will sign the pledge, support urgent measures to deliver Fair Dementia Care and, if elected, assist to quickly deliver these two actions that will help address the inequity currently faced by people living with advanced dementia.

You can sign up to the pledge and get more information on the Fair Dementia Care campaign by visiting www.alzscot.org/fairdementiacarepledge.

Thank you in anticipation of your support.

Yours faithfully

Alzheimer Scotland would like to thank William Hill and Newsquest (The Herald and Times group) for their unwavering support for the Fair Dementia Care campaign.



**Alzheimer
Scotland**
Action on Dementia

DEMENTIA AWARENESS WEEK

31 May
– 6 June

Show your support for people living
with dementia now and in the future

Making sure nobody faces dementia alone.

#DementiaAwareness



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