

**PE1480/L**

Petitioner Email of 18 May 2015

Dear Chris,

Thank you very much for your email.

There are quite a few points that I would like the Petitions Committee to consider, which I will detail below. I apologise in advance as to how many, but as it is such an important issue I really feel the need for them to read them and deliberate. Thank you.

Notes referred to:

1. I and others, like Mr Jackson Carlaw are extremely concerned and disappointed by the lack of action from the Scottish Government on this very important matter. I first addressed the Public Petitions Committee in September 2013 and since then I have lost my husband to one of the most cruellest diseases, dementia.
2. I realise that change takes time, I was advised of that when I spoke with Mr Alex Neil the then Cabinet Health Minister at the meetings both Frankie and I had with him when he gave us hope and promises, time which in March of last year when my husband turned 65, no one could have ever imagined that time was running out for Frankie...no one.
3. There are approximately 3500 people in Scotland under the age of 65 with dementia. Has any Government Minister or Department actually advised of the cost of free personal care for these people, when they are assessed as needing? I say "when they are assessed as needing it" as opposed to "at point of diagnosis" I am led to believe that there seems to be some confusion in certain circles as to these two points. I would like to clarify that I have always stated that it is "when they are assessed as needing it". Speaking from personal experience, my husband was diagnosed with dementia when he was 59 and did not need personal care then, but as he deteriorated, then he needed personal care.
4. He like others, had lost his job and his income through no fault of his own. Dementia as you will be aware is a disease of the brain, NOT of age.
5. This dreadful disease robbed him of his mind, the sight in one eye, he was doubly incontinent, he lost control of his bladder and bowel, his mobility, his dignity and finally his life to a disease which there is no cure for.

6. On the 17th April last year the day after he died I could have decided not to carry on with the campaign, because after all Frankie did not need personal carer, but I am receiving letters, emails, phone calls from other young people and their carers who are being blatantly discriminated against because of an age on their birth certificate, and are pleading for me to carry on. How many more people who are terminally ill and aged under 65 I have to ask have died having to pay for their personal care?

7. I have already addressed 4 Councils in Scotland regarding this matter and they have supported me unanimously and have written to the First Minister, Nicola Sturgeon to advise her of their support for Franks Law. One council which is the 3rd largest Council in Scotland and have supported Franks Law, advised me that they do not charge anyone for personal care. Two Councils have received replies back.

8. As noted below regarding the decision that "no one with a terminal illness in Scotland will pay for their personal care in Scotland in the last 6 months of their lives" Not only do I find that appalling, insensitive and insulting to anyone who has had to watch their loved one die in front of their eyes. NO expert, NO dementia consultant, NO doctor told my son and I in November 2013 that Frankie would die in April 2014....neither did NONE of these experts tell my son and I on Frankie's 65th birthday on March 28 2015 that he would die 19 DAYS LATER.....and yet from correspondence it would appear that someone sitting behind a desk is predicting when a person will die. When I voiced my concerns about 6 months end of life with the Cabinet Health Minister in January, she advised Dr Stewart and myself that she and the First Minister took their guidelines from Cosla and the DWP.

Correspondence sent and received since January 2013

6th January 2013: I wrote to the then First Minister Alex Salmond of the difficulties we were experiencing regarding personal care and benefits.

25th January 2013: Reply from the said FM advising me to seek help from Cosla and also that it was up to Councils what to charge for personal care.

18th November 2014.....Letter from Mr Alex Neil to Mr David Stewart, Convener, regarding terminally ill people under the age of 65 advising working positively with Cosla to ensure clear guidelines to Local Authorities regarding no charging for personal care.

February 2015: Letter from the Cabinet Health Minister Shona Robison to Mr John Pentland, Convener regarding people under the age of 65 with complex needs?. My thoughts on complex needs. (Actually these people do not have complex needs, they are dying with a terminal disease. No disability, illness, condition or disease waits around until a person reaches 65 then strikes)

12 March 2015: Letter from Jamie Hepburn, Minister for Sport, Health Improvement and Mental Health to Angus Council Chief Executive to advise that the Scottish Government are considering what further action to take and the letter states that the Scottish Government has already ensured that no one in the last 6 months of a terminal illness is charged for the care they receive at home.

My question then is....(hypothetically, if say someone had told a person under 65 that they had only 6 months to live and that person didn't have to pay for their personal care at home, what would then happen if that person were to live for say another 4 months? Because as the rules state now, personal care for the under 65's is only for 6 months.)

April 17 2015: A 6 page letter from myself was handed by a family member personally to Mr Alex Salmond regarding the ongoing campaign to introduce Franks Law. In it I have asked many questions, not only in memory of my late husband but for many people in Scotland whose shoes "I have walked in" because I know what it is like to be discriminated against because of their age. I do personally feel that the Scottish Government have possibly lost sight of what Franks Law is about.....one small word...and one big word....and these are AGE DISCRIMINATION. Free Personal Care as you will all be aware was introduced 13 years ago in 2002 when retirement age for men was 65, it is now 67 or even older.

20 April 2015: Letter from Cosla to the Public Petitions Clerk advising that "whilst there has been some general discussions on potential anti-poverty measures with the Scottish Government, they have not formally discussed the extension of Free Personal Care to people aged under 65.

(This appears to be a confusing message as to the extensive talks they have held with the Scottish Government?)

I was asked at one of the Council meetings last week had I personally received any reply from the Cabinet Health Minister since myself and Dr William Stewart, a Consultant Neuropathologist at the Southern General Hospital in Glasgow met with her and they were disappointed to hear that I had not received any personal reply since our meeting on the 29 January this year.

Chris I do sincerely hope that all these valid points are shown to the Petitions Committee at the meeting on the 26th May 2015.

Once again, many thanks for all your help.

Kindest Regards

Amanda Kopel