

PE1480/P

Petitioner Email of 26 November 2015

Dear Sigrid,

My apologies for not replying sooner to you with my submission.

The submission which I would like put forward to the Public Petitions Committee for their consideration at the next meeting are as follows:

I have always said that although I had experience of living with my late husband who was a young person with dementia and lost his life at the young age of 65, I did not have experience of living with someone with MND, MS, Parkinson's or other brain degenerative disease. However, when I am asking for free personal care for the under 65s with dementia, I am including these other people as well.

I would like the threshold for free personal care, for those under the age of 65 who are "assessed as needing it", not at "point of diagnosis". This is a very important statement as it is not always synonymous when someone is diagnosed with the condition. There is a huge difference in cost, as no two people will progress at the same rate with a terminal disease. Also I would like to point out that not everyone under the age of 65 may need personal care in their lifetime. We are constantly being told that we are all living longer, but sadly the people, like my late husband and others under the age of 65 never got that chance when they were diagnosed with a terminal disease. This is a very important statement as it is not always synonymous when someone is diagnosed with the condition.

As the dementia progressed, my late husband lost his job, and his income, and because he had not yet reached state pension age, he was unable to draw any of the pension, which I would like to add, he had paid into all his working life, a grand total of 45 years, from the age of 15. So basically my husband had actually paid for his personal care over the years. Surely some departments should have communicated with each other and when my husband was assessed as needing personal care and dying with a terminal disease, he should never have been charged for personal care. The amount which he had to pay for personal care, when he was assessed as needing it, would have been a pittance compared to the amount which he had contributed to over the 45 years.

Who knows if dementia had never come to our door, that my late husband may have lived until he was in his 80s or 90s, and drawn that state pension which he had contributed to all those years?

I feel very strongly that the current test for free personal care to be flawed because it discriminates against the under 65s. I was always lead to believe that age discrimination in any situation in our country was illegal.

At present, one day separates the difference between a person paying for personal care and that same person not paying for it. The day they were 64 years of age they have to pay for personal care, and yet on the stroke of midnight that evening when they turn 65, personal care is free. The care both days would have been the same, there is no difference in the care that person would receive.

Which brings me on to the "6 months end of life guidelines" and that no person pays for personal care in the last 6 months of their lives. I and others who have sadly lost their loved ones at a young age question who is predicting a persons end of life? Dr W Stewart a consultant who attended the first meeting with me which we had with the present Cabinet Health Minister in January of this year, advised the Minister that "his profession got it wrong on end of life", and that he had been a consultant for many years and his wife, and that no one in his profession could predict 6 months before a person died.

I advised the Health Minister that no expert, doctor or consultant who were caring for my husband professionally over the time he had dementia came and told myself or my son in November 2013 that my late husband would lose his life to that dreadful disease in April 2014. Neither did any of these same experts in their field told us on my late husband's 65th birthday on March 28th 2014 that he would lose his life 19 days later.

Hypothetically, what if we had been advised that he only had 6 months to live, and he lived over the 6 months of not being charged for personal care at end of life? What then would have happened if say, he had lived another 4 months or more? Would he have been asked to begin paying again for peal care, as he had not passed away in the stipulated time as laid down in black and white, or does the free personal care carry on until the day he died?

Alzheimer's Scotland have recently published the figures for people with Dementia in Scotland which make very interesting reading.

90,000 people over the age of 65 have Dementia, and only 3200 under the age of 65 have Dementia. A very small figure as I am sure you will agree?

The people over the age of 65 will have reached pension age and be drawing that pension and getting free personal care. Yet the people under 65, like my husband and others who have sadly lost their lives to Dementia, did not draw that pension and yet were charged for personal care.

Their life expectancy was reduced dramatically the day they were diagnosed, and ironically as the law stands at the moment, if they had been lucky enough to reach 65, personal care would have been free of charge.

Their battle, which they are never going to win with these diseases, which there is still no known cure for is hard enough, without the added burden of scraping together money to pay for personal care.

It is time that people in Scotland are allowed to die with the dignity and respect that they deserve, but sadly because of a law which was passed almost 14 years ago, they are denied this. It is ageism.

No disability, no illness, no condition, no terminal disease waits until a person reaches 65 then strikes.

None of us know what our future holds, or when we may be struck down with any of the above. We may go into a ripe old age and never need personal care. However, if we are under 65 and any of these strike, the people of Scotland need to know that our government has delivered the justice, equality, fairness and compassion which we have heard many times. It is time to deliver Frank's Law.

On a final note, the day my husband died in my arms, I could so easily have torn up the campaign as he was no longer in need of free personal care. Also in June of this year, I turned 65, and as the present law states, if I am ever assessed as needing personal care It will be free. People ask me why I am still fighting to have Frank's Law introduced? Well, I have walked in these people's shoes, and I know what it is like for them and their families to be blatantly discriminated against because of the age on their birth certificate.

Kind Regards

Amanda Kopel