

PE1480/V

Letter from Dr Amanda Kopel of 17 September 2016

Thank you for forwarding on the Scottish Government response. Unfortunately it does not really address the issue of the future plans for the Scottish Government and I remain uncertain of what is due to happen.

Age is continuous between birth and death.

None of us can escape that fact, so why should any human being in Scotland be discriminated against because they did not follow the rules by being diagnosed with Dementia under the age of 65?

I'm sure the committee would agree that no disease, no disability, no condition, no illness waits until a person reaches 65, then strikes?

Of course this age discrimination applies not only to people with Dementia, but others under the age of 65 who also broke the rules, by being diagnosed with other terminal diseases.

People, who, when they were assessed as needing help with personal care, at a time in their lives, we're not only battling for their lives, but having to battle a law which was introduced 14 years ago.

A law which was passed in 2002 and it was agreed at that time that further discussions would be held in the future regarding free personal care for the under 65s. It would be helpful if a member of the committee could advise me what dates, following that decision in 2002 were these important discussions held?

Certain steps, albeit small steps, I am advised, are being taken to address this age discrimination which is still existing for the under 65s in Scotland. The £6m which was offered to be shared between the 32 councils in Scotland was at least a start, and I hope that it was ringed fenced by each council so that the under 65s who were assessed as needing personal care and who were originally paying for it, are now not being charged?

However, how many more people under the age of 65 in Scotland are going to lose their dignity, their respect and ultimately their lives, going to their grave having to pay unfair charges, before an archaic law is changed which would help them? Their battle is difficult enough without battling bureaucracy.

I ask the committee to imagine that if it were their loved ones, their family members or even themselves who were being treated so unfairly, would you not like to know that there was a system in place, which would benefit all who were assessed as needing the help, and not just those lucky enough to have reached 65?

Please, I also ask you to come and walk in that other persons shoes for 24 hours to understand what it is like to be discriminated against because they didn't follow the rules by becoming ill, some terminally. Because I truly believe if you did, and you saw the heartbreak, despair and their hopes continuously being dashed by the indecision to change an archaic law, the matter would be resolved as a matter of

urgency. As to the 6 months end of life guidelines which has been in place since April 2015, which states that "no one in the last 6 months of their lives, regardless of age has to pay for personal care in Scotland,"

1 - Who is accurately predicting the final 6 months in a human beings life? As I was advised by a consultant that no one in his profession could ever accurately predict the last 6 months of a persons life. This is no reflection on any of the medical profession in any way, I am just pointing out a fact.

2 - What would happen if that person did not die at the end of the 6 months and lived for say, a further 4 months, which could and has certainly happened? Does that person carry on receiving free personal care until they sadly die, or do the authorities advise that person that they must begin paying again as the rules state " it is for only 6 months" I am not asking the Government or Councils to withdraw funding from any other groups which they already fund, what I am asking is that the funding is shared out equally, fairly and justly, which is every human beings rights.

Everyone of us, will, at some point in our lives need help, and that help should be there for all ages, not just for the chosen few, who have been lucky enough to have reached 65.

Every person is an individual, and just as that person has individual characteristic etc, one thing is certain, no two people will reach a stage due to ill health in their life at the exact same time.

Scenario..... Two people one aged 64, and the other person aged 65, both have dementia, both have reached a stage in that disease and have been assessed as needing help with personal care. The care is exactly the same, yet the younger person has to pay for that personal care, whilst the person over 65 does not. One day separates whether a person pays for that personal care, the day before their 65th birthday, or does not pay, the following day when they reach 65.

No one, regardless of age, creed, colour or gender should ever be discriminated against in Scotland....and certainly no person under the age of 65 who is in the advance stages of any disease which is robbing that person of their life, should be either. They deserve the same dignity and respect that the over 65s and other groups receive.

I would also like to conclude that I am in total agreement with the SACT petition 1533 which has been submitted and which will also be discussed at the meeting.

Yours sincerely

Dr Amanda Kopel LLD