End of Life Assistance (Scotland) Bill

Wilma Lawrie

I am a disabled person living with what is termed, a rare medical condition namely osteogenesis imperfecta (brittle bones), and am hugely concerned about the End of Life Assistance (Scotland) Bill and the implications it will have on my life and those of many other disabled people. For this reason I wish my submission to be considered by the Committee and would welcome the opportunity to give oral evidence to the Committee.

Do you agree a person should be able to request end of life assistance from a registered practitioner?

No, because according to this part of the Bill the ‘designated practitioner’ does not need to be the doctor with whom the person has been registered for health care. A different practitioner would have no familiarity with the person’s medical condition beyond what is recorded in any case notes and will have much less experience of their psychological state and what has created that state of mind. Such a practitioner would not be best placed to carry out a full assessment of such a request. It is my personal experience that what has been recorded in my case notes contains many inaccuracies due to lack of knowledge of my medical condition but also due to preconceptions and misconceptions of medical staff.

Some of the worst ‘care’ I have received has been when I have been at my most vulnerable, including when very ill with a serious bone infection, in hospital.

I am thankful however, that it seems that the majority of practising physicians across Scotland are opposed to euthanasia and would be unlikely to agree to participate in “end of life assistance”. I would have very little faith in a physician treating or caring for me if I felt they would take part in such assistance.

Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

No. As someone who has worked professionally (directly) and voluntarily (indirectly) with young people all my adult life it alarms me that the minimum age is 16. In a matter of such seriousness it must be recognised that there is a huge difference in the maturity of a 16 year old compared with an 18 year old. It would therefore be critical that the minimum age criterion should be 18 years.

In terms of connection, my understanding is that registration with a medical practitioner in Scotland needs continuous residence of 3 months. The Bill states, “that it is not necessary that the requesting person should have been registered with the same medical practice throughout the [18 month] period”.

1
I would imagine, therefore, that it would be quite straightforward for someone outwith Scotland to take a lease on a property near to a General Practitioner who was sympathetic to “end of life assistance” or to come to live with a relative or friend in Scotland.

Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

No. These 2 categories will include the majority of people who are considered seriously or moderately ill or disabled.

It will cover not only people who are expecting to die in the near future but also those living with degenerative conditions who may have many valuable and constructive years of life ahead, people living with fairly common and disabling conditions such a heart or lung disease, arthritis and diabetes (insulin-dependent) that reduce independent living would also be included, as would alarmingly, disabled people who are not ill in the normally accepted sense but are incapacitated to the extent of needing support from others (these conditions will be very wide ranging).

Any person in Scotland in any of these categories would qualify for “end of life assistance” under the Bill. Surely these numbers could run into hundreds of thousands and perhaps more than one million. The added qualification that the person must be someone who “finds life intolerable” is utterly meaningless as anyone who has reached the point of applying would be at that stage.

Are you satisfied with the several stage consent and verification process?

No. It seems highly flawed. It is not clear how the 6-month prognosis would be decided. Many terminal conditions might well be given less than 6 months if left untreated but this would be unlikely to lead to death in such a short period if appropriate treatment were to be given. I am concerned that the 6-month prognosis assumes non-treatment but know of many people who live much longer than predicted and have a friend whose mother was told she would die before she was 10 – she is now in her 50’s and leads a full, active life with support.

As someone who lives with pretty much constant pain, at times managed by high doses of controlled drug analgesia, I know that my experiences of pain control when in hospital have been radically different on occasions when I have been left in severe pain at times. Good pain control and palliative care are crucial and can change an individual's views of their future life.

I am also concerned that it is not made clear in the Bill what means of “end of life assistance” may be given and this would suggest that there would be no limits.

In relation to the second formal request, I feel that the minimum period of 15 days is far too short and would make the person applying for “end of life assistance”...
assistance” feel unduly pressured. I think that the minimum must be at least one month and a maximum of a more suitable time, again to avoid the person feeling undue pressure. Surely at this second stage, it cannot be the same “designated practitioner” who does the approving, as their views would be unlikely to have changed. A second opinion should be sought from someone entirely separate from the first stage. The same would apply to the psychiatrist involvement and any such psychiatrist would surely have to have more than a mere discussion with the applicant and undertake a very full examination too. Additionally, I do not feel that a relative or anyone who is likely to gain from the death of the individual should be allowed to express their views to a psychiatrist.

As a disabled person, I have at times felt pressured from external sources to make decisions that would not be in my best interests. Without the support of people who have experienced similar pressures, I could have made wrong decisions that would have had major impacts on my quality and experience of life in the widest possible sense.

Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

No, as you will gather from my earlier comments.

Other considerations on the Bill not included in answers to the above questions

I am very concerned that this Bill comes from the misguided belief that “it is generally accepted that support for assisted dying appears to be growing in Scotland and across the United Kingdom” and that the extent of this piece of legislation would mean that it would apply to hundreds of thousands of seriously ill and disabled people across Scotland including those of us and our allies who fought long and hard for the Disability Discrimination Act 1995 and 2005 and the subsequent Equality Act 2010 (the impact of these pieces of legislation is still not fully recognised and acted upon by the NHS in their Equalities Strategies).

To state that a person must be “permanently physically incapacitated to such an extent as not to be able to live independently” and in the Explanatory Notes that “persons able to live independent lives without the need for any assistance would not qualify under the provision of the Bill” is frightening. If this Bill becomes legislation I will fear for my life and the lives of other disabled people because I believe it could cause doctors and other medical personnel who currently assist us to live ‘equal’ lives to alter their thinking. They may believe that this Bill is what we actually want – a completely wrong diagnosis. I would feel hugely vulnerable.

People who acquire disabilities through injury etc may feel that their lives are no longer worth living due to ingrained societal and media perceptions of disabled people but if they are given the support and opportunity to meet with disabled people who lead full, active lives with or without supports, whether
that be in the form of employing personal assistants or whatever, they can realise that, in fact, whole new worlds and opportunities can open up to them. It is the fear of the unknown, which is greatest.

There is much publicity given to Dignitas, the Netherlands euthanasia and Oregon legislation and the tragedy of suffering with a disability. The media has a great role to play in the public perception of living with a disability. I would hope that the Scottish Parliament would continue to play its role in actively challenging the misconceptions around living with a disability, whether one needs assistance to live independently or not.

Disabled people, do, on occasions need encouragement to live and not to give in to society’s (incorrect) view that our lives and situations are so tragic, burdensome and insufferable that we would want to die. One does need, at times, to have incredible will and inner strength to rise above such views and especially so if those are the views of our loved ones.

It is crucial to me that I know that those who care for me, ie doctors and other medical personnel, guarantee that they will do their utmost for me and that they support my continued life and its value. I will be hugely concerned that if the Bill succeeds then those who I rely on will give up on me when I need them most.

I am concerned that this Bill singles out sick, ill and disabled people and that we will be more eligible for assistance with suicide than the rest of the members of Scottish society. We do deserve the best care and support to live full lives with whatever we would so need.

I feel that those people who support this Bill fear disability and terminal illness whereas the reality of the situation is that I firmly believe that I have a contribution to make in the world we all live in. Whilst I believe in freedom of choice, I feel that this Bill will eventually lead to no choice for disabled people and terminally ill people.

Whilst I obviously strongly oppose the End of Life Assistance (Scotland) Bill, I do ask that the Scottish Parliament gives serious consideration to providing full and firm guidance and instruction to the NHS in Scotland to provide good quality care to those people who would have been covered by the Bill, that there be more than adequate levels of social care funding given to local authorities to enable disabled people to live full, positive and equal lives and that other legislative changes be looked at to provide greater safeguards and supports to all to live full lives as valued, equitable and cherished members of Scottish society in the twenty first century.

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