End of Life Assistance (Scotland) Bill

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“To be or not to be, that is the question”

Should we be pro-active in hastening death? This is the moral and ethical dilemma before us.

I submit my thoughts as an individual who has had cause, after a great deal of consideration and soul searching, and personal experience, to change my mind on this very sensitive topic.

I had always thought that when the time came and life was intolerable that “a wee jag” was the answer.

I always thought that if someone loved you enough, they would give you the elixir of death.

I always thought we had the “right to die” as well as “the right to live” – and I still do, but with reservations on how this might occur.

My beliefs were simplistic. If someone is in pain or distress and no longer wishes to tolerate that condition, then they should be allowed to quietly “shuffle off this mortal coil” with a little assistance.

My opinions were very objective with no personal experience. Now they are undoubtedly subjective - so does this give them more or less validity?

I will state my case and then make comments after extensive reading to try to clarify my own feelings on the matter.

My mind was changed during the last days of my mother’s life, and the weeks of reflection thereafter.

So, firstly to address the questions:

- At present, I do not agree that a person should be able to request end of life assistance from a registered medical practitioner.
- I am not satisfied with the requirements for age and connection with Scotland as set out in the Bill.
- I accept that there may be extreme cases which require particular attention as regards a request for End of Life Assistance, but I believe that we are not in a position to consider that yet.
- I am not convinced by the stages of the consent process.
- I do not think the level and nature of safeguards are stringent enough to protect the vulnerable.
- I will address other considerations more fully in the contents of this paper.
I think we have to be very careful in dealing with an issue which is so emotive and so fuelled by the media.

While there are some extremely distressing situations where the compassionate response for ultimate palliation is death, additional freedom for the few in being helped to commit suicide places an obligation on others – and indeed on society in general.

To move in this direction upsets the balance of freedoms in society and exposes the vulnerable to serious risks.

My concern would be that people would feel that the only compassionate response to a request for assisted suicide would be to concur.

This could place huge pressure on relatives who wish to comfort and support a terminally ill loved one but not by means of assisted suicide.

Both my parents always said that if they were suffering they would hope that someone would love them enough to help them end their lives before they lost dignity and usefulness.

When my mother was diagnosed with pancreatic cancer she did not want to have any treatment other than palliation when appropriate.

The cancer was savage in its assault and her stay in a large general hospital in Glasgow was nothing less than a nightmare. Sickness and pain ruled both our lives and a busy ward staff had neither time nor expertise to deal with either of us.

There was minimal personal care for my mother and absolutely no recognition of my pain and distress whatsoever.

To address her situation my mother was so heavily sedated that, on several occasions, I thought she was dying before my eyes.

In total despair, I asked the nursing staff if anything could be done and was told that this was the way it would be until the end as that was the nature of the disease – and that was that.

I may well have acceded to assisted suicide at that time if that had been my mother’s wish such was the distress for both of us.

Finally my mother was transferred back to our local hospital in Campbeltown and a dreadful situation was transformed.

My mother was treated with kindness and compassion and her dignity restored by attention to her personal care, and her emotional needs addressed.
I was also cared for and my own pain and distress addressed and acknowledged by compassionate honest communication and professional counselling.

The whole family unit was involved in the care programme and the expertise of all concerned brought peace back to our tattered emotions.

I had time to talk to my mother and say all the things I wanted to and she also had that opportunity while pain free, but not sedated beyond communication.

These last days were more precious that I can say and neither of us would have wished any intervention during that, still difficult, time.

I was with her day and night for her last week and was by her side when she died.

In my intense grief and sadness, there was peace and an overwhelming sense of fulfilment. It had been a privilege to be on the last journey in death as in life.

I had experienced the value of palliative care, and this was to greatly challenge my hitherto held ideas about assisted suicide.

Since my mother’s death on Christmas Eve, I have been reflecting deeply about the whole issue and reading both sides of the debate.

I have read “Easeful Death” by Mary Warnock and Elisabeth Macdonald and there are certainly some very erudite and convincing arguments for the option of assisted suicide in extreme cases. I probably would agree that in very rare situations, where palliative care is not an option, that an “easeful death” would be a healing situation and a compassionate response.

However, in the Bill in question, I feel there are too many loopholes and I am concerned that there is insufficient weight given to the value of every individual human being which should be central to any discussion.

In “Easeful Death”, Mary Warnock states that “there are many people who suffer acutely from the foreseen end of their life, and who ask that they be helped to die not on account of any principle but on account of the very nature of their suffering, which they see as the total indignity of being unable to do anything for themselves or have any control over the way their life is lived.

They hate the severe intimacy of enforced illness. They were once, like Kant’s moral theory, people of free will, choosing what they did and independently deciding how they should live. Now that that has gone, their life has no value for them”

If the Bill, as it would seem to, endorses that such people as described here, can readily request assisted suicide and that request be granted, then I cannot agree with the substance of the Bill.
As a society, if we endorse this concept of the worthlessness of a person when they become so ill as to require support, then we are in danger of fostering a malaise in our own morality.

A civilised society is judged by how it treats its weakest and most vulnerable members and not by how it reinforces that strong and beautiful are always best.

To leave it to patients to decide when their suffering has become unbearable and hopeless, and to permit others to cooperate in killing them at their request, implies far too casual a regard for that human life.

I don’t think we can always take at face value “autonomous” requests to have life ended pre-emptively.

In many cases what people really want is not death at all, but that their pain is controlled and that their worth as a person is still affirmed.

Schockenhoff, the German moral philosopher wrote, “The picture a person gains of him or herself, depends not least on who he or she is in others’ eyes.”

As a society we have to ensure that, not only do we continue to value the weakest and most vulnerable, but that we also tell them of their worth and affirm their very uniqueness.

If a call for assisted suicide is based, not on the inability to endure unbearable pain, but on a feeling of worthlessness or uselessness, then we have to find a way to enable people who endure such impotence of emotion to regain their intrinsic value as a human being.

We have to find a way to enable people to realise that just because they are terminally ill or feel that for whatever reason, they have nothing to offer, then we must challenge that misconception.

Perhaps we need to be encouraged to take a different view ourselves.

I have had the privilege recently of having meaningful discussions with a patient with just weeks to live.

I was the one healed and affirmed in this situation where honesty and vulnerability were shared and embraced and so the patient became counsellor and healer with a great contribution to make.

There is more to conversation at the end stage, other than the banal issues of “what did you have for your lunch” or “did you sleep well”.

This is patronising in the extreme, and perhaps the whole concept of palliative care should include funding for, not only beds and medication, but for the provision of physicians with expertise in counselling and facilitating patients and relatives to engage in honest discussions.
There is much rhetoric on the situation in the Netherlands and Oregon and, as we know, “you can prove anything by statistics”.

However, some figures are worth repeating. The analysis of two major surveys in the Netherlands by Keown showed that in 1990 out of a total of 129,000 deaths from all causes, voluntary euthanasia – defined as the intentional, active termination of life at the patient’s request – occurred in about 2300 cases (1.8%), and that physician assisted suicide occurred in about 400 cases (0.3%). It also estimated however, that in additional 1000 cases (0.8%) physicians administered a drug with the explicit purpose of hastening the end of life without an explicit request of the patient – that is, they committed non-voluntary euthanasia.

Regarding the 1000 cases of non-voluntary euthanasia, this was justified by reference to the patient’s ‘death agony’ and ‘unbearable suffering’.

On interviewing the doctors, the reasons given were the absence of any prospect of improvement (60%); the futility of all medical therapy (39%); avoidance of ‘needless prolongation’ (33%); the relatives inability to cope (32%); and ‘low quality of life (31%)

Pain or suffering was only mentioned in 30%.

Keown also notes that the doctors did not list ‘agony’ as a reason for killing the patients. Keown’s conclusion is that the slide from voluntary to non-voluntary euthanasia between 1984 and 1990 was swift.

This is a concern with any legislation that allows any form of assisted dying or euthanasia. Old chestnut maybe, but it still has its skin on! Are these alarm bells we hear ringing across the valley of the shadows?

If I compare the above reasons to my own situation there are distinct parallels:

1. There was no possibility of improvement for my mother
2. Any medical therapy would have been futile
3. What is the definition of prolongation?
4. Before my mother was in the palliative situation, I certainly was having difficulty coping
5. My mother’s quality of life was indisputably ‘low’.

These criteria seem to meet the requirements for assisted suicide.

That would have been quite the worst thing that could have happened.

The Scottish Bill may have differences, but it states that all palliative care options will have been explained to patients requesting end of life assistance. I would suggest that this does not go far enough.

I would also express grave concern that someone of 16 years of age could request an intervention which would end their life.
I would express grave concern that someone in a depression may request end of life assistance. During such a depression the only thing the patient wants is to get out of that black tunnel and is in desperate need of compassion and understanding. They need to know that their life is valued and worthwhile and not a signal that it should be ended.

I would also be concerned that if the lethal cocktail given by the physician, was not lethal enough, what would then happen, as euthanasia would not be a legal option?

While the Bill addresses those who should not influence a patient’s decision, it does not make allowance for the fact that the patient will often opt for the altruistic option to save relatives the burden of their care.

The Bill does not address the stress that can drive people to make the wrong decision to avoid being a nuisance.

The use, or more realistically, abuse, of the word “burden” is one we should consider carefully.

Our intrinsic value as a human being is exploited if we even suggest that assisted dying should be an option to avoid anyone being “a burden”.

This would be a great indictment on us as a society of caring individuals, and we might well remember “not to ask for whom the bell tolls”, as we look into our own mirror of the future.

The Bill does not allow for the problem of pressure on an ageing or infirm population who are constantly reminded by the media that the State just cannot afford to keep such people.

The Bill does not challenge the fact that there is just not enough or adequate Palliative Care in this country, and does not make any allowance for the old chestnut of post code prescribing – or perhaps post code palliative care.

So, in conclusion, I would admit that I do not have an answer to the problem of the very few for whom there is no real option, but I would suggest that we are not at the stage of endorsing assisted suicide until we have fought for the provision of palliative care for all.

At present, palliative care is very much seen as a last ditch option and its potential is far from understood.

Before we consider assisted death options, we should ensure that every single person in this country has end of life options. By this I mean that palliative care should be on the agenda in every community; should be high on the list of priorities when it comes to health budgets; should be taken up by every political party as a priority, and should be something that all of us should embrace.
Only after we have offered patients the best care possible, physically, emotionally and spiritually, can we possibly consider the worst case scenario of helping them end their own life.

We must ensure that we embrace people who are terminally ill with the knowledge that just because they feel useless, they must not feel worthless.

At whatever stage in life, a person still has love and wisdom and experience to share, and that should be valued.

Many of the patients who would meet the criteria for the Bill would, in reality, have to make the decision to end their life before they actually needed to, and so could potentially be deprived of some existing quality time.

And as we all know, no one can really predict life expectancy accurately in every case.

The patient who would fit the Bill, in my opinion, may, just may, think differently if s/he were able to be affirmed, and enabled to take control of their own life, and see that it is valued, respected and unique right up till that last heartbeat.

There is a world of difference in a society which helps people to die well through excellence in nursing and palliative care and one which embraces assisted suicide or euthanasia.

I would therefore reject acceptance of the Bill as it stands.

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