End of Life Assistance (Scotland) Bill

Anonymous

I am commenting on this Bill as a private individual who is strongly in favour of it. I request that my identity is kept private and confidential to the clerk to the Committee ie not disclosed to the public or to members of the Committee.

My perspective is largely informed by the fact that although I currently enjoy a high quality of life, I have experienced almost 100% loss of independence for a considerable period of time. My condition is not degenerative but combined with normal aging, it is not unlikely that I will at some point become very dependent again and find that loss of independence, with no prospect of regaining it, intolerable. Knowing that this situation could arise, I also wish to know that I would have the right to request legal end of life assistance.

Some of my comments suggest amendment to the Bill but my intention in making these suggestions is partly to pre-empt problems with application and interpretation which may arise after an Act is passed and partly to try to meet some of the legitimate concerns which I think certain groups may have with the Bill.

Question 1

Registered general medical practitioners are the right people to facilitate end of life assistance but I would not be opposed to other categories of competent people being included among those who may act as designated practitioners under the Bill such as nurses with a specified amount of experience and/or a requisite qualification to perform this role.

I have concerns about the onerous nature of the role of a designated practitioner as drafted. My comments fall into two categories. One is about the nature of the role itself and the other relates to concerns about a lack of specification in some of the Bill’s provisions.

I think the level of personal responsibility involved in the role of designated practitioner is often going to be too heavy for one person to take on alone – unless he or she chooses to do so, perhaps because the requesting person and his views are so well known to the general practitioner. I therefore suggest that it should be possible for someone who is asked to act as a designated practitioner under the Bill to elect at any stage in the process, to share the duties of the designated practitioner with another general practitioner who could be in the same practice or not. This would be a right of the designated practitioner so that although the original designated practitioner would need to obtain the approval of the requesting person to the co-opting of a second designated practitioner, if the requesting person and the designated practitioner could not agree on a second designated practitioner, the designated practitioner could decline to act at all.
Apart from the personal responsibility involved in performing the role of designated practitioner, at a very practical level I think that general practitioners could find themselves in difficult situations because there is no provision for what happens if the designated practitioner becomes unable to act eg due to illness - or even if the designated practitioner will be on holiday during the process. The way the Bill is drafted, the requesting person would have to check with the designated practitioner and make sure that he or she would be available for the duration of the process and the requesting person would simply have to start the process again if something unforeseen happened. The latter situation (or indeed the situation where the designated practitioner dies) could be very distressing for the requesting person and the lack of an alternative provision could put undue pressure on designated practitioners to make themselves available through sickness and holidays. A right to share the duties and responsibilities of the designated practitioner with a second general practitioner would not only alleviate the onerous nature of the duties of a designated practitioner but also solve these practical difficulties.

There would obviously need to be provision for how the duties of a designated practitioner would be shared. I would suggest that the original designated practitioner performs the full role as laid out in the Bill but that he or she may involve and consult with the second designated practitioner as much or as little as he or she wants to. If, however, the designated practitioner died or became unable to act for any reason (including holidays), the second designated practitioner could take over, simply by notification by both of the general practitioners to the requesting person, and become the first/main designated practitioner for all of the purposes of the Bill - and as such be free to appoint another designated practitioner if he or she chose to. The Bill’s references to the opinion or satisfaction of the designated practitioner would be deemed to be to the opinion or satisfaction of whoever was acting as the first or main designated practitioner at the time.

More clarity and specification in some places in the Bill would be in the interests of people who to take on the role of designated practitioner.

Clause 6(3)(a)
It should be clarified that it is in the designated practitioner’s reasonable opinion whether or not it is practicable for an employee of the care home to act as one of the witnesses.

Clause 6(4)
Anyone in the same medical practice as the designated practitioner should be precluded from acting as a witness to protect designated practitioners from being accused of collusion.

Clause 9(4)
This clause could be interpreted to impose quite a heavy obligation on the designated practitioner to have tried certain forms of communication. The limits of the designated practitioner’s obligations in this respect could be limited so that he or she is obliged eg to act reasonably in trying to communicate with the requesting person.
Clauses 7(2), 8(3) and 11(3)
If challenged, how would a designated practitioner prove that he or she had discharged his obligations to have satisfied himself in these clauses? I think it is intended to be a subjective test and that the designated practitioner could point to the paper work required by the Bill and his notes of discussions with the requesting person – but I think the Bill could say something to put beyond doubt that the designated practitioner’s view on the matters on which he or she has to be satisfied is unchallengeable.

Clause 10
The Bill should specify that the agreement on provision of assistance must be made at a face to face meeting between the designated practitioner and the requesting person. This would have the advantage of helping the designated practitioner to fulfil his duties under clause 11(3).

Question 2
16 is the right age for a person to have the right to request end of life assistance. If people are considered old enough to marry and have the responsibility of a child, they must also be old enough to take decisions relating to their quality of life extending to ending their lives.

The requirement to have been registered with a medical practice for at least 18 months seems sound. It is probably long enough to dissuade people from moving to Scotland to take advantage of the law and short enough not to be a barrier to someone who legitimately wants to use the law.

Question 3
I am satisfied with the eligibility criteria which are very narrowly drawn. I don’t think our society is ready for a more general right to end one’s own life where there are not fairly extreme extenuating circumstances.

Referring to both of the eligibility tests, I think it is very important that there is a connection between the first part of the test and the additional requirement that the requesting person must find life intolerable. I believe it is the intention that the requesting person must find life intolerable as a result of either the terminal illness or the incapacity leading to dependence. I don’t think it is intended that the requesting person might find life intolerable for another reason eg death of a spouse/child/pet or something else altogether unrelated. The drafting of both tests needs to be amended to make this clear.

In my view clause 4(2)(b) would cover a requesting person who was physically incapacitated eg from birth and who at 16, wished to exercise his right to an assisted death. I think it could be usefully clarified that it is also intended to cover someone who is physically incapacitated for any reason and who has lived in a dependent manner for some time but who subsequently finds life intolerable without there being any change in circumstances. With reference to my point above, whilst extraneous factors should not come into
the eligibility test, a requesting person should not have to show that something has changed to make them suddenly find life intolerable; it is a subjective test but it must relate to terminal illness or physical dependence.

Questions 4 and 5

I think the procedure for requesting end of life assistance is generally sound and that in the main there is adequate protection and safeguards for both the requesting person and the designated practitioner. Given the narrow eligibility criteria, I think the timescales are about right. The steps involved in making a single request and the requirement for a double request will protect against a person doing something rash. The fact that each of the two requests must be witnessed by two non connected people protects against undue influence. There however quite a few points around the procedure and safeguards which I feel should be tightened up.

1. Some of the suggestions I made under Question 1 above for the protection of the designated practitioner, would also help to make the procedure smoother.

2. With reference to clauses 5(2) and 6(5), in some cases a person may not actually know that he or she is a relative, a person who would benefit from an estate or that they have another interest in a death but they might have good reason to know for sure or to check. This could be provided for by the addition of eg the words, “or has good reason to know of or to suspect”.

3. With reference to clauses 7(4) and 8(3), it is the informing of the requesting person which triggers (1) the 15 and 30 day periods which mark the window for the making of the second formal request and (2) the 28 day period within which end of life assistance may be given. There is no obligation to inform the requesting person or about or when that is to be done. If for any reason the requesting person is not notified – or it can’t be proved that he or she was notified - the time periods don’t commence which would make the 15, 30 and 28 periods potentially open ended. The designated practitioner should be obliged immediately to inform the requesting person of the first and second approvals in a specified and provable manner to make sure that the time periods start to run as intended.

4. The notification of approval could perhaps also usefully state for the avoidance of doubt, in the case of the first approval, the precise dates of the window within which the second request must be made and in the case of the second approval, (a) the precise time and date after the expiry of the two clear day cooling off period when assistance may be given and (b) the precise time and date of the expiry of the 28 day period within which assistance may be given.

5. The Bill should specify that the agreement on how end of life assistance will be given must be witnessed.
6. Since by the time the requesting person and the designated practitioner are entering into the agreement about how end of life assistance will be given, the second approval would necessarily have to have been given already, I think that the agreement as to provision of assistance should state the start time and date and the end time and date of the 28 day period within assistance may be given.

7. Clause 11(3) says that assistance can only be provided if the designated practitioner is satisfied … that the requesting person “still wishes to proceed” and clause 11(6) says the designated practitioner must be present “at the end of the requesting person’s life”. For the designated practitioner to fulfil the requirements of clause 11(3), clause 11(6) really should provide that the designated practitioner must be present both at the giving of assistance and at the end of life.

Question 6

1. I find the evidence in the background papers about the minor extent to which similar rights to end of life assistance in other jurisdictions have actually been taken up very compelling and reassuring. This low take-up reinforces my own belief that only people in very extreme situations would ever resort to using this legislation to secure end of life assistance. In my experience, human beings generally cling to life and the narrower and more limited their lives become, the more they relish them and value what they can still do. Even people who have been quite certain and vociferous in saying that they wouldn’t want to be here if A, B and C happened backtrack when faced with A, B and C. But I also believe that there are some circumstances which for some people would be utterly intolerable and that if a person’s natural desire to survive and exist has been extinguished to the extent that they personally ask for assistance to die, it is unconscionable that they are not legally entitled to get that assistance.

2. Beyond the small group of people which is likely to use this legislation, I believe that a wider category of people who fear finding themselves in an utterly intolerable position would be saved much distress and angst simply by knowing that they could legally access end of life assistance if life became intolerable in the way they fear – but that the majority of these people would die naturally without ever reaching that point and without the stress of worrying that they might.

3. The fact that even people who have been certain that they would choose to end their own lives in certain situations can and do change their minds is another reason that I support the terms of this Bill. The Bill makes it very clear that the only person who may instigate a decision about ending his own life is that person and the only other person who may be involved in that decision is an independent medically qualified person. By implication it is clear that this kind of
decision is not one for families to take, however well-meaning – at least not where the relevant person is able to express his own sound mind.

4. The policy background paper makes the foregoing point, saying that the Bill will give greater protection to the vulnerable – presumably because it will, by implication, criminalise assisted deaths which are not carried out in accordance with the Bill. At present, it is very likely that a number of painful, failing lives are quite rightly truncated humanely and compassionately by strong pain relief and that they are never investigated. If a situation is brought to the attention of the Procurator Fiscal, he or she has discretion on whether or not to prosecute someone who has given palliative care which borders on end of life assistance. I think that the Bill might usefully say something, eg in the preamble, around its intention not being to fetter the discretion of the Procurator Fiscal by implication.

5. A designated practitioner in an assisted death should possibly be excluded from the people who can competently certify a death. This consequential provision would provide further protection of the vulnerable against a wayward general practitioner. An exception could be where two general practitioners are acting as the designated practitioner.

6. I don’t think that the giving of advice on suicide is intended to be covered by the Bill’s definition of “assistance”. I think the Bill should clarify the position on this to avoid any implication that it is criminal to give advice to someone without going through the legal process.

**Minor drafting points**

With reference to clauses 1(2) and 2(1)(a), in order to make it clear that you can only seek assistance for termination of your own life, either Clause 1(2) has to include the words “requesting such assistance” after the words, “to enable a person” OR Clause 2(1)(a) has to include the words, “in respect of his own life” after the words, “the person who wishes such assistance”.

With reference to clause 6(3)(b), it would eliminate problems of voluntary workers etc if the words “or otherwise connected to the service” were added to the end of the clause.