Preamble and position statement

We are delighted that this issue, and hopefully legal reform, is being given serious consideration. EXIT* supports a relatively conservative approach to law reform on end of life issues. With proper legislation, we do not accept that fear of ‘inevitable abuse’ is at all well-founded. But we do accept that unfounded fear might conceivably occur, and that it could be distressing. With that in mind; and also to allay some of the concerns of critics; and also in the interests of superior legislation; we favour a system whereby End of Life Assistance is of the nature of an exception to the rule of existing law, and as such may be argued on an individual case-by-case basis. The objective would be to bring about a system under which such individual exceptions could be permitted for exceedingly deserving cases. The extent and remit of such exceptions to the rule can then move with the light of experience and public opinion. The alternative is creating in advance a system of check-boxes, under which assistance will be allowed, which we would argue is far less desirable.

Future scenarios cannot always be predicted with accuracy. Public interest might suggest initial cases be handled through the judicial system, with public scrutiny, and until sufficient examples create a consensus on which exceptions to the rule should be allowed. Even if the bill does not approach legislation exactly in this manner, some degree of flexibility might perhaps be considered so that any new law can be reviewed, refined and modified in the light of experience.

Concerning specific points raised in the Call for Written Evidence:

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

Yes. But it must be clear that the registered medical practitioner is willing to consider such request without pre-judging the options. Only in this way could a patient feel a) assured that the request will be considered without prejudice, b) that the practitioner is examining palliative care options with the patient without prejudice and is open to the eventual wishes of the patient, c) an atmosphere of trust is in evidence within which to explore all available options. The practitioner must also consider the request without predetermination in order to make an initial assessment of whether the patient has capacity (In other words: not assume that a request for end of life assistance implies delusional or depressed states; and certainly not that incapacity in one sense implies incapacity to make a competent request).
Are you satisfied with the requirements for age and connection with Scotland as set out in the Bill?

Partially. The attitude of consent in Scotland, and the Age of Legal Capacity (Scotland) Act are important. At 16 years of age, a person may or may not fully understand the implications of a decision to end her or his life. It is a situation more exceptional than when a person is over the age of 21. EXIT has debated the age question at length in relation to provision of information on suicide (even though such information is commonly available in bookstores). For a person who is over the age of 21, we feel that an adult can be assumed to have capacity and the right to make such decisions, unless ‘alarm bells ring and there is evidence to the contrary.’ Although the Bill makes provision for psychiatric assessment, we would like to see especial care and consideration given to any request by someone who is under 21. We are particularly mindful that many teenagers go through a ‘phase’ of feeling suicidal, or that life is not worthwhile. This does not mean that such a person can not make a competent request, but simply that there are extra factors to be considered with great care. Just as they do for persons over 21, the requests need to be handled openly, responsibly, with transparency and lack of bias, and with full compassion. In this way public feeling – often even more sensitive when the life of a person in the full bloom of youth is concerned – can also be properly satisfied.

Imagine, for instance, a borderline case of a teenager who has a terminal and unbearable disease. Denied the opportunity to speak about end of life assistance openly and without bias, she or he feels compelled to make a decision alone – and with whatever gruesome end that might entail. Perhaps, given proper legislation and open scrutiny, the situation might have led him to ‘weather the storm.’ On the other hand, were there no possible respite, he could be availed of dignified, certain assistance – rather than an ignoble and possibly botched attempt that could serve to increase his physical, mental and emotional torment during his last moments even further.

Consideration of borderline cases can also help when applying tests to adults. The young and the very old may have similarities in feeling they are not allowed complete control of their own life. EXIT's most common letter of thanks is along the lines of, “Thank you for giving me the knowledge so I know what to do, should I ever need to.” For most of our members, the information on how to end their lives is never used; but it gives them immense reassurance, hope and courage to face an uncertain future. It gives back a sense of control.

It is this very sense of owning one’s own life that an effective end of life assistance bill could and would provide. Following on from this, EXIT feels less than comfortable about the 28-day cut-off (section 11(2)). The knowledge of ‘a way out’ is one of the major benefits of such legislation. The experience of EXIT is mirrored by granting of requests in Netherlands and in Oregon, where many patients who have had a request granted do not go on to actually use it. This does not mean the request was pointless: on the contrary. Immense comfort is derived from the knowledge that there is someone there
who is willing to help in the last resort (in the way the patient wants). Many illnesses can be unpredictable. Additionally, where pain is the issue (often it isn’t, but it is one that is much feared), then the pain which is often the most difficult to palliate occurs in the final phase just before death. If the patient has gone to the trouble of making a request which has been granted, it might be inhumane to suddenly withdraw it. It could even precipitate untimely action on behalf of a desperate patient. Therefore we would recommend other safeguards if there are concerns over a time period.

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

The criteria we think of are ‘unbearable and unrelievable.’ Public knowledge has broadened our understanding, especially with cases such as that exhibited by Debbie Purdy, that being terminally ill is an inappropriate restriction. We could envisage certain cases of mental anguish even, that were unrelievable and unbearable by any reasonable standard, such as have been exhibited in test cases abroad. But these cases might best provide the necessity fully to review and modify legal provisions rather anticipating them. Law is sufficiently flexible to have responsible review periods written into a statute, after all. This is sometimes better than trying to envisage the particular anguish of a case that has yet to occur.

The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

It is important that at least one person who knows the eligible person well is able to give evidence. In some cases it might be hard to find sufficiently suitable persons, and in such cases the judicial system, or a review process set up under it, must be able to determine a lack of selfish interest and so on. A similar consideration has been put forward by the DPP of England & Wales in setting forth reasons not to prosecute (persons assisting those who travel to Switzerland).

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

Although the involvement of a psychiatrist is welcomed, it should not be forgotten that capacity is ultimately a legal test, not a medical one; and that the decision is based on proper consideration of medical evidence, not ultimately made by medics. Para 9(4) does not strike me as clear enough. Capacity requires that the eligible person retains the information upon which the decision is made, not simply remembers making it.

Another important point is to ensure that any assessment of capacity takes into consideration, and provides where at all possible, optimum situations or scenarios where an eligible person’s capacity is enhanced (much work has been done on this by the professions).
We would also prefer to see the bill framed along the lines set out in our preamble - providing for a system of exceptions to the present rule of law rather than just saying in advance who qualifies. With the law as it stands, the courts have no power to make such an exception; even if there were to be a general rational consensus within the professions, and even backed by public outcry. The present lack of clear legislation for exceptional cases leaves the Procurators Fiscal in a potentially embarrassing situation. Compassionate ‘crimes’ have in some cases been handled by the courts very lightly. It is hardly good enough to lump a doctor (or other person acting compassionately, unselfishly, and at the competent and persistent request of another) with a common murderer.

**Do you have any other considerations on the Bill not included in answers to the above questions?**

I would like to see guidance included with the bill to set forth its aims and principles, of respecting autonomy, of compassionate motivation, of making available through medicine the options to relieve suffering, of openness and transparency, of a default to respect life but a willingness to accept that in some exceptional cases the person may place the relief of suffering above continued existence.

The primary objective and underlying principle should be to relieve suffering, and that (as with any medical intervention) by the least intervention necessary to achieve the aim.

Only by making clear at the outset the principles upon which any bill is passed, can we ensure that sufficient guidance is provided to those responsible for implementing it, and ensuring its proper observance and interpretation. Otherwise we could face a quagmire of future ambiguities, uncertainties and tussling over semantics. Guiding principles must be clear, both to avoid abuse, and to avoid legal wrangles – perhaps while a patient suffers. They are also necessary to ensure compassionate consistency. Finally the fear of abuse, even if groundless, must be properly addressed by showing requests can only be granted in exceptional circumstances, when they are persistent, and when the eligible person has a clear case, in full knowledge of all other options and, with that knowledge, able to decide whether to make a request.

**General statement**

Whether one believes in a religion or not (and we maybe have to accept that a large proportion of Scots do not), there isn't anyone who doesn't appreciate kindness and compassion. Kindness and willingness to help another may also result in harm of course, and the law places reasonable limits. But rational thinkers on all sides eventually tend to agree that we should allow a person, if not interfering with the liberty of others, to be free to pursue her or his own good in her or his own way. It has been argued that death cannot be included in this pursuit since it negates life itself: but this misses the point. Death might
not be ‘part of life’ but the dying process certainly is. People have a legitimate wish to be able to control that in their own way.

It has also been suggested that there is a wider danger – to other members of society. That they will become fearful of their doctors. Or feel pressured. Due vigilance and openness must ensure that no request is ever granted where there is a suspicion of nightmarish influence from malicious doctors or greedy relatives. But the distress of imaginary fears can be treated in extreme cases by the psychiatric profession. The distress of a person suffering excruciating indignity from very real and present end-stage physical disease is not just equally deserving of having it attended to; it trumps the vague imaginings of someone who just needs reassured and protected.

This is not about protecting adults from themselves: it’s about giving adults proper respect at a time when they need it most.

Exit thanks the members of the Committee for kindly taking the time to consider our points made above. We would be happy to answer further questions if the committee wish us to do so.

Chris Docker M.Phil (Law & Ethics in Medicine)
Director
EXIT