End of Life Assistance (Scotland) Bill

Independent Association of Nurses in Palliative Care

The Independent Association of Nurses in Palliative Care (IANPC) was recently created by a group of experienced palliative care nurses to ensure that good quality palliative care is available to those who require it regardless of diagnosis or place of care. The aims of IANPC are:

To promote palliative nursing education through the provision of educational events

- To inform international, national and local palliative care strategies, policies and systems of care
- To share good palliative nursing practice through a dedicated website and an electronic newsletter
- To oppose the legalisation of euthanasia/assisted suicide in the UK

Using the questions suggested in the response guidance information as section headings this document answers the specific questions, asks for further clarification on some issues and clarifies why IANPC takes this stance against assisted suicide.

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

   No.

   IANPC firmly believes that such legislation puts medical practitioners in a position that few would choose to be in. Indeed many Doctors may have sound ethical and moral reasons not to be involved in what in effect is life ending treatment. This may lead to only a few medical professionals and their associated teams dealing with many of the cases that come forward. Would Scotland then be in danger of creating its own Doctor shopping system like Oregon?

   We also believe that such legislation would have a negative impact on the therapeutic relationship developed between all practitioners (not just doctors) and dying patients which could result in dying people being unable to discuss their innermost issues in the fear that this may lead to them being assisted to die. We already know that there is evidence of “involuntary” euthanasia being practiced in countries where this type of legislation is already in place and believe this abuse would happen in Scotland too.

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

   No.

   IANPC suggests that young people above 16 but still in adolescence, although legally defined as an adult, may not have the necessary the life experience or maturity to make such a decision. Many of these young people
will have been ill for many years and are coping with the change to adulthood as well as the issues their illness presents to them. It is therefore not fair or appropriate to allow them to consider ending “an intolerable situation” during this often turbulent time in a young person’s life. Indeed cases have been presented as part of earlier attempts to legalise assisted dying in the UK to show that an “intolerable” situation in adolescence can become one that is very tolerable in adulthood.

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

No.

Indeed IANPC would suggest that the two categories identified in the Bill can be interpreted in so many different ways that a significant amount of Scots could avail themselves of assisted suicide were it to become law. We identify our concerns more fully below.

♦ The term terminally ill is often used for people whose life expectancy is defined in weeks and months rather than years and in the Bill suggests these people would have a life expectancy of less than 6 months. However there is clear evidence to suggest that it is very difficult to say with any authority how long people with an advanced life limiting illness have left to live. A much clearer definition is required to prevent abuse of assisted suicide legislation.

♦ There are immense problems regarding the use of the adjective “intolerable”. IANPC suggests that the word is highly subjective, and by its very nature could make assisted dying available to many more people than was initially intended. Indeed currently many patients coming into specialist palliative care services for care and support report that they are suffering from intolerable symptoms and issues. However following a period of intense management using the expertise of a specialist team the majority then experience satisfactory levels of quality of life and enjoy the remaining time they have left with their families. It would therefore seem that a more proactive approach in allowing people who are suffering intolerably to access this type of care rather than pushing through any new assisted suicide legislation should be employed.

♦ We are also concerned about the people who are classed as those who are permanently physically incapacitated and unable to live independently. Again this could have a very wide interpretation. It could include people with sensory impairments whose life is not limited by their affliction. It could also apply to anyone else who has a disability/illness that prevents them from living independently. IANPC firmly believe that this would open the door to a system that allows the assisted death of just about anyone who can prove that they cannot live independently and that this causes them to suffer.

4. The Bill outlines a two-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?

No.
As we have noted above IANPC believes that only a few Doctors or Psychiatrists would wish to be part of this process and as such we believe that this increases the chance of the process being managed less rigorously. This could then lead to requests for assisted dying to be rubber stamped with little regard for objectivity in assessment process. This may be especially true if a payment for the assisted dying service is being paid to such practitioners.

We also note that the designated practitioner need not be the Doctor the person requesting assisted suicide is registered. In these circumstances how can the designated practitioner fully assure themselves that the applicant meets the criteria for an assisted death?

IANPC believes that a discussion of alternatives such as palliative care is not sufficient. There is a vast difference in hearing about a means of care than actually experiencing it. We would suggest that applicants need to agree to having trial of palliative care provided by specialist practitioners as is the case in Belgium. Here the experience of palliative care often leads to a withdrawal of the application. We also feel that the cooling off period is too short and would not allow for the exploration of other means to reduce the person’s suffering such as a trial of palliative care.

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

No.

One of the safeguards in the Bill is that the person requesting assistance to die should have been registered with a medical practice for at least 18 months prior to the request. What safeguards are there to prevent people living elsewhere registering with a Doctor who practices assisted suicide but not actually using their service. There are many ways around the system of registering with a medical practice to make use of the assisted suicide law. Does Scotland really want to be recognised as a “death tourism” destination?

The Bill does not really give the reader any information on the means that would be used to assist in a person’s death. This means that those requesting assisted suicide are unable to make a fully competent decision about what is in their best interests as they do not know how this act will be carried out. E.g. is it painful, involve injections and so on.

IANPC notes that there is no conscience clause in this Bill to safeguard health and social care practitioners who do not wish to be involved in assisted suicide. We feel that many practitioners’ belief systems would not allow them to be party to this and that this could affect their choices in employment.

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

Yes.

The Explanatory Notes suggest that if the “Oregon” Model is followed in Scotland, potentially 55 people per year would end their life through the use
of the Act, which may result from this Bill. However this Bill would seem to include euthanasia as it states that the means includes "the administration of appropriate means" and talks about "persons who wish their lives to be ended". This would significantly increase the number of such requests and we would ask if the safeguards identified in the Bill would have the capacity to cope with this?

In addition IANPC is concerned that the Bill makes no mention of the role of any professionals other than Doctors, although it suggests someone other than the designated medical practitioner could provide the assistance to die. In other countries where euthanasia is available there is a significant role for nurses as they are in more contact with dying people than any other professional group. Further clarification is required about who and who cannot be part of this process.

The Explanatory notes suggest that the Crown Office Procurator Fiscal Service would have the power to investigate any deaths which give rise to public concern. What safeguards will NHS Scotland and other healthcare providers have in place to monitor and investigate the use of the assisted dying service?

As with any changes in medical treatment or healthcare there is the potential that the promotion of assisted suicide might be fuelled by an economic agenda. Assisted suicide has the potential to save NHS Scotland and Local Authority Social Care Services a substantial amount of money that would otherwise be used to provide continuing care and palliative care to this vulnerable group of people. What safeguards are in place to ensure that this does not occur?

Finally we note that the designated practitioner is obliged to be present at the applicant’s death. We are not sure why this is especially if the applicant self-administers the medication. This needs to be clarified more fully as it suggests that the designated practitioner is administering the assistance to die.

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