End of Life Assistance (Scotland) Bill

Dr Fiona Downs

Those who become vulnerable through illness or disability deserve special care and protection. Adherence to this principle provides a fundamental test of what constitutes a civilized society.

This bill would have far-reaching and potentially irrevocable implications for Scotland.

It contains many areas of concern.

I do not agree that a person should be able to request end of life assistance from a registered medical practitioner. A right to die is not the same as a right to be killed. Patient autonomy is effectively a negative right, designed to protect patients from unwanted medical intervention rather than put them in a position to dictate a course of treatment. A change in the law to allow medical assistance with suicide would mark a significant shift in the doctor-patient relationship.

The low age of 16 seems incredible given the number of teenagers who might find life intolerable for a limited period.

This bill may pressurize the frail elderly and the physically disabled.

I am not satisfied with the process from first request to designated medical practitioner to second request to psychiatrist. Perhaps the easiest way to assess its potential effects is to consider the situation of a patient who wishes End of Life Assistance to die and ask questions in a logical way throughout the simulated process.

- To whom is the first request directed? Is it always a GP? Could it be a Private Practitioner?
- What if GP opts out?
- Is this part of general medical services? Will there be an ELA (End of Life Assistance) DES(Directly Enhanced Service)? Will there be an on call person or an on call team? How will this service be funded? What training will be provided? How will the practitioners be supervised/validated?
- How long will each consultation last?
- How will the designated practitioner or psychiatrist ascertain that the patient is not acting under undue influence?
- What guidance in this regard will be provided?
- There is no requirement for the psychiatrist or designated practitioner to formally assess whether or not the requesting patient is depressed and treat if appropriate. Will this be addressed?
- Agreement on provision Will this be at any time the patient chooses or 9 -5 Mon-Fri? The place where end of life assistance is given must be
private and therefore, presumably, only a home or private room in a private hospital /nursing home / hotel room would be suitable. Presumably even a single room in a hospital ward is not private. If the assistance were to occur in a public place, the public cannot have access at that time. Who pays for e.g. police to keep the public away?

- Who will actually provide end of life assistance?
- How exactly will it be done?
- How will complications be dealt with? – vomiting, aspiration, allergic reaction
- How can confusion with existing hospice/palliative care services, which do provide end of life care, be avoided?
- The designated medical practitioner must be present – for what purpose and in what capacity?
- The act does not mention the PF (Procurator Fiscal). Will the patient and relatives be informed that the PF will investigate?
- The Act says end of life assistance means assistance including the provision or administration of appropriate means to enable a person to die with dignity etc but only a person unconnected with the patient may provide End of Life Assistance. Therefore no relative spouse or civil partner may procure any drugs for the patient. These will need to be brought by the End of Life Assistant. How will this be policed? Will two people be required? Will the pharmacist be implicated?
- Who will the PF interview? When? What delay to funeral arrangements might be anticipated?

I would suggest the bill does NOT provide a detailed process of systematic checks and safeguards.

- What about fluctuating capacity?
- What is “as far as reasonably practicable?”
- It is unreasonable to expect doctors to have sufficient knowledge of applicants re unbearable suffering, mental capacity, freedom from coercion and prognosis to enable them to make informed and reliable judgements about ending their lives.

Other considerations

- Figures provided in the Explanatory notes are erroneous and misleading
- In Oregon in 2008 (60 deaths in total) 19.4 deaths per 10,000 by PAS 19.4/10000 x100 = 0.194 % (roughly 2 per1000)
- In Oregon since 1997 there have been average of 36 deaths from PAS per year 401 out of 363,758 deaths in this 11 year period Thus 401/363,758 x100 0.11 % Roughly 1/1000 (Not 0.001% as written in page 12)
- Rate has almost doubled in 11 years but as the bill says figures were low initially therefore numbers have probably quadrupled from initial levels in 11 years
- Costs
• Costs On The Scottish Administration

The suggestion that there will be “minimal if any costs” is unlikely to be true. It is likely to be a considerable cost through Health Boards.

• GP enhanced services or specific training if GPs opt out
• On call for deaths
• Revalidation requirements (and validation of tools used in this setting)
• Education
• Overseeing
• Time for interviews
• Questionnaires for depression
• Capacity – may need to observe all day
• PF report and police interviews

• Local Authorities and Other Public Bodies

Costs may indeed be minimal for the death and there would be a reduction in the overall time given to patients by social services. Instant deaths would be easier and cheaper.

There may be a risk of reducing incentives to pursue palliative care solutions. How will this task be subsumed into existing workload and how prioritized? What would be the effect on staff? What about conscientious objection?

Counselling – Workers would need training in counselling and possibly require counselling themselves.

• NES

Education needs would be significant

Having delivered awareness raising sessions in ACP, I would suggest this would be contrary to (and is likely to highjack) much of the ACP strategy.

• COPFS

Having striven to ease the burden on relatives of patients dying of mesothelioma and having considered their concerns, I think this bill would significantly increase the workload of the Procurator Fiscal (PF).

The PF would ask Police Officers to investigate the death and they would interview relatives, medical staff and the person providing End of Life Assistance, possibly including the pharmacist. Relatives of patients with mesothelioma have stated that they feel under suspicion in these circumstances and referral to the PF in this situation is likely to instil the same feelings.
Why suggest a non-PF Post Mortem (PM)? It could be refused by relatives as relative consent is required for an authorized PM while a PF PM is mandatory.

Costs to Others

Direct payment to the End of Life Assistants
Private practice End of Life Assistants
I suspect £675 is a very conservative estimate, particularly if there is investigation by the PF and the need to procure drugs.
If the patient changes his mind after all arrangements are in place, will he be charged for services?

Additional Implications

Numbers are very uncertain. The numbers in Oregon are collated from voluntary reporting. Reliability and therefore extrapolation are questionable.

“A change in the law to allow PAS (EOLA) would have profound implications for the role and responsibilities of doctors and their relationships with patients. Acting with the primary intention to hasten a patient’s death would be difficult to reconcile with the ethical principles of beneficence and non-maleficence.”
GMC

Confidence in medical attendants would reduce. It may bring comfort to a sophisticated few but unease to many ordinary patients and their relatives.

In Oregon in 2004 more than two thirds of the recorded legal prescriptions were issued by doctors who were not the applicant’s regular practitioner (Doctor shopping). It is unlikely that the proposed EOLA doctor role will be compatible with a regular GP role. Consider the situation of a patient’s carer who witnesses the death and then attends that same GP with her terminally ill husband.

The cost of bereavement support for relatives and staff is likely to be substantial.

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