End of Life Assistance (Scotland) Bill

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As a medical practitioner I would draw to your attention how uncomfortable this makes me feel. I enclose two attachments for your consideration and would draw your attention to this being more far reaching than any other single thing in the history of medicine. Prospective medical students would have to consider the possibility of being involved in decision making around euthanasia/PAS, potentially involved in prescribing or administration of a drug directly intended to kill a patient.

The Scottish Government is at this moment trying to improve palliative care for all and not only those with a diagnosis of cancer through “Living and dying well”

The majority of cases of public/press interest do indeed centre around patients with a chronic degenerative neurological condition and it is here that a close working alliance between neurologists and palliative medicine need to be formed. This would pave the way for greater discussion and involvement of that small minority of patients to be involved at every stage of their journey, no matter how uncertain that path is.

Attachment 1

What has Palliative Care to offer?

When I graduated in medicine at Edinburgh, I remember that we had to recite a version (as far as I can recall) of the Hippocratic oath, ?maybe the traditional, maybe the modern version and this embodied the ethical principles that I was about to embark upon in my medical career. All versions contain common responsibilities that are at the very foundation of medical practice and ethics. Words such as Respect, Dignity, Conscience, confidentiality, putting your patient first and phrases such as “utmost respect for human life”, and “remain true to the purpose of healing and promoting health, not death”. The declaration of Geneva 1948, penned following the atrocities of the second world war embodies many of these words and statements. From the Hippocratic oath itself,

“I will use my power to help the sick to the best of my ability and judgement; I will abstain from harming or wrongdoing any person by it.”

“I will not give a fatal draught to anyone if I am asked, nor will I suggest any such thing”

So in considering physician assisted suicide or euthanasia, this already goes against the very principles I have just mentioned.

But I am a palliative medicine consultant and I help people to die. The fundamental difference between what I do is that I aim to alleviate pain and
other distressing symptoms at the end of life, when someone is dying and not before

It seems that including euthanasia and PAS would throw away over 2000 years of holding to the practice and art of medicine that doctors would only be dedicated to healing.

So I entered clinical medicine with the sole intention of making patients better. I have however been involved for the past 15 years with people who sadly for the majority are unable to be cured, but even if we can’t make them better (from their incurable/progressive/degenerative condition), I certainly try to the best of my ability to look after that patient until they die, attempting to help pain and other distressing symptoms, allowing people to get on with living, until they die.

Once it becomes obvious that a person has reached the point of no return and have identified that a person has reached (as we call it) the terminal phase of their illness and is actively dying (identifying this point can often be an art in itself), then we would focus on peace and comfort, treating pain, distress, noisy breathing, agitation and move away from further attempts at treating the underlying disease, which would now be both pointless and meddlesome. Palliative care, is still however, active care up until a person dies. It is much more than just the physical care and any active therapy thought to be helpful will continue to be used.

One can trace back the origins of the modern hospice movement to the 1960s and the founding of St Christopher’s hospice by the late Dame cicely Saunders.

Recent advances in modern medicine have raised the expectations of the public often to such an extent that people think there are therapies that will continually prolong life. This is true to a certain extent and advances in cancer treatment have meant that we have seen an increasing number of patients who do not die until their cancer is at a much more advanced stage than before. Death has literally been postponed and life prolonged, but at what cost? Palliative care can help explore what is possible and what is realistic along side our colleagues who specialise in cancer treatment.

Palliative care will always be there for patients and their families no matter how ill someone is, no matter how seemingly impossible or serious the situation. Palliative care will always have something to offer, even if only the security of being in Roxburghe House or being there for patients and families. But at the same time as the expectations of society for prolonging life, there is the move away from simply taking the doctors advice and an ever increasing ethical awareness of autonomy... my life, my body, my disease, my decision and my death, where I say and when I say. This autonomy has been so elevated within society in recent times that people feel it is their right to have control over their own destiny and even life and death itself. So here we are considering PAS and euthanasia. Topics that feel so wrong and alien to me...
personally and against the already mentioned principles of practising medicine in the first place.

Palliative medicine developed almost exclusively for the end of life care of cancer sufferers, but the majority of patients we hear about in the media are around patients suffering from progressive, incurable life limiting illnesses that are not cancer. Degenerative neurological conditions such as Motor neurone disease and multiple sclerosis and Parkinson’s feature strongly.

What palliative medicine is currently embracing is expanding out of an almost exclusively cancer related specialty and becoming available for other chronic, degenerative and incurable illnesses.

The Scottish government are at present attempting to improve palliative care for all groups through their initiative called “living and dying well”. If we get this right, we aim to improve the delivery of palliative care across the board to all those who need it, when they need it, wherever that might be, in hospital, hospice, care home or their own home.

We all know that expanding and improving services comes down to money in the end and everybody (including the government) knows the fragile state of the finances at present.

In palliative care we try to balance what is possible and realistic against that which is unrealistic expectation

Palliative care affirms life and dying is a normal part of life, just as is birth

We intend to neither hasten nor postpone death. We would discourage over treatment and treatments without any hope of benefit...when enough is enough and when it is time to acknowledge that a person is dying.

We embrace the ethical framework of beneficence (doing good) and non-malificence (not doing harm) and we would encourage autonomy through real desire to work with our patients.

We concentrate on patients Living and (when it is time) dying well. This is palliative care.

We need the government and NHS boards to fully embrace the rollout of “Living and dying well” as there will have to be an increase in the number of those involved in looking after the terminally ill to include many more of those patients who don’t have cancer. Palliative care through living and dying well has the potential to allow the majority of the terminally ill live life to the full until they die.

But I acknowledge the small minority for whom despite all best intentions, life remains uncertain and intolerable as in those who hit the media headlines. It is this minority of patients (often always non cancer) in whom the identification
of the dying phase may be fraught with a much greater element of uncertainty
and this in itself becomes intolerable.

[Terry Pratchett on the last Dimbleby lecture said that he could not get on with
living until he sorted out exactly when he was going to die]

It is in these situations that these very people need an intense engagement
with palliative care services all the way along this very uncertain path. There
would also need to be at that person’s disposal the very best that nursing and
social care has to offer with support all the way into and through the terminal
phase of their illness.

Every time I read the principles behind palliative care, especially to neither
hasten (PAS/euthanasia) nor postpone death (attempting to keep someone
alive at all cost at the expense of quality of life) it is always a very difficult one
and a fine balance. To literally treat someone to death goes against
beneficence and non-malificence. But the deliberate cutting short of
someone’s life, before they would otherwise die does not fit into my practice
as a doctor. I respect that death is a natural process and I do not feel that I
could be involved in holding the keys of life and death. I could not write a
prescription for a drug intended to kill a patient let alone administer it. Nor
could I send a patient to see a colleague who felt comfortable with this as
again I would still be involved in the process.

Although there is a move away from the practice of “paternalism” (doctors
telling patients what to do) as it is thought to go against autonomy, there are
still many patients who listen to and trust doctors and are more willing to take
their advice (more than say a politician).

Palliative care often deals with very complex and difficult pain and symptom
management. We admit that we are not perfect and pain and symptom
management can sometimes be difficult to achieve and be less than ideal, but
it is the approach to that caring that is so important and it is here that palliative
care has a lot to offer and teach by example.

Cancer and other life limiting illnesses do not have to be painful
Death does not have to be unpleasant
Palliative care aims to prevent suffering at the end of life through symptom
management (as already mentioned)
Palliative care tries to identify futile or burdensome therapies (or bad
medicine) which can include the administration of feeding and fluids. What
use can these be to someone actively dying, in a coma and unable to
swallow?
There can be great dignity in death without euthanasia/PAS

So let us consider death and why we would feel the need to have control over
it.

It all stems from the false perception that all death is awful.
Many people die suddenly, unexpectedly and it happens so quickly that there would have been no time for preparation and as in a fatal accident, it would be over in a flash.

Many people die quietly and peacefully in their sleep.

Then there are those who gradually fade away and the waiting, watching by relatives is often very painful and emotional, frequently far worse for those left behind than for the patient themselves. We are fearfully and wonderfully made…..as we die and the body shuts down, it is the thinking conscious parts of the brain that will go first and we see people “going into a coma or sleep” whilst our breathing and heartbeat may continue for some time under reflex control.

Palliative medicine is all about trusting a team of like minded professionals who will do all in their power to help you live until it is time to die and when that time comes, that same team will do all that is possible to help with distressing symptoms if there is indeed a problem.

So there will always be a small number of patients for which, despite the best palliative care and support who will still feel that life is not worth living. They will indeed need the greatest care and support at every stage of their journey but I would still not be able to condone euthanasia or PAS. The ethical principles of justice and utilitarianism means that I would support that which is of most benefit to the majority of society, so the needs of the many outweigh the wants of the few to protect society and especially the vulnerable members of society.

The Scottish government need to push onwards towards the goal of letting people live and die well (all people not just cancer sufferers) and this should be their aim, not embracing an end of life assistance bill.

Palliative care is multiprofessional multidimensional care
PAS/euthanasia seems cold, frightening and very one dimensional

We do not want the inadequate funding of palliative care to unintentionally result in the promotion of euthanasia/PAS. The Scottish government should support improving palliative care for all and not an end of life assistance bill.

Attachment 2

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

No. The doctor/patient relationship would be adversely affected if this Bill became law. On a practical level the Bill makes no comment about the level of competence which a doctor will need to demonstrate. How would this be decided? Nor does it deal with education and training in how to end a life and
there is no mention of personal and professional support for doctors who participate.

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

No. I would be seriously concerned that a 16 year old would be allowed to end their lives at an age when they cannot drink or drive a car. How could we even contemplate a youngster being even mentally or psychologically mature enough to make one of the most important decisions, concerning their own death.

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

No. The scope of the Bill as drafted extends to a significant number of people when in fact it is actually addressed to a minority who subjectively feel ‘intolerable despair’

4. 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?

No. The views, feelings and wishes of patients change over time and may alter frequently during the course of an illness. Patients who wish to get assistance to die because of distressing physical symptoms often change their minds when these symptoms are addressed through appropriate palliative care. There are difficulties in assessing the mental capacity of some patients and not all doctors are aware of the possibilities of palliative care.

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

The safeguards in the Bill fail to acknowledge uncertainties in clinical practice and are unlikely to prevent vulnerable people who seek to end their lives because they feel a burden to others or who cannot see a reasonable alternative.

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

The Bill fails to recognise the involvement of other professionals in the proposed process and focuses on the role of doctors. Pharmacists could also be involved in the process. There is no provision for practitioners who would choose to opt out of this process and the Bill does not provide adequate legal protection for practitioners who choose to engage around the final act of assistance e.g. if a community pharmacist were called upon to dispense a lethal draft of medication for a patient how could they be sure that the whole process had been carried out according to the letter of the law?
The principles of assisted dying are contrary to the principles of palliative care and the two are not compatible. Palliative care services are highly developed in the U.K. but are less so in countries which permit assisted dying.

As a Palliative Medicine Consultant I see how patients benefit from high quality palliative care. However this is not available to all. I am encouraged by 'Living and Dying Well' the national action plan for palliative and end of life care and feel that the Scottish Government should actively promote excellence in palliative care and adequately fund palliative and end of life care.

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