End of Life Assistance (Scotland) Bill

Dr John Walley

I am writing this letter in response to the publication of the End of Life Assistance (Scotland) Bill by the MSP Margo MacDonald. I currently work as a consultant in Palliative Medicine at Accord Hospice, but this submission represents a personal rather than a corporate response.

I have been a doctor since 1995 and have worked in specialist palliative care for approximately 9 years, the last 3 of which have been as a Consultant in Palliative Medicine. My clinical experience in caring for people dying of all conditions is therefore extensive. I have considerable experience of helping patients going through extremely distressing periods of their lives. This has included journeying with people when, in spite of our very best efforts, their symptoms have remained poorly controlled or they have suffered from spiritual, psychological or social distress which has been impossible to alleviate. As such, I welcome the discussion that Margo MacDonald’s Bill has provoked, as situations where we are unable to effectively manage a patient’s physical or existential distress causes patients, their families and those caring for them great distress. My conclusions however are markedly different to those set out in the Bill.

I have a number of concerns with the Bill.

1. Firstly there is only limited research evidence surrounding requests for euthanasia or physician assisted suicide. In addition the term ‘dignity’ is used frequently within the Act, but not defined. What evidence we do have from research such as that conducted by Harvey Chochinov suggests the concept of dignity is complex. The threat to a persons’ dignity produced by an incurable illness goes beyond physical debility or suffering and often includes emotional and spiritual concerns. Peoples’ sense that their dignity is threatened or lost has been linked strongly with concerns about being a burden to others and psychological issues such as anxiety and depression. A perceived loss of dignity therefore may be amenable to intervention, by addressing physical, social, psychological or spiritual needs. Also there is evidence to suggest that dignity can be restored by affirmation of the person as a valued individual, regardless of their physical capabilities. I would suggest therefore that a better response to the difficulties of unrelieved suffering is further research into ways of relieving suffering and the perception that dignity has been lost, rather than seeking to end that person’s life. Also, there is evidence that the way a person with a threatened sense of dignity is perceived by those caring for them may have a direct effect on the patient’s sense of themselves. At the simplest level, this can be about respecting a persons’ sense of self and privacy, but on a deeper level, the affirmation of the person as a valued individual and meeting that person at the place of their suffering can have a significant positive impact on their perception of suffering. The perception that the medical practitioner agrees that the person’s...
life is not worth living then may in fact foster and encourage a sense of lost dignity, therefore making requests for euthanasia more likely.

2. The request for assistance in ending a persons' life is often linked to a sense of being a burden to others. Again the limited research we have in this area suggests this goes beyond mere physical dependence and may reflect deeper concerns. Facilitation of patients’ and families’ communication, and support for both the patient and their family, may have very positive effects in reducing distress in these circumstances. Also whilst the Bill attempts to safeguard against external coercion, it cannot safeguard against the internal pressure to request assisted dying for the perceived benefit of ones’ family, even when ones’ family would be strongly opposed to this. Facilitation of communication between patients and their families, as well as practical assistance are therefore, in my opinion, better responses than legalising assisted dying for people at the most vulnerable time of their lives.

3. From a practical point-of-view, the Bill suggests that the first registered medical practitioner to whom a request for physician assisted suicide is made is responsible for pursuing the assessment and management of that patient. Unfortunately this may lead to a doctor of only one year's experience being (or feeling) obliged to deal with the request for physician assisted suicide. It is my experience that requests for euthanasia are invariably complex. Assessing people in this situation invariably takes considerable time and requires the highest levels of skill and experience in communication as well as a thorough knowledge of what specialist palliative care can offer if the situation is to be managed effectively. It is unrealistic to expect either junior medical staff, or indeed the majority of busy general practitioners, to meaningfully or safely undertake this work.

4. The Bill requires a level of prognostic accuracy, which unfortunately at present we do not possess. This is particularly the case for diseases other than cancer such as congestive heart failure or chronic obstructive pulmonary disease, where our ability to prognosticate is frankly inadequate to fit the Bill’s purpose.

5. The Bill suggests that the minimum time between the two requests for assisted dying should be approximately 2 weeks. It is my experience that many patients who request euthanasia subsequently change their minds. This seems to be due to improvements in their care, their symptoms or coming to terms with their situation. However, it is my experience that this process often takes longer than 2 weeks. Again we have a paucity of evidence to support my clinical experience, but if anything this is an argument against the intent of the Bill, rather than for it.

6. The proposed involvement of a psychiatrist in assessing the person requesting euthanasia is re-assuring; however the Bill limits the involvement of the psychiatrist to assessment of a patient’s mental
capacity for making such a decision. It is my opinion that one or two visits with a person is inadequate to ensure that a treatable psychiatric condition such as depression or even appropriate sadness in response to the losses associated with having a terminal condition have not been missed or misunderstood. A thorough review by a psychiatrist, preferably over a number of weeks, would be required to exclude a significant mental disorder which may be amenable to therapy in the setting of an incurable illness. In addition, the majority of psychiatrists, whilst very expert in their field, have only limited experience in caring for people with progressive, incurable physical illnesses.

7. The Bill, particularly in the accompanying briefing document, draws parallels with the withdrawal of treatment and the act of killing. Whilst ethicists have on occasion struggled to make this distinction, the majority of people caring for patients have little difficulty in doing so. Withdrawal of active therapy which is prolonging a person’s life by artificial means is very different to the intentional act of ending somebody’s life. Also situations where the use of medication to control a person’s symptoms leads to the shortening of their lives whilst in the terminal phase of their illness is, with modern palliative care, uncommon. However, the principle of ‘double effect’ allows for a medical practitioner to shorten somebody’s life in their terminal phase as an unavoidable secondary consequence of giving medication to alleviate distressing symptoms. In these circumstances, it is my opinion that the intent to alleviate suffering, as opposed to intent to kill, is a clear and morally important distinction.

8. The introduction of physician assisted suicide is likely to irrevocably alter the relationship a patient has with their doctor. At present, as defined in Article 2 of the Human Rights Act, no individual in society has the right to take another’s life, except under specific circumstances such as when acting as an officer of the law. The erosion of this principle is a significant step for Scotland as a society. The majority of medical professionals based on BMA and Association for Palliative Medicine surveys are opposed to this power being given to them. The Bill as it stands in no way appears to be in concert with the Human Rights Act legislation, in spite of Ms Macdonald’s attempts to suggest otherwise.

9. Comparisons are made between Scotland and countries where physician assisted suicide or euthanasia is allowed. Palliative care services in these countries are of a different quantity and quality in comparison to those in Scotland. Direct comparisons are therefore difficult to draw and should be treated with caution. It can be argued that the legalisation of euthanasia or physician assisted suicide in these countries has hindered the development specialist palliative care and as a consequence, generalist palliative care. We are fortunate in Scotland to have well developed generalist palliative care services actively supported by specialist services. There is a danger that the
introduction of physician assisted suicide or euthanasia may erode this necessarily expensive service provision.

10. The majority of doctors are opposed to physician assisted suicide. Significantly a large proportion of doctors working in specialist palliative care in a recent Association for Palliative Medicine survey were against legislation to legalise physician assisted suicide. This will lead to many doctors having to conscientiously object to providing assessment for or the completion of physician assisted suicide for their patients. This would then necessitate the patient being assessed by a doctor that they did not know, making this assessment more difficult for the doctor involved, but also more distressing for the patient and their family. It also would reduce contact with medical staff that the patient knows in what would be one of the greatest crises of their life. Continuity of care is frequently highlighted by patients as very important in providing satisfactory medical care when they have advanced illnesses and the Act may hinder this provision. In addition, if only a small number of medical practitioners are willing to undertake this work it is likely that patients will struggle to have a timely review of their request and may need to travel to do so. Also it is likely that doctors who personally support euthanasia or physician assisted suicide may preferentially undertake this work, potentially affecting the objectivity of the advice and assessment a patient may receive.

11. It is my experience that the period leading up to a person’s death can provide valuable opportunities for the patient and their family to demonstrate their love and care for each other. On occasion this can include resolution of long standing conflicts, although this is not always the case. This can have long lasting benefits. Euthanasia or physician assisted suicide is likely remove this opportunity for patients and their families which may have long term consequences for the families’ grieving process. Weighed against this are the effects of seeing a loved one suffer towards the end of their lives. Research in this area is limited, but it is clear from that which is available that patients’ relatives perceive their loved one to be in greater distress than patients themselves report. This needs to be taken into account when supporting families in caring for their loved one and also in considering evidence based on families’ recollections of the highly distressing events surrounding a loved one’s death. In my experience it can be difficult to predict whether journeying with a loved one through unrelieved suffering will produce a worsened or eased grieving process after they have died. What is clear is that those journeys, whilst very difficult, have light in them as well as darkness. Knowing that they have walked that difficult road with their loved one can provide families considerable comfort in grief.

Finally should this act become law, I would be unable to be involved in its working. My deeply held Christian faith would prevent me from intentionally taking another persons life unless my own life was threatened. In light of this and being aware of my profession’s views on this issue every effort to coerce
doctors to be involved in physician assisted suicide or euthanasia when they object should be strongly opposed.

I would be delighted to discuss these issues further and am most easily contacted via my work address which is written below.

Dr John Walley
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