

The Secretary
 Legal and Social Issues Committee
 Parliament House
 Victoria

25.8 2015

SUBMISSION

Inquiry into to End of Life Options

Sir,

It is held on humanistic grounds that the terminally ill have the right to determine, as much as is possible, the time place and manner of their death. It then becomes how best to legislate for this, using the experience of overseas jurisdictions that have enacted legislation.

Clause 1. Assess the practices within the medical community to assist a person to exercise their preference for the way they want to manage their end of life, including the role of palliative care.

COMMENT

a. Medical status.

There are no public positions from most of the key medical bodies relating to this subject. Currently in Australia voluntary euthanasia is illegal but may nevertheless occur although there is no current data about its incidence. In its absence, a terminally ill person is cared for by their doctor until death occurs 'naturally' or else admitted either to a Palliative Care Unit (PCU) or nursing home. Advanced Health Care Directives do not change this. While used in hospitals for the withholding or withdrawal of futile treatments, locally, non acceptance of Physical Assisted Dying (PAD) would likely mirror the situation overseas where it is not used, particularly with end stage dementia where most needed.

b. Palliative Care.

Palliative care in PCUs should be offered to all of whom most will benefit; consultations to inform what palliative care there can offer need to be arranged so that there is a minimum of discomfort for the afflicted person. Nevertheless there are issues about their exact role. As overseas hospices seem to operate differently, the following are general comments about local PCUs.

1. Pain, when suffered, is said to be controlled in approximately 90% of persons treated. What happens in the other 10% - are they left in limbo? When pain is controlled in those 90%, what is the incidence of unwelcome effects of opioids when high doses are needed, such as a decreased level of consciousness, constipation, vomiting and so on?

2. How often are high doses of opioids, **above those needed to control pain**, ('terminal sedation') used to end a person's life? If with overt intent, this is voluntary euthanasia if not involuntary euthanasia. On the other hand, to claim that death from this is incidental to the treatment of pain ('double effect') is nonsensical. This obfuscation is compounded by the existence of life supporting procedures. If these were halted, indicating intent, there is no need to give excessive opioids. If retained, there is the anomalous situation of, on the one hand, a procedure to end life, on the other, life sustaining procedures being maintained. Apart from this it is a slow process with the person comatose for some length of time having little control on what happens and where the attending doctors must dissemble.

3. What is the incidence and management of existential suffering in PCUs? This is the loss of bodily functions causing a loss of autonomy, dignity and life satisfying activities. Experience in Oregon and from local public expressions of anguish indicate that this is most often the reason for a request for PAD. Options for its care are limited with little or no indication for opioids. It is not known how often persons in PCUs suffering in this manner request (unsuccessfully) for PAD.

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4. Would nembutal or other appropriate drugs be used in PCUs where their use no longer an offence? Presumably like individual doctors they, as an entity, would be able to opt out.

5. Palliative care does not meet the needs of all. A small number of the terminally ill, were PAD legalised, will avoid admission to a PCU. This should not affect their use and development.

c. Psychiatric referral.

A similar situation exists with psychiatric intervention with claims that referral should be mandatory for all. This is on the assumption that it will allow persons to be identified on whom the attending/review doctors jointly miss the diagnosis of depression, allowing the psychiatrist to correct any resulting error in their assessment of capacity.

There is no evidence supporting this nor is there evidence that a psychiatrist, after only one consultation for a person they have not previously seen, can accurately assess capacity as has been acknowledged by psychiatrists in peer reviewed articles. This particularly so when it is contrasted against the assessment by the attending doctor who has cared for his patient over time, who has had the support of other health professionals involved in the treatment of that person and is backed up by a second independent review doctor.

Add to this are a number of unwelcome effects of mandatory referral. It needs to be recognised that these occur with persons suffering a horrific death.

1. Mandatory referral raises the possibility that a psychiatrist could overturn an acceptance by the attending/review doctors of a request for PAD (where the depression is usually not treated). This would result in the person still depressed, still wanting PAD with their suffering prolonged.
2. Nevertheless, after review of all persons by a psychiatrist, the result surely must be that the joint assessment of capacity by the attending/review doctors is rarely, if ever, overturned. An inefficient use of medical resources.
3. For a terminally ill person the consultation, transport and delays thereupon could be distressing.
4. The person may resent the obligatory nature of the consultation(s), and regard it as a restriction of their autonomy.
5. Whatever, it is an unnecessary intrusion into the final movements of the life of these persons. With the criterion of severe suffering met, all that is required is a brief check on the bed side whether their decision is enduring.

The above supports that the interests of the terminally ill are best served by psychiatric referral being left to the discretion of the attending/review doctors as occurs in all overseas jurisdictions.

Clause 2. Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdiction.

COMMENT

Some features of overseas jurisdictions are considered.

a. Overall operation.

In Oregon, the Dying with Dignity Act has been in operation for 18 years. The system is well controlled with a general acceptance, few if any complaints and with no undue increase in its use. This model has been followed by other states in the USA (Washington and Vermont) and has been used as a model in two major reports, in the UK Falconer Report and in Canada with the Royal Society of Canada's submission.

Voluntary euthanasia in Holland/Belgium each has operated since 2002. In Holland its increasing use is of concern and may reflect that the conditions to accept requests are too liberal resulting in voluntary euthanasia longer being the option of last resort. Both countries have pushed the envelope in ways that are unlikely to be unacceptable in Australia. These include Holland accepting persons with mental illness and early stage dementia and in Belgium of having no lower age limit.

b. Means of death.

In Oregon, under specific conditions, a script is given to the afflicted person who, after having acquired the medication, can to a large extent take it when and where they wish. A process which defines PAD. In contrast, in Holland in a rather unspecified incidence, a lethal combination of drugs is given intravenously.

c. Eligibility criteria.

In Oregon, the criterion is that the expected life survival is less than six months. This is easily applied but with several negatives. The estimation of survival is inaccurate as well as being illogical with a decreased life expectation being the sole reason to accept a person's request for assistance to end their life. The possible interval between their achieving the medication and taking it allows possibility there is a treatable depression influencing the decision made occurring.

In Holland the criterion is intolerable irremediable suffering for a person in an advanced stage of a terminal illness. This is more germane to the person's situation. It may not be as easily applicable as in Oregon with the need to assess the severity of their suffering. It has been objected that such a criterion is subjective and accordingly unreliable. However, unrelieved severe pain is usually indubitable as is existential suffering. If so, the decision the person then makes, whether or not to request PAD, is accepted without further ado.

d. Security.

Accepting PAD ala Oregon and the eligibility criterion ala Holland, the following is an amalgam of security measures used in overseas jurisdictions.

1. The attending doctor to ensure that the diagnosis is unequivocal and the decision for life termination is enduring, informed and independent.
2. Corroboration by an independent second doctor.
3. Referral to a psychiatrist or other experienced health professional be made when either of the attending/review doctors consider it needed.
4. Strict well defined eligibility criteria stating that the person has a terminal illness in an advanced stage with irremediable and intolerable suffering.
5. An independent body to annually review that all involved health professionals have observed the conditions set by the Act.
6. An annual public disclosure of the results of an Acts implementation.
7. Documentation from the attending/review doctors, the pharmacist and other involved health professionals.
8. Means of achieving the security of the script and medication prescribed are set.
9. Regular parliamentary reviews.
10. A precise definition of a terminal illness with appropriate exclusions of diseases not meeting it.

e. Adverse outcomes.

In the overseas jurisdictions employing these conditions, no 'slippery slide' has been observed, after many years of operation with thousands of persons involved. This includes the abuse by family member either financial or of life-hastening, a decline in standards of medical practice and non compliance with eligibility criteria. The latter should not be confused with 'liberal' legislation allowing outcomes some do not accept. Outside the ambit of these there are a number of speculative statements about effects on the health system which overseas experience has nothing to say. These include that acute hospitals will be crowded with these patients, that the public's faith in the medical

profession will be diminished, that voluntary euthanasia would increase the incidence of non voluntary euthanasia and find its way into the curriculum for teaching undergraduates.

Clause 3. Consider what type of legislative changes may be required, including an examination of any federal laws that may impact such legislation.

COMMENT

There is a need for Acts enacted by State legislatures having features as above. As well the Commonwealth Criminal Related Material Offences Act should be repealed. In this, any person assisting or encouraging another person to suicide or attempting suicide, are liable to prosecution even though suicide itself is not an offence. It should be noted that terminally ill persons could need help in a number of ways including taking the medication or acquiring it from a pharmacist.

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