



NSW.ACT

Euthanasia Discussion Kit

Discussion Part Two: Evaluating Legislation

This paper contains the following:

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Summary

The existence of euthanasia legislation in the Northern Territory shows that it is not enough to think about whether we are for or against euthanasia. If there is going to be euthanasia legislation, then we must ensure that it is as responsible as possible, and that it reduces any risks and dangers to the barest minimum.

This paper looks at some of the criteria by which legislation should be assessed. If legislation is supposed to be about voluntary euthanasia, how do we ensure that this is the case? How do we make sure that people are not killed against their will?

This paper argues that there are four main components to responsible legislation for voluntary euthanasia:

- A process which ensures that the patient is properly informed about their illness and possible courses of treatment, and that they make the request for euthanasia entirely

of their own free will and while not suffering temporary depression or other temporary problems.

- A standard means of recording each stage of the process. Proper documentation can ensure that both patient and doctors know what their rights and duties are. It also needs to provide full evidence of what has and has not been done - have all the rights of the patient been respected, and all the duties of the doctors been fulfilled?
- A mechanism for ensuring that death certificates and records will be carefully checked by the Coroner's office to see whether they have conformed to the law.
- A clear legal requirement that doctors will be prosecuted for the death unless there is adequate evidence that the euthanasia law has been properly followed.

The Northern Territory legislation does not seem to fulfil these requirements. Its process seems reasonably sound, but does not appear to have adequate documentation of each stage of the process. It seems to be more concerned to protect doctors who perform euthanasia, than to ensure that patients and society are protected against doctors who might, as happens in Holland, kill people who have not requested euthanasia.

The rest of this paper explores these issues in more detail.

If your state were to pass legislation allowing voluntary euthanasia, what would you want it to include to ensure euthanasia is voluntary and people are safe?

The framework for evaluating legislation

Whether we are personally for or against euthanasia, we have to face the reality that there is euthanasia legislation in the Northern Territory; legislation may be passed in other states. The Northern Territory legislation, and the proposals in other parts of Australia at the present time, are about voluntary euthanasia. How do we make sure that such legislation is as responsible and as safe as possible? How do we test such legislation against what its supporters claim it is about?

This is a complex issue, and requires some complex thinking. Often a number of ideas need to be held together. It may take some patience to work through the points set out below.

Basic principles

The NSW Synod in 1995 affirmed three basic principles which should be "considered foundational in any debate about euthanasia": These three principles are intended to be read together., especially the first and third.

All human beings have the right to life and to freedom from arbitrary interference and society should do all that lies within its resources to sustain, maintain and enhance the life of all its members;

Society has a responsibility to provide accessible and affordable high quality medical care, palliative care, and support services to all who need them, so that euthanasia is never a result of society's failure to provide adequate services;

There is a time to live and a time to die. The Department of Health's Dying with Dignity guidelines should be fully implemented by the medical professions and widely understood in the community, so that people are not in fear of their proper time of death being postponed by futile treatment.

The church has a responsibility to ensure that any euthanasia legislation is consistent with these conditions, particularly the first one. The second and third requirements rest on a number of matters, such as health care budgets and normal medical practice, as well as the approach taken in euthanasia legislation itself.

Society has the responsibility to determine what size health care budget lies "within its resources", and how to use that budget most effectively to "sustain, maintain and enhance the life of all its members".

The Synod was not making a statement about what size the health care budget should be. Rather these principles oppose the view that people who are old, terminally ill or disabled are a "drain" on society and that euthanasia should be used to solve this "problem".

Euthanasia must not become an excuse for limiting the responsibilities of the health care system, for ignoring the needs of people who are old, disabled or dying, for giving them inadequate treatment, or for cutting back on budgets for palliative care and support services. If euthanasia is ever acceptable, it is only as last resort for the patient, not as a social policy to be imposed on people to help balance the budget.

Criteria related to the specific issue of euthanasia

General principles

How can we make sure these principles are fulfilled? Any legislation on euthanasia should include a statement of basic principles and values and make clear that the legislation must be interpreted in accordance with them. One way of doing this would be to include principles such as the following into its preamble .

Euthanasia is an option of last resort for the patient and must be entirely voluntary; it is available for those patients who decide that their wishes cannot be met in any other way.

Euthanasia is not an alternative to adequate provision of accessible and affordable high quality medical care, palliative care, and support services to all who need them.

It is preferable for patients to choose other treatment options (which include palliative care) and that high quality advice on those options must be given before a request for euthanasia is accepted.

Euthanasia is not a "social policy", that is, it is not an action that individuals, families or society may take for granted as an ordinary or everyday event. Rather it is an option available to an individual on a totally voluntary basis, in exceptional circumstances.

This should, of course, also be evident throughout the legislation, in the process leading to euthanasia and in the documentation of that process.

Society has a responsibility to ensure that treatment options are affordable and accessible. People should never have to choose euthanasia because they cannot afford the care they need to make their level of suffering acceptable.

Appropriate Procedures and Accountability

The synod resolution also implies several criteria by which any legislation on euthanasia should be assessed:

The legislation must provide procedures to ensure that the death is voluntary.

The legislation must protect people from being killed under the guise of euthanasia. This means that the legislation must provide adequate mechanisms of accountability .

The legislation should clearly distinguish the euthanasia for which it provides from withdrawal of futile treatment.

The needs of different stakeholders

Proposed legislation needs to be evaluated from the quite different perspectives of various stakeholders:

- Those seeking euthanasia for themselves, to ensure that it is workable in the situation in which they will make the request.

- Health professionals (doctors, nurses) who will be asked to assist with euthanasia and who are willing to do so.
- Health professionals who will be asked to assist with euthanasia and who are unwilling to do so (no one should be forced to participate in euthanasia)
- Those who do not want euthanasia for themselves, but who others might think should die. They have the right to live, and the right to expect that legislation ensures that no one else can decide that they would be better off dead. These people include

people who are terminally ill and in severe pain
 people who have illnesses where a significant number of patients seek euthanasia
 people who are aging, especially the very old and frail,
 people who are disabled
 people who are not mentally competent
 groups of people who may be at particular risk of being killed under the guise of euthanasia, because of attitudes such as homophobia, racism, and so on.

- Coroners and police who have the responsibility to detect and prosecute unlawful deaths, ie any involuntary deaths which perpetrators attempt to pass off as "euthanasia".

Most of the discussion by those in favour of euthanasia seems to ignore the need for such assessment, and to look at euthanasia legislation only from the viewpoint of those seeking euthanasia. This is ethically unacceptable, since it opens the way to murder.

We need to be very careful in assessing legislation. Many of the speeches in support of such legislation are actually speeches in support of the principle, and fail to deal with the practicalities.

For a bill to be a responsible proposal, it is not enough that it be well-intentioned. It must actually contain the mechanisms to make it work effectively within the framework set out above.

Mechanisms mean not merely setting out a set of steps to be followed, but providing for accountability. The process must be adequately documented. Someone must have the responsibility to assess the documentation and take action where the requirements of the legislation have not been fulfilled.

Criteria applying to any legislation

In addition to this framework related to the specific question of euthanasia, there are also **three sets of criteria which the UCA would apply to any legislation** on matters where the church has an interest:

Is the purpose of the legislation consistent with demands of social and economic justice, human rights, or other ethical standards to which we are committed as a church?

Does the legislation generally fulfil its own stated purpose? Does it contain all the essential elements required to fulfil its stated purpose? Is it workable? Is it self-consistent, or does it contain elements which contradict its purpose or which would prevent it from fulfilling its purpose?

Are the assumptions made in the legislation are appropriate? Are the assumptions reasonably consistent with the actual situation and needs of society? Are the assumptions consistent with the purpose of the legislation? Or are its assumptions so out of touch with reality that the effect of the law will be significantly different from its stated purpose or from the requirements of social justice and human rights?

Has the legislation been reviewed by the Aboriginal and Torres Strait Islander Social Justice Commissioner of the Human Rights and Equal Opportunity Commission?

Are there other principles, stakeholders or criteria that should be taken into account in assessing legislation?

Legislation - what should it include?

Because we are talking about the death of a person, rigorous procedures of accountability must be provided. The whole procedure must ensure that the legislation is

- only used as a last resort,
- in response to definite requests, and
- that the coroner is able to assess whether or not the conditions laid down by the legislation have been fulfilled.

Some current proposals lack adequate safeguards and procedures. Others appear to propose adequate procedures but fail to provide adequate mechanisms of accountability.

Provisions for euthanasia usually provide for two alternatives. The first is that the health professional assist a patient to commit suicide (eg supplying appropriate drugs). The second is that the doctor takes direct action to bring about the patient's death. This means that the person is, where possible, in control of their own death and it is only where the patient cannot act for themselves that the doctor takes action. Euthanasia legislation covers both cases because normally assisting a suicide is a criminal offence.

Ethically, there is a deep gulf between voluntary and non-voluntary euthanasia. In the first, the patient makes the decision and the doctor responds to it. In the second, doctors decide, on their own initiative or in consultation with the family, that someone who cannot make a decision for themselves would be better off dead. Legislation and guidelines must respect this gulf.

This paper deals only with voluntary euthanasia. Non-voluntary euthanasia, the decision to terminate life where patients are not competent to make a decision but are in severe pain and require significant help to stay alive, would raise quite different issues and require a separate paper. If non-voluntary euthanasia were accepted, it would require quite different procedures for making the decision and holding doctors accountable, and therefore require completely separate legislation.

Some of the questions that should be asked of any legislation for voluntary euthanasia include the following.

Immunity for actions in accordance with the act

The purpose of euthanasia legislation is to exempt **actions in accordance with Act** from the provisions of civil and criminal law, and from any professional disciplinary proceedings.

Does the legislation require and enable the Coroner to distinguish actions in accordance with the legislation from actions not in accordance with the legislation?

Values and philosophy

- Has the legislation been developed in consultation with the range of Indigenous and ethnic communities in Australia, to take account of cultural issues (these are more than simply language translation)?
- Does the legislation clearly exclude involuntary euthanasia? Does it make clear that doctors do not have the right to make decisions on behalf of patients to artificially hasten death?
- Does the legislation provide a framework of values and philosophy for its interpretation, so that there are barriers to its misuse in health policy in the future?

- Does the legislation ensure that euthanasia is defined as an option of last resort for the patient, and that such a decision may only be made by the patient?
- Does the legislation recognise that different people will make different decisions in apparently similar circumstances, and that society and health professionals should respect each decision?
- Does the legislation respect the patient's right to decide when life has become unbearable because of physical pain or other forms of suffering?
- Does the legislation protect the patient from an overly hasty decision, by requiring that the doctor not fulfil the request if he/she believes effective palliative care is available which has not yet been tried by the patient?
- This is not in contradiction to the previous point. It has been found that many people who talk about euthanasia change their mind once they are provided with appropriate palliative care.
- What guidance is offered to the Coroner to ensure that he/she will rigorously scrutinise the documentation associated with these deaths? How is the Coroner to distinguish those deaths which are exempt from the Crimes Act (because they comply with the legislation) from those deaths which come under the Crimes Act (because the requirements of the legislation were not fulfilled)?

Is the patient making an informed decision?

- Does the legislation ensure that before the request is fulfilled, the patient has had access to a second opinion about the nature of their illness, possible treatments, and likely development of the illness?
- Does the legislation ensure that the patient has had expert advice about available palliative care?
- Does the legislation encourage consultation (and involvement of family or designated friends in such consultation) with a non-medical person such as a chaplain, psychologist or social worker to review issues and options?

The underlying issue may not always be the medical one. It may involve a problem which can be dealt with in some non-medical way, eg with the help of family or community.

- Any non-medical consultant invited into the process should be committed to a client-centred approach - helping the patient articulate their issues and finding solutions the patient considers appropriate.
- Does the legislation ensure that the person is not suffering from treatable depression or simply in need of someone to talk to about their illness?
- Has an adequate period been allowed for the patient to reconsider his or her request in the light of eg improved palliative care.

Safeguards

- Is the procedure adequately documented? Is each requirement and stage of the process documented, so that everyone is clear (a) what the legislation requires and (b) that in this case, it has been fulfilled?
- The legislation usually requires a certificate that the conditions have been fulfilled. This should be in the form of a checklist and require the relevant information to be filled in, so that all those involved know what the legislation requires and are sure that the conditions have been satisfied.

- Does the doctor have to be satisfied, from talking to the patient, that he/she is making the decision freely, voluntarily, "after due consideration" and without pressure from other parties?
- Does the legislation safeguard people of non-English speaking background: does it require that there be an interpreter present when the request is made, if the doctor does not speak the patient's first language?
- Does the procedure give the doctor backing to encourage a patient to try palliative care, if palliative care is readily available and known to be effective and acceptable in most cases of the illness?
- There is a fine line here. The patient should make the final decision about whether they want palliative care or euthanasia. The point is that the patient should not make the decision prematurely or unnecessarily.
- Many patients who think they want to die change their mind once their symptoms are relieved. Doctors should not be put in the position of being expected to accede to a request for euthanasia, when they know there is a high probability that the patient would make a different decision once they experienced palliative care.
- However, in the end, the patient is the person who experiences the situation. It is appropriate for the legislation to ensure that once palliative care has been tried, the patient's decision to request euthanasia is respected.
- Does the procedure and documentation ensure that the patient has to confirm the request immediately before it is fulfilled, so they have a real option of withdrawing the request?
- One of the problems is ensuring requests are destroyed when they are withdrawn. This is partially overcome if the patient has to sign confirmation of the request immediately before the request is fulfilled.
- Most proposals for euthanasia make it conditional on the patient having a terminal illness. Since life itself results ultimately in death, the definition of terminal illness is important. Does the legislation define terminal illness in a specific manner, eg at least x % probability of death within, say 3 months?
- If the proposal refers to people with physical disability, does it provide an appropriately limited definition of circumstances where euthanasia is a possibility?

Accountability

- Is there a mechanism by which doctors will be held accountable for the quality of the advice they provide about treatment and palliative care options?
- There is a problem here because there is inadequate accountability in medicine generally. (Stephen Leeder, Professor of Community Medicine at Westmead Hospital pointed this out at a Wesley College seminar 22 April 1996). However, as euthanasia is about patients choosing death, it is obviously particularly important that doctors be held accountable for the advice that leads to such a choice.
- Does the legislation ensure that doctors, other health workers or other people involved, are protected when they have fulfilled the legislation, but are held fully accountable where the death was not voluntary euthanasia?
- Does the legislation require that the death certificate indicate that the death occurred in accordance with the provisions of the legislation, so that this provides a signal that the accountability provisions of the Act should be set in train.
- Is the procedure adequately documented, so that doctors can be held accountable? Was the advice that the doctors gave the patient about their illness and possible treatment competent and adequate?

- Is the procedure adequately documented from the patient's point of view? For example, does the certificate require that they give brief but specific information about what they think is their illness and their treatment options? If not, once they are dead, how is anyone to know what they really thought was happening to them?
- For example, asking a patient to sign a form saying "I have been fully informed about the nature of my illness and available treatment" is unrealistic (but is in the NT legislation). It would make more sense to ask the doctor to state that they have given the patient advice that they are suffering from X illness, and have Y% chance of dying, and that the patient was advised of ...treatment options, and for the patient to sign a confirmation of this.
- Does the legislation ask the Coroner to evaluate the certificates and medical records to ensure that the conditions and procedures of the legislation had been fulfilled? Since euthanasia is a new situation, it cannot be assumed that current legislation about the role of the Coroner will cover this responsibility.
- Does the legislation require the police to initiate an inquiry if a family member or friend of the deceased questions whether the death was voluntary euthanasia?
- Does the legislation require that the documentation should be referred to the police for action, where the Coroner finds that the legislation has not been complied with?
- Does the legislation provide for adequate reporting to the Parliament and the public about the incidence of euthanasia and relevant factors involved?
- Does the legislation ensure that reporting is comprehensive, including matters such as disease, location, age, sex and race.

Sanctions

- Is there both (a) a process to detect misuse of the procedures and (b) penalties for misuse of the procedures, such as gaining a certificate of request by deception?
- Is it clear that unless the procedures are complied with and documented the death will be treated as homicide in accordance with the Crimes Act?

In each of the above sections, what do you agree with, what do you think should be left out, what would you add? Why?

A background paper "Euthanasia - critique of legislative proposals" is available from UnitingCare NSW.ACT on [request](#). It looks at the Northern Territory legislation, the proposal defeated in the ACT in 1995, and the proposal of the AIDS Council of NSW.

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