

27 April 2018

Dear Deputies

I have a number of concerns about the requete proposing that the States of Deliberation agree in principle to change the law to allow 'assisted dying'.

The requete does not define the term 'assisted dying'. Although campaign groups are arguing that this is distinct from assisted suicide, there is no stable, internationally recognised definition of the term and it is most frequently used as being synonymous with the term euthanasia. Technically euthanasia refers to any situation where a third party actively ends the life of someone who is dying or to relieve pain and suffering. If the patient administers the means of ending their own life this can be defined as assisted suicide, however if the means of causing death has been prescribed by a Dr it may also sometimes be included under the umbrella of euthanasia. By simply using the term 'assisted dying' with no qualifying definition, the requete is completely open ended.

The requete proposes that the States agree to change the law without actually carrying out any research into whether is necessary or desirable or whether such a change is supported by the people of Guernsey. Much of the impetus for this requete seems to have come solely from individual and highly subjective anecdotes.

Do we know how many terminally ill people in Guernsey actually do die in pain and suffering?

If so how is this measured? Lots of anecdotes are being put forward but many of these seem to be based on the relatives perceptions, rather than on clear evidence of the individuals experience. It isn't even clear when these deaths occurred, or even if those concerned were in receipt of end of life care in Guernsey.

When did the States last review of end of life care in Guernsey? Is it as good as it could be? Is it possible to improve end of life choices and palliative care to the extent that we would not need to consider introducing complex and challenging new legislation? Currently no States funding is given to the hospice yet we are considering investing resources in offering to assist people to end their lives. What message does that give about how compassionate a society we are? We don't even provide States funding to support the Cheshire Home which implies we are less worried about choices and dignity in life for some, than we are about choices and dignity in death for others.

Clearly there are a number of people in Guernsey who do support 'assisted dying' and are actively campaigning for a change in the law. However it was not an election issue and there has been little consultation to gauge public opinion. It may well be

appropriate to debate whether Guernsey should look at the option of 'assisted dying' as part of a wider review of end of life care and to vote on whether research and consultation into the issues should go ahead. Is it not appropriate at this stage and on the basis of a single debate to decide to change the law. Especially not on such an ethically complex and controversial issue as this.

Consider the debate on the disability strategy. International human rights law is very clear about disability rights, Guernsey is one of the few jurisdictions in the world that does not have disability discrimination legislation, the underpinning law that would permit this to be developed was already in place and campaigners had made an evidence based case and were supported by multiple established charities and disability organisations. Few people had any ethical or philosophical argument against such a law. The only question seemed to be whether people in Guernsey were being discriminated against to the extent that we need to legislate to prevent it. Accordingly the States carried out a review of disability and inclusion in Guernsey before agreeing in principle to develop disability discrimination legislation as part of a wider disability and inclusion strategy.

Contrast that with the impending debate on assisted dying. There is no clear internationally accepted definition of the term 'assisted dying.' International human rights law remains equivocal on the issue. Few jurisdictions permit any form of euthanasia or assisted suicide and the issue remains controversial in those that do. There are innumerable complex ethical, legal and practical issues to be considered and little concrete evidence as to the extent of the need for such an end of life option in Guernsey. In this case however the request is asking for an agreement to change the law without any wide ranging review of end of life care in Guernsey.

Those campaigning for 'assisted dying' claim this is distinct from 'assisted suicide' as the option will only be open to those who are terminally ill, whose life expectancy is within a specific limited period and who are deemed to have the mental capacity to make the decision independently. This they assure us safeguards vulnerable people. It is they claim a matter of personal choice and that people should have a right to be able to end their life when they choose. They claim that this is about having compassion for those who are dying.

However none of this is quite as simple as it appears to be.

1. It isn't possible to predict life expectancy in a terminally ill individual with 100% accuracy and sometimes the assessment can be inaccurate by many months or even years. However, even supposing this can be determined. How do we decide at what point it is right to consider someone is dying and it is therefore permissible for them to end their life. At what point does assisted suicide change to assisted dying under this definition. A number of campaigners are suggesting a cut off point of 6 months. They don't give any rationale for this and seem oblivious to the arbitrary discrimination that this causes. Some people with incurable life limiting conditions can be significantly more disabled, dependent and in need of pain control and yet have a longer life expectancy, than others who may be only weeks away from death.

2. One of the biggest concerns about legalising any form of euthanasia is that it leaves people vulnerable to pressure from others. The obvious way to protect vulnerable individuals is to limit offering the choice to adults who are deemed to have the mental capacity to make an independent decision.

This may indeed provide some safeguards but it is also discriminatory and by default says it is acceptable to make children, adolescents, those with intellectual disabilities or those with mental health conditions, endure what we as competent adults want the right to escape. Where is the compassion in that?

The problem then arises as to whether to legalise assisted suicide for anyone who asks, or even to provide euthanasia for those who are unable to communicate their wishes but who appear to be suffering. This is a hugely more contentious option and opens up a pandora's box of ethical considerations.

3. It isn't clear what is meant by mental capacity to make the decision or who would be expected to judge this. A person who has just been diagnosed with a terminal illness may be experiencing shock, grief and fear. Others who have already had a long period of treatment and increasing dependence on others, may experience periods of despondency and feel that they are a burden to relatives and that their life has no purpose. One of the criticisms of some jurisdictions that do permit euthanasia, is that little psychological support is offered to dying patients and capacity is not always determined by careful evaluation of the person's current psychological state. This is a significant issue bearing in mind that in other circumstances we consider it a matter of such grave concern that someone should be considering taking their own life, to the extent that we actually have legal provision to detain them against their will for their own protection.

4. The claim that this issue is solely about personal choice is patently absurd. If you are asking for assistance in taking your own life you are clearly involving at least one other and probably several other people. With regulated and limited access to assisted dying, a considerable amount of the responsibility for the decision will rest with the Doctors who have to determine life expectancy and capacity.

What reasons do people give for wanting the option of assisted dying? The first and most obvious is that they don't want to die in pain and suffering. It isn't however clear what is understood by this. Are we asking for the right to choose this option at the point at which pain relief fails or are we saying people can choose to die long before this point because they fear being in pain. Others talk about quality of life and loss of independence. In many cases what they are implying is they fear being disabled and believe their life would no longer be worth living. The problem is that by endorsing the right to assisted death for such reasons, we would be reinforcing the idea that life with such a disability is not worth living. What message does that send to people who are not dying but have similar levels of disability, who may indeed have lived with such disability for many years?.

I understand why people support the idea of assisted dying. Both my husband and my son have without giving much thought to the matter have said yes of course people should have the choice.

Therein lies the problem, we are asking the wrong question. We should be asking do you want such high quality care and support for people at the end of life that no one on Guernsey should fear having an undignified and painful end? That support for people with disabilities in Guernsey is so good that we see no difference in the value of life for someone who has a disability than we do for the able? That we have a society that provides high quality mental health care and supports people through psychological pain and distress as much as we would someone with a physical illness?

Historically Guernsey has not been very proactive in protecting the vulnerable. Much of the care of Guernsey's disabled and vulnerable still depends on charitable funding and/or volunteer support and we do not yet have any disability discrimination law or capacity law. Until such laws are in place and are established it would not be appropriate to bring in any law permitting any form of euthanasia.

The States already have to make challenging decisions about the cost effectiveness of new treatments that might give someone an additional year or two of decent quality of life without offering long term cure. If voluntary euthanasia provides a cost saving over longer term palliative care, how do we ensure that this does not influence such funding decisions?

Regardless of whether you think some form of euthanasia should be available or not. This is not a simple issue about personal freedom. Total freedom of choice leaves the vulnerable exposed. Limiting it to a specific group is inherently discriminatory. The decision to actively cause death impacts on the relationship between doctor and patient; on how we manage end of life care; on our attitudes to what we consider "quality of life"; and on how we value individuals who have a disability.

This is a hugely emotive issue which presents significant ethical, legal and possibly constitutional challenges. Even if you support the idea of voluntary euthanasia in principle. Please vote against this request at least in favour of a more evidence based and consultative approach to the issue.

Thank you for reading this.

Yours sincerely

Catherine Hall