Response ID ANON-D24X-6Y64-U

Submitted to Assisted Dying - Private Members' Bill
Submitted on 2023-01-26 10:18:51

Introduction

1 What is your name?

Name:
Dr Rick Thomas

2 What is your email address?

Email:
Rick.Thomas@cmf.org.uk

3 Are you responding on behalf of an organisation?

Yes

4 If you answered "yes" to the previous question please state which organisation

Organisation:
Christian Medical Fellowship

5 Are you responding as an individual or a group?

Group

6 Are you resident on the Isle of Man?

No

7 May we publish your response?

Yes, you can publish my response in full

Support for Proposal

8 In principal, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

Disagree

Please explain the reasons for your response:

1. Insufficiently clear definition

'Terminal illness' is defined as 'a progressive disease, which can reasonably be expected to cause death.' We appreciate that it can be fiendishly difficult accurately to predict how long a patient with a terminal illness might 'reasonably be expected' to survive. In one sense, life itself could be described as a terminal illness – one in one of us dies eventually. But in another, less frivolous sense, equating a terminal illness with a progressive illness that can reasonably be expected to cause death, without any mention of a time limit, captures a whole range of progressive illnesses that may (or may not) eventually prove fatal but perhaps not for five or ten years, or even longer.
Conditions such as muscular dystrophy, multiple sclerosis, progressive pulmonary fibrosis, cystic fibrosis, chronic obstructive pulmonary disease, chronic heart failure, dementia etc, are all captured by this definition. In many cases, when well-managed, they are compatible with life over many years. High quality palliative care can control symptoms in almost all cases. The 'intolerable' can become tolerable.
We suggest these (and other) ultimately fatal diseases do not fall within the scope of the term 'terminal illnesses' as commonly understood. As presently worded, the proposals would make assistance to die available to people who will not imminently die of their illness but who choose to end their lives for other reasons, even to those with existential angst or simple weariness with life.
While we fundamentally oppose such a Bill in its entirety, if it were to go forward, we would strongly suggest that the phrase 'within six months' be added to the definition of terminal illness so that it reads 'a progressive illness, which can reasonably be expected to cause death within six months.'
Far from strengthening safeguards, the current wording bypasses this safeguard that has been proposed in similar Bills in other jurisdictions.

2. Lack of an automatic requirement for expert mental health assessment

We strongly suggest that every person requesting assistance to die should automatically be assessed for mental health and capacity by a psychologist or other appropriate specialist, and not just if one of the two doctors assessing capacity is 'unsure.'
Existential angst - fear of loss of independence, autonomy and dignity - is the most common reason given for requesting assisted dying. Conditions like anxiety and depression are amenable to treatment. Without qualified assessment of capacity, it is

inevitable that some patients who could have been successfully treated will instead be helped to die.
We strongly urge that assessment of mental capacity, to include any evidence that the patient's request might be (knowingly or unwittingly) coerced, be made a requirement in every case, and that the assessment be made by a suitably qualified mental health specialist.

3. Lack of requirement of necessary experience

The safeguards proposed state that two registered medical practitioners should independently confirm the person is terminally ill. A 'registered medical practitioner' could equally refer to a recently qualified doctor or to a senior specialist with 30 years clinical experience. It is a fearful responsibility to give to someone lacking much in the way of clinical experience. Accurate prognosis is extremely difficult, even in the most experienced of hands. We suggest that the assessment of 'reasonable expectation of life' should be made by those best qualified to make it.
We recommend that the Bill stipulate that at least one of the two doctors required to confirm the person is terminally ill should have had a minimum of ten years' clinical experience in a field relevant to the condition involved.
Also, when looking for the second signature, it would be natural for the attending physician to seek out someone known to be supportive of assisted dying. In this way, the system as drafted is seen to be open both to inexperience and unconscious bias.

4. Lack of requirement to involve the family

The proposed safeguards do not require the attending doctor to talk with the family. We suggest this is a significant omission that should be corrected in preparing the Bill, for the following reasons:
• As part of safeguarding against the risk of coercive influence by family members who may have a pecuniary interest in the patient's estate, or whose own struggles to cope emotionally with the distress and/or care needs of the patient, put pressure on the patient to 'do the right thing'. The attending doctor, and other healthcare professionals such as the applicant's family doctor, are well placed to discern such dynamics.
• Family members are potential 'casualties.' Assisted dying, like any other act of suicide, leaves scars on friends and family that may never heal. The pain of loss, and possible feelings of guilt (did we do enough?) may be mixed in with relief that their loved-one is no longer suffering. A caring doctor offering the opportunity to talk through these matters, or signpost others like Cruse, can be a great help to friends and family as they process their feelings.
We suggest that a requirement to engage with family members be added, as a mandated duty upon the attending doctor.

5. Inadequate time for reflection

We suggest that 14 days is a very short time frame in which to decide to be killed. Obviously, the decision is irreversible and death within 2 weeks feels very rushed when the outcome is the end of a person's life. Having an even shorter time frame for patients who are expected to die within 30 days is perhaps intended to accommodate clinical realities, but still feels like an unseemly rush to accelerate the coming of death.

A study of over 8,000 Irish adults showed that, over time, people who express a wish to die do change their minds, and the likelihood of a change in mind increases as time goes on (Briggs, R, Ward, M and Kenny, R A, 'The 'Wish to Die' in later life: prevalence,
longitudinal course and mortality. Data from TILDA', Age and Ageing, 2021, 50, pages
1321-1328).

How is the attending doctor to be satisfied that his patient's intention is a 'settled' one? It appears to be left entirely to his or her subjective perception.
Also, given that in recent polls a majority of doctors have indicated their unwillingness to be personally involved in assisting suicide, it is likely that patients will not get to make this decision with a doctor who knows them, but will instead be in the hands of an unfamiliar doctor who is in support of assisted dying. This, in turn, introduces the
risk of bias. The removal of continuity of care, especially at the end of life, could have very negative effects.

6. The risk of incremental extension in scope and scale

There is evidence from all the jurisdictions where assisted dying, assisted suicide or euthanasia have been legalised of incremental extension in application.
In practice, once any so-called 'right' is established in law, experience shows that incremental extension takes place over time. There is a steady increase in absolute numbers of cases and a gradual inclusion of those who are outside the stated boundaries of the law. There is also pressure to extend the law as activists bring new cases to the courts using the same general arguments of autonomy and compassion. It has proved impossible to draft legislation that can adequately safeguard vulnerable people.

Take two Benelux countries as examples of extension. In 1984, the Supreme Court in the Netherlands established a set of criteria that should be followed for a physician to cause the death of a person by euthanasia without fear of prosecution. From 1984 to 2002 a series of legal decisions led to a widening application of euthanasia for the hard cases, including people living with chronic depression (mental pain) and children who were born with disabilities.
This led in 2001 to the Dutch Parliament officially legalising euthanasia, the law coming into effect in April 2002. Over the next decade the rate of euthanasia deaths increased three-fold. By 2007, voluntary euthanasia (1.7%), non-voluntary euthanasia (0.4%) and terminal deep sedation accompanied by withdrawal of nutrition and hydration (8.2%), accounted for around one in ten Dutch deaths.
In the same year (2002), Belgium's law came into effect permitting euthanasia for those in a 'medically hopeless' situation – the 'hard' cases. Over the next ten years the rate of euthanasia in Belgium increased eight-fold. In 2010, 954 Belgians died by euthanasia; in 2019, the figure had risen to 2,655. Today, Belgium has some of the world's most liberal euthanasia laws, which are not restricted to the terminally ill or to competent adults. Children of any age are also eligible, as long as they ask for it themselves and have the agreement of parents, and people with psychiatric conditions are also eligible.
Despite the extent of the laws already in place, lawmakers in The Netherlands are currently inquiring into how further to expand legislation in order to permit euthanasia based on having a 'completed life,' allowing people to be killed if they are tired of life and feel it is complete but have no serious illness.

7. Pressure and subtle 'coercion'

The pressure on vulnerable people to end their lives, to 'do the decent thing' perhaps in order to relieve the burden of care from, or liberate finances for, other members of the family, or to relieve pressure on a beleaguered health system, becomes almost irresistible in an environment where assisted suicide becomes normal. A 'right to die' is effectively replaced by a 'duty to die'.

It's not just the patients who might experience pressure. The obvious danger is that the economic pressure to cut costs will determine clinical priorities and inevitably place systemic pressure on clinical commissioning groups to prematurely end the lives of patients. Are we to believe that pressure will not be present when the choice could be between a few hundred pounds for a lethal cocktail or £100,000 for an extended period of palliative care?

At the heart of the hospice movement is the commitment to help people 'live until they die.' Kindness and compassion, company and communication can restore a sense that life is worth living, that a loss or productivity does not mean a loss of value, that dependence on help from others is a normal part of the human condition, and that dignity is conferred on vulnerable people by giving them time, love and tender care. Along with expertise in symptom-control, these things can transform end-of-life experience, for patients and care givers alike.

8. Long-term effect on Doctor/patient relationships and on doctors themselves

We are concerned, too, about the effect that the introduction of assisted dying might have on the doctor-patient relationship. Trust is crucial to this relationship. The patient's confidence that the doctor will always act in such a way as to 'do no harm' is foundational to the relationship. Giving doctors the power deliberately to end the lives of their patients will inevitably redefine the nature of the relationship and risks undermining that essential trust and confidence.

The long-term effect on doctors and nurses themselves could be equally damaging. They enter the profession with a vocation to improve the lives of their patients, and will instead be asked to end those lives. It is not surprising that palliative care physicians are those most opposed to changing the law. There is also the risk that, over time, doctors could become hardened to causing death, and even begin to see their most vulnerable patients as 'disposable.' Such patients might then decide not to ask for medical help, for fear that they be encouraged to consider assisted dying by doctors whom they feel they can no longer fully trust.

Lord McColl of Dulwich described this change in medical conscience as 'chilling'. In a speech in the House of Lords in 2003, reporting on a visit to the Netherlands, where euthanasia had been legalised, he said: 'Noble Lords will be aware that the Select Committee visited Holland. When we inquired of a doctor what it was like doing the first case of euthanasia, he said, "We agonised all day. It was terrible." But he said that the second case was much easier and the third case – I quote – "was a piece of cake." We found that very chilling indeed.'

9. Wider ethical concerns

There is, of course, a significant financial cost to the provision of high quality, widely accessible palliative care. But we would humbly suggest that the cost to society of legalising assisted suicide is much greater.

It would inevitably strengthen the perception that people with certain types of disease or disability have lives 'not worth living', that they would be 'better off dead', and that the costs of their care would be better directed towards healthcare provision for the more socially or economically 'productive' members of society.

The quotient of compassion in the caring professions and respect for human life in society in general would inevitably ebb. Little wonder that disability rights groups are among the most vociferous opponents of these proposals. It is our conviction that the calibre of a civilised society can be measured by the investment it is willing to make in the care of its most vulnerable members.

10. Reduced incentive to invest in palliative care

We take issue with the claim that the introduction of assisted suicide has no adverse effect on palliative care services. We suggest the 'evidence shows that palliative care and assisted dying do not, and cannot, co-exist harmoniously. They do not rise and fall together because they are not complementary but are diametrically opposed both in theory and practice. One can truly flourish only at the exclusion of the other.

'Before permitting assisted suicide in 1997, Oregon, for instance, was comparatively advanced in palliative care provision, ranked highly in the US for hospice utilisation, hospital ICU utilisation, pain policy and advance care planning policy. After 2000, palliative care funding and provision stagnated as assisted suicide, encouraged by health insurers, took hold. ...

'A similar pattern of diminution in palliative care has been observed since 2012 in the Netherlands, where investment is a third less than in the majority of European countries which prohibit assisted death. The same has occurred in Belgium since 2008 where promised increases in palliative care failed to materialise while the workload in doctor-assisted deaths climbed incrementally, sparking mass departures of palliative care specialists angry that their units were being turned into 'houses of euthanasia' and their functions reduced to preparing patients and their families for lethal injections.' (Caldwell S. Palliative care and assisted dying – never the twain shall meet. Published in Conservative Woman, 19 November 2021.)

We urge Tynwald to commit the necessary resources to training a new generation of palliative care specialists and multiplying palliative care units and mobile symptom control teams across the island, until excellent end of life care is available to every citizen.

In our view, the proportion of dying patients whose symptoms cannot be well-controlled through high-quality, easily accessible palliative care is vanishingly small.

11. Freedom of Conscience

We appreciate, and record our thanks that consideration has been given to the conscience rights of healthcare professionals. However, we are concerned that the requirement for 'effective referral' undermines those rights. Requiring those who conscientiously object to refer a patient on to a colleague who does not share the same beliefs makes them complicit. This appears to be understood by the General Medical Council whose guidance does not require 'effective referral' provided the patient has the information they need to access the services they seek.

Moreover, the World Medical Association has recently voted to protect conscientious objection for medical personnel concerning assisted suicide and euthanasia by excluding a provision that would mandate 'effective referral' in its International Code of Medical Ethics (https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/). We believe the Bill for the Isle of Man, as proposed, would fall foul of both this Code and GMC guidance.

This is not true simply where involvement is direct. The same complicity, moral injury and moral harm results from indirect involvement of all kinds, whether for medical, nursing or support staff. The issue should not turn on the threshold of involvement but on the threshold of objection. For example, one person's conscience would be troubled by providing administrative support for appointments with doctors assessing eligibility for assisted dying. For another, whose conscience is calibrated differently, only direct involvement in the delivery of the dying substance might trigger objection. People vary in the thresholds at which they experience moral complicity and thus moral injury. It is simply not possible to draw up tidy categories – these activities represent 'direct' involvement and thus qualify for conscience rights to be respected, whereas those activities represent 'indirect' involvement and do not qualify – and we suggest that no survey will be able to draw lines that are workable in practice.
If assisted dying is legalised, we strongly recommend that the legislation include:
i) a statutory right of conscientious objection that will apply equally to all healthcare professionals, and cover both direct and indirect involvement, rather than relying on the guidance published by professional regulatory bodies;
ii) an institutional right of conscientious objection so that an individual hospice, for example, could decide not to provide assisted dying, without risking their funding. If this is not present in draft legislation, it would place an intolerable strain on the ethos of many existing services.

9 Do you think that there should be a limit on their life expectancy?

6 months

10 Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

No

11 If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

No

Eligibility

12 Do you agree that assisted dying should be available only to people over the age of 18 Years?

Yes

13 Should they have to be permanent residents of the Isle of Man?

Yes

14 If you agree they should be permanent residents please state for how long.

For over 5 years

If you have ticked "Other", please provide some details:

Process

15 Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

Not Answered

16 Should any health professional be able to conscientiously object to being part of an assisted dying programme?

Yes

17 Do you agree that if either doctor is unsure about the person's capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

Yes

18 Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

Yes

19 Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

No

20 Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?

Yes

21 Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

No

22 Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

Not Answered

23 Should this be able to be stored securely in the person’s home until they decide whether they want to take it or not?

No

24 If they change their mind should the medication be returned to the pharmacy immediately?

Yes

25 Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

Yes

26 Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

Yes

27 Should it be possible to include the provision of assisted dying in a “living will” or advanced directive?

No

28 Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

Any other comments...:

See comments in response to Q8

Data collection and audit should include details of how eligibility was agreed - was a mental health specialist opinion sought, were family members consulted, was there a history of pre-existing mental health vulnerability, etc? Data should be audited annually, and made available for research purposes and to guide policy development.
We strongly suggest there should be an independent annual review of the functioning of any legislation that does come into effect.

We agree that assisted dying should be limited to those who are resident in the Isle of Man for a minimum period of five years and urge the House of Keys to resist any pressure to open their doors to those seeking assisted dying from other parts of the UK, or beyond.