Assisted Dying for Terminally Ill Adults (Scotland) Bill

Introduction

This submission by Dr Rick Thomas (Rick.Thomas@cmf.org.uk) is on behalf of the Christian Medical Fellowship (CMF). We are happy for the submission to be published and attributed to CMF.

The Christian Medical Fellowship is an association of around 4,500 doctors, medical students, nurses and midwives in the UK that exists to unite and equip them to live and work for Jesus Christ. CMF includes many members who live and work in Scotland.

Executive Summary

CMF recognises the good intention behind this Bill namely, to protect citizens in Scotland from having to face a prolonged and painful death. However, we do not agree with the proposed solution – to legalise assisted dying. In our view, it cannot be right to attempt to solve issues around end-of-life care by assisting patients to kill themselves. We believe, with H L Menken, that *'there's always an easy solution to every human problem – neat, plausible and wrong*.'

In the Foreword, the reader is introduced to the idea that there are limits to palliative care and that, when those limits are reached, a legal next step should be available in the form of assisted dying. We believe that this misrepresents the efficacy of palliative care. The number given - namely 11 per week - of those whose symptoms cannot be controlled by palliative care, is supplied by Dignity in Dying, an organisation that exists to promote assisted dying and that cannot be regarded as an unbiased source. The figure is not referenced and is simply an estimate but is quoted as if a fact. In our view, the Bill's proposal is thus predicated on an unproven assumption. Good quality palliative care is effective in virtually all cases. It has long demonstrated that it is possible to control discomfort and distress effectively – killing the pain, not the patient.[1]

We recognise that ensuring access to the best palliative care from remote and small communities throughout Scotland, including island communities, is a challenge. The lure of a far cheaper alternative – assisted dying – is therefore very real. Though at first sight assisted dying may appear plausible, we seek to explain below how, in our view, it is misguided and wrong.

A brief summary of our concerns includes:

- ***Definition*** – in particular, that progressive disease (not expected to lead to imminent death) is equated with terminal illness (normally understood to imply death is expected within six months). In our view, the lack of a defined time limit, within which the patient is expected to die, to define the availability of assistance to die, renders the application of the Bill's provisions overly 'elastic'
- ***Safety*** – in particular, that it is not a requirement to include routinely an assessment of mental health, carried out by a qualified and experienced specialist. Also, safeguards against

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[1] Hearn J, Higginson I. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. Palliat Med July 1998,12; 5:317-332

the risk that vulnerable people feel coerced into accepting assistance to die appear to be lacking

- ***Extension.*** The Bill appears to ignore experience in other jurisdictions, where assisted dying has already been legalised and where its application has extended inexorably in both scope and scale
- ***Family*** – there is no mention of a requirement to involve family members in the process of decision-making. We suggest that this requirement be added, whether or not the patient is deemed to have capacity
- ***Reflection –*** in our view, 14 days is a very short time frame in which to decide to be killed
- ***Coercion –*** we are concerned that vulnerable people will feel a coercive pressure to 'do the decent thing', whether to ease pressure on stretched healthcare resources, or to liberate loved ones from the burden of ongoing care
- ***The effect on doctors and nurses*** – we are concerned about the psychological effect on doctors and nurses of killing someone with a substantial life expectancy. More generally, we are also concerned about the impact that legalising assisted dying will have upon doctor-patient relationships, in particular the erosion of confidence in doctors who are employed by cash-strapped health authorities looking for ways to reduce costs.

We do not believe that the proposals fit the problem. The problem is not that palliative care is ineffective. It is that palliative care is not accessible across Scotland. The solution is not to eradicate the patient, but to invest in training and provision of more excellent palliative care services. We are concerned that legalising assisted dying 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. We suggest that this would be out of step with the deepest intuitions of the people of Scotland.

Q1. Which of the following best expresses your view of the proposed Bill?

Fully opposed

1. **The proposals, as drafted, are unsafe and not fit for purpose.**

We recognise and appreciate that the current proposals aim to improve safeguards to a better degree than previous proposals. However, we identify several areas in which we believe the current proposals fall short:

A) Insufficiently clear definition

'Terminal illness' is defined as 'a progressive disease, which can reasonably be expected to cause [their] 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 might 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.

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 anxiety 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 previous Bills.

B) 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 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. At 1.1 (Safeguards), bullets 2 and 3 could be replaced with **'In every case, a full assessment of the mental health and capacity of the person requesting assistance to die should be made by a psychologist or other qualified mental health professional.'**

C) 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 suicide. In this way, the system as drafted is seen to be open both to inexperience and unconscious bias.

D) Lack of requirement to involve the family

The proposals 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 involved, 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 can be a great help to friends and family as they process their feelings.

We propose that the requirement to engage with family members be added, as a mandated duty upon the attending or independent doctor, as part of the Declaration (Step 1 of the Process 3.1).

E) 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.

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 discretion. 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 passed on to 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.

F) The risk of incremental extension in scope and scale

There is evidence from all the jurisdictions where assisted suicide or euthanasia have been legalised of incremental extension in application. In the example of Oregon, details of patients dying under the Act[2] show a substantial number do not have terminal illnesses, even though the Law was intended to extend only to that category of patients. In 2013, 16.9% of those receiving assistance to die under the Act did not have cancer, heart disease, chronic lung disease or motor neurone disease but were classified as having 'other illnesses.' A footnote in the 2013 Oregon Public Health Division report on compliance with the Act explains that this *'includes deaths due to benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson's disease, and Huntington's disease), musculoskeletal and connective tissue diseases, viral hepatitis, diabetes mellitus, cerebrovascular disease, and alcoholic liver disease'*. Whilst many of these conditions might be considered life-shortening, it is not credible that all these cases were terminal. They fell outside the terms of the Oregon Act.

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[2] http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf

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.[3]

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.[4] 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.[5] This would mark a fundamental shift in the purpose of medicine – from preserving life to ending it – that would result in an equally fundamental change in the nature of the doctor/patient relationship.

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.

If these proposals become law in Scotland, it will only be a matter of time before someone with a non-terminal, but life-controlling condition claimed to have a settled conviction that he or she wished to end their life, and that the law unfairly discriminated against them by denying them the right extended to those with a terminal condition.[6] It would be very difficult to hold the line; sooner or later a 'hard' case would come before a judge who would rule in favour of extending assistance to die to someone who was not terminally ill. A precedent would have been set in case law; the line would have been crossed.

We suggest that the current lack of definition in the wording of the Bill makes such incremental extension inevitable in Scotland, and we contend that the autonomous rights of the individual are, in practice, outweighed by the rights of vulnerable persons to the protection of the state.

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[3] Saunders P. https://www.carenotkilling.org.uk/press-releases/dutch-euthanasia-stats/

[4] Euthanasia and assisted suicide laws around the world. Guardian 17 July 2014 bit.ly/WmgaXm

[5] https://www.houseofrepresentatives.nl/news/plenary-session-about-citizens-initiative-%E2%80%98completed-life%E2%80%99

[6] Truchon c. Attorney General of Canada, 2019 QCCS 3792 (CanLII), quoted in Slaw, Canada's online legal magazine: http://www.slaw.ca/2019/09/17/challenging-the-quebec-end-of-life-legislation-and-medically-assisted-dying-in-truchon/

G) 'Pressure and 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. It is impossible to draft legislation that incorporates effective safeguards against this unintended pressure. A 'right to die' is effectively replaced by a 'duty to die'.[7]

It's not just the patients who might be put under 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?

I) Effect on doctors and nurses

We have concerns about the effect on the doctor/nurse-patient relationship of assisted dying legislation. 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 could become hardened to causing death, and even begin to see their most vulnerable patients as 'disposable.'[8] 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 ben 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]

The solution does not fit the problem

The three main factors in someone requesting assistance to die are:[10]

i) a perception (usually mistaken) that they are alone in the world and that no one really cares about them
ii) a feeling (again, usually mistaken) that they are a burden on others and that people would be better off if they were dead

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[7] https://www.telegraph.co.uk/comment/personal-view/4736927/Right-to-die-can-become-a-duty-to-die.html
[8] Keizer B in Ross W. Dying Dutch: Euthanasia spreads across Europe. Newsweek, 12 February 2015
[9] McColl I. Lords Hansard, 6 June 2003: Column 1681
[10] http://www.nhs.uk/Conditions/Suicide/Pages/Causes.aspx

iii) fear of loss of dignity and control. (Fear of pain or discomfort comes further down the list)

Contrary to common perception, the main reason given for requesting medical assistance to die is not uncontrolled pain, nor even the fear of such pain, but the fear of loss of dignity, of becoming a burden to others, or of becoming dependent. In Oregon in 2013, such existential reasons were by far the most common ones given for seeking assisted dying – 93% cited 'loss of autonomy,' 89% 'loss of enjoyment of life' and 73% 'loss of dignity.'[11] 'Pain' did not figure in the top five reasons given. The 2019 figures tell the same story, with 86%, 90% and 72% respectively, 'pain' again outside the top five reasons given.

90% of those who end their lives by suicide suffer from some form of mental illness including depression, bipolar disorder, borderline personality disorder and alcohol or drug misuse.[12] The 2013 Oregon figures show that less than 3% of cases were referred for a formal psychiatric assessment, although 26% met the criteria for depression.[13] Baroness Sheila Hollins, former president of the UK Royal College of Psychiatrists, comments: '*Researchers have found that some patients who have ended their lives under the terms of Oregon's assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity; it is common in elderly people and it is treatable. But in some cases in Oregon, it has not been diagnosed by the doctor who assessed the patient's capacity and prescribed lethal drugs. Oregon's law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened.*'

It is inevitable that many people suffering a terminal illness will also experience depression, anxiety and perhaps other psychological conditions. What will not be immediately clear is the degree to which those mental health conditions may account for the settled intention to end their own lives. It can be fiendishly difficult, even for well-acquainted family doctors, to assess the contribution that loneliness, depression or the desire not to be 'a burden' may be making to their patient's request for assisted dying. Even apparently settled wishes can change unaccountably, and apparently irreversible conditions can remit.

Successfully treating depression may change a person's outlook significantly, even if it doesn't change their prognosis. But it would appear from the experience in Oregon, for example, that routine psychiatric assessment is being overlooked. It is almost as if the declared wish to end one's life trumps all therapeutic considerations. But existential angst is not a terminal illness. Value and dignity are conferred by compassionate care, love and kindness. Depression and anxiety are amenable to medical treatment. We believe there is a better way to deal with the problem than to eradicate the patient.

The UK has been a world leader in the hospice movement, building on the foundations laid by pioneers like Cicely Saunders who famously said: *'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.'* Those values still undergird the practice of good palliative medicine, providing high quality end-of-life care, controlling pain effectively and enabling people to 'live until they die.' We submit

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[11] http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf

[12] https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/help-for-suicidal-thoughts/

[13] Levene I, Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. JME 2011;37:205

that the solution to ‘prolonged and painful death’ is not to do away with the patient, but to provide access to high quality palliative and hospice care.

A 2016 Marie Curie report[14] estimated that 1 in 4 people in Scotland who would benefit from palliative care when they are dying do not receive the care that they need. **By legalising assisted suicide, the incentive to invest in palliative care will be reduced rather than increased.**

‘*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.’[15]

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

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.[16] Little wonder that organisations representing disabled people are among the most vociferous opponents of these proposals. It is our conviction that the calibre of a civilised

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[14] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/challenging-inequities-in-palliative-care.pdf

[15] Caldwell S. Palliative care and assisted dying – never the twain shall meet. Published in *Conservative Woman*, 19 November 2021.
https://www.conservativewoman.co.uk/palliative-care-and-assisted-dying-never-the-twain-shall-meet/

[16] Wyatt J. Matters of Life and Death. Nottingham, England: IVP,2009 (2nd Edn):207

society can be measured by the investment it is willing to make in the care of its most vulnerable members.

Q2. Do you think legislation is required, or are there are other ways in which the Bill's aims could be achieved more effectively? Please explain the reasons for your response.

The proposals are aimed at reducing the number of painful, prolonged and distressing deaths in Scotland. In his Foreword, Liam McArthur MSP estimates that 11 people die 'badly' every week in Scotland, in spite of excellent palliative care. His comment refers the reader to an article, produced by Dignity in Dying, that is anecdotal and unreferenced, and simply declares that 'some dying people experience severe pain and other symptoms that result in suffering,' and that 'this suffering occurs even when high-quality specialist palliative care is present, meaning improving the provision of care will not address this problem.' No evidence base for such claims is supplied, yet all that follows in the article is predicated on this claim. Yes, there are some heart-rending stories by people whose loved ones have died in uncontrolled pain, but without some kind or robust evidence, it is speculative to claim that there is a significant cohort of dying patients whose suffering is beyond the ability of palliative care to relieve. Readers will take note of the fact that Dignity in Dying is the most prominent campaigner for assisted dying in the UK. For Liam McArthur to base his case on their publication 'The Inescapable Truth about Dying in Scotland' (2019) suggests that he shares their bias.

As a group made up largely of doctors, many of whom are involved in palliative care, we are aware of the hard cases, those whose symptoms are indeed very difficult to control. But we are also aware that, where there is access to the best palliative care, the proportion of terminally ill patients for whom this is true is tiny. We consider that the risks to vulnerable patients, the credibility it would give to the notion of 'a life not worth living,' and the undermining of confidence in the doctor-patient relationship, were assisted dying to be legalised, far outweigh any benefit to terminally ill patients.

In summary, we do not believe this legislation is required, and that if it does get on to the statute book, then harms will far outweigh benefits. As noted in our introduction, we believe that the aims of the Bill – to relieve suffering at the end of life and provide a good death – will be achieved far more effectively by investment in improving the scope of and access to palliative care for all Scottish residents.

Q 3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Fully Opposed

Step 1 – Declaration

Please see above under answer to Q.1

We are particularly concerned about safeguarding. The proposals as they stand:

- Lack an automatic requirement for expert mental health assessment
- Do not make it a requirement that the registered medical practitioners should, between them, have the necessary clinical experience for the task

- Do not make it a requirement to consult with family members
- Do not make clear how the two doctors will satisfy themselves that pressure and coercion are not in play

Step 2 – Reflection

The proposals as they stand:

- Do not give adequate time for reflection and do not make it a requirement for non-directive, independent counselling to be available

Step 3 – Prescribing/delivering

The proposals as they stand:

- Envisage a scenario where one HCP visits the home of the person seeking assistance to die. It is quite likely that family members, and possibly even friends, will be gathered there, in a state of high emotion. We suggest that a minimum of two HCPs are needed
- The 'medicine' in question has to be self-administered, by mouth, in the presence of the HCP. In the event, the patient is unable to bring themselves to take the medicine and requests the assistance of the HCP. A legal 'line in the sand' stands between the patient and the HCP being able to administer the draught. The consultation gives no guidelines for the HCP to follow in such situations.
- The barbiturate cocktail is unpleasant to take, may be regurgitated, or simply not fully effective. The common misconception is that the patient will fall asleep quickly and die within minutes. The reality is often different. It may take much longer before the patient dies, and sometimes they do not die following the prescribed dose. These are very distressing scenarios, for the patient if still aware, and especially for the family. It is not clear from the consultation document if the HCP must wait until death has occurred. Who confirms death? Once again, we suggest that the HCP should not have to deal with these scenarios alone.

Q 4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Neither support nor oppose

We have written at some length about our safeguarding concerns in answer to Q1 (and in Q3 Step 1 – Declaration). Please see above.

Q 5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

Neither support nor oppose

Whilst we welcome the requirement to complete a declaration, questionnaire and follow-up form, we consider the process of reporting and scrutiny to be insufficiently robust. As yet, the reporting body has either not been formed or not decided upon. We strongly suggest that **statutory** internal and external scrutiny are needed, involving CCGs and NHS Trusts internally, and a body equivalent to the Care Quality Commission in England (CQC) externally. Without a statutory requirement in place, we have no confidence that a sufficiently robust and accountable process will result, and that reporting will be little more than box-ticking. The consequences of that would be that trends will not be visible, ongoing public health measures will be uninformed, and research will be hampered.

Q 6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

We appreciate, and record our thanks, that a consideration of conscience has been included in this proposal. For doctors, GMC guidance does not include the requirement to refer to another doctor who would not share the first doctor's conscientious objection, provided the patient has access to the information they need to access the help they seek.

The GMC appears to recognise that onward referral brings with it moral complicity and thus constitutes moral harm to the objecting doctor. This would contravene human rights legislation[17] and is unacceptable. In similar circumstances, the Nursing and Midwifery Council does require nurses to refer directly and this, we believe, constitutes moral harm to them.

If assisted dying is legalised, we strongly urge that:

1. a **statutory** right of conscientious objection be included, that will apply equally to all healthcare professionals, rather than relying on the guidance published by professional regulatory bodies
2. an **institutional** right of conscientious objection, so that individual hospices etc can 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.

RJT December 2021

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[17] https://www.equalityhumanrights.com/en/what-european-convention-human-rights