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RESPONSE TO WHITE AND WILLMOTT

RODNEY SYME*

The following article is a reply to 'A Model Voluntary Assisted Dying Bill' by Ben White and Lindy Willmott. The comments made were not subject to peer-review and reflect the opinion of Rodney and his critique of the Model Bill.

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I INTRODUCTION

Ben White and Lindy Willmott once again provide a valuable contribution to the discussion of voluntary assisted dying. Their paper, *A Model Voluntary Assisted Dying Bill*,¹ is an extremely valuable and necessary contribution to this important subject. I assume that this is a Model Bill for Australia as it draws heavily on analysis of the Victorian Voluntary Assisted Dying Act, and the model has no correlation to laws or practices in Europe (Benelux countries or Switzerland).

Otto von Bismarck stated that ‘politics is the art of the possible’, and as a consequence, the Victorian law emerged as a mass of compromises; a bureaucratic tangle rather than an act of brevity, which White and Willmott rightly support (their Model is 27 pages compared to the Victorian Act of 130 pages). Application of existing rights under the rule of law and intelligent use of regulations will aid brevity. Described by the Victorian Premier as the safest legislation in the world, with 68 safeguards, it is as a result, a most complex piece of legislation and correspondingly difficult to implement. This difficulty in implementation has been magnified by the government’s interpretation that one of the assessing doctors must be a ‘specialist’ in the disease leading to a request for assistance,

¹ Ben White and Lindy Willmott, ‘A Model Voluntary Assisted Dying Bill’ (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 (‘Model Bill’).

despite this not being specified in the legislation. None of the 20 other jurisdictions with assisted dying laws has such a requirement.

White and Willmott published their paper before the Western Australian parliament passed their legislation in December 2019. The WA Act thankfully avoided this ‘specialist’ trap — this Model also correctly avoided this mistake. This interpretative error in Victoria has proved to be a serious roadblock to effective implementation of the law.

I come to this critique from a long and deep personal association as a medical practitioner with people requesting voluntary assisted dying and from the experience of having provided assistance to several hundred people. My comments on the Model Bill come from a medical perspective rather than a legal one. The areas that concern me in this Model are: the time line for assistance and the eligibility criteria; the matter of choice in carrying out Voluntary Assisted Dying (‘VAD’); the training and education of doctors; the damning requirement for a person to be an Australian citizen; and the burdensome delay between passage of legislation and its implementation.

Before addressing these matters, I would like to offer some comments on the values which must be upheld.

II VALUES

I fully support the values expressed by White and Willmott but would like to expand some of this discussion.

With regard to autonomy, I would add the complement of responsibility. If we want autonomy regarding those decisions which are vital to us, we must be prepared to take responsibility for those decisions. This relates to the value of freedom of conscience — my autonomy cannot override that of another, reflected in their conscience, who disagrees with me. If I want the autonomy to make decisions about my end of life to be respected, I must accept the freedom of conscience of a doctor to refrain from assistance. This principle applies equally to a doctor’s autonomy in the decision regarding how voluntary assisted dying should be carried out. A doctor should not be put under duress to provide a lethal injection when the person making that request is quite able to take responsibility for that decision.

It is a fundamental aspect of medical practice to reduce suffering. Everything a doctor does is surely based on this principle. We must sometimes cause temporary pain in order to relieve suffering, but never cause prolonged suffering if it can be avoided. Nowhere is this principle more relevant than at the end of life. At this point, when cure is not possible, when there is intolerable suffering which the doctor cannot measure, the relief of suffering is the most important aspect of treatment. At this point it becomes not just a question of reducing suffering but of abolishing it, if that is requested by the suffering person in full knowledge of the consequences.

The rule of law is a fundamental principle of our society. In medicine, it prevents a doctor providing treatment to which the patient has not agreed and equally, it protects a doctor who refuses to provide treatment with which he or she does not agree. Thus, a doctor can refuse to provide a prescription for contraceptives, to provide for sterilisation, or to deny a request for abortion. They can refuse to provide any treatment which they believe would be harmful or have no benefit, or for moral reasons. While I fully support the right to conscientious objection in relation to VAD, I fail to see why this right to refuse a treatment needs to be enshrined in a new law — it already exists.

If conscientious objection is to be specifically enshrined in this legislation (Clauses 38-39), then the Model's requirement is that such doctors or institutions must refer a person making a request to a doctor who is likely to provide VAD, or to a body which has data as to who will or might — in Victoria no such body of data formally exists. I would argue that, in addition, this principle is enshrined in traditional medical practice and bodies (Medical Boards) that oversee medical practice, and in common law. I know of no other piece of legislation that attempts to regulate medical practice as does any voluntary assisted dying law (as passed to date in Australia). Other areas which influence end of life (abortion, refusal of treatment) are not so circumscribed. More particularly, the area of palliative care which involves practice at the end of life and affects the timing and manner of death is not regulated in any specific sense — there is no requirement for informed consent, assessment of mental competence, second medical opinion, or report of death to any authority. I do not suggest that these matters be formally addressed as they would significantly impede effective palliative care, but point out the stringency of VAD law compared to its lack in palliative care. Essentially the same group of patients are involved.

III THE SIX-MONTH TIME FRAME

The major flaw of the Victorian and WA legislation is the basic six-month prognostic time frame for qualification (it does extend to 12 months for persons with a neuro-degenerative disease). White and Willmott correctly acknowledge the prognostic difficulty of this determination and the discrimination that it creates. The six-month time frame derives from legislation in Oregon and has been slavishly continued in the US and followed into Australia. The simple reason for its use was that it was the time frame in the US for determining funding for palliative care. There is no logic for it in a medical sense. The whole aim of this legislation is to allow the legal relief of intolerable suffering (the Oregon Act does not mention suffering), and it is evident that this arbitrary time frame is exceedingly difficult to implement — the further one recedes from the actual time of death the more difficult prognosis becomes.

It is also discriminatory. Intolerable and unrelievable suffering is the root cause for requests for VAD, and intolerable suffering is not confined by time. Just as some people with terminal illnesses may have no intolerable suffering, or only in the last few weeks of their illness, others may have intolerable suffering well before the six-month deadline. Disease does not respect time. Many people, and I am noting people with terminal cardiac and respiratory diseases, may have great suffering from breathing difficulties, pain and fatigue, but not have a predictable prognosis — they tend to die suddenly from a complication of their illness. This provision also excludes the frail aged (who inhabit our aged care homes), a condition which is not a valid medical diagnosis, yet is recognised as a harbinger of demise but in which prognosis is often difficult to make — they might die tonight or survive for 12 months.

Eli Stutsman, an Oregon lawyer much involved in developing the Oregon Bill, has acknowledged that it is discriminatory for at least 20% of people with intolerable and enduring suffering. The Model Bill advocates the removal of the six-month prognostic limit, with which I fully agree, arguing (Clause 9(e)(ii)) that the person must be diagnosed with a medical condition 'that will cause death'. Here, I disagree.

IV THE DISEASE WILL CAUSE DEATH

This phrase implies that the illness must have a terminal trajectory. Again, it is evident to anyone with experience of residential care homes and other places, that there are many people with non-progressive illnesses (i.e. not terminal) who have intolerable suffering but are not dying. Take for example, a person who has survived a profound stroke, who is completely paralysed unilaterally, cannot talk, is incontinent and bedbound — they may survive in this state for years; or a high quadriplegic (or any person with profound spinal paralysis) like Christian Rossiter for example. This completely ignores a group of people with severe unrelievable pain but who are not dying. There is a not inconsiderable group of people suffering from such chronic pain — people with advanced polyarthritis; people with chronic spinal and other musculoskeletal pain; people with advanced chronic bowel conditions; and people with faecal and urinary incontinence which challenges human dignity. The time that they must continue to suffer makes their quantum of pain and suffering often far worse than a person dying of cancer.

In a perfect ethical world, all these people should be considered in a Model Bill. If we want to move forward with legislation these situations should be part of the debate. Equally, attention should be given to those people suffering from long-term psychiatric illnesses which have defied effective treatment. If the issue we are attempting to address is intolerable suffering, then we should not confine the debate to physical illness.

Going one step further, just as disease does not respect time, it also does not respect age. Disease and suffering do not unfortunately suddenly begin at 18, nor does the ability to make informed decisions not exist before then.

V WHO SHOULD MAKE THE CHOICE REGARDING METHOD OF VAD?

Respect for autonomy ought to allow a suffering individual who meets the criteria of VAD to make their choice as to method — doctor administration (by injection) or self-administration by mouth. In countries where both are available (The Netherlands and Canada) the overwhelming majority of assisted deaths are by injection. This is not surprising in The Netherlands, where the Dutch medical body (RDMA) determined in 1984 that the doctor should remain with the patient until death occurred. Death by oral ingestion intrinsically takes longer than by lethal injection, sometimes markedly so, and a

number of initial oral plans have been terminated by injection due to the time factor. For this reason, as much as any other, lethal injection is the preferred method in The Netherlands — it is a medical preference rather than a patient preference.

This does not mean to say that, given a choice, a majority of people will not choose doctor administration. They are likely to believe that it will be safer with fewer complications, and they will not have to take the responsibility for their decision. White and Willmott acknowledge that evidence for greater safety and fewer complications with injection compared to oral administration is limited, but this perception undoubtedly influences decisions. My own personal experience, supported by Swiss organisations (Dignitas and ADMD), who have data on several thousand fully observed orally assisted deaths, is that where appropriate support, information and preparation are provided, complications are virtually zero and safety is not in question. The major variable is the time to death, but the vast majority occur within 10 to 25 minutes.

Very few Australian doctors will have had any close experience of orally assisted dying. In order to be able to support and reassure people, they need appropriate training before becoming involved. I believe the training programme, in addition to legal aspects, should include medical advice.

Unfortunately, the injection process leads to a highly medicalised death by medical appointment, commonly carried out in hospital, which has shown to be an unwelcome choice for most people. I have found that when people are involved in discussion about the question of responsibility for the decision, none have disagreed with me as to where it should lie. Oral administration places control over the process entirely in the hands of the individual and has the added protection that death will not occur without consent — people do not take the medication unless their suffering is truly intolerable. They can die at home surrounded by their family at a time of their choosing, not that which suits the doctor. There is actually no need for medical attendance with oral administration, unless requested by the person — the doctor does nothing except provide confidence, important as this undoubtedly is. Nurse practitioners and well-trained volunteers can do this equally well.

There is a likelihood that the high incidence of injection in Canada was related to the rushed implementation of the legislation there without any period of education of the community or the medical profession.

VI DELAY IN IMPLEMENTATION

The Model Bill continues the 18-month delay period from the passage of the legislation to the implementation. Given that 53 persons used the Victorian Act in the first six months, it is likely that 150 or more people will be denied access by this delay. While I fully support a delay in order to have smooth implementation, given the experience already available, this time should be kept as short as possible.

VII CITIZENSHIP

During the first six months of the Victorian Act, at least five people who met the medical criteria for assistance have been denied by the requirement for citizenship or permanent residency status. This particular requirement has been included in the Victorian law, and regrettably also in WA, for the necessary reason of preventing VAD 'tourism'. However, this well-intentioned requirement failed to realise that there are many thousands of long-term Australian residents, particularly from NZ, UK, Europe and other countries who have not taken out citizenship and are thus ruled out. It takes considerable time (and expense) to complete the citizenship process when time for action is at a premium. Strictly legislated residency criteria could achieve the same end without harm to suffering people.

VIII EVALUATION OF THE MODEL BILL

This depends largely on the interpretation of 'model'. The Oxford dictionary defines it in two relevant senses — as 'exemplary or excellent of its kind' or 'an excellent example of quality' (depending on edition) but also as 'a particular design or version of a product'. This Model Bill can be evaluated in a general sense according to this definition or viewed as a practical model for future presentation to Australian parliaments, with a view to improving legislation and avoiding previous ambiguities and problems. I have taken the former approach in this analysis, while recognising the pragmatism in the latter approach.

I therefore suggest the following changes to the Model:

1. Expand the eligibility criteria to include people with intolerable and unrelievable suffering but who do not 'have a medical condition which will cause death' (i.e. further broaden the time limit) (Clause 4(a)).
2. Shorten the implementation period to 12 months or less if ready before then (Clause 2(2)).
3. Remove Clause 4(e) re refusal to participate.
4. The medical practitioner's autonomy should also be respected (Clause 5(b)).
5. Clarify the meaning of 'supervised self-administration' to indicate that this may be in the presence of a doctor, a nurse practitioner or registered trained volunteer (Clause 31(b)).
6. Delete reference to Australian citizen or permanent resident and replace with other strict residency criteria (Clause 9(b)).
7. Modify Clause 9 (e)(iii) re terminal illness.
8. Expand Clause 14 to include 'completed approved legal and **medical assessment training**.'
9. Consider reviewing Clauses 27, 28 and 29 in the interest of brevity — none of these witness requirements exist for witnessing of Advance Care Directives.
10. Clause 29(1)(ii) requires a witness to assert 'that the person appeared to have decision-making capacity in relation to voluntary assisted dying'. Clause 17 indicates that this is a medical decision, not one to be made by a lay witness (applies also to Clause 32).
11. Clause 36 is covered by common law.
12. Clause 38(1) is covered by common law.
13. Clause 39 includes a necessity for facilities which refuse to be involved in VAD to make this clearly known in all relevant notices and documents.
14. Review of the Act (Part 9) should be in 2-3 years.
15. Schedule 1 indicate clearly that access to VAD does not mean that administration must immediately follow.
16. Re Part 6 — some consideration needs to be given to reporting situations where requests are refused in order to allow the Board to assess deficiencies in the eligibility criteria.

IX AREAS THAT FALL OUTSIDE THE MODEL

1. Provision for assistance to persons with chronic unrelievable psychiatric illness.
2. Provision for persons under 18 with intolerable and unrelievable suffering.

I acknowledge that these two areas are more contentious than any matter addressed in the Model Bill, but these issues have been raised, debated, and addressed by parliament and the courts in The Netherlands and Belgium. They have been acted on, subjected to judicial scrutiny and found to have worked effectively. I accept that if the narrow view of the Model is the focus of White and Willmott, then these issues are too premature for Australian parliaments, but they are the boundaries that must not be overlooked in the broad view of the Model.