Legal and Constitutional Affairs Committee

Inquiry into Voluntary Assisted Dying

Submission by Hon. Robert Clark

Introduction

1. I make this submission as a former Attorney-General and MP in Victoria, who was extensively involved in the Parliamentary debate on Victoria's Voluntary Assisted Dying ("VAD") legislation in 2017.

2. I make this submission to provide the Committee with information about the Victorian legislation and its implementation and about the implications of the Victorian experience for any proposal to introduce VAD into the Northern Territory. As the Committee will be aware, the Victorian legislation has been the starting point for all other VAD regimes in Australia.

3. In short, the Victorian VAD legislation and its implementation do not provide a good precedent for a VAD regime for NT, and the Victorian experience highlights the inherent and unavoidable adverse consequences of introducing any VAD regime. The Committee should not accept any claims that the Victorian regime shows that VAD can work well.

4. Based on the Victorian experience, and other Australian experience of which I am aware, my responses to the four key questions raised by the Committee are as follows:

    1) VAD should not be made legal in the Northern Territory.

    2) Not applicable.

    3) It is not possible to make sure that an eligible person can access VAD in a safe and effective way.

    4) No monitoring can ensure VAD is delivered safely and effectively. However, if VAD is introduced, the regulatory and accountability regime should involve:

        a) regulation and/or oversight by one or more persons or bodies who are not specialist regulators or overseers of VAD alone, and thus are detached from and independent of the VAD regime; and

        b) the collection and publication of the widest possible range of data that would allow informed public debate about how the VAD regime is operating and would inform governmental and legislative decisions about whether the regime should be changed or discontinued.

The Victorian VAD regime

Overview

5. The Victorian experience illustrates how an assisted suicide regime structured in a way similar to that proposed for the NT actually works in practice. In Victoria:

    - There are minimal qualifications or experience required for the doctors involved
    - There is minimal training required for whether decisions are voluntary and is no coercion or undue influence
    - Approvals are issued almost entirely on the paperwork alone
    - There are no audits of actual compliance or random case reviews
    - There are no requirements for practitioners to report adverse events
    - There is no independent and impartial oversight or regulation
    - There's been a high concentration of cases with a small number of doctors
    - Doctors who disagree with assisted suicide are being forced out of public hospitals
    - The coroner is excluded from looking at assisted suicide cases
    - Having medically assisted suicides hasn't reduced other suicides
    - There are still widespread shortages of palliative care.

6. A crucial problem is that many front-line doctors in Victoria don't have good knowledge of the patients' condition or of what palliative care can do, yet they are the ones whose poorly informed advice can turn their patients away from getting better advice and instead start them on the path to assisted suicide.

7. As well, the legalisation of assisted suicide in Victoria is steadily changing attitudes among medical practitioners away from striving to do whatever they can to help solve the problems that are causing their patient to want to die, and instead towards feeling that it's the patient's choice so the doctor's role is simply to tell the patient the facts about assisted suicide and how to get it if they want it.

Regulation and oversight

8. The Victorian legislation's oversight and accountability structure seems to have been based on the principle of "hear no evil, see no evil, speak no evil". In other words, it seems designed for the regulator to find out nothing, investigate nothing and report nothing that could suggest that assisted dying has been anything other than an unblemished success. Permits for an assisted death are given by the relevant government department almost exclusively on the submitted paperwork alone. There are no audits of actual compliance, no random case reviews of what occurred, no adverse event reporting requirements for health professionals and no rights for concerned parties to contest.

9. Victoria's Voluntary Assisted Dying Review Board ("VADRB") is made up mainly of members who have a strong commitment to assisted suicide. This has meant its role has been little more than that of a cheerleader rather than that of an independent and impartial regulator. The Board tells the public how well things are working regardless of the facts, it avoids publication of any contrary evidence, and it lobbies for further expansion to the law.

10. The regulatory focus has been on reviewing the paperwork and ensuring the records are in order, rather than on any investigations of whether what actually occurs behind the paperwork complies with legislation. (See, for example, VADRB 2023-24 Annual Report p.30, available at https://www.health.vic.gov.au/sites/default/files/2024-09/voluntary-assisted-dying-review-board_annual-report-2023-24.pdf)

11. Particularly concerning is that in the two years prior to the most recent annual report not a single application for an assisted suicide permit has been refused (VADRB 2023-24 Annual Report, p.8). Rather than this being due to 100% practitioner compliance with the legislation, the VADRB's annual report makes clear this has been achieved by the expedient of applications not being formally determined until the initially submitted paperwork has been got into order (see VADRB 2023-24 Annual Report, p.25, text under "Timeliness"). The public is given no idea of how defective initially submitted paperwork has been, let alone how defective actual compliance has been.

12. Furthermore, the data that are published in Victoria are a bland range of the numbers of cases that have progressed through the various stages through to death, together with some demographic data, data on practitioner involvement and a listing of the main medical conditions involved. There is also some data on palliative care receipt by those who seek VAD, but nothing to indicate whether such palliative care receipt meant the patient was simply on the books of a palliative care service, or whether they were actually receiving the level of care they need.

13. Important statistical data not reported on by the VADRB include the reasons for patients seeking VAD (as distinct from their underlying medical conditions), the specialities of the doctors actually handling VAD cases, whether or not those doctors were the patient's treating doctors, and the times that elapse between permits for VAD being issued and the patients' deaths. Even the list of underlying medical conditions that is published is incomplete and simply aggregates many conditions into "other".

14. Crucially missing from annual reports as well has been any detail on the reasons why some applications for permits for VAD were not granted in those years when that occurred or what investigations, if any, the VADRB undertook of those cases.

15. To make matters worse, the Coroner is totally excluded from any role in relation to VAD deaths unless the VAD substance was not administered in accordance with the legislation. In practice, this means the Coroner has no role in any cases where death appears to be by VAD unless perhaps evidence of non-compliance were to come to light, which is very unlikely, because those involved in any non-compliance are unlikely to confess, there is little scope for third parties to become aware of or complain about non-compliance, and the VADRB seems to have little, if any, active or effective role in scrutinising or referring non-compliance.

16. The exclusion of the Coroner also means that unless evidence of non-compliance comes to light, there is no possibility for any post-mortems to be done to make sure the diagnosis of terminal illness was correct or to see if there is any evidence of complications or distress in dying.

Practitioner training, qualifications and participation

17. A variety of sometimes inconsistent claims have been made about the extent of training and experience needed to qualify to administer VAD in Victoria, and about the levels of practitioner support for VAD. Some have argued that the system is safe because of the rigor of the training and qualifications required, while others consider that the prescriptiveness of the VAD regimes and thus the training required is excessive. Some have claimed that there is widespread support for VAD amongst health practitioners, while others have lamented the low number of practitioners training to participate in VAD.

18. In fact, the evidence from Victoria is that the training for VAD is mainly about how to follow the required steps in the process and how to fill out the paperwork correctly, rather than about how to identify and protect patients against risk factors or how to counsel patients in ways that

avoid implicit practitioner recommendations of VAD. This negates the claim that rigorous training has helped ensure that VAD is working safely.

19. For example, according to research by the Australian Care Alliance, the part of the Victorian prescribed training that covers voluntariness, including assessing the absence of coercion, totals five minutes, including a 2 minute 10 second video and slides that take a further 2 minutes 50 seconds to read. (Australian Care Alliance submission to the Victorian legislative review, at p.7 - https://assets.nationbuilder.com/australiancarealliance/pages/171/attachments/original/1726714047/Australian_Care_Alliance_submission_to_Review_of_the_Voluntary_Assisted_Dying_Act_2017_-_Victoria_%281%29.pdf)

20. Furthermore, the claim that the legislation mandates a high level of professional qualifications is incorrect. The Voluntary Assisted Dying Act 2017 ("the VAD Act") at s.10 requires that each co-ordinating medical practitioner (ie, the one handling the paperwork) and each consulting medical practitioner (ie, the second doctor) must hold a fellowship with a specialist medical college or be a vocationally registered general practitioner. (As Committee members will be aware, vocationally registered general practitioners are GPs who have done specified additional training, in effect, to specialise in being GPs. There are just under 10,000 such GPs in Victoria, about 1 in 4 of all GPs.) In addition, one of the two doctors involved must have practised for at least five years after completing their fellowship or vocational registration, and one of the two doctors must have "relevant expertise and experience" in the disease, illness or medical condition expected to cause the patient's death.

21. These qualification requirements have many shortcomings. For a start, there is nothing to prevent the two doctors involved from being in the same clinic or other practice. Despite claims made in the Victorian Parliamentary debate, neither the legislation nor statutory guidelines nor the expertise and experience requirement would exclude it. There is no power in the VAD Act to make such guidelines and the expertise and experience test seems able to be satisfied simply by the standards of vocationally registered GPs. In other words, it is possible for VAD to be assessed by two GPs provided at least one of them has had prior experience of patients with similar conditions, and without any requirement for involvement of a specialist in the usual meaning of that term.

22. The provision of VAD in Victoria has been concentrated with a small number of practitioners. For example, the VADRB reported that in 2023-24 the ten doctors with the highest VAD case load co-ordinated or consulted on 55% of all VAD cases (VADRB 2023-24 Annual Report p.6). This means that large numbers of patients are being counselled by doctors who have a strong personal commitment to assisted suicide, many of whom have been long term supporters of and advocates for VAD legalisation, and who have geared their practices to process the paperwork involved. This has created a serious risk that doctors holding such views will be so predisposed to regard VAD as the best outcome that they will be blind to what palliative care would be able to do for the patients who come to them, and blind to the risks that a patient seeking VAD may be lacking legal capacity, suffering from treatable depression or subject to subtle coercion or undue influence from family or friends. Indeed, there is a further risk that some of these doctors from time to time will disregard legislative requirements in order to give their patients what they regard as the benefit of assisted suicide.

23. Rather than the claim that there is widespread practitioner support for VAD and that the limited practitioner participation in VAD is due to onerous (perhaps excessively onerous) training requirements or stringent qualification requirements, it is more reasonable to conclude that large numbers of practitioners are quietly voting with their feet to keep well away from VAD, leaving VAD and its promotion to a minority of highly vocal VAD-supporting practitioners and

other advocates, who at least in Victoria have been assisted in driving out dissenters and stifling objection by the top down instructions from the government to health departments and hospitals to ensure the universal deployment of VAD.

No reduction in other suicides

24. There is no evidence of a reduction in general suicide in Victoria compared with other Australian states since the commencement of the VAD regime, and indeed there is some evidence of an increase in suicides amongst those aged 65 and over (see, for example, David A Jones, *Did the Voluntary Assisted Dying Act 2017 Prevent "at least one suicide every week"?*, Journal of Ethics in Mental Health, Vol.11 2020 - https://irp.cdn-website.com/c0d44f22/files/uploaded/Did_the_Voluntary_Assisted_Dying_Act_2017.pdf). This is in stark contrast to the repeated claims of advocates at the time that the legislation would help avoid suicides by people with terminal illnesses.

25. Indeed, even the data on which those claims were based – data produced by the Victorian Coroners Court from their statistical database for the Parliamentary inquiry that preceded the VAD legislation - was later heavily qualified by the Coroners Court itself, pointing to limitations in its data coding and analysis and observing that grouping the data in the way the Court had initially presented might be "not ultimately a useful exercise" (Coroners Court of Victoria, Further Submission (No.1037) to the Legal and Social Issues Committee Inquiry into End of Life Choices, p.3 - not currently available online, copy can be provided on request).

26. In fact, non-medical suicides by terminally ill people in large part consist of those who end their life impulsively, such as jumping from a multi-storey car park after being given adverse test results by their oncologist, and those who end their life in circumstances of loneliness and lack of support. In Victoria, an emblematic example of the latter was a suicide by a person who was living alone and whose condition had deprived her of her lifetime pleasure of reading. Surely, rather than saying VAD should be the community's response to a person in such a situation, the compassionate community response should be to make it easier for such a person to receive more home visits or for someone to sit and read to them.

Availability of VAD cf. palliative care

27. It is often claimed the reported data shows that most patients who seek VAD are receiving adequate palliative care, so that absence of palliative care is not a factor leading them seek VAD. However, published figures such as those in Victoria do nothing to indicate whether those VAD recipients were actually receiving the level of palliative care they needed or whether they were simply on the books of a palliative care provider or receiving inadequate basic or limited care from an overstretched service. In Victoria, the relevant descriptors used in published data are whether the person "accessed" palliative care services and what the "duration of engagement" was. No details are given about the level or adequacy of the palliative care if any, they actually receive. (See Victorian Voluntary Assisted Dying Review Board ("VADRB") 2023-24 Annual Report p.22 - https://www.health.vic.gov.au/sites/default/files/2024-09/voluntary-assisted-dying-review-board_annual-report-2023-24.pdf .)

28. In fact, Victoria has serious ongoing shortfalls in palliative care, especially high-level specialist palliative care, and particularly in rural and regional areas. At the time the VAD legislation was passed in 2017, palliative care service providers estimated that 10,000 patients a year were dying in avoidable pain due to the absence of palliative care, compared to the 150 or so patients a year who advocates estimated would want VAD. Many of the examples of painful

and distressing deaths raised in the Victorian Parliamentary debate were examples that palliative care experts pointed out could have been readily avoided with proper palliative care and if the treating doctor had the professional knowledge they should have had to refer their patient to a suitable palliative care practitioner.

29. For most of the course of the public and Parliamentary debate on the Victorian VAD Bill, the government made no response to the many concerns raised about inadequate palliative care. Late in the course of the Parliamentary debate, when doubts arose as to whether the Bill would receive sufficient support to pass the Legislative Council, the government hurriedly announced a package that provided only $9 million a year in ongoing palliative care funding, compared to the $65 million a year minimum that Palliative Care Victoria estimated was needed.

30. On the Victorian government's own admission, the package provided home-based palliative care for only 1,215 terminally ill patients a year compared with the estimated 10,000 patients a year in need. In other words, the package barely met the needs of one Victorian in seven who was not getting palliative care. The package provided no additional inpatient palliative care beds, and the extra funding in the package for palliative care consultancy services provided less than one-third of the funding needed across Victoria, where 60 per cent of consultancy services were unable to meet demand.

31. There was also no funding in the package to increase the palliative care workforce nor for education in palliative care for other health professionals. That was despite the fact that ignorance amongst health professionals about modern pain relief techniques was (and remains) one of the biggest contributors to needless pain for dying patients.

32. Since VAD was legalised, while there have been some announcements of increases in palliative care funding, as Committee members will be aware, government announcements such as these often simply go towards meeting increasing needs or covering increased costs, without actually improving availability levels.

33. Instead of ensuring adequate palliative care is available for every dying Victorian who needs it, the Victorian government and health bureaucracy have given far greater priority to achieving the universal availability of assisted suicide than the universal availability of palliative care. For example, the government has introduced a statewide delivery service to deliver VAD substances to the home of the recipient, whereas the government has introduced no similar service for the home delivery of pain relief or other palliative care medication, even though many patients in need of pain relief live in remote parts of the state.

34. This has been defended on the basis that that pain relief is available through standard pharmacy access, whereas without a delivery service it would be hard to get VAD substances in remote areas. However, this ignores the fact that it is also hard, if not impossible, to get home delivered pain relief in remote parts of the state, as no doubt is also the case in NT. Yet the Victorian government chose to overcome the former problem for dying patients but not the latter, notwithstanding the fact that widespread shortfalls in the availability of palliative care, particularly high-level palliative care, place patients at risk of deciding to accept assisted suicide as a very poor second choice when they would not have done so if they could have obtained the palliative care they needed. The NT would be doing the same if it were to introduce a Territory-wide VAD substance delivery service but not a Territory-wide palliative care medication delivery service.

35. The lack of adequate palliative care in Victoria is consistent with the experience in NSW. While the then government committed a further $743 million in funding for palliative care at the time the NSW VAD legislation was passed, it was reported in September 2023 that that funding had subsequently been cut by $150 million as part of budget savings, while an additional $97 million had been provided to implement VAD (Daily Telegraph, 28 September 2023 -

https://www.dailytelegraph.com.au/news/nsw/palliative-care-funding-ut-by-150-million-while-assisted-dying-gets-97-million/news-story/01cc696038a4df722eedf3f3ab3b6e4e)

36. While the details of the shortfalls and cuts in palliative care in Victoria and NSW are specific to those states, the broader implication relevant to the Committee is that bland assertions about the ready availability of palliative care in other Australian jurisdictions, and glib assurances that difficulties in accessing adequate palliative care are not or will not be a reason for patients seeking assisted suicide, are unlikely to be correct and any such assertions or assurances should be treated with great scepticism.

37. This conclusion about inadequacies in palliative care is further supported by evidence published on the Palliative Care Australia web site as at 25 November 2024 that:

    " Each day around 400 people die of a terminal illness, yet more than three in five (62%) do not receive specialist palliative care at any stage. Current data presents a confronting picture of access to palliative care, and on our current path this will only get worse. Without action, our future is one of diminishing care for people and families living and dying with terminal illness."

    (https://palliativecare.org.au/campaign/better-access-to-palliative-care-worth-voting-for/)

38. The human face of this lack of palliative care in Australia, despite the legalisation of VAD in all states, is shown by the harrowing account given on the same PCA web page of the painful and distressing death experienced by a family member due delayed and inadequate palliative care availability, even in a public hospital, coupled with a lack of understanding by many hospital staff of the patient's palliative care needs.

39. This account of a family member's death is yet another example of the sort of experience suffered by many dying patients and their families that are cited in Parliamentary debates as examples of the need for assisted suicide yet, when looked at more closely, are examples of the continuing inadequacy of palliative care.

VAD's effects across the health system

40. The legalisation of VAD in Victoria has had a major impact on doctors and other health professionals whose work involves end-of-life care, whether in hospitals or in the community, and this has had effects for patients. The Committee should abandon any thought that VAD can be introduced so it's there for those who want it, while life can continue unchanged for everyone else.

41. When VAD was legalised in Victoria, it was presented as an option that should be available for the relatively small number of people who wanted it. However, once the legislation was passed, VAD supporters sought to make VAD pervasive throughout the health system, so that it becomes an integral part of what is offered to anyone facing end of life, the consequences of which I discuss in detail below in relation to the implications of VAD for the NT.

42. Legalising VAD has also meant VAD is a topic now frequently raised with doctors by terminally ill patients and their families. While it may be considered a good thing that patients know they have that choice, the availability of VAD creates the risk that family and friends will unconsciously see VAD as a way of resolving their own distress and feelings of helplessness in the face of the patient's distress, rather than pushing to get better care for the patient. It also creates scope for subtle steering of a patient's views by offspring with little interest in caring for their aging parent or who have their eyes focussed on their inheritance. Needless to say, elder abuse is as serious a problem in Victoria as it is elsewhere, and terminally ill patients dependent on their adult children for care are particularly vulnerable.

43. Legalising VAD has also resulted in serious adverse consequences for health professionals who disagree with VAD, whether they disagree in general or in its manner of implementation. As referred to above, VAD has been institutionalised throughout the Victorian hospital system. The Victorian government and health department have pushed all public hospitals that may have terminally ill patients to make VAD readily available and to brook no dissent from their practitioners. VAD supporters within hospital administrations and clinical practices have often sought to drive out or silence anyone who does not support VAD or the way it is being deployed, to the point where many practitioners working in public hospitals now feel unable to raise concerns about VAD, including about the ways VAD is occurring within their hospital either generally or individual cases, lest they suffer adverse professional or career consequences, or else they are leaving the Victorian hospital system altogether.

Safeguards v impediments

44. Many VAD practitioners and other VAD supporters have been critical of various provisions in Victorian and other Australian VAD regimes that attempt to provide safeguards, such as the prohibition currently in place in Victoria and South Australia on practitioners initiating discussions of VAD.

45. Critics have described this as a "gag clause", but in fact the prohibition has the important role of avoiding the implicit practitioner recommendation of assisted suicide that can so easily be construed by the patient if the practitioner raises the subject. There is an enormous imbalance of knowledge and power between practitioners and patients, particularly given the fear, distress and uncertainty that is likely to be in the minds of many patients facing a terminal diagnosis and the final stages of their life. As a result, patients are highly dependent on their practitioner for advice, and often desperate for any indication about what the practitioner thinks they should do, which they then act on.

46. Some VAD practitioners and other advocates have also criticized the statutory prohibition on VAD being assessed remotely via telehealth, as reflected in Recommendation 13 of the Expert Panel's report. While critics of the prohibition point to the benefits that telehealth can bring for much medical treatment for patients living remotely, advocating its extension to VAD disregards the even greater difficulties of detecting mental illness, coercion or other family pressure, or lack of capacity, via a video link or by telephone, when it can be difficult enough for practitioners to detect these matters even in an in-person assessment.

47. Another important limitation on VAD is restrictions on practitioner administration of lethal substances. There have been recurring calls to remove those restrictions in states such as Victoria that have them, on the grounds that many patients would prefer practitioner administration even if they could consume a lethal substance themselves. The Expert Panel also proposes permitting practitioner administration for all VAD.

48. However, such restrictions have the important role of making it more likely that the suicide is truly voluntary, because the physical act of taking the substance requires psychologically a greater commitment to wanting to proceed than simply submitting to actions taken by another. This is particularly so in cases where a patient is hesitant in orally expressing their wishes. Perhaps even more importantly, it is far harder for a patient to change their mind once they have made the arrangements for a doctor to attend to administer the substance, whereas with self-administration they have the option to change their mind right up to the last minute.

49. Patient self-administration is also a safeguard against doctors proceeding to euthanise a patient because they believe it is in the best interests of the patient to do so, even though the patient does not or cannot unequivocally consent. Regrettably, experience in Victoria and

elsewhere shows that there are doctors who are willing to act in this way, because of their fervent belief that euthanasia is the best outcome for their patient, regardless of what the law might say.

Pain v autonomy

50. Many MPs and other advocates for VAD in Victoria placed great emphasis on the need for assisted suicide legalisation as the alternative to terminally ill patients experiencing what they claimed would otherwise be an unavoidably painful death.

51. However, avoiding painful deaths is not a valid reason for VAD because almost without exception pain and other physical symptoms can be resolved with proper palliative care. Despite this, MPs and advocates calling for VAD still often rely on false claims of unavoidably painful deaths to try to make their case. No doubt they do so because appealing to other reasons, such as a desire for autonomy, is far less likely to convince undecided MPs to vote for VAD, with all the far-reaching adverse consequences that brings.

52. It's particularly ironic that MPs campaigning for VAD give examples of painful deaths as the reason, when what their examples really show is the need for better palliative care – yet that's the very palliative care that can so easily be neglected if assisted suicide is legalised.

53. In contrast to what is argued publicly, the main rationale for VAD that VAD practitioners and academics give outside of public debate is their views about personal autonomy. Some have even argued that it doesn't matter that people decide on assisted suicide on the grounds that their life is a burden to others, because it is still a valid and voluntary choice that they have the capacity to make, so long as they are informed of the relevant facts and information.

54. However, the conception of autonomy that underpins support for VAD is flawed and simplistic and overlooks practitioners' responsibilities to frightened and distressed terminally ill patients. Those responsibilities extend far beyond simply giving them the facts about their options and leaving it to them to make up their minds. Practitioners also have a responsibility to provide both emotional support and practical guidance to their patient.

55. For example, when a patient tells a doctor they want to die because they are a burden on their family, the doctor's first reaction should be: "What can I do to help you with the reasons you are thinking that way?" rather than simply saying to themselves (as some advocates seem to think): "Well, just because they feel they are a burden doesn't mean their decision isn't voluntary, so let's go ahead with assisted suicide if that's what they want."

56. A further fundamental flaw in the argument that VAD is about personal autonomy is that a medically assisted suicide does not just involve the person who suicides, it also involves those who are required to provide the assistance for it. Indeed, it also involves fundamental changes to a jurisdiction's health system, a system that provides care for everyone across the jurisdiction. Legalising VAD has already caused far-reaching changes in Victoria to how doctors' responsibilities to terminally ill patients are perceived and has introduced systemic risks of inadequate or erroneous advice and inadequate palliative care and other support that affect all terminally ill patients. These consequences can only be expected to increase as VAD in Victoria continues to become further entrenched in the health care system.

57. No individual's desire for autonomy can be absolute when that autonomy unavoidably means that multiple others will suffer unfairly as a result. The desire for autonomy for some should not come at the expense of harm to many.

Implications for the NT of the Victorian experience

58. The single most important implication for the NT of the Victorian experience is the inevitable and systemic adverse effects for patients that any VAD regime will create.

59. For the reasons I have described, bringing assisted suicide into the NT health system will change medical practice in ways that result in many patients accepting assisted suicide because they haven't been properly informed and reassured that fears they hold are in fact unfounded.

60. In other words, a patient's assisted suicide will often not be a matter of informed and considered patient choice, it will be due to VAD creating systemic tendencies within the health system that for many patients will lead to decisions based on deficient advice from service providers.

61. This result is inherent in the nature of a medically assisted suicide regime and can't be overcome by any claimed safeguards, however extensive.

62. If VAD is legalised, this will occur in the NT whether or not VAD assessments and provision occur exclusively through a specialist VAD delivery service. This is because any doctor in the NT who is treating a terminally ill patient might be asked for their views and advice about VAD.

63. As I've pointed out above, a health system, like many other service sectors, is one where there is a huge imbalance of knowledge and power between consumer and service provider, and thus where the consumer is highly dependent on the information and recommendations provided by the service provider.

64. With all such sectors, there is a heavy obligation on those responsible for its regulation, in this case, the Legislative Assembly, to ensure that the legal framework within which the service sector operates does not expose consumers to systemic risks, as VAD unavoidably does.

65. With VAD, the imbalance of knowledge and experience between doctor and patient means the terminally ill patient is dependent on the doctor not only for facts, but for what they may explicitly or implicitly recommend, and for emotional reassurance. Thus, for many patients, it will be how their conversation goes with their doctor that determines whether they decide to go with assisted suicide or decide to go with palliative care.

66. On the one hand, a patient may conclude along the lines:

    "I don't want to die, but I don't know if I can go through with what is going to happen from here. Doctor says they will do their best to relieve my pain, but she can't guarantee the results. I asked about assisted dying, and doctor says that at this stage many patients choose that as an option and it's something I should seriously consider. I think that's what I'll do."

67. However, if they have had a different conversation with the doctor, the same patient may conclude:

    "I've been really worried about whether I can go through with what is going to happen from here. However, I've had a good discussion with the doctor. Doctor says they've helped lots of patients through these final stages and she and her colleagues will be with me every step of the way. She says there are very good pain relief medicines these days and they can almost always relieve pain and other symptoms. She says she has seen lots of patients use their final weeks to make their peace with the world, say their farewells to loved ones and sort out any loose

ends in their life. I don't want to die, but I'm now going to make the most of whatever time I've got left."

68. It is of course those patients who are marginalised and disadvantaged, or who have grown up to believe that "doctor knows best", who are most vulnerable to and dependent on the doctor for the advice and guidance that will determine their decision.

69. If assisted suicide is legalised, the systemic risks of incomplete or erroneous advice and inadequate emotional support will arise in multiple ways.

70. Most pervasively, once the Legislative Assembly has characterised the question of assisted suicide or not as simply an exercise of autonomous patient choice, many doctors will be increasingly likely to respond to patients asking about assisted suicide by providing a purely factual presentation of it as a medical option, rather than recognising that they also have a professional responsibility to respond to the patient's vulnerability and need for reassurance and emotional support in order to lay unfounded fears to rest.

71. As well, if the NT is like Victoria, many doctors advising patients will not have good knowledge of what palliative care options are available or of what specialist palliative care can achieve and therefore will be at risk of misadvising their patients even if they are trying to do their best. Based on the doctor's poor advice, many of these patients may decide to go down a path that ends in VAD, whereas if they had not been misadvised they would have found out that palliative care could do more than their doctor thought, that their fears about dying in pain were unfounded and that their existential fears were able to be resolved.

72. Further, as in Victoria, and particularly if VAD in the NT is provided exclusively through a specialist service, the provision of assisted suicide is likely to be concentrated with those doctors whose personal views are inclined toward assisted suicide and strongly inclined to think it is the best choice for many patients. As in Victoria, this is likely to create a high risk of their views resulting in them not properly advising their patients about what palliative care could do or about what the patient's likely experiences through to end of life would be, and of not being alert to risks of depression, coercion or lack of capacity.

73. As well as these attitude changes in medical practice, legalising assisted suicide is likely to shape the attitudes of family and friends away from fighting to get the best possible palliative care and other supports for their loved one and towards thinking that if the Legislative Assembly says assisted suicide is OK, it might be the best outcome for the distress that the patient's suffering is causing for everyone involved, thus leading them to validate the patient's thinking along those lines.

74. No independent regulation or monitoring, however independent and however extensive, is going to be able to protect against the effects of these attitude changes that legalising assisted suicide will produce, because the misadvised patient, often validated by family and friends, will believe they are taking the best course available to them, and the misadvising doctors will be oblivious to the fact that they could and should have given their patient better advice and support.

Monitoring of a VAD regime

75. For the reasons I have given, any regulation or monitoring of a VAD regime can only hope to curb some of its more egregious consequences; it cannot render it safe and effective. However, to that limited end, some conclusions about better regulation and monitoring can be drawn from Victoria and elsewhere.

76. The highest priorities for any attempt at regulation and monitoring of VAD should be to ensure true impartiality in the regulatory and oversight regime and to require the collection and publication of the widest possible range of data about how the regime is operating.

77. Experience shows that without an impartial regulator with sufficient powers and responsibilities, just about every criterion and procedural step that may be included in the legislation as an intended safeguard can be bypassed. Criteria can be interpreted very loosely by pro-VAD practitioners, and procedural steps can become empty "tick a box" formalities.

78. The Expert Panel report seems to follow one of the worst aspects of the existing Australian regimes by proposing to place regulation and oversight in the hands of a specialist Review Board. The problem with this is that no-one who is opposed to VAD is likely to be willing to take on a role with such a Review Board, whereas supporters of VAD will be very willing to do so. As with the Victorian VAD Review Board, an NT Review Board is likely to become a cheerleader for VAD rather than a regulator. In other words, the nature of VAD and the likely membership of a Review Board make such a board a prime candidate for what is commonly referred to as "industry capture".

79. Instead, regulation of any VAD regime should be placed with a regulator whose responsibility for VAD regulation sits alongside responsibility for regulating other areas of health practice, where the regulator is intrinsically less at risk of being partial and subject to industry capture. While I am not familiar enough with the detail of health oversight in the NT to be confident in recommending an alternative, the placing of regulation with the Chief Medical Officer could be one such option. However, even with regulation being headed by an officeholder or entity such as the CMO who is impartial from VAD, it will be important also that that regulator ensure that the hands-on regulation of VAD within their office is not conducted by staff drawn from a VAD background, or who work solely on VAD oversight.

80. Another important aspect of independent and impartial monitoring is that the primary responsibility for reviewing VAD deaths should be vested in the Coroner rather than in a Review Board. This is important not only for impartiality, but because it is part of the core business of the Coroner to scrutinise deaths for any factors that might give rise to concern. This does not mean that the Coroner should be required to conduct an inquest or other investigation of every VAD case, but it would mean that the Coroner, rather than a Review Board, would examine the reported information about the death, and the Coroner would have the capacity and discretion to conduct an investigation, or even an inquest, where it appeared to the Coroner that there were good grounds to do so, and then to make any required reports or recommendations about the regime. Further, if in future the NT Coroner commences to undertake systemic reviews, the Coroner will have a detailed database on which a systemic review of the operation of the VAD regime could be conducted.

81. Another important aspect of effective monitoring is the scope for third parties to make informed contributions to assessments of eligibility for VAD. For example, where one of the assessing practitioners is not the patient's regular GP, or the specialist whom the patient has been consulting about their condition, it should be mandatory for the assessing practitioner to consult the regular GP or relevant specialist as part of their assessment. In Victoria, the legislation simply contains a bland provision encouraging the assessing doctors to consult with the regular GP, but no obligation to do so. As far as I am aware, such consultation seldom occurs, because often neither the patient nor the assessing doctor will want anything to get in the way of them obtaining VAD. However, the patient's regular GP or relevant specialist will often have information that would put the VAD application in very different light, such as evidence about coercion, conflicts of interest, mental illness or questionable mental capacities.

82. Family members often will also have important information to contribute, and a way should be sought to provide for their contributions in relevant circumstances, while taking into account considerations about privacy. One example of a possible provision could be that an assessing practitioner who has doubts about various factors, such as lack of capacity or coercion, could be required, or at least empowered, to halt their assessment unless the patient allows consultation with relevant family members. However, it is important in this context to reiterate that any attempted safeguard such as this that is based on the discretion or judgement of the assessing practitioner is likely to be of limited effect, since the biggest risk in such assessments is that the assessing practitioner will have a one-eyed commitment to VAD that will cause them not to recognise or heed such risk factors in the first place.

83. For this reason, and contrary to the Expert Panel's recommendation 20, it would seem highly desirable to give concerned family members and others who have sufficient and genuine interest in the rights and interests of the person seeking VAD some opportunity in cases of serious concern to seek review via NTCAT of an intended authorisation of VAD, as appears to be the case via QCAT under the Queensland VAD legislation.

84. Another aspect of better monitoring is the collection and publication of data. The Victorian experience shows that the VAD Review Board and Health Department seem to gather and publish as little as possible of any data that could reflect adversely on how VAD is working in practice. In part this is because the legislation is drafted so that little reporting is mandated, and in part because the Board and the Department don't collect or publish even what they could. However, having a wide range of data collected and published will be vital for ensuring informed public debate and informed governmental and legislative consideration of how VAD in the NT is operating. Neither VAD supporters nor VAD opponents, if they are confident about their arguments and interested in the true facts, should have any grounds to oppose the collection and publication of the widest possible range of data about how any VAD regime in the NT was working out.

85. To help ensure the collection and publication of the widest possible range of data and other information, it may be desirable for any legislation to specify those requirements in some detail. Consideration could also be given to vesting some responsibility for setting standards and requirements for data collection and publication in the Department of Corporate and Digital Development.

86. In concluding, I reiterate that while I have put forward some important ways in which the regulation and monitoring of a VAD regime could be improved compared with existing Australian regimes, any such better regulation and monitoring would only go a small way to curb some of VAD's most egregious consequences. No regulation and monitoring are able to overcome the inevitable and gravely harmful effects of the system-wide changes in attitudes and practices towards caring for and helping others that VAD will produce, and it will be far better for life in the NT for VAD not to be introduced at all.

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