Submission No 101

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: New South Wales Bar Association

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NEW SOUTH WALES
BAR ASSOCIATION

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The Hon Wesley Fang, MLC
Chair, Standing Committee on Law and Justice
Legislative Council
Parliament House
6 Macquarie Street
Sydney NSW 2000

By email: law@parliament.nsw.gov.au

Dear Chair,

Inquiry | Voluntary Assisted Dying Bill 2021 (NSW)

1. The New South Wales Bar Association (**the Association**) welcomes the Standing Committee on Law and Justice's (**the Committee's**) inquiry into the provisions of the Voluntary Assisted Dying Bill 2021 (NSW) (**the Bill**).

2. The Bill engages with what is the most significant of all human rights – the right to life. Indeed, the existence and operation of other human rights are predicated on the effective guarantee of the right to life.[1]

3. This submission considers the Bill from the perspective of the various, and sometimes conflicting, obligations under international human rights law. With those obligations in mind, and being conscious of the need for certainty of operation of the provisions of the Bill if enacted, the Association also makes suggestions on specific provisions of the Bill.

4. This submission does not otherwise consider the merits of the Bill. As in its previous submissions to the Parliamentary Working Group on Assisted Dying on the Voluntary Assisted Dying Bill 2016 (NSW) and Voluntary Assisted Dying Bill 2017 (NSW), the Association's primary concern here is to ensure that the policy aims of the Bill are pursued in a reasonable and proportionate manner and in conformity with human rights and common law norms.

Human rights considerations arising from voluntary assisted dying and similar laws

5. Voluntary assisted dying laws engage a number of human rights considerations including:

[1] Zdenkowski, *Human rights and euthanasia*, occasional paper of the Human Rights and Equal Opportunity Commission, December 1996, p 9.

(i) the right to life;
(ii) the prohibition on cruel, inhuman or degrading treatment;
(iii) rights to freedom of thought, conscience and religion;
(iv) rights to privacy and family life; and,
(v) the rights of persons with disabilities.

6. This section of the Association's submission considers these rights and draws on international experience considering how these rights engage with laws prohibiting assisted dying.

Recognition of the right to life in human rights law

7. The principal articulation of the right to life in human rights law is Article 6 of the *International Covenant on Civil and Political Rights* (**ICCPR**).[2] Article 6(1) provides relevantly:[3]

> *Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.*

8. Article 6(1) does not deal expressly with the subject matter of the Bill, namely the ability of certain terminally ill persons to invoke a legislative procedure by which they can request and receive assistance to end their lives voluntarily. This framework contemplated by the Bill can, therefore, be considered a form of 'active' euthanasia, rather than 'passive' euthanasia.

9. There is much debate about whether laws that permit active voluntary euthanasia violate Article 6.[4] The critical question in the debate is whether it is possible for a person to *waive* their right to life (or, in other words, *consent* to the ending of their life). It can be noted that it is now generally accepted that there can be a waiver of the right to life in narrowly defined circumstances, which requires the waiver to be authentic, reliable and valid.[5]

10. Article 6(1) of the *ICCPR* finds its analogue in art 2(1) of the *European Convention on Human Rights* (1950) (**ECHR**), which reads as follows:

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[2] The ICCPR was adopted by the United Nations General Assembly on 16 December 1966 and entered into force on 23 March 1976. Australia signed the ICCPR on 18 December 1972 and ratified it on 13 August 1980: [1980] ATS 23.

[3] The right to life is also recognised in numerous other treaties, including in Article 3 of the *Universal Declaration of Human Rights*, Article 6 of the *Convention on the Rights of the Child*, Article 10 of the *Convention on the Rights of Persons with Disabilities* and Article 1 of the Second Optional Protocol to the ICCPR.

[4] Indeed, there is ongoing debate internationally about whether the right to life includes the right to decide to end a life. The position in Europe is clear that it does not: see http://www.echr.coe.int/Documents/FS_Euthanasia_ENG.pdf. For Australian consideration of this issue, see https://www.humanrights.gov.au/our-work/rights-and-freedoms/projects/human-rights-and-euthanasia.

[5] Zdenkowski, *op cit*, pp 14-15.

Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

11. The leading authority of the European Court of Human Rights on the complex issue of voluntary assisted dying is *Pretty v the United Kingdom*[6]. In that case, Ms Pretty was in the final stages of motor neurone disease. She was paralysed from the neck down, had 'virtually no decipherable speech' and was being fed through a tube. Her life expectancy was a matter of only months or even weeks. However, she had full mental capacity. Because of her disease, Ms Pretty was unable to end her own life. She sought an undertaking from the United Kingdom's Director of Public Prosecutions not to prosecute her husband if he assisted her to 'commit suicide', as the latter was a criminal offence under the *Suicide Act 1961* (UK) (**the Suicide Act**).

12. The Court held that that the prohibition on assisted suicide contained within s 2 of the Suicide Act did not violate the negative and positive aspects of art 2 (the right to life) of the *ECHR*, finding that the right to life could not, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die. In other words, the state was not required to sanction actions intended to terminate life by legalising assisted dying.

Prohibition on cruel, inhuman or degrading treatment

13. Article 7 of the *ICCPR* states:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

14. The purpose of art 7 is 'to protect both the dignity and the physical and mental integrity of the individual.'[7] 'Cruel, inhuman or degrading treatment' can include the suffering experienced by a person reaching the end of a terminal illness.

15. However, in *Pretty*, the Strasbourg Court held the Suicide Act did not violate the equivalent prohibition in the ECHR (art 3).

Rights to freedom of thought, conscience and religion

16. Article 18(1) of the ICCPR states:

Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching.

[6] Application Nº 2346/02 (29 April 2002); (2002) 35 EHRR 1 (***Pretty***).
[7] UN Human Rights Committee, General Comment No 20: Article 7 (Prohibition of Torture, or Other Cruel, Inhuman or Degrading Treatment or Punishment), UN Doc HRI/GEN/1/Rev.1 at 30 (10 March 1992), [2].

17. In *Pretty*, the European Court of Human Rights also held that the Suicide Act did not contravene the equivalent article of the ECHR (art 9).[8]

Rights to privacy and family life

18. Article 17 of the ICCPR states:

> 1. *No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation.*
>
> 2. *Everyone has the right to the protection of the law against such interference or attacks.*

19. This right concerns personal, or individual, autonomy.

20. In *Pretty*, the European Court of Human Rights stated that 'the ability to conduct one's life in a manner of one's own choosing may...include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned...even where the conduct poses a danger to health or, arguably, where it is of a life-threatening nature'.[9]

21. Related to the 'family' aspect of Article 17 is Article 23(1) of the ICCPR, which states:[10]

> *The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.*

22. The European Court of Human Rights has had the opportunity to consider the equivalent article in the ECHR (art 8) in a series of cases.[11] In those cases, the Court has observed that a *prohibition* on assisted dying engages, but does not necessarily violate, the right to privacy and family life. In this context, the Court has considered the right to privacy includes 'an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence.'[12]

Rights of persons with disability

23. Special mention should be made of the rights of persons with disability.

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[8] The Court held that not all opinions constitute beliefs in the sense protected by art 9(1) of the ECHR, and a belief in assisted suicide was such an opinion: *Pretty* [82]-[83].
[9] *Pretty* at [62].
[10] See also art 16 of the *Universal Declaration of Human Rights* (1948) and art 10(1) of the *International Covenant on Economic, Social and Cultural Rights* (1966).
[11] *Hass v Switzerland* Application N° 31322/07 (20 January 2011) (***Hass***) *Koch v Germany* Application N° 497/09 (19 July 2012), *Gross v Switzerland* Application N° 67810/10, *Nicklinson and Lamb v United Kingdom* Application Nos 2478/15 and 1787/15 (23 June 2015).
[12] *Hass* at [51].

24. The Convention on the Rights of Persons with Disabilities[13] contains numerous rights, relevant to persons with disability and voluntary assisted dying laws, including Article 10 (right to life), Article 12 (equal recognition before the law); and Article 25 (health).

25. Historically, there has been significant opposition to voluntary assisted dying legislation from persons with disability.

26. That opposition generally flows from real concerns about, for example:

    (i) whether disability alone will be seen as a ground on which a person will be eligible to use voluntary assisted dying legislation;
    (ii) whether there will be sufficient protection for persons with disability from pressure, coercion or other inappropriate use of voluntary assisted dying legislation; and,
    (iii) whether health, policy and legal resources directed to the enactment and operation of voluntary assisted dying legislation will lead to a diminution in resources available to enable persons with disability to access health and other care.

27. For this reason, the Association suggests that the community of persons with disability be recognised as a community with a significant interest in the operation of the Bill, and that consideration be given to views expressed by persons with disability about the Bill and, if the legislation is enacted, during any review.

Comments on specific provisions of the Bill

28. With the above human rights considerations in mind, it is undoubtedly important for any legislation containing a voluntary assisted dying framework to have a clear operation and be free from ambiguity, particularly as it relates to eligibility to access voluntary assisted dying, assessment of eligibility and enforcement.

29. The structure of the Bill as at 26 October 2021 is based on legislation that has already been passed in Victoria,[14] Western Australia,[15] Tasmania,[16] South Australia[17] and Queensland.[18] While legislation in each of those jurisdictions is similar, there are some significant differences.

30. This section of the Association's submission comments on specific provisions of the Bill. Conscious of the need to ensure any voluntary assisted dying legislation operates clearly and free from ambiguity, the Association has sought to identify possible ambiguities in the Bill, and highlights some differences in the voluntary assisted dying legislation in Australian states which may be of assistance in ensuring

[13] Australia ratified the CRPD in July 2008 and the CRPD entered into force for Australia on 16 August 2008.
[14] *Voluntary Assisted Dying Act 2017* (Vic) (**Victorian Act**).
[15] *Voluntary Assisted Dying Act 2019* WA) (**WA Act**).
[16] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (**Tasmanian Act**), to commence on 23 October 2022.
[17] *Voluntary Assisted Dying Act 2021* (SA) (**SA Act**), to commence on a date to be proclaimed which is expected to be in early 2023.
[18] *Voluntary Assisted Dying Act 2021* (**Queensland Act**), to commence on 1 January 2023.

any legislation enacted in New South Wales is interpreted and applied in the manner in which Parliament intended.

Principles (cl 4)

31. The Association commends the careful attention to the drafting of the principles in cl 4 of the Bill.

32. It is important that express recognition has been given to the equal value of every human life in cl 4(1)(a), the first of the principles to which all persons exercising a power or performing a function under the legislation will need to have regard, and the principles concerning autonomy, informed decision-making, quality of care, protection from pressure and duress and respect for various personal characteristics (e.g. cl 4(1)(b), (c), (d), (j) and (k)).

33. Those principles engage the various human rights considerations identified earlier in the Association's submission.

Requirements for access to voluntary assisted dying (Part 2)

34. Clause 15(b) of the Bill states that a person may access voluntary assisted dying if the person has been assessed as eligible for access to voluntary assisted dying by the person's coordinating practitioner and consulting practitioner. The eligibility criteria itself appears in cl 16(1) of the Bill.

35. Clause 16(1)(d) states:

> *the person is diagnosed with at least 1 disease, illness or medical condition that—*
>
> *(i) is advanced, progressive and will cause death, and*
> *(ii) will, on the balance of probabilities, cause death—*
> *(A) for a disease, illness or medical condition that is neurodegenerative—within a period of 12 months, or*
> *(B) otherwise—within a period of 6 months, and*
> *(iii) is causing suffering to the person that cannot be relieved in a way the person considers tolerable,*

36. The Association below comments on the expressions 'advanced, progressive and will cause death' (appearing in cl 16(1)(d)(i)) and 'suffering to the person that cannot be relieved in a way the person considers tolerable' (appearing in cl 16(1)(d)(iii)).

'Advanced, progressive and will cause death' (cl 16(1)(d)(i)

37. The expression 'advanced, progressive and will cause death' in cl 16(1)(d)(i) of the Bill is identical to that used in the equivalent clauses in the WA Act[19] and the Queensland Act.[20]

[19] WA Act, s 16(1).
[20] Queensland Act, s 10(1).

38. The Tasmanian Act requires the condition to be 'advanced, incurable and irreversible' and be 'expected to cause the death of the person'.[21] However, s 6(2)(a) of the Tasmanian Act expressly provides that a condition is 'incurable and irreversible and is expected to cause death of the person if there is no reasonably available treatment that is *acceptable to the person* [emphasis added]'.

39. The Victorian Act[22] and SA Act[23] require that the condition be 'incurable' in addition to 'advanced, progressive and will cause death'. However, there is no definition of 'incurable' in those Acts.

40. The expression 'advanced, progressive and will cause death' without the requirement that the medical condition be incurable, would appear to allow access to the voluntary assisted dying regime in circumstances where a person has refused potential treatment that is not acceptable to them. For example, where a person with cancer declines to undergo chemotherapy treatment. This is consistent with the general entitlement of a person to refuse treatment and procedures, including the right to refuse water and sustenance resulting in death.

41. The Explanatory Note accompanying the Bill does not state that this is the intended effect of the expression. However, the Queensland Law Reform Commission Report No.79, 'A legal framework for voluntary assisted dying' (**QLRC Report**),[24] stated that 'whether a person has a condition that is advanced, progressive and will cause death is a clinical assessment based on an individual's own particular circumstances, including their condition, their comorbidities, and the available treatments that they are prepared to accept, noting the right to refuse medical treatment'.[25]

42. The word 'advanced' as appearing in the expression could be construed in a number of possible ways:

    a. 'Advanced' could mean the temporal timeframe *until death*. However, as cl 16(1)(d)(ii) deals with the requisite timeframe until death, it is unlikely the word 'advanced' appearing in cl 16(1)(d)(i) would cover the same ground.

    b. On another view, 'advanced' may mean the temporal timeframe of the *expected duration of the disease*. One difficulty with such an interpretation is that a person with a condition that will necessarily cause them to die within a very short period less than 6 months, and whom has intolerable suffering, would not be eligible to access the regime until their condition passed a temporal marker in the expected duration of the condition. Such an outcome appears arbitrary, and indeed contrary to the main premise of the Bill that persons who will die within the requisite timeframe and whom are suffering intolerably, ought to be provided with access to voluntary assisted dying if they so choose.

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[21] Tasmania Act, s 6.
[22] Vic Act, s 9.
[23] SA Act, s 26(1).
[24] May 2021, p 91 [7.13].
[25] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3–4. See also Explanatory Memorandum, Voluntary Assisted Dying Bill 2019 (WA) 5.

c. A third possible construction of the word 'advanced' is that the symptoms of the disease are advanced or well established in the context of the spectrum of symptoms the person would be expected to suffer. However, if the requirements relating to the time until death and the intolerable suffering are satisfied, whether or not the spectrum of expected symptoms are 'advanced' would seem to be irrelevant.

43. The QLRC Report notes that 'term "advanced, progressive and will cause death" was recommended by both the Victorian Ministerial Advisory Panel and the Western Australian Ministerial Expert Panel after extensive consultation with the community and the health profession'.[26] The QLRC Report goes on to say:[27]

> *The words 'advanced and progressive' make clear that the condition must be 'very serious and on a deteriorating trajectory'.[28] In Victoria, guidance for health practitioners explains that:[29] 'Advanced' refers to a point in the trajectory of the patient's medical condition, and 'progressive' indicates that the patient is experiencing an active deterioration such that they will continue to decline and not recover.*

44. Consequently, it seems that the WA Panel may have understood 'advanced' to mean 'very serious' and by contrast, the Victorian Panel may have understood 'advanced' to mean a 'point in the trajectory of the patient's medical condition'.

45. Having regard to the number of different ways the term 'advanced' could reasonably be interpreted, the Association suggests a definition of the term 'advanced' be included in the Bill.

'Suffering that is not tolerable' (cl 16(1)(d)(iii))

46. The requirement that the condition 'is causing suffering to the person that cannot be relieved in a way the person considers tolerable' (cl.16(1)(d)(iii)) requires a subjective assessment by the person seeking access to voluntary assisted dying as to whether the pain is intolerable. That is, the person themself is the arbiter of whether their own suffering is intolerable. The same requirement is included in the Victorian Act,[30] WA Act,[31] SA Act[32] and Queensland Act.[33]

47. There is no definition of 'suffering' in the Bill, Victorian Act, WA Act or SA Act.

[26] QLRC Report, p 91 [7.14].
[27] QLRC Report, p 91 [7.15].
[28] WA Ministerial Expert Panel Final Report (2019) 34.
[29] Vic Guidance for Health Practitioners (2019) 37. See also Vic Ministerial Advisory Panel Final Report (2017) 69.
[30] Victorian Act, s 9(1)(d)(iv).
[31] WA Act, s 16(1)(c)(iii).
[32] SA Act, s 26(1)(d)(iv).
[33] SA Act, s 10(1(a)(iii).

48. The Queensland Act defines 'suffering' for the purposes of the eligibility requirement in that Act as follows:[34]

> ***Suffering**, caused by a disease illness or medical condition, includes -*
>
> *a. physical or mental suffering; and*
> *b. suffering caused by treatment provided for the disease, illness or medical condition.*

49. The Tasmanian Act requires that the person 'is suffering intolerably in relation to a relevant medical condition'.[35] The Tasmanian Act also provides an extensive definition of when this occurs, which centres around the opinion of the person suffering. Section 14 provides that a person is suffering intolerably in relation to a relevant medical condition if –

> *(a) the person has a relevant medical condition; and*
> *(b) persistent suffering that is, in the opinion of the person, intolerable is being caused to the person by any one or more of the following:*
> *i. the relevant medical condition or the relevant medical condition together with the person's other medical conditions;*
> *ii. anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the relevant medical condition or from the relevant medical condition together with the person's other medical conditions;*
> *iii. the treatment that the person has received or the combination of that treatment with the treatment of other medical conditions of the person;*
> *iv. anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the treatment that the person may receive in relation to the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions;*
> *v. the complications of a medical kind arising from, or related to, the treatment of the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions;*
> *vi. anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the complications of a medical kind arising from, or related to, the treatment of the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions; and*
> *(c) there is no reasonably available treatment that, having regard to both the treatment and the consequences, including side effects of the treatment, is reasonably likely to –*
> *i. improve the person's relevant medical condition, or overall health and wellbeing, in a manner, to an extent, and in a period of time, that is acceptable to the person; and*
> *ii. in the opinion of the person, lessen the person's suffering to an extent that is acceptable to the person.*

[34] Queensland Act, s 10(2).
[35] Tas Act, s.10(1)(e).

50. The wording in the Bill requires that the person is diagnosed with at least 1 disease, illness or medical condition that is causing suffering to the person (cl.16(1)(d)(iii)). Consequently, there must be a causal connection between the disease, illness or medical condition and the suffering.

51. Intolerable pain caused by a medical condition is a clear example of suffering that will fall within the scope of this provision. However, in the absence of a definition of suffering, or non-exclusive examples of situations that will satisfy this provision, it is unclear from the wording of the Bill itself whether it is intended that there be limits on how far the causal link is able to be taken.

52. For example, it is possible that intolerable suffering caused *by a treatment* for a medical condition does not fall within the scope of the provision on the basis that it is not caused *by the condition* itself. As mentioned above, the Queensland Act directly caters to this situation by including in its definition of 'suffering' that which is 'caused by treatment provided for the disease, illness or medical condition'.

53. It is also unclear, for example, whether the expression 'is causing suffering' is intended to encompass suffering arising solely from anticipation of suffering that may (or may not) arise, as is provided for in the Tasmanian Act.[36]

54. For those reasons, the Association suggests that the meaning of the term 'suffering' should be further clarified in the Bill.

Capacity (cl 16(1)(e))

55. Whether or not a person seeking voluntary assisted dying has decision making capacity for the purposes of cl 16(e) is determined by reference to the definition of that term in cl 6(1) of the Bill. Pursuant to that definition, a person has decision making capacity if they have the capacity to:

    a. *understand information or advice about a voluntary assisted dying decision required under this Act to be provided to the patient, and*
    b. *remember the information or advice referred to in paragraph (a) to the extent necessary to make a voluntary assisted dying decision, and*
    c. *understand the matters involved in a voluntary assisted dying decision, and*
    d. *understand the effect of a voluntary assisted dying decision, and*
    e. *weigh up the factors referred to in paragraphs (a), (c) and (d) for the purposes of making a voluntary assisted dying decision, and*
    f. *communicate a voluntary assisted dying decision in some way.*

56. The Bill defines a 'voluntary assisted dying decision' in cl 6(3) to mean:

    a. *a request for access to voluntary assisted dying, or*
    b. *a decision to access voluntary assisted dying.*

[36] Tasmanian Act, ss 14(b)(ii), (iv) and (vi).

57. There is a presumption that the person has capacity to understand information or advice about voluntary assisted dying if it reasonably appears they understand an explanation given (cl 6(2)(a)), and they are presumed to have decision making capacity unless they are shown not to have the capacity (cl 6(2)(b)).

58. These introductory provisions relating to capacity are broadly similar to the equivalent provisions in the other jurisdictions.[37]

59. In relation to capacity to remember, the Victorian Act,[38] SA Act[39] and Tasmanian Act[40] each require that there be capacity to retain or remember information relevant to the decision to the extent necessary to make the decision.

60. By contrast, there is no express requirement in the WA Act[41] and Queensland Act[42] that the person must have the capacity to remember or retain information necessary to make the decision.

61. A significant difference between the Bill and the legislation in all other jurisdictions except Western Australia[43] is the absence in the Bill of additional provisions clarifying the circumstances in which there will be decision making capacity. In particular, every other jurisdiction includes a provision to the effect that 'if a person does not have decision making capacity to make a particular decision, it may be temporary and not permanent'.[44]

62. In general, these additional provisions provide that, in determining whether or not a person has decision making capacity, regard must be had to the following:[45]

    a. a person may have decision making capacity to make some decisions and not others;
    b. if a person does not have decision making capacity to make a particular decision, it may be temporary and not permanent;[46]
    c. it should not be assumed that a person does not have decision making capacity to make a decision:
        i. on the basis of the person's appearance; or

[37] Tasmanian Act, s 12, Victorian Act, s 4, SA Act, s 4, WA Act, s 6, Queensland Act, s 11.
[38] Victorian Act, s 4(1).
[39] SA Act, s 4(1).
[40] Tasmanian Act, s 12(1).
[41] WA Act, s 6(2).
[42] Queensland Act, s 11(1).
[43] The WA Act does not include an equivalent provision but it does not include a requirement that the requisite information needs to be remembered or retained.
[44] Victorian Act, s 4(4), SA Act s 4(4), Tasmanian Act s 12(3) and Queensland Act s 11(3) each provide that 'capacity can change or fluctuate and a person may temporarily lose capacity and later regain it'.
[45] Victorian Act, s 4(4) and SA Act, s 4(4). The Tasmanian Act, s 12(3), and the Queensland Act, s 11(3), are in slightly different terms.
[46] The Queensland Act provides 'capacity can change or fluctuate and a person may temporarily lose capacity and later regain it': s 11(3).

ii. because the person makes a decision that is, in the opinion of others, unwise;

d. a person has decision making capacity to make a decision if it is possible for the person to make a decision with practicable and appropriate support.

63. Although the Bill does not include these additional provisions clarifying the circumstances in which there will be decision making capacity, they are consistent with the New South Wales Attorney General's online publication entitled 'Capacity Toolkit' which is described as being 'Information for government and community workers, professionals, families and carers in New South Wales' (**NSW Capacity Toolkit**).[47]

64. This is relevant, for example, to the *Guardianship Act* 1987 (NSW) where a 'person in need of a guardian' is defined to mean a person who, because of a disability, is totally or partially incapable of managing his or her person (s 3(1)).

65. In relation to assessment of capacity, the NSW Capacity Toolkit states:[48]

> *If the person is unable to make a decision about something now, think about whether the decision may be delayed to a later time when the person may be able to make the decision for themself. Delaying the decision will give them the greatest control over their own life.*

66. The NSW Capacity Toolkit provides checklists in relation to a number of areas that focus on the capacity of the person being assessed to understand at the time of the decision 'not hours or days before or after'. For example, the Capacity Toolkit includes in its checklists the following questions:

a. Does the person understand the nature and effect of the enduring guardianship document they are making **at the time it is made**, not hours or days before or after it is made? (p. 77)

b. Does the person understand the nature and effect of the advance care directive **at the time it is being made**, not hours or days before or after it is made? (p. 96)

c. Does the person understand the nature and effect **at the time that the medical or dental decision is required**, not hours or days before or after it is made? (p. 103)

d. 'Does the person understand the contract **when they are signing it**, not hours or days before or after the contract is made?' (p.112)

e. Does the person understand the nature and effect of the power of attorney document they are signing **at the time it is being made**, not hours or days before or after? (p. 130)

[47] https://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf; pp. 1, 27, 33-44, 61-62.
[48] Capacity Toolkit, p32, see also p23. https://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf.

f. Does the person understand the nature and effect of the will **at the time the will is being made**, not hours or days before or after? (p. 138)

67. It is unclear whether a person seeking access to voluntary assisted dying is required by the Bill to maintain uninterrupted 'decision making capacity' for the entire duration of the assessment process, which commences at the time of the first request for voluntary assisted dying and is completed after the final review (cl 8). In particular, it is unclear whether the prerequisite for capacity that the person must 'remember the information or advice … to the extent necessary to make a voluntary assisted dying decision'[49] is intended to be construed as meaning that the memory must endure for the entire voluntary assisted dying assessment process without lapses.

68. Alternatively, the Bill could be interpreted to mean that decision making capacity, including the ability to remember requisite information under cl.6(1)(b), is only required:

a. at the points in time when each voluntary assisted dying decision is made by the person seeking access to voluntary assisted dying; and,
b. at points in time when decision making capacity is expressly required to be considered by medical practitioners and others under the Bill.

69. The structure of the Bill itself provides some support for this construction. For example, the requirement in cl 6(1)(b) that the person remember the information or advice is expressly limited to 'the extent necessary to make a voluntary assisted dying decision'.

70. Each of the following is a 'voluntary assisted dying decision' for the purposes of the definition in cl 6(3):

a. the first request for voluntary assisted dying (cl 19);
b. the written declaration requesting access to voluntary assisted dying (cl 43);
c. the final request for voluntary assisted dying (cl 48);
d. the administrative decision to either self-administer or have the voluntary assisted dying substance administered to the person (cl 57(1)).

71. The Bill does not identify the ramifications of failure to satisfy the eligibility criteria in cl 16, including decision making capacity, between each voluntary assisted dying decision. However, the Bill does identify the ramifications for the assessment process of failure to satisfy the eligibility criteria at each step of the formal assessment process by medical practitioners. With some exceptions, if the health practitioner assesses the patient as ineligible for access to voluntary assisted dying under the eligibility criteria in cl 16 of the Bill, they must assess the person as ineligible for voluntary assisted dying. These provisions provide support for a construction that requires ongoing decision making capacity without lapses in memory.

[49] Bill, cl 6(1)(b).

72. The Association recommends that the Bill be clarified to make it plain whether:

    a. Decision-making capacity, and the ability to remember requisite information in particular, is required to continue unabated for the course of the voluntary assisted dying assessment process; or

    b. Decision-making capacity, and the ability to remember requisite information in particular, is only required at the particular points in time when that is formally assessed by medical practitioners and intermittent lack of capacity between those times will not affect access to voluntary assisted dying if all requirements of the Bill are ultimately satisfied.

73. If it be intended that that the person applying for VAD under the Bill only be required to have capacity at particular points in time when the Bill expressly provides that there must be capacity, the Association recommends that the wording used in the other jurisdictions[50] be adopted which includes (amongst other things) a provision to the effect that 'if a person does not have decision making capacity to make a particular decision, it may be temporary and not permanent'.[51]

Exclusions from eligibility (cl 16(2))

74. A person is not eligible for access to voluntary assisted dying merely because the person has (cl 16(2)):

    a. a disability, or
    b. a mental health impairment within the meaning of the *Mental Health and Cognitive Impairment Forensic Provisions Act 2020* (NSW).

Decisions assessing persons as being ineligible (cll 25, 35, 29 and 40)

75. The Association acknowledges that cl 16(2) of the Bill expressly provides that a person is not eligible to access voluntary assisted dying merely because of disability or relevant mental health impairment, but the Association submits that it would be appropriate to reinforce this exclusion in provisions which use or apply the eligibility criteria in cl 16(1).

    a. The assessment provisions in cll 25 and 36, and the outcome provisions in cll 29 and 40, each require that a positive decision be made in relation to each of the eligibility criteria in cl 16(1).

    b. It would be appropriate that these provisions also require a negative decision to be made in respect of each of the exclusions in cl 16(2). This could be achieved by:

    c. amending cl 25(2) as follows:

[50] Except Western Australia, but note that there is no express requirement that there be capacity to remember in Western Australia.
[51] Vic Act, s 4(4), SA Act s 4(4), Tas Act s 12(3). The Qld Act provides "capacity can change or fluctuate and a person may temporarily lose capacity and later regain it" (Qld Act, s 11(3)).

For the purposes of subsection (1), the coordinating practitioner must—

(a) make a decision in relation to each of the eligibility criteria, and
(b) make a decision whether the circumstances in section 16(2) apply or do not apply.

d. amending cl 29(1) as follows:

The coordinating practitioner must assess the patient as eligible for access to voluntary assisted dying if the coordinating practitioner is satisfied—

(a) the patient meets all of the eligibility criteria, ~~and~~
(b) section 16(2) is satisfied, and
(c) the patient understands the information required to be provided under section 28(1).

e. amending cl 36(2) as follows:

For the purposes of subsection (1), the consulting practitioner must—

(a) make a decision in relation to each of the eligibility criteria, ~~and~~
(b) make a decision whether the circumstances in section 16(2) apply or do not apply, and
(c) independently of the coordinating practitioner, form the practitioner's own opinions on the matters to be decided.

f. amending cl 40(1) as follows:

The consulting practitioner must assess the patient as eligible for access to voluntary assisted dying if the consulting practitioner is satisfied—

(a) the patient meets all of the eligibility criteria, ~~and~~
(b) section 16(2) is satisfied, and
(c) the patient understands the information required to be provided under section 39(1).

Reviewability of ineligibility

76. The Association suggests the exclusions in cl 16(2) ought to be available as bases for grounds of review by the Supreme Court. This can be achieved by adding, in each of cll 109(1)(a) and (b), a further sub-paragraph to the following effect:

(v) a decision whether the circumstances in cl 16(2) apply or do not apply or whether cl 16(2) is satisfied.

77. The Association recognises that whether the eligibility criteria are met is not provided as a basis for a ground of review in cl 109, and assumes that this is a deliberate legislative choice in circumstances where doctors are best placed to make such decisions. However, allowing for review on the basis of the cl 16(2) exclusions has the potential to provide an important protection for persons with disability.

78. If this suggestion is adopted, it would be necessary to also amend cl 113 by adding two new paragraphs as follows:

> *the circumstances in cl 16(2) apply,*
>
> *the circumstances in cl 16(2) do not apply.*

79. The Association suggests that these paragraphs be inserted after the present para (b), such that the order follows the order of the grounds in cl 109.

80. It would also be necessary to ensure that each of cll 114 and 115 refers back to the new paragraphs.

No obligation to continue (cll 20 and 54)

81. The Association notes the 'no obligation to continue' provisions in cll 20 and 54, in each of Divs 2 and 6 of Pt 3. In order to reinforce the importance of these provisions, there should be a further 'no obligation' provision in each of Divs 3, 4 and 5 of Pt 3, even if these provisions are stated as being to avoid doubt.

Offences (cl 125)

82. The Association notes that the provisions concerning pressure and duress will provide some protection for persons with disability, but protection could be reinforced by including any disability of a person induced to make a request for access, or to access, voluntary assisted dying as an aggravating factor as to sentence.

83. To reinforce the protection of persons with disability against pressure and duress, or generally under the legislation, the Association suggests a new clause following the present cl 125:

> In sentencing a person who has been convicted of one or more offence under one or more of sections 123, 124 or 125, the Court is to take into account, as an aggravating factor:
>
> (a) any disability of the person against whom the offence was committed, and
>
> (b) any mental health impairment (within the meaning of the *Mental Health and Cognitive Impairment Forensic Provisions Act 2020*) of the person against whom the offence was committed.

Review of Act (cl 190)

84. The Association suggests the following be included in cl 190 as principles which any review of the legislation must include, or considerations to which regard must be had in any review:

    a. the equal value of every human life;
    b. the availability of high quality care; and
       whether persons with disability have been over-represented in those accessing voluntary assisted dying during the period under review.

Conclusion

85. The Association hopes this submission assists the Committee in its important work in inquiring into the Bill.

Yours sincerely

Michael McHugh SC
President