Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
Stewardship
Respect

6 April 2023

Justice and Community Safety Directorate
GPO Box 158, Canberra ACT 2601

Submission to the ACT Government regarding voluntary assisted dying

Who we are

Calvary is a charitable Catholic not-for-profit organisation with over 18,000 staff and volunteers. We have a national network of 14 public and private hospitals, 72 residential care and retirement communities and 19 community care service centres. Calvary operates across seven states and territories within Australia. We provide aged and community care, acute and sub-acute health care; and specialist palliative care and comprehensive care for people in the final stage of life.

In the ACT, we operate:

- Calvary Public Hospital Bruce (including Clare Holland House)
- Calvary Bruce Private Hospital
- Calvary John James Hospital
- Calvary Haydon Retirement Community
- Home Care Service Centre – Bruce

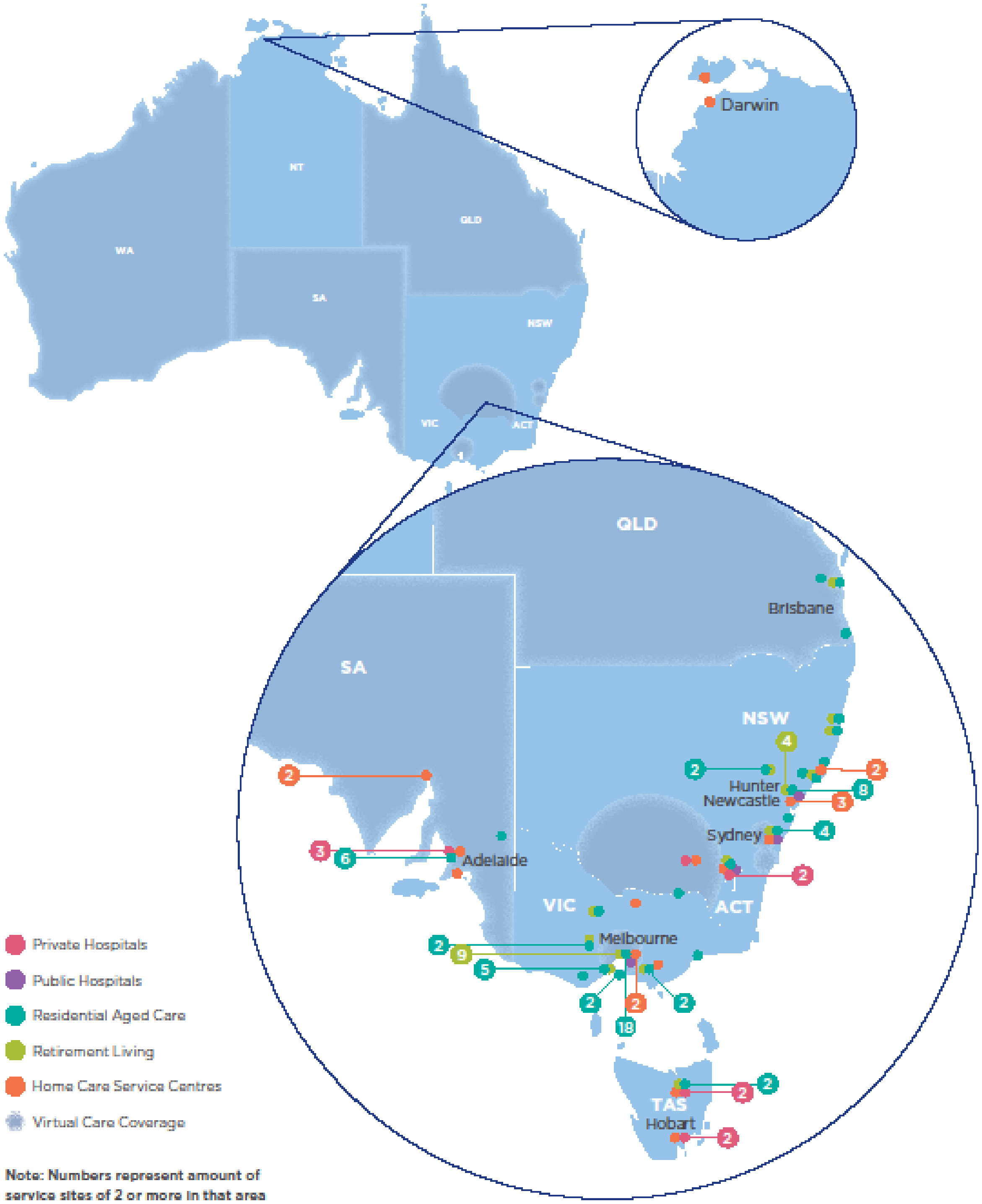
Founded on 4 November 1885 by the Sisters of the Little Company of Mary, our mission is to provide quality, compassionate health care to the most vulnerable, including those reaching the end of their life.

Full details of the extent of our footprint and the services we operate are set out in the graphic on the following page.

Calvary's role in the ACT community

Calvary is the largest provider of palliative care services in the ACT. We operate inpatient hospice services at Clare Holland House, which is the only specialist palliative care inpatient facility in the region, and services in the ACT and NSW catchment area. We also operate specialist outpatient, motor neurone multidisciplinary outpatient clinics for the ACT. Our services provide home-based palliative care both in homes and in all residential aged care facilities in the ACT. We support Calvary Public Hospital Bruce with a palliative care consultancy service and we have an onsite research team who lead end of life and palliative care research. This group has achieved outcomes that have led to a model of care change in palliative care nationally.

Where We Provide Care



Note: Numbers represent amount of service sites of 2 or more in that area

Calvary's approach and concerns

Calvary has a long and proud tradition of providing quality, compassionate health care to the most vulnerable in our community. Our mission focuses on healing and accompanying the dying. We seek to make people feel welcome, heard and cared for, whatever their experience and situation.

For this reason, Calvary has a well-known and well-documented history of opposing voluntary assisted dying. In jurisdictions where voluntary assisted dying is legal, we do not abandon patients, residents, clients or their families because they express a wish to explore voluntary assisted dying. We treat everyone with compassion and respect. While voluntary assisted dying is beyond our scope, we remain focused on providing all the care that falls within our scope to the fullest extent possible, namely high quality palliative care. This includes:

- relieving pain and other physical and psycho-social symptoms of illness and frailty; and
- withdrawal of life-prolonging treatments when they are futile or overly burdensome, or when a person wants them withdrawn and gives informed refusal of these treatments.

Calvary's focus is providing holistic, supportive care to people approaching their end of life, and support for their families and loved ones, so they can live the fullest lives possible.

Of particular concern to Calvary in this discussion of a voluntary assisted dying model for the ACT is the removal of safeguards that have been, until this point, included in all Australian voluntary assisted dying models. Voluntary assisted dying cannot be safely legislated for the relatively small number of people who die each year who may choose the option of voluntary assisted dying without unintentionally, but foreseeably, causing risk to the many other vulnerable people who may not wish to access this option, but may feel duty bound, forced or pressured to choose this option in order to alleviate the burden on others and themselves. They may be afraid that dying will be costly, lonely and frightening because of a lack of social, emotional or financial support.

Discussion of voluntary assisted dying tends to focus on the first word "voluntary" highlighting individual freedom and choice, and even by necessity the last word "dying" but the overlooked middle word "assisted" demonstrates that a request for voluntary assisted dying always requires the involvement of other people. It directly involves family and friends, health professionals, and health service providers. It indirectly impacts broader society and particularly the most vulnerable and marginalised therein. Respect for personal autonomy is important, but it must be weighed against the impact on other people. Just as dying is a normal part of being human, so too is being interdependent on other people. To be human is to be intrinsically relational with the community around us. It is not possible to legalise voluntary assisted dying without impacting the many people who do not want to access it and this impact must be taken into account.

If the Government is insistent on pursuing a voluntary assisted dying model for the ACT, it must also commit to long-term investment in palliative care, including research, support and infrastructure. This investment must have longevity. It cannot be allowed to dissipate once voluntary assisted dying legislation has been passed and the issue fades into the background. If the ACT Government truly believes that voluntary assisted dying is a choice, then it must honour this by ensuring that high quality palliative care is available to all.

For these and other reasons discussed in Calvary's response, Calvary calls for an Assembly level inquiry. We request the Assembly to insist on a public inquiry phase. Whilst the Government currently states that the legislation has yet to be drafted, it is unclear from the discussion paper exactly what provisions the legislation might include. It is especially important that feedback is able to be offered in relation to actual proposed legislation (a Bill) rather than a series of proposals flagged in consultation papers which may or may not be debated in the legislative chamber.

Vulnerability of older and elderly Australians

This consultation process for the development of a voluntary assisted dying bill in the ACT comes in the environmental context of the Covid-19 pandemic's fourth year and two years after the Royal Commission into Aged Care Quality and Safety's final report was tabled in federal parliament. According to the Honourable Anika Wells MP, Federal Minister for Aged Care, the work of the last two years has been "just the start" of addressing the aged care crisis and putting "people back in the centre of aged care."[1] The many instances of neglect and abuse of vulnerable people, which are detailed in the final report, are of great concern to Calvary in the discussion of voluntary assisted dying. The Royal Commission into Aged Care Quality and Safety found that the prevalence of elder abuse in Australian residential care is at least 39%, not including financial, social or sexual abuse.[2] The report states that this abuse is mainly committed by family members. Given that the age of people who apply for access to voluntary assisted dying in other states is predominantly older, the concerns of the final report must be considered in this discussion.[3]

Our response to the issues raised in the Discussion Paper

The Voluntary Assisted Dying in the ACT Discussion Paper issued by the Justice & Community Safety Directorate in conjunction with ACT Health Directorate and Canberra Health Services in February 2023 raises a number of key questions the ACT Government is considering in the development of a voluntary assisted dying model for the ACT.

We have identified a number of concerns within the discussion paper and the questions it poses.

What is voluntary assisted dying?

The discussion paper does not provide a definition of voluntary assisted dying, noting that each Australian state has its own legal definition, but the discussion paper refers to voluntary assisted dying as "a safe and effective medical process that gives an eligible person the option to end their suffering by choosing how and when they die."[4]

In the Victorian and South Australian legislation, voluntary assisted dying is defined as "the administration of a voluntary assisted dying substance and includes steps reasonably related to such administration."[5] The New South Wales legal definition is almost identical, describing voluntary assisted dying as "the administration of a voluntary assisted dying substance and includes steps reasonably related to the administration."[6] And again, in Queensland, it is almost the same wording, i.e. "the administration of a voluntary assisted dying substance and

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[1] The Honourable Anika Wells, "Minister for Aged Care - Op-Ed: Minister Wells' op-ed reflecting on the final report of the Royal Commission into Aged Care Quality and Safety," accessed 6 April 2023, https://www.health.gov.au/ministers/the-hon-anika-wells-mp/media/minister-for-aged-care-op-ed.

[2] Royal Commission into Aged Care Quality and Safety, "Elder Abuse in Australian Aged Care Facilities," accessed 6 April 2023, https://agedcare.royalcommission.gov.au/news-and-media/elder-abuse-australian-aged-care-facilities.

[3] In Victoria, which has had voluntary assisted dying laws in operation since 2019, the Voluntary Assisted Dying Report of Operations (July 2021 to June 2022) listed the median age of applicants for voluntary assisted dying as seventy-three (73) years and noted that half of all applicants were aged between sixty-five and eighty-one (65-81) years. Safer Care Victoria, "Voluntary Assisted Dying report of operations (July 2021 to June 2022)," accessed 27 March 2023, https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-2021-to-june-2022.

[4] Voluntary Assisted Dying Discussion Paper, issued by: Justice & Community Safety Directorate in Conjunction with ACT Health Directorate and Canberra Health Services (hereafter referenced as "Discussion paper"), https://hdp-au-prod-app-act-yoursay-files.s3.ap-southeast-2.amazonaws.com/8416/7567/8207/Voluntary_assisted_dying_Discussion_Paper_PDF_version.pdf, 4.

[5] *Voluntary Assisted Dying Act 2017* (Vic) s 3(1) and *Voluntary Assisted Dying Act 2021* (SA) s 3.

[6] *Voluntary Assisted Dying Act 2021* (NSW) s 5.

includes steps reasonably related to that administration."[7] In the Tasmanian legislation, voluntary assisted dying is defined as "the administration to a person, or the self-administration by a person, of a VAD substance under this Act."[8]

The use of the word "safe," in this context, requires some clarification. Ordinarily, safe means "not exposed to danger" or "not liable to be harmed."[9] In safety and quality literature, safe is defined as "the avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered."[10] Voluntary assisted dying involves a process by which a lethal substance is introduced into a person's body with the intention of causing death. The description of voluntary assisted dying as safe may seem intuitive to proponents of the legislation, but for others it may be less clear. We need to ask what "safe" means here. Is "safe" supposed to indicate that the voluntary assisted dying substance is painless and works effectively? Or is the word a comforting equivocation that covers the stark reality of what the substance is designed to do? Transparency regarding the effects of any drug or medical treatment is central to patient-centred care.

Eligibility Criteria (Questions 1-7)

Question 1 – What should the eligibility criteria be for a person to access voluntary assisted dying?

It is with concern that we note that the ACT Government is discussing broadening the eligibility criteria from that of the voluntary assisted dying models used in other Australian jurisdictions. In stating the purpose of this consultation, the discussion paper notes that voluntary assisted dying legislation in all Australian states is "subject to robust oversight and safeguarding frameworks."[11] We are concerned that the ACT Government is considering narrowing this oversight and removing some of these safeguards. The legislation in the Australian states has been broadly consistent on the criteria determining eligibility with some exceptions. It therefore seems that any deviation from these general norms requires demonstration of careful thought and consideration.

From a human rights perspective, safeguards play an important role in addressing power and vulnerability. Good legislation protects people and their rights, even when these people are not able to advocate for themselves. In its guide to the right to life, the ACT Human Rights Commission notes that the right to life "should not be interpreted narrowly."[12] It understands issues such as homelessness and life expectancy to fall within its scope. Therefore, safeguards to ensure that no one who does not genuinely want voluntary assisted dying is persuaded into it by undue influence also falls under this right. Other people may feel that they have right to death, but rights have never been unfettered. They must always be weighed against the good of the most vulnerable people, including those who cannot advocate for themselves.

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[7] *Voluntary Assisted Dying Act 2021* (Qld) s 6.

[8] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 5.

[9] Definition from the Oxford English Dictionary.

[10] Australian Institute of Health and Welfare, "Health care safety and quality," accessed 6 April 2023, https://www.aihw.gov.au/reports/health-care-quality-performance/health-care-safety-and-quality.

[11] Discussion paper, 5.

[12] ACT Human Rights Commission, "Factsheet: The Right to Life," accessed 4 April 2023, https://hrc.act.gov.au/wp-content/uploads/2015/03/Right-to-life-281011.pdf, 3.

Question 2 – What kind of suffering should a person be experiencing or anticipating in order to be eligible to access voluntary assisted dying?

People at the end of life can experience significant psychological, physical, spiritual and existential suffering. Suffering affects the whole person and the person's sense of self and their sense of dignity.

The implicit suggestion that the ACT adopt a model like that of Tasmania, in which a person's suffering can be "expected, anticipated or actual" is concerning, both in itself and in the context of removing other safeguards.[13] The inclusion of suffering that a person is not yet experiencing but anticipates experiencing in the future is concerning because dying is so poorly understood and fear of physical pain. Being a burden on family, loss of autonomy and dignity are all prominent fears at the end of life. These experiences are often manageable through high quality palliative care, but people often find it difficult to talk about or seek help with these experiences and their fears.

If a person ends their life prematurely, this is a loss to all. No person is an island. We are all dependent on each other and our communities. The state has a role to promote values which enrich the lives of each person and the community as a whole and to mitigate any forms of suffering which diminish a person. This suffering must be addressed first. This principle can be seen in operation elsewhere in government. For instance, the reconciliation movement within Australia which promotes healing the relationship with our First Nations peoples is an example of state championed values that enrich the lives of each person and the community as a whole.

Question 3 – Should a person be expected to have a specified amount of time left to live in order to be eligible to access voluntary assisted dying? If so, what timeframe should this be? Should there be a different timeframe for different conditions, for example for neurodegenerative disorders? If there is no timeframe required, what should a prognosis be instead?

In all Australian states, a medical practitioner must expect the person to die within six (6) months, or, in the case of neurodegenerative disorders, twelve (12) months. The exception to this is Queensland where a medical practitioner must expect the person to die within twelve (12) months for neurodegenerative and non-neurodegenerative conditions alike.

There is some suggestion in the discussion paper that this requirement is overly burdensome, stating that "some view these timeframes as bureaucratic and unduly restrictive."[14] Moreover, it states that "a narrow time period may deny relief to some people who are suffering intolerably, but whose condition is not expected to cause death within the prescribed period.[15]

However, broadening or completely removing the timeframe for expected death will further place vulnerable and fearful people at risk. The discussion paper says that "research suggests that it is unlikely that more people would be *eligible* for voluntary assisted dying under such a model, but that they would become eligible *earlier* in their disease progression" (emphasis added).[16] It does not comment on whether this will increase the number of people who *complete* the process by taking the voluntary assisted dying substance. In the absence of data on this and in

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[13] Discussion paper, 9.
[14] Discussion paper, 9.
[15] Discussion paper, 9.
[16] Discussion paper, 10.

the context of our society's poor understanding of death and dying, this is a valid concern. If a person is anticipating suffering, there is a risk that their own judgement of what will happen may be flawed, because they are fearful of the unknown. As a society, it would be a failure on our part to allow a person to end their own life because they are experiencing the anxiety and uncertainty about a disease that will cause their death. In such a scenario, a person might be "exercising their autonomy," but they would be acting out of fear and vulnerability. Again, it is important to note that autonomy is not an absolute value and it does not outweigh other values, such as protecting vulnerable people, even when the vulnerability arises from their own fear of illness, pain and death.

Question 4 – How should a person's decision-making capacity be defined or determined in relation to voluntary assisted dying?

If the ACT Government is considering broadening the eligibility criteria, as the discussion paper suggests, ensuring that a person applying for access to voluntary assisted dying has decision making capacity becomes even more important. Removal of the timeframe from expected death, the citizenship and residency requirements and the restriction of access to adults would all make the evaluation of decision-making capacity even more critical.

The discussion paper indicates that decision-making capacity in relation to voluntary assisted dying will be presumed, unless it can be demonstrated that the person does not have capacity. More broadly, a person is considered to have medical decision-making capacity if they can comprehend and retain the information necessary to make the decision and use this information as part of their decision-making process.

In the Australian states, decision-making capacity in relation to voluntary assisted dying is presumed, unless there is evidence to the contrary. In Victoria, to have decision-making capacity in relation to voluntary assisted dying a person must be able to understand information relevant to the decision and the effect of the decision. They must also be able to retain this information as necessary to make the decision. Moreover, they must be able to use this information as part of the decision-making process and they must be able to communicate the decision in some way, whether by speech, gesture or other means.[17] The other states are broadly the same, although in Queensland a person must also be capable of "freely and voluntarily making decisions about access to voluntary assisted dying"[18]

In the Australian states, if the coordinating or consulting practitioner is unable to determine whether a person has decision-making capacity in relation to voluntary assisted dying, the coordinating or consulting practitioner must refer the person to a psychiatrist or another registered health practitioner with the necessary skills and training to make a decision on this matter. However, they are not bound to adopt the decision of the psychiatrist or other registered health practitioner who made the decision.

These question regarding decision-making capacity also have some bearing on the next question regarding access to voluntary assisted dying for minors.

Question 5 – Should voluntary assisted dying be restricted to people above a certain age (for example, people 18 and over)?

All Australian states with voluntary assisted dying legislation require a person to be aged 18 or older to be eligible.

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[17] *Voluntary Assisted Dying Act 2017* (Vic) s 4(1).
[18] *Voluntary Assisted Dying Act 2021* (Qld) s 11(1)(b).

It is important to note that lowering this age requirement removes a safeguard embedded in all Australian voluntary assisted dying models up until this point. This is particularly concerning within the context of the discussion about removing other safeguards, such as ‘cooling off’ periods, timeframe from expected death and residency requirements.

How decision-making is defined will also be relevant. The section preceding this in the discussion paper, on decision-making capacity, suggests that decision-making capacity ought to be presumed and not determined by a health professional. However, this section on the minimum age states: “If a registered medical practitioner considers that a young person has the maturity and capacity to make their own decisions about voluntary assisted dying, denying them this choice may result in increased suffering and unfair outcomes.”[19] This raises questions about how decision making capacity is to be assessed in minors if it is presumed in adults.

Another issue to be considered is mental illness in young people. Whilst the model being discussed does not propose that mental illness be a condition that makes a person eligible, there needs to be protects for vulnerable young people who are suffering from mental illness.

There are also concerns as to how the removal of this safeguard interacts with the removal of other safeguards. For instance, if the timeframe from death is removed, then death may not be necessarily imminent. This is especially true if a person need not have exhausted all treatment options.

The discussion paper also does not address the issue of parental consent.

Question 6 – Should a person be an Australian citizen or long-term resident of Australia to access voluntary assisted dying in the ACT?

A person ought to be an Australian citizen or long-term resident of Australia to access voluntary assisted dying in the ACT. The discussion paper notes that “there may not be a need to require residency requirements [sic] for the ACT” because all the Australian states have voluntary assisted dying. Whilst it is true that all Australian jurisdictions, except for the ACT and the Northern Territory, now have voluntary assisted dying legislation, removing the requirement for a person to be an Australian citizen or a long-term resident of Australia to access voluntary assisted dying may result in ‘voluntary assisted dying tourism.’ In other words, people may travel to the ACT from other countries which either do not have voluntary assisted dying legislation or have legislation with narrower eligibility criteria in order to make use of the ACT model. Given that the ACT has a small healthcare sector, this raises serious questions about how these services would be provided and who would pay for the provision of these services.

Question 7 – Given every Australian state now has voluntary assisted dying laws, is there any need for voluntary assisted dying in the ACT to be restricted to people who live in or have a close connection to the ACT?

As above, if the ACT Government adopts a voluntary assisted dying model that is inconsistent with the models in other Australian jurisdictions, this may give rise to ‘voluntary assisted dying tourism’ and additional pressure on the ACT’s small healthcare sector. The question of how such a service would be funded also needs to be addressed.

This is particularly complex given that residents of nearby New South Wales regions rely on health care provided by the ACT health services. In order to accommodate these border communities, it would be most fitting to adopt

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[19] Discussion paper, 11.

eligibility criteria consistent with the eligibility criteria of the New South Wales legislation and allow people living in border communities access to voluntary assisted dying in the ACT, without incentivising the ACT model over the New South Wales model.

What should be the process for requests and assessments? (Questions 8-16)

Question 8 – What process should be in place in the ACT to ensure that an eligible person's access to voluntary assisted dying is safe and effective?

As has been stated previously in this submission, voluntary assisted dying cannot be safely legalised for the comparatively small number of people who wish to access it, without being unsafe for the most vulnerable and marginalised members of society who do not wish to access voluntary assisted dying, but may feel compelled to do so in order to ease the burden of dying for their loved ones and themselves.

The effect of the inherently unsafe nature of voluntary assisted dying may also be compounded by the removal of safeguard that have previously been a part of every Australian voluntary assisted dying model. The ACT Government ought to consider very carefully before removing any of these safeguards, particularly when this would mean that the ACT model differed significantly from the New South Wales model, which is currently being implemented. Given the geographical situation and the fact that many people in parts of New South Wales rely on ACT health services, a broadening of eligibility criteria, for instance, could be problematic.

Question 9 – If a coordinating health professional or consulting health professional declines to be involved in a person's request for voluntary assisted dying, should they be required to take any particular action?

This question is somewhat ambiguous, because in other Australian jurisdictions where voluntary assisted dying is legal a medical practitioner only becomes the coordinating practitioner (coordinating health professional as it is referred to here) when they accept a person's first request for voluntary assisted dying. In like manner, a medical practitioner only becomes the consulting practitioner (consulting health professional) when they accept a referral from the coordinating practitioner. If a medical practitioner declines a first request or a referral, then they do not assume the role. In the event that a coordinating or consulting practitioner wishes or needs to revoke their role, the legislation in each state allows for the role to be transferred to another practitioner.

Therefore, it would seem that the question that is actually being asked here is "If a health professional declines to act as a coordinating health professional or a consulting health professional in a person's request for voluntary assisted dying, should they be required to take any particular action?"

In the Australian states, the voluntary assisted dying navigator service or equivalent is the mechanism set up to assisted people to access voluntary assisted dying. In the event that a health professional declines to act as coordinating health professional, either because they are not qualified to do so or because they have a conscientious objection, the voluntary assisted dying navigator service is there to assist the person to find a health professional with the requisite voluntary assisted dying training. The health professional may need to inform the person that the voluntary assisted dying navigator service exists for this purpose, but then it should be left to the voluntary assisted dying navigator service to do their job. As they have a complete list of voluntary assisted dying trained health professionals, they are best placed to do this.

Question 10 – Should witnesses be required for a person's formal requests for voluntary assisted dying? If so, who should be permitted to be a witness?

It is important to be clear about the issues being raised here. This section of the discussion paper states that "[t]here are questions about whether there are aspects of the voluntary assisted dying request and assessment process that present undue barriers to access voluntary assisted dying, rather than as effective safeguards. For example, the ACT could choose to offer alternative options for people who are unable to write or sign documents and use translators for different languages as required or consider other communication such as use of gestures or disability aids."[20]

However, such provisions can already be found in the voluntary assisted dying legislation of the Australian states and these provisions do not in any way necessitate the removal of the requirement for a person's formal requests for voluntary assisted dying to be witnessed.

For instance, in New South Wales, another person may sign the declaration on the person's behalf, provided the person is unable to sign the document themselves and they have instructed the other person to do so. A written declaration can be made through the use of an interpreter.[21] A first request, final request and administration decision can be made verbally or by other means of communication such as gesture.[22]

The question of witnesses and the question of alternative communication options for people who are unable to write or sign documents are two separate questions. Legislation in other states demonstrates that the use of translators and non-verbal communication methods are consistent with the requirement for witnesses to a formal request.

Moreover, the requirement that a formal request be witnessed is also consistent with most legal processes which involve major decisions and may be subject to undue influence. For instance, for a will to be legal in Australia, it needs to be witnessed by two independent witnesses who are not beneficiaries of the will. This is an important safeguard and one that cannot be dismissed lightly given that voluntary assisted dying is a major life and death decision, on which undue pressure may come to bear.

Question 11 – Should the process for seeking access to voluntary assisted dying require that a person take time to reflect (a 'cooling off' period) before accessing voluntary assisted dying?

Perhaps a better question to ask here is "Are there reasons why the ACT model should not include a 'cooling off' period, as all other Australian states require?" It is worthwhile examining the existing models in the states to understand how the 'cooling off' period works.

In Victoria, South Australia and Queensland, a final request for voluntary assisted dying can only be made at least nine (9) days after the day on which the person made the first request and one (1) day after the day on which the consulting assessment found the person to be eligible for access to voluntary assisted dying.[23] However, in all three (3) states, this is not a requirement if the coordinating medical practitioner considers that the person's death is likely to occur or the person is likely to lose decision-making capacity (Queensland only) before the expiry of the time period and that this judgement is consistent with the prognosis of the consulting medical practitioner set out in the consulting assessment report form.[24]

Similarly, in New South Wales, the final request must be made no earlier than five (5) days after the day on which

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[20] Discussion paper, 17.

[21] *Voluntary Assisted Dying Act 2021* (NSW) s 43(4).

[22] *Voluntary Assisted Dying Act 2021* (NSW) s 19(3), s 48(3), s 57(3).

[23] *Voluntary Assisted Dying Act 2017* (Vic) s 38(1); *Voluntary Assisted Dying Act 2021* (SA) s 56(1); *Voluntary Assisted Dying Act 2021* (Qld) s 43(1).

[24] *Voluntary Assisted Dying Act 2017* (Vic) s 38(2); *Voluntary Assisted Dying Act 2021* (SA) s 56(2); *Voluntary Assisted Dying Act 2021* (Qld) s 43(2).

the first request was made and not until the day after the day on which the consulting assessment was completed.[25] However, this requirement can be waived if the coordinating practitioner reasonably believes that the person is likely to die or lose decision-making capacity in relation to voluntary assisted dying, before the end of the designated period. This opinion must be consistent with the opinion of the patient consulting practitioner.[26]

In Tasmania, a person must not make a second request until forty-eight (48) hours after having made the first request, unless in in the opinion of the primary medical practitioner (coordinating practitioner) the person is likely to die within 7 days or the person is likely to lose decision-making capacity within forty-eight (48) hours.[27] Similarly, a final request until forty-eight (48) hours after the person made the second request, unless the primary medical practitioner (coordinating practitioner) believes that the person is likely to die within seven (7) days or the person is likely to lose decision-making capacity within forty-eight (48) hours.[28]

The discussion paper raises concerns that a ‘cooling off’ period is “adding stress to an already stressful time” by requiring people to wait for access to voluntary assisted dying when “they may already be in the final days of their life.”[29] However, as illustrated above, the voluntary assisted dying legislation of the Australian states already provides for situations in which a person is likely to die or in some cases lose decision-making capacity before completing the ‘cooling off’ period.

Moreover, ‘cooling off’ periods serve an important function. The alleviation of pain and other physical and psycho-social symptoms of illness are a core part of palliative care, but this can be complex and it can take time, sometimes days, to achieve. Many of the factors that influence a person’s desire for death can be treated, but it is a process that takes time.

Dying is mostly living and even when a person is dying life continues to unfold. People may have experiences that prompt them to reassess their goals. In a process driven approach to voluntary assisted dying, there is a risk that the completion of the voluntary assisted dying process, which has its own rhythm and milestones, may become an end in itself rather than just a means. The end is always a choice which should be surrounded with freedom. Freedom requires time and space away from pressure and points of influence, essentially a different context in which to look at a decision. In consumer law – and this is a consumer driven approach – cooling off periods are critical points of protection which create spaces for uninfluenced reassessment.

Question 12 – Should a person have a choice between self-administration and administration by an administering health professional or a voluntary assisted dying substance?

The discussion paper notes:

“Some have argued that to truly exercise self-determination around voluntary assisted dying, a person should have a choice about the method of administration.”[30]

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[25] *Voluntary Assisted Dying Act 2021* (NSW) s 49(1).

[26] *Voluntary Assisted Dying Act 2021* (NSW) s 49(2).

[27] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 30(2).

[28] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) s 53(2).

[29] Discussion paper, 18.

[30] Discussion paper, 19.

However, agency is important here. A measure of direct responsibility over the act itself is desirable. Therefore, self-administration should be the default option. If a person is unable to administer the voluntary assisted dying substance themselves, then it may be administered by a health professional. However, once the health professional has established an intravenous line, it should be for the person to push the button that releases the substance into the line. The stated goal of voluntary assisted dying is to enable a person to end their suffering by dying. The person exercising their autonomy in this manner ought to remain the active agent at all times. This is not the case when a health professional administers the substance, rather than merely making the administration possible. When this happens, the healthcare professional becomes the agent of the action, which is to introduce a lethal substance into the person's body. In that moment, if the person says no in thought or deed, the meaning of the action has changed.

Administration by a health professional also raises the question of moral distress, which occurs when a health professional knows the morally correct action to take, but feels powerless to take that action. A health professional may not want to administer the voluntary assisted dying substance, but may feel powerless to say no in the face of a person's request. It would be imprudent to unnecessarily put any clinician in this situation. The discussion paper does not address the additional pressures this might place on a small healthcare sector, although this concern is noted elsewhere in the document.

Question 13 – Should one method of administration be prescribed as the default option, or should methods differ depending on the circumstances? Does this need to be prescribed in legislation, or is it a matter best determined between the registered medical practitioner and patient?
The default method of administration ought to be patient administration. If the patient is unable to self-administer the voluntary assisted dying substance, then it ought to be administered by a health professional, but with the provisions below in Question 14.

Question 14 – Are additional safeguards required when an eligible health professional administers the voluntary assisted dying substance (as compared with self-administration) and, if so, what safeguards would be appropriate?
When the voluntary assisted dying substance is administered by a health professional, there needs to be additional safeguards to ensure the person is acting freely and without coercion. For instance, it is common to administer the substance intravenously. In this case, a practitioner ought to set up the intravenous line, but the patient should be the one to press the button that releases the substance into the line. This enables the patient to have agency in the act itself and also provides somewhat of a safety mechanism, i.e. if the person shows reluctance to begin the patient-controlled intravenous line, a 'cooling off' period may be necessary.

Question 15 – Should administration of the voluntary assisted dying substance to an eligible person be witnessed by another person? If so, who should be permitted to be a witness?
If a person is having the voluntary assisted dying substance administered by a practitioner, a witness to the administration process should be required. For example, in New South Wales, the witness ought to be at least 18 years of age, not be a family member of the administering practitioner and not be employed or engage under a contract for services by the administering practitioner. The witness ought to certify that the person appears to be acting voluntarily and without coercion and that the administering practitioner administered the voluntary assisted dying substance to the person in the presence of the witness.

Question 16 – What safeguards are necessary to determine whether or not a person has taken the voluntary assisted dying substance, and to return the voluntary assisted dying substance if it has not been taken?
There must be a clear system for returning any unused voluntary assisted dying substance to the pharmacy for the safety of all involved. The models in the Australian states all use a 'Contact Person' appointed by the person to return any unused voluntary assisted dying substance to the voluntary assisted dying pharmacy service.

The role of health professionals (Questions 17-24)

Question 17 – Who should be permitted to be a person's coordinating health professional or consulting health professional? For example, a registered medical practitioner, a nurse practitioner or someone else?

Currently, all Australian states require the coordinating practitioner or consulting practitioner to be a registered medical practitioner who has also fulfilled certain training requirements. This is the norm in Australia, but the ACT Government appears to be attempting to change this. In fact, the language in which this question is phrased, i.e. using the terms "coordinating health professional" and "consulting health professional," could be seen as an attempt to legitimise the broadening of this role to allow a nurse practitioner or even "someone else" to fulfil it. It is not clear to whom the discussion paper is referring when it says "someone else." Is it suggesting a registered nurse could fulfil this role? Or another health professional? Assessing a person's eligibility for voluntary assisted dying is a complex process. There is a reason this role is currently only held by medical practitioners, who have practiced for a certain period of time and completed certain professional qualifications, in addition to the voluntary assisted dying training.

The Coordinating practitioner is required to make complex and weighty professional judgements about the person's disease, illness or condition, prognosis, decision-making capacity and their ability to act freely and without coercion. The Western Australia Voluntary Assisted Dying Board Annual Report 2021-2022 found that nearly all (91.2%) persons who underwent a first assessment for voluntary assisted dying did not have a previous relationship with their Coordinating Practitioner.[31] This means that this professional judgements are being made without any prior knowledge of the person and their medical, psycho-social or personal history.

If the ACT Government expands the list of professions which are permitted to act as a coordinating or consulting health professional from medical practitioners to include nurse practitioners, it is important that people in these professions also have clearly protected rights to conscientious objection.

Question 18 – What minimum qualification and training requirements should there be for health professionals engaged in the voluntary assisted dying process?

In the Australian jurisdictions with voluntary assisted dying legislation, there are certain minimum qualification and training requirements for health professionals engaged in the voluntary assisted dying process.

As stated above in answer to Question 18, all the Australian states require the coordinating or consulting practitioner to be a registered medical practitioner. In some states, a nurse practitioner or a registered nurse may act as the administering practitioner. In others, this is also reserved to medical practitioners. To change the requirement that a coordinating or consulting practitioner be a registered medical practitioner, as the discussion paper suggests the ACT Government is considering, would be a major departure from the existing Australian voluntary assisted dying models and needs more substantial justification than the concern that the ACT's small healthcare sector may make it difficult to find a coordinating or consulting practitioner. The ACT Government would need to demonstrate that this would be safe and that other health professionals have the requisite skills and knowledge.

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[31] Voluntary Assisted Dying Board, "Annual Report 2021-2022," accessed 4 April 2023, https://www.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf, 11.

For example, in Victoria, the coordinating practitioner required to hold a fellowship with a specialist medical college or be a vocationally registered general practitioner. Also required to have practiced as a registered medical practitioner for at least five (5) years after completing their fellowship with a specialist medical college or vocation registration and have relevant expertise and experience in the disease, illness or condition which is expected to cause the death of the person being assessed.[32] Unless each consulting practitioner can fulfil the requirements of at least 5 years practice after completing a fellowship with a specialist medical college or vocational registration and have has relevant expertise and experience with the disease, illness or medical condition expected to cause the death of the person being assessed.[33]

Question 20 – Should registered health practitioners or other health professionals be free to initiate a discussion about voluntary assisted dying, providing information alongside other treatment and management options such as palliative care, where appropriate?

When a registered health practitioner initiates a discussion about voluntary assisted dying with a patient, it can unintentionally place the onus on the person to justify their own ongoing existence, at a time when they may already feel like a burden on their family, friends and the healthcare system. Because of this, voluntary assisted dying can never be brought up by a health care practitioner as just another neutral option to consider alongside palliative care options and treatment options.

The discussion paper says that the prohibition on registered health practitioners in Victoria and South Australia has "been identified as an unnecessarily strict safeguard[1] [sic, no footnote provided] and a barrier."[34] The paper notes that "such a restriction of information does not occur in any other area of medicine."[35] However, no other area of medicine intentionally and directly brings about the death of the patient. It is fitting that there are stricter safeguards on the discussion of voluntary assisted dying.

The paper identifies the prohibition as being a barrier to "[a]ccessibility for people with low levels of health literacy, or who feel unable to raise voluntary assisted dying for cultural, religious or personal reasons."[36] However, people with low levels of health literacy are particularly vulnerable to the misinterpretation of health information, poorer health outcomes and less engagement with the healthcare system overall.[37] People with poor health literacy often do not have the skills to understand and use the health information provided to them.[38] Lower levels of health literacy are also associated with decreased patient involvement in shared decision making, which is key to patient-centred care.[39] Given that there is also a strong association with some of the social determinants of health,[40] there is a risk that, if voluntary assisted dying information is provided without patient request, this may be interpreted as

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[32] *Voluntary Assisted Dying Act 2021* (Vic) s 10(1-3).

[33] *Voluntary Assisted Dying Act 2021* (Vic) s 10(2-3).

[34] Discussion paper, 24.

[35] Discussion paper, 24.

[36] Discussion paper, 24.

[37] Australian Institute of Health and Welfare, "Health Literacy," accessed 6 April 2023, https://www.aihw.gov.au/reports/australias-health/health-literacy.

[38] AIHW, "Health Literacy."

[39] AIHW, "Health Literacy."

[40] AIHW, "Health Literacy."

a negative evaluation or the person's life and an admission that palliative care cannot adequately provide symptom management.

In short, when a registered health practitioner initiates a discussion about voluntary assisted dying, the value of a person's life becomes dependent on their will to live. It creates a cultural risk of failure to see non-voluntary assisted dying options. The key point in end of life conversations is the person's life, because dying is mostly living, and this includes their thoughts and hopes about their death. If these conversations are narrowed to merely the means of bringing about death, the focus on a person's life is lost. This is not a good model of care. We have noted elsewhere that the voluntary assisted dying process is, in some ways, a consumer model, but health professionals do not sell other drugs to people and voluntary assisted dying should be no exception.

Question 21 – Should health professionals be required to provide certain information to a person who asks about voluntary assisted dying, in addition to providing information about other treatment and management options such as palliative care?
A health professional should not be required to provide certain information to a person who asks about voluntary assisted dying. In the Australian states, the voluntary assisted dying navigator service, or equivalent, exist for this reason, i.e. to facilitate access to voluntary assisted dying for those who want it and to link people with practitioners who are qualified and willing to provide access to voluntary assisted dying. This is not a responsibility that ought to be imposed upon health professionals.

Question 22 - What categories of persons or professionals should be permitted to conscientiously object to being involved in voluntary assisted dying? Should this be limited to registered health practitioners?
Anyone who might reasonably be involved must have a right to conscientious objection. This includes health care workers, who are not registered health professionals, but may otherwise be required to be involved in voluntary assisted dying in some way, such as aged care workers.

Question 23 – Should health professionals who conscientiously object or who choose to not participate in the voluntary assisted dying process be required to declare their objection or non-participation to a person who is or may be interested in accessing voluntary assisted dying?
If a health professional does not provide voluntary assisted dying services, they need to inform the person that they do not provide these services. However, this is sufficient. No individual health professional delivers all services and they are not expected to account for that. For instance, a neurosurgeon is not required to explain why they do not provide oncology services.

Question 24 – Should health professionals who conscientiously object or who choose to not participate in the voluntary assisted dying process be required to refer a person to other health professionals? Is there anything else that health professionals should be required to do if they conscientiously object, such as provide certain information about voluntary assisted dying?
No, to require a health professional to formally refer to another health professional is a violation of their conscientious objection. In the Australian states, information regarding access to voluntary assisted dying is publically available and there is a voluntary assisted dying navigator service, or equivalent, which assists people with accessing voluntary assisted dying.

The role of health services (Questions 25-26)

Question 25 – Should a health service be permitted to not facilitate voluntary assisted dying at its facilities, for example at a residential aged care facility, a hospital, or accommodation for people with a disability?
Health services should not be forced to facilitate voluntary assisted dying at their facilities. It is one thing to give people a legal choice and it is another to require health services to provide this services. No one health services provides all services.

This section of the discussion paper says that "[s]ome faith-based organisations may have a preference not to facilitate voluntary assisted dying."[41] It is worth noting that a conscientious objection, institutional or personal, arises from deeply held and consistent moral convictions. It should not be misunderstood as a mere matter of preference that is arbitrary or whimsical. For instance, the ACT Human Rights Commission, which supports the right to freedom of thought, conscience, religion and belief, notes that a conscientiously held belief is a belief that a person genuinely and cogently holds on a weighty and substantial aspect of human life and this belief is worthy of respect and not incompatible with human dignity or the fundamental rights of other people.[42]

Calvary services are not a random assemblies of doctors, nurses, allied health professionals and administrators. These individuals are drawn together by a common purpose and values – this purpose creates the distinct institutional identity, character, culture and purpose. Health services with an institutional conscientious objection to voluntary assisted dying often attract staff who share their ethos. If forced to provide or facilitate voluntary assisted dying, these health services may lose staff, who are confronted and deeply affected by the experience, at a time when workforce is difficult to obtain. This would also send the message that personal autonomy is only valued insofar as it aligns with the views of the state. Communities are the backbone of society and we are all strengthened when we nurture and support communities, including faith-based communities, where people can maintain a sense of personal coherence and integrity while making a contribution to the common good.

Question 26 – If a health service wishes to not facilitate voluntary assisted dying at its facilities, what is the minimum the provider should be required to do so that a person's access to voluntary assisted dying is not hindered?

Calvary operates services in four states which already have voluntary assisted dying in effect, Victoria, Tasmania, South Australia and Queensland. Our services and our staff do not obstruct or try to prevent people from accessing voluntary assisted dying services where this is legal. If a person requests information on voluntary assisted dying services, there is publically available information on where they can access these services. There is also, in each state, a voluntary assisted dying navigator services, or equivalent, which helps patients navigate the process. Our services can provide the contact details for the navigator services upon request.

Death certification and notification (Questions 27-28)

Question 28 – What should be recorded as the cause and manner of death for a person who has died by accessing voluntary assisted dying?

If a person has died by voluntary assisted dying, then voluntary assisted dying ought to be recorded as the cause and manner of death. This becomes particularly relevant when considering widening the eligibility criteria. If the timeframe from expected death is removed, then there will be people who die from voluntary assisted dying whose disease is not advanced and their death was not proximate.

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[41] Discussion paper, 28.

[42] ACT Human Rights Commission, "Right to Freedom of Thought, Conscience, Religion and Belief," accessed 6 April 2023, https://hrc.act.gov.au/humanrights/guides-and-publications/detailed-information-enshrined-rights/right-to-freedom-of-thought-conscience-religion-and-belief/.

Oversight, reporting and compliance (Questions 29-33)

Question 29 – What sort of oversight mechanisms are needed to ensure voluntary assisted dying is safe and effective? In particular, should oversight focus more on retrospective compliance or prospective approval? Should oversight mechanisms be independent from government?

The oversight mechanisms ought to be focused on prospective approval rather than retrospective compliance and the oversight mechanism must be independent of the ACT Health Directorate and the ACT Government, in order to function entirely independently. It is important that there is oversight of the voluntary assisted dying process as it happens and not after it has occurred.

To state the obvious, this is a matter of life and death and the stakes for getting it "right" are as high as they can possibly be. A retrospective review process is no safeguard for a person, if the person is already dead by the time the review takes place. It is appropriate that there is a rigorous oversight model and if that imposes some additional, but reasonable, requirements on the coordinating health professional, this is also justified.

However, a prospective approval process does not need to be barrier to access, if designed well. The discussion paper cites "evidence emerging from the early Victorian experience that the permit (pre-authorisation) process constitutes a potential barrier to timely access."[43] This evidence is qualitative data from interviews conducted with medical practitioners in the year after voluntary assisted dying become operational in Victoria. Many of the criticisms of the prospective approval model within the paper were regarding processes that are not inherent to a prospective approval model. For instance, the forms administered by the Voluntary Assisted Dying Review Board Secretariat were found by study participants to be complicated and the mandatory online system (portal) was found to be unintuitive and difficult to navigate. Neither were the criticisms universal, with some participants saying that the prospective approval process had an important safeguarding role for both patient and doctor.[44]

Concluding Remarks

Calvary's position on voluntary assisted dying is well-known and well-documented. If a voluntary assisted dying bill is passed in the ACT, Calvary will not participate in its implementation or delivery.

Calvary's mission is to accompany people and relieve suffering, but never to harm or intentionally cause death.

We will continue to offer high quality palliative care and partner with stakeholders who have similar objectives.

We look forward to discussing these matters further.

Please direct any questions you may have to Calvary's National Director of Mission, Mark Green:

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[43] Discussion paper, 33.

[44] Ben White, Lindy Willmott, Marcus Sellars, & Patsy Yates, "Prospective oversight and approval of assisted dying cases in Victoria, Australia: a qualitative study of doctors' perspectives," *BMJ Supportive and Palliative Care*, published online 6 June 2021, doi: 10.1136/bmjspcare-2021-002972.