

- **CHECK AGAINST DELIVERY**
- **Traditional owners:** I acknowledge the Gadigal people of the Eora Nation on whose ancestral lands we meet, and pay respect to the Elders past and present. And I acknowledge and welcome Aboriginal and Torres Strait Islander people here today.
- It is a privilege to be leading the development of the Voluntary Assisted Dying scheme in the ACT.
- And it is incredibly humbling to be in this room.
- Can I thank every person here for your passion, advocacy and care. And sincerely thank the organisers and all the team for a remarkable conference, and for the opportunity to speak today.
- I will be sharing a brief update on how our legislative model for voluntary assisted dying in the ACT is developing, and some key elements within that, as we near the introduction date of the Bill.
- At the outset, I need to stress that the positions I share today are not necessarily the final settled positions of the ACT Government, Ministers or Cabinet.
- But, they will give you an indication of how our consultation and analysis has evolved, and why we are considering what we are.
- But first, how did we get here?
- As you know, the ACT and Northern Territory were banned for 25 years from being able to legislate for voluntary assisted dying. All states were able to, and did, legislate for voluntary assisted dying while our territories were banned.

- Following years of sustained community and political pressure, that was finally overturned in December last year. The ACT Chief Minister, former NT Chief Minister Marshall Perron, Andrew Denton and I were in the Senate as our rights were finally restored. A moment I'll never forget.
- In the ACT, we had been hopeful of this result. We also had known for some time that voluntary assisted dying has extraordinary community support, and knew the community would have high expectations of us getting to work once our rights were restored.
- Because of this, we had been preparing a discussion paper so that consultation could begin quickly. Many of you in this room contributed to that.
- While being banned from legislating for voluntary assisted dying is unenviable, the silver lining is that as the states have progressed during this time, we have been able to observe the consultations, the development of legislation, and the operation of voluntary assisted dying schemes.
- This, together with expert advice, led to a discussion paper which homed in on areas of the Australian model which we believed were worth testing with the ACT community.
- The ACT also has unique characteristics which further supported a detailed consultation: we're a small jurisdiction; yet, our health system serves a large catchment; and we are a human rights jurisdiction.

- In early February we began our consultation. This concluded in April, with hundreds of detailed submissions, many workshops and thousands of Canberrans participating in a detailed survey about their preferences and expectations for a scheme. We released our report of what we heard in June. We have moved quickly.
- In releasing the ‘what we heard’ report, we indicated that this was what the community had told us, and that we would respect this by exploring those issues further. This is the work we have been undertaking these past few months.
- In summary, we have taken an evidence-based approach drawing from the passage and implementation of legislation in other jurisdictions, and informed by genuine and extensive community and expert consultation. We have listened.
- From the beginning, I have been guided by three clear principles as we’ve worked through this.
- That our model should:
 - Protect and promote human rights;
 - Have necessary safeguards without being unduly burdensome;
and
 - Have the support of the clinical community.
- Having regard to these objectives, it is worth emphasising that our community consultation and further analysis has provided general support for the ‘Australian model’.

- In particular, that an eligible person has an eligible condition that is advanced, progressive and expected to cause a person's death; that the person is intolerably suffering; that the person has decision-making capacity; and that the process for request and assessment of eligibility reflect the three-step model in all states.
- However, there are some areas where our community consultation suggested other or different preferences, and I want to detail some of the direction that has evolved as we have worked through these, particularly as we have engaged with our clinical community.
- First, with regard to eligibility criteria. Two key areas we sought further views on were the requirement of a timeframe to death, and the requirement that a person be 18 and older.
- In our consultation, we heard strong views on the difficulties in estimating timeframes for people nearing the end of life.
- We heard consistently from the community, academic experts and other jurisdictions that estimating life expectancy is "inherently uncertain and imprecise", and that doing so can contribute to unpredictable and unfair outcomes. Further engagement with health professionals has supported this.
- Timeframes can also operate arbitrarily, in that there may be very little to distinguish between a person who is expected to die within the specified time limit, and those with similar conditions whose prognosis is slightly longer. This is exacerbated by the fact that different health professionals may assess timeframes to death in different ways, with different outcomes.

- Rigidly applied, timeframes may also give rise to injustices, such as where people are terminally ill and suffering, but are forced to continue to suffer until they are close enough to death to meet the eligibility time period.
- Research has found that removing the timeframe to death criterion is unlikely to result in more people being eligible for VAD, but that people would become eligible earlier in their disease progression, reducing the stress and difficulty of having to access VAD very close to death.
- What I can advise today is that our preference is firming that a person with an advanced, progressive and terminal condition may access voluntary assisted dying without the coordinating or consulting practitioner having to estimate whether they fit into a specific time until death category.
- With regard to access for under 18s, this is something that we did publicly consult on.
- That consultation demonstrated some strong support for this, particularly from those with lived experience of mature young people suffering intolerably near the end of their lives.
- The argument being, principally, that young people under the age of 18 also experience intolerable end of life suffering through terminal illnesses and should have the same end of life choices as adults.
- Because of the support we heard, we have considered and tested this further, especially in light of the other criteria, including that a person must have decision-making capacity.

- It is clear there are policy complexities, particularly in relation to a young person's emerging capacity and autonomy, and in assessing their decision-making capacity. While the concept of Gillick competency is known and recognised, its application in this context is untested. This presents a significant risk to both the support of the clinical care community and the potential impact on implementation timeframes.
- Further, there would be limited demand for this in the ACT due to the very small numbers of young people that would be eligible. Initial modelling and clinical experience indicate that for a small population like the ACT, uptake of VAD by mature minors would be expected to be extremely infrequent.
- Considering this, together with the complexity of its implementation, and the resulting delays that would affect the overall scheme's implementation, a preference is emerging to not continue pursuing this in our legislative model.
- However, noting the understanding and policy application is evolving, and the human rights considerations, we consider this would be worth revisiting in a legislated review of the Act which would occur after several years of VAD being accessible.
- There are two other areas I wish to touch on briefly.
- The availability of practitioners who can assess eligibility and who are willing to participate in VAD is critical for equitable access to VAD by all who may wish to do so.
- Narrow or inflexible health professional qualification requirements to participate in the provision of VAD unnecessarily limit the pool of health professionals available to support people who wish to access VAD.

- So, we have explored the role of health practitioners in the ACT VAD model, including whether highly skilled Nurse Practitioners with appropriate experience in palliative care, aged care or end of life care can play a greater role in the ACT than other jurisdictions.
- Public consultation demonstrated strong support for Nurse Practitioner involvement.
- The ACT is a small jurisdiction with a limited health workforce and workforce pressures, particularly in the primary care sector.
- Given this, and that cross-border arrangements are currently restricted under the models applied in Australian states, a preference is emerging that certain Nurse Practitioners be able to act as a coordinating or consulting practitioner as long as the other coordinating or consulting practitioner is a medical practitioner.
- It is also very likely that both Nurse Practitioner and Registered Nurses will be able to act as an administering health professional in our model.
- Finally, we have been giving very considered thought to access for people in care facilities.
- We know that some people who wish to access VAD in the ACT will rely on facilities for care, nursing or accommodation, and those organisations may actively oppose VAD, for religious or other reasons, such as lack of organisational capacity.
- We heard serious concerns from the community regarding this.
- Like in Queensland, a preference is emerging in our policy development that a care facility may decide their level of involvement with VAD, so long as they do not hinder access to VAD and comply with minimum standards.

- This includes allowing a health professional access to the facility, or facilitating transfer of the patient where this is not practicable, together with the facility publishing information about its involvement with VAD and how it complies with the minimum standards, and requiring the facility to have an internal policy regarding this access.
- In short, a facility does not have to participate but it will be unlawful to hinder access and to not meet these minimum standards.
- However, we are considering whether there would be merit in extending protections further - in that there would be no distinction in approach whether a person is a permanent or non-permanent resident of a facility.
- In this way, the model would promote person-centred care and flexibility.
- To prevent these strict obligations on care facilities from disincentivising those facilities from agreeing to care for a person who is seeking or may seek to access VAD, we are also considering making it explicitly unlawful for a care facility to refuse and/or withdraw services to a person on the sole basis that they may seek access to VAD.
- Can I particularly thank every person and organisation who has engaged so openly with the ACT Government as we have worked to develop our model.
- As we refine and finalise our policy development and legislation, I hope this brief summary has given an indication of the considered approach we have taken and an indication of some elements you will likely see in an ACT voluntary assisted dying scheme when our Bill is introduced before the end of this year.