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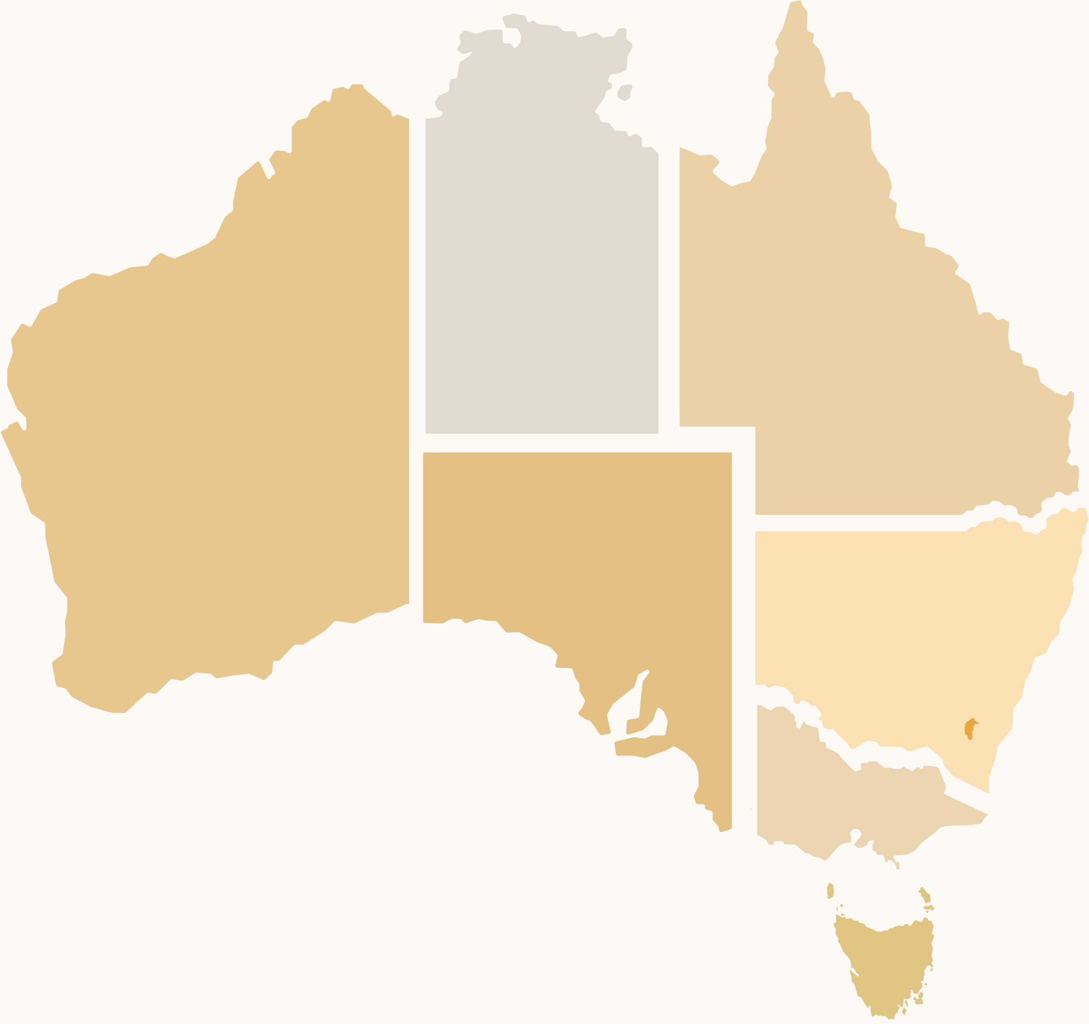
# The Australian model

## Lessons from Australia on legislation and implementation of assisted dying



Research paper

By Torrin Wilkins, June 17th 2025

Centre

Commissioned by

CAMPAIGN FOR DIGNITY IN DYING.

# Contents

# Author

**Torrin Wilkins**

*Director of Centre Think Tank*

Torrin is the Founder and Director of the Centre. His experience includes authoring over a dozen papers and over one hundred policies. His policies have been backed by an All-Party Parliamentary Group of over 260 MPs and included in various party manifestos.

## About Centre

We are an independent non-profit foundation and cross-party think tank. Our mission is to rebuild the centre ground and to create a more centrist and moderate politics. We support better public services and a strong economy inspired by policies from the Nordic countries.

To achieve these goals, we work with people from across the UK and party politics. This includes engaging with politicians and our networks, which include academia, politics, and law.

Our work includes creating new conversations by hosting events and conducting interviews. We also produce new policy ideas to better inform debate, publish papers, and release articles. We aim to build consensus, shape public opinion, and work with policymakers to change policy.

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## Commissioned by Dignity in Dying

This paper was commissioned by Dignity in Dying, which is a national not-for-profit campaign and membership organisation campaigning for change across the UK. Dignity in Dying believes everybody has the right to a good death, including the option of assisted dying for terminally ill, mentally competent adults.

This paper was commissioned for £10,000. We retained editorial control over the paper, and we signed a contract with Dignity in Dying setting out the full terms. The invoice, contract, and general information on transparency can be found on our “Transparency” page in the footer of our website.

We also approached Dignity in Dying both about this paper and our previous event as a result of our shared position on this issue. Payment for this paper was also received before this project began.

All policy proposals are our own and do not necessarily reflect those of Dignity in Dying.

Commissioned by

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IN DYING.

## Foreword from Dr Simon Opher MP

I write this foreword at the moment when the Terminally Ill Adults (End of Life) Bill will soon begin its third reading in the UK Parliament. During the committee sessions and the Commons debates, I often raised what we can learn from the Australian model.

This paper demonstrates many of these lessons and shows that a safe system with choice, dignity and protection from coercion was achieved in a country with laws similar to our proposed bill.

Practitioners within this system are supported by a range of statewide systems and are allowed to speak openly with patients about their end-of-life choices. It also ensures that practitioners can opt out of the system and that liabilities are clear and exact.

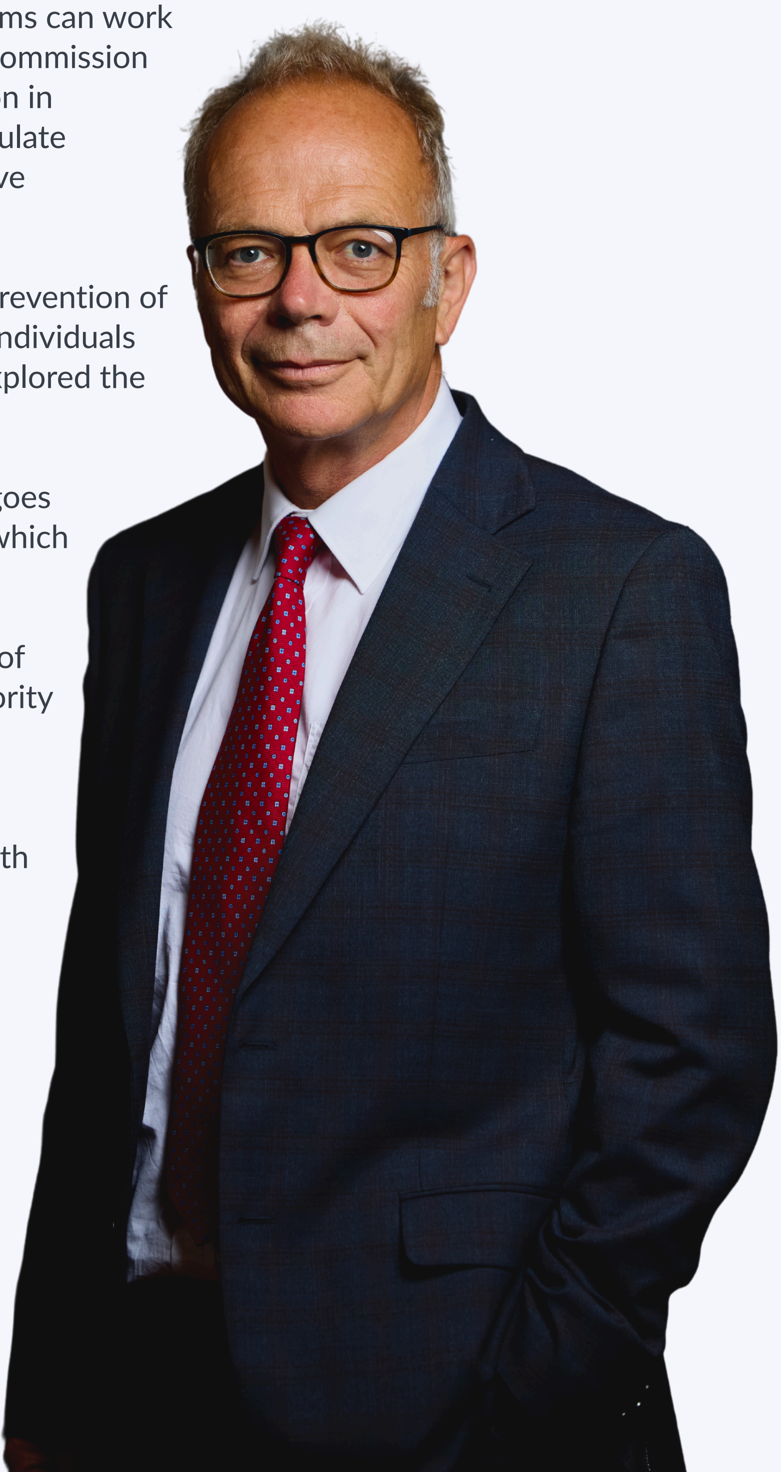
Palliative care has also improved, as it has in most countries where assisted dying has become legal. The firsthand accounts within this paper show how palliative care and assisted dying systems can work together. Already, our bill has prompted a Commission into Palliative Care and an extra £100 million in funding, and I am hopeful that this will stimulate improvements across the country in palliative care services.

Another thorny issue is the detection and prevention of coercion. This paper found no evidence of Individuals being coerced into an assisted death and explored the extensive safeguards to prevent coercion.

The UK legislation is ground-breaking and goes even further on safeguards than Australia, which is shown to be safe.

The law change is supported by some 75% of people across the country, with a clear majority in favour in every constituency and across multiple faiths, ages, politics and genders. We have the chance to pass landmark legislation that will help UK law catch up with public opinion and countries like Australia.

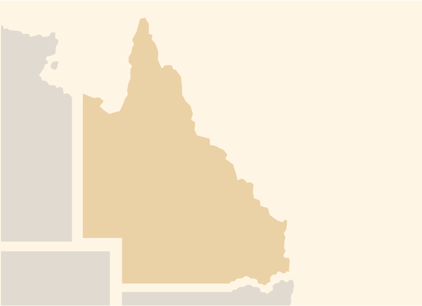
I hope Parliament takes this once-in-a-generation opportunity.



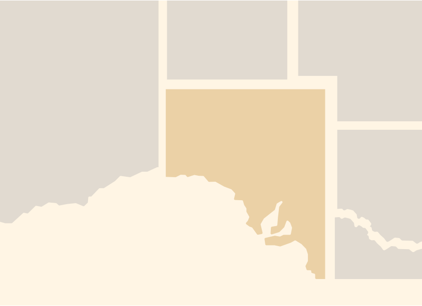
Dr Simon Opher

**Labour Member of Parliament for Stroud and General Practitioner**

# Summary

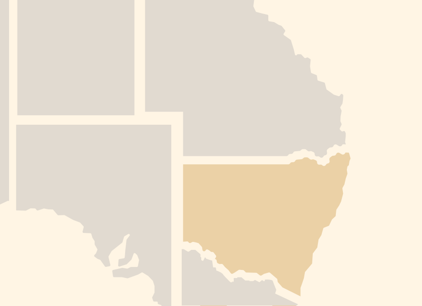


With more than 100 individual safeguards, the Australian model is safe, and there are no reports or evidence of people being coerced into an assisted death. The health professionals we spoke to told us that the only instances of coercive behaviour they have seen are attempts to persuade people not to choose an assisted death.



An in-depth analysis of the Australian system also highlights the extensive safeguards, many of which only become apparent after the implementation of the legislation, such as training, guidance, statewide services, and methods to detect coercion.

Assisted dying implementation has benefited palliative care. This includes almost a billion Australian dollars in additional palliative care funding. Australia also provides a model for cooperation between palliative care and assisted dying systems, especially as many individuals use both services at the same time.



With safe and well-functioning systems in place, public opinion has also shifted further in favour of assisted dying. The opinion of medical bodies has also shifted, with organisations adopting neutral and supportive positions.

To understand all of these issues, this paper includes extensive interviews with practitioners who have seen the system firsthand, loved ones who understand what the system is like for those accessing it, and an MP who has passed a state bill to legalise assisted dying.

# Introduction

Debates within the UK often focus on potential issues and ideas. Our original paper, "The Case for Dignity", provided a brief overview of the system within Australia and the United States. It addressed some of the concerns within the UK around palliative care and coercion by looking at the evidence from states within these countries.

This paper aims to build upon this approach by understanding how the Australian State and Territory systems work and what lessons we can take from them. It seeks to provide a clear picture of this system, to understand how assisted dying systems have adapted to real-world application, and to gather policy lessons that can be applied to the UK. We are clear from the outset that our position is in favour of assisted dying, and our primary aim is to learn lessons that will strengthen our system.

Australia is an ideal country to learn lessons from due to our close ties and shared historical links. Something that has benefited this paper has been the number of people now living in Australia with personal experience of both the UK and Australian systems.

The system of states and territories within Australia, each with a government, means each has developed in slightly different ways. This allows them to learn and cooperate, and it provides us with the opportunity to learn from each of these systems.

To fully understand this system, we conducted a series of interviews with those involved, including family members of those who have had an assisted death, practitioners, and politicians. These interviews provide a greater understanding of the issues from the ground level.

At the end of this paper is a list of recommendations that can be derived from the Australian experience. These lessons are useful to politicians and campaigners alike, showing how assisted dying could be implemented in the UK and expanding on the international evidence available.

# Impacts of assisted dying

**Additional investment in palliative care**

Assisted dying legislation has been followed by almost one billion Australian dollars in additional palliative care funding across every state. These are alongside ten-year plans to improve palliative care services and technology in the area.

**More than 100 individual safeguards**

The systems in Australia have over 100 individual safeguards, many of which can only be fully seen after implementation. These include state-wide services, training, and guidance, which act as checks.

**Signs of convergence, not a slippery slope**

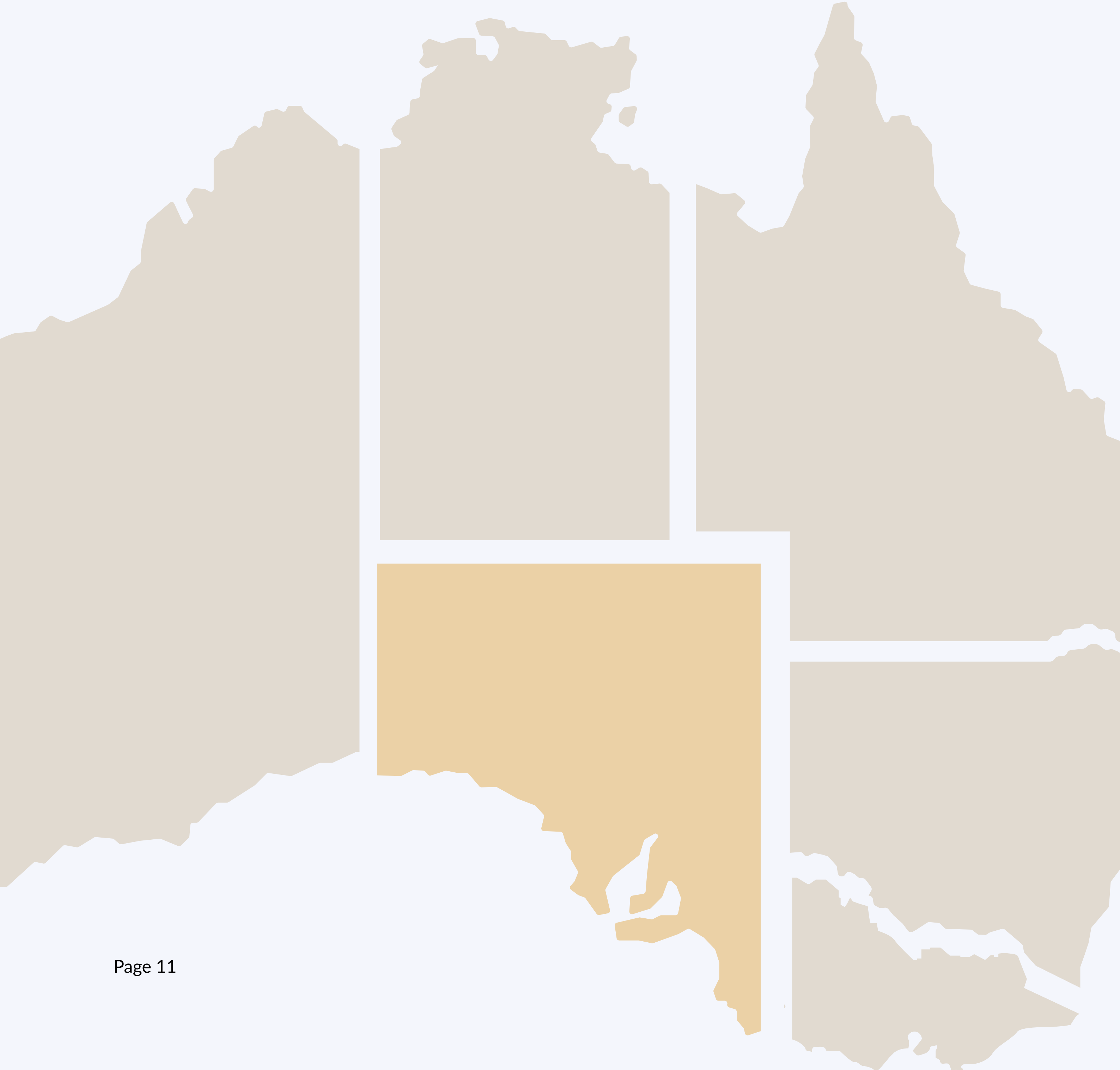
There are no signs of a slippery slope or that the nature of laws in Australia has significantly changed since adoption. States generally keep in line with each other and learn from each other rather than sliding towards significantly looser or more relaxed requirements.

- As a result of the safeguards, there are no reports or evidence of people being coerced into an assisted death. This paper does include an analysis of some reported coercion or lack of choice due to palliative care, but it could find no evidence of this when analysed in full. The system has also shown it can detect coercion, as we heard from practitioners with cases of people being coerced out of an assisted death.
- Public opinion and the opinion of medical bodies have shifted further in favour of assisted dying over time as states have legalised assisted dying. The recent shift of the Australian Medical Association to a neutral stance is one example of the continuing movement on the issue as territories change their laws.
- A system of local, regional, and national coexistence has emerged between palliative care and assisted dying. Whilst not perfect in every area, palliative care and assisted dying services do cooperate in some local areas and very often coexist for individuals as well.

- Individuals choose to access assisted dying for a variety of reasons. The mix of information and public knowledge available ensures individuals are making informed decisions.
- Surveys and interviews in this paper point to assisted dying not impacting or increasing the use of palliative care services, in part a result of the growth in conversations around end-of-life choices, including palliative care. National Policy Director of Palliative Care Australia, Josh Fear, made this point when he said, “What we have heard from the sector is that the introduction of VAD in every state has led to an increase in conversations about end-of-life choices[1].”

## Chapter one

# Evidence gathering



### Overarching questions for this paper

- What challenges has the Australian system overcome during implementation and real-world application?
- Are there any areas that Australian States and Territories have been unable to fix?
- What areas of the Australian experience can be applied to the UK?
- How did Australia turn the principle of access to assisted dying into a fully functioning system?
- Have the concerns which have been raised within the UK around coercion, a slippery slope and palliative care materialised within any of the Australian State and Territory systems?

### Interviews

The interviews conducted for this paper were used to provide an in-depth perspective by allocating an hour for each interview. The individual did not have to speak for this length of time, and it was made clear that they could go over this. The aim was to truly understand the system, but also the people behind it and who have seen it first-hand from all aspects. We were then able to complement these interviews with wider studies and evidence from Australia.

### Interviewee breakdown

We spoke to individuals with experience in Western Australia, New South Wales and Queensland. More than half of these interviewees were from Western Australia, in particular our interviews with four practitioners who operate within the assisted dying system.

To place this in context, there are a total of 114 trained practitioners in Western Australia[2], and we interviewed four practitioners for this paper. This is 3.5% of the practitioners within Western Australia trained to deliver assisted dying.

We aimed to ensure we asked a wide range of people to be interviewed, and we were able to indirectly ask all of the Voluntary Assisted Dying practitioners within Western Australia to take part in our interviews, which is why this state was so heavily represented.

Western Australia was of particular interest, where assisted dying has been available since 2021[3], in large part being the largest Australian state by area, and it has a population of just below 3 million people[4]. This is a similar population to the North East of England, whilst being hundreds of times the size.

The state, therefore, experiences large difficulties as a result of a low population density, where delivering and accessing assisted dying can be challenging. Our interviews highlighted how assisted dying can be delivered within extremely rural and isolated areas.

Another characteristic that a large number of interviewees shared was moving from the UK to Australia, just like a large number of Australians. Of particular use is where interviewees had worked and had an understanding of both healthcare systems, allowing them to make comparisons between the two. It also allowed them to discuss the assisted dying system already operating within Western Australia and how such systems and processes could work within the UK.

**Interview format**

The interviews consisted of two elements: pre-set and follow-up conversations or questions. The first element was the pre-set questions, which each interviewee was sent in advance and could then be altered to match their particular areas of experience or specialisms. The second element was follow-up conversations, which normally looked at points raised by the interviewee, additional questions which came up from the answer, and context from other interviews which had been conducted.

We also informed them before the interviews that we would also ask follow-up questions prompted by their answers or previous points raised by other interviewees.
All interviewees were told in advance of the interview where the interviews would be published and in what formats. We also sent them an outline of the funding for the paper and a link to our transparency page, which contains details on this and previous projects.

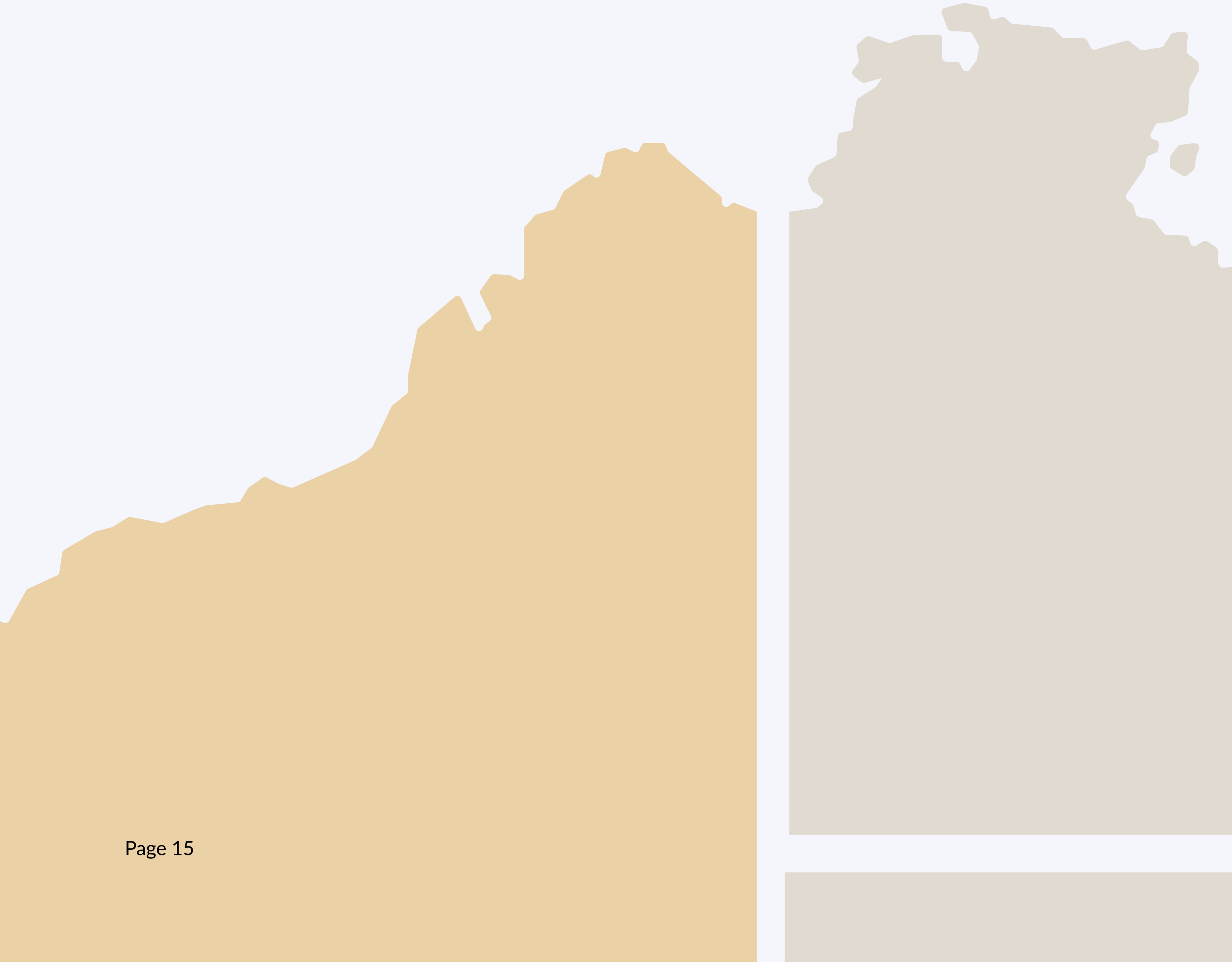
**Interviewee details**

- Alex Greenwich MP - Alex Greenwich MP is an independent member of the Sydney Legislative Assembly and has been in the New South Wales Legislative Assembly since 2012. He introduced the Voluntary Assisted Dying Bill 2021 to the Legislative Assembly in New South Wales. The bill had 28 co-sponsors from across both houses, the greatest number of co-sponsors ever achieved in Australia for a piece of legislation. This bill became law after it received Royal Assent in May 2022.
- Liz Smyth - Liz Smyth spoke about the experience with her brother Rob Smith, who was diagnosed with stage four lung cancer in October 2022. He died at the age of 39 after accessing voluntary assisted dying in the state of Queensland. Liz is from Hertfordshire and was with Rob in Queensland when he died.
- Pauline McGrath - Pauline McGrath spoke about her experience of the assisted dying system with her husband, David Levitt, who was the Director of General Paediatrics and Dermatology and Director of Paediatric Education at the Queensland Childrens Hospital. He also spent many years as the sole paediatrician at the Mater Refugee Complex Care Clinic, where he cared for outpatients and children transferred from the Republic of Nauru. He accessed assisted dying in 2023 and, after his death, he was awarded the 2023 Childrens Health Queensland Medal of Distinction.
- Brigitte Tampin - Brigitte Tampin is the widow of Paul Tampin and has a personal experience of the assisted dying system within Western Australia. Paul grew up in London and then moved to Australia. He was then diagnosed with stage four lung cancer, which had spread to his liver. Paul decided to access assisted dying in 2022.

- Dr Clare Fellingham - Dr Clare Fellingham was originally born in London. She trained at St. Georges Hospital Medical School and then moved to New Zealand and finally to Australia. She is a consultant anaesthetist, holds a clinical diploma in palliative medicine, is studying for a masters in bioethics, and is deputy director of the clinical services at Royal Perth Hospital and led the introduction of the assisted dying programme at one of the metropolitan health services in Western Australia.
- Dr Anna Negus - Dr Anna Negus has been a provider under the Western Australia Voluntary Assisted Dying Act since legislation was passed. She completed her medical degree in the UK before emigrating to New Zealand for specialist anaesthetic training. She is a specialist paediatric anaesthetist, has a Diploma in Clinical Education, and has extensive experience in developing world medicine.
- Dr Nancy Burge - Dr Nancy Burge graduated from University College London in 1982. She then worked as a general practitioner in Brighton and then the Isle of Skye before moving to Perth in Western Australia in 2015. She was among the first doctors to undergo training when Western Australia legalised assisted dying.
- Dr Paddy Glackin - Dr Paddy Glackin was an inner-city general practitioner in central London for 20 years and was the Deputy Chair of the British Medical Association Medical Ethics Committee from 1996 to 1999. He successfully brought a motion to the British Medical Association Conference in 2005, calling for it to change to a neutral position on changing the law to permit assisted dying. He then moved to Australia in 2014, becoming a general practitioner. He is now a voluntary assisted dying practitioner and the Western Australia Country Health Service Clinical Lead for Voluntary Assisted Dying.

Chapter two

# The UK Bill Compared to the Australia



The Australian model has similarities and potential similarities to the UK.

**The Australian Model**

Within this paper, the term "Australian model" refers to the broad model used by Australian states and territories. In some parts of this paper, for instance, on palliative care and prognosis criteria, separating each state to compare their policies is necessary. In other sections, particularly when looking for more lessons the UK can learn, the states may be used as a single example. One instance where this happens is for information given to individuals within New South Wales, where it is simply provided as evidence of best practice.

**Similarities**

- The UK has devolved laws around assisted dying, and Australia also devolves these powers to states and territories. Within the UK, legalisation is now being considered in Scotland, and the Isle of Man is now going ahead with law reform. The only other countries with this level of devolution around assisted dying laws are Australia and the United States.
- The six-month prognosis proposed within the UK is similar to the primary prognosis in use within Australia.
- Similar safeguards are built into the system, including two doctors signing off on individual cases and similar eligibility criteria.
- The inclusion of a signed statement by a witness.

**Differences**

- Although the main prognosis in use is six months, states also have a twelve-month limit for neurodegenerative conditions, and some states have separate rules around prognosis.
- The bill being proposed within the UK includes a panel system. This is not just different when compared with Australia; it is a unique assisted dying safeguard.

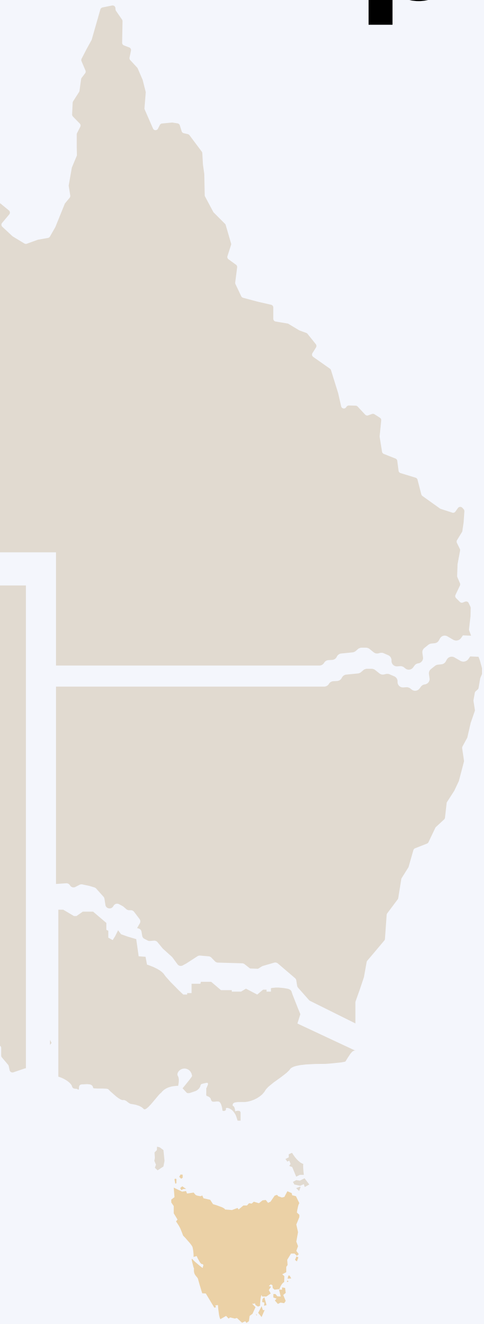
**Post-Implementation Nature of Australian Laws**

- The implementation of the bills within Australian states and territories means many of the proposed safeguards are now a reality. This includes some of the over 100 safeguards used by Australian states, such as the state-wide care navigators or the state-wide pharmacy services. The UK legislation, in comparison, places these as powers given to the Secretary of State, which will later be implemented. These additional safeguards will only be apparent once these systems have been created.

The similarities, differences, and more advanced nature of the assisted dying system within Australia provide a perfect opportunity to find lessons applicable to the UK.

## Chapter three

# Impact and implementation



A key factor in the success of these systems was the implementation period and the bodies created to manage this. Since implementation, assisted dying in Australia has seen a large change in public and professional opinion.

In all of the states and territories where assisted dying has been implemented, the concerns before adoption and the support after appear to be similar.

**The situation before implementation**

As explained below, all polling conducted on assisted dying within Australia shows support across all groups polled. However, before assisted dying was implemented, fears were expressed about the systems being implemented.

These included coercion, concerns around underrepresented groups, a struggling palliative care system pushing people to use assisted dying, that individuals may go through doctor assessments until they receive access to the system, the bill would undermine suicide prevention, and that the system lacked safeguards and opposition for religious reasons. These concerns were detailed in a report by the New South Wales Committee on Law and Justice when the bill was being proposed[5].

Concerns were also raised by Indigenous groups around the Northern Territory law reform, and "…the Central Land Council, which represents the Indigenous population in the Northern Territory, strongly opposed the law, deeming it culturally inappropriate[6]." and other groups which proposed specific changes to legislation, such as disability groups which called for suicide prevention funding[7].

**Passing new laws**

When discussing how the law in New South Wales was passed, Alex Greenwich MP said that it depends on two core areas: "The principle of access to voluntary assisted dying is one that the public supported, getting the details on the process right, which was an important part of that, and obviously, ultimately saw the bill pass."

There appear to be four main reasons for successful law reform in Australian states and territories. These included existing public support, advocacy for assisted dying by various groups, including mentions of the debates on law reform, the use of previous law reforms as precedent, with evidence of other state laws being cited, public consultation on the issue, and government support for the proposed bills[8].

**Implementation**

To oversee the implementation of assisted dying and to ensure these views were taken on board during the process, each state and territory set up an implementation taskforce or a similar board. These oversaw the implementation of the legislation and handled public engagement around the new systems.

The board in Western Australia was made up of practitioners, the President of Palliative Care WA, Aboriginal representatives, those with experience in rural areas, geriatric specialists, Members of Parliament, and a specialist anaesthetist[9]. Alongside this leadership team, the implementation period also included outreach activities such as an implementation conference, regular public updates, and webinars.

This heavy emphasis was highlighted by Dr Anna Negus, who said of the state-wide care navigator services: “The SWCNs went out into the community and gave providers practical advice, support, and personalised education sessions. These education sessions were provided for a variety of health providers, such as palliative care, GPs, nurses, and community practitioners. I think that was probably one of the biggest reasons why VAD was implemented successfully in WA.”

States and territories may also create sub-committees to handle specific aspects of this implementation. Queensland set up a set of subcommittees alongside the implementation. States and territories may also create sub-committees to handle specific aspects of this implementation. Queensland set up a set of subcommittees alongside the implementation Taskforce, which were tasked with setting up each aspect of the system. This includes individual statewide services, functioning digital systems, training guides, guidelines, conducting community engagement, and providing regular updates on implementation[10].

Put together the community engagement, engagement with stakeholders, and work with different services. This gave the new statewide services a clear view of how to adapt or fit into the existing system, whilst taking on board the views of the community.

The implementation period is also important given the extent of outreach efforts. In the table below, the implementation includes the time between the bill passing or receiving assent to being fully implemented and open to applications. To understand the wider picture for implementation periods, we used the timeline from pages 32 to 34. The dates for implementation were:

## Implementation period by state

| State | Period | Total |
|---|---|---|
| Victoria | 29 November 2017 to 19 June 2019 | 1 year, 6 months, 21 days |
| New South Wales | 19 May 2022 to 28 November 2023 | 1 year, 6 months, 9 days |
| Queensland | 23 September 2021 to 1 January 2023 | 1 year, 3 months, 9 days |
| Western Australia | 10 December 2019 to 1 July 2021 | 1 year, 6 months, 21 days |
| South Australia | 24 August 2021 to 31 January 2023 | A total of 1 year, 5 months, 7 days |
| Tasmania | 22 April 2021 to 23 October 2022 | 1 year, 6 months, 1 day |

A clear pattern for implementation emerges, with all states and territories having a period of around one and a half years in length, with only one implementation period lasting more than 1 year and 6 months.

When speaking about the right amount of time to implement assisted dying, Alex Greenwich MP said: “I think an implementation period of around 18 months to three years is appropriate. Health systems can move fast when they are given the directive of legislation.”

**Shifting opinion**

As mentioned previously, public opinion and the opinion of advocacy groups were divided around assisted dying legislation. However, since implementation, public opinion has also shown two key features: support has remained consistent, as we were unable to find any poll where Australians opposed assisted dying, and support has steadily increased over time. An analysis of polling over the past 60 years shows increasing support, decreasing opposition, and a decrease in those who are undecided[11].

In one poll conducted in 2017, released just before Victoria became the first state to vote for assisted dying legalisation, 87% of Australians supported assisted dying for those who are "...hopelessly ill and experiencing unrelievable suffering with no chance of recovery[12]."

Polling conducted after multiple states had implemented laws in 2022 showed continued high levels of support across Australia, including when broken down by different religious groups[13]. This extended to all party affiliations and all religious affiliations[14] and across age groups and gender[15].

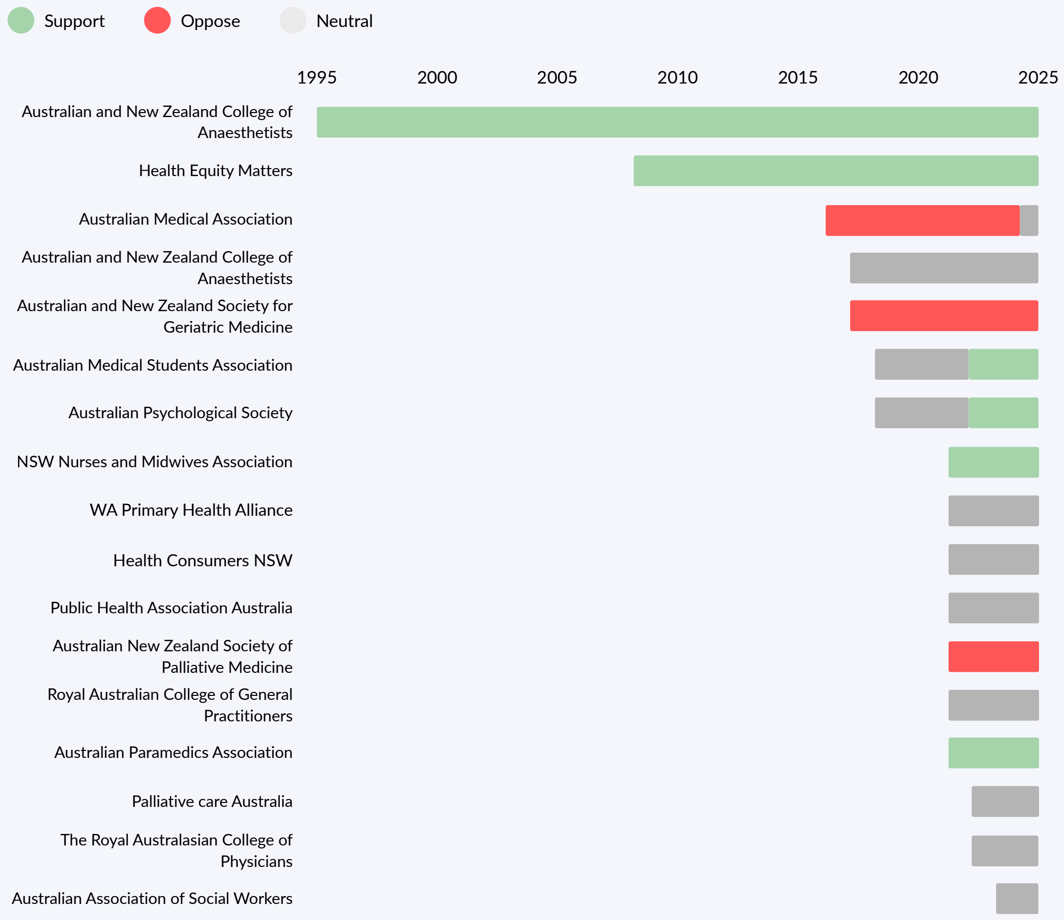
Opinion has also shifted within the medical profession around assisted dying. Dr Paddy Glackin said: "...certainly, what we are seeing is that the more exposure people have to assisted dying, for those who do not have a deeply held objection, the more positive they feel it is. We have had VAD in pretty much all of our little country hospitals around here." Even within areas such as palliative care where Palliative Care Australia remains neutral on the issue, the choice is still respected by those in the profession, and their National Policy Director, Josh Fear, said: "...the great majority of palliative care workers say they are comfortable providing information, support, and care for someone accessing VAD[16]."

This is backed up by polling where, in Victoria, support from doctors increased from 53% in 2007 before the law was passed[17], jumping to 73% in 2021[18] after assisted dying legislation was implemented. The polling available shows a shift in opinion amongst physicians.

This is not to say opinion has shifted amongst all groups who initially opposed the bills passed in Australian states and territories. The polling in 2021, for instance, still shows limited support amongst those specialised in palliative care or geriatric medicine. What is clear, however, is that a wider shift has taken place.

**Figure 1: Opinion of medical bodies over time**

As opinion has shifted amongst these groups, the opinion of medical bodies has also moved from some opposition to assisted dying, primarily to support or neutrality or having no clear position on the issue. The chart below tracks their position, in large part using published position statements or statements within reports outlining their position on assisted dying.



Australian Nursing and Midwifery Federation
Support, 1995 - “The ANMF (Vic Branch) supports legislative reform that enables persons who meet the criteria to choose to die with dignity in a manner acceptable to them; and not be compelled to suffer beyond their wishes[19].”

Health Equity Matters (formerly the Australian Federation of Aids Organisations)
Support, 2008 - "...when individual cases are clinically evaluated and confirmed for their presentation and specific circumstances, and it is evident there are no other options to relieve a persons pain and distress, that it is entirely appropriate to have a process whereby that person can rationally request an end to their life...[20]"

Australian Paramedics Association
Support, 2021 - "The Australian Paramedics Association (NSW) was today announced as a member of the NSW Voluntary Assisted Dying Alliance, a coalition of 29 unions, health and community groups working together to support voluntary assisted dying (VAD) law reform in NSW[21]."

Australian Medical Students Association
Neutral, 2018 - "At the time of writing, both are illegal in all Australian jurisdictions and so adopting a measured position on voluntary assisted dying is integral to progressing and improving how we care for people nearing the end of their lives[22]."

Switched to support in 2022 - "AMSA believes that under a safe legal framework, VAD extends the right to self-determination at the end of life[23]."

NSW Nurses and Midwives Association
Support, 2021 - "Earlier this year, NSWNMA delegates endorsed an updated position supporting legislative change, noting the nine previous attempts to introduce voluntary assisted dying laws in NSW[24]."

Australian Psychological Society
Neutral, 2018 - "The APS neither endorses nor opposes VAD[25]."

Switched to support in 2021 - "The APS supports a compassionate and safe assisted dying framework, whereby voluntary assisted dying (VAD) is available as part of a full range of care options...[26]"

Australian Association of Social Workers
Neutral, 2023 - No clear position opposed to or against assisted dying, but "...practice in this space needs to be driven by the appropriate legal and ethical frameworks...[27]" Also used the Wayback machine, and this statement has been on their website since 2023.

Palliative Care Australia
Neutral, 2022 - No clear position opposed to or against assisted dying, instead focuses on supporting palliative care and changes to assisted dying[28].

WA Primary Health Alliance
Neutral, 2021 - "WAPHA supports patient-centred decisions in end-of-life care and respects that this may include palliative care and requests for VAD[29]."

Australian and New Zealand College of Anaesthetists
Neutral, 2017 - The ANZCA released a set of 38 individual policy positions[30] alongside stating that “ANZCA has a neutral position on voluntary assisted dying laws as it considers that this is an issue for the people and governments of Australia and New Zealand to determine[31].”

Health Consumers NSW
Neutral, 2021 - “Health Consumers NSW does not take a formal position on whether voluntary assisted dying should or should not be legalised[32].”

Public Health Association Australia
Neutral, 2021 - “PHAA recognises the diverse and strongly held views in Australia on the subject of end-of-life choices[33].”

Royal Australian College of General Practitioners
Neutral, 2021 - “While not taking a formal position on whether voluntary assisted dying should or should not be legalised, the RACGP recognises that if assisted dying becomes a legal option, some patients will request it…[34]”

The Royal Australasian College of Physicians
Neutral, 2022 - “The RACP respects and supports all members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important[35].”

Australian Medical Association
Opposed, 2016 - “The AMA believes that doctors should not be involved in interventions that have as their primary intention the ending of a persons life[36].”

Switched to Neutral in 2025 - “While members expressed a range of opinions, it was made clear that an updated AMA statement must support doctors and patients who choose to participate, and those who choose not to participate in VAD, where legally available in Australia.” The position statement also includes additional proposed improvements for assisted dying systems and ensuring support for doctors delivering assisted dying[37].

Australian and New Zealand Society for Geriatric Medicine
Opposed, 2017 - 53% of their members opposed assisted dying legislation, whilst 24% supported it[38].

Australian New Zealand Society of Palliative Medicine
Opposed, 2021 - "ANZSPM does not support the legalisation of euthanasia and physician-assisted suicide, but recognises that ultimately these are matters for government to decide, having regard to the will of the community and, critically, informed by appropriate research and consultation with the medical community, including palliative medicine practitioners[39]."

**Statutory reviews**
The primary way in which assisted dying systems are updated is through regular reviews of assisted dying systems on a state and territory level. However, this area of assisted dying systems is relatively new, with limited long-term reviews published. The two reviews which have been released so far are the five-year review for Victoria and an interim review for New South Wales.

The reviews are specifically focused on the functioning of assisted dying systems alongside engagement with the views of stakeholders. Out of this, they propose recommendations for how the system can be improved; in the case of Victoria, this included five key recommendations split into thirteen parts.

The review for Victoria concluded that the assisted dying system was "operating as intended, providing a safe and compassionate end-of-life choice to eligible Victorians"[40] It also pointed out where systems were not functioning or stakeholders did not feel the system was working. In one case, it included that "Many family members and carers did not feel prepared and supported before, during, and after the VAD process" and directly called for targeted resources[41].

The recommendations of this review are mostly broad policy proposals, such as to "Initiate further enhancements to the VAD portal to improve functionality and processing time", something which may need to be strengthened. However, other proposals, such as to "Improve awareness of VAD as a legal end-of-life option through enhancement of information and resources," seem to have created concrete reforms, with the proposals to remove the gag clause emerging after the report was published[42]. In response to this review, the government in Victoria published a response where it accepted all of the recommendations[43].

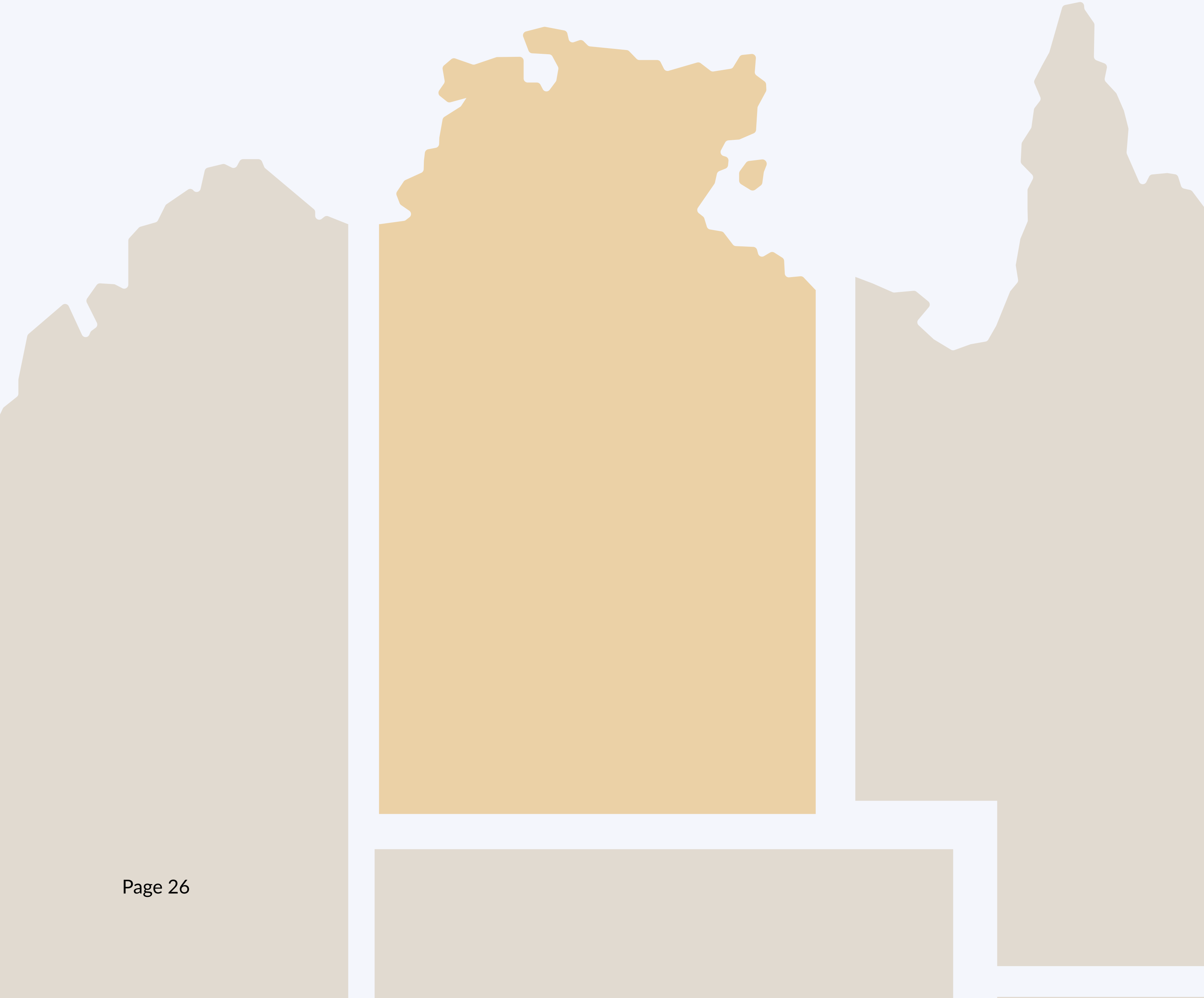
The New South Wales interim review is more limited as it looks at the initial implementation period. However, it does make some suggestions, including around regional access to voluntary assisted dying[44].

These reviews are detailed and propose solutions. In the case of Victoria, this has led to concrete legislative proposals to improve the functioning of the assisted dying system. The reviews also ensure that the systems are continuously monitored and do not remain static where issues occur.

As will be discussed in the next section, the main changes proposed as a result of these reviews have been to bring states in line with each other.

## Chapter four

# UK concerns, Australian reality



The Australian system shows the realities of assisted dying law in practice. A safe, compassionate system which puts choice at the core of the process. The debate within the UK, however, has seen fears around coercion, in particular, individuals who may not be able to access palliative care. That and a slippery slope towards a system that allows those without terminal illnesses to use the system.

### Slippery slope or limited movement

One concern which has been raised is the possibility of a slippery slope. The idea is that whilst the UK may start with a more restricted model, it will end up with a model with fewer restrictions, allowing access for individuals who are not terminally ill, non-adults, and those without mental competency, or the argument that Parliament or the courts will significantly expand the law over time. For instance, starting with a model of assisted dying similar to the one used in most areas of Australia and ending up with a model similar to Canada.

One area with a unique situation is the Northern Territory. This territory was the first area in Australia to legalise assisted dying, only to have this nullified by the federal government through the Euthanasia Laws Act 1997. This was against the wishes of the Northern Territory and caused significant tension. One federal minister even remarked, "We are not going to have some tin pot town at the top of Australia tell us what to do[45]."

Whilst the Northern Territory was the first area of Australia to legalise assisted dying, it can now legislate on this issue again and is the last area of Australia without a law. A 2024 report commissioned by the Northern Territory Government made a series of recommendations around assisted dying laws. Whilst the Northern Territory law in 1995 was limited to those with a terminal illness without specifying a timescale before death, the recent report suggests a criterion of a 12-month prognosis[46]. If eventually implemented, this would be stricter and more conservative than the original 1995 legislation.

At the time of writing, the only state looking to amend an existing bill is Victoria. This was the first state to implement assisted dying laws, which are still in place and have one of the most restricted laws within Australia. Only the Northern Territory adopted legislation before this, twenty-two years before the Victorian legislation, limiting the lessons that could be learned. As a result, the state of Victoria is, since the review, looking to move further in line with other states and territories.

The first proposal within Victoria is to remove the gag clause, a proposal which has already been discussed[47]. The clause is not a safeguard for those using the system, but it did leave people uninformed, lacking the full set of options they were eligible for at the end of life.

The second proposal is to merge the two prognosis criteria: 12 months for neurodegenerative conditions and 6 months for all other cases. The proposal here is to merge the two criteria into a single 12-month prognosis, the same as the prognosis already used in that state for neurodegenerative conditions and in line with Queensland.

The final proposal is to remove the third assessment for those with neurodegenerative conditions. This is of particular interest given that it maintains the existing 12-month criteria for neurodegenerative conditions and instead looks to other ways in which the system can be streamlined for these individuals.

It should also be stressed, however, that these are essentially undebated proposals at this stage, and it is difficult to tell whether these proposals will be accepted, rejected, or amended. They also do not extend the law to new categories of individuals, for instance, those who are not terminally ill and move them in line with other states in other areas.

Overall, the laws passed in Australia have not been significantly altered. Whilst states and territories are considering changes, these are also not evidence of a slippery slope, in part as they do not seem to be sliding in one direction.

This does not point to a slippery slope leading towards the Canadian model or another more relaxed system, which includes individuals who are not terminally ill or do not have mental competency. A defining feature of this model is that every state and territory which has adopted a law includes a requirement that individuals have a condition expected to cause death.

Instead, every state conducts regular reviews of their systems to ensure they are functioning well. It is also where any amendments around prognosis are based on existing experiences of other states, which have not recorded any issues or problems.

**Convergence**

Rather than thinking of this as an issue of slopes, it may, in part, be an issue of convergence. The idea is that devolved areas often mimic similar devolved areas when creating and implementing legislation. Convergence appears to be a factor in decisions, rather than being a rule that all areas follow.

Part of the reason this is a known factor in Australia is the mention in multiple states and territories that they are basing their law on another state or trying to keep in line with states which have legislated before them.

For instance, in Western Australia, a consideration was that "...where possible, consistency with the Victorian legislation has been maintained"[48].

This has also been seen where the proposed rules in the Northern Territory are informed by "...preferring not to depart substantively from established practices" from other areas of Australia[49]. This led to a proposal of a 12-month criterion rather than the previous law in the Northern Territory.

Another consideration in the Northern Territory has been the evidence and experience available from other states. For instance, the Australian Capital Territory does not require a specific life expectancy prognosis and has diverged from other states in this respect. However, this approach was rejected by a report commissioned by the Northern Territory Government as there was "...insufficient evidence to support taking such an approach in the NT," alongside stating the wish not to diverge from established practices[50].

Alex Greenwich MP also spoke about how this approach of learning from other states, saying "I would argue we did it the best in terms of being able to look at what has been working in the other states and what has not been working," and he listed areas where they learnt from other states, including on not adopting a gag clause and specialist involvement in cases.

All of these examples show the power of sharing best practices within a devolved system and how it may create more caution around moving away from the other established systems within that country.

States and territories seem to have concerns around divergence, including:

- Other states with far more evidence and experience around implementing a particular set of rules
- Wanting to fall into line with other areas rather than diverging significantly
- States seem to support each other in implementing these laws

More widely, this convergence can be seen within other countries which have devolved powers around this issue. American states are the other example where all use a six-month diagnosis as their basis and are heavily based on the law developed in Oregon.

This may also be happening within the UK, where, in Scotland, the age limit criteria look likely to increase from 16 to 18 years old, with the proposer of the bill agreeing to raise the minimum age[51]. This would bring both the bill in Scotland and the UK into line with each other around the age criteria.

This model of cautious review over long periods, learning from others, and use of best practices is very far removed from the concerns around a slippery slope.

### The legal slippery slope

Another element of the slippery slope, which is distinct from the Australian experience, is the concerns around a slippery slope led by the courts. This situation has occurred in countries including Canada, Germany, and Colombia.

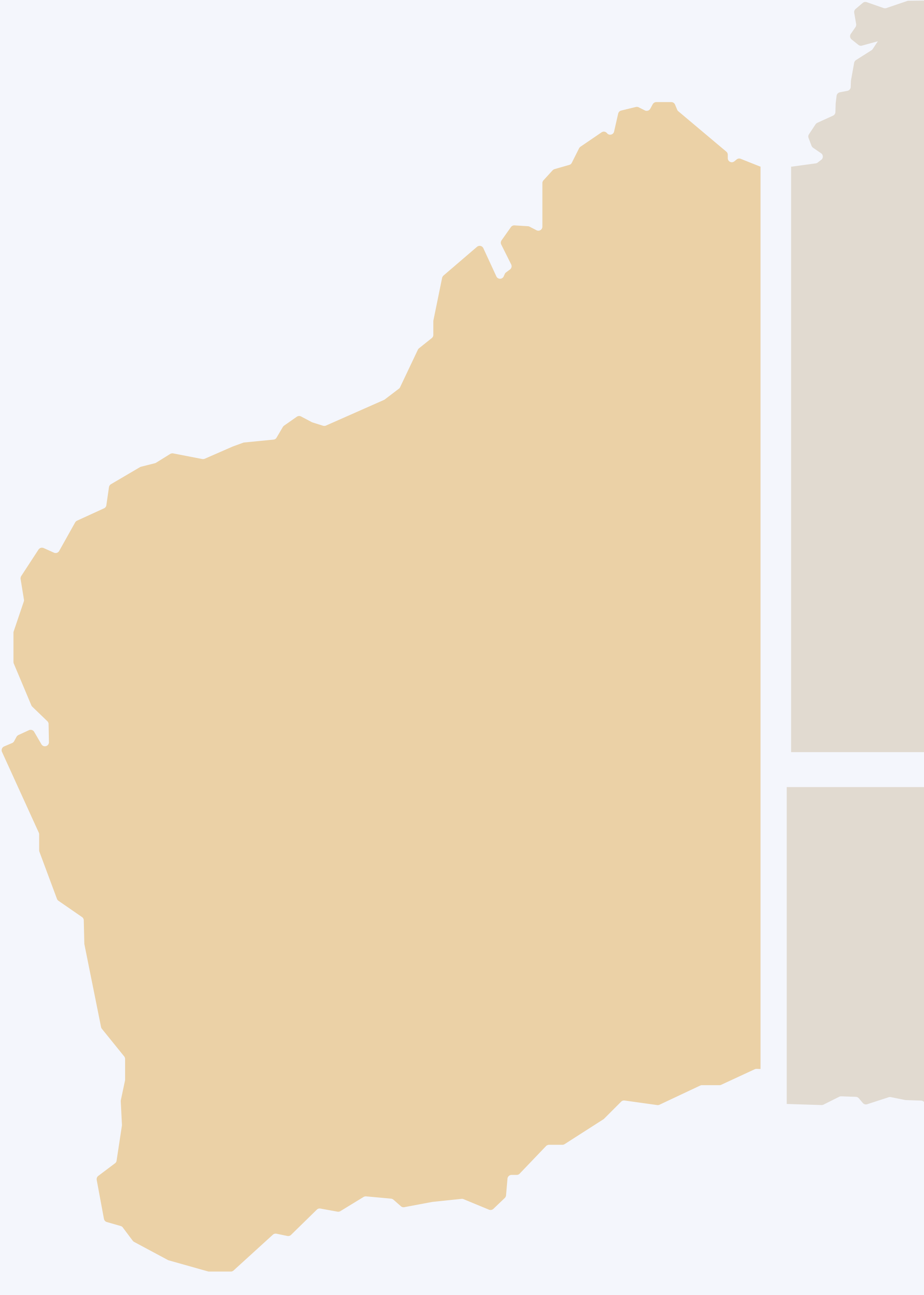
In these cases, the reason for this expansion is not a national Parliament, as is the case for the UK. Instead, it is courts and constitutional challenges which are the driving force behind these law reforms.

- In Canada, the courts effectively led the process with rulings around the Charter of Rights and Freedoms. This moved the Canadian Parliament towards expanded scope for assisted dying each time, even when there were attempts to limit the scope of legislation[52]. They have twice delayed them, which would allow MAID where the sole underlying medical condition is a mental illness[53].
- Germany also had a similar situation where the Bundestag restricted the law on assisted dying, and then the courts deemed this as unconstitutional[54].
- In Colombia, the High Court first allowed assisted dying and then extended the law to individuals who are not terminally ill[55].

The primary issue around the expansion or slippery slope for assisted dying laws comes from the courts, not parliaments.

## Chapter five

# Palliative care



The link between palliative care provision and assisted dying legislation is often a highly debated topic. This includes funding for palliative care before, during, and after the law change.

There is also a question of the wider impact on palliative care services and what the UK can learn from the Australian experience of implementing assisted dying alongside improving palliative care systems across the country.

The most prominent change which has occurred within Australia is the consistent increase in palliative care spending, which came alongside assisted dying legislation. The scale of this funding was described by Dr Paddy Glackin in our interview with him, where he described the challenges palliative care faced before additional investment. He then said, "...what we got before assisted dying was a huge investment in palliative care. So we had a very small number of visiting services here. We now have three times as many visiting specialists as we had [before]."

The increased investment also happened at some level within every state and territory which also has assisted dying legislation in place. To illustrate the scale of this investment further, below is a timeline for each state showing the improvements in palliative care alongside where assisted dying legislation was passed. In each of these funding settlements, funding which is mentioned as specifically for assisted dying services has been removed.

### Victoria

**Inquiry into end-of-life choices**
The Legal and Social Issues Committee of the Victorian Parliament ran an inquiry into end-of-life choices. This supported both improvements to palliative care alongside assisted dying[56].
9 June 2016

**Additional funding for palliative care**
$55.65 million in additional funding for palliative care over five years, with $19 million of immediate funding[57]. This funding was linked directly to assisted dying legislation as it was announced "...in an effort to gain the needed support of several rural MPs for the Voluntary Assisted Dying Bill 2017 to be voted on in Parliament in the coming weeks[58]."
29 November 2017

**Legislation passed**
Assisted dying within Victoria was legalised through the Voluntary Assisted Dying Act 2017[59].
29 November 2017

**Act comes into force**
The Act comes into force, and the system is open to requests[60].
19 June 2019

## New South Wales

### Palliative Care Framework launched

The End of Life and Palliative Care Framework was launched, which would last until 2024[61].

2019

### Additional funding for palliative care

Within New South Wales, assisted dying was passed through the Voluntary Assisted Dying Act in 2022[62]. In our interview with Alex Greenwich MP, he said that "access to palliative care for citizens of New South Wales. Those are actual words in our Act, and they compel the government to back those words up with expenditure. And soon after the legislation passed, the government announced record funding..."

19 May 2022

### Legislation passed

A funding increase of $743 million over five years for palliative care, which was later changed to $600 million[63]. The stated reason for the reduction in additional funding was a result of being unable to find more staff to work in the palliative care sector[64].

9 June 2022

### Act comes into force

The Act comes into force, and the system is open to requests[65].

28 November 2023

## Queensland

### Palliative Care inquiry launched

14 November 2018 until 31 March 2020 - An inquiry was created into aged care, end-of-life, and palliative care to improve these services[66]. This suggested improvements to the palliative care system, including looking at opening a new hospice and increased funding, alongside recommending that assisted dying be legalised[67].

14 November 2018 until 31 March 2020

### Additional funding for palliative care

Palliative care funding increased by $171 million alongside a workforce and community-based palliative care plan[68].

October 2020

### Legislation passed

Assisted dying in Queensland was introduced through the Voluntary Assisted Dying Act 2021.

23 September 2021

### Act comes into force

The Act comes into force, and the system is open to requests[69].

1 January 2023

### Western Australia

**Palliative Care ten-year plan launched**
The government launched a ten-year plan for palliative and end-of-life care[70].
2018

**Additional funding for palliative care**
$41 million in additional palliative care funding after doctors called on the government to improve palliative care before legalising voluntary assisted dying[71]. This funding was directly linked to assisted dying and "looking at this issue in [the] entirety[72]."
9 May 2019

**Additional funding for palliative care**
$17.8 million additional investment in palliative care services[73].
10 October 2019

**Act comes into force**
The Voluntary Assisted Dying Act 2019 was passed in the Western Australian Parliament[74].
10 December 2019

**Additional funding for palliative care**
A total of $10.1 million in additional funding was specifically for palliative services[75].
20 August 2020

**Act comes into force**
Assisted dying system finished implementation[76].
1 July 2021

### South Australia

**Received Assent**
The government launched a ten-year plan for palliative and end-of-life care[77].
24 August 2021

**Additional funding for palliative care**
Finished implementation and open to applications[78]."
31 January 2023

**Additional funding for palliative care**
$7.5 million invested in a Palliative Care Navigation Pilot[79].
30 May 2023

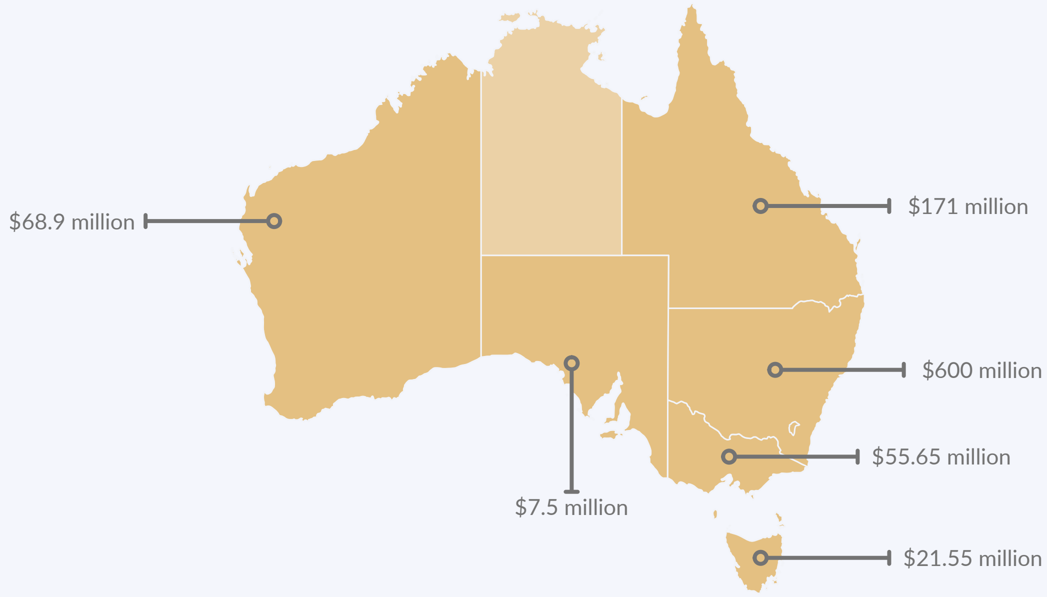
### Tasmania

**Received Assent**
$21.55 million of additional funding for palliative care was announced as an election commitment, and this promise was later fulfilled. This was part of a wider $52 million package to improve palliative and community health care[80].
8 April 2021

**Received Assent**
The End-of-Life Choices (Voluntary Assisted Dying) Act 2021 bill received Royal Assent[81]."
22 April 2021

**Act comes into force**
Completed implementation and open to applications[82].
23 October 2022

## Figure 2: Funding by state



The total funding of almost a billion Australian dollars is a large investment and is limited to spending which occurred shortly before and after the implementation of assisted dying legislation. It does not include later investments in palliative care and country-wide funding for projects, for instance, $63 million of government funding in 2023[55].

This breakdown also gives a clear picture of where additional funding was targeted. There was a particular focus on improving palliative care services in areas which are often underserved, for instance, areas without easy access to a hospice or rural areas where access was limited. The specific areas for additional funding included improving how palliative care is delivered, including telehealth, after-hours care, home care, hotline services, and the number of palliative care beds available. Between the different states and territories, there is significant overlap in the areas where funding expanded.

The investments were often alongside wider strategies and implementation plans for palliative care. In particular, the Western Australia ten-year plan ensured the investments were targeted and created six core priorities with a set of building blocks for each. This was alongside the national strategy to ensure that "...all Australian governments [should] ensure that evidence-based, quality palliative care is available to everyone who requires it[56]."

**Conversation around end-of-life choices**
One of the reasons put forward for the additional focus on palliative care by the practitioners we interviewed was the greater focus on end-of-life choices. National Policy Director of Palliative Care Australia, Josh Fear, made this point when he said, "What we have heard from the sector is that the introduction of VAD in every state has led to an increase in conversations about end-of-life choices[57]."

This link between conversations and additional funding was seen by the practitioners we spoke to. As Dr Anna Negus said, "...what it forced the community to do was to say, we really need to improve the systems that are in place to improve the end-of-life process for everybody involved," or, as Dr Paddy Glackin explained, "...I think it probably helps focus all of our minds on the needs of patients at the end of life to have multiple options and to have access to the care that they need at this time."

There are also circumstances where the additional funding is directly linked to the assisted dying bill. Alex Greenwich MP discussed the link in New South Wales, the state where more than half a billion Australian dollars was assigned to palliative care. He said, "Because just the debate of the legislation opens politicians minds to the reality that we are all going to die, and some people do not die well. In New South Wales, we enshrined the right to good quality palliative care in the legislation."

The increase in palliative care funding seems to have, in part, come from the acute awareness that no one should be placed with a choice between a lack of palliative care options and assisted dying. This was referenced by those inside the system, and there was a clear strength of feeling on this issue.

Dr Paddy Glackin spoke about the patchy palliative care service in Australia before assisted dying was introduced. He said, "And so the profession was very clear, patient groups were very clear, everybody was very clear that it would be absolutely unacceptable to be placed in the position where people were having to look at assisted dying because of a lack of access to palliative care." In short, no one should have to choose between struggling with palliative care and assisted dying.

This was echoed by Dr Anna Negus, who said, "What we cannot do is say that if a patient is unable to access good palliative care, they will not be forced to look at Voluntary Assisted Dying as their only option to relieve suffering. Reports suggest palliative care is lacking in parts of the UK. VAD is an end-of-life choice, not a substitute for good palliation."

In both of these cases, Anna and Paddy point out the need for good palliative care and how this is vital for those accessing assisted dying to have choices around other end-of-life options.

**The wider impact on palliative care**

Palliative Care Australia and Australian Voluntary Assisted Dying services reported that around 80% of individuals used both services[86]. This does not even seem to be a shorter engagement with palliative care; in fact, one study in Victoria shows that individuals accessing assisted dying had a longer engagement with palliative care[87].

Palliative Care Australia also found that "18% of respondents say that the introduction of VAD has resulted in an increased demand for palliative care[88]" with the same study finding just 2% saying it had decreased demand.

A study commissioned by Palliative Care Australia reported that "...there is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards"[89], showing that palliative care services have advanced in areas with assisted dying.

It is also the case that assisted dying has not diverted funding away from palliative care. Dr Clare Fellingham addressed this issue when speaking about the additional funding for palliative care in Western Australia. She said that "...whilst palliative care spending has grown and increased, VAD spending has remained incredibly static and very, very low."

When asked whether assisted dying had been used as a result of a struggling palliative care system, Dr Nancy Burge strongly refuted this and said, "Many of my patients have access to Silverchain palliative care services. I do not think it has hampered them in any way at all. So I think that is just a red herring of an argument. It just does not apply."

The picture of palliative care and assisted dying created here is far from one of struggling palliative care services causing individuals to use assisted dying services. Instead, they have been strengthened in almost every way with almost one billion Australian dollars in additional funding. Some palliative care workers noted an increase in uptake for palliative care as a result of assisted dying legislation, alongside 80% of individuals accessing assisted dying also accessing palliative care services, and these individuals doing so for longer than those not accessing assisted dying.

Whilst more research on this area is required, and it does not account for individual cases, there is some evidence that conditions are the primary reason for choosing assisted dying.

### Coexistence

Whilst addressing the fears around palliative care and assisted dying is important, it is also important to understand how these systems coexist in practice. This cooperation appears to be one way in which concerns around palliative care can be reduced, especially where assisted dying services refer individuals to palliative care services. It is important that both services can coexist and that good relations are built between assisted dying services and palliative care services.

During the initial period of implementation and the first years of services, assisted dying services appear to have successfully reached out to other services. Dr Anna Negus spoke about the work done by the State-Wide Care Navigator Service to discuss concerns about the system, saying, "[the State Wide Care Navigator Service] were key in helping to dissipate fears, talk very openly, and say, "You tell me how you want it to work, and we will help you make it work in that way". They helped make sure it was a coordinated and sensitive approach."

### Individual first care

One of the reasons a good working relationship is particularly important is for those with a terminal illness. Most individuals accessing assisted dying also access palliative care services, and for those who use the services, they can go hand in hand.

This extends to individuals who have a substance for assisted dying and are receiving palliative care at the same time, something which appears to be very common within Australia. Not only are there the statistics that 80% of individuals who access assisted dying use palliative care, but Dr Anna Negus said that within her area, "...I would say an overwhelming majority of my patients receive palliative care right up until they die, whether or not they receive voluntary assisted dying as well. We actively encourage them to pursue that and to continue their treatments."

We also heard of individual cases where both services are used at the same time. Dr Nancy Burge spoke about one such individual, saying that "...one of my longest-standing VAD patients is under Silverchain palliative care and has lots of input and help from them. And they are aware that she has got the substance and may take it." This was also mentioned by Brigitte Tampin, whose husband accessed assisted dying and palliative care. She said, "They told me, because I am on my own, to get palliative care through Silverchain. It is a place where you can call them 24 hours a day if you need any help. Because I was on my own, that was very reassuring for me."

### Distinct services with cooperation

This model for cooperating between assisted dying services and palliative care enables them to maintain separation whilst ensuring cooperation and communication between the two services. Assisted dying systems refer individuals to palliative care or other relevant services, and palliative care can refer individuals who wish to explore assisted dying to the navigator services[90].

The opposite situation also occurs when all individuals accessing assisted dying are also referred to palliative care services. For instance, the model in the Northern Adelaide Local Health Network is where all VAD patients are referred to palliative care services[91].

This has also become normalised amongst the wider palliative care workforce, and the majority of the palliative care workforce are comfortable with providing some level of support. This includes 82% who provide patients, families, and carers with information on assisted dying and "supporting their decisions" alongside 83% who "...are comfortable providing ongoing support and care to a person or family…" who are accessing assisted dying[92].

In some local areas, this is already happening on a wider level. Dr Clare Fellingham said of her local area that they have developed a wider relationship with other providers. She said, "We have developed a fantastically collaborative relationship with our palliative care specialists in my healthcare organisation, where they are happy to refer patients to us, they are happy to collaborate with us, they are not happy to offer this care themselves to patients, but they do not inhibit patients from accessing it. And that is really, really, really important."

Practitioners we spoke to discussed their own experiences of palliative care and assisted dying, working together. Dr Paddy Glackin, when speaking about the local community hospice in Albany, said, "…since their mission is to help people die in the manner and place of their choosing, they would carry through on that. And it has been a tremendously positive experience." The Albany Community Hospice allows individuals to access assisted dying whilst residing on the premises[93].

There are examples within Australia of palliative care providers altering their position on assisted dying. The process for one hospice highlighted some of the key factors in this change, including the importance of community and staff engagement, long implementation periods for palliative care providers, information, sharing experiences from other areas with assisted dying, and understanding that assisted dying is part of end-of-life care. All of this led them to adopt a position to "assist and support those patients who feel they are suffering intolerably, and who wish to access Voluntary Assisted Dying[94]."

Alongside this cooperation, there is also the integration of services at a higher level. This includes integration into wider pathways and resources such as the National Cancer Plan, which includes assisted dying pathways. One aim is "supporting the healthcare workforce with skills and resources on broaching difficult conversations about palliative care, advance care planning, end-of-life care and VAD with consumers, including their carers and families, enabling an earlier introduction to palliative care[95]."

In these three areas of cooperation with individual referrals, hospices reviewing their policies, and national-level integration, the two services can remain separate whilst enabling cooperation. This relationship is not perfect, and issues do still occur, but
This cooperation also creates a broader understanding of how these services work together and a distinction as to what each service is for. Whilst they are different systems with different purposes, they also have the same goal: to improve choice at the end of life.

The services have distinct goals, which may form part of a single pathway for a patient; cooperation ensures both work in the best interests of individuals who wish to access both. More broadly, Dr Clare Fellingham said, "I think the more that we can champion the narrative that palliative care and voluntary assisted dying can not just coexist but are aiming for broadly the same outcome, the better those conversations will be."

Achieving this cooperation in practice will take time and will need to be built into any assisted dying service, whether in the UK or Australia. When asked about how to achieve this, Dr Paddy Glackin said, "I do not have an easy answer for that other than we just build bridges, do not fall out with people, and when we are setting up services, we recognise a proportion of patients will want to go this route, and therefore we have alternative pathways that they can follow."

### Challenges to coexistence

However, this relationship does not mean that in some areas relationships do not exist or individuals struggle to access assisted dying. For instance, Dr Nancy Burge said about the lack of access she had to some hospitals, “For instance, many of the public or private hospitals are run by religious organisations. And so, if you are in one of those hospitals and you want to access VAD, I am not allowed to set foot in that hospital for the purpose of VAD in any form.”

Whilst a role exists for the Voluntary Assisted Dying Board where cases breach the rules, these may be difficult to prove.

### UK palliative care

The UK palliative care system faces many of the issues Australia faced before additional funding and focus. However, in 2021, the UK came at the top of the latest Quality of Death and Dying study[96].

This means that even throughout the implementation process for assisted dying and the first few years of operation within Victoria, Australia as a whole, still lagged behind the UK in terms of palliative care.

The core challenges include improving data collection to ensure the scale of the challenge within the palliative care sector is understood. This includes updating IT systems and ensuring all hospices report data. These challenges were highlighted in a 2022 study of the sector, as the survey on the sector this was based did not include all hospices, and it included incomplete data[97]. This should then be included as part of wider NHS Workforce Plans. This also includes wider improvements in data collection, such as the number of terminally ill individuals within the UK.

Another issue is lack of coordination, as “Fewer than half of respondents said they had a key contact person to co-ordinate their care”[98], and more generally, the variety of settings for end-of-life care. These include hospitals, at home, in the community, care homes, hospices, and specialist palliative care units. As a result, we need more coordination between systems, something called for by Dr Sarah Cox, who argued that “...a central hub or phone line to help people navigate and coordinate care would be transformational[99].” A similar challenge within South Australia was tackled with the introduction of a Palliative Care Navigation Pilot just after the implementation of assisted dying in that state.

There are also wider issues around funding and training for staff which need to be addressed. The challenges faced in Australia and the UK around palliative care are similar; this is of particular interest given the improvement seen in Australian states and territories.

### Investing in the UK palliative care system

Within the UK, the debate around assisted dying legislation has continued alongside the wider focus on improving palliative care services. The government has already invested £100 million in funding for hospices[100].

This funding has also been directly linked with the assisted dying debate and the renewed conversation around end-of-life choices. Toby Porter, CEO of Hospice UK, said of this funding that "I do not think the hospice funding [recent government package of £100 million] would have materialised had the assisted dying debate not taken place when it did [101]."

This additional funding will not by itself fix the palliative care system, and more needs to be done. However, additional investment of this kind puts the UK in line with the Australian experience, and this funding should be increased over time, especially if the wider political discussions around end-of-life care continue alongside the debate on assisted dying.

This is alongside the Commission on Palliative Care, which was set up "...to identify the current strengths and significant shortfalls in the provision and the barriers that exist in the current systems of such care[102]." This commission was created "in response" to the assisted dying bill being debated in Parliament and the consensus which has developed around it on the need for improved palliative care systems[103].

**Palliative care and then assisted dying**

One of the arguments put forward around assisted dying is that it should be implemented only after palliative care services are fixed[104]. However, even with the best palliative care available, it does not eliminate suffering. A recent study shows that even with the highest standard of care available, 7,329 people, or 20 people per day, will die without any pain relief[105].

The Australian experience shows that this investment does not necessarily need to come in a particular order. For instance, Western Australia launched a ten-year plan less than two years before assisted dying, and states like South Australia invested money in their system after assisted dying was implemented.

Finally, as shown above, assisted dying has led to several benefits around awareness, an increase in the use of palliative care, and the number of people who use the service. The same goes for calls to simply focus on palliative care and viewing assisted dying as a distraction to this goal. If anything, assisted dying increased the focus on end-of-life choices and increased funding for palliative care services.

The relationship between assisted dying and palliative care should be one of cooperation, openness, and building trust wherever possible. Whether it is on a local or national level, these services should aim to work together in the interests of the individuals using them, where possible.

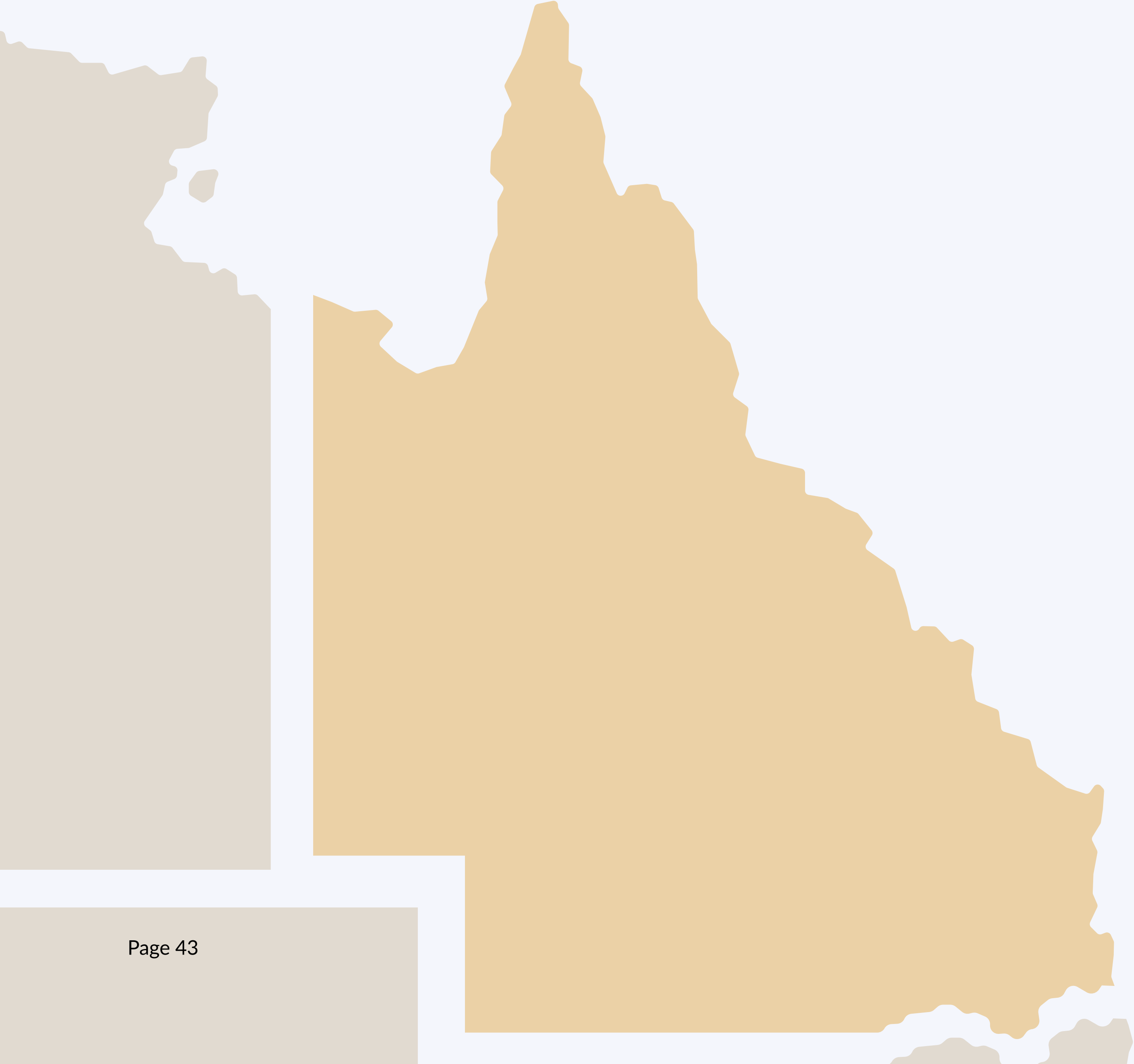
The debate within the UK and Australia also highlights the almost universal support for additional palliative care funding, now a reality for Australia and with additional investment in the UK. Just as in Australia, this support for palliative care should continue long after assisted dying laws are implemented.

It is also clear the extent to which these systems coexist as end-of-life choices. The system operating and running assisted dying within the UK will need to create a new model of coexistence with palliative care services. This is not limited to the additional funding delivered alongside assisted dying, but also includes local and national cooperation.

If we can improve palliative care alongside introducing assisted dying, then choice at the end of life will also be expanded for everyone.

## Chapter six

# Individual experience and care



The experiences of those who use assisted dying include the individual using the service, but also their partners, family, and friends, who show the other side of this system. The aim is to understand why people access assisted dying, whether they are satisfied with the system, and how informed they are about the system.

### Reasons for accessing assisted dying

The reasons for accessing assisted death vary greatly between individuals. It is also important to understand that choice means that others may have very different wishes from our own. For instance, some people would prefer a death with as little medical involvement as possible. Our interviews also highlighted the reasons an individual may decide to access assisted dying; these included:

- The ability to choose when you pass away and at what time or date. Brigitte Tampin said on the timing that "…it gave him enormous peace of mind that he could say when he wanted to go, and that he was in control."
- Loss of dignity.
- Loss of autonomy. In fact, in our interviews, something mentioned repeatedly was the autonomy that the option of assisted dying gives people. For Pauline McGrath and her husband David Levitt, she said of this choice, "Whether he chose to go down that path, he remained totally in control of that decision."
- The choice of who is with you when you pass away. For instance, some individuals may want family members around them when they pass away, which can be very difficult to achieve with other forms of end-of-life care. Brigitte Tampin said one of the main things assisted dying meant for her is that "I can be there. That is the other gift that I feel, you know, I could do all this for him. I could be there with him. It was beautiful."
- An increased choice about where you pass away; this was shown in Western Australia and South Australia, where almost 50% of those using assisted dying died at home compared to 14.8% for the general population[106].
- Enabling people to prepare for death and to make specific arrangements for the day they die. This includes being able to say goodbye to friends and family on the day, deciding what they would like to do on the day, and making arrangements for loved ones. In our interview with Brigitte Tampin, she said about her husband, "That was all scheduled for 1 and 2 pm so that he could say his final goodbye…and he was just comfortable in his recliner chair watching golf in between if he did not sleep, and that was his lovely environment."
- The wish for a non-medicated death, which some individuals prefer.
- Assisted death acts as a safety net depending on how a condition progresses. Liz Smyth described this for her brother Rob as "a bit of insurance. He was not certain that he was going to do this, but knowing that he could took a weight off an otherwise extremely stressful and terrible situation in many other ways."
- Brigitte Tampin said that for Paul, "…if he would not be able to tolerate that, then he could say, "I do not want to live anymore." He was, for these last few months, very jolly, very content."

- Intolerance of strong painkillers such as morphine may exacerbate suffering through intractable nausea and vomiting or cause unwanted sedation. This includes where even the best forms of palliative care are unable to prevent pain.
- Individual wishes about how they or their death should be remembered by their family, children, and friends.
- Loss of independence was also cited as a reason; for instance, losing the ability to walk and eat. The largest factor here seemed not to be the fact that they were unable to do these actions, but it was often tied to what they wanted their last memory to be, such as drinking or eating something they particularly enjoyed before passing away. Brigitte Tampin also discussed the wish Paul had not to lose independence. Brigitte Tampin said, "Well, like I said right from the beginning, he did not want to suffer. He did not want to be dependent on anyone to walk; he did not want to become bedridden, unable to go to the bathroom, and so on. He wanted to be independent with that."
- The decline was caused by the condition, in which the individual would soon die given their terminal diagnosis.
- In our interview with Dr Nancy Burge, she mentioned that some individuals with end-stage "…COPD (Chronic Obstructive Pulmonary Disease) and they know it might be a horrible death…."

Dr Clare Fellingham also said for the individual, "It comes with such a unique sense of relief for that person and an unprecedented level of gratitude for offering them agency in the context of their inevitable death. The ability to allay fear and relieve suffering and anxiety, and ultimately to take control of a disease that has all but consumed them, is the most extraordinary gift."

When looking abroad, it appears that the main factor in choosing an assisted death is the specific condition of an individual. A study focused on countries with assisted dying systems in place, consisting of "Australia, Belgium, Canada, Luxembourg, the Netherlands, New Zealand, and Switzerland and 9 jurisdictions in the US"[107] concluded that the use of assisted dying systems across these countries was more consistent with choices being made around "illness-related factors"[108] as "the relative proportion of MAID rates by disease was remarkably similar across jurisdictions[109]."

This is opposed to being based on external factors such as the availability of palliative care and other factors such as "social assistance,"[110] despite the large differences between these countries. Those with low socioeconomic status are less likely to access assisted dying[111].

### Overall satisfaction

Overall satisfaction with assisted dying services is high amongst those using the system, including family members. This includes agreement with the statement: "The person I care(d) for received satisfactory care from their treating team," which resulted in 69% selecting strongly agree or agree and 15% selecting neutral or do not know[112]. However, this may be a result of some individuals being rejected from the process. 82% of VAD practitioners who answered also agreed that "Eligible people are generally satisfied with the care they receive[113]."

The first five-year review of the assisted dying system also reported that 91% of assisted dying applicants, their families, and their contacts responded that they had received excellent service[114].

However, despite this high satisfaction for individuals who use the system, one area which has been highlighted is the lack of knowledge of these systems for the general public.

### Information

To expand public knowledge and understanding of the system, a variety of materials have been released by state and territory governments. A state which provides a wide range of information in accessible formats is New South Wales.

The state provides a range of guides, including easy-to-read guides[115], a set of guides in a wide range of languages[116], alongside information for interpreters[117].

Another area of guidance is for Aboriginal people, which is provided in Western Australia. In particular, this focuses on some of the barriers which exist to understanding assisted death as an unfamiliar concept for many[118] and in New South Wales, which includes the option to die on the country[119].

The other useful aspect of the support provided includes fact sheets on specific areas of the system, for instance, around tissue donation and assisted dying[120], a step-by-step guide if someone dies at home[121], alongside a handbook explaining every step of the process[122].

### Public knowledge

However, despite these materials, knowledge of assisted dying systems varies between different states and territories. In areas with newer laws, such as the Australian Capital Territory, 85% of people knew about the new law, with just 3% saying they knew nothing about the law[123].

A report in Victoria looked at "addressing gaps in community awareness,"[124] and the report in Western Australia said that "the Board is concerned that many patients are beginning the voluntary assisted dying process late in the course of their illness, which may indicate a lack of awareness[125]."

These issues were highlighted in our interviews, and Dr Nancy Burge said, "I find it extraordinary even now that people sometimes have no idea that it exists," and Dr Clare Fellingham said, "...we do see these very polarising opinions from very supportive to very, very opposed. And we do see patients being actively prohibited from seeking access to assisted dying, or patients being fobbed off, or misinformed, or at worst, being judged and being treated unfairly in the context of the fact that this is a legally available option in their end-of-life care."

Dr Paddy Glackin also raised similar concerns: “We have a lot of evidence that this is not happening and that patients are not getting the information that they need.” These concerns are also highlighted in the state reports, where people are either unable to get information or are given the wrong information.

To improve the level of information and to ensure individuals are informed about all of their end-of-life choices, Dr Paddy Glackin said that as part of the three-year review, it suggested, “…there needs to be proper information. We need posters, we need leaflets, we need a publicity campaign.”

**Options around delivery methods**
There are multiple options for assisted death within Australian states including: oral, assisted oral, and practitioner-administered. Some states allow practitioner-administered assisted death based on preference; others allow it if an individual is unable to ingest the substance and therefore has no other option[126].

We spoke to Dr Nancy Burge about this particular choice for individuals accessing assisted death in Australia. She said, “...there are some people who cannot open the bottles, or they just cannot swallow, or, for various reasons, they are worried that they might mess it up or something. So those people do need to have a practitioner as an administrator.” Dr Nancy Burge also discussed assisted oral and said, “I have helped someone make up the bottle and drink the substance when they have not been able to do it themselves.”

The system in Australia ensures there are always options to allow access to assisted dying. These include oral and assisted oral; if they have a feeding tube, then administration can be carried out using this or IV administration by a practitioner.

## Chapter seven

# Safeguards against coercion

Another concern is that individuals will be coerced into having assisted death, either through pressure from those around them or as a result of other services failing to meet their needs. Palliative care is often the focus of coercion concerns, which were discussed in the previous section.

When viewed individually, each aspect of the assisted dying system within Australia delivers a particular function. However, when taken together, all of these measures create a web of different safeguards for an individual going through the assisted dying process.

This web of safeguards is similar to the Swiss cheese model, where multiple layers of prevention can increase the chances of identifying issues. There are over 100 safeguards within assisted dying legislation in Australian states, such as Western Australia[127].

Below, some of the main safeguards used within Australian states and territories are split into broad areas to show the safeguards used within these systems:

Information

- Informing people with widely available information to ensure everyone within the process is properly informed. This includes information shared by the statewide care navigator services to individuals, practitioners, and other bodies such as palliative care providers.
- General openness around discussing death and forward planning for the end of life.
- Transparency around the functioning of the system is ensured through regular reports containing statistics about any issues within the system.
- A need for practitioners and voluntary assisted dying staff to report each step of the process.

Opportunities to spot issues

- Extensive interaction with individuals and groups of medical professionals. This includes those outside of the system, such as medical professionals and specialists, their nominated contact person who returns the substance, hospital staff, palliative care staff, family, and friends. It also includes extensive time spent with people within the process, including practitioners within the statewide care navigator service and the statewide pharmacy service.
- The Voluntary Assisted Dying Board can spot issues within the system and refer issues to the authorities.
- Inclusion of those with a deep knowledge of the individual within the process. These include family doctors and GPs, especially where they have known the individual throughout their illness or for extended periods. This also includes knowledge of other family members, through either interaction or as their doctor.
- Checks by two doctors who decide whether to begin the process, check that there are no issues, and both sign off that an individual meets the eligibility criteria.

- In Western Australia, a Written Declaration signed by the individual who wishes to access an assisted death or someone signing on their behalf, alongside two independent witnesses who are not beneficiaries, must also be signed. These witnesses are not simply signing the declaration; they are a safeguard against coercion, confirming "...that the patient making the declaration appeared to freely and voluntarily sign the declaration[128]." This is alongside the individual also making a First Request and a Final Request to access assisted dying.
- Specific time limits between the first and final requests can only be overridden if both practitioners agree that the patient is about to die or lose capacity.

Removing individuals from the system where there is any suspicion of coercion

- Clear reporting processes for raising concerns. Anyone can report an issue, including the public, medical practitioners, hospice staff, GPs, assisted dying practitioners, and Statewide care navigator services, which can actively look into any possible signs of coercion. In serious cases, the courts also deal with non-compliance with the law.
- A Statewide care navigator service with the ability to decide that they should not go through the process.
- Clear eligibility criteria often include being over 18, residency requirements, suffering, a prognosis that meets the criteria, and having the decision-making capacity to make the decision voluntarily and without coercion. All of these criteria are safeguards that are checked throughout the process. If an individual does not meet the eligibility criteria, then they will not have access to assisted dying.

A terminal diagnosis

- A terminal diagnosis means that this is not about whether someone will die, but when. Often, an assisted death only moves the timing by a matter of days or weeks. As Dr Clare Fellingham said, "...we are not talking about people who have a choice between living and dying. We are talking about people who only have a choice about dying. And it is the manner and the timing of that death that we are talking about."
- A disability or a mental health condition by itself does not meet the criteria.

Choice

- Additional choice around palliative care options. As has been explained for the Australian context, alongside assisted dying legislation, additional palliative care funding either precedes or proceeds assisted dying legislation.
- Access to assisted dying also improves awareness of end-of-life options, including palliative care.
- When an individual requests an assisted death, the opportunity for discussions around other options, such as palliative care or other options for treatment options, is provided.
- The ability to start, stop, or pause the process whenever an individual would like.
- Reminders from staff that the individual can say no at any point in the process, and checks during the process to ensure the individual would like to go ahead.

Protections
- The law, training, guidance, and required existing experience for practitioners involved in the process.
- Controls around the substance are put in place by the statewide pharmacy services. They control every aspect, from delivery, advising on using the substance, and returning it if unused. The nominated contact person must return any unused substance.
- Specific training on assisted dying for practitioners involved in the process and clear rules about the experience required to be part of the system.

These safeguards prevent coercion, ensuring it is easy to end the process where it exists and in the context of countries without an assisted dying system.

Whilst there are some concerns that these safeguards may be difficult to navigate, we found the opposite from interviewees. Pauline McGrath explained how these safeguards are seen by those who would like to go through the process. She said, "And there is absolutely layer upon layer. It is not onerous as a patient at all because it was an opportunity for us to get to know the team as well. So it was a symbiotic relationship. They were assessing us and by the same token, they were supporting us as well, and it gave us, you know, opportunities to discuss what was important for David at the end of his life. What did this look like? What was his vision of that? How would he like to see it play out? Which was helpful for me as the person, you know, right next to him, alongside him, to understand what he wanted as well." This appears to be by design, especially considering how conversations around coercion between practitioners and individuals who would like to access the service take place.

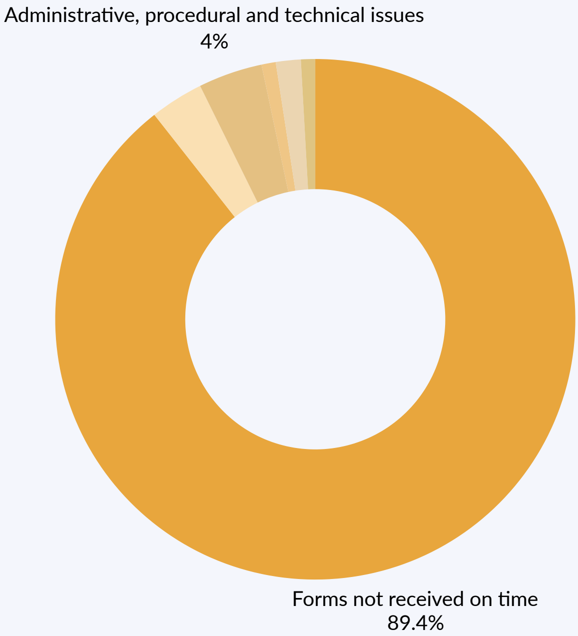
**Real-world case studies and reported issues**
Whilst these safeguards aim to catch issues within the system, it is also important to see whether any issues have been reported. In short, we could not find a single case where an individual had accessed an assisted death despite not meeting the eligibility requirements or had been coerced, by either circumstance or those around them, into having an assisted death.

This takes into account the extensive information from the statewide care navigator voluntary assisted dying reports and reported cases of individuals being coerced out of an assisted death, which show concerns are picked up within the system. Dr Paddy Glackin said, "...we see lots of individual patients who come under more or less pressure from their oncologists, their palliative care physician, the haematologist, and family members trying to push them away from pursuing the assisted dying option."

Compiling information from each statewide report allows for an overall picture of the Act. The figures below are referrals by the board to relevant authorities; as a result, not all of these referrals will be upheld.

**Figure 3: Reports made by the Boards**

Breakdown includes forms not received on time: 404, the assisted dying substance was not returned on time: 15, administrative, procedural, and technical issues: 18, an error in the interpretation of the Act: 4, substance supplied to the individual had expired: 7 and other: 4.



Western Australia

The reports made in Western Australia include one instance relating to the timeliness of an authorised disposal of the substance in 2021-2022[129]. In 2022 until 2023, there were three referrals relating to the timeliness of an authorised disposal of the substance, 164 reports of forms not received on time, and one issue with informing the person making a First Request and the Board of the outcome of a First Request[130]. 2023 until 2024 saw one referral relating to the timeliness of an authorised disposal of the substance, 234 reports of forms not received on time, and one issue around the operation of voluntary assisted dying within the state health system[131].

Queensland

“At the time of the writing of this report, there is an ongoing coronial investigation into a death in the community related to the ingestion of a voluntary assisted dying substance[132].”

South Australia

The South Australia review found 23 episodes which did not comply, which were “...all related to administrative and technical issues that did not affect the clinical care of the patient or the voluntary assisted dying pathway for the patient”, “7 instances whereby the VAD substance supplied to the patient had reached expiry date”, and whilst one matter was referred to the Australian Health Practitioner Regulation Agency, no action was taken[133].

Victoria
In 2020, "…the Board found one case to be non-compliant with the Act. The Board found that while the applicant was eligible for a voluntary assisted dying permit, there was a failure to comply with the procedural requirements of the Act by a medical practitioner[134]." In the same year, there were four cases where there was "an error in the interpretation of the Act by a medical practitioner which resulted in the first request being made to a medical practitioner who did not go on to become the coordinating medical practitioner" and two cases where the substance was returned a few days late[135]. In 2021-2022, there were three cases of delays in returning the substance and someone both signing on an applicants behalf and acting as a witness to the document[136]. In 2021, a case was not compliant with the Act as it breached the rule that "one of the coordinating or consulting medical practitioners has practised for at least five years after completing a fellowship with a specialist medical college or vocational registration[137]." In July 2022 to June 2023, there were "two cases non-compliant with the Act. Both cases were determined as non-compliant because there was a delay with the return of the substance to the Statewide Pharmacy[138]."

From July 2023 to June 2024, the non-compliant cases include three as a result of a delay in the return of the substance, one due to an error in the Contact Appointment Form, and six due to late submission of forms[139].

**Media reports**
There are also news reports on potential issues within the assisted dying system. One case which has been widely reported was the case of Australian man Cyril Tooze, who attempted to access voluntary assisted dying after being[140] "...given a nine-month wait time to receive home care support..." However, one of the only mentions was that "He will meet with a second doctor on the 26th as part of this process[141]" and this is the last update on the process.

However, Dr Cam McLaren, oncologist and founder of Voluntary Assisted Dying Australia and New Zealand, clarified that: "He did not access voluntary assisted dying, so the system worked[142]." Whilst he was originally unable to access home care support, Cyril Tooze was given temporary assistance[143]. We also heard during our interviews cases where assisted dying services would help individuals to access other services, such as palliative care.

The Australian system does pick up cases of coercion, just not in the way that is often feared. Instead, people are coerced away from the system, and individuals are prevented from using the system as a result. Dr Paddy Glackin explained, “Where we do see quite a bit of coercion, it has been in the board reports and many of us have seen that and our patients report it; if any coercive behaviour is happening, it is in the opposite direction.”

There are a few cases of issues within the assisted dying systems in Australian states and territories. Even in these cases, they are not limited to assisted dying, or, in the widely reported case of Cyril Tooze, he was able to access support and did not access assisted dying.

When placing safeguards into this context, they are far safer than the complete lack of safeguards that exist at present.

**The Australian model is better than no system**
When understanding how safe the Australian model is, it is also important to understand just how unregulated and safeguarded the UK is without a legalised and regulated system for assisted dying.

The first challenge is that whilst the UK does not have a legalised system for assisted dying, other countries do. As a result, individuals access services overseas such as Dignitas. The current UK system has no safeguards at all for those with enough money to travel abroad. The only people who struggle to access this option are those on lower incomes, rather than those with the means to travel abroad.

There are also concerning increases in suicides among those who are terminally ill. Those with low survival cancers or Chronic Obstructive Pulmonary Disease (COPD) were 2.4 times more likely to die by suicide compared to those not diagnosed with a severe health condition who had similar socio-demographic characteristics[146].

There is no way to say with complete certainty how many of these are a result of a lack of access to assisted dying, although there is some limited evidence to understand the scale of this issue. Numerous documented instances of individuals taking their own lives as they are unable to access an assisted death exist. Between 2002 and 2024, a total of 608 individuals accessed Dignitas from the UK[147].

It is therefore important to understand that law changes in both the UK and Australia are about adding safeguards and ensuring individuals do not need to seek assisted dying abroad.

**Australian assisted dying safeguards in a wider context**

To understand how extensive these safeguards are, it is important to look at other choices within our medical system, which may result in death. A living will, for instance, involves refusing further medical treatment. This needs to be "written down, signed by you [and] signed by a witness"[147] and does not involve a doctor signing off. If the living will is valid and applicable, then it is legally binding in England, Wales, and Northern Ireland, meaning "...doctors must follow it[148]."

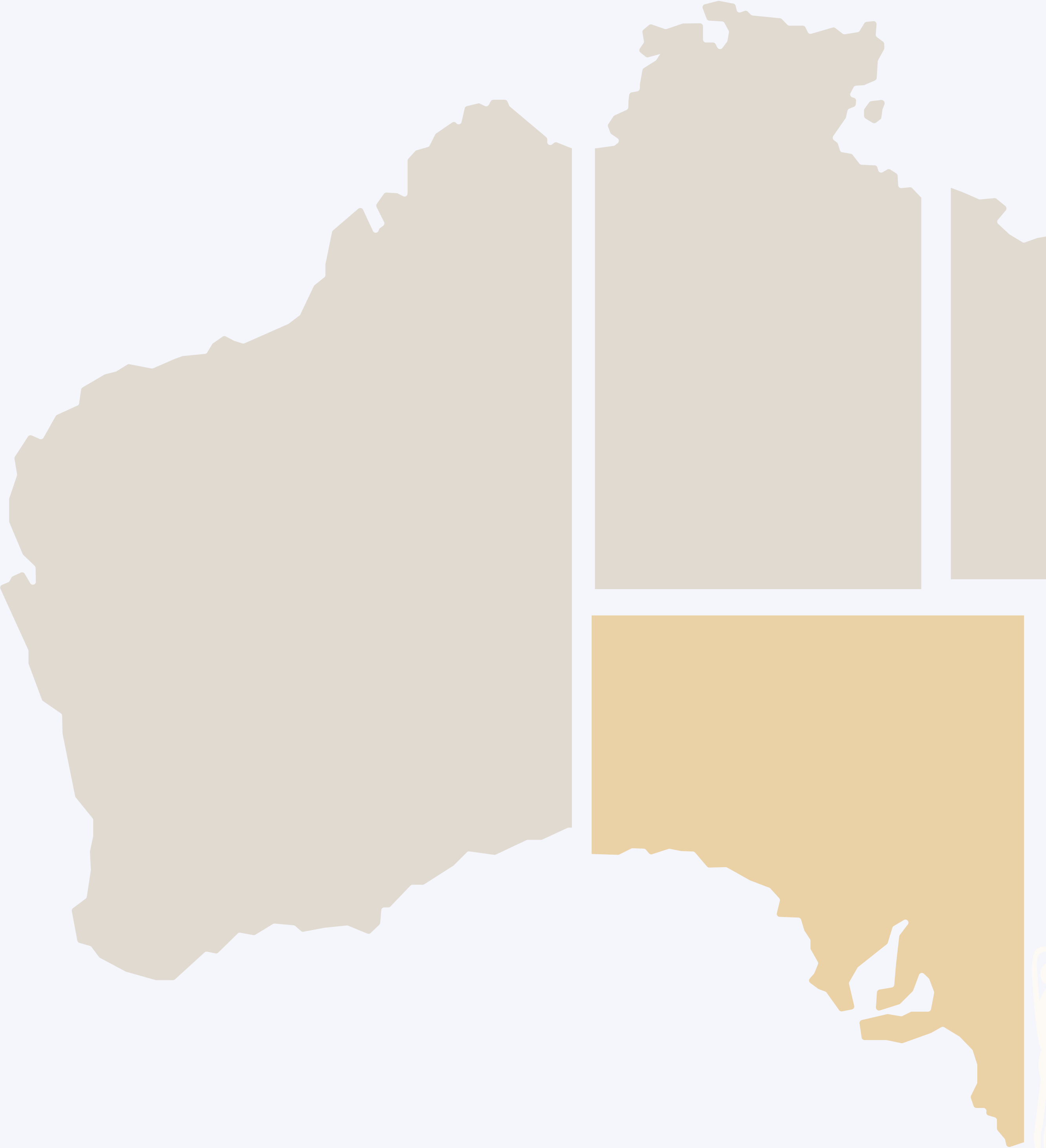
With living wills, it is important to understand that an individual is making decisions about medical treatment that may lead to death. Not only that, but the "future" element means they are making decisions for a future situation without the full details of that situation.

There is also a range of other choices which may be made, which can or, in some cases, will result in death. These include refusing or discontinuing treatments, withdrawing life support, and discontinuing feeding tubes.

It is important to note that the large difference between these choices is the active intervention required to provide an assisted death. Advance end-of-life decisions and removing life-sustaining treatments involve withholding or removing treatments which result in death. Assisted dying is for those already dying, being given a substance to end their life, giving them a choice over the time and location of their death. Yet with one, we trust people to make these choices; we respect their bodily autonomy to make these decisions independently and to do so free of coercion.

## Chapter eight

# Medical professionals



The role of medical practitioners within the assisted dying system includes deciding on eligibility, detecting coercion, and having conversations with patients about assisted dying. This includes training and exams alongside the guidance and resources available to practitioners. This section explores how clinicians are supported to provide effective services and structures to support those going through the process, and will focus primarily on Western Australia, where material is available.

### Existing experience required

Before being trained to be involved in the assisted dying process, practitioners must first pass the requirement for existing experience.

The requirements in Western Australia include six to ten individual requirements for each type of medical professional, including the length of time with a registration, which is ten years for a medical practitioner with a general registration, meeting a minimum number of hours, not having any issues on their professional record that would make them unsuitable, and having two professional referees[150].

This existing experience benefits practitioners, particularly in having conversations around assisted dying. Dr Nancy Burge said of this, "...as GPs, we are used to having difficult conversations about things they might not find easy to share; we are used to asking people deep, meaningful questions about things that they might not want to share. So in some ways, that stood us in good stead."

### Training modules and exams

Alongside this initial experience, practitioners are also required to go through training modules. This training appears to have been particularly useful when the system was initially implemented and provided opportunities to meet with other providers. Dr Nancy Burge said, "The training, I think, was useful. In the early days, there was a little email group of local Perth doctors that we had met, and we talked about things and had a little email discussion. So if there were issues that we were not sure about, we could talk through."

Dr Clare Fellingham also explained how the training was developed as it "...is offered by the Department of Health in Western Australia but was designed by the Queensland University of Technology, who have a health law centre, and they were tasked with developing the training, which is extremely rigorous."

The training delivered is useful for practitioners. In Victoria, 97% found the training helpful or very helpful, and 93% were confident or very confident in their knowledge of Voluntary Assisted Dying legislation[151].

After completing the training sessions, the next step is to pass the exam to become part of the system. Dr Paddy Glackin described this as "...a tough exam with a 90% pass mark. And you are only allowed one or two resets…you are only ever accredited for three years at a time."

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As with other yearly reports, the yearly reports for Western Australia contain information on the number of individuals trained to work within the system. This includes a breakdown of the number of practitioners and nurses who have accessed the training[152]. This training is undertaken by a wide range of individuals, including GPs and practitioners of varying specialities. This includes those in geriatrics and palliative medicine[153].

**Materials and guidance**

A range of training materials and guidance is available to practitioners. This covers almost every aspect of the system for every level of healthcare worker and connected services. The guides and resources are in a range of formats, including checklists, tables, webinars, and flow charts. These resources allow anyone to see how the system works and give clear information to both practitioners and individuals alike.

There are multiple access points for information and training. The primary access point is the state or territory website for the respective health departments. A good example of this is the Queensland Voluntary Assisted Dying page, which acts as a hub for information, help, and support[154] Similar sites exist for other states, such as the South Australian version, which contains a large list of translated information[155].

This is alongside whole process handbooks or guides which are offered by states for practitioners; the Western Australia handbook, for instance, is 91 pages in length[156]. These handbooks also exist in other states, including Victoria, Tasmania, New South Wales, and Queensland.

Alongside these more extensive resources, there are also many areas of guidance, templates, and support which make up this expansive network of training. These include:

- Examples of every form which will be used within the process from the first request to the Notification of Death Form[157].
- The use of checklists, in particular on specific areas such as Voluntary Assisted Dying in Acute Hospitals[158].
- The use of a series of videos specialised for specific groups, such as for clinicians[159].
- Guidance for all levels of healthcare providers, for instance, local health districts[160].
- Broader guidance for all healthcare workers to ensure they know their obligations, even if they have not undergone training[161].
- Guidance for pharmacists involved in the system, including a question and answer format[162] and specific guidance around handling of the substance, including interaction with other acts[163].
- Fact sheets focusing on a specific aspect of the system, for instance, around filling out Medical Certificates of Cause of Death[164].
- Specific scripts for discussions with those who would like to access assisted dying[165].

- Frequently Asked Questions guides for all health professionals[166].
- Assisted dying conversation guides for GPs using pathways, for instance, where a GP initiates a discussion around assisted dying and other end-of-life options[167].
- Tables explaining which particular health professions are and are not able to participate[168].

## Liability

One concern that has been raised about the legalisation of assisted dying is the level of liability that doctors and healthcare professionals who participate in the process may face if they make a mistake or if something goes wrong within the assisted dying process. To understand how these concerns are addressed, we should look at Western Australia and the experience of the four health practitioners that we interviewed as part of this paper. Legal liability, the consequences of their actions, and the amount of responsibility that they face are something that we spoke to them all about.

When assisted dying was enacted in Western Australia, the decisions that healthcare professionals make within the process are protected by a good faith clause. This means that as long as the decisions that healthcare professionals make as part of the process are in good faith, they cannot be held liable for them. Dr Anna Negus explained that in Western Australia, “legislation states that as long as the providers act within the law and do not breach the criteria of the Act, such as the waiting periods or data entry, then they are not criminally culpable.”

When Dr Nancy Burge spoke about small mistakes that a practitioner may make during the process, she said, “If you made a bureaucratic mistake, but it was in good faith, then you would be protected within the law.” She gave an example of this in her own experience, saying, “I have done one report; the consulting practitioner had done a report, and the two dates of birth did not match up. Well, clearly, we were not trying to fiddle with anything. And once we got it sorted out, they [the Voluntary Assisted Dying Board Secretariat] amended it, but they picked that up.” Nancy later said that every submission is read and checked for errors and that, if something were not to feel right, this will be communicated with the doctor and can be corrected.

The protection from the good-faith clause is supported by the rigid and clear legislation used by all states, making it easier for healthcare professionals to follow. In part due to the clarity around eligibility and the steps that healthcare professionals must take before they can provide a patient with an assisted death.

Within all states, the legislation includes strict eligibility criteria. This includes criteria around an individuals age, residency, medical condition, and decision-making capacity. This is alongside extensive guidance for all practitioners around the process. This regulation includes the Act itself, set out in the law, policy, guidelines, education, training, system design, architecture, and funding[169].

From this, it is clear that medical professionals who engage with the Act will not be held legally liable solely for participating in the process, and it reaffirms the experience of Dr Clare Fellingham that you need to be in breach of the law to face any legal implications.

There are several protections to ensure practitioners do not break the good faith clause. First is the extensive guidance and training offered. Second is the weight of the law, which Dr Clare Fellingham described as "...the doctors who ultimately would have their professional registration, their career, or potentially even their livelihoods on the line would be very abreast of those..."

However, whilst this good faith clause exists, one case from Victoria was mentioned by Dr Nancy Burge, which shows the repercussions in cases where clearer falsification is found. She explained, "There was a case where a doctor made a falsification on a document related to VAD. And it was something to do with changing a date and backdating it. And he got fined a lot of money," and the individual was fined $12,000[169].

The good faith clause, alongside the Voluntary Assisted Dying Board ensuring compliance and the sanctions within the system, strikes the right balance.

Dr Anna Negus also clarified that being a practitioner delivering assisted dying, even with the practitioner-assisted options, does not impact indemnity. She said, "We have all spoken with our medical indemnity providers; they say they will cover us provided we act within the regulations."

**Practitioner and patient conversations**

One element which stands out in our interviews with practitioners is the connection between them and individuals going through the assisted dying process. Dr Clare Fellingham said, "...you develop this incredibly deep relationship with a patient, whether you have actually cared for them long-term or not, or whether you have just met them for the process of offering them assisted dying..."

There is also evidence that throughout the process, the continuation of care was an important aspect of doctor participation in assisted death and the ability to be "involved" until the end of their life[170].

As has been mentioned, there is not just training for doctors, but they must have years of experience. Dr Nancy Burge went on to say, "I think, as experienced doctors, you can have a sense of what is going on. And if there was coercion, we would have that sense that something was not right and would delve further."

The starting point for any conversations around coercion is that any individual who does or does not want an assisted death has full choice, controls the process, and has to proactively make a formal request to access assisted dying. Dr Paddy Glackin said, "Well, the first thing is here, you do not have to reject it. If you do not ask for it, it never happens."

Dr Clare Fellingham expanded this further and explained that "…provided that the conversation is in the context of a medical consult and that you do not just talk to them about assisted dying, you talk to them about absolutely everything that exists for them in the end-of-life care spectrum, which includes palliative care, but will include other things such as social support, psychological support, and prioritising their goals of care through careful and thoughtful advanced care planning."

The interviews also show first-hand how a practitioner assesses an individual for any evidence of coercion and then can report issues if needed. The setting of these conversations and the use of background are particularly important. Dr Paddy Glackin said that he likes to "...whenever possible, [have] these consultations in the patients home because that allows you to really see the context and see who else is present and just to ask them why." Dr Clare Fellingham also explained that one of the first steps is to "...ask them about their background, their upbringing, their schooling, their life experiences, and their childhood. We really get to know these people."

Dr Clare Fellingham then explained that "I go into a range of in-depth questions with the person. I would then actually talk to the family, potentially on their own, as well, and try to corroborate the two stories. I would often reach out to their general practitioner or other treating specialists. And then if there was any doubt at all, the simple answer is that they would not be able to be found eligible to access assisted dying because of the voluntariness; the V of Voluntary Assisted Dying is that voluntariness. So I would have no problem acting within the remit of the law and saying, I am sorry, I cannot convince myself that you are acting voluntarily, that this is entirely your wish and therefore I am not finding you eligible and you are welcome to find a second opinion, in which case they could seek another assisted dying practitioner."

Dr Anna Negus discussed a case where there were concerns around an individual accessing assisted dying, saying, "In the end, he decided not to pursue it. The safeguards prevailed. In his case, we could not find any particular evidence of coercion, but there were lots of subtle issues which raised suspicion. We have discussed the case during our specialist group meetings with all providers, and this is the only case of suspected coercion to date in WA. We followed the system, and we found we have lots of different avenues to go down to ask the appropriate questions. So I think if we encourage openness, people are more likely to be able to communicate any concerns. We are then able to make the right decisions as we did in this one instance."

The bar appeared to be very low for all of the practitioners, and if they saw any sign or evidence of coercion or had any suspicions, then they would not feel comfortable proceeding. This was mentioned by Dr Clare Fellingham and by Dr Nancy Burge, who said, "If you had concerns about coercion, I would probably not want to just complete the first assessment there."

This was also shared by those on the other side of the process, and Brigitte Tampin was confident in the system to spot cases of coercion. “I mean, there was no coercion at all because I only did what he wanted, and he wanted this. I supported it because I would feel the same. But there was never any coercion. Absolutely not. And I believe, I mean, I have not been in that situation, but I am pretty sure that the staff from voluntary assisted dying would be extremely cautious with these things and be aware of these things. And it has to be that person to say, “I want to go” to signal that he wanted to access an assisted death.

These conversations act as a supportive measure for those who would like to access the service whilst also assessing whether an individual has a settled will, is free from coercion, and can gain a deep understanding of why an individual would like to access the service, including whether it is being driven by a lack of other services. The bar for rejecting an individual also appears to be very low, meaning any doubts are taken seriously.

All of this, alongside the ability to involve specialists in the conversation where they agree and all of the other interactions individuals have within the system, creates a safeguard to detect any potential concerns.

### Raising concerns

We also spoke to practitioners about how easy it would be to raise concerns within the system for members of the public, family members, or if practitioners themselves had concerns.

There is a clear set of pathways for raising concerns or ending the process:

- A practitioner can simply not complete the first or second assessment
- Consultation with colleagues to gain a consensus on cases
- Consult with the statewide care navigators
- Reaching out to specific professionals, including psychiatrists, senior social workers, and geriatricians
- Seeing an individual multiple times
- A practitioner speaking to the consulting practitioner
- Using the Voluntary Assisted Dying Board or Commission for advice or to report issues
- Members of the public and family members can contact their health ombudsman, complaints commissioner, a State Administrative Tribunal, or the Australian Health Practitioner Regulation Agency
- Raising the issue with a hospital through either feedback or a formal complaint, depending on the issue

### Preventing conversations, Victoria, and the gag clause

Victoria is a cautionary tale for gag clauses which prevent doctors from bringing up assisted death with patients. However, it does not prevent family members or individuals they know from bringing up assisted dying with them, or the individual themselves from bringing it up to the practitioner. There have also not been any issues in states and territories without this clause.

However, it does have an impact on individuals who do not know about assisted dying but would access the service if they did know. This potential to prevent conversations about end-of-life care removes options, even when an individual is eligible in every other respect.

This lack of knowledge is also a serious issue, even in states where assisted dying is legal. Outside of those who are terminally ill, knowledge of these schemes is often low. Seventeen months after assisted death was legalised in Queensland, just 33% of individuals knew that assisted dying was legal, and 26% said they would know how to access assisted dying if they wanted to[171]. In particular, individuals who were not aware of assisted dying included "...older people (who may not be Internet literate) and those from culturally and linguistically diverse (CALD) backgrounds were particularly mentioned[172]."

This lack of knowledge, coupled with a gag clause, is a real challenge when practitioners are one of the primary sources of knowledge for a person who is terminally ill. Australian states and territories require the opposite: increased awareness and information around the system. It can also prevent individuals from having full knowledge of their end-of-life options.

These conversations around assisted dying are not one-sided either. In states like Western Australia, the provision for these conversations is that the practitioner must also speak about all end-of-life options an individual has, including palliative care and other treatments[173]. With these provisions in place, removing the gag clause is likely to start conversations on end-of-life care more widely, with assisted dying simply being one of the options available.

This lack of information has a particular impact on Aboriginal and Torres Strait Islanders, and in this context, "This restriction is seen as a significant barrier, denying patients a comprehensive understanding of all available options, which is essential for making informed decisions about their end-of-life care[174]."

As a result of these challenges, the government in Victoria has decided to scrap the provisions[175]. Dr Clare Fellingham responded to this by saying "...we are delighted that the Victorian government…has decided to take steps to remove the gag clause from the Victorian Act because they found that it was of no benefit and it did cause extra harm."

### Conscientious objections

Built into the system of assisted dying within all states is the ability for practitioners to conscientiously object and to decide not to take part in the assisted dying system. However, the situation around mitigating conscientious objections is mixed, with some states requiring practitioners to pass individuals and others not requiring them to do so.

Dr Nancy Burge spoke about the situation in Western Australia, where "…you do actually have a legal obligation to say, no, I am not part of this, but this is where you can get the information. But sadly, that does not always happen." This strikes a balance between the individual being able to still access information and someone to contact, whilst ensuring the practitioner does not have any part in the main process.

Dr Paddy Glackin also spoke about some of the challenges this creates within institutions, saying "...we have seen the institutions that have specifically forbidden their employees from sharing prognostic information. We have seen doctors who have refused to take part in case conferences and multidisciplinary team meetings if they have any concerns that the information that they share might be used for the purposes of assisted dying."

For states such as Victoria, this obligation does not exist at all. As a result, there have been cases in hospitals which have not passed individuals on to a contact able to discuss assisted dying[176].

In urban areas, the impact of these objections can often be mitigated using the voluntary assisted dying statewide care navigator service. For these individuals, it serves the purpose of linking individuals who wish to access the service with practitioners who are willing to take part. In effect, this allows practitioners to conscientiously object to taking part in the process whilst the individual still has a clear route to access an assisted death.

However, in rural areas, this is a larger challenge, particularly given the remote nature of the areas being served and the already small number of practitioners in the area[177]. In these areas, the state-wide care navigator services are of particular use.

These barriers are also often more challenging within institutions which object to assisted dying. For instance, those in palliative care facilities may be transferred out of the facility to another location to access an assisted death, something particularly difficult given how unstable individuals are at that time[178].

There are a number of ways in which states have balanced objectivity and individual choice. These include:

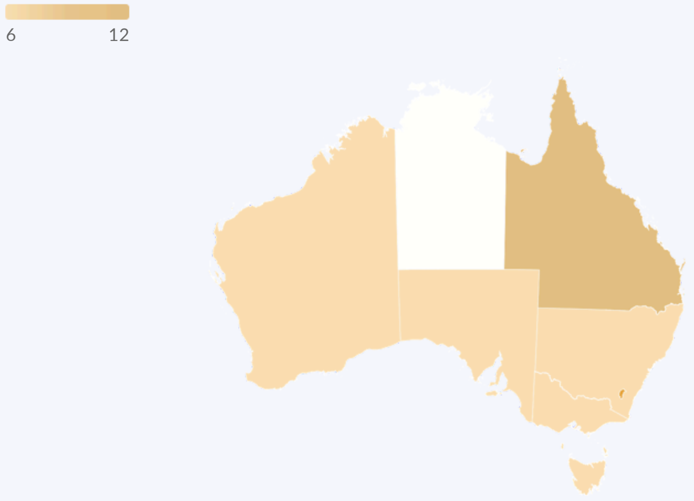
- Ensuring that doctors pass people on and objections are not used to block people from an assisted death.
- Some states consider a palliative or aged care facility to be a person's home, allowing them to access assisted dying even if the institution objects[179].
- Whilst one solution is to ensure facilities have clear policies on assisted dying, in areas such as Victoria, even these are often unavailable. This leaves individuals unable to make clear choices around their end-of-life options[180].

**Prognosis**

The requirements for prognosis vary across Australian states and territories. A noticeable feature is that, despite different expectations around how long an individual will live, the prognosis in all states has always been that the person is expected to die from that condition. This was even the case, including for the Northern Territory and the Australian Capital Territory.

There is also a specific prognosis in most states for those with neurological conditions, which extends the usual six-month prognosis to twelve months. When we discussed the use of this separate diagnosis in Western Australia, Dr Anna Negus pointed out that this did not lead to decisions that were rushed, in fact: "...these people have had these neurological conditions for years and years and years. It is not like they suddenly got diagnosed with one and now they are going to voluntary assisted dying."

## Figure 4: Prognosis eligibility criteria by state



Source: Australian Bureau of Statistics: States and Territories (2021) (boundaries), Simple maps (points)

A clear breakdown of the precise wording of the prognosis required in each state and territory can be found below.

Victoria

Expected to die in six months or twelve with a neurodegenerative disease, and must be experiencing suffering which the individual considers unacceptable[181].

New South Wales

Has an illness or medical condition that will, on the balance of probabilities, cause a person's death within six months, or within twelve months if it is a neurodegenerative disease, which cannot be relieved in a way the individual considers tolerable[182].

Queensland
Expected to cause death within 12 months and must be experiencing suffering which the individual considers intolerable[183].

Western Australia
On the balance of probabilities, will die in six months or twelve with a neurodegenerative disease and must be experiencing suffering which cannot be relieved in a manner that the person considers tolerable[184].

South Australia
It will cause death within six months, or within twelve months if it is a neurodegenerative disease. The condition must be advanced and progressive, and the person must be experiencing suffering that cannot be relieved in a manner they consider tolerable[185].

Tasmania
Expected to cause death within six months, or within twelve months if it is a neurodegenerative disease, and the person must be experiencing suffering that they consider intolerable[186].

There is a clause within this bill which allows the Voluntary Assisted Dying Commission to accept an individual with a condition which is expected to cause death and is advanced, irreversible and incurable without meeting the prognosis criteria. The commission must look at whether an individuals prognosis means they should be exempt. This involves medical records and a practitioner with specialist knowledge of the condition to advise the commission using these records[187]. Only one exemption to this requirement has ever been given in 2022, which was for the shorter six-month prognosis criteria[188], with no exemptions given in 2023[189]. The VAD Commission considers each application for exemption on the merits of the application[190].

Australian Capital Territory
Must be “approaching the end of their life” and “any treatments for the conditions that are reasonably available and acceptable to the individual have lost any beneficial impact”, but no timeframe is specified[191].

Northern Territory
While the law was in place, a terminal illness which cannot be reversed “...without the application of extraordinary measures or of treatment unacceptable to the patient...[192]”

Proposed UK law in 2025
Death is reasonably expected within six months[193].

The main challenge is the level of accuracy around the diagnosis. A study looking at terminal cancer in Australia “...showed that most patients with an expected survival time of less than six months died within six months.”[194] alongside a study finding that “70%” of people died within six months[195], with the remaining 30% living longer than the six-month diagnosis.

There have also been studies within the UK. One prominent study is around the use of a surprise question where clinicians are asked if they would be surprised if a patient were to die within a specific period. This is an "...alternative to a standard prognostic estimate…It does not require clinicians to collect clinical data or to use a scoring algorithm, nor does it require clinicians to make a specific estimate about length of survival…"[196] and has some uses for referring patients to palliative care.

Whilst these studies show the inherent challenges with prognosis, there are also some aspects of assisted dying that deal with this challenge.

First is a specific level of probability for any prognosis, which is clear to practitioners and individuals accessing the service. Dr Paddy Glackin explained the system in Western Australia and that "...our legislation is very clear that on the balance of probabilities, the person must have an advanced progressive disease from which is likely to kill them and from which they are likely to die within six months. That is extended to twelve months for neurodegenerative diseases." Other states use terms such as "likely" or "expected." This makes it clear to everyone involved in the process that a six-month prognosis is a metric which indicates the individual is nearing the end of life.

Second, this six-month prognosis is required to start the process by the time the first assessment takes place. This means that those accessing assisted dying are often seen to have weeks or days left to live, not months. As Dr Anna Negus explained when speaking about rare cancers, "They have died at the same point they would have died, give or take a few days or a few weeks, mostly..." Where the prognosis is closer to two months, the accuracy level is much higher, at around 90% of people dying at or before the prognosis[197].

Third is the additional checks that practitioners can use within the system when there is any doubt. Dr Nancy Burge said that, "...if I am seeing a patient and I am not sure whether they are eligible on medical grounds because of their prognosis, I will sometimes reach out to their specialist and get notes." There are several options open to the coordinating practitioner and the consulting practitioner. They can assess the prognosis themselves, which is especially useful when a patient has decided to discontinue treatment and has not seen their specialist for extended periods. They can also consult with a specialist, if they agree to be part of the process, to confirm the prognosis.

These checks sit alongside two other features of the process. The first is that individuals must have some form of intolerable suffering, which adds additional safeguards to an existing prognosis. The second is that in our interviews, we heard that those accessing assisted dying do not want to die and will often take any available treatments before accessing assisted dying.

Ways to potentially improve prognosis measures and explanations include:

- Where possible, practitioners discuss the maximum prognosis, the minimum prognosis, as well as the prognosis the practitioner expects.
- Where doubt or the individual seeking an assisted death would like additional information, involving multiple practitioners in the process to check prognosis, such as their specialist, if they agree to be involved.
- Informing patients about any other treatments available, including future treatments.

**Workforce**

Assisted dying systems, given that they create a new care pathway, also face their workforce challenges.

A core issue is that the number of practitioners involved in the assisted dying system is low compared to demand, particularly for rural areas where the number of practitioners is already limited. In Western Australia, “This distribution of provision places a high burden on a small number of practitioners…”[198] meaning a few practitioners are taking a large share of the cases. The state and territory reports show the scale of this challenge, with 593 first assessments and 277 practitioner-administered deaths, with just 114 trained practitioners[199].

There are also cases within Australian states where doctors are unpaid for their assisted dying services, and there is “No guidance is given by Medicare about what such services may be and which MBS items may be available for medical practitioners to claim in relation to them[200].”

This complex process will only make the process harder to access for individuals and harder to deliver for practitioners. Any assisted dying system needs a clear and easy-to-use system for payment for work within the assisted dying system, such as assessments.

Another way that Western Australia supports their workforce is through shared learning between these smaller groups of practitioners involved in the assisted dying system. Dr Anna Negus shared her experience of these and said, “So we ended up setting up a group, we had regular meetings, and that was useful. It is basically like you would have in a hospital system: you have morning meetings, and you talk about patients, you talk about difficult situations, and I think that experience from other providers is probably one of the most helpful resources we have, so we try to pool those resources.”

In Queensland, specific communities of practice exist specifically for assisted dying practitioners to learn, speak to other practitioners, attend webinars, access mentors, and access counselling[201].

Over time, the assisted dying workforce has continued to expand. For instance, in Western Australia, a total of 114 practitioners were trained in 2023-24[202], up from 70 people who had completed training in 2021–22[203]. This is mirrored in every state with more than one annual report.

### Impact on other treatments and medical science

Finally, we also asked the practitioners we interviewed whether assisted dying may have any negative external impact on rare diseases, rare cancers, or research into these areas.

Dr Paddy Glackin answered this question by saying that it had not and that “Australia has excellent research centres which do superb work on common and uncommon diseases and rare diseases. We have seen the genetic revolution that has happened recently. We are seeing MIBs, MABs, MUBs, all kinds of incredible and incredibly expensive and incredibly specific new medications.”

Dr Anna Negus also spoke about the medical science aspect and said, “The other thing that I have had patients [volunteer for] is [to] donate their bodies to science after they have died because they have something weird and wonderful. Voluntary assisted dying, I know, has helped a couple of patients organise that in advance.”

Specific guidance also exists in this area in Tasmania, for instance, specifically around becoming an organ donor[204].

## Chapter nine

# Structures and services

There are several services that allow assisted dying to be delivered. The function of these services is to ensure the system is transparent, easy to navigate, and complies with the law. The services created in Australian states are vital to achieving these goals, and the three main ones are the Voluntary Assisted Dying Statewide Care Navigator Services, the Voluntary Assisted Dying Statewide Pharmacy Services, and the Voluntary Assisted Dying Board. Alongside these main services and smaller services, the system also interacts with other services such as complaints commissioners.

### Voluntary Assisted Dying Statewide Care Navigator Services

The Statewide Care Navigator Services are a vital system in the delivery of assisted dying services. This includes individuals who would like to access the service and practitioners who would like to be linked to those individuals. Dr Clare Fellingham said, “They are the absolute linchpin around which the entire state-based service revolves, and without them, I do not think we would be able to offer assisted dying care.”

Key functions

- Provide the first port of call for those looking to access assisted dying services
- Ability to set up contact between practitioners willing to provide assisted dying services and individuals seeking the service
- Help with finding a second doctor to assess an assisted dying request
- Running the Regional Access Scheme to send doctors to rural locations
- Setting up video links for individuals in rural locations
- Gathering information for a practitioner, such as access to notes and recent hospital letters, to assist in the eligibility criteria
- Provide education about assisted dying services to GP surgeries, nursing homes, and hospitals
- Linking patients to external services such as palliative care, mental health support, or aged care assessments
- Arranging for a trained professional to pronounce life extinct
- Provide bereavement support to families

Taken from the interview with Dr Nancy Burge

The service has the primary goal of linking together all of the groups involved in the assisted dying process. Dr Anna Negus described the role as “Whenever a patients family has a problem, I usually put them onto the care navigators, and then they link them up with different service providers such as counselling, mental health services, or grief counselling. So they have a huge, wide range of networks, but a lot of what they do is bridging the gap between the doctor, the patient, and the health facilities and linking all of those people together to make sure everybody is on the same side.” The navigator services also link patients to external services, as Dr Nancy Burge says, “They link patients to other services. So if they have not got access to palliative care, they can link them into Silverchain, mental health, or aged care assessments. The other thing that they do for me, which I find useful, is that sometimes they will access medical evidence.”

Alongside these core roles, the navigator service also runs outreach sessions. Dr Anna Negus explained the information sessions run by Navigator Services, saying, "Usually the SWCNs will make an appointment and go to the institution requiring education on Voluntary Assisted Dying; they will listen to concerns and establish what support is needed. They usually offer an hour-long education session for the group. Whether or not the patient decides to go ahead, they try and just make sure everyone is comfortable and that everyone has had a chance to talk about the issues that they have." There are also examples of these Community Education sessions alongside discussion of the process[205].

The funding from this service is, as Dr Clare Fellingham explains, "...a government-funded group of healthcare practitioners." However, the system still needs additional funding, and we heard from practitioners in our interviews about the lack of funding[206].

The teams within the navigator services have multidisciplinary backgrounds, allowing for conversations between practitioners and the sharing of different perspectives. Dr Nancy Burge said they include "...physiotherapists, nurses, and social workers," and Dr Clare Fellingham also included in this "..a couple of allied health practitioners, such as speech therapists..." Dr Anna Negus also described this as a community "We also communicate very much through the organisation of the statewide care navigator system, and I think that open communication among all of the providers is key in making sure that if anyone has any concerns, then they are relayed to the next provider, who can ask a few questions or try and look for specifics." This system allows practitioners to pool resources in more complex cases, and it allows practitioners to learn lessons collectively from cases.

One area where state-wide care navigator services serve a particular purpose is in rural areas. In particular, Western Australia is the largest state within Australia and the worlds second-largest administrative division.

To ensure access, states have set up Regional Access Support Schemes (RASA). These include financial support available for travel, particularly for individuals accessing assisted dying in rural areas[207]. Whilst one of the reasons for this scheme is the restrictions around the use of telehealth, it also supports those in remote areas, defined by the Queensland service as 50km to the place of consultation[208].

This scheme also plays an important role in finding practitioners during the process. Dr Nancy Burge said, "...there are some very, very rural, far-flung places. So they will support people and find them a practitioner."

These navigator services exist in every state, although most acts do not mention the creation of a specific navigator and where they do, the details around their role are limited. Despite this, every state has created a similar service.

**Voluntary Assisted Dying Statewide Pharmacy Services**

Key functions

- Controls storage, usage, and handling
- Support for practitioners writing and, if needed, collecting prescriptions
- An on-call service where they deliver the substance to the individual accessing an assisted death
- Provide training and education to practitioners, including workshops on topics such as cannulation
- Debrief practitioners after an assisted death
- Deliver the medication, including to difficult-to-reach or rural areas
- Provide information to the person accessing an assisted death. This includes outlining the process, how to make the mixture, and the protocol around timing. Alongside this, information on other medications to ensure their stomach empties properly, calming, and anti-nausea medications.
- Ensure the spouse knows who will pronounce life extinct
- Also, discuss the arrangements around assisted death, including who they are going to ask to do the medical certificate, which funeral home they will use, and which individuals will be with the person when they take the substance down to smaller details, for instance, whether they would like music.
- Organising the process again if someone does not access an assisted death after six months, but would still like to have access to one.

Taken from the interview with Dr Nancy Burge

The pharmacy service also takes on an educational role, and Dr Paddy Glackin explained that "If the patients are going to be patient-administered, then they do a lot of educational work as to exactly how to store, how to keep things safe, how to prepare, what to expect, how to prepare themselves, and they are available to provide ongoing advice."

The service also steps in to support practitioners when needed. Dr Nancy Burge explained one circumstance where "I had some elective surgery and I was off, so I was at home and there was a problem with one of my prescriptions, and the pharmacist came to my home and sorted it out." In this situation, they went the extra distance to support Nancy to ensure she could complete a prescription. This also shows that whilst smaller mistakes do occur, they are corrected using the layers involved in the assisted dying system.

### Voluntary Assisted Dying Board

The final of the three main layers of the assisted dying system is the Voluntary Assisted Dying Review Board. Whilst it uses this name in most states, some states call this body the Voluntary Assisted Dying Board or the Voluntary Assisted Dying Commission.

- Focused on ensuring safety and adherence to the legislation.
- Checking on the activities of practitioners.
- Analysing and publishing data on the functioning of the system.
- Ensuring forms are handed in on time.
- Functioning as a point of contact, practitioners can report any issues.
- The main source of information is a practitioner who has questions about the criteria or other areas related to legislation and further steps which can be taken.
- Focusing on improvements to the system and making recommendations around this.

Taken from the interview with Dr Anna Negus

The tasks also include "…deciding whether to approve or refuse applications for access to voluntary assisted dying, keeping a list of registered health practitioners who are willing to provide voluntary assisted dying services[209]."

### Other services

Whilst these are the core services, other specific services also exist. For instance, in Tasmania, a fourth system operates under the system, the Voluntary Assisted Dying Statewide Clinical Service. This offers advice and support to hospitals and the government, including planning and governance requirements[210].

### Compliance

The final element of this system is how it interacts with and is kept in check by other aspects of the Australian healthcare system. There are several organisations which include:

- The Australian Health Practitioner Regulation Agency (AHPRA)
- State complaints commissioners cover a wide range of individuals who are also involved in the assisted dying process. These include "…doctors, dentists, nurses, surgeons, midwives, physiotherapists, chiropractors, psychologists, pharmacists, Chinese herbalists, occupational therapists, optometrists, osteopaths, podiatrists, paramedics, radiographers, and Aboriginal health practitioners[211]."
- Patient advocacy organisations. One example of this is the Australian Patient Advocacy Alliance[212].
- Review bodies such as the South Australian Civil and Administrative Tribunal (SACAT) "…has power to review decisions made by a Coordinating or Consulting Medical Practitioner that impact a patients eligibility to access voluntary assisted dying[213]."

Within the UK, these roles are also carried out by similar bodies such as the General Medical Council, which handles complaints against practitioners within the UK[214] and the role of patient advocacy groups such as The Patients Association.

### VAD portal and digital infrastructure

Another area, which is not often seen as a specific statewide service, is the digital infrastructure which connects the other assisted dying services.

The Victoria state system allows for submitting forms and accessing training[215]. The Queensland Voluntary Assisted Dying Review Board Information Management System is similar in scale and includes the ability to complete forms and applications to work within the system[216].

However, the most advanced of these systems appears to be the Western Australia Assisted Dying Information Management System. This includes a set of resources. The ability to apply to work within the system, access to training, and forms which can be uploaded by practitioners, including for the first request, consultation, authorised disposal, and notification of death[217].

Our interviews also highlighted where statewide services acted as digital gateways for practitioners. Dr Nancy Burge explained that "…for some of the consultations, they can set up the video links" when speaking about the statewide care navigator in Western Australia.

These digital measures also increase compliance, in particular with the ease of submitting forms. Dr Nancy Burge said, "Because everything that we do, we have to fill in online for the VAD board," and Dr Paddy Glackin also reiterated the point that "You must at each point enter all your data into the system to be approved to go to the next point. I think it is clear you are working within a clearly defined, lawful framework."

However, for any of these benefits to be realised, practitioners need to be able to understand the system regardless of their level of digital literacy. To tackle this, the portals include a comprehensive set of training videos, for instance, in South Australia, where these include easy-to-understand video guides covering every aspect of the portals[218].

The digital systems link the system together and provide evidence that practitioners are operating within the law. These measures, alongside smaller-scale support for practitioners from the statewide services in setting up video links, ensure that digital technology operates properly within the system.

### Telehealth

Despite the existence and advances being made around data and digital infrastructure, issues do remain around more basic communications. The ban on telehealth within Australia is the primary example of this and includes the use of telehealth, telephone calls, and emails when discussing suicide, which in Australia includes assisted dying. This particularly impacts large states such as Victoria and Western Australia, where there are recorded issues with this restriction. This is despite every state having a "Voluntary assisted dying, not suicide" clause or similar, specifically stating assisted dying was not suicide, and the bill in Victoria did not mention suicide.

These restrictions impact the basic operations of the service. This includes prescriptions being emailed to individuals, forcing practitioners to meet individuals in person even if this is unnecessary, and it generally extends the amount of time it takes to access the service[219].

The Australian Medical Association also advocates that legislation should not prohibit the use of telehealth to provide VAD services, in particular with the impact on rural communities and those unable to travel[220].

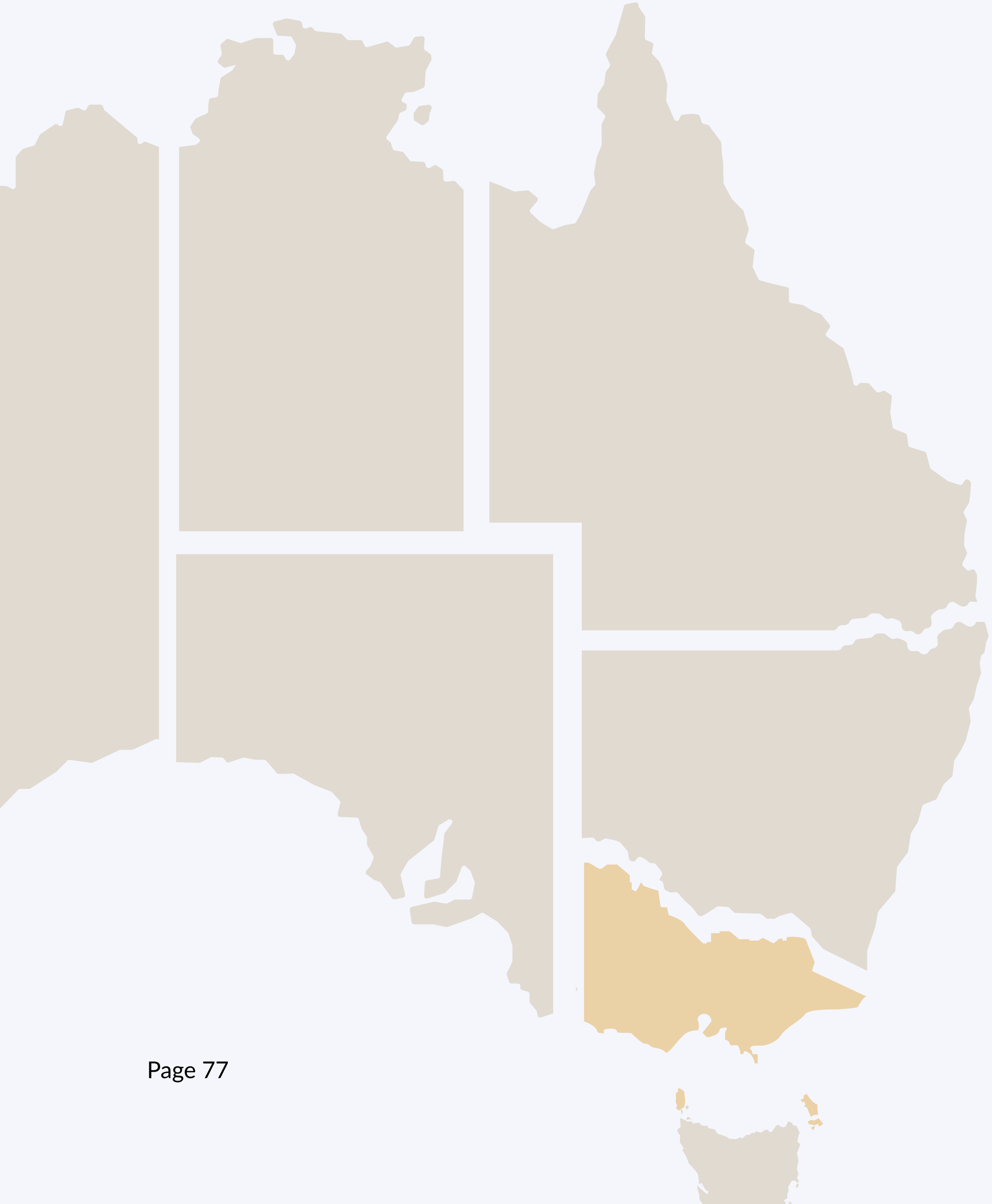
This law unnecessarily impedes access to assisted dying without acting as an extra safeguard.

### International cooperation

International cooperation on assisted dying systems mainly exists in the form of Voluntary Assisted Dying Australia and New Zealand (VADANZ). This is a membership body which shows the importance of international cooperation between practitioners. The body works to “Identify research needs and opportunities for collaboration across jurisdictions.”[221] Dr Anna Negus said of VADANZ that it “...has been meeting for the last two years. VADANZ raises discussion about changes or suggestions to improve care. They are an excellent resource and further serve to link everyone up with different providers who can help each other.”

## Chapter ten

# Lessons and policy proposals



There are various policies we can use and lessons we can learn from the Australian experience of assisted dying. There are some key lessons from Australia and policies we should adopt from these experiences. As one practitioner said after their interview, we do not need to reinvent the wheel; it already exists. The systems already used within Australian states and territories are tried and tested, and we can adopt lessons from these systems without much modification.

Our proposals can be applied to the process within Westminster, Holyrood, the Tynwald in the Isle of Man, and within overseas territories such as the Bailiwick of Jersey and the Bailiwick of Guernsey.

**Ensure assisted dying has the necessary support to function as a standalone care pathway.** Assisted dying should be valued as an end-of-life choice, but to ensure services operate effectively, it must be accompanied by a dedicated operating and capital budget, tailored training and guidelines, and independent oversight from a dedicated board, including pay scales and data collection.

In this system, practitioners act as a safeguard by referring and checking the eligibility of the individuals who wish to access it. From this point, the individual then accesses assisted dying using the dedicated assisted dying service. This creates a dedicated service and does not prevent communication with other services.

**Communities of Practice for practitioners involved in assisted dying.** Regional or local groups should create communities of practice where practitioners have the opportunity to discuss cases they are dealing with, share knowledge, and learn, which includes attending webinars, accessing mentors, and accessing counselling.

**Create Implementation and Operation Areas.** Implementation and operation areas would be the areas which assisted dying navigators, pharmacy services, and implementation task forces would cover. Within Australia, these are states and territories; however, we should aim for smaller areas. The new areas should be at either the ICB level or based on larger clusters of ICBs. For individual islands, a single area would likely be sufficient. These would be smaller and more localised than the Australian statewide services, which often cover millions of people.

**The creation of Implementation Task Forces.** During the implementation period, the creation of the assisted dying system should be overseen by a set of implementation task forces similar to the one created in Queensland. These should oversee the creation of state-wide services, digital infrastructure, training guides, and guidelines, conduct community engagement, and provide regular updates on implementation.

**The creation of Voluntary Assisted Dying Care Navigator Services.** The voluntary assisted dying care navigator services are vital to the functioning and delivery of assisted dying services, acting as a point of contact for individuals and practitioners. When speaking about her positive opinion of the Statewide Care Navigator Service, Dr Clare Fellingham said: “I will strongly recommend that if the UK goes ahead and legalises assisted dying, they adopt a similar model.”

In Australia, whilst some states include a specific reference within their bill to an Assisted Dying Care Navigator and Pharmacy Service, others did not but still went on to create a service to fulfil this function. Whilst a reference to this may be useful in legislation, it is in no way essential to the creation of such a service.

There are some concerns that the Western Australian name is too long and complex, at eight words in length[222]. We should aim to shorten this, or to create an approved shortened version, whilst maintaining a standardised name across the delivery areas.

**Voluntary Assisted Dying Pharmacy Services at the ICB level.** The pharmacy services within Australia have proven to be successful and act as an extra safeguard within the process, both through the basic functions of the service and their outreach work. They also play a vital role in informing those using the service and providing the substance. Within the UK, the Secretary of State would be given the power to make provisions around many of these areas, including prescribing, dispensing, transportation, storage, handling, disposal, and record-keeping[223]. A similar UK service to the Voluntary Assisted Dying pharmacy service should be created to carry out these tasks based on the system in Australia.

The Pharmacists Defence Association previously said that assisted dying care pharmacy services would be feasible within the UK[224].

**Spearheaded new agreements for international cooperation and learning on assisted dying.** We should cooperate with countries internationally, learning from the example of Voluntary Assisted Dying Australia and New Zealand (VADANZ). With Australia, New Zealand, and West Coast American states such as Oregon, Washington, and California all using similar laws, there are plenty of opportunities to share best practices and lessons from these systems. We also asked Alex Greenwich MP about potential cooperation between Australian states and the UK if assisted dying became available within the UK, and he said, "...I know that New South Wales Health would be happy to provide any knowledge or expertise, and share experiences with the UK on how to implement the laws."

**Ensuring that medical practitioners are free to discuss end-of-life options.** The cautionary tale of the state of Victoria, which scrapped the gag clause it originally implemented, shows that gag clauses unnecessarily restrict access to the system. The UK should avoid this system, allowing medical practitioners to discuss assisted dying alongside other end-of-life options, including palliative care, as is the case under the bill at present.

**Additional funding and a ten-year plan to support palliative care.** In Australia, the focus on assisted dying also meant a renewed focus on end-of-life choices more widely, and additional funding was received for the services. The UK is already making some progress in this area, just as Australia did, but there is more work to do. This should come alongside a ten-year plan, similar to one implemented in Western Australia.

**Enabling cooperation between assisted dying and palliative care.** The experience of Australia shows that there will be individuals who wish to use both services. This should be used as the basis for cooperation between the two services, where agreement can be reached on an individual, local, and national level.

The core goals of implementation task forces and assisted dying care navigators should be to build these bridges. This includes understanding what agreements on cooperation can be created and running outreach activities, which include tackling misconceptions about assisted dying.

**A framework to ensure those in a hospice can use assisted dying.** Clear protections are needed, including ensuring all hospices have a clear and public policy for prospective residents on assisted dying, including whether the substance can be kept at the hospice and transfer policies where this is not possible.

**A digital portal for practitioners and the public.** Victoria and Queensland use digital services which allow practitioners to submit forms and show they are complying with the Act. The UK has the opportunity to learn from this, something which would fit with the existing government aim to move towards improved digital services[225]. This digital record should handle training applications and courses, form submissions, log all requests, rejections, pauses, deaths, the location of the substance, and anonymised records of any concerns, including coercion. This would improve compliance and ensure proper data collection.

**Annual and five-year reports on the operation of the assisted dying system.** Each year, a series of local reports collected using shared standards alongside a national report collating the results of these reports should be published. It will combine the data on all aspects collected through the digital portal and will give a complete picture of how the system is functioning. These reports improve transparency and allow the public to directly see how the systems are functioning. Annual reviews are already planned within the proposed bill[226], this is alongside the planned five-year reviews.

**Wrap-around support and proper payment for practitioners involved in assisted dying services.** Any medical professional who is involved in any step of the assisted dying process should be paid for their time. This should start during training and for each case should last from the first request to any work required after an assisted death, such as bereavement support. This needs to use a clear payment structure for each step of the process on a per-hour basis. If possible, this should be built into the wider system, for instance, embedded within the first request form detailing the number of hours taken to streamline payments. Overall, all time spent working within the assisted dying services should be compensated to ensure the workforce feels valued.

Wrap-around support for these services is also necessary. In particular, when dealing with individuals who have been in the long-term care of a practitioner. This includes easy-to-access mental health support and advice.

**A training hub with access to extensive training, guidance, and information.** Australia has an extensive set of training and guidance for those inside and outside the assisted dying system. This helps to create compliance whilst maintaining high standards. The information should include specialist material for medical professionals and the public. The UK should also create a central training hub and, when creating guidance, should learn from international examples, including Australian states. This is particularly true for training around coercion, where international lessons will be key in properly equipping practitioners to detect issues. The current bill already makes provisions for training, including specific training on capacity and coercion[227].

**A role for practitioners who have provided long-term care for individuals.** The involvement of practitioners who have provided long-term care to the individual seeking an assisted death should be built into the system alongside specialists and multi-disciplinary teams. Speaking to Australian GPs showed their vital role in checking for coercion, discussing prognosis with experience of their conditions, and having a deep understanding of an individual they have treated for years or decades.

The current proposed bill makes it possible that a doctor with lengthy experience of a patient may be involved in assessing the individual, as the assessing doctor may make "enquiries" and inform their GP practice, but it does not extend their involvement beyond this function[228]. Expanding this role may include creating a specific role for long-term and family GPs willing to be involved in the process. This would be based on some of the roles we saw practitioners with close involvement with patients undertaking such as signing up to provide background information to the two doctors checking eligibility if they are not directly involved in the process, acting as a point of contact for the care navigator service and being linked up for bereavement support for other family members in their practice.

**Work to improve prognosis whilst being clear about any uncertainty.** Anyone who has a terminal prognosis, including those who would like to access assisted dying, should have information and choice. At present, NICE guidance specifies that a dying person should be given "accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism"[229] Checks, including a declaration of understanding, could be added to ensure the individual accessing assisted dying services understands their prognosis and any uncertainty that may exist around it. This can be integrated into the existing eligibility checks by the two doctors, which would provide opportunities for confirmation without slowing down the process. The two doctors already need to check if an individual has a terminal prognosis, and this would be an additional layer to this check. This can also be added to the Written Declaration.

**Ensure access to the system for those who are unable to ingest the substance.** The Australian model shows the importance of ensuring options for those who are unable or find it harder to ingest the substance. Whilst the current bill does not allow for the administration of assisted dying by practitioners, it does allow for other forms of administration. Under the current bill proposed in the UK, it allows for "The co-ordinating doctor…to prepare the approved substance, a medical device for administration and to assist the person with ingestion and/or self-administration"[230].

Using the Australian experience, the methods open to the UK include self-administration using a drip or through an existing feeding tube.

Within the Bill

- Work to improve prognosis whilst being clear about any uncertainty.
- A role for practitioners who have provided long-term care for individuals.
- Ensuring that medical practitioners are free to discuss end-of-life options.

Implementation Process

- Ensure assisted dying has the necessary support to function as a standalone care pathway.
- Wrap-around support and proper payment for practitioners involved in assisted dying services.
- A training hub with access to extensive training, guidance, and information.
- A digital portal for practitioners and the public.
- Enabling cooperation between assisted dying and palliative care.
- Communities of practice for practitioners involved in assisted dying.
- Spearheaded new agreements for international cooperation and learning on assisted dying.
- The creation of implementation task forces.

Existing Secretary of State Powers:

- Voluntary Assisted Dying pharmacy services at the ICB level.
- The creation of voluntary assisted dying care navigator services.

Outside of the bill

- A framework to ensure those in a hospice can use assisted dying.
- Additional funding and a ten-year plan to support palliative care.

# Conclusion

In conclusion, this paper has shown that assisted dying in practice is about choice, control over how life ends, and dignity at the end of life. Australia offers invaluable lessons for the UK and other countries considering adopting assisted dying.

Whether it is learning from the guidance given to practitioners, using the series of safeguards used within Australian states, or creating versions of the successful Statewide Services alongside their Boards, there are numerous lessons for legislators.

We can also learn from the challenges faced by Australia, particularly the “gag clause” within Victoria. In short, where a perceived safeguard is, in fact, an unnecessary barrier to informed decision-making, it should not be adopted by other countries.

Learning these lessons will benefit practitioners, those using the system, and the wider public.

### The final word

At the conclusion of each interview with relatives of those who accessed assisted dying, they were asked a final question: what they would like politicians or the public to know about assisted dying within Australia or the wider system. These thoughts perhaps give the best insights into what this system means for those who have seen it firsthand.

Brigitte Tampin focused on how it was not just that there are misconceptions around coercion but that “…it is really about fulfilling their wishes and dying peacefully, with dignity, reducing suffering for the person who is dying, but also for the people who are left behind.”

Liz Smyth viewed the system primarily as a backup or alternative option, saying, “It is less than half of the people who apply who go through with it. And it is not because they do not qualify; it is just because they do not do it for one reason or another. But knowing they can, I think, makes a massive difference. People facing the end of their life have enough to be afraid of, and they do not need to be afraid of that as well.”

Pauline McGrath said, “That voluntary assisted dying is a civilised way to die. It is a humane and compassionate option, but it is an option in a toolbox of end-of-life care. And what it did was take the panic away from David. It allowed him to enjoy what little life he had left because he could turn his mind to other things, not just how it was he was going to die.”

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## Disclaimers

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Nothing to disclose.

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