

PARLIAMENTARY DEBATES

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GENERAL COMMITTEES

Public Bill Committee

TERMINALLY ILL ADULTS (END OF LIFE) BILL

Sixth Sitting

Thursday 30 January 2025

(Morning)

CONTENTS

Examination of witnesses.
Adjourned till this day at One o'clock.

No proofs can be supplied. Corrections that Members suggest for the final version of the report should be clearly marked in a copy of the report—not telephoned—and must be received in the Editor’s Room, House of Commons,

not later than

Monday 3 February 2025

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The Committee consisted of the following Members:

Chairs: PETER DOWD, CLIVE EFFORD, SIR ROGER GALE, † CAROLYN HARRIS, ESTHER McVEY

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|---|---|
| † Abbott, Jack (<i>Ipswich</i>) (Lab/Co-op) | † Opher, Dr Simon (<i>Stroud</i>) (Lab) |
| † Atkinson, Lewis (<i>Sunderland Central</i>) (Lab) | † Paul, Rebecca (<i>Reigate</i>) (Con) |
| † Campbell, Juliet (<i>Broxtowe</i>) (Lab) | † Richards, Jake (<i>Rother Valley</i>) (Lab) |
| † Charalambous, Bambos (<i>Southgate and Wood Green</i>) (Lab) | † Sackman, Sarah (<i>Minister of State, Ministry of Justice</i>) |
| † Francis, Daniel (<i>Bexleyheath and Crayford</i>) (Lab) | † Saville Roberts, Liz (<i>Dwyfor Meirionnydd</i>) (PC) |
| † Gordon, Tom (<i>Harrogate and Knaresborough</i>) (LD) | † Shah, Naz (<i>Bradford West</i>) (Lab) |
| † Green, Sarah (<i>Chesham and Amersham</i>) (LD) | † Shastri-Hurst, Dr Neil (<i>Solihull West and Shirley</i>) (Con) |
| † Hopkins, Rachel (<i>Luton South and South Bedfordshire</i>) (Lab) | † Tidball, Dr Marie (<i>Penistone and Stocksbridge</i>) (Lab) |
| † Joseph, Sojan (<i>Ashford</i>) (Lab) | † Woodcock, Sean (<i>Banbury</i>) (Lab) |
| † Kinnock, Stephen (<i>Minister for Care</i>) | |
| † Kruger, Danny (<i>East Wiltshire</i>) (Con) | Lynn Gardner, Lucinda Maer, Jonathan Whiffing,
<i>Committee Clerks</i> |
| † Leadbeater, Kim (<i>Spen Valley</i>) (Lab) | |
| † Malthouse, Kit (<i>North West Hampshire</i>) (Con) | |
| Olney, Sarah (<i>Richmond Park</i>) (LD) | † attended the Committee |

Witnesses

Dr Chloe Furst, dual trained geriatrician and palliative care physician, South Australia; board member of Voluntary Assisted Dying Australia and New Zealand

Alex Greenwich MP, Member of Parliament for Sydney, Parliament of New South Wales

Professor Meredith Blake, University of Western Australia

Public Bill Committee

Thursday 30 January 2025

[CAROLYN HARRIS *in the Chair*]

Terminally Ill Adults (End of Life) Bill

Examination of Witnesses

Dr Furst, Alex Greenwich and Professor Blake gave evidence.

11.30 am

The Chair: We are now sitting in public and the proceedings are being broadcast. I remind Members to switch off any electronic devices. We will now hear oral evidence from Alex Greenwich, MP for Sydney in the Parliament of New South Wales, and from two witnesses joining via Zoom: Dr Chloe Furst, a dual-trained geriatrician and palliative care physician in South Australia and a board member of Voluntary Assisted Dying Australia and New Zealand, and Professor Meredith Blake from the University of Western Australia. Could the witnesses briefly introduce themselves for the record, starting with Alex Greenwich?

Alex Greenwich: My name is Alex Greenwich, Member for Sydney in the New South Wales Legislative Assembly, and I introduced our voluntary assisted dying laws.

Dr Furst: Hi, nice to see you all. I am a geriatrician and palliative care specialist in South Australia. I have been quite instrumental in the implementation of South Australia's voluntary assisted dying laws. I am a practising practitioner with experience with over 150 patients.

Professor Blake: Nice to see you all. I am a professor of criminal law, and health law and policy, in the law school at the University of Western Australia. I have been writing, researching and presenting in the area of end-of-life choices for about 25 years.

The Chair: Before calling the first Member, I remind all colleagues that questions should be limited to matters within scope of the Bill. We have to stick to the timings set out in the programme motion. The first session will finish at 12.30 pm, so can we stick to the points and keep them as short as possible, please? Members who wish to ask a question have indicated that, and I will call them in no particular order. I will start with Simon Opher.

Q265 Dr Simon Opher (Stroud) (Lab): I would like to direct this question to Dr Furst. There has been some concern in this country about the efficacy of end-of-life medications. Could you share some of your experience in Australia about how effective they are and any problems you have encountered?

Dr Furst: The medications are completely effective. I have not experienced any failures. One of the things I feel quite comfortable reassuring my patients and their families is that this medication absolutely works.

In terms of oral administration—the default option in South Australia unless the patient cannot consume the medication or has problems with absorption—it

puts them to sleep within a couple of minutes. They are heavily sedated, as if undergoing an anaesthetic, and then death ensues—that is, the heart stops and respiration stops. For about 95% of patients, that happens within about half an hour. There is a small, small percentage of patients who will continue to be sedated but circulation will not cease for some hours after that. We warn patients and, more importantly, their families that this may be the case, and that is an enzymatic issue.

The medication it is highly effective. Personally, I have not had any experience where patients have had complications—vomiting, respiratory distress or any other concerns. Certainly in South Australia, those have not been issues that have been reported to us. I think there have been a couple of cases of vomiting elsewhere, but the medication has worked in all cases, as far as I am aware, around Australia as well, so this has not been an issue.

IV administration is also highly effective. By the time the medication has been administered completely, the patient is deceased.

This works—it is peaceful. Patients say to me, “I want to go to sleep and not wake up,” and that is absolutely what happens. It is a very peaceful death.

Q266 Dr Opher: Just to confirm—you have not had any failures of treatment, as far as you are aware?

Dr Furst: There have been no failures of treatment in South Australia, as far as I am aware. I am not aware of any other particular ones around the country that have been heavily broadcast to us.

Q267 Naz Shah (Bradford West) (Lab): To follow up on that, there is no requirement that the doctor is present when the person self-administers the substance that leads to assisted dying. Am I correct? If that is the case, why does the law not make it necessary for the doctor to remain present until death, because at that point, the doctor would pick up any complications, would they not?

Dr Furst: Every legislation within Australia is slightly different. For South Australia and Victoria, you are correct—well, there is pretty much no obligation all around Australia for a doctor to be present for self-administration. The reason for that is to give individuals autonomy over their death, and over the time and place of their choosing. We in South Australia do touch base with what we call the individual's contact person to understand if there have been any complications and to check in after the death. A large number of our patients, though, will seek out support from a voluntary assisted dying nurse navigator, who is often present in the house just as a support person. We do also have a lot of feedback from them as to any complications, but the doctor often, or a nurse, will come at a later time to declare life extinct.

The reasoning was that we did not think that there would be complications and we wanted to give people autonomy. We work on a permit system in a lot of jurisdictions in Australia, so people have a permit; they get given their substance and they can take their substance at a time of their choosing. They might have the substance in their house for weeks or months, potentially. Again, there is no obligation to follow through with taking that

substance, which we also think is quite important. We know that in Australia, about 30% of patients who have a permit or who are approved for voluntary assisted dying actually decide that they do not want to consume the substance, but it is about giving them that choice and autonomy, and the strength to maybe pursue other lines of therapy.

Q268 Naz Shah: We have had lots of witnesses testifying about gaps in palliative care and end-of-life care provision here in the UK. What is the current state of palliative care and end-of-life care provision in Western Australia, please?

Dr Furst: I am in South Australia, but a recent survey by Palliative Care Australia surveyed over 900 palliative care specialists, and more than 80% of patients receiving voluntary assisted dying are actually getting combined palliative care and voluntary assisted dying. In our legislation in South Australia, there are key provisions for the monitoring of the funding to palliative care to ensure that no palliative care funding is diverted to voluntary assisted dying, but we feel very strongly that palliative care and voluntary assisted dying should go hand in hand. That is a feeling that is being seen around the country now. Palliative care physicians who are finishing off training now see voluntary assisted dying as part of their core business. It is no longer seen as something that should be provided by separate practitioners. It is really becoming quite integrated.

Professor Blake: I am coming in from Western Australia. We were the second jurisdiction in Australia to introduce voluntary assisted dying laws. Ours have been operative since July 2021, so we have had the opportunity to collect quite a lot of data. Year on year, the number of people utilising voluntary assisted dying in Western Australia is increasing. In the year 2023-24, there were 292 deaths by voluntary assisted dying, which represented 1.6% of WA deaths. I agree with Chloe and confirm her view around the palliative care side of things: 83.8% of those persons who accessed voluntary assisted dying were also accessing palliative care.

Q269 Sarah Green (Chesham and Amersham) (LD): On that point about palliative care, I will direct my question to Dr Furst. What has been the response from palliative care professionals to the introduction of assisted dying in Australia? We have heard evidence from people working in the sector in the UK, but I am keen to hear about your experience in Australia. I understand that Palliative Care Australia's national workforce survey explicitly looked at this, so I am keen to hear what its findings were.

Dr Furst: It has been a journey, certainly. Victoria started their voluntary assisted dying in 2019. I would be lying if I said that the palliative care community were completely on board with it at that point, but over the last five to six years there has been a real shift in mentality. We have seen that they can go hand in hand. Palliative care is about end-of-life choices. Voluntary assisted dying is about end-of-life choices. It is about putting the patient and the individual front and centre, and working with them. That is fundamental to palliative care. We have realised that voluntary assisted dying is a promotion of palliative care and it gives back choices.

Probably some of the older palliative care clinicians have not embraced voluntary assisted dying quite as much. That is probably very generalised, but certainly new consultants and new doctors that are coming through really see this as something that they want to do. I do not think that there is any animosity any more between the practitioners that choose to work in this space and those that do not. I get huge amounts of support from other palliative care physicians that do not necessarily act as practitioners. There is no real divide. It has been embraced, to be honest. In another five years, I think there will probably be very few palliative care practitioners who do not support this, unless they are true conscientious objectors for their own reasons—I guess, probably religious reasons. Palliative Care Australia and the peak medical bodies in Australia have generally shifted to see this as part of patient choice.

Alex Greenwich: The journey to voluntary assisted dying in New South Wales, and indeed across every Australian state, has benefited palliative care access and funding. In New South Wales, 85% of people who have accessed voluntary assisted dying are receiving palliative care. As part of the process, the co-ordinating and consulting practitioners also advise them on palliative care. The doctors are trained on the latest advances in palliative care. Baked into the principles of our legislation is access to palliative care for all citizens of New South Wales. Importantly, throughout our debate, whether Members supported or opposed the reform, our entire Parliament came together to ensure palliative care received an increase in funding and any access issues were addressed. The Australian experience with voluntary assisted dying is that it benefits and strengthens the palliative care system.

Professor Blake: Can I can I add to that? The Voluntary Assisted Dying Board in WA, as in all the other jurisdictions, produces a report. The very strong sentiment of the Voluntary Assisted Dying Board, and indeed within the Western Australia community, is that voluntary assisted dying is seen as part of the end-of-life journey. The board's report states that the statistics and experience of Western Australians

“confirms...that voluntary assisted dying is an established and enduring end of life choice”.

For that reason, there has been quite a significant awareness that practitioners should be able to bring up voluntary assisted dying with the patient as part of that suite of end-of-life choices. That has been something that the evidence has suggested is very important, because if the practitioners are feeling that they cannot raise it in that context, that is having a detrimental effect on the patients who would like information on it. That has been our experience in Western Australia.

Q270 Jack Abbott (Ipswich) (Lab/Co-op): My question is to you, Mr Greenwich. I understand that in New South Wales—and please do correct me if I am wrong—similarly to the Bill we are proposing, you adopted legalised assisted dying for those who are terminally ill and will die within six months, but you also added an additional criterion, which was within 12 months for a neurodegenerative disease such as motor neurone disease. That element is not proposed in our Bill, but we have heard from other witnesses over previous days about that issue. What reflections might you have regarding that, and why did you add that element into the Bill beyond the six months that we are proposing here?

Alex Greenwich: Thank you very much for your question. At the outset, I will just stress that every jurisdiction should legislate the form of voluntary assisted dying that is appropriate to them. In New South Wales, that was six months for a terminal illness, or 12 months if that terminal illness was a neurodegenerative disorder. We had learned from the other schemes in Australia that that was going to be important because of the decline that occurs in neurodegenerative disorders like motor neurone disease, for example. It was because of that that we went down that path.

Professor Blake: I should add that in Queensland, there is no such distinction in life expectation between other diseases and neurodegenerative diseases. Queensland legislation is different: it sets a 12-month period of expected death, and the reason for that approach was in response to feedback from people living with neurodegenerative disease that they felt that they were being put in a different position to people suffering from, or experiencing, other terminal illnesses. The Queensland Parliament took a different approach to address that particular feedback.

Dr Furst: From South Australia's perspective, we are similar to New South Wales; we have less than six months for all conditions bar neurodegenerative conditions, which is less than 12 months. As a clinician, personally, I think that 12 months for neurodegenerative conditions is really helpful, because—as you have heard—if you are looking at prognosis and trajectories, with things like cancer, a patient will be going along and then often have quite a steep and rapid decline. That six-month prognosis is quite noticeable, but for patients with conditions like motor neurone disease, their decline can be slow and very distressing to them. Also, when trying to balance the prognosis along with getting them through the process, 12 months is really helpful, so if there was any chance, I would be strongly advocating for that.

Q271 Kim Leadbeater (Spennings Valley) (Lab): Thank you to the witnesses for joining us this morning. I would like to address my comments to Alex Greenwich, if I may, but also come back to Dr Furst and Professor Blake.

It is really valuable for us as a Committee to hear your reflections on the experience of the process of passing this legislation. How did you manage to keep that process patient-centred but also take into account the concerns around the broader societal issues, particularly when it comes to equality and human rights—those really important issues? What was that process like, and what are your reflections on it? Also, Dr Furst and Professor Blake, one thing that I feel really strongly about is having really good training around assisted dying, and end-of-life care and choice. Would you like to make any comments on what that looks like?

Alex Greenwich: Thank you very much for that question. I will take you through a little bit of the journey to voluntary assisted dying in New South Wales, what encouraged action, and then the safeguards that we put in place.

The New South Wales coroner had reported to us that there were a number of really horrible suicides of people with terminal illnesses who felt they had no option—that those were cruel and lonely suicides. That was backed up by paramedics and police who would arrive on site. Myself and my parliamentary colleagues decided, “We can do better, and we can regulate in this

space.” Voluntary assisted dying in New South Wales is an important form of suicide prevention. What voluntary assisted dying does, in the model that we legislated, is ensure that a person who has a terminal illness and knows that it is going to be a cruel and painful end of their life is instead directed to a doctor—a doctor who will be able to take them through all of their palliative care options, provide and link them with social supports, and give them the choice to have a death that is better than their illness would otherwise provide.

It has been important to make sure that our legislation is limited to that cohort of people who are terminally ill and know they will have a cruel end of life. Our legislation is not about people with anorexia nervosa. It is not about people with a disability. It is not about people who are feeling a burden. It is about a very limited and narrow cohort of people who know that they are going to have a very cruel and painful end of their life, and want that control to know that they can have a death that is better than what their illness would otherwise provide.

We have ensured that decision-making capacity needs to be enduring. We have ensured that a person cannot be under any form of coercion. We ensured that we had a really strong period of implementation, from the time the Bill was passed to 18 months later, when it came into effect, to make sure that our health system and the various doctors required training.

In New South Wales, the experience of voluntary assisted dying is that it has been a form of suicide prevention, and that it has also been, as I explained earlier, very pro-palliative care. As I reflect on our parliamentary debate, it was also one of the first times that our Parliament had grappled with the concept of death. We were very honest about it, and we were very honest in having to admit that we are all going to die, that there are some people with some terminal illnesses who are going to die in a really cruel and painful way, and that we could provide them with an option of control, peace and respect. We believe, and our annual reports into our legislation indicate, that we have been able to provide that. I am happy to answer any further questions, but I will wrap up on that.

Professor Blake: Given that the Western Australia legislation has been in force rather longer than the other jurisdictions that have been talked about today, we have had the opportunity to reflect upon it—I am speaking here as a lawyer; I assume that is why I have been invited to talk—and that has revealed some of the very good things about the working of the legislation, but also some of the challenges that have emerged.

As Dr Furst has said, the legislation in all Australian jurisdictions varies slightly, but it follows a particular legislative model, and is highly prescriptive. It requires a number of requests and, in Western Australia, assessment by two different practitioners. In Western Australia, there is no judicial double-checking of that process. Although I note that that is contemplated within the UK law, that is not something that we have found to be necessary or even appropriate in Western Australia, and I think that would be the case in other Australian jurisdictions.

One of the issues we have experienced is that there is a struggle to get people to take up the training, whether that be medical practitioners or nurse practitioners. One of the thoughts around that has been the very

prescriptive nature of the model, which requires a lot of work on the part of the practitioners. It is worth bearing in mind when looking at your piece of legislation that the more prescriptive it is, the more work it requires on the part of practitioners, and that is a lot of work. We need those people to undergo the training in order that the process is done properly and all the safeguards that are included within the legislation—and they are extensive—are respected. That is something to bear in mind.

We have prescriptive provisions around capacity and voluntariness and lack of coercion. I would add that we also have a requirement around residency. If we are looking at when the legislation has come before a tribunal or judicial body, the only circumstance—in Western Australia, at least—where it has come before the tribunal, which is the State Administrative Tribunal, has been where the practitioner has regarded the patient as not eligible on the grounds of not fulfilling the residency requirements. There has been no other ground on which a matter has been taken to a judicial body.

You asked about the training. That is an essential requirement for practitioners who are involved in making assessments and in the whole process. It is intrinsic to the operation of the Act. The feedback I have heard is aligned with what Dr Furst has said—that no divisions have arisen within the practitioners here, and that those who have chosen to do the training are indeed very valued and very much appreciated by the people who have accessed the scheme.

I will say two more things about the regulation. One is that in the report that has been handed down, the only negative feedback has been about delays. That has been identified as being due to a lack of education among health professionals. One of the recommendations of the report is that education really needs to increase so that people's journey on VAD is not unnecessarily delayed and, perhaps, their wishes are not able to be granted.

The second thing is on conscientious objectors: 13.7% of applications for VAD in Western Australia from 2023 to 2024 were declined on the basis of conscientious objection. But in Western Australia, unlike some other Australian jurisdictions, if a practitioner declines to become involved in the process, they are required by law to give the patient an information sheet outlining options around voluntary assisted dying. That is actually mandated in the legislation.

I have probably said enough for now, so I will hand over to Chloe.

Dr Furst: I completely agree with Meredith that the training is fundamental. For most jurisdictions, it probably takes a full day. It is often an in-person event followed by an exam, which you have to pass. In South Australia, we had a whole lot of mandatory questions that you actually had to pass to be eligible, to make sure that you were upholding the legislation.

This is so different from anything else in medicine. In any other part of medicine that I practise, if I see a process that I think can be improved—if I see efficiencies that can be made or bits of the system that are not adding to patient care—I can choose to adapt the process as I see fit to give the patient the care that I want to give or that is compatible with what the patient wishes. That is so different from voluntary assisted

dying, where, as Meredith said, it is so legislated, down to who can be a witness for various documents. As a doctor, the amount of documentation that is required for voluntary assisted dying is second to nothing. We just do not do that kind of documentation in any other areas of medicine. So it is quite different, and it really does require being quite precise around that documentation and making sure that you are meeting all the timeframes and guidelines. The training is hugely important in terms of the operational component.

There is also the training around end of life and conversations, and how you support the patient and the families. That is a lot harder to teach. That is, I guess, why people will fall into this, and why a large number of palliative care doctors will do it—because it is already second nature to them or they already have the relationship with the patient and they see these conversations as something they are good at and good at facilitating.

So there are two parts of that training that are really important, and then, as Meredith said, there is also the training we need to be giving to the rest of our workforce, and really all health practitioners. A patient might ask the social worker, the orderly or the dietician about assisted dying, and they have to know how they can respond and how they can connect that individual to the right practitioner. That is really important. We have done a lot of work in South Australia, as all the other jurisdictions have, around upskilling the whole workforce, because this is everyone's role and job.

I also wanted to speak briefly on what we in South Australia call the gag clause. In South Australia and Victoria, we are not allowed to bring up voluntary assisted dying with patients, and that is really, really problematic. From my perspective, it leads to poor provision of care. In medicine, when I am talking to a patient, in every other area, if they needed treatment, I would be obliged, and it would be good practice, to tell them about all the treatment options that are available to them. If someone had cancer, I would want to be telling them about good palliative care, potentially surgery, and radiotherapy and chemotherapy, yet voluntary assisted dying is the one thing we are not allowed to talk about and is taken off the menu. Some people may not know that voluntary assisted dying is available to them. They might be waiting for me as the doctor to bring it up to them. I have brought up every other option for them; why am I not able to talk about voluntary assisted dying? I just think it is really important that we do not stigmatise voluntary assisted dying and that we see it as a valid option for people.

Professor Blake: To add to what Chloe said, in Western Australia practitioners can raise voluntary assisted dying as long as it is in association with other end-of-life choices, but the way the legislation is worded is confusing, so one of the recommendations in the most recent report is that that be removed altogether so that voluntary assisted dying is treated like any other treatment option. As Chloe indicated, the evidence was that treating voluntary assisted dying differently can compromise the whole end-of-life journey, because it interferes with discussion of other end-of-life options. The strong recommendation from the board is that it be removed altogether and that voluntary assisted dying be treated just like any other appropriate treatment option so that the patient has a true choice.

The Chair: Colleagues, before we continue, let me say that we have 13 questions and less than 30 minutes, so the question and the answer need to be no more than two minutes.

Q272 Daniel Francis (Bexleyheath and Crayford) (Lab): I want to ask about capacity. Chloe, I think you said patients are sometimes given the drug some time before they die, so I want to understand where capacity assessments are taken and at what stage during the process.

Dr Furst: Capacity assessments are taken every time a doctor sees the patient. In my state, that would be at first assessment—first request—then a consulting doctor would come and do another hour-long assessment of the patient and assesses capacity at that stage, and then I would come back as the co-ordinating doctor for a second or third assessment of the patient, and assess capacity. They would then be given their drug, if it is self-administered. We assume and hope that they retain capacity, and we strongly advise patients and families that, should they lose capacity, they will have voided their permit and they cannot take the drug, but there is less oversight of that. However, we know that the majority—over 80%—of these patients are connected with palliative care, so we often have community teams going in and seeing them, and we are still touching base with them, maybe more peripherally, and checking capacity as we are having conversations or as we are coming and doing home visits from a palliative care perspective. If it were deemed that the patient is quite delirious, the permit would be voided and we would remove the substance from the house. If it is practitioner administration, we are also, obviously, testing capacity right at the moment that we are administering the substance.

Q273 Dr Neil Shastri-Hurst (Solihull West and Shirley) (Con): I will direct this question initially to Mr Greenwich. The issue of coercion has been a significant concern to many in the debate. In line with the New South Wales legislation, the Bill as proposed does not provide a definition of coercion, either explicitly or by reference to other legislation. Have you found that to pose a difficulty in your jurisdiction?

Alex Greenwich: In New South Wales, our legislation deals with and goes through coercion in quite some detail, with pathways to assess it. It deals specifically, for example, with a situation in which someone is under coercion from a person who is a beneficiary of their will; obviously, the person seeking voluntary assisted dying then becomes ineligible. In the space of coercion, that is a key part of the training for a doctor who will be a consulting or co-ordinating practitioner. We have made it a criminal offence in New South Wales, and indeed our board will report on it and on whether eligibility for access to voluntary assisted dying has been denied to someone. Our most recent report indicates that it has.

The overwhelming experience is that having voluntary assisted dying in place is itself a safeguard from coercion for people with a terminal illness. If someone wants to end their life quickly, voluntary assisted dying through a regulated process is not the option that they are going to take. Someone engaging in voluntary assisted dying will be assessed against coercion and against decision-making capacity, and will have to make sure it is an enduring decision.

When we talk about coercion, and the concern that people may currently have in the UK about people with a terminal illness feeling in any way coerced, the experience in New South Wales and elsewhere in Australia is that voluntary assisted dying has provided a safeguard in that regard. Our legislation, the training and the reporting is very clear on that.

Q274 Danny Kruger (East Wiltshire) (Con): Can I have one minute with Dr Furst and one minute with Mr Greenwich? Dr Furst, I have had a look at the reports of the South Australia Voluntary Assisted Dying Review Board, and I can find no data on referrals for additional assessments of eligibility or decision-making capacity, or reasons why people were considered ineligible. There is no provision for reporting on complications, the time between the administration of the drugs and loss of consciousness, or the time between the administration of the drugs and death, and as we have heard there is no requirement for a doctor to be present. I do not understand how you can say that there is no evidence of coercion, issues around capacity or complications at the death, because you clearly do not collect the evidence on those things.

Dr Furst: I do not think that is the case. We are seeking out from relatives—within a month, normally—around any complications. As I said, we are also informally speaking to the nurse practitioners who are on site, but I do not think that that has been published as part of our state report. In terms of coercion, I would say that it is much more likely that patients are being coerced into invasive and intensive treatments, like cancer treatments such as chemotherapy, than being coerced into voluntary assisted dying.

Q275 Danny Kruger: Okay. Thank you very much for that.

Mr Greenwich, you said a couple of things. You said that voluntary assisted dying supports palliative care in terms of funding. I read that although New South Wales committed to spending an extra 743 million Australian dollars on palliative care, in fact the budget was cut by 249 million Australian dollars in 2023; at the same time, New South Wales allocated 97 million Australian dollars in new funding to assisted dying. I do not understand how you think that palliative care benefited from this introduction.

You talked about suicide prevention. The fact is that unassisted suicide rises in states that have assisted suicide laws, because suicide is contagious. It is too early to tell what is happening in New South Wales, but in recent years in Victoria unassisted suicide rose by 50%, while in New South Wales, before it had this law, it stayed the same. Again, I do not understand how you think that this helps with suicide.

We have just heard about the so-called safeguards and we heard yesterday from Australian colleagues. Do you agree that the safeguards that were introduced were in fact impediments to access and that it would be the right thing to do to remove them?

Alex Greenwich: I will try in the time to answer all three of those questions and I am happy to provide more information on notice as well.

On the palliative care funding, it is accurate that New South Wales had a record boost in palliative care funding. Not all of that could be expended as the workforce was

being trained up, but that commitment from all sides of our Parliament is there. You can always seek to improve palliative care funding; that in no way should be competing at all with voluntary assisted dying.

When it comes to the question of suicide, as I addressed in my opening statement, voluntary assisted dying is a form of suicide prevention. If someone wishes to end their life, voluntary assisted dying is not the process they are going to take. It is a process that provides a safeguard to ensure that people are getting full information on palliative care and getting social supports.

In terms of the safeguards in our legislation and being proposed in your legislation, it is really important that you have in your head and in your heart the experience of a person with a terminal illness who is going to have a cruel and painful death. We are talking about people who are dying and who want to have a death better than their terminal illness would otherwise provide them with. We are talking about a small cohort to whom we in New South Wales sought to give peace, dignity and control. We are really proud that we did.

The Chair: I remind colleagues to stay within scope of the Bill, please.

Q276 Kit Malthouse (North West Hampshire) (Con): I want to go back to the issue of gag clause/doctor initiation. Alex, could you quickly talk to us about the thought processes? Can you say why some states introduced it and why you did not? How in legislation have you circumscribed the way doctors should approach this with patients? Perhaps our two medical guests could talk about how, in territories where there is not a gag clause, doctors are obliged not to lean towards a particular recommendation, as they might do with other courses of treatment.

Alex Greenwich: Our experience in New South Wales was based on evidence from doctors and people with the lived experience of a terminal illness. It is an extremely confronting thing to be told that you have a terminal illness, to be told that you have six months to live or to be told, if you have advanced bowel cancer, for example, that your end of life will look like you are going to be choking on your own faeces.

In New South Wales, we decided that it is important that that person, who has been told that they have a terminal illness, is able to have a full conversation with their doctor about all their options—one of those options being that they could have a better death than their illness would otherwise provide them with. We decided that being able to really talk through with your doctor all your options—from access to palliative care, to social supports, to what the process of voluntary assisted dying looks like—was so important. We believe that it is working really well in practice. We would be concerned about gagging those conversations, as that would ensure that a patient is not receiving the full information about their end-of-life choices.

Q277 Kit Malthouse: But how did you approach that in the legislation? Is it silent as to what doctors should do, or does it have a prescription?

Alex Greenwich: Yes. In our legislation we make it clear that the doctor has to make sure that the patient is aware of their palliative care options, and we have referral pathways for psychosocial support as well. All

that is prescribed in the legislation. Obviously, in the training for voluntary assisted dying a lot of that stuff is covered. In the legislation, we also define the things we want to have in that training.

Kit Malthouse: Doctors?

Professor Blake: In Western Australia, which was the second jurisdiction to introduce voluntary assisted dying—

The Chair: Order. I am sorry, Meredith, but we have to move on to the next question.

Q278 Tom Gordon (Harrogate and Knaresborough) (LD): My question is probably more for Alex. When you were coming to the criteria and the safeguards in the Bill in your state, how did that then interplay with other regions and states nearby? Obviously, in the UK the Bill that we are looking at would be applicable to England and Wales. Scotland has its own assisted dying Bill, which is happening at the minute, and we will hear about that later on. Is there information you can share? Can you talk about how different states and regions interplay with each other when they have assisted dying laws?

Alex Greenwich: New South Wales was last in the nation when it came to adopting voluntary assisted dying, and that was actually beneficial because we were able to draw on the experiences of particularly Victoria and Western Australia to make sure that things like the gag clause were not in place. With all respect to the introducer of the Bill, as a result of the Australian experience this is not a revolutionary law reform. It has been tried and tested, we have appropriate safeguards in place throughout Australia, and they work.

Tom Gordon: On that—

The Chair: Order. I am sorry, but you are only allowed one question.

Q279 Rachel Hopkins (Luton South and South Bedfordshire) (Lab): My question, directed at Chloe, is about the practical application of access to doctors for patients, as suggested in the proposed legislation, and how doctors have those conversations with patients—particularly, when it comes to geriatricians, older patients. We heard from somebody yesterday who said that there were concerns around how older people were treated, and the potential risk of elder abuse. I would be interested in the practical application of those conversations, in your experience.

Dr Furst: First up, a patient has to specifically ask me about voluntary assisted dying. They have got to use words that really imply that that is what they want. I will often ask any relatives to leave so that I can have a conversation just with them, to try and reduce the risk of coercion, and then invite the family back.

One of the practical things that I often ask the patient is when they started thinking about this. Is it something that they have always considered should be a right, or is it more of a new-found belief given their current suffering? I want to understand what their current suffering is. I ask specifically whether they feel a burden on their family and friends. It is an hour-plus long conversation to really understand them and their suffering.

Again, I make sure they understand all the other treatment options available to them and what good palliative care looks like. I will often be prescribing other medications as part of that good palliative care—opiates and anxiolytics. As a geriatrician, I am also making sure that their mood is also addressed, and that this is not a reactive depression. I am really doing a holistic and comprehensive geriatric assessment as part of that voluntary assisted dying assessment as well.

Q280 Dr Marie Tidball (Penistone and Stocksbridge) (Lab): This question is for Dr Furst and Professor Blake. Many of us on the Committee are committed to the need to protect disabled people and to ensuring that the Bill has as many safeguards in as possible. We heard evidence yesterday that anorexia may qualify under assisted dying laws in other jurisdictions. Have there been any cases of people with anorexia accessing assisted dying in Australia, and in your view do the respective laws across Australia allow for that? Secondly, are there any lessons that we can learn on building in safeguards in relation to those with learning disabilities?

Dr Furst: All around Australia, mental health as the primary terminal illness is excluded, so anorexia by definition is excluded. I have had a patient come to me with anorexia as their terminal illness requesting voluntary assisted dying. It is a relatively easy assessment because they do not meet the standard criteria, and I was able to explain to them that they were not eligible. But it opens the opportunity to have good, in-depth conversations with them about what they are going through.

I cannot talk to the learning disabilities question, other than to say that every time a patient comes to me the assessment is directed to the patient. I saw a patient today with motor neurone disease who is on continuous bi-level positive airway pressure and is using Eyegaze. The assessment and conversations I have with her are based around what she can do for me. I have had patients who have been able to put a thumb up and down, and I have had trachy patients. I cannot necessarily talk about learning disabilities, but as a holistic practitioner you are trying to make sure that the patient in front of you understands everything and is given the full opportunity to express their wishes.

Professor Blake: I would just say—

The Chair: Order. I can only take one answer. I am sorry, Meredith, but we have not got time. It is one answer to one question.

Q281 Sojan Joseph (Ashford) (Lab): Dr Furst, can I ask a follow-up about anorexia? I know that anorexia is not classified as a terminal illness, but long-term starvation can lead to severe physical health conditions, and patients may end up in palliative care. Do you have any experience of those cases in Australia?

Dr Furst: We have experience of those cases in palliative care, but I would still say that they are not eligible for voluntary assisted dying. None of us would feel comfortable, because the condition has to be irreversible. Capacity-wise, you would have to make sure that they had capacity, and I would question whether someone that is anorexic truly has capacity around their illness.

Q282 Lewis Atkinson (Sunderland Central) (Lab): Mr Greenwich, we are minded that as well as passing really good legislation we want to get public confidence

behind this. We have heard a level of concern from disabled people's representative bodies about the inadvertent implications of this law for disabled people. Were those concerns shared when you took your legislation through, and how it has gone since the implementation of the legislation?

Alex Greenwich: In New South Wales, and across Australia, having a disability or complex mental health issue like anorexia does not make you eligible at all for voluntary assisted dying. The legislation we are dealing with and you are dealing with is not for people with a disability or anorexia nervosa, and not for people who feel they are a burden. It is for people with a terminal illness who may want the choice of a death that is better than what the illness would otherwise provide.

We worked closely with disability groups in New South Wales. Their main concern was that they would be treated equally in terms of access to the law if a person with a disability had a terminal illness. The key point is that this legislation is a safeguard to those concerns. To the point about people who are starving themselves, that is happening today in the UK because people do not have access to voluntary assisted dying. They are starving themselves to death rather than accessing a regulated scheme where they can discuss all their options and choices.

Q283 Jake Richards (Rother Valley) (Lab): This question is probably best for Alex. Yesterday we heard evidence about the health inequalities in our society and fears that they would be exacerbated by the introduction of assisted dying. What was the experience in Australia?

Alex Greenwich: If I think of our health system and how we adopted voluntary assisted dying, like all health systems we were under pressure following the covid pandemic. By legislating in this space you give your health system the priority of dealing with this, making sure doctors are trained to be able to address it and that there is a good implementation period. I believe the Bill has two years, and I think that is completely appropriate to make sure your health system gets up to speed. When it comes to end-of-life choices and healthcare, voluntary assisted dying provides a great deal of honesty and safeguards.

The Chair: I think this will probably be the last question.

Q284 Sean Woodcock (Banbury) (Lab): This question is for Meredith Blake. Does it concern you that a large proportion of people who opted for assisted dying cited being a burden as their reason?

Professor Blake: That is not the evidence that we have got.

Sean Woodcock: Let me just clarify. The state's own report in 2023-24 had 35%.

Professor Blake: We have in a place a system whereby at least 20 case studies are examined by the board every year to look at the reasons behind the taking up of the option. As a means of checking up on how the system is working, that has proven to be very workable.

There are people who feel that they are a burden. People can feel that they are a burden, and that is part of their autonomous thinking. People have their own

views of their own life. The system in place is adhering to the very well-established tests for valid decision making in healthcare generally. If we are talking about people making decisions because they feel like they a burden, well, people make decisions about their healthcare in all sorts of contexts. We have a system of ensuring that decisions are valid, which has proven to be long-standing and successful. That is that the person has capacity, that their decision is voluntary, and that they are informed of the relevant facts and information. That test has stood the test of time, and our legislation, and the legislation throughout Australia, seeks to replicate it.

I would add that with our voluntary assisted dying laws, there is a very clear emphasis on the information that the patient is entitled to. The information that the practitioner has to give to the patient is extensive. It must go through the palliative care options. It must go through with them what voluntary assisted dying involves, and it must also include discussion of, “What if the voluntary assisted dying moment does not work?”

The list of matters that must be discussed by the practitioner is very extensive. In no other sphere of medicine where a patient is working with their healthcare practitioner does this level of informed consent apply. In terms of medical practitioners ensuring that people have the capacity to make the decision, are making it

voluntarily and have all the relevant information at their disposal, we cannot find anywhere, in any other context of healthcare, the level of safeguards and protections that we find in this sphere.

If there are people who are saying they are a burden, that does not mean that their decision is not voluntary. That does not mean that they do not have the capacity. It simply is an expression of how they feel. The key thing is not whether they think they are a burden; the key criteria are whether they have the capacity and whether their decision is voluntary and free from coercion. Health practitioners make those assessments all day, every day.

Sean Woodcock: I am taking that as a no.

The Chair: Order. I remind colleagues that it is unacceptable for a Member to interrupt a witness once they have started answering. That brings us to the end of the time allocated for the Committee to ask questions. I thank all witnesses on behalf of the Committee for their evidence.

Ordered, That further consideration be now adjourned.
—(*Kit Malthouse.*)

12.30 pm

Adjourned till this day at One o'clock.

