OFFICIAL REPORT
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Health, Social Care and Sport Committee

Tuesday 5 November 2024

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

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HEALTH, SOCIAL CARE AND SPORT COMMITTEE

29th Meeting 2024, Session 6

CONVENER

*Clare Haughey (Rutherglen) (SNP)

DEPUTY CONVENER

*Paul Sweeney (Glasgow) (Lab)

COMMITTEE MEMBERS

*Joe FitzPatrick (Dundee City West) (SNP)
*Sandesh Gulhane (Glasgow) (Con)
*Emma Harper (South Scotland) (SNP)
*Gillian Mackay (Central Scotland) (Green)
*Carol Mochan (South Scotland) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Julian Gardner (Voluntary Assisted Dying Review Board)
Liam McArthur (Orkney Islands) (LD)
Professor Ben White (Australian Centre for Health Law Research)

CLERK TO THE COMMITTEE

Alex Bruce

LOCATION

The Sir Alexander Fleming Room (CR3)

Scottish Parliament

Health, Social Care and Sport Committee

Tuesday 5 November 2024

[The Convener opened the meeting at 10:22]

Interests

The Convener (Clare Haughey): Good morning, and welcome to the 29th meeting in 2024 of the Health, Social Care and Sport Committee. I have received no apologies.

Today, we begin our scrutiny at stage 1 of the Assisted Dying for Terminally Ill Adults (Scotland) Bill. By virtue of rule 12.2.3(a) of standing orders, Liam McArthur is attending the meeting as the member in charge of the bill. I welcome you, Liam.

I also welcome to the committee Elena Whitham, who is replacing Ruth Maguire. The first item on our agenda is a declaration by Elena Whitham of any relevant interests.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): I have no interests to declare at this point.

Decision on Taking Business in Private

10:23

The Convener: The second item on our agenda is a decision on whether to take agenda item 6 in private. Do members agree to take that item in private?

Members *indicated agreement.*

Assisted Dying for Terminally Ill Adults (Scotland) Bill: Stage 1

10:23

The Convener: The third item on our agenda is our first evidence session as part of our scrutiny at stage 1 of the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

We begin our scrutiny by considering the implementation of assisted dying in other jurisdictions. The first session is with witnesses who are involved in the application of assisted dying law in Victoria in Australia. I welcome to the committee Julian Gardner, who is the chairperson of the voluntary assisted dying review board, and Professor Ben White, who is professor of end-of-life law and regulation at the Australian centre for health law research. We have received apologies from Katherine Waller, who is the project manager for voluntary assisted dying training at the Australian centre for health law research.

We move straight to questions.

Brian Whittle (South Scotland) (Con): Good morning. I have a question about the impact of the state of palliative care on people’s decisions to take up the opportunity to have assisted dying. Is there any evidence that the state of palliative care has an impact on such decisions?

Julian Gardner (Voluntary Assisted Dying Review Board): The statistics in Victoria for each of the five years have been that either 80 or 81 per cent of people who have accessed voluntary assisted dying have also received or, at the time of their death, are currently receiving palliative care. That seems to be quite a high number.

There was a conference in Australia last week at which Palliative Care Australia released information from a large survey that it had done among its members. I do not have access to that yet, but I am sure that you could obtain it. The information indicated a growing acceptance of voluntary assisted dying among palliative care practitioners. More importantly, it speculated that there had been an increase in demand for palliative care because there had been more conversations about the options for end-of-life care in general.

Brian Whittle: Just to clarify, are you saying that palliative care providers are part of the process, with the ability to impact on and input into the process of assisted dying, and that their opinions are sought?

Julian Gardner: No, not necessarily. However, a person might receive both palliative care and voluntary assisted dying. There are some cases in which a palliative care specialist will be one of the two assessing doctors, but that is not necessarily the case. Does that answer your question?

Brian Whittle: Yes. We are looking at the impact on the number of people potentially seeking to have an end-of-life alternative when there is a system in which palliative care is not so good compared with a system in which palliative care is really good. That is what I am trying to get at.

Julian Gardner: The way in which it is treated here in Australia is that they are not alternatives. They operate concurrently, so it is not an either/or situation. I think that the Palliative Care Australia survey indicates that there has been no negative in the sense of taking people away from accessing palliative care.

Brian Whittle: The state of palliative care in Scotland just now is that not everybody has the ability to access it. Given that, potentially, there are people who are not able to get the palliative care that they need, is there any evidence that that is driving them towards a different decision about ending their life?

Julian Gardner: I am not aware of any empirical evidence on that one way or the other.

Professor Ben White (Australian Centre for Health Law Research): I agree with the points that Julian Gardner has made. In Australia, there is a requirement that, as part of the process of seeking voluntary assisted dying, people are informed about palliative care. It is a legislative duty, so we can have confidence that the individuals who seek voluntary assisted dying are aware that palliative care exists in a way that others in the community might not be. I suspect that some of that is what is driving the high rate of utilisation of palliative care. Julian talked about an 80 per cent figure, which is replicated largely across Australia. Those who seek voluntary assisted dying are highly likely to be engaged in and receiving palliative care.

Brian Whittle: Thank you—that is very helpful. Are the people who seek assisted dying required to provide their reasons for doing so?

Julian Gardner: Some people offer statements, but they are not required to do so. They have to meet all the criteria—that is, they have to be at the end of life and be experiencing intolerable suffering, as well as meeting the other eligibility requirements. They do not have to say that it is because of one reason rather than another, although some of them do that. Some states collect that information. In Victoria, there is no requirement to collect it.

10:30

Paul Sweeney (Glasgow) (Lab): In Victoria and elsewhere in Australia, can people take the decision early, shortly after receiving a terminal diagnosis, in anticipation of their condition deteriorating over time? For example, if someone has pancreatic cancer and they know that the usual course will lead to significant pain later, as the condition progresses, and that it may ultimately lead to terminal delirium or agitation, can they decide that they will administer the medication to end their life at the point where that real deterioration takes place? Rather than the decision being made at the point when the medication has to be administered, can the decision be made in anticipation that the condition will deteriorate over time, with agreement with clinicians or relatives that the medication will be administered at that point?

Julian Gardner: I will clarify the law in Victoria. There are two methods by which the medication can be administered. One is self-administration, whereby the person has to swallow some liquid. The other is practitioner administration, which involves an intravenous application. If a person qualifies and they obtain the medication, it is delivered to them, they keep it in a locked box and they have to choose when to take it.

In the case that you outlined, as long as the person meets the requirement of being within six months of death, they can have the medication. They may receive sufficient comfort from knowing that they have it and they have autonomy and control over their life, and they may not take it straight away. They may take it a few weeks later or they may not take it at all. Is that what you were getting at?

Paul Sweeney: Yes. It was about whether the individual would have sovereignty after the agreement had been put in place, in that, at any point in the progression of their condition, they could determine when to take the medication. There may be a scenario where someone enters a state of delirium and they are not necessarily aware of their surroundings. At what point does that sovereignty become questionable? Can they have a pre-emptive understanding with relatives who will help them to take the drug?

Julian Gardner: No—absolutely not. If the drug is administered by a practitioner, the practitioner has to be satisfied that, at the time of the administration, the person has decision-making capacity. If the person possesses the medication themselves and they have dementia, delirium or whatever and they lose capacity, they are not going to know that they have the medication and what they have to do to mix it up, so they are not going to take it.

Paul Sweeney: Okay. That is helpful. Thank you.

Julian Gardner: It is quite different from your bill, which, as I understand it, contemplates a medical practitioner being with the person every time.

The Convener: Professor White, do you want to add anything to that?

Professor White: I have nothing further to add on that.

The Convener: Moving on, I have some questions about the means of death. The bill does not specify the means of death, other than to say that the person will be provided with an “approved substance”. It does not specify a particular drug. How do you respond to claims that the medications that are used in assisted dying in other jurisdictions are not well researched or evidence based?

Julian Gardner: The professor who heads the pharmacy here in Victoria makes the point that 100 per cent of the people who have taken the medication in whichever form have died, generally within a very short timeframe, although there are outliers where people have lapsed into a coma quickly but have stayed alive for a few hours. We have not had any issues in Victoria and I am not aware of any situations in other states where the medication has not been totally efficacious.

The Convener: If the medication was not totally efficacious, would that information be recorded in all states?

Julian Gardner: I assume that it would be. If we had such a case in Victoria, we would include it in our annual report. I have not heard any of my counterparts in other states talk of such a case.

The Convener: You said that there have been occasions when someone has not died in the timeous way that we would have expected. What are the complication rates in Victoria and in Australia as a whole, and what type of complications most commonly occur?

Julian Gardner: I do not know that I would use the term “complications”. The fact that somebody might take two hours to die is not considered to be a complication. Death normally occurs within 30 minutes, but it is not deemed to be a complication if somebody takes two or three hours. The vast majority of deaths occur within a shorter timeframe.

The Convener: I take your point about complications, so I will not use that word in this next question. Where there are adverse events, for example if someone vomited up part of the medication that they had taken and there were issues or difficulties, are the healthcare professionals around the person allowed to intervene? If someone is on their own or with another person—the legislation being very different—how are people trained to respond? Is there a protocol or guidance in place?

Julian Gardner: In Victoria, someone who is administering the medicine themselves receives three medications. The first, which is taken about an hour in advance, is a relaxant; the second is an anti-emetic, to reduce the risk of regurgitation; the third is the pentobarbital, which will cause the person's death.

We have had reports of people who have vomited a little bit, but that has not caused them not to die within the normal timeframe. We have had reports of people who have not consumed all the medication, but it is of such potency that people probably only need to use a third of it anyway in order to cause death. None of those cases has caused what I would call an adverse event. Some of them may have been a bit distressing for the family present to see the person have a bit of a hiccup during the process of drinking the medication, but there has not been an adverse event.

Professor White: In Western Australia, there are records of complications, as you have described them, convener. Some of them include difficulties getting an IV line in, for instance. We have both self-administration and practitioner administration. There may be some regurgitation of the substance. The events that we talk about in the Western Australian board report have been relatively minor and the report notes that all the people who experienced such issues around taking the medication have still died.

Julian Gardner mentioned Professor Michael Dooley earlier. He was the chief pharmacist who developed the medication protocol for Australia. Where self-administration or practitioner administration happens in other jurisdictions, there are sometimes standardised processes, but sometimes there are not such processes. From the very start in Australia, however, the model was to have a medication protocol, which had prescribed medication, prescribed steps and the times, including the ones that Julian mentioned earlier. One of the upsides is that that adds regulatory control, and there is a consistent systematised way of taking the medication.

I am aware of a study of 500 cases in Australia that covers how the protocol has been used. It is not yet published, but I am sure that the author would be pleased to send you a copy once it is published. I understand that it will be available in due course, and that evidence may be of interest to the committee.

The Convener: Before we move on, I put on record my entry in the register of members' interests: I work as a bank nurse for NHS Greater Glasgow and Clyde.

Paul Sweeney: In relation to the substances that can be used, in Australia, is that kept open and is a review done independently by practitioners, or does the legislation define the substances?

Julian Gardner: The substances are not specified in the legislation. The way in which you obtain authority to write a script for the medication varies a little bit from state to state. Here in Victoria, once you have completed all three requests, a permit can be issued to prescribe the medication, but the only medications that can be prescribed are those set out in the protocol.

Paul Sweeney: That is helpful. Thank you.

Gillian Mackay (Central Scotland) (Green): Good morning to those joining us online. Is the service that is currently set up in Australia, and in Victoria specifically, a specialist service that has been set up to deal with assisted dying, or does it sit within other established healthcare services?

Julian Gardner: It is not a specialist service, with one exception in New South Wales, which I will let Professor White talk about. It is simply a mix of general practitioners and specialists who undertake the prescribed training, and who meet the qualification requirements on length of experience and admission to a college of specialists. They might be medical practitioners who are employed in public hospitals, or they might be in private practice.

Ben, would you like to talk about New South Wales?

Professor White: Yes. In New South Wales, as Julian Gardner mentioned, and also in Queensland, a specific service was set up, which is able to assess eligibility and provide voluntary assisted dying, if that is required. Ideally, the model is provided locally, so it would happen in a public or private setting where the person lives. However, Australia is a big place—states such as Queensland have a very large geographical area to cover—so the service is actually about ensuring statewide access. It is called Queensland VAD—voluntary assisted dying support and pharmacy service. It is an integrated service, and as part of its function, if there is no local capability—if there are no practitioners who can assess eligibility in a particular area—the service is able to travel, meet the patients, assess them for eligibility, and so on. Therefore, there is a specialised service, but it is more about covering off statewide access where that is needed. It is not the starting point, if that makes sense.

Gillian Mackay: So, if I am understanding—

Julian Gardner: May I just quickly add to that? We do have a specialist pharmacy, though, which is centralised and Government run, which delivers the medication no matter where a person lives, free of charge. We also have a specialist service in Victoria that uses what we call "care navigators". They are generally nurses, and they do a lot of the liaison to ensure that people have access and to overcome access difficulties. Sorry for interrupting.

Gillian Mackay: Not at all. That is very useful, thank you.

Professor White, to come back to what you said, was the specialist service established purely due to issues of rurality and the size of the state that must be covered, or were there other considerations?

Professor White: In Queensland, when the service was initially established, the idea of outreach and ensuring statewide access was not contemplated as part of that body's role, but it became clear that there was a need; for example, some remote areas did not have access to practitioners who could assess voluntary assisted dying, which is why the centralised service, which includes both the pharmacy and the navigators that Julian Gardner mentioned, stepped in to do that role.

New South Wales, which was the Australian state to pass such laws most recently, set up an access service that had that designated role from the start; however, the focus is on ensuring access where local access is not possible. It is not the default—it is not that that service provides voluntary assisted dying—but it is there if you do not have practitioners in your area who are able to assist or no one is able to provide voluntary assisted dying where you are and whatever part of the state you might live in.

10:45

Gillian Mackay: Julian, I come back to what you said a couple of minutes ago about the training that practitioners receive. Could you give us an overview of what that training looks like? Does it vary by state, or is it set out in the legislation that is provided in Australia?

Julian Gardner: In Victoria, the Secretary of the Department of Health specifies the training. I will, however, defer to Professor White, because we contracted him and his expert team to prepare and deliver the training in Victoria and, indeed, in some of the other states, so you could not talk to a better person than him.

Gillian Mackay: Great. Thank you.

Professor White: I will endeavour to answer the question. I acknowledge that, although she unfortunately could not join us tonight, Katherine Waller manages that overall project.

As Julian Gardner has mentioned, we designed and delivered the training in Queensland, Western Australia and Victoria. The training varies slightly but globally takes about six hours. The goals are to ensure that all practitioners who are involved in providing voluntary assisted dying understand the eligibility criteria and how the oversight process and reporting would work, and that anyone who is providing voluntary assisted dying has done the training. An assessment component is attached. Anyone who is involved in that process will have that baseline level of knowledge about voluntary assisted dying.

Gillian Mackay: What level of resource was provided to healthcare providers to be able to upskill and train clinicians when voluntary assisted dying first came online?

Professor White: Do you mean apart from the training that was provided free of charge by the state? Of course, practitioners were not necessarily funded to do that training and some of it, I imagine, was done in their own time—is that what you mean?

Gillian Mackay: Yes.

Professor White: Most practitioners did the training in their own time. Practitioners have continuing professional development and other requirements. That is not the case in all places in the world. Sometimes, practitioners are given funding to be able to complete the training; that it was not funded was perhaps a disincentive to do it, because training of about six hours is a big ask for practitioners. One of the balancing questions when thinking about training is that although, yes, it is an important safeguard and gives confidence that there is a baseline level of knowledge, we also need to ensure that it is accessible and possible for practitioners to do in a busy practice.

Gillian Mackay: That is great. Thanks, convener.

Sandesh Gulhane (Glasgow) (Con): I refer people to my entry in the register of members' interests as a practising national health service general practitioner, and I note that I chaired the steering group for the bill.

May I pick up a bit more about training, please? Professor White, you said that there is a baseline of knowledge. Is there a requirement for an annual review or oversight of the training?

Professor White: It varies state by state, but the approach that has been taken in the states that we have been involved in has been to require a renewal of the training after three years. The process to get accredited is rigorous: the Department of Health in those three states sets the pass rate for the assessment at 90 per cent. The benchmark is very high and it is a rigorous course, so the view was that three years would be an appropriate period after which to renew the training.

There is a more focused renewal training package in each of those states. The thinking is that it might be more appropriate for someone who has been providing voluntary assisted dying for three years to renew by way of refresher rather than spending the entire six hours. However, there is also scope for someone who has not practised voluntary assisted dying in that period to redo the complete package as part of a refresher.

Sandesh Gulhane: Is a different amount of training required for the different parts of what happens? For example, is there a bespoke version of the training for your care co-ordinator or the doctor who would administer the medications?

Professor White: Training is provided for everyone who is involved in providing assisted dying. By that, I mean that it is provided for those who do the first assessment and the second assessment, and for an administering practitioner—in Australia, we have provision for someone who is able to do the practitioner administration once a person has been assessed as eligible. All those people do the same training.

In addition, many of the states—although not all of them—produced a shorter training package for anyone else who might be involved in voluntary assisted dying more generally. For example, in Queensland, all healthcare workers—in other words, the full spectrum of people who are involved in healthcare provision—were given access to a free 45-minute training programme to ensure that people knew what voluntary assisted dying was and how it worked. If someone does not want to be involved—if, for example, they are a conscientious objector—it is important for them to know what their rights and responsibilities are. Therefore, a second, more generic training package was also provided.

Sandesh Gulhane: I have a question about workload. In Australia, is assisted dying something that is provided by independent practitioners who perform that role in particular, or is it added on to the role that, for example, a general practitioner would perform here?

Professor White: I would say that there is a high degree of variability in how the system operates. The first point to make is that the Commonwealth Government in Australia, through the funds that it provides for health services, excludes some aspects of the voluntary assisted dying process. That is largely historical—when voluntary assisted dying was not lawful, it was suggested that funding for it should be excluded. However, there are still some public funds that can be claimed for things such as conversations.

Public funding for those who provide assisted dying in the public health sector is relatively limited. Sometimes they are given additional workload, and sometimes they are not. Practitioners in private practice sometimes charge independently—sometimes they charge through private billing—and sometimes they do not.

I am sorry that that is a slightly unhelpful answer, but there is a high degree of variability across the public and private sectors. There is also a high degree of variability state by state. For example, in Queensland, about 90 per cent of voluntary assisted dying happens through the public system, whereas, in other states, it is a much more even spread. There is a high degree of variability.

Sandesh Gulhane: With my final question, I want to focus on workload. Obviously, your system is very different from ours. Here in the United Kingdom, we do not charge. How many people per capita would you say go through the assisted dying process? I do not mean how many complete the process; how many at least start the process? If we had that information, that would help us to work out what that would mean for the workload over here.

Professor White: In that regard, I would refer to the board reports, which include two types of figures. One of those is probably an easier shorthand to think about. Calculations have been done on the percentage of deaths that occur in each of the states through voluntary assisted dying. That varies from about 0.8 per cent to up to almost 2 per cent.

You rightly say that there is a cohort of people who apply for or make inquiries about voluntary assisted dying but who do not end up dying through that path. With regard to the calculations that you are talking about, I think that there are two data points that should be looked at. One of those is the percentage of deaths that occur through assisted dying, and the other is the data from the VAD reports on the number of first requests, which is the initiation of the voluntary assisted dying process. Julian Gardner might want to comment on that.

Julian Gardner: The figures for Victoria show that we have a very low usage compared with other states—only 0.84 per cent of all deaths in Victoria occur through voluntary assisted dying. Without having a calculator in my head, I think that the figure for first assessments would be about 1.9 per cent of deaths. That is not the same as the figure for the percentage of the population who go through a first assessment—I cannot give you the figure for that.

However, I can say that there are concerns that a number of medical practitioners—especially those who work in very busy GP practices—find it very difficult to find the time to get involved with assisted dying. That is a disincentive. We have a concern that we are overreliant on a small cohort who do a very large number of cases.

Carol Mochan (South Scotland) (Lab): One of the key provisions in the bill is about safeguarding. The assessing doctor is required to form an opinion on whether the person has been subjected to any pressure. Have there been cases in which anything has been picked up in that regard? Within your structures, is there a robust process to ensure that things are picked up or that there are at least conversations with people who might choose to go down this route?

Julian Gardner: Our system is very much reliant on the two assessing medical practitioners. If they form the view that there is no evidence of undue influence, coercion or abuse, the review board has no way of assessing how they came to that conclusion. However, we talk to a reasonable percentage of family members after the event, and we have not had any reports of that nature in Victoria in the five years in which the system has been in place. The only reports that we have had have been the reverse, in that people have experienced coercion—that might be too strong a word—or undue influence not to go ahead with ending their life, generally from relatives who have objections or from faith-based institutions. As I said, we do not have any way of assessing how individual medical practitioners come to their conclusions.

Carol Mochan: Professor White, you spoke about training. Are parts of the training about picking up on those elements?

Professor White: Absolutely. That is an area of focus, because that is part of the eligibility criteria. A specific component is focused on training doctors in detecting coercion and in the sorts of conversations to have. We should recognise that medical doctors have such conversations with patients in relation to other end-of-life decisions. In end-of-life practice, doctors routinely assess capacity to ensure that decisions are ones that people want to make.

Building on Julian Gardner's comments, I note that voluntary assisted dying in Australia is the most scrutinised end-of-life decision that there is. A range of other end-of-life decisions, including those relating to withholding or withdrawing life-sustaining treatment and to palliative sedation, do not have anything like that scrutiny. For voluntary assisted dying to occur, you need not only one doctor but a second independent doctor, who will have a separate conversation on their own with the patient to explore all the issues. As Julian Gardner said, it is doctors who do that.

The chair of the Western Australia voluntary assisted dying board has said that the people in the system are the safeguards and that doctors play a really important safeguarding role. From the interviews that we did with doctors who provide voluntary assisted dying, we know that they consider their decisions as very grave and significant. Allowing someone to take the next step in voluntary assisted dying is very serious, so doctors are very careful and cautious.

I will make a final point in relation to coercion. We interviewed the family members of patients as part of our research, and this came through loud and clear. Some family care givers reported their loved ones saying, "If I have to be asked again if this is what I really want!", so I took a great deal of confidence from how strong that theme was, with everyone being keen to ensure that the person really wanted to end their life by asking, "Are you sure that this is what you want?"

Carol Mochan: As elected members, we often hear people say that people might wish to go down this road because they feel as though they are a burden to their family or to the medical practitioners who are so caring with them. I want to be clear that, based on what you said earlier, you have robust systems in place to ensure that people know all the options and support that are available in terms of palliative care and can easily access them.

Professor White: That is one of the requirements of the law. When someone is being assessed for voluntary assisted dying, they must be given information about other treatment options, including palliative care. Those options form part of every discussion and each of the eligibility assessments.

11:00

David Torrance (Kirkcaldy) (SNP): Can the witnesses provide an overview of the extent to which assistance with assisted dying is allowed by the laws in Victoria and the rest of Australia, and the form that such assistance can take?

Julian Gardner: I am not quite sure what you mean by "assistance", but let me have a go at having a guess. In Victoria, if you receive the medication to administer yourself, somebody else is allowed to mix it up, but only you can hold the glass and lift it to your lips. They cannot assist you in any other way, but they can assist you in taking the medication. That is not the case in every state. For example, in Western Australia, that is not allowed, as I understand it.

Is that what you meant by “assistance”?

David Torrance: Yes. If someone has a physical impairment that means that they cannot lift the glass to their mouth themselves, is someone allowed to help?

Julian Gardner: Once again, in that case, the law varies—unfortunately, we are a federation. In Victoria, if you are physically unable to raise the glass or to ingest the medication, you are eligible to have a practitioner give you an injection. That is how we get around that. In other states, to varying degrees, people have a choice about which way they want to take the medication, whether they want to take it themselves or have a doctor administer it, but they cannot have somebody lift it to their lips.

David Torrance: Professor White, do you have any comments?

Professor White: I have nothing further to add, other than to note that maybe I have not understood the bill that is proposed in Scotland, but I understood that it was to be self-administration only. Thinking about the issues that Julian Gardner has raised, we know that there is a cohort of people for whom self-administration might be challenging, and I recognise that self-administration can happen in different ways.

It was certainly an important consideration in Australia. The starting point was to think only about self-administration but, in Victoria, it became clear that there is a cohort of people who might not be able to access that because they have a physical disability so, to avoid discrimination on the basis of physical disability, the option of practitioner administration where self-administration is not possible became part of the debate and discussion around the Victoria law.

Julian Gardner: In Victoria, it is also possible to administer the medication yourself via a nasogastric tube or a percutaneous endoscopic gastrostomy—PEG—tube.

David Torrance: Do you keep statistics on the proportion of those who seek assisted dying but have a physical impairment that would prevent them from self-administration?

Julian Gardner: In Victoria, you have to have a physical limitation before you can get a practitioner to assist you. We are not necessarily talking about somebody who already has a physical disability; we are also talking about people who have a physical disability partly because of the condition from which they are suffering. The figures in Victoria show that 18 per cent of people who take the medication had a practitioner administer it, so we can reasonably conclude from that that they either had a physical limitation or were unable to do it. For example, with some particular forms of cancer, you just cannot swallow the medication. I cannot, however, separate those who were unable to ingest the medication from those who were physically unable to administer it.

In other states, there is more of a choice, so their figures would reveal that information for you.

Emma Harper (South Scotland) (SNP): Professor White mentioned conscientious objection. I have had a constituent who is a health professional contact me about that.

I am interested in how the law in Victoria provides for the option of conscientious objection. There are issues around providing information and support or assessing a person for voluntary assisted dying, or even supplying medication—that would involve pharmacists and nurses, which is who I am thinking about. Will you say a bit more about how the law works in Victoria and elsewhere in relation to supporting persons who conscientiously object?

Professor White: Julian, I can start on this one.

Julian Gardner: Yes, you can do the overview.

Professor White: There is some variation across Australia, although the starting point is that conscientious objection is strongly and clearly protected in the legislation in all the Australian jurisdictions. That is clearly stated and set out in a specific section in each of the acts.

There are some differences about what people with conscientious objections need to do when they are asked about voluntary assisted dying. In Victoria, for example, there is no legal requirement under the act for people to do anything further in terms of referring or providing information. We have heard in some of the interviews that we have done that that has led to situations in which a patient has asked their GP about voluntary assisted dying, and the GP has said, “No, I don’t want to talk about that—I am a conscientious objector,” and that has been the end of the conversation. The person is then left with a dead end, because they have spoken to their GP and are not quite sure how to find voluntary assisted dying.

In other states, such as Queensland, again, there is strong protection for conscientious objection, but there is a minimal requirement for a conscientious objector who receives, for example, a first request for voluntary assisted dying to at least share information about the care navigator service that we discussed. That would be as simple as saying, “Here’s a phone number and this is the voluntary assisted dying care navigator service.” I think that that model provides better access for patients, because it can be difficult to navigate the system—that is one of the barriers that has been identified in Victoria—and having that minimal requirement ensures connection to it.

Those are broadly the ways in which the issue has been handled here in Australia.

Emma Harper: I forgot to mention that I have an interest, in that I am still a registered nurse, with experience in the perioperative environment and clinical education.

I have a final question. Has there been any assessment of staff who have felt pressure to participate in voluntary assisted dying when they have actually been firmly conscientiously objecting?

Professor White: I have not come across that situation in the work that we have done, or in the work that I have read about. One thing that has happened is that, as part of health services' education for staff, one of the first threshold issues is to ask, "Do you want to participate or not?" That has been very clear in the roll-out of the law.

I should mention that, in Australia, all the jurisdictions had a designated implementation period. In some places, the law was started and then voluntary assisted dying was available the next day. In Australia, the law was passed and there was generally an 18-month implementation period. A big part of that was about establishing structures and systems in health systems, including for the issue of conscientious objection.

I have not come across that situation in my research to date, although that is not to say that individuals have not felt that way. Julian, I do not know whether you have evidence of that.

Julian Gardner: No, I have not had any instances of it. One example that I had involved the opposite, in that the head of a clinical unit was a conscientious objector and was causing great difficulties for staff, but I have not come across it the other way round.

Emma Harper: Thank you.

Joe FitzPatrick (Dundee City West) (SNP): I want to ask about how the legislation has developed since it has come into force, particularly in Victoria, where it has been in force for nearly five years. Some people are concerned that, if the legislation is introduced in Scotland, there will be an inevitable, as they would say, slippery slope to expansion. On the other hand, when we pass legislation in a new area, we would expect that legislation to be reviewed and finessed.

Perhaps you can tell us about how the law has developed in Victoria in particular, and elsewhere in Australia. Have there been changes to the eligibility criteria? Have the criteria expanded or contracted? Have the safeguards that were included in the legislation in Victoria when it was first brought in been made more robust or relaxed? Finally, how have the numbers changed over time? Has there been a massive increase, or have the numbers stabilised?

Julian Gardner: The Victorian legislation has been in operation for five and a quarter years, and there have been no changes to the act at all. I suppose that one could argue that because Victoria was the first state—there had previously been 51 bills introduced in various state Parliaments in Australia before ours was successful—the other states have, in the main, learned from some of our lessons. Those states have not made the eligibility criteria any wider, in my view, but they have removed some of the unnecessary restrictions that we have in Victoria.

For example, in Victoria, a doctor is not allowed to raise the topic—the person themselves has to raise it. In most other states, however, the doctor can, as long as they tell the patient about every other option, including palliative care, say, "There are many options for end-of-life care, and this is one of them." To that extent, there have been improvements in the other states, but there have been no changes to the Victorian act.

We heard all about the slippery slope when we consulted on the legislation in Victoria. One could look at Oregon, where the legislation has been in place for 30 or 40 years, and there have been two minor amendments, neither of which could be said to have broadened it. We can never positively say what a future Government would or would not do, but there is certainly no evidence of a slippery slope.

Professor White: I can confirm that that is the position across all the Australian states. The law is still as it was passed at the time. The Victorian law is being reviewed, but—this is probably relevant to your question, Mr FitzPatrick—the Victorian Government has publicly stated that it will not be reopening the law. There is a review, but the public statements to date have said that the law will not be changing.

The Convener: I call Sandesh Gulhane.

Sandesh Gulhane: What is the minimum age for eligibility?

Julian Gardner: In Australia, one becomes an adult at the age of 18—that is uniform across all states.

Sandesh Gulhane: Why was 18 chosen as the number? That might have been because of what you have just said.

Julian Gardner: Because that is the age at which someone becomes an adult in Australia. It was simply to make the legislation consistent with all other laws relating to adulthood.

The Convener: I call Emma Harper.

Emma Harper: I am okay, convener—I have had my questions answered.

The Convener: I call Elena Whitham.

Elena Whitham: Good morning. Before I ask a few questions, I declare an interest, as I am a member of the Humanist Society of Scotland and a member of the Parliament's cross-party group on end-of-life choices.

Professor White, you have spent a lot of your career researching voluntary assisted dying, and you are here today to speak to us in that capacity. Can you give us your views on the Scottish bill as drafted? What has it got right, and where could it be improved?

You mentioned your concerns about discrimination based on disability, which is why there are slightly different administration routes in Australia. Can you speak to that aspect, please?

Professor White: Yes, of course. My colleague Lindy Willmott and I made a submission to the committee that touches on some of that; I will pull out some of those points. On the point about self-administration, I highlight the fact that the need for all people to be able to access voluntary assisted dying if that is their choice, even if they may have a physical disability, is an important consideration.

One thing in the bill that is significant and valuable is that it has removed one of the challenges that we have in Australia around timeframes. In Australia, the timeframe varies between six and 12 months, depending on the nature of someone's illness or which state they live in.

11:15

The Australian Capital Territory has taken a similar approach to Scotland, in that it does not have a specific timeframe for eligibility. I make that observation in the context of eligibility criteria operating holistically. We are talking about people who have an advanced progressive illness that has reached the stage of an illness that is going to cause their death; it is a cohort of terminally ill people. Removing the arbitrary nature of whether the timeframe is six months, eight months or 12 months is a significant step forward in the Scottish bill. I wanted to mention that area as being a positive.

With regard to the use of the phrase "premature death" in relation to a person's relative eligibility, it was unclear to Lindy and I what value the word "premature" offers; we thought that it could add confusion. Whether a death is premature depends on a range of considerations, such as life expectancy and the progression of the illness, so we did not think that the inclusion of "premature" necessarily added value. That is one of the issues that we would mention.

I will mention one more issue if I may; I would be happy to follow up with further written thoughts if that would be useful. One thing that the Scottish bill does not address is the issue of institutional objection. In Australia, the first series of laws did not mention institutional objection, and that was a problem in practice. In a different way from individual conscientious objection, where it is just one person who objects and you can navigate around that, the fact that an institution as a whole does not allow voluntary assisted dying to happen can have significant issues for people in that institution.

The subsequent three states after Victoria, and indeed the Australian Capital Territory, have specifically dealt with institutional objection in the legislation by creating a framework that makes sure that patients do not miss out, regardless of where they may be cared for. There is some variation across the state and territory laws, but the framework aims to respect institutional views. Having seen the challenges that that can cause in practice, I raise that area for consideration in relation to the Scottish assisted dying bill.

Elena Whitham: Thank you for that. I see that Julian Gardner would like to come in.

Julian Gardner: I would like to draw your attention to the issue of the requirement that there be a 14-day period between the start of the process and it going ahead. Here it is nine days, and in New South Wales it is only five days.

I am going to bore you with some statistics. Of those who have a first assessment in Victoria, 34 per cent die before they get to the point of having the medication dispensed. Of those who die without medication, 60 per cent die within 14 days of the first assessment. You can shorten that period, as you can in the Scottish bill. I was told last week that 25 per cent of the cases in Queensland and WA involve a request to shorten the nine-day period, so unless you have a vastly different health system, I suspect that the majority of people who seek such end-of-life care would die before they ever got the medication, because 14 days is too long.

Elena Whitham: That is very helpful. You have both answered a couple of my other questions, but I have a final question on safeguarding. If we get to the amending stage with the bill, is there anything that you would caution us about putting in place? We have already mentioned the timeframes, the so-called gagging clause and so on, but is there anything that you would advise the committee to think about if we get to that stage?

Julian Gardner: The process here is very bureaucratic. It has a large number of safeguards, because, as Ben said, this is a very serious form of medical treatment. It is a very difficult area because of the interface between law and medicine.

I am not sure that I would point to any other particular safeguards. We have one that is a problem—as you have in your bill, we have a requirement for 12 months' residence. We have discovered that, as people become close to death, they move back home to be with family. There might well be people who come from south of the border in order to have the support of their family who become ineligible because of the residence requirement, so you might need to have a provision that says that an exemption could be granted in special circumstances.

Professor White: I will briefly make a global point about the next stage of the bill, which Elena Whitham mentioned. Because we are talking about a serious issue, there is a temptation for parliamentarians to focus so heavily on safety that we sometimes forget about access. One of the challenges with the Australian models generally is that there was so much focus on safety and safeguards that sometimes there was not enough debate about and consideration of the need to ensure that the law was capable of being used.

Each time a new safeguard is proposed, it is worth asking whether the issue has already been addressed and whether the proposed safeguard will materially make things safer or whether it will simply make it harder to access voluntary assisted dying. That is a global consideration for further debates or discussions about adding a new safeguard. Focusing too much on safeguards can result in a model that is unwieldy and unworkable without being safer.

The Convener: Brian Whittle has a very brief supplementary question.

Brian Whittle: I want to clarify how you got to the position of defining what a terminal condition is. Was there any pressure from a cohort outside of that definition to be included?

Julian Gardner: In most cases—and certainly in Victoria—two doctors have to form the view that the condition is expected to cause death within six months or, in the case of a neurodegenerative condition, 12 months. That is one way in which the term "terminal" has been prescribed.

With regard to pressure from outside, the debate—which I am sure will go nowhere in the short term—is in relation to people with dementia. Sadly, during the course of that condition, at some point, people are likely to lose capacity and, therefore, become ineligible. That is the only area where we have seen any pressure to expand the nature of "terminal".

Professor White: The Australian model is premised on a terminal illness. We have been through seven reform processes across the states and territories, and no other model, other than a focus on terminal illness, has been proposed.

The Convener: I thank Professor White and Julian Gardner for their attendance this morning. I hope that you will be receptive to the committee writing to you if we have further questions.

Thank you very much—I see that you are both nodding in agreement. I wish you a very good evening.

Subordinate Legislation

Registration of Births, Deaths and Marriages (Scotland) Act 1965 (Prohibition on Disposal of a Body without Authorisation) Amendment Regulations 2024 (SSI 2024/281)

11:22

The Convener: Agenda item 4 is consideration of one negative instrument. The purpose of the instrument is to amend regulations 4 and 5 of the Registration of Births, Deaths and Marriages (Scotland) Act 1965 (Prohibition on Disposal of a Body without Authorisation) Regulations 2015, so that a person who has died in England, Wales or Northern Ireland and whose death is subject to a coroner’s investigation, can be buried or cremated in Scotland, with the consent of the coroner, before the conclusion of the coroner’s investigation and prior to death registration.

At its meeting on 29 October 2024, the Delegated Powers and Law Reform Committee considered the instrument and made no recommendations on it. No motion to annul has been lodged in relation to the instrument. Do members have any comments?

As members have no comments, I propose that the committee makes no recommendation in relation to the instrument. Do members agree?

Members *indicated agreement.*

The Convener: At our next meeting on Monday 11 November, we will continue to take oral evidence as part of the committee’s stage 1 scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

That concludes the public part of our meeting.

11:24

Meeting continued in private until 11:56.

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