

OFFICIAL REPORT AITHISG OIFIGEIL

# Health, Social Care and Sport Committee

Tuesday 12 November 2024



The Scottish Parliament Pàrlamaid na h-Alba

**Session 6** 

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# HEALTH, SOCIAL CARE AND SPORT COMMITTEE

31<sup>st</sup> 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:

Eleanor Deeming (Scottish Human Rights Commission) Dr Murray Earle (University of Edinburgh) Liam McArthur (Orkney Islands) (LD) Professor Colin McKay (Edinburgh Napier University) Dr Mary Neal (University of Strathclyde) Dr Stephen Potts (Royal College of Psychiatrists in Scotland) Lynda Towers (Law Society of Scotland)

### **CLERK TO THE COMMITTEE**

Alex Bruce

LOCATION The Sir Alexander Fleming Room (CR3)

# **Scottish Parliament**

## Health, Social Care and Sport Committee

Tuesday 12 November 2024

[The Convener opened the meeting at 09:00]

## Decision on Taking Business in Private

**The Convener (Clare Haughey):** Good morning and welcome to our 31st meeting in 2024 of the Health, Social Care and Sport Committee. I have received no apologies for the meeting.

We will continue our scrutiny of the Assisted Dying for Terminally III Adults (Scotland) Bill at stage 1, so, under rule 12.2.3(a), Liam McArthur is attending the meeting as the member in charge of the bill. Welcome, Liam.

The first item on our agenda is to decide whether to take agenda item 4 in private and whether members agree to take equivalent items on future agendas in private. Are we agreed?

Members indicated agreement.

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

#### 09:00

**The Convener:** The next item on our agenda is evidence from two panels on the Assisted Dying for Terminally III Adults (Scotland) Bill at stage 1. We begin our scrutiny by taking evidence from stakeholders who focus on the legal, human rights and equalities considerations that are related to the bill.

I welcome to the committee Dr Mary Neal, reader in law at the University of Strathclyde; Eleanor Deeming, legal officer at the Scottish Human Rights Commission; and Lynda Towers, a public policy committee member at the Law Society of Scotland. We are expecting Dr Murray Earle, lecturer in medical law at the University of Edinburgh. I note that Dr Neal has made a request not to be filmed as part of this morning's proceedings and that the committee has agreed to her request.

We move straight to questions from Emma Harper.

**Emma Harper (South Scotland) (SNP):** I have a couple of questions on the human rights issues that are related to the bill. The committee's briefing papers provide information on the European convention on human rights, article 2 of which is titled, "Right to life". Article 8 is titled, "Right to respect for private and family life" and article 14 is titled, "Prohibition of discrimination". In the context of human rights, does the bill contain sufficient protections for vulnerable groups? If you have concerns, what could be done to address those?

Eleanor Deeming (Scottish Human Rights Commission): Good morning. Thank you very much for inviting me to participate on behalf of the Scottish Human Rights Commission. It is important to say that the commission neither supports nor opposes the enactment of legislation permitting assisted dying. Our role is to ensure that the debate is informed by the applicable human rights framework. In setting out that human rights framework, we have concentrated particularly on the rights that are protected by the European convention on human rights and the United Nations Convention on the Rights of Persons with Disabilities.

A human rights analysis does not provide a definitive answer to the question whether to adopt legislation permitting assisted death. If legislation is adopted, the key point is that, to be compliant from a human rights perspective, the legislation must have in place appropriate and sufficient safeguards, particularly to ensure free and informed consent of anyone accessing assisted dying.

It is especially important to consider the rights of particular groups of people, such as disabled people, in the debate on whether to adopt legislation. We have concerns about aspects of the bill, such as the lack of review mechanisms both prior and post a decision, and we consider that improvements should be made to the bill. There is also the need for a focus on the UNCRPD, particularly in relation to supported decision making, in the bill's capacity assessment provisions.

I can stop there, or I can go into further detail on article 2 or 8 of the convention.

**Emma Harper:** I am sure that we will have more questions on that. You also mentioned disability, and concerns have been raised about that.

I would be happy to hear from other panel members if they want to come in.

Lynda Towers (Law Society of Scotland): I emphasise that the Law Society is taking a neutral position on the bill and that our concerns are about ensuring that there are as many safeguards as possible.

Under the various human rights regimes, there is no entitlement to a regime that would allow for assisted dying of any kind. On the other hand, if you choose to have such a regime, the important thing is that it includes safeguards for all people who are likely to be affected by it.

At the end of the day, it will be the courts that will decide whether those safeguards are sufficient, in this country and potentially in the European Court of Human Rights. Although one can raise concerns at this stage, it is very difficult to reach a definitive view as to whether all the human rights requirements would be met, given the wide range of people who might well be covered by the bill and who will have different rights.

Clearly, the UNCRPD sets out rights for disabled people, so the requirements are slightly different in the context of somebody who does not suffer from disabilities. Questions might well have been raised about whether the bill would be discriminating against the human rights of other groups of people by defining it as narrowly as has been done. One can understand why that has been done, but there might well be human rights issues raised, such as those raised down south during consideration of the England and Wales bills. Again, although those issues are being raised at the moment, it is very difficult to be definitive about whether any bill, until you see it put together completely, will in fact meet all the human rights requirements. That is a matter for the courts.

**Dr Mary Neal (University of Strathclyde):** I echo the concerns that have been raised by the other witnesses, and what both of them have said about the human rights regime containing no imperative that there be a bill of this kind at all. It does not stipulate that assisted dying needs to be allowed. However, if a jurisdiction chooses to allow assisted dying, it becomes a question of safeguards and a question of equality under human rights law.

As the previous witness said, quite a few interesting human rights arguments are being aired south of the border at the moment. The Terminally III Adults (End of Life) Bill has just been published there. In particular, two really interesting human rights arguments that have been aired there are an argument under article 2 and one under article 14 of the convention. It is important for the committee to consider those arguments in its deliberations.

Under article 14, as the other witness said, the argument is that, once assisted dying is allowed within a jurisdiction, questions begin to arise about discrimination and about whether the rules for eligibility will discriminate against some groups who are not eligible. Once you start to allow it for some people, the question that arises is whether human rights require that you allow it for others, too. That has been discussed by academics in England and Wales as a potential slippery slope argument-that is, no matter how tightly you try to draw the eligibility criteria, whatever criteria you put in place will include some people and exclude others. It then becomes a matter for the courts to decide whether that is compatible with the European convention on human rights.

Under article 2, an argument is being aired to the effect that, although the article does not preclude assisted dying, it might preclude a state providing assisted dying. Obviously, that is as much of an issue in Scotland as it is in England and Wales, because the national health service would be involved in both cases. That is another interesting human rights argument that is being aired in England and Wales that also applies here.

It would be interesting for the committee to look at both those arguments, because neither of those two issues has been tested in the courts, and there is no real way of saying—nobody can guarantee—that, were the bill to pass in whatever form, one or both of those arguments would not succeed and result in a problem with compatibility.

**Emma Harper:** That is interesting. We are not human rights experts; obviously, that is why you are here today to help us. In addition to the other human rights aspects of the bill, I am interested in

hearing your thoughts on the information collection and review provisions. Are they drafted in such a way that they would ensure effective on-going monitoring of human rights compliance? If not, how should they be strengthened?

**Eleanor Deeming:** The bill does not make any specific post-decision review requirements in a judicial sense. The UN Human Rights Committee has recommended that, in order to comply with the right to life, states should consider introducing, in an independent or some sort of judicial capacity, prior reviews of requests for assisted dying. In the Nicklinson case, the Supreme Court considered systems whereby a judge or independent assessor would make a determination as to the voluntary, clear, settled and informed wish to die, as a robust means of reducing concerns about inappropriate use.

Article 2 requires that there is sufficient subsequent review to ensure that there is effective, independent and prompt investigation of deaths. That is why we have recommended that the Parliament considers including a system of judicial or independent oversight, with both prior and subsequent reviews, to comply with human rights standards. That would provide a much higher degree of scrutiny and stronger safeguards around the right to life.

It is also important to note that article 10 of the UN Convention on the Rights of Persons with Disabilities protects the right to life on an equal basis with others. I point the committee to the UN special rapporteur on the rights of persons with disabilities, who laid out a set of safeguards, saying that, if assisted dying is to be permitted, it must be accompanied by strong safeguards to protect the right to life of disabled people. I will not list all the safeguards, but one of them is on the appropriate collection and reporting of information on each request for and intervention in assisted dying. The more reporting and data collection there is, the stronger the safeguards will be. Obviously, we must respect people's privacy and individual autonomy.

**Emma Harper:** Before Lynda Towers comes in, I note that our briefing says:

"The Bill contains requirements on information collection, annual reporting and a general review of the legislation after five years. However, it is not clear if this is sufficient to meet human rights requirements."

If we are talking about setting up a review body or an expert panel to look at assessment of figures and data gathering, is that a challenge in terms of monitoring and evaluating if the legislation comes into place?

**Lynda Towers:** We recognise that there has to be sufficient review of whatever kind. I do not think that we have taken a position on prior review in

the context that Ms Deeming talked about, but we certainly have concerns about the subsequent review evidence and how that would be assessed.

There are a number of issues here, some of which are about human rights and some of which are more practical. We feel that the period of five years before the legislation is looked at again is quite long and there may be a question whether a sunset clause with an earlier period should be applied, which would allow the Parliament to go back and look at what was happening at that time.

#### 09:15

Alternatively, if a separate review body is set up—we have not taken a view on that—the period should perhaps be shorter than five years. Having such a review body will inevitably mean that it will take time for things to be set up for reviews and all the rest of it, so five years will be a short time and it is inevitable that things will leak into a longer period.

We also have concerns about what a review body would look at. We looked at the forms that were to be applied in the context of providing information to strengthen and safeguard rights, and we understand that there is a desire to keep the system as non-bureaucratic and as straightforward as possible. However, given the nature of the evidence from the forms that are before us, it might be very difficult to see what additional factors are put into particular reports and what the deciding factors are.

It is probably not enough to say that we are satisfied that the information that is required under the bill is being provided; we might need to look at the context in which it is being provided. We are not suggesting that there be huge reports. However, under the Mental Health (Care and Treatment) (Scotland) Act 2003, I am a convener in tribunals, and the papers that we see include some information that indicates that things are being done within a legal framework and how that legal framework is being applied in particular cases. Looking at the forms might provide additional information to allow for a more constructive review at the end of the day, and it might give people an idea of the matters that are being considered in the context of decision making, particularly by doctors.

#### Emma Harper: Thank you.

**Brian Whittle (South Scotland) (Con):** Good morning. I appreciate the witnesses giving up their time to be here. I want to chat about the definition of "capacity" in the bill. Under the bill, it must be established that patients

"are not suffering from any mental disorder which might affect the making of the request".

It strikes me that any terminal diagnosis will have some sort of mental health impact. In those circumstances, does the definition of "capacity" in the bill have the effect of excluding anyone with a mental disorder? How do we square that circle in relation to the definition of "mental disorder"?

**Dr Neal:** It is tricky, because the definition of "terminal illness" in the bill refers not to a specific life expectancy but only to any illness from which a person cannot recover. There are some mental health issues from which people cannot recover and which might be expected to shorten life. In that sense, unless the definition is tightened considerably, there is a risk that such conditions could form the basis for someone to seek assisted dying under the bill. There are lots of issues with that definition of "terminal illness", and that is one of them. Unless the condition struck at someone's capacity to make a decision, that option would not be ruled out.

Having capacity does not mean the absence of any mental health condition; it just means having decision-making capacity. In healthcare law, decision-making capacity is judged on a case-bycase basis. As long as someone has the capacity to make a particular decision, their lacking capacity in other areas or their being affected by a mental health condition in some way is not necessarily relevant. Therefore, there are risks.

When the previous bill on assisted dying was considered by the Scottish Parliament, there was some discussion about whether an enhanced level of capacity should be required for end-of-life decisions. Doctors are very good at assessing capacity, and they do so all the time. It is not necessarily a formal process. Every doctor assesses the capacity of every patient during every consultation.

In one sense, assessing capacity is a very ordinary thing for doctors to do. In another sense, we are talking about what would be the ultimate and most final decision that anyone can make, and there is a risk baked into the definition of terminal illness in the bill, in that it is foreseeable that someone could decide to end their life because they are unable to recover from a mental condition that is causing them considerable suffering. All of that needs to be looked at. The definition of terminal illness in particular needs to be looked at to ensure that mental health conditions are excluded. Otherwise, as things stand, there is that risk.

**Brian Whittle:** Dr Neal has just said that doctors make decisions about capacity on a daily basis. In talking about the definition of capacity, and given what we are discussing, is that element of subjectiveness a problem?

**Eleanor Deeming:** I highlight that our view is that further work is needed on the capacity provisions in the bill. Article 12 of the UNCRPD is on the right to equal recognition before the law, and that requires careful consideration. Further attention needs to be given to the role of supported decision making in the capacity assessment process. That is with a view to ensuring equal recognition, but that must be alongside robust safeguards to ensure the absence of pressure and undue influence.

The bill appears to refuse assisted dying to someone on the basis of a diagnosis of mental disorder that is unrelated to the reason why they are seeking assisted dying. We have concerns that that could be discriminatory, unless it can be justified in the individual circumstances. We highlight in our written evidence that one approach would be to offer support to all people who are considering assisted dying, in the form of peersupport counselling so that they can consider their decision before embarking on the process.

**Lynda Towers:** Again, I have two fundamental approaches to this issue. I totally agree with what has been said at a high level about what the convention says and the questions of support. In this area of law, that way of thinking is now coming in, but it is certainly not with us yet in the context of providing sufficient support. That would be a very important aspect.

There are also questions about referring to capacity at all. We are all very comfortable talking about capacity, but the European thinking is now taking a different approach in which capacity should be assumed, and even the use of the word "capacity" is now being challenged.

In the context of what is happening in Scotland, it is very difficult to be precise about capacity at all, because so many different things are going on in the world of capacity. We have the proposed amendment to the Mental Health (Care and Treatment) (Scotland) Act 2003 as a result of the Scott review, part of which involves looking at what capacity is and at the definition of mental disorder and what it should comprise. At the same time, we have a review of the Adults with Incapacity (Scotland) Act 2000, and the definitions of capacity in those two pieces of legislation are not necessarily the same in all contexts. We also have other pieces of legislation that refer to capacity and to people who may not have full capacity, whether that is because they are children or because of disabilities. Those things are also under review.

When you have a piece of legislation, you have to take a view on the definition at that particular time but, if there is to be further thinking about and reviews of those pieces of legislation, and when so many potential changes are going through, this is a very unfortunate time to have to consider what "capacity" means. It is very difficult to decide what capacity is, and that is even before we get to the practical issue that, if I have a mental disorder, although I might have capacity and be fine, I might not be fine in the next hour, and I might be different next week. Capacity is a very variable concept.

Furthermore, not all mental disorders necessarily affect capacity. For example, the capacity to take your life might be different for people with certain mental disorders, and that is different from the capacity to take your medication on a particular day to make you better. That is a matter for the committee's next panel of witnesses, but it is important to consider that capacity can change considerably and that that could affect what happens in the context of the bill.

The Law Society has taken the view that, because of those uncertainties, the bill is probably correct in excluding mental disorder, which I think it does. However, if I had to argue the point in court, I think that I could also argue that the wording does not necessarily exclude all kinds of mental disorder. Therefore, there is a degree of uncertainty about what the term "mental disorder" means.

**Brian Whittle:** Do I have time to ask another question, convener?

**The Convener:** I need to bring Sandesh Gulhane in now, but I will bring you back in if we have time later, Mr Whittle.

**Sandesh Gulhane (Glasgow) (Con):** I declare an interest as a practising national health service general practitioner and as the chair of the medical advisory group that advised on the bill.

I am interested in what is being said about capacity. As a doctor, I judge capacity all the time. That can involve anything from giving a drug that could potentially kill somebody to a decision on the need for surgery. In the case of surgery, we have to assess whether someone can consent to the piece of work being done. Is it appropriate that a doctor's ability to make those judgments in all other circumstances is also used in the bill?

**Dr Neal:** That depends very much on how you regard the process of assisted dying. Is it like any other treatment that a doctor will routinely assess capacity for and provide? Is it treatment or not? On whether you, as a doctor, should approach assisted dying differently, the prior question is whether it is like everything else that you do. Is it just another kind of treatment? If it is not, perhaps the approach should be different.

Lynda Towers: You make capacity assessments all the time, regardless of whether you are always aware of it. You ask yourself

whether a patient has the capacity to make a decision, whether it is about taking the medication that you have given them or about proceeding with something. The difficulty goes back to my point that capacity is not the same in every circumstance. The underlying approach must be the same, but you would be asking yourself a different question at the end of the day, namely, "Does this person have the capacity to do this particular thing?" Someone deciding that they do not want to take the paracetamol that you have given them might not have a particular impact, but with regard to a decision to proceed along the lines of what is set out in the bill, you might have to ask yourself different things. There is no onesize-fits-all approach.

Practising lawyers do the same job in deciding whether a client has the capacity to take a particular decision. We might come to that later. However, someone's decision about whether they want to accept my legal advice on something is a very different matter from whether they have the capacity to take a step from which they cannot go back. Capacity is not a one-size-fits-all thing that applies in many different circumstances. What you are doing might be the same exercise, but you might be doing it at different stages along a road, if I can put it in that way.

**Gillian Mackay (Central Scotland) (Green):** Good morning. What are the practical implications of the devolved competence limits for implementation of the bill, particularly around specifying an approved substance for assisted dying? I ask Lynda Towers to comment first.

#### 09:30

Lynda Towers: It is just like old times. The devolved situation presents issues, but I note that, in the Presiding Officer's opinion, the bill is within the Scottish Parliament's legislative competence, and Liam McArthur has also indicated that that is the case. I do not think that people would argue with me that there are things that will have to be done if the bill is to fall under the Parliament's legislative competence. As long as it is within competence by the time that it is lodged in the Parliament in whatever form it takes, and provided that it has all the bells and whistles from various consents, it would then be within competence.

I appreciate that it is not always easy to see what the issues are. Two of the big competence issues are the application and use of the drugs and the regulation of the medical profession. If there was a desire and willingness to sort out those devolved/reserved issues, there is nothing to say that that could not be done. However, it would require the United Kingdom Government to be willing to give whatever consents were necessary in whatever form. My caveat is that those things take time, whether they would form part of a bigger package or be designed solely to deal with the bill. It would also require a degree of agreement with the Scottish Government in order to make whatever approaches were necessary.

There are devolved/reserved issues. I do not think that they are necessarily fatal, but it would take time to resolve them. Approaches would have to be made and there would need to be a degree of willingness on the part of the UK Government.

Dr Neal: My understanding is that the bill is within the Parliament's legislative competence because section 22 says that any provision in the bill that is not within the Parliament's legislative competence would fail, which would mean that the bill would pass without those provisions. My work is mainly on conscientious objection, which is addressed in section 18. If the necessary permissions were not forthcoming from Westminster, the bill would pass without a conscience provision, which alarms me and, I am sure, would alarm everyone in the medical and healthcare professions who would be seeking to rely on it.

When the bill was published, it really concerned me that, although it contains the conscience clause—presumably to provide reassurance to the medical professions that there is a will to protect them—nothing is said in the policy memorandum or the explanatory notes to flag up that, as things stand, section 18 would be completely ineffective, additional permission would be needed, and section 22 would kill the conscience clause if the permission was not forthcoming.

I am sure that the intention of those who are behind the bill is to ensure that everything is in place and that the bill passes with a conscience clause. However, the bill is set up not to include that clause if the worst comes to the worst. That is alarming for professionals and it is alarming to me, as someone who works on conscience.

**Gillian Mackay:** I will go back to Lynda Towers for a response to my next question. The member in charge of the bill has identified orders under sections 30, 63 and 104 of the Scotland Act 1998 as options for addressing potential competence issues. Do you have any views on the advantages or risks of that approach?

**Lynda Towers:** There are issues with any process that is out of your control—in this case, two of the three actors are not under Mr McArthur's control, if I can put it that way.

Having said that, it is not at all uncommon for a bill to have issues at the beginning of the process and to look very different at the end of it, with additional provisions in place by the time that it is passed. Equally, in considering whether a bill is within legislative competence, the Presiding Officer will have received her own advice, which nobody around this table will see. She must have had assurance that the bill is capable of coming within competence.

There is a requirement to define legislative competence as narrowly as possible to ensure that a bill can proceed through Parliament. It is quite clear what will be necessary in the context of this bill, and I do not think that anyone is arguing that the particular provisions that we are discussing are a problem.

Such provisions have been in all the various bills that have passed through Parliament, so the issue is not new. I gave internal advice on the very first bill on the subject, which was introduced by Margo MacDonald; it had similar issues that affected conduct and presentation in relation to doctors. That issue was identified at that time as it would, even then, have required resolution of the difficulties with regard to how doctors are regulated.

I can understand that there are concerns that, if the matter is not sorted, there will be an issue with the bill. I have no doubt that the legislation would be challenged at that stage, if those matters, which are in the public domain, were not resolved. It would then be for the courts to determine that those particular provisions did not apply and had no effect.

There would be a concern about that, but I would be very surprised if the bill got that far without those matters being resolved.

**Dr Neal:** I reiterate that the bill is technically legislatively competent because of section 22. However, the provisions in question, which are currently ineffective and would need to become effective, are particularly important.

I have spoken already about conscience. None of the previous bills in the Scottish Parliament has got to the point at which permission has had to be negotiated, so we do not really know what would happen if, after a stage 1 vote, we were looking to get permission for those things. I am not aware that that has ever been tested.

The medicines issue—that the Scottish ministers are able to approve a substance—is fundamental to the whole bill. If that cannot happen, it is difficult to see how the bill, or a system of assisted dying in Scotland, can go ahead. I agree with what Ms Towers said: if that provision in particular was not to end up being part of the bill, that would be pretty fatal.

The conscience clause worries me more, in the sense that the bill could pass without it.

Gillian Mackay: That is great—thank you.

#### The Convener: I call David Torrance.

**David Torrance (Kirkcaldy) (SNP):** My question is on conscientious objection. How clear a view do witnesses have of the roles and activities that are likely to be covered by the conscientious objection section as it is currently drafted? Does Dr Earle want to come in on that?

#### **Dr Murray Earle (University of Edinburgh):** Apologies for my lateness, convener.

I somewhat disagree on the necessity for a conscience clause in the first place, because the medical profession is not required to act contrary to their professional judgment. However, I agree with Dr Neal that such a clause is a good idea. Nevertheless, there is a "but". If we are going to have such a provision, that is good—it brings the medical profession on side. More than that, however, we need some form of referral so that a medical practitioner, if they do not wish to act in accordance with the act, as it would be, can refer someone to a practitioner who does. Naturally, that becomes problematic when we look at the Highlands and Islands and so on, where that might be difficult to do.

We can learn a lot from other conscience clauses, such as those that are in the abortion legislation. We must be quite careful, however, as I do not think that the analogy fits very well here because of who the patient is. In the context of this bill, the patient is the person who wishes to die; in the abortion context, the patient is the would-be mother of the being that will no longer survive. Although the analogy breaks down a bit, I would, on the whole, strongly support a conscience clause, and certainly one that is beefed up so that its mechanics can operate better for the workings of what is required in the bill.

**Dr Neal:** I disagree on both counts, which is rare, as I very rarely disagree with Murray. I disagree that a conscience clause is not necessary; I think that it is absolutely necessary in a bill of this kind, simply because, if assisted dying passes into law in Scotland, healthcare professionals will encounter it during their work and, when they do, they will need protection from having to become involved in it.

I think that the British Medical Association has talked about setting up an opt-in system. Such a system would be far preferable to what is being proposed through the bill. However, even with an opt-in system, you still need a conscience clause, because you cannot exclude the possibility, for example, that an in-patient in a hospital or hospice decides to speak about it there, or with their GP. Even if there is a parallel opt-in system, you cannot exclude the possibility that ordinary people working in the NHS during their everyday practice will be confronted by the issue, so they will have to have an opt-out.

I agree that the conscience clause needs to be beefed up considerably, but not in the way that Murray has suggested. One of the mistakes that people make when drafting conscience clauses for assisted dying bills is that they tend to copy and paste, in whole or in part, conscience clauses from abortion legislation.

two circumstances. however. The are completely different, as Murray has said. In the abortion situation, the patient is up against a time limit-time is really of the essence. As well as the legal time limit that is imposed by law, there is also the sense that the earlier an abortion is performed, the less of an ethical issue it poses. For various reasons, therefore, the imperative in abortion is to try to get the patient treated as soon as possible. In assisted dying, the imperative is not the opposite, but it is very different, in so far as we are trying to ascertain that the wish to die is an authentic, settled wish. In other words, we are trying to ensure that the patient is as certain as possible that they want assisted dying before they access it.

The duty to refer is morally problematic; it involves a degree of moral complicity in the practice. In the case of abortion, it is generally agreed that compromise is necessary, legally and ethically, because of the time limits that are involved. We ask healthcare professionals to engage in what is called in the literature the conventional compromise-in other words, to compromise their moral integrity to some extent, which is an important thing to ask healthcare professionals to do. In abortion, that compromise might be necessary; in assisted dying, the case for a compromise is much weaker. There is very little case to be made, especially if you are setting up a system for the first time. The onus is really on those setting up the system to design that conflict out of it, which is perfectly possible to do, and on policy makers and those charged with implementing the system to ensure that as few people and their consciences as possible come into contact with the process, to minimise the potential for conflict.

Although the case can be made in the abortion situation for requiring a slight compromise of moral integrity, the same case cannot be made for assisted dying. Referral is much more ethically problematic and difficult to justify in that context than in the abortion context.

#### 09:45

The conscience clause needs to be much stronger in other ways. The word "participate" in section 18 of the bill is very problematic. In the Doogan case, the Supreme Court, in relation to section 4 of the Abortion Act 1967, held that to mean only direct or "hands-on" involvement.

As you will all have been looking at the bill in great detail, you will be aware that healthcare professionals and others would be expected to do, or would need to take on, a spectrum of tasks in a system such as that. If only direct or hands-on involvement is protected, that leaves a spectrum of supportive and facilitatory roles that are not protected, and that is a problem because health professionals' objections are much more widespread, and maybe much more deep seated, in relation to assisted dying than in relation to abortion.

The current wording in the bill is that the conscience clause also refers to

"anything authorised by this Act".

That is problematic, because one of the main arguments that proponents of assisted dying in Scotland make is that we do not know what the current law is and that it is unclear.

We have heard all those arguments many times. If the current law is unclear, it will be difficult—if not impossible—to ever know what the act authorised. "Authorised" means made lawful by that was also established in the Doogan case.

If the current law is unclear, it will always be unclear what was authorised by the act, and if the conscience clause applies only to things that were authorised by the act, we can never know what it covers. Terminologically, the conscience clause needs to be thoroughly rewritten, and any expectation of referral in that context is difficult to justify.

**David Torrance:** What are the risks of including the conscientious objection section in the bill when implementing it might be beyond the legislative competence of the Scottish Parliament?

Lynda Towers: Bearing in mind that there will be concerns from those in the profession, it would be prudent to have a conscience clause in the bill. It has to be a working conscience clause in the sense that it must be effective, and it might be that your next panel—particularly those on the doctors' side—will be able to assist you better as to what they consider is needed in a conscience clause.

We cannot necessarily say that it will be beyond the competence of the Parliament, because, hopefully, by the time that the bill is passed it will have been amended to allow Scottish ministers to give whatever authorisation is necessary.

Guidance has been referred to. We all learned from the Covid inquiry the difficulty of relying on guidance in order to give legislative effect—in the widest sense possible—to something. I caution against trying to put things into guidance that should perhaps be in the primary legislation, particularly in relation to a clause such as this, as to what a particular word means and how far it interacts with the process.

It would be desirable to have the legislation as clear as possible, and, if necessary, to have definitions, recognising that there is always a danger that, when including definitions, you will leave something out. It would be dangerous to leave something as subjective as this issue to guidance as opposed to having it in the primary legislation. Getting the conscience clause correct in the bill is the right way forward. That would have to be part of discussions as to whether doing so works and whether there is power to make whatever changes are necessary. However, that does not mean that you should not be thinking about it now.

**Dr Neal:** I have two points. First, I strongly agree with that. Guidance is not law and guidance does not give legal rights. Professionals should be looking for a legal right to opt out rather than at guidance that can change and be revised without any need for a legal process. They need rights, and statutory rights are the gold standard.

Secondly, anyone who has managed to have a quick look at the Terminally III Adults (End of Life) Bill-the Leadbeater bill-which was published last night at 10pm, might have seen that it includes, at clause 4(1), a no-duty provision. In essence, it says that doctors and other health professionals are under no duty to discuss assisted dying as an option with patients. I suggested that idea to the BMA over the summer, and it became the BMA's policy. I am pleased to see it in the Leadbeater bill, because that discussion is a form of indirect involvement-it is not hands-on and direct involvement in the assisted death itself-so it would not be covered by a conscience clause unless that was redrafted to include it. Having a separate no-duty provision is really important in bills of this kind, and I urge those who are involved in the Scottish bill to think about including one.

It is not a ban. In some Australian states, there is a ban on doctors raising assisted dying with patients, and that could potentially put doctors at risk of false accusations that they had mentioned assisted dying. A no-duty clause does not put doctors at any risk at all. It simply protects them from raising assisted dying if they have a moral objection to discussing that with or offering it to a patient.

I am not sure whether a no-duty clause would be caught by the legislative competence issue that catches a conscience clause. If that issue is surmountable, I would like to see not only a conscience clause but a no-duty clause in the bill. Obviously, I do not agree with the duty to refer, which is also included in clause 4 in the English bill. However, the protection that a no-duty clause gives is important.

David Torrance: Thank you.

**Sandesh Gulhane:** This is a genuinely fascinating session.

I would like to speak more about the role of the courts. Dr Earle, I will start with you. I will specifically address the slippery slope argument that we began discussing earlier. I want to take that to its extreme and to hear your opinion on it. Suppose that I have diabetes, that I decide to go down the assisted dying route and that I can argue in court that I am being discriminated against as I am not allowed to do so for that condition. Obviously, that is an extreme. Do you foresee a way in which we could slowly move from the position of having fairly tightly worded reasons for being able to access assisted dying to the inclusion of conditions such as diabetes, on a rights basis?

**Dr Earle:** Yes, I do. However tightly we think that we draft something, perhaps there will always be a fissure. For example, we were talking about mental health elements earlier. A member put a question and there was a discussion about moving towards the inclusion of comorbidity with mental health conditions. The bill excludes mental health conditions, but it also kind of does not, in the sense that the mental health conditions suffered would also need to be terminal. You would need to establish that your diabetes is, in fact, terminal. That is where the slippage might come in.

At the moment, the bill is quite tight, but we have seen abroad that there has been slippage the so-called slippery slope. We have seen that because people have claimed a rights basis for their exclusion, or, rather, they have claimed that their rights are being breached because they have been excluded. In parts of the bill, I can definitely see equality issues arising because of exclusion, although not in the example of diabetes, which you talked about. I would use the example of people with neuromuscular conditions who cannot selfadminister the substance, which relates to Gillian Mackay's question earlier on the administration of the substance.

There are plenty of places in the bill where there can be a slippage—as is the case with any bill like this—and it comes down to the issue of implementation, which concerns the issues that we have already mentioned, such as the filling in of the forms, the capacity assessments and the consent assessments. The practice around those processes has to be incredibly tight. That approach needs to be bolstered by guidelines, as Mary Neal said, that relate to an actual legislative provision—the approach must be set out in law, and the guidelines are there just to help to keep the medical practitioners on track and in compliance with the law.

The general answer to your question is, yes, there are points at which there can be a slippage, but it is up to the other parts of the legislation to avoid that at the policy level.

**Sandesh Gulhane:** Dr Neal, I see that you are nodding, and I acknowledge what you said earlier. Is there a way to stop the courts from moving the definition on without a parliamentary change to primary legislation? Is there a way to keep the definition tight?

**Dr Neal:** The short answer is no, unfortunately. One of the things that you do when you enact legislation of this kind—even though it is not your intention—is invite challenges from those who would like to see a broader law and an alteration of the eligibility requirements. Almost as soon as such a bill is passed, people who are invested in having the provisions extended will try to do so.

You are far more likely to see a Nicklinson-type challenge rather than a diabetes challenge straight away but, as you said, that is why we talk about a slippery slope, not a cliff. It starts with a Nicklinson-type challenge, then there are challenges from other people. Now, some jurisdictions have got to the point at which people who are tired of life are seeking assisted dying. Those jurisdictions have different laws from us but-this holds true of any assisted dying law-no matter how tightly a law is drafted, you cannot control what the courts will decide once an issue is in their hands. If a court is hearing an issue, it is because there are two compelling arguments, and the court may well choose to side with those who want to expand the law.

I see everywhere in the text of the bill the potential for slippage. The bill talks about a condition from which the person is "unable to recover". I highlight that phrase because that does not mean that the condition is untreatable. Kim Leadbeater MP's Terminally III Adults (End of Life) Bill talks about untreatable conditions, but this bill just talks about conditions from which the person cannot recover. An inability to recover might be due to-I will use extreme examples, just to make the point-the person not taking their medicine, being unable to stick to a diet or refusing treatment. Everyone has the right to refuse treatment but, if you refuse treatment for a condition that, without treatment, can cause your early death, you would potentially become eligible for assisted dying, under the eligibility criteria in the bill.

There is a lot of potential for slippage, and the provision of the service could be expanded quite

considerably without the legislation ever having to go to court or come back to the Parliament. I think that just normal practice could expand the number of people who come under the eligibility criteria and the range of people who seek assisted dying. That could be accomplished without any further legal process.

Eleanor Deeming: I want to come in on the question of the likelihood of human rights-based challenges. Obviously, we cannot say what the likelihood of any challenge being successful is, and we cannot presuppose what any arguments might be-an argument under human rights law is different from a judgment. However, I want to highlight that the European Court of Human Rights in Strasbourg wanted to bring in the concept of the margin of appreciation, which you will have heard of under human rights law. The margin of appreciation is a concept by which the court, in certain areas such as this, recognises that states themselves are best placed to judge the conditions in their own state. It recognises that there are very different opinions on the particularly moral and ethical issues presented by the topic of assisted dying and that there is no uniformity of opinion throughout Council of Europe member states.

#### 10:00

As recently as last year, in the case of Karsai against Hungary, you again see the court at Strasbourg level re-emphasising that this is an area where states are afforded a wide margin of appreciation. That is not to say that it would never intervene under article 2 where it needed to ensure that stringent safeguards were in place to support the right to life, but it was clear that, from the perspective of article 8, the margin extends not just to the decision to intervene or legislate in this area, but, once an intervention has been made, to the detailed rules that are laid down to achieve a balance between different interests.

Therefore, I think it important to note that, at the Strasbourg level, unless there are very clear problems with the operation of the framework in a particular state, a wide margin of appreciation is offered to states in this area. The court absolutely recognises that, in this case, a trend is emerging towards decriminalising what it terms medically assisted suicide, but it has still restated the importance of having a wide margin of appreciation for states.

**Sandesh Gulhane:** [*Interruption*.] I apologise to Dr Neal, but we are really tight for time, so I will ask a question directly and perhaps you can roll the answer that you were going to give into that.

From what we have already heard, it seems that, if the bill goes through, the will of the Parliament is very much to have a tight definition. Given that, would it be appropriate for the courts to override the will of the Parliament in that way? Lynda Towers talked about a sunset clause earlier, but would a five-year sunset clause allow the Parliament to look at slippage, at changes and at court cases and ask whether that is what it wanted, or whether things have changed? Is that why we need a sunset clause?

**Lynda Towers:** I will take the second part of your question first.

Yes, if you have a sunset clause, you will have to have a further debate in the Parliament. You will also have to take into account what has been happening, which would obviously involve looking at cases, how things have worked and all the rest of it. So, yes, that would give the Parliament a further chance to proceed on that basis.

Although I absolutely agree with what has been said in the context of the European conventions, it is worth remembering that the Supreme Court in this country has also indicated that it is pretty unwilling to become involved in cases that are perhaps more to do with social rather than regulatory aspects. If a doctor does something wrong under the legislation, the court might be more willing to look at that, instead of at the question whether that is how the legislation should operate. I think, therefore, that the courts would be pretty unwilling to become involved by saying that various aspects of the bill were not appropriate.

However, we should never say never, because we will always have challenges in these particular areas. What you need to defend against—or resist, if you like—is the legal challenges that come along. I always say to clients that they cannot stop somebody raising a court action. The best that they can do, whether it be a contract, a court case or whatever, is to be in such a position that they can defend and successfully resist a challenge. That is really the exercise that the committee is engaged in at the moment—making the legislation as strong and as clear as possible.

I am not quite as pessimistic as Dr Neal about being able to make a successful challenge immediately without any changes to or any further development in the legislation. However, I have done a lot of litigation in my time, and when it comes to what the courts will do or decide, my view is, "Never say never." I have given up predicting the outcomes of court cases to mywell, let us just say that I have given up. [Laughter.] Having said that, you need to make sure that as much as possible is clear on the face of your bill. That goes back to the point that I made earlier about having an understanding of what you are saying, so that the courts cannot make other definitions or two arguments about what a particular word means.

It also has to be dynamic, because the one thing about the ECHR is that it is not a piece of legislation that arrived in 1954 and nothing has happened since then. It reflects society and how society operates. Therefore, what might have been okay 20 years ago is not now appropriate. A very good example of that is the withdrawal of subsistence. I was involved in the very early Law hospital case in Scotland. I think that that would never have been thought about 20 years earlier. It was about withdrawing subsistence so that people could die, following the persistent vegetative state cases.

Society changes. It is not hard and fast, so, inevitably, there will be some development of the bill, whatever happens, whether it is correct or whether it is just society changing. That does not mean that you should not try to achieve a degree of legal certainty at the moment, to reflect what you want to happen at the moment, but you should also reflect that you cannot have it so tied down that it later ceases to be operational.

Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP): I remind members that my entry in the register of members' interests states that I am a member of the Humanist Society Scotland. I have a quick question for Lynda Towers. The Law Society's submission expresses concern about solicitors being used as proxies. My understanding is that, as the bill is currently drafted, they would be involved in the process by having to sign for somebody who is physically unable to do so. Will you expand a little bit on why the Law Society has concerns in that regard?

Lynda Towers: It is not uncommon at the moment for solicitors to act as proxies for people, particularly in the area of wills, where a particular patient may be incapable of signing a will but is perfectly clear in their mind and has capacity. The process of that is that a solicitor can sign what we call a docket on the bottom of the will to enable that. The docket basically says, "I have read out this will to the individual, he or she has confirmed that that is what they intend by way of the will and I am signing on their behalf." I did one of those relatively recently. I was satisfied that the person had full capacity. I then read out the will to that person and asked, "Is this what you want?" The person said, "Yes," and I signed the docket. In that process, all that I am doing is putting a signature in the position of the person who is unable to sign.

The bill is expanding on that. Although the solicitor would be signing as a notarial execution, as we would call it, they would also have to satisfy themselves that the person understood the effect of what they were doing. The solicitor would not just be signing because the patient or person had said, "I want this to happen," but would have to satisfy themselves that the person understood the

implications. Doing that might, in effect, go into giving legal advice to that patient. If lawyers give legal advice, they are obliged to go through a whole lot of bureaucratic, if you like, steps to establish a client-solicitor relationship.

Therefore, you are asking lawyers to do something more than has been done in the past. You are creating a new relationship, and the lawyer would have to be satisfied that they had explained all the legal implications of the document. That is probably not what was intended, but given the way that it is worded, that is the effect of the provision. If it were purely in the context of a notarial execution, as we do for wills, that additional step of having to set up a client relationship would not be required. That is what the two issues are.

Elena Whitham: Thank you, that is very helpful.

**The Convener:** I am mindful of the time, so I ask members and panel members to be concise with their questions and answers, please.

**Paul Sweeney (Glasgow) (Lab):** Thank you, convener, and thanks to the witnesses for their insightful comments so far.

A number of respondents to our calls for views on the bill have raised the question whether doctors would have a "duty to raise" assisted dying as a reasonable treatment option with end-of-life patients, as current court decisions, such as Montgomery v North Lanarkshire Health Board, require doctors to discuss all reasonable treatment options with their patients so that the patient can make a fully informed decision.

Clause 4(1) of the UK bill introduced by Kim Leadbeater MP explicitly refers to no "duty to raise" the subject with patients and clause 4(2) clarifies that by providing that medical practitioners may exercise "their professional judgement".

In the Scottish bill by Liam McArthur MSP, section 18(1) refers to a general requirement. Indeed, it provides that

"An individual is not under any duty (whether arising from any statutory or legal requirement) to participate in anything authorised by this Act to which that individual has a conscientious objection."

Considering the bill as drafted, do you think that the status of assisted dying as a reasonable treatment option needs to be further clarified? Dr Neal, you could perhaps start us off.

**Dr Neal:** The conscience clause in section 18 of the Scottish bill does not remove that possible duty on doctors. We can argue or discuss whether assisted dying counts as treatment and as a reasonable treatment option. The practical reality is that if assisted dying is introduced, is provided by doctors and becomes accepted and normalised in society, it will count as such. You can look to the example of abortion, which is now routine healthcare and talked about as medical treatment. That was not how it was seen back when abortion was introduced, but it is very much how it is seen now. The same process of normalisation should be expected with assisted dying. Even if it is not immediately perceived as treatment, that perception would come along very soon after its introduction.

There would be a common-law duty on doctors to discuss assisted dying as treatment with their patients unless the statute specifically prescribed that they did not have to do so. That is why the Leadbeater bill has clause 4 in it and why the Scottish bill needs something similar. Section 18 would not exclude that duty, because it refers to participating—in other words, being in a hands-on, direct capacity—but indirect bureaucratic, administrative and ancillary tasks that are remote from the actual death are potentially not covered. We need both.

**Paul Sweeney:** Would you like the Scottish bill to be amended along the lines of what is drafted in clause 4 of the UK bill, to insert that explicit requirement?

**Dr Neal:** Yes. As well as the conscience clause, the Scottish bill needs a separate no duty clause.

**Paul Sweeney:** Does anyone else have a view on that point?

Lynda Towers: The Law Society does not have a view, because it is a matter of policy for the committee. However, I note that you would need to consider the matter in the context of the current case law, which suggests that a doctor does not have to put all options but must put all reasonable options to the patient. That takes us back, therefore, to the questions of what is reasonable and what is treatment, and I do not know the answers.

**Paul Sweeney:** Section 22 of the bill, which is about the limitations of the bill, refers to the

"regulation of the health professions"

and to reserved competence. Is there an implication there for the regulation of medical professions?

**Dr Neal:** I expect that a no duty clause could potentially be caught in the same problem as the conscience clause, in that they could both fall within the reserved powers. Although we need both those clauses, there is obviously an issue around getting permission to include them.

**Paul Sweeney:** Okay. That is, therefore, a matter of interaction between the two Governments.

Joe FitzPatrick (Dundee City West) (SNP): Although some of this area has been touched on under Gillian Mackay's question at the very start, I want to ask about the requirement for selfadministration. The member in charge is very clear in his explanatory notes that the policy intention is that patients accessing assisted dying would have to "self-administer the substance" used to end their life.

#### 10:15

However, there is some suggestion that perhaps the wording in the bill is less clear. Is the wording clear enough to meet the member in charge's policy intent—and is that a good thing? Last week, we heard from colleagues in Australia, who were concerned about making sure that everyone had access to the new right; physician-assisted means were important to people who would not be in a position to take a substance themselves.

First, is the wording clear? Secondly, is there a concern over the human rights of people who might not be able to take a substance themselves to access that end-of-life choice?

Lynda Towers: The question whether a person should be able themselves to administer the means might well result in questions over discrimination. It goes back to the original point that we talked about: if there is a disability—which word is so widely defined that it would undoubtedly catch something of that instance—that person could be discriminated against and there might well be a human rights argument in that. I can understand why the policy is as it is, but there might be an issue and you might need to look at it again.

The first part of your question was about the wording. I have not looked at that sufficiently closely, so I do not want to comment at the moment.

**Joe FitzPatrick:** Perhaps you would write to us on that. There is some suggestion that it may not be as clear as the member intended, so it would be useful to hear from you. It is in section 15(1).

**Eleanor Deeming:** On the first point, I will look again at section 15(1). Certainly, in our written submission and in my preparations for this evidence session, I have been going by the policy memorandum on the requirement for self-administration. I am happy to look at that and come back to the committee with specific views on that subsection.

On the issue of self-administration, as you have said, the bill does not address the situation of a person who is unable, because of a physical illness, to act on their wishes and who would require the physical assistance of others. Although I can point to nothing at a Strasbourg level that says that that is definitely discriminatory, we think that, given the purpose and policy intent of the bill, consideration should be given to whether there is an objective and reasonable justification for drawing that distinction. We have put that at the end of our written evidence, under a section on discrimination in the additional comments.

Dr Neal: I will not duplicate what others have said, but I highlight the requirement in the bill that a medical practitioner must remain with the person until they die. We know that, in some jurisdictions in which assisted dying is lawful, people get into difficulties. When it comes to self-administration, therefore, I have a question about the role of the person who remains with the adult until they die. What are they permitted to do if the adult gets into difficulty? Are they permitted to carry out the death themselves? Presumably, they would not try to resuscitate the adult. There needs to be a lot more clarity about the role of that person and what they are allowed to do. In other words, does something in the bill already allow for euthanasia rather than assisted suicide?

**Dr Earle:** I find the current wording problematic. I agree with colleagues that it is potentially or actually discriminatory if, because of their disability, a person cannot access what is essentially a right that has been enacted; there is an equalities issue and therefore, possibly, even a devolution issue.

All the case law—Pretty, Purdy, Nicklinson and Ross—has been about people who would not have been able to self-administer. The case law that the Supreme Court and the Court of Session have dealt with concerns the very people who would be excluded from the terms of the bill.

The committee heard from witnesses from Australia, which is perhaps the place to look at. Victoria and New South Wales have a parallel system that involves a different clause with different requirements in such cases. For example, in Victoria, if someone cannot self-administer, they can apply for physician administration, but further conditions must be met, such as the physician being satisfied that the person cannot selfadminister.

If there is no possibility for physician administration under the terms of the bill, somebody who is physically unable to selfadminister might have a family member who is willing to help them, but the physician who is with the patient—although they might not necessarily be in the same room—could, in this country, be complicit in manslaughter, because a family member is helping. If we take things to the nth degree, there is potential for problems. For a bill that seeks to elide the possibility of criminal conviction, the potential for criminal law to be broken is extremely problematic. It is to the committee's credit that that possibility was discussed in the consultation.

Joe FitzPatrick: Thank you.

**Brian Whittle:** Dr Earle, I am looking for clarity on how we consider conditions such as Alzheimer's. Someone who was deemed to have capacity to make the decision might develop a degenerative condition such as Alzheimer's, which might mean that they slip below the level at which someone is deemed to have capacity. Where does the bill sit in that regard?

Dr Earle: That takes us to advance decision making. In that regard, the bill might dovetail with the Adults with Incapacity (Scotland) Act 2000. From case law, we know that, even if somebody loses capacity or has fluctuating capacity, if a decision on a matter that clearly relates to a future scenario was made when they did have capacity, that decision would be considered to be valid in law. There is an open question about how that could happen in this particular scenario, and I do not necessarily want to comment on it, because, as colleagues have said, each case and each person's capacity will be different. In a situation in which someone had fluctuating capacity, such as in the example that you gave in relation to Alzheimer's, that individual case would have to be assessed, as would need to happen in each such case. There would be dovetailing and interaction between different pieces of legislation.

**The Convener:** I thank the witnesses for their attendance and their assistance in the committee's scrutiny of the bill. Their evidence has been very helpful.

I briefly suspend the meeting to allow for a change of witnesses.

10:23

Meeting suspended.

#### 10:39

On resuming—

**The Convener:** We continue our scrutiny of the Assisted Dying for Terminally III Adults (Scotland) Bill with our second panel of witnesses, who will focus on mental health considerations related to the bill.

I welcome Professor Colin McKay, professor, centre for mental health practice, policy and law research, Edinburgh Napier University; and Dr Stephen Potts, consultant in liaison psychiatry, NHS Lothian, who is representing the Royal College of Psychiatrists in Scotland. The committee has received apologies from Dr Arun Chopra, medical director of the Mental Welfare Commission for Scotland, who would have been the third witness on this panel.

We move straight to questions, and I call Paul Sweeney.

**Paul Sweeney:** I thank our witnesses for joining us this morning.

I want to begin with the crossover or interface between mental and terminal illness. The bill, as introduced, states that, to be eligible for assisted dying, the person must have the mental capacity to make the request for an assisted death. Included in the definition of capacity is that a person should not be

"suffering from any mental disorder which might affect the making of the request",

with "mental disorder" defined under section 328 of the Mental Health (Care and Treatment) (Scotland) Act 2003 as

"any ... mental illness ... personality disorder; or ... learning disability".

How common is it for people facing the end of their lives to be suffering from mental health problems such as depression and anxiety?

**Dr Stephen Potts (Royal College of Psychiatrists in Scotland):** I take it that that question is directed primarily at me.

First, thank you for the opportunity to give evidence as part of the committee's appropriate and very detailed scrutiny of the bill. We have addressed the issue specifically in section 4 of the royal college's written submission, but, in answer to your question, mental illness is common in life and therefore common in those approaching the end of their lives, particularly as a result of terminal illness. The most common problems are likely to be depression, problems with alcohol and impairment of capacity arising from delirium in those who are severely physically unwell. Notably common is depression, accompanied by the risk and thoughts of suicide, which are clearly relevant to the decision to seek assisted dying if it is legally available.

**Professor Colin McKay (Edinburgh Napier University):** I am not competent to comment on that issue personally, but on behalf of Dr Chopra, who is not here, I can point you to the written response, which refers to studies from the Netherlands and Oregon indicating that between 8 and 47 per cent of patients requesting physicianassisted suicide—which is obviously much narrower than the end-of-life aspect—exhibited depressive symptoms. That is a very wide range, but I guess that the point is that the number will be significant.

Dr Potts will be more competent to speak to this than I am, but when we talk about, say, depressive

symptoms, the fact is that lots of people have depressive symptoms without being clinically depressed. I guess that it is a continuum.

Dr Potts: Can I add to that?

Paul Sweeney: Please do.

**Dr Potts:** I am sure that this will be apparent to many of us who have considered the possibility, but one response to the diagnosis of a terminal illness is a depressive reaction. How could we not have such a reaction? One of the jobs for psychiatrists working in the area, and the doctors whom they work with, is to come to a decision whether a depressive reaction—that is, an understandable human response to a diagnosis of a terminal illness—is the situation with the patient in front of you, or whether they have developed, in addition, a depressive illness that might stand in need of its own treatment.

**Paul Sweeney:** Is it quite difficult to determine whether the diagnosis was the stimulus for mental ill health or whether it was a pre-existing condition?

**Dr Potts:** Yes, it can be particularly difficult, with continuing uncertainty all the way up to the decision whether to recommend, say, antidepressant treatment.

**Paul Sweeney:** Do you have concerns that the qualifying criteria for eligibility, as defined in the bill, are too restrictive?

**Dr Potts:** Can you elaborate on that question a little bit? I am not sure that I fully understand it.

**Paul Sweeney:** Are you concerned that "mental illness", as defined in the 2003 act, would be a disqualifying criterion?

**Dr Potts:** Yes, and that is addressed in the very first part of section 4 of our response. The bill states that the person must not be

"suffering from a mental disorder that might affect the making of a request".

Well, any mental disorder might affect the making of a request. The question at issue for the doctors involved is whether the mental disorder does affect the making of the request. We have recommended that, if the bill is passed at stage 1, the wording be amended to reflect that concern.

#### 10:45

**Paul Sweeney:** I do not know whether you have had an opportunity to look at the UK bill as introduced—the Terminally III Adults (End of Life) Bill—but its qualifying criteria do not refer to mental illness. However, at clause 30, it states that the secretary of state may introduce a code of practice on "the assessment of whether a person has a clear and settled intention to end their own life",

#### which would include

"recognising and taking account of the effects of depression or other mental disorders (within the meaning of the Mental Health Act 1983) that may impair a person's decisionmaking".

#### Is that perhaps a better definition?

**Dr Potts:** I think that that bill has just been introduced at Westminster today, so a bit more time and scrutiny would be required to answer that question.

### Paul Sweeney: Okay-fair enough.

Is the requirement for a psychiatrist to be the arbiter of the threshold necessary, or should doctors with other specialisms be able to make that decision?

**Dr Potts:** It should not necessarily be restricted to doctors. For example, nurse specialists, physiotherapists, occupational therapists and others may well be relevant in assessing somebody's capacity to seek assisted dying. Psychiatrists often work within multidisciplinary teams that are composed of people from those different backgrounds. That requires discussion among the team members, each of whom might make their own assessment of the patient and come to a conclusion. Therefore, it should not necessarily be limited to psychiatrists.

**Professor McKay:** We agree that the definition excludes too many people. I am not even sure that that was intentional, because it looks as if, in the drafting of the bill, the test of incapacity in the Adults with Incapacity (Scotland) Act 2000 has been taken and made into a test of capacity. The impact of that is that, if someone has a mental disorder that might affect the making of their request, you do not even have to think about the second part of the test, on capacity, which is a slightly odd thing. I think that the ethical issue is whether the mental disorder means that the person is not really able to make a genuinely autonomous decision about ending their life, so the focus should be on capacity.

If the capacity test in the Adults with Incapacity (Scotland) Act 2000 is felt to be too narrowly drawn because there is a presumption of capacity, you could introduce some kind of test, such as the one in the Mental Health (Care and Treatment) (Scotland) Act 2003, which is about significant impairment of decision-making ability. That would be better than just having something that basically says that, if someone has a diagnosis, they cannot access assisted dying.

Paul Sweeney: That is helpful. Thank you.

**Elena Whitham:** The witnesses have already answered a few of the questions that I had, but I would like to take some time to explore a little bit about whether discrimination will occur if neurodivergence is included within the definition of mental disorder. Will you also talk about Alzheimer's and the issue of fluctuating capacity that we heard about from the earlier witnesses? Does either of you have concerns with regards to those two issues?

Dr Potts: I will take the second issue first, which is about the potential eligibility for those with Alzheimer's or other forms of dementia. In our written response, we raised the question whether a diagnosis of dementia would render someone eligible for assisted dying. It is not clear from the bill whether it does that, but the possibility is there that somebody with a clear diagnosis of dementia may retain capacity up to the point of requesting assisted dying. Therefore, it appears that, under the current wording, it is possible that somebody with dementia would be eligible. We have concerns about that, and we have expressed them in our written submission. We have sought clarity on whether it is intended that dementia would be included.

With regard to your point about fluctuating capacity, that is recognised more in the condition of delirium than in dementia. It tends to come on later in the course of a dementing illness, and it can make it hard for those who are assisting a patient to know what they want if their capacity varies from morning to afternoon, for example. On an issue as important as this, it is important that the capacity is taken at its best, as far as is possible. If you have somebody who regularly loses capacity late in the day, but they retain capacity in the morning, you go with their morning decision as much as you can.

I am not sure whether that has answered your question, but I will come on to the question of neurodivergence. The definition of mental disorder that is used in the bill is the one under the current mental health act—the Mental Health (Care and Treatment) (Scotland) Act 2003. However, as we have pointed out, there are proposals to change the definition of mental disorder and to remove from it learning disabilities or autism. If there is parallel legislation changing the definition of mental disorder, that might make the definition of mental disorder outdated from the moment this bill comes into force.

**Professor McKay:** I would be slightly less worried about that. From my understanding of the progress on that proposed change, which is in response to the Scott review of mental health law—for full disclosure, I was a member of the committee of that review—I do not think that we will be changing the definition of mental disorder any time soon. It is under consideration, but it will probably be a while before any legislation comes forward. If the definition were changed, it would be perfectly possible to change any definitions that hang off it. In fact, there are lots of pieces of legislation which hang off the definition of mental disorder in the 2003 act, so that is a practical issue for later on.

On the question of including neurodivergence, would that be discriminatory because neurodivergent people will not be allowed to access assisted dying, or because they will be allowed assisted dying? Again, it is better to focus on the issue of decision-making ability, rather than on a particular diagnosis. If a person who is neurodivergent is still able to formulate a competent decision and they are seriously terminally ill and near the end of their life, I would argue that it would be discriminatory not to allow them to access assisted dying. We always have to bear in mind that the question is not about someone accessing assisted dying because they have neurodivergence, but about whether a person with neurodivergence who is terminally ill, near the end of their life and suffering should be able to access it. I would argue that they should be able to.

On the question of dementia, I essentially agree with Dr Potts's position. By the time you get to the end stages of dementia, clearly you will have lost capacity and would not be able to access assisted dying. However, it is a tricky one, in that dementia falls between classical mental disorder and neurological physical conditions. One argument might be that, if it was felt that dementia in itself could not be the terminal condition that would justify assisted dying, you could provide for regulations to exclude specific conditions, which might include dementia if that was the will of Parliament. However, I think that a person who has another physical condition, who may have a diagnosis of early dementia but also has stage 4 cancer, for example, should be able to access assisted dying if they are competent to make a decision.

**Elena Whitham:** That is very helpful. I have a follow-up question. For the purposes of the bill as it is drafted, and with the existing law—the 2003 act—as it stands, am I right to infer that neurodivergence would be included in the definition of a mental disorder, versus what may come forward from the Scott review at some point in time?

**Professor McKay:** To be honest, it is not 100 per cent clear what is included in the current definition of mental disorder. I think that psychiatrists generally accept that autism would be included in the 2003 act definition, for example, but I am not sure that a condition such as attention

deficit hyperactivity disorder would be treated as a mental disorder for the purposes of the 2003 act. It is slightly fuzzy, which is one of the reasons why I think that it is better to focus on the impact of any condition on decision-making ability.

Dr Potts: I would agree with that.

**The Convener:** I refer to my entry in the register of members' interests. I have a bank nurse contract with NHS Greater Glasgow and Clyde, and I commissioned the Scott review when I was Minister for Mental Health.

I want to ask about learning disabilities. We know that learning disabilities are on a very broad spectrum, but we also know that many people with learning disabilities die a lot younger than the general population, and often of illnesses that would perhaps have been picked up earlier in other adults. Learning disabilities are one of the exclusions in the bill, so I am keen to hear, particularly from you, Professor McKay, because you raised the issue of capacity as opposed to diagnosis, what you think about that and how that could be addressed.

**Professor McKay:** You could address it in a couple of ways. You could take out the reference to mental disorder altogether and I am not sure that the bill would be any the worse for it, because you would still have the requirement that the person has to be capable of understanding information about making a request, making a decision, communicating and so on. That is a very familiar test of capacity that is already well understood, so I am not sure that the definition of mental disorder has to be clear about that.

With most of these things, the issue is to get the policy right and then work out how you draft it. You would need to decide whether it should be possible for a person with a learning disability to access assisted dying if it becomes legal for other people. My answer to that would be that it should be possible if the person meets the other tests—in that they are terminally ill and so on.

This is a different issue, but I think that the tests around terminal illness might need to be tightened up. An adequate test for terminal illness and a test of capacity are the things that we need. A person with a severe or profound learning disability would, arguably, not be able to access assisted dying, but that is probably correct. A person with a mild to moderate learning disability, if they understand what is happening to them and are able to make that choice, should be able to. That should be the policy intent, and it is a question for parliamentary drafters to think about how to make that reality.

**Dr Potts:** I will add to that. One of the clearest areas of consensus in the Royal College of Psychiatrists survey of our members is the view

that if you have a terminal cancer, it is discriminatory to exclude you from assisted dying if you also have a learning disability, autism or another mental disorder. The issue is what happens when there are two conditions, one of which might influence the decision making over the other. If it is clear that you have a mild learning disability and you retain capacity, and the bill passes and you then develop cancer, you should have access to the service that everybody else does.

**Gillian Mackay:** You have both mentioned the concerns that you have that people with dementia and Alzheimer's could come under the bill. What additional safeguards should there be for those people?

**Dr Potts:** It is more for the drafters of the bill to put in the safeguards for others to comment on than it is for us as a college to recommend changes to the bill. However, under the bill, someone with an early-stage dementing illness and comorbid cancer is likely to be referred to a psychiatrist for assessment of their dementia. Then the question will be around the degree of their dementia and the extent to which it erodes or removes their decision-making capacity.

The bill currently includes that, but says very little about how to go about it or what happens if there is doubt or disagreement or if capacity changes if the dementia progresses during the assessment process.

**Professor McKay:** I will expand on something that I have already said. It is helpful to look at the definition of terminal illness. One of the safeguards would be to be clear about whether or not dementia could be the condition that would justify someone seeking assistance to end their life.

If the intention behind the bill is to limit its use to the very hard cases, as it were, in which it feels like we are prolonging someone's suffering when they are in physical pain and discomfort, I argue that it might be safer to explicitly exclude dementia or to have a definition in section 2 that makes it clear that dementia is not in and of itself a condition that would trigger the right to request assisted dying.

## 11:00

On the capacity test, we have probably already answered the point, but I repeat and agree with the position of the RCPS. A diagnosis of dementia in itself should not prevent someone from having access to the same rights as other people in relation to any physical condition from which they might suffer.

There are other safeguards that you might want to build into the decision-making process. There is

the issue of what the tests are and who applies them. Another issue is what support and guidance you have in difficult cases. Wherever you draw the line, there will be difficult cases.

We suggested in our response that perhaps just leaving that to doctors is not the best approach. I am not saying that that could not work. Again, this is probably jumping on a little to issues around coercion, family pressure and so on, but, particularly where there are doubts about aspects such as capacity, we would probably prefer building in more of a multidisciplinary approach to such decisions, possibly through a panel or something like that. That might be an additional and helpful safeguard, and it might be helpful in difficult dementia cases, for example.

**Dr Potts:** I will raise a further consideration, which in part is in response to the question. The bill does not define, except in very general terms, the level of training or expertise of the psychiatrist to whom a referral is made in cases of doubt. It might well be that, if there is access to a central register of psychiatrists who are willing to be involved, that will ensure that you get a psychiatrist who is overseen, where there is data about their practice, where there is accreditation and where they have expertise in assessing exactly such situations. That is one of the recommendations that we have made.

Although many of our members have expressed a wish to opt out of participation in any questions around assisted dying, a proportion—16 per cent, I think—have indicated a willingness to opt in to a central register if that was set up.

**Professor McKay:** There are models for that. For example, under the 2003 act, the Mental Welfare Commission for Scotland operates the second opinion doctor process.

One of the other anxieties about the bill is the idea that lots of doctors might opt out and you might end up with maverick practitioners, as it were, with people who are very pro-assisted dying just coming in and saying that they will sign off anybody. A register with a degree of oversight and regulation would be a helpful safeguard.

**Paul Sweeney:** I turn to the issue of capacity, which we have discussed to some extent already. Does either of you have any concerns about the ability of non-psychiatric doctors to assess the capacity of people seeking an assisted death?

**Dr Potts:** Assessing capacity for decisions about medical treatment should be part of the core skills of all doctors in all specialties and should not be reserved to a specialist who is regarded as having additional expertise. Can psychiatrists assist with that? Yes. Do we do that regularly? Yes.

I will give you an example. I work alongside the renal unit in the Royal infirmary of Edinburgh. Sometimes, I am asked to assess people who have decided that they wish to stop dialysis and die. I am asked to make, or assist the kidney specialists in making, assessments of their capacity to come to that decision, and to advise on what the next step should be. I am not asked to see all those patients. I trust my nephrology colleagues to make good, appropriate assessments of their capacity and to refer to me only in cases of doubt, which is what has happened over the past 10 or 15 years.

**Professor McKay:** Yes, as Dr Potts said, that should be core practice, because doctors have to get consent from patients and they must know that the patient has given informed consent or decide whether they are not able to give informed consent. That should be a core practice of every medical practitioner—and, indeed, other practitioners, such as lawyers.

That said, the level of training could perhaps be improved. However, in the context of the bill, that would be very fixable. For example, we might want to put in requirements for a certain degree of training or certification before these particular decisions are taken. Practice could be improved, but it could be improved through training and guidance.

**Paul Sweeney:** I think that the financial memorandum to the bill sets aside funding for training purposes, but it does not specifically mention training in relation to assessing capacity. Would you prefer that that was further clarified in the bill?

**Professor McKay:** As I said, if there was more training for everybody on assessing capacity in relation to their other business, it would not cost that much more.

I get that this is obviously a very special and different kind of issue, for which we might want more intensive training. If we are talking about implementation, that training should be provided for in the bill. Part of our general theme is that, if we as a country are going to do this, we should do it properly. That means having proper infrastructure to make sure that the decisions are robust and defensible—and that includes training.

**Paul Sweeney:** To what extent are you satisfied that the process set out in the bill adequately facilitates what is needed to assess an individual's capacity to seek assisted dying? Are you content that the bill as introduced has sufficient definitions of a process and the safeguards?

Dr Potts: My short answer would be no.

The bill provides that, if either of the assessing doctors has doubts about a person's capacity,

they "may" refer to a psychiatrist—that is, they do not have to.

The bill also provides that they are required to "take account of" the psychiatrist's assessment of capacity, but it is not clear what "take account of" means. For example, it could mean that I have heard your opinion and I disagree with it, so we are going ahead.

**Paul Sweeney:** Your view is that the language should be strengthened to place an obligation.

**Dr Potts:** Yes. The language within the bill itself should be strengthened, and not left to a future code of practice.

Paul Sweeney: That is helpful.

**Professor McKay:** I think that those comments are fair enough.

I would also say that I do not particularly like the forms that are in the schedules at the end of the bill, which feel very much like a tick-box exercise. For such a consequential decision, I would want to see the person explaining how they have come to the decision, that the patient has capacity, is not being coerced and so on.

The safeguards could be tightened up in the bill, notwithstanding that a lot of that would have to be fleshed out in the code of practice.

**Paul Sweeney:** I presume that, if there were such strengthening of language in the bill, extra demand would be placed on psychiatry services in Scotland. What is your assessment of the impact that that would have on the psychiatry workload in Scotland. How practical might that be?

**Dr Potts:** It is inevitable that there will be a demand for increased activity by psychiatrists and our colleagues as a result of the bill, if it passes. That will require resources. There will need to be an estimate of the likely level of provision required and a level of resource provision that matches that.

**Paul Sweeney:** The financial memorandum to the bill estimates that there will be 25 assisted deaths in the first year, rising to 400 deaths by year 20. That is also based on an assumption that 33 per cent of people who enter the process will not proceed. Do those projections seem like a workable caseload?

**Dr Potts:** I know that the committee has taken evidence from Canadian witnesses. In Canada, we have seen an almost exponential increase in the provision of assisted dying, to the level where it now accounts for 4 per cent, or more, of all deaths. It has increased very dramatically in a short space of time.

One of my college's concerns is that the numbers projected initially are an underestimate,

and that the rate of increase is also an underestimate.

Paul Sweeney: That is helpful.

**The Convener:** Following on from Mr Sweeney's questions, I note that, under the bill as introduced, the two doctors that sign off capacity could be two foundation year 2 doctors. In your opinion, would they have the level of training and expertise to be able to do that?

**Dr Potts:** I will give another short answer—no. As far as the psychiatry role is concerned, we have recommended that the level of expertise should be at least equivalent to that of approved medical practitioner under the 2003 act. Essentially, that is a psychiatrist who has completed their core psychiatric training and has three more years of higher training to go before they become a consultant. It is a middle-grade doctor role, not an FY2 role.

**David Torrance:** Good morning. My questions are around the Scott review and capacity decisions. Is the approach to capacity outlined in the bill, which is taken in large part from the Adults with Incapacity (Scotland) Act 2000, still fit for purpose in light of the recent review of the area?

**Professor McKay:** As I said, although the approach is taken from the 2000 act, it has been taken in a way that makes it not work properly. That needs to be addressed.

The Scott review had criticisms of capacity as a test, partly reflecting the fact that the UN Committee on the Rights of Persons with Disabilities has criticised capacity as being something that is less scientific than it appears to be. It is an unduly binary test that can be used to remove people's autonomy when they have not had enough support to make decisions for themselves. The context for that is legislation that tries to allow as many people as possible to make decisions for themselves.

We suggested in the Scott review that we should develop a new test, which we called "Autonomous decision making". It would look at what the barriers might be to a person making a choice for themselves and how those barriers might be overcome. The focus would therefore become less an assessment of what is in the person's head and more an assessment of how we can find out what they most want to happen and how can we help them to make that happen.

For the purposes of the bill, I would say two things about capacity. First, it is slightly different, because this is about whether we need to put in safeguards to prevent people who may be vulnerable from accessing assisted dying when they really should not. It is perhaps reasonable to be slightly more conservative. The Committee on the Rights of Persons with Disabilities wants to really broaden the tent so that pretty much everybody can make their own decisions for themselves. However, I am not sure that we should be doing that with the bill.

Secondly, the recommendations of the Scott review are with the Scottish Government, but I do not think that it will make any fundamental change around capacity for several years. For the moment, capacity as a concept is broadly understood by the profession. There are more and less scientific ways of assessing it. With improved training and guidance, I think that it is workable as a test, provided that people are given the right support and a careful enough assessment. Although I was on the Scott review and we advocated a new test, for the purposes of trying to make the bill work in the context of the legal framework that we have, the approach is probably your best bet.

**Dr Potts:** The relevant legislation here is the Adults with Incapacity (Scotland) Act 2000. The bill reverses the usual presumption. Under the 2000 act, it is presumed that we all have capacity to make all decisions until somebody—a relevant professional—proves, on the balance of probabilities, that we do not. I do not fully understand the reasons for reversing that in the bill, requiring that capacity rather than incapacity is proved.

**Professor McKay:** I would not be surprised if it was just a drafting mistake.

The other thing about capacity goes back to the questions about workload. I do not have any particular expertise in assessing capacity, but if people want to access assisted dying, they will have to have a capacity test of some kind. For lots of people, of course, there will not be any question about their capacity. There will be plenty of people for whom it is abundantly clear that they are fully competent to make the decision. I do not think that you are suggesting that every single person would need to see a psychiatrist.

Dr Potts: Definitely not.

#### 11:15

**David Torrance:** Professor McKay mentioned that the recommendations from the Scott review are with the Scottish Government. Are there any that can improve the bill?

**Professor McKay:** I am sure that there are. The Scott review is 1,000 pages long, so I am trying to think about which recommendations would be particularly relevant.

It is more about the approach that the Scott review recommends. In the longer term, one of the issues is the balance between the right to request assisted dying and the right to access palliative care. One of the things that the Scott review recommends is that, when considering people's human rights, you should consider what are called their economic, social and cultural rights, which include the right to adequate healthcare. It would be helpful to have legislation that ensures that people get the support that they need and are not forced to take a decision that they would not otherwise take because of a lack of adequate services.

The other broad issue in the Scott review that I would come back to is that of who takes the decisions. As I said, I think that the bill is slightly too narrowly focused on two doctors taking a decision whereas, particularly if areas such as coercion and undue influence are involved, other voices need to be heard in the decision-making process.

**Sandesh Gulhane:** I refer members to my entry in the register of members' interests, which states that I am a practising NHS GP. I also chair the medical advisory group on the bill.

I thank the witnesses for coming and for their evidence. I was struck by a couple of things that have been said so far. We heard from the previous panel about the potential for doctor shopping until people find somebody who will, as Colin McKay said, sign off on anything. Might a register, as you have suggested, stop that occurring?

**Dr Potts:** Are you talking specifically about doctor shopping for an approving psychiatric opinion?

Sandesh Gulhane: Yes.

**Dr Potts:** Yes. A register could do that, provided that there was provision for a second opinion from somebody else on the register. In other words, opinions are sought from the registered professionals; if there is doubt or disagreement, it is reasonable to allow room to request a second opinion through the same route, but not a third, fourth or fifth opinion. I am not so clear about whether that could also apply to the assessing doctors who refer to psychiatry. There is certainly room for doctor shopping there.

**Professor McKay:** Some sort of registration and oversight would be helpful to guard against the maverick practitioner. We suggested that consideration might be given to a broader model, such as an ethics committee-type of model. That is not unheard of in other areas, such as, historically, gender reassignment, human tissue donation, in vitro fertilisation and even research. If an academic researcher wants to interview a person with a learning disability, they have to justify that to an ethics committee, and one might think that the decision that we are discussing is more consequential than that one. It is about having something that supports a more nuanced, individualised and multidisciplinary process.

It is very difficult, in primary legislation, to capture all the complexities of an individual case and the question of when it might or might not be ethically justified and appropriate to permit assisted dying. It is also a bit of an abdication of responsibility just to hand that over to doctors on their own—that is not necessarily what doctors should be doing on their own. Some kind of panel or committee approach might be the way to go.

**Sandesh Gulhane:** As GPs, we spend a lot of time with our patients and we see what the family dynamic is. How can we assess coercion and ensure that there is no coercion, either positively or negatively, outside of that structure?

**Dr Potts:** I will take that first, if I may. Previous bills have assigned to psychiatrists the role of assessing coercion, and I do not think that that is any part of our skill set, any more than it is of any other doctor's, so I am pleased that this bill does not do that. That said, the risk of coercion is clearly there, and we must have a system in place that minimises it.

I am more concerned about people choosing assisted dying out of an internal sense of pressure, duty or obligation than I am about external explicit coercion. I bring to this territory another role as an independent assessor of transplant services under the Human Tissue Act 2004, in which there is a duty to explicitly assess coercion on somebody who has come forward as a potential living donor of an organ. I have seen 100 or more such cases, and only in two or three have I identified explicit coercion and the transplant has not gone ahead. In a larger, though still small, number, I have identified internal pressure or a sense of duty or obligation as the potential donor's reason to donate, and the transplant has not gone ahead. We are talking about small numbers, but I am more concerned about internal duty and obligation than I am about external pressure in that context, and I would apply the same to this context, too. I do not know whether that answers your question.

**Professor McKay:** There is obviously a hugely difficult philosophical question about when that sort of internalised thing is actually an impairment of your autonomy and when it is your autonomous decision. I guess that it is really for the Parliament, representing society, to decide when we think that that is socially acceptable and when it is not.

On the question of the influence of others and undue influence, the Adults with Incapacity (Scotland) Act 2000, when it comes to such issues, tends to put responsibility on mental health officers and social workers to assess, say, family dynamics. Under that act, doctors assess the person's capacity to make relevant decisions, but other people are looking at the broader family situation, too. A GP who knows a person might have some insight into family dynamics, but I suspect that a lot of GPs will opt out of this, and the medical assessor will probably be someone who does not know the person very well.

I note that, in its response, Social Work Scotland says:

"The critical factor requiring consideration is the holistic environmental experience of the individual wishing to end their life earlier than medical expertise would suggest will occur in the usual course of illness. This requires understanding and assessment of the social and relationship influences and context, including how close relationships and influence/power dynamics impact on individual decision making. Social Work Scotland suggest that a wider multi-agency assessment of eligibility is therefore indicated."

Again, it is all about having a broader range of voices in the decision-making process to look at family dynamics, in particular, that might be influencing the person's decision making.

**Dr Potts:** Perhaps I can elaborate on my previous answer. In the field of human organ donation, the relevant regulatory body is the Human Tissue Authority, whose system requires explicit assessment of possible coercion applied to living donors. It provides independent assessors to each transplant unit, oversees them and provides training. This sort of thing can be done, and it has been done by a UK regulatory body for the past 18 years. Therefore, there is a model that could be applied to this bill.

**Sandesh Gulhane:** We talked earlier about how, when you are diagnosed with a terminal illness, you will naturally have—or you should have—a depressive reaction of some description. Other mental health issues might play into that, and you mentioned social issues such as alcohol that could play a role. You have mentioned internal coercion, but should we also consider such other matters with regard to coercion?

Dr Potts: It is probably a little too anecdotal, but I will refer to a now-deceased patient of mine from years ago. He was referred to me because a Dignitas leaflet was found on the locker next to his dialysis space. I asked him why he had been exploring Dignitas and going to Switzerland. It was because, in his view at the time, his life was intolerable. Following discussion over several meetings, it became clear that there were problems, underlying alcohol relationship problems and a depression, all of which could be, and were, treated. He was successful in feeling better about his life, continuing on dialysis, getting his depression treated, dealing with his alcohol and his family pressures, and he lived another 14 years. That is an anecdotal way to answer your question. Can the issues be addressed? Yes, they can. Can they make a difference? Very definitely.

**Professor McKay:** If the wish is to tighten up the bill, that might be partly about the definition of terminal illness, which at the moment is

"an advanced and progressive disease ... from which they are unable to recover and that can reasonably be expected to cause their premature death".

As I understand it, you could have a cancer diagnosis and be some years from death and would still be subject to that definition. It would not be unreasonable to have something that says that this is for people who, as the policy statement suggests, are "close to death". I think that perhaps the policy intention should be that this is for people who are dying or who will die very soon, although I know that prognoses are problematic in terms of time periods. Tightening the legislation so that it applies to people who are in the process of dying might avoid the situation where a person gets a diagnosis, has a reactive depression and says, "That's it. I'm ending it today," when they might have afterwards regretted that decision. I agree that you need safeguards against that. I think that there are ways to build them in.

**Sandesh Gulhane:** Lastly, we have talked about a panel, registers and lots of different ways of assessing. A lot of that is really just for cases of doubt, as Professor Potts has already mentioned. We have to be clear that most cases will be pretty straightforward, so this is for those special cases. Do you think that, for the assessors to use such a pathway, some form of credentialling, which would obviously involve extra training, would be important?

**Dr Potts:** Do you mean for the co-ordinating doctor and the independent doctor?

**Sandesh Gulhane:** Yes—for people throughout the process, really.

**Dr Potts:** If we applied the model of a central register of psychiatrists, there would need to be some form of credentialling to get them on that register. If we have a central register for psychiatrists, why not have a central register for co-ordinating and attending doctors? However, that might limit the ability for a patient to seek assessment from their own GP or relevant specialist, as they may not be credentialled. There is a risk that requiring the assessment to come from those first two doctors—the co-ordinating and the independent doctor—might prevent a patient from asking for assisted dying from the doctors they know best and who are currently treating them for their terminal illness.

**Professor McKay:** Having a register might deal with some of the other difficulties in the bill around things such as conscience clauses and people opting out and what to do if a doctor says, "I'm

sorry, that's not something I do." We were concerned about the idea that a doctor who has a fundamental objection would have a duty to find you another practitioner. If there is a register, that problem goes away. It becomes a process that people can access.

#### Sandesh Gulhane: Thank you.

**Brian Whittle:** Good morning. I think that the bill as drafted means that if you are going to access assisted dying, it has to be self-administered. That brings up the question of continued capacity throughout the whole process. Let us say that you decide that this is your direction of travel. You have a degenerative illness that you know will bring you to a position where self-administering will become more and more difficult. Is there a danger that that rushes people into making a decision and into accessing assisted dying before they potentially would like to?

#### 11:30

**Dr Potts:** To some extent, that goes beyond my role as a psychiatrist. There are people with neurodegenerative conditions who retain cognitive capacity but might not be able to lift a cup to their lips to take the medication. That could be intensely frustrating for them if the thing that prevents them from accessing assisted dying is that they cannot self-administer.

In other jurisdictions, notably Holland and Belgium, there is much more use of active administration of medication, sometimes by intravenous injections. There are jurisdictions where a doctor can set up an intravenous infusion and all the patient has to do is to press a button to release the medication into their bloodstream. The question in relation to the bill is, does that count as self-administration? Is that assisted administration by a doctor? Yes, but who has taken the final decision? It is still the patient.

There is the possibility that a patient, could, for example, with the blink of an eye, turn on a machine that administers the medication. As I read the bill, that would still count as self-administration.

**Professor McKay:** Ethically, the line that we are trying to draw is between people who are able to choose assisted dying and people who we should regard as not being able to choose assisted dying. Their physical ability is not part of that ethical calculation. There is certainly an argument that to deny somebody, because of their physical disability, the ability to end their life, which other people have the ability to do, is discriminatory and could be subject to challenge. I am not saying that a challenge would succeed.

Our view is that the safeguards need to be around making sure that the person meets the

criteria in terms of the seriousness of their condition and of their wish to end their life. How the treatment is administered is not the key issue.

However, we accept that there might be a wish to be absolutely sure that we do not tip over into helping people, in a more assertive way, to end their life too easily. I can see why the bill takes the approach that it does. Personally, I would say that it would be better to have, as Dr Potts said, some kind of minimal intervention. There certainly would need to be clarity about what constitutes helping to administer the substance. I think that you have had evidence in that regard that mentioned people being able to hold up their head and lifting the medication to their lips.

In principle, I would suggest that it ought to be possible for people who physically cannot administer the substance themselves to have assistance in doing so. It is striking that a lot of the court cases have been brought by people with motor neurone disease and other degenerative conditions for whom that would be a very pertinent issue. However, I understand that—as with a lot of this—we are proceeding very gingerly and trying to avoid unintended consequences.

**Brian Whittle:** To follow up my question, I want to ask about advance directives. I do not know whether that falls within your capability. Say that there is a situation—it might be a comorbidity or a dementia-type scenario—in which someone lacks capacity. When they had capacity, they made an advance directive setting out what they wanted to do at a certain time, but enacting that would require the intervention of another party. Should such a scenario be considered?

**Professor McKay:** I would argue against providing for advance directives to be the authorisation for assisted dying. One thing that I would say is that we do not currently have very clear law on advance directives about other things, such as the refusal of treatment. In England, there is a provision in the Mental Capacity Act 2005 about an advance decision to refuse treatment. In Scotland, the common law applies, and we do not really know what the law is.

The Law Society has done a lot of work on this, and the Scott review made some recommendations on legislating on advance directives so that you can make one. The presumption is that such a directive would be binding on you in future, but there would be various provisos that would mean that it would not be applied in particular circumstances—if, for example, there were a reason to believe that the person had changed their mind.

Until we have a clearer framework for advance directives in the law generally, I do not think that we should be putting them into assisted dying. Indeed, we should probably never put them into assisted dying. I think that it would be safer to stick with the person's contemporaneous wish.

**Dr Potts:** My understanding of the medical advisory group's recommendations in this respect is that advance directives should be excluded in determining a patient's eligibility. When it comes to declining future possible medical treatment, advance directives can be notoriously difficult to interpret in the face of the particular set of circumstances that apply. To anybody seeking to write an advance directive, we would normally recommend that they appoint a proxy decision maker to interpret the directive in the light of the circumstances on the scene. That does not mean that the proxy decision maker helps them do what they have said that they want to do.

**Carol Mochan (South Scotland) (Lab):** I have learned a lot from the discussions, but there is something else that I have been wondering about. In lots of our evidence, particularly the written evidence, there has been discussion about support for patients and staff in this process. Can you say a few words about whether it would be helpful for psychological support, perhaps, to be available to staff and patients involved in the process? Do you think that, before going through the process, patients should have some specific support?

**Dr Potts:** I suppose that the answer to that question partly depends on what is meant by "support". In an ideal world, every medical service should have access to psychosocial assessment and management for their patients where that is needed. The fact is that the provision of support across medical specialties is highly variable; some palliative care and oncology services have a lot, while others have very little.

Would patients seeking assisted dying potentially need psychosocial support alongside support from their usual medical practitioners as they navigated the process? I think that the answer has to be yes. How would they access it? Would enough be available to them? That is unclear, except that provision is patchy.

As for whether staff members might need it, if you are part of a nursing team and one of your patients seeks and is granted assisted dying, that is likely to be a significant emotional issue for you and for the rest of your team, and you might well need some discussion about it. As with what happens after a suicide on a psychiatric ward—a very significant adverse event—there should be routine provision of psychological support to all the members of the team from all of their disciplines.

**Professor McKay:** I have no particularly worked-up proposition for exactly what support would look like, but I agree that support would be

important. There are examples of such support in other areas of healthcare, whether it be advocacy under the 2003 act, doulas in relation to midwifery or some of the other end-of-life support that already exists in relation to palliative care.

One question for the bill might be: whose job is it to make sure that such support is available? It might be an issue for health boards, for example, to ensure that that is the case. After all, if we do not have that, I am not sure where support will be found.

**Carol Mochan:** Do you have a view on patients receiving counselling? In your last response, you talked about others assessing what people need in response to the position in which they find themselves.

**Dr Potts:** If somebody has, say, terminal cancer and possibly an associated depressive illness, it should not take a request for assisted dying to get the necessary counselling made available to them. That is a perverse incentive to request assisted dying, even when you do not really want it. There should be appropriate access to counselling, support and psychological treatment for those who need it, but how is a determination to be made about who needs it and what form they need? That probably has to fall initially on the assessing doctors, with the opportunity to refer on as required.

Carol Mochan: That is very helpful. Thank you.

**The Convener:** I thank our witnesses for their attendance; you have been very helpful to the committee in our on-going scrutiny of the bill. Please feel free to leave while the committee's work continues.

# Subordinate Legislation

## National Health Service Superannuation and Pension Schemes (Miscellaneous Amendment) (Scotland) Regulations 2024 (SSI 2024/272)

## 11:40

**The Convener:** The next item on our agenda is consideration of a negative instrument. The purpose of the instrument is to amend the regulations on the NHS superannuation and pension schemes in Scotland. The instrument introduces legislative changes to the schemes, including retirement flexibilities, amendments to abatement rules and final pay controls, changes to the 2015 regulations regarding inflation and other miscellaneous amendments. The policy note states that

"the instrument also introduces a new employer contribution rate from 1 April 2024 and reforms the employee contribution rates in the NHSPS(S) in two phases from 1 October 2023 and 1 October 2024."

The Delegated Powers and Law Reform Committee considered the instrument at its meeting on 5 November 2024 and made no recommendations in relation to it. No motion to annul has been received. I know that Sandesh Gulhane wishes to make some comments. Before I pass over to him, I put it on record that I am a contributor to an NHS superannuation and pension scheme.

**Sandesh Gulhane:** I declare my interest as a practising NHS GP and, obviously, as a contributor to the NHS pension scheme.

I have a number of questions that I would like to put on the record and to which I would like answers from ministers, where appropriate. I would like to know what the anticipated financial impact of the amendments are on NHS staff pensions and, more importantly, on the overall sustainability of the pension schemes. What is the long-term strategy for ensuring the financial sustainability of NHS pension schemes in Scotland, given the rise in contribution rates? How do the amendments align with broader public sector pension reforms in Scotland and how do they compare to similar changes across the rest of the UK? To what extent would the changes to pension contributions and retirement flexibilities influence NHS staff recruitment and retention in Scotland? Can we explain the rationale behind the introduction of the final pay controls and what impact they will have on pensions for NHS staff who are near retirement age?

My final comment is that, with the changes that we see here, people who use the NHS pension

scheme are totally and utterly unable to easily see their pension and to understand what is happening and what tax implications their pensions might have. That is important, because we are at a time when our NHS is on its knees and we need to make it easier for staff to do more work. However, what can happen is that staff who do more work will be landed retrospectively with a huge tax bill because of pension contributions, which means that they have, in effect, paid to go to work and to help us in our NHS. There are simple changes that can be made to stop that happening, and I urge the Scottish Government to look at those, both to make that easier and to allow people to see their pensions, as I have been contacted by a number of constituents who are unable to do so.

**The Convener:** Thank you, Mr Gulhane. I take it that by "some staff" you are referring to medical staff?

#### Sandesh Gulhane: Yes.

**The Convener:** I see no objection to the committee writing to ministers and asking for relevant clarification on some of those issues. Are you content with that?

Sandesh Gulhane: Yes.

**The Convener:** Thank you very much. I propose that the committee does not make any recommendations in relation to this negative instrument. Do members agree?

Members indicated agreement.

The Convener: Thank you.

At our next meeting, on Tuesday 19 November, we will continue taking oral evidence as part of the committee's stage 1 scrutiny of the Assisted Dying for Terminally III Adults (Scotland) Bill. That concludes the public part of our meeting.

#### 11:44

Meeting continued in private until 11:57.

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