OFFICIAL REPORT
AITHISG OIFIGEIL

# Health, Social Care and Sport Committee

**Tuesday 21 January 2025**

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

# Tuesday 21 January 2025

## CONTENTS


| | Col. |
|---|---|
| **SUBORDINATE LEGISLATION** | 1 |
| Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025 [Draft] | 1 |
| **ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL: STAGE 1** | 14 |


## HEALTH, SOCIAL CARE AND SPORT COMMITTEE

**2nd Meeting 2025, 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:**

Georgina Finch (Food Standards Scotland)
Dr Miro Griffiths (Not Dead Yet UK)
Dr Gordon Macdonald (Care Not Killing)
Dr Gillian MacDougall (Friends at the End)
Jenni Minto (Minister for Public Health and Women's Health)
Professor Gareth Morgan (Scottish Christian Forum on Assisted Dying)
Fraser Sutherland (Humanist Society Scotland)
Alyson Thomson (Dignity in Dying Scotland)
Michael Veitch (Christian Action Research And Education)
Greig Walker (Scottish Government)
Dr Gillian Wright (Our Duty of Care)

**CLERK TO THE COMMITTEE**

Alex Bruce

**LOCATION**

The Sir Alexander Fleming Room (CR3)

# Scottish Parliament

## Health, Social Care and Sport Committee

*Tuesday 21 January 2025*

*[The Deputy Convener opened the meeting at 09:00]*

## Subordinate Legislation

### Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025 [Draft]

**The Deputy Convener (Paul Sweeney):** Good morning, and welcome to the second meeting of the Health, Social Care and Sport Committee in 2025. Unfortunately, the convener is unable to attend today's meeting in person and will be joining us online. As deputy convener, I will convene the meeting in her absence. I have received no apologies for the meeting.

Our first agenda item is on United Kingdom subordinate legislation. We will take evidence on a consent notification on the Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025. This is a UK statutory instrument on which the UK Government is seeking the Scottish Government's consent to legislate in areas of devolved competence. The committee's role is to decide whether it agrees with the Scottish Government's proposal to consent to the UK Government making the regulations within devolved competence and in the manner that the UK Government has indicated to the Scottish Government.

At our previous meeting, we considered the notification and agreed to invite the Minister for Public Health and Women's Health to give evidence today. We have until tomorrow, 22 January, to respond to the Scottish Government's notification, which we will do immediately after this morning's evidence session. I therefore invite members to debate and decide how they wish to respond in a letter to the Scottish Government.

I welcome to the committee Jenni Minto, the Minister for Public Health and Women's Health; Georgina Finch, who is a senior policy adviser at Food Standards Scotland; Neel Mojee, who is a lawyer for the Scottish Government; and Greig Walker, who is project lead on constitution and UK relations at the Scottish Government. I thank you for joining us.

Before we move on to questions, minister, I believe that you would like to make a brief opening statement.

**The Minister for Public Health and Women's Health (Jenni Minto):** Thank you. I am pleased to join the committee to consider the notification on the UK Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025.

The proposed reforms that would be delivered by the UK statutory instrument have been co-developed under the provisional food and feed safety and hygiene common framework. The instrument proposes two Great-Britain-wide reforms for regulated products. The first is to remove requirements for periodic renewal of authorisations for three regulated products regimes. The second is to allow authorisations to come into effect following a ministerial decision, which would be published in an official register rather than being prescribed by statutory instrument.

We need to modernise the regulated products service. Food Standards Scotland and the Food Standards Agency assess applications for those products and provide advice to the respective ministers who decide whether the products can be sold. The instrument would implement a more proportionate approach to reviewing products that are already authorised for sale by focusing on evidence-based safety concerns as they arise, instead of review being driven by fixed renewal points every 10 years. The majority of products have years of safe use. Removing set renewal periods will allow a more targeted approach to regulation, in which FSS and the FSA use powers to review authorisations as new evidence emerges around the safety of a product that is on the market.

The second of the reforms will allow authorisations to come into force following a ministerial decision. Authorisations would be published in an official public register, rather than being prescribed in a statutory instrument. Such authorisations will reduce the timescales for products to reach the market and will not impose the use of valuable parliamentary time. That approach would align with authorisation processes that are used by other regulators in the UK for similarly regulated products.

FSS and the FSA provide technical and scientific scrutiny through skilled and experienced staff and expert independent scientific advisory committees. They assess individual applications and provide a safety assessment from which risk management advice and recommendations are formed for subsequent ministerial decision. The proposed process squarely aligns with

internationally recognised principles and maintains transparency.

Overall, this is an opportunity to deliver reforms that prioritise efficiency in the authorisation of regulated products and focuses resources on new products that require more input when access to the market is being sought for them.

FSS and the FSA have earned the trust of the public through their rigorous approach to risk analysis. In the proposed reforms, food safety will continue to be the priority. The reforms will also result in improvements in efficiency and the maintenance of robust safety standards.

I ask the committee to agree that the Scottish ministers should consent to the reforms in the GB SI. I am happy to take any questions.

**Sandesh Gulhane (Glasgow) (Con):** We have a complex piece of work in front of us minister, so I have a number of questions. Does the status of FSS as a non-ministerial office create any challenges for the proposal?

**Jenni Minto:** I do not believe so. There is strength in the fact that Food Standards Scotland, which was set up under the Food (Scotland) Act 2015 to protect the public from risks to health that may arise in connection with food consumption, is independent of Government and that it has the option and opportunities to take advice from independent scientists, as it regularly does. I believe that that is the best way to protect consumers' interests regarding food and feed safety.

**Sandesh Gulhane:** What resources are in place to enable Food Standards Scotland to deliver that?

**Jenni Minto:** Every year, in common with every other body that is funded by the Scottish Government, FSS sets a budget to allocate its resources to the various areas that it has to cover. Those areas include the food standards regulation regimes that we are here to talk about today, along with providing the public and Government with advice on the food that people consume and improving the extent to which the Scottish public, and people more widely, have diets that are conducive to good health. There is a budget process every year, along with an audit process that looks at Food Standards Scotland's budget and its outcomes. It is a key organisation within Scotland.

**Sandesh Gulhane:** How can accountability mechanisms be strengthened to ensure that businesses and regulators remain fully responsible for any safety lapses, especially in light of the loss of parliamentary oversight?

**Jenni Minto:** One key reason for the change is to allow Food Standards Scotland to ensure that it has the capacity to look ahead and do horizon scanning, looking at risk rather than timespans. I have been having conversations for almost the past two years with Geoff Ogle, the chief executive of Food Standards Scotland. We meet fortnightly to understand areas of concern or risk in Scotland's entire food landscape.

**Sandesh Gulhane:** I have a final question. How can a balance be struck between supporting innovation in the food and feed industries and ensuring sufficient consumer protection, particularly in the context of a faster approval process for new products?

**Jenni Minto:** The process that has been worked on collaboratively by Food Standards Scotland and the Food Standards Agency allows for what you have just set out. Food safety is key. Because so many new products are coming on to the market, we must ensure that we can give consumers, and the businesses that use those standards, the right scientific evidence and data to know that products are safe. I am pleased that the work, which has been going on for a number of years, has been a true collaboration approach between the two food standards agencies in GB. They worked consistently through the different options and took ideas to their boards at the same time. It was a truly collaborative way of working and one that I was really pleased to see.

**Emma Harper (South Scotland) (SNP):** Good morning, minister. I am interested in the science of food additives and have been following the work of Professor Tim Spector, Chris van Tulleken and Carlos Monteiro in São Paulo in Brazil on the chemicals that are added to ultraprocessed foods.

I agree with the minister that the public trust Food Standards Scotland and the Food Standards Agency because of their work, which includes work on food crime. Yesterday, I met the head of food crime at Food Standards Scotland, and it was pretty eye watering to hear about all the work that is being done on that.

The Scientific Advisory Committee on Nutrition looks at the evidence on new products that will potentially come on to the market, which will take up its time. Do you have enough assurance that that committee will keep you informed about all the products that are coming on to the market, especially as new evidence emerges, based on the work of Tim Spector and Chris van Tulleken?

**Jenni Minto:** I recognise the work that Emma Harper has been doing on food safety. As I have outlined, I have regular meetings with the chief executive of Food Standards Scotland. It was set up to have the mechanisms to ensure that it remains the competent authority for food and feed in Scotland and that it has official controls. It is important to recognise that it does internal audits

on its science and that external audits are carried out by independent scientists.

Emma Harper made a point about the ability to horizon scan and see what is new and what is coming on to the market, which will be a key aspect of the changes that are being proposed. Currently, just under a quarter of Food Standards Scotland's time is spent on ensuring that we match the 10-year standards, whereas the proposed changes will mean that important resources can be freed up to ensure that we can look to the future to see what potential new additives could be coming on to the market in Scotland.

Georgie, do you want to add anything to that?

**Georgina Finch (Food Standards Scotland):** You have covered everything that we have spoken about. Food Standards Scotland is continually horizon scanning. We are aware of developments in appropriate areas around us and consider them as they happen. Where necessary, we seek input from the appropriate scientific advisory committees. Food Standards Scotland engages with the minister and is also directly answerable to the committee.

**Emma Harper:** You mentioned feed. Food Standards Scotland looks not only at products that are for human consumption but at products for animals. We know that some products are added to the food of ruminants for emissions reduction. One of those products was mentioned in the chamber last week, because there seems to be a perception—perhaps because of fake news on the internet—that some products are not safe. However, they are rigorously tested before the products are even added to feed for our dairy cows, beef cattle or sheep.

I seek reassurance that my understanding is correct—that the products are rigorously tested and safe and that, therefore, people should not believe what they read on the internet.

**Jenni Minto:** You are absolutely correct. Both Food Standards Scotland and the FSA concluded in their safety assessments that there are no safety concerns when Bovaer is used at the approved dose. As you have said, all feed additives are rigorously tested with safety assessments, which ensures that the products are safe. Businesses must demonstrate that the additive is safe for the animal, consumers, workers and the environment.

**Emma Harper:** Thank you.

09:15

**Gillian Mackay (Central Scotland) (Green):** Good morning, minister. The statutory instrument summary indicates that both FSS and the FSA have the ability to review authorisations and take action if new evidence raises safety concerns. However, do those agencies currently have the resources to proactively and continuously review emerging evidence, ensure that businesses meet their obligations and enforce compliance effectively? Given that the Scottish Government's budget outlines a 1.6 per cent cut to FSS funding, how can the Scottish Government guarantee that those critical public health responsibilities will not be compromised?

**Jenni Minto:** This area is a returning agenda point in my conversations with Geoff Ogle. As I mentioned, about 22 per cent of the regulated products service's time is spent on 10-year renewals. That reduces FSS's capacity to deal with new product authorisation in a reasonable timeline. We are expecting more than 300 products to come back over the next two years. The reforms are going some way to steady the state of things, to ensure that we have the right resource to put into the new horizon-scanning areas.

It is important to recognise that the change allows us to bring regulation of those products in line with that for other food and feed products that we regulate, and that Food Standards Scotland maintains the power to consider any product authorisation that is needed at any time. That has been part of the work that Food Standards Scotland and the FSA have been doing together to direct the right resource to the right areas, to ensure that we have robust population health and safety through food standards.

**Gillian Mackay:** Accepting the statutory instrument would create further divergence from European Union food regulation at a time when the EU is maintaining rigorous standards. How does the Scottish Government justify that move, particularly given its stated ambition of one day rejoining the EU and the need to align with its food safety framework to do so?

**Jenni Minto:** It is fair to say that all the products that would be affected by the changes that we are talking about were rigorously reviewed for safety through the EU. We have worked with the FSA, but we still horizon scan to ensure that we are matching the EU's standards as well.

Greig, can you add a wee bit about the work that is being done with the EU?

**Greig Walker (Scottish Government):** Certainly. The Scottish Government has an alignment policy, which is a consideration even if the advice on a particular proposal comes from one of the non-ministerial departments. The notification in this instance sets out where the proposal would sit with regard to EU law as it stands. Of course, EU law evolves, and the

alignment policy requires consideration of that, as the minister has said.

I am not a food policy official—I am a core Scottish Government official—but what is interesting about this particular context is that there is an applicable provisional common framework. As part of the reset of relations between the new UK Government and devolved Governments, and with the EU at the same time, common frameworks potentially have a really important role. The framework is a good illustration of that co-development, collaboration, joint consultation and action. Because it is a UK framework, there has been four-nations development, although we have a three-nations SI including GB, because Northern Ireland is directly subject to EU law. There will always be visibility of the EU law position, because of the framework and what is happening in Northern Ireland.

As the minister said, there will be the horizon scanning, which will involve looking at the scientific evidence as well as the legal position.

**Gillian Mackay:** Given that products will no longer be subject to a 10-year reauthorisation process, how will the proposed change make the food environment safer? At the moment, I am hearing that what is proposed will simply speed up another side of the process. It sounds as though resources are simply being moved from renewing authorisations every 10 years to looking at the massive number of new feed additives and so on that will require to be researched. How, overall, will the proposed change make the food environment any safer? Will it not simply shift resource from one side to the other and potentially miss things as a result of continually reviewing evidence rather than having a 10-year regulated framework?

**Jenni Minto:** The key thing is to recognise that FSS and the FSA are moving towards a risk-based way of looking at food standards and additives. That is consistent with what is happening in other areas. It is important to recognise that, when there is a finite resource, it is necessary to make decisions about where best to put that. If you are set up to check something every 10 years, you might miss a risk assessment that has come through, because you might think, "Well, I don't have to look at that one till later."

However, we are now putting in the resource to ensure that FSS captures all risk assessments on different products to ensure that, as new evidence emerges on a specific product that could result in authorisation being modified, suspended or stopped, that process will be maintained. FSS has a very clear and transparent risk framework, which it monitors regularly. It will pick up any risks in relation to products to ensure that they are properly checked and that the evidence, data and science on them are captured.

**Gillian Mackay:** Thank you.

**Brian Whittle (South Scotland) (Con):** Good morning, minister. The standard of the food that is allowed to be consumed is an area that interests me greatly. If my reading is correct, under the current system, products are reviewed every 10 years, which prompts the question, "Are they not always continually assessed?" Conversely, if the requirement to review products every 10 years is taken away, my concern is that there will be no need to continually look at products.

At the end of the day, the issue comes down to resource. My concern is that the system that you are proposing to move to, if it is operated properly, will be more resource heavy, yet the resource that is provided to FSS is reducing. If we were to consent to the SI, which would take away ministerial responsibility, how could we guarantee that FSS would continually review products, when new evidence is always emerging?

**Jenni Minto:** As I have said in previous answers, the work that Food Standards Scotland does is a continuum. It is always horizon scanning and checking where new risks may arise. The proposed change will allow the resource that went on a 10-year process to be allocated as needed as new products come in.

Another thing that it is important to recognise is the fact that there will be transparency. Although there will not be a statutory instrument on this, there will be a register of items, so it will be fully transparent which products have been checked. That is important to recognise. I will bring in Georgina Finch.

**Georgina Finch:** I understand Brian Whittle's point, but looking at the 10-year renewals takes resource from Food Standards Scotland and the Food Standards Agency. We expect 300-plus renewal applications over the next two years, as well as 22 per cent of our current case load being renewals. In the majority of cases, there are no risks identified with those applications and there is not necessarily any new evidence that has come to light. However, they have to be looked at and put through the risk analysis process, which takes up considerable resource.

Only three regimes have the 10-year renewal process; the other nine do not. We propose that we do not look at products on an arbitrary 10-year renewal timeline but, instead, focus our resources into our current work of horizon scanning and understanding new risks that come out regarding any products. We look across different countries and see what they are doing. We see what scientific publications are coming out. We use all that information to inform our priorities for looking

at particular areas and considering when it is necessary to put them through the full risk analysis process. We have examples of that on our website, where you can see areas that we are considering under risk analysis that do not have 10-year renewals, but we are looking at them anyway because we have identified risk.

The important point is that what we are asking to deliver will focus resource where it is needed.

**Brian Whittle:** Thank you. My concern is that, under the current system, the products are reviewed every 10 years. You say that it is resource intensive to do that, which indicates to me that, over the 10-year period, the products are not being continually reviewed. If they had been, the process at the end of 10 years would not be so arduous. You are now suggesting that we move to a system where the products are continually reviewed, which would be intensive. If that is the case, I go back to my concern around the resource for FSS.

**Georgina Finch:** Those risk-horizon scanning activities already happen. If a risk arises on any application that has not reached its 10-year renewal period, we will consider it and look at whether it is necessary to put it through the full risk analysis process. If any risk is identified in relation to that product, we do not wait for the 10-year renewal, and we will consider it appropriately.

**Brian Whittle:** If we are doing that anyway, why do we need to change the policy?

**Georgina Finch:** That is because we have the addition of the 10-year renewal, which is not necessary just because the product has been on the market for 10 years. We are asking to remove the arbitrary 10-year renewal. We are not asking to do anything different, but that will enable us to focus more resources on our continual horizon scanning and reassessment, as appropriate.

**Joe FitzPatrick (Dundee City West) (SNP):** Thank you, minister, for coming to the meeting; this is quite a technical document and the stuff around it is quite difficult to understand, so it is helpful to hear from you directly.

My questions are on an area where it would be good to allay some fears. Going back to the point that Sandesh Gulhane made about wider food and feed landscapes, we know that in Scotland, across the UK and across Europe there are really high food and feed standards. However, that is not the case across the rest of the world.

We know that the new President of the United States of America is very keen on his country's products, many of which would not meet our food and feed safety standards and therefore would not get into our markets. I want to give you the opportunity to allay any fears by saying that the proposal does not provide an easier route to market for products such as chlorinated chicken and so on.

09:30

**Jenni Minto:** When I have been discussing the issue with Food Standards Scotland, which has been happening over the past couple of years, the spotlight has always been on the future—that is, on what could happen. In my discussions, it has always been clear that what we need to do with the resource is ensure that we can carry out horizon scanning, and that we can work with international scientists and gather data and evidence from countries around the world to make sure that we have the best and the highest food standards in Scotland.

I am pleased that Food Standards Scotland's work is, as Ms Harper noted, well respected. It is also transparent, which is key. People are able to access Food Standards Scotland's website to see the work that has been taking place. The proposed change does nothing to change any of that—it just enforces what we are doing.

**Emma Harper:** I want to highlight the case of a diet pill that was sold in America and then came to Britain. It has now been relabelled as a poison. That is down to the work that the Food Standards Agency is doing. The diet pill 2,4-dinitrophenol—DNP—is a poison, and it was reclassified in legislation. That is part of the work that you do to highlight certain products, which you might then act to ban or to reclassify, which is what happened in that case. Is that correct?

**Georgina Finch:** I have not worked on that, but I understand that considerable work has been put into dealing with DNP. I imagine that, when you met the head of the food crime unit, he had considerable amounts to say on DNP, which, as I understand it, is a dangerous chemical and has been touted for a number of different uses. Those are absolutely the sorts of areas that we concentrate on.

**Emma Harper:** I will pick up on Joe FitzPatrick's point about the impact of the new US President on products that will be marketed in or brought to this country. The US Food and Drug Administration has the "Food Defect Levels Handbook", which sets out acceptable levels of defects in food. That allows certain levels of insect parts, mould, mites, dust and even—dare I say it?—rat poo.

We do not have anything like that in Europe or in the UK. I am assuming that the Food Standards Agency and Food Standards Scotland will be horizon scanning for products that might be brought to the market from the USA for instance. I have concerns about the acceptable level of

defects in the products that are coming from America.

**Jenni Minto:** I think that it is fair to say that, as has been noted on a number of occasions just in this past half hour, Food Standards Scotland is robust and has people's respect. I again underline that any authorisation decisions are underpinned by robust evidence that is based on scientific and technical scrutiny through both Food Standards Scotland and the FSA. That is open and transparent, and risk assessments are published and publicly available. That is very important when we are talking about food standards and safety.

**The Deputy Convener:** Thank you, minister, for attending. We will now move on to agenda item 2. You are, of course, welcome to leave at this point or you can stay to watch the rest of the proceedings.

Under this agenda item we will formally consider, in the light of the evidence that we have just heard, the type 1 consent notification sent by the Scottish Government relating to the Food and Feed (Regulated Products) (Amendment, Revocation, Consequential and Transitional Provision) Regulations 2025.

If members are content for consent to be given, the committee will write to the Scottish Government accordingly. If that is the agreed approach, we will have the opportunity in the letter to raise any related questions or concerns or to ask to be kept up to date on relevant developments. However, if members of the committee are not content with the proposal, the committee may choose to make one of the three recommendations that are outlined in paragraph 13 of the clerk's note.

I invite comments from members of the committee in the light of the evidence that we have just heard.

**Gillian Mackay:** We should not be consenting to the SI for a number of reasons. The divergence from alignment with the EU, as I outlined in my questions to the minister, is a big concern. As Brian Whittle said in his questioning, the only piece that we seem to be removing from the puzzle is the 10-year re-authorisation. At the moment, those come to the Parliament as SSIs. Removing that process would remove parliamentary scrutiny of whether we want those chemicals to have another round of 10-year authorisation and whether we want them in our food environment. Taking that power away from the Parliament would be regrettable. We would also, potentially, not see the authorisations for new feeds coming to the Parliament. On that basis, we should not be consenting to the SI.

**Brian Whittle:** In general, I do not see the advantage of removing ourselves from the process of double-checking the FSA and the FSS. As I have tried to say, probably clumsily, if we are consistently reviewing foodstuffs, renewing authorisations after 10 years is almost a rubber stamp, because there is not a huge amount of work to do at the end of the 10 years. Removing the 10-year review would mean that there was no need to consistently review products. I am not suggesting that that is what is happening, but if the resource given to the FSS is consistently reduced, it will be less and less able to review. That concerns me.

Having seen the issue come up several times in this committee over the past 10 years, I have always said that our food standards are extremely high, even in relation to the EU, so that is not what concerns me; my concern is whether the FSS has the ability to continually review at a level that we would accept. I am minded to accept the SI, but I would appreciate it if we could put those concerns in the letter to the Government.

**The Deputy Convener:** I am sure that we can incorporate those comments. As there are no further comments from members, the committee has the following options. It can write to the Scottish Government approving its proposal to consent to the statutory instrument and highlighting any related comments or concerns, or it can write to the Scottish Government rejecting the proposal. Am I right to conclude from what I have heard that Gillian Mackay's position is that the provision should not be made at all?

**Gillian Mackay:** Yes.

**The Deputy Convener:** In that case, it seems that there is dissent in the committee and I understand that you wish to press that to a division, Gillian. I will put the question and members can indicate verbally whether they are content.

The question is, that members are content for the committee to write to the Scottish Government indicating approval of its proposal to consent to the proposed UK statutory instrument. Are we agreed?

**Gillian Mackay:** No.

**The Deputy Convener:** There will be a division.

**For**

Joe FitzPatrick (Dundee City West) (SNP)
Sandesh Gulhane (Glasgow) (Con)
Emma Harper (South Scotland) (SNP)
Clare Haughey (Rutherglen) (SNP)
Carol Mochan (South Scotland) (Lab)
Paul Sweeney (Glasgow) (Lab)
David Torrance (Kirkcaldy) (SNP)
Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP)
Brian Whittle (South Scotland) (Con)

**Against**

Gillian Mackay (Central Scotland) (Green)

**The Deputy Convener:** The result of the division is: For 9, Against 1, Abstentions 0.

We will write to the Scottish Government approving the statutory instrument with the caveats that were outlined by members.

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

09:40

*Meeting suspended.*

09:43

*On resuming—*

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

**The Deputy Convener:** The next item on our agenda is to take evidence from two panels of witnesses as part of our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill at stage 1. By virtue of rule 12.2.3(a), Liam McArthur is attending as the member in charge of the bill and I welcome him to the meeting.

We begin today's scrutiny of the bill by taking evidence from organisations that are in support of the bill. I welcome to the committee Dr Gillian MacDougall, who is a trustee of Friends at the End; Professor Gareth Morgan, who is convener of the Scottish Christian Forum on Assisted Dying; Fraser Sutherland, who is chief executive officer of the Humanist Society Scotland; and Alyson Thomson, who is director of Dignity in Dying Scotland. We move straight to questions.

**Sandesh Gulhane:** I have two declarations of interests to make, as a practising national health service general practitioner and as the chair of the medical advisory group that advised on the bill.

Good morning, panel members. How would you respond to concerns that assisted dying prioritises individual autonomy over the rights of some of the more vulnerable people in society?

**Alyson Thomson (Dignity in Dying Scotland):** Thank you very much for the question. The current ban on assisted dying is not only failing dying people and their families; it lacks compassion, denies choice and exacerbates suffering. Crucially, there are no up-front protections or safeguards built in. As it stands, people who are facing a bad death are often forced into making very desperate decisions, which can involve taking action behind closed doors, where there is no scrutiny or regulation.

09:45

The suicide rate for terminally ill people is 2.4 times what it is for the general population, according to Office of National Statistics findings. We know that hundreds of Britons have had an assisted death at clinics in Switzerland. All that happens with absolutely no up-front oversight, checks or protections. There is only a check after the fact, when it is too late and somebody is dying.

The most dangerous thing that the Parliament could do is nothing. Inaction does not decrease suffering or put in place the vital and crucial protections that dying people, and the rest of us, need.

**Sandesh Gulhane:** To follow up on the stat that you just gave us about the suicide rate being 2.4 times higher for people who have a terminal illness, do you have any information on how they commit suicide?

**Alyson Thomson:** I can certainly get that further information from the ONS and send it to the committee. We know that, across the UK, 650 people a year take their lives when they have a terminal illness, and the number of attempts that are made is far higher than that.

**Sandesh Gulhane:** Thank you.

Would anyone else like to come in on my original question and give your response to concerns that assisted dying prioritises individual autonomy over the rights of some of the more vulnerable people in society?

**Professor Gareth Morgan (Scottish Christian Forum on Assisted Dying):** I am here on behalf of the Scottish Christian Forum on Assisted Dying. In particular, we are trying to make an argument from a Christian ethics perspective on all this.

Personal autonomy is important, but the relief of suffering is most important of all. Christian compassion argues that you do not force people to suffer if there are alternatives. We know from the stats that have been presented to you that, every year, many hundreds of people in Scotland suffer painful deaths that would potentially be avoided if the bill becomes law. We start from a position of love and the desire to reduce suffering, and by saying that we do not want to force people to endure terrible conditions that could be avoided.

Our main stance is that the bill offers a massive way forward on the relief of suffering. In some ways, I would describe it as being equivalent to the advent of analgesia in childbirth, due to the revolution that it can bring about in reducing human suffering.

**Dr Gillian MacDougall (Friends at the End):** I have to declare that I was until recently an NHS Lothian ear, nose and throat consultant, and I retired in April. I was also a member of the medical advisory group that Sandesh chaired.

By enacting an assisted dying law, we would bring the whole topic of "How I am going to die" into the public domain, which would make those conversations easier and actually protect the vulnerable. The fact that two independent doctors have to say that there is no coercion involved, that the patient is eligible and that they fulfil all the criteria makes it much more likely that the vulnerable will be protected.

**Fraser Sutherland (Humanist Society Scotland):** To add to and echo what Aly Thomson said, the bill provides a framework for there to be oversight and assessment of a process. There is currently no legislative process in place.

We are also talking about terminally ill people with reference to how they are defined in the bill. The issue is inherently about people who are dying and in the last part of their life. We are discussing the people who wish to have access to the process. That is clear from the bill's definitions of terminal illness. I am sure that you will come on to that issue.

**Sandesh Gulhane:** To ask you a direct question, Professor Morgan, given the membership that you represent, how do you respond to those who consider that intervening to assist in someone's death can never be ethically acceptable?

**Professor Morgan:** Clearly, there are Christians on both sides of the debate; I think that the committee will be hearing from others who take a different view. It has rarely been held that it is a widespread Christian view that you should not intervene—on the contrary. So much modern medical practice in hospitals, for example, originally arose from the work of churches and faith-based organisations, with the establishment of hospices and so on. The relief of suffering is important, and the idea that you cannot relieve suffering if it will shorten someone's life does not conform with most people's understanding of Christian teaching.

**Sandesh Gulhane:** I come to my final question. We heard evidence last week that the disabled community as a whole is against assisted dying. Is that something that you are aware of, and what would you say in response?

**Alyson Thomson:** I sat in on the evidence session last week, and a number of issues were brought up regarding the inequalities and difficulties that disabled people face around independent living, accessibility, accessible housing and social care. I can completely understand why we need to make urgent progress on all those fronts, but we do not do that by banning choice for dying people. All that that does is exacerbate the suffering for a group of people who are dying. The bill does not give people a choice between living or dying; that choice has already been taken away. The bill gives a choice between two kinds of death.

We know, from our own polling, that the majority of disabled people support a terminal illness assisted dying law. We speak to many people who are disabled and take a different view. I have a letter from a group of prominent disabled activists, which I believe has been circulated to Parliament. In the letter, they say:

"We do not wish disabled people to be cited as a homogenous group in efforts to deny dying people choice."

The other thing that they say, which I think we can agree with, is that absolutely all the inequities that I mentioned have to be tackled—they "need urgent attention"—but that it would be a mistake to think that, in opposing assisted dying for dying people, those wider problems will be fixed and we would do anything to increase protection and safety for disabled people. We would not. We would keep assisted dying overseas and underground, where it is neither compassionate nor safe.

**Elena Whitham (Carrick, Cumnock and Doon Valley) (SNP):** Good morning, panel members. First, I remind the committee of my entry in the register of members' interests, which notes that I am a member of the Humanist Society of Scotland.

A common argument against assisted dying is that it would be the start of a slippery slope, either to an increasing number of people having an assisted death, or to more permissive laws, with expanded eligibility and fewer safeguards. I would like to explore the slippery slope argument with the witnesses. How do you respond to assertions that human rights challenges to the bill are likely and will inevitably lead to an expansion of the legislation?

**Alyson Thomson:** On the slippery slope argument, no country that has ever introduced the type of narrow law represented by the bill has ever expanded its eligibility criteria. The Health and Social Care Committee at Westminster carried out an inquiry in the previous session of Parliament, and that was one of its main conclusions. It found that jurisdictions that have introduced assisted dying on the basis of terminal illness have not changed the law to include eligibility on the basis of untreatable suffering.

We can see that if we look around. Oregon, for example, has had the same law with the same eligibility criteria since 1997. That is where we got the most evidence from. The law in Oregon has not changed at all.

I would not say that challenges would not be brought, but it is our view that they would not be successful. The courts, including the Supreme Court, have made it clear that it is for Parliaments to decide on an assisted dying law for Scotland and the UK. The law that this Parliament enacts is the law that we will get.

I think that something is missed by a focus on the slippery slope argument, which is hypothetical and not based on evidence. The evidence that we have shows the suffering that exists under the current law. The issue is the cost of doing nothing, forcing people to suffer against their wishes, based on fears rather than evidence.

For example, the Office of Health Economics found that, in Scotland, every year, 591 people—11 people a week—suffer as they die, even with access to the best palliative care. That is a real statistic and evidence, whereas the slippery slope is an unfounded fear that is not borne out by any of the facts or realities.

**Elena Whitham:** Do other witnesses want to come in on that?

**Dr MacDougall:** We should acknowledge that the opposition will say that Oregon has changed the rules. However, it has not changed the eligibility criteria except for residency status. You used to have to be resident for a year, and the authorities have reduced that. That is where that contrary statement comes from. The people are still terminal and at the end of their life. There is no slippery slope as such.

**Elena Whitham:** Does any of the witnesses have any argument as to why there is a difference in the way that the law was enacted in Canada and the challenges that arose there versus, as Aly Thomson set out, the different legislative landscape in Scotland?

**Dr MacDougall:** As I understand it, the difference is that the Supreme Court of Canada decided that it was everybody's human right to have an assisted death if they asked for it—everybody's. It was as broad as that. It was not restricted to terminal illness or any other specific diagnosis. The Government was then charged with making rules in each state to fit with that court ruling. It started off with people who were terminally ill and then there was a human rights challenge because people pointed out that the original Supreme Court ruling was that the right was for everybody who wanted it.

That is a very different starting point from primary legislation that says from the outset that the person must be terminally ill. Our courts have repeatedly put the matter back to Parliament. They have repeatedly refused to say that it is against anybody's human rights to deny them an assisted death.

**Alyson Thomson:** The law was also tested against the constitutional Canadian Charter of Rights and Freedoms and found to be in breach of it. We do not have a similar charter or framework here. Therefore, Parliament is able to set the terms of the bill.

**Elena Whitham:** Do the witnesses have any views on whether any amendments could be made to prevent a broadening of the law once it was in place to prevent such challenges?

**Professor Morgan:** I am inclined to agree with the other witnesses that the drafting of the bill is clear on that and it is hard to see how the criteria could be widened purely by virtue of court action. There are important debates about how assisted

dying sits within human rights law, and you will be aware of the European Court of Human Rights judgment that says that, provided that there are reasonable safeguards, it is perfectly legitimate for a country to enact provisions for assisted dying. However, any kind of assisted dying in conditions that are not related to terminal illness would clearly need new primary legislation.

**Elena Whitham:** My final question is about the assertion that the bill normalises assisted dying and that numbers could increase on the back of that. From the recent figures from Canada, we can all see that increasing numbers of citizens are using their right to an assisted death. How would you come back on the assertion that that expansion of uptake is evidence of a slippery slope as well?

**Fraser Sutherland:** That demonstrates that more people are aware that assisted dying is an option. A lot of people wait until they see how it works in practice before they make any decisions about the use of assisted dying. It is clear that, once it is in practice, people feel more comfortable with it because it becomes more of the norm. That is not a slippery slope. It is just that the eligible people who would have been able to access it a few years before now feel more comfortable with the system because it has been in place for some time. They might be aware of friends and family who have accessed it in the past.

There is an idea that more people accessing the right to assisted dying is evidence of a slippery slope but, if the eligibility criteria have stayed the same, it is only an issue if you inherently have a moral and ethical problem with the principle in the first place.

If more people are accessing the right, and they meet the eligibility criteria, it just means that more people clearly have a choice about what they want at the end of their life—and the will.

10:00

**Alyson Thomson:** In jurisdictions that have terminal illness legislation such as that proposed, assisted dying accounts for less than 1 per cent of all deaths. Even in countries with wider unbearable suffering laws, it accounts for around 3 to 4 per cent of all deaths. I agree with Fraser Sutherland that the numbers tend to increase as people become more aware of the option, but that is from a very small base, and it is still low in comparison with other end-of-life choices and treatments.

When the issue last came before the Parliament, and, indeed, when previous health committees considered previous bills on the matter, we did not have the evidence from all the other jurisdictions that we have had since. Countries such as New Zealand and Australia, and other parts of the US, have legislated on assisted dying. We now have that evidence, and you will see that, for the majority of people, palliative care provides a good death. Some people have the extra choice that they need, some will receive a prescription and not go on to use it, while others will take the prescription and have a better death than they would otherwise have done. It does not fundamentally change society, other than making conversations about and the culture around dying, death and bereavement more open, more honest and more transparent.

**Professor Morgan:** I do not think that we should see an increase in uptake as a bad thing. I agree with the others that the numbers are never likely to be very large, but every single case will almost certainly involve substantial suffering being avoided. Therefore, it has to be seen as a good thing.

**Dr MacDougall:** The media have picked up that, in Canada, the figure has gone up to 5 per cent of deaths in the past year—that is, in 2023, when the most recent report was produced. Also, it is 6 per cent in the Netherlands. We would expect numbers to get to that level. Obviously, a similar law has been in place for a large number of years in the Netherlands, but the figures have plateaued at 6 per cent, and the rate of increase seems to be slowing in Canada, too. Time will tell, but it looks like the figures are reaching their peak.

**Elena Whitham:** Thank you very much.

**Emma Harper:** My question might relate more to the next theme, but I am interested in hearing your thoughts on the bill's proposed age limit of 16, given that, in other legislation, the age limit is 18. That is clearly different.

**Dr MacDougall:** I can see why 16 was chosen. In Scotland, 16 has traditionally been seen as the age of adulthood, so the provision is in line with the Scottish legal framework with regard to competence and such things. We in FATE do not have a strong view on the matter, and if the committee felt that the limit should be raised to 18, we would support that. The question is, what do young people think?

**Professor Morgan:** We felt quite strongly from a Christian perspective that if you allow people to make decisions as adults on other issues at 16, that should be the age here, too.

However, as you will be aware, we have made comments on other aspects of the eligibility criteria, which we hope you might be willing to consider at stage 2. I do not know whether you want to talk about that now, but we think that reducing the 12-month residency requirement, for example, would avoid quite a substantial barrier. There are details like that that could be addressed.

The age limit of 16 is perfectly sensible and appropriate. Obviously, the number of people with terminal illnesses at that age will be small, but it seems a bit unfair to deprive young people of the same right that they have under other legislation.

**Fraser Sutherland:** It is important for people who are against the status quo to make the argument. Sixteen is the age of majority in a number of areas, particularly in healthcare, in which young people have capacity, if they are assessed as such. It is important to respect that.

The other thing to remember is that there is an additional capacity test in the bill to ensure that people are aware of the decisions that they are making and their outcomes. That will apply to 16 and 17-year-olds, as it does to adults. The doctors involved have to be absolutely sure that the person has the correct capacity to make the decision and that they are doing so voluntarily and free from coercion, whatever their age. If people are suggesting that the age has to be raised, they will have to make the argument as to why it should be different from other legislation.

**Emma Harper:** Thanks. I do not want to take over anybody else's questions, so I will leave it there.

**The Deputy Convener:** Would panel members support the inclusion of additional safeguards for younger people, such as a requirement to undergo a specialist paediatric psychiatric assessment?

**Fraser Sutherland:** I come back to Elena Whitham's question about human rights challenges. One of the challenges with that requirement is that we would struggle to add additional barriers that are based on age that do not apply to other groups. There is scope for a capacity test, and what that test would look like could be up to medical practitioners. If an assessment is needed, perhaps it is for them to make that decision. I think it would be wrong to set out particular barriers for age groups in primary legislation. That could result in a legal challenge, because people could say that it applies to them only on the basis of age discrimination.

**The Deputy Convener:** Do any other members of the panel have a view on that provision? No.

Should there be a narrower definition of what a terminal illness is for the purposes of the bill? A prognostic timescale could be included or the bill could specify that a condition must be untreatable, for example.

**Professor Morgan:** No, absolutely not. If we are trying to relieve suffering, the criteria in the bill seem appropriate. The more that it is narrowed down, the more people will suffer and not be able to have an assisted death.

**The Deputy Convener:** Are there any other opinions on that provision?

**Dr MacDougall:** The committee has heard repeatedly from a variety of medical and healthcare professionals that adding in a prognostic month does not add anything and is, at best, a guess, so we would not support narrowing the definition.

As a doctor, I understand what is meant by progressive, advanced and terminal. It means that the patient will not get better; they are dying of that condition. I expect that, when they die, that condition will be the number 1 cause that I will put on their death certificate. It is very clear to me what that means.

**Fraser Sutherland:** The other thing to remember is the impact of adding time limits. There is strong evidence to suggest that patients wait too long to access assisted dying when there is a time limit, because they might think that they will live longer than doctors advise them. In Victoria, Australia, where the legislation stipulates a six-month time limit, 45 per cent of withdrawn applications are due to the patient dying less than two weeks after making the first request. When a time limit is put in place, it has an impact on people's choices because they are unsure of the timeline.

As Gillian MacDougall said, it is not a perfect science in which doctors are able to give people a definitive number. They cannot say that someone will meet a six-month or a 12-month time limit.

**The Deputy Convener:** Has anyone considered how a narrow definition would work in relation to existing social security definitions, or the impact that that might have on access to benefits at the end of life?

**Dr MacDougall:** It is very important that we do not have two different definitions in the legislation. That would make no sense. It would mean that, on the one hand, people could access a benefit, but, on the other, they would not have a choice as to where or how they die.

**The Deputy Convener:** That is helpful. Are there any other views on that?

**Fraser Sutherland:** I would agree with that.

**The Deputy Convener:** I see nodding; opinions are fairly consistent on that.

We will move to questions from Brian Whittle.

**Brian Whittle:** I will ask a wee supplementary to Emma Harper's questions about the age of eligibility. That is a cluttered market. There are different legal ages for doing different things. The age for access to adult care support is 18 and the legal age for drinking alcohol is 18, for example. Even the judicial system treats people who are

under the age of 25 differently than it treats the rest. Why 16 for this legislation? Why are you comfortable with 16?

**Dr MacDougall:** I have met some very mature 16-year-olds who would totally have the capacity to make a very appropriate decision that is in their best interests. I have also met some very immature 24-year-olds. If access is restricted to over-18s or over-21s, that would be open to challenge.

**Brian Whittle:** I am making an argument against it, but you are right that there are those who are mature and very capable at 16 and there are those who are older than that but are not. One of the dilemmas that we face with the bill is safeguards.

**Alyson Thomson:** I know that you will have an evidence session with the member in charge of the bill in a couple of weeks, who I think would explain that the decision to apply the age of 16 to the bill was to synchronise with the eligibility age in other bits of current medical law in Scotland, such as the age at which someone could refuse treatment. However, those on the panel would acknowledge that, in other jurisdictions with a similar law and for which we have the evidence, the age of eligibility tends to be 18. Dignity in Dying Scotland would not have a problem with an amendment that would take the age of eligibility to 18, and we would also recognise that the number of people in that age group of 16 to 18 who would pursue an assisted death is so small as to be practically negligible.

**Brian Whittle:** I move to what I was actually going to ask questions about: the concern that a lack of access to palliative care would push more people towards assisted dying. I have to be honest that that is one of my concerns. Too many people in our society do not have access to the palliative care that would give them comfort towards the end of life. Do witnesses want to comment on that?

**Dr MacDougall:** All of us are unanimous in wanting better access to palliative care for everybody. The evidence from other jurisdictions is quite clear that the vast majority of patients who choose an assisted death are already in the palliative care system or have access to that system and have chosen not to use it. Even those people who have good palliative care want to have the option of an assisted death.

**Brian Whittle:** Having taken evidence from other jurisdictions, I would argue that that is not the case. Some people in other jurisdictions have said that the lack of palliative care is a contributory factor, especially for those people in poor communities who have the disadvantage of having less access to palliative care. That issue will have to be addressed.

**Alyson Thomson:** The evidence that we have is that the people who have an assisted death overseas do not tend to be from poorer or marginalised communities—quite the opposite—and that the majority are enrolled in palliative care.

I mentioned the Westminster Health and Social Care Committee inquiry. Another of its findings was that, in jurisdictions that have legalised assisted dying, end-of-life and palliative care can improve. The inquiry can point to a number of jurisdictions where massive investments in palliative care were made at the same time as assisted dying was introduced. A whole host of other end-of-life practices improve as well, as conversations about death and dying and the culture around those things open up, as people have more open and transparent conversations and as more doctors are trained in supporting people at end of life.

**Brian Whittle:** If we extrapolate from that, were the bill to be passed, you would ask for there to be an increase in investment in palliative care at the same time. That is what you would expect to happen.

**Alyson Thomson:** I would certainly support that investment and also definitely support measures to enshrine palliative care as a right in Scotland. What dying people need is excellent palliative care. The majority of us will need good palliative care as we die, but the people who go beyond the reach of that care need excellent care and more choice. Indeed, the Westminster inquiry heard, even from palliative care specialists who are opposed to assisted dying in principle, that palliative care is not effective in 100 per cent of cases.

**Brian Whittle:** Would you accept that, for those people who are moving towards the end of their life, the option of palliative care should be there—which it currently is not for a lot of people—at the same time as the option of assisted dying?

**Alyson Thomson:** Absolutely. People need excellent care and more choice. There is a line in the bill that says that somebody's palliative care and treatment options should be explained during that initial request conversation. You are looking at increasing awareness of palliative care, social care and other treatments that people who seek an assisted death could have.

10:15

**Dr MacDougall:** The bill stipulates that the two doctors who assess the patient in relation to an assisted death "must" explore the palliative care that they have had and whether it has something to offer. That provides an opportunity to ensure that those who should have access to palliative care can access it. They could access it as they

go through the process of assisted dying, or they could pause the assisted dying process and say, “Let’s try palliative care first and then see how I feel.”

**Brian Whittle:** That works only if palliative care is available.

**Dr MacDougall:** If I was seeing a patient in an area where palliative care was not available and felt that they should have palliative care, I would be shouting that from the rooftops.

**Brian Whittle:** I think that lots of people shout that from the rooftops.

**Professor Morgan:** From the perspective of Christian ethics, it is a case of both/and—there is no way that assisted dying should ever be seen as somehow making up for shortages in palliative care. Of course we need more palliative care, and Christians were at the forefront of the hospice movement, when a lot of the palliative care in the UK started.

However, as has been said, there are plenty of cases in which even people who have very good palliative care say, “I do not want to go through all this. I am suffering.” Most of our members are lay or ordained Christian pastors and have heard people say, “I can’t take any more of this. I hope the Lord will take me tonight,” or, “Can’t the doctor just give me something to finish this?” That happens even if people are receiving palliative care, because that care is not always effective and, even if their pain is relieved through palliative care, there can still be many other very distressing symptoms, as we have heard.

It is very much a case of both/and. We cannot use the argument that we want to wait until palliative care is perfect before enacting assisted dying legislation, because they are both very important in alleviating suffering. Every day that this legislation is delayed, more people are suffering.

**Brian Whittle:** I do not think that anybody is arguing that we cannot do anything until palliative care is perfect, but people have been saying that there needs to be access to palliative care. That is the concern.

**Professor Morgan:** We agree on that.

**Gillian Mackay:** To what extent do the witnesses acknowledge the feeling of being a burden as an example of potential coercion, as defined in the bill, and the risk of such feelings being internalised coercion for some who might consider an assisted death?

**Dr MacDougall:** That is a really complex issue. The notion of burden encompasses physical symptoms, social care, practical things such as how often the bed sheets need to be changed, incontinence issues, witnessing a loved one in pain or distress, and other horrible symptoms. In particular, breathing and swallowing difficulties as a result of some cancers are incredibly difficult to palliate, and I have looked after patients who have been at risk of torrential bleeding from head and neck cancers. That is really difficult. It is really challenging for loved ones to look after a family member at home. I think that most of us, if we were given the choice, would, ideally, like to die at home, but we recognise that it would be hard for family members to look after us.

I think that most patients who say that they want an assisted death because they want to reduce the burden on loved ones are really saying that they just want to shorten the time that their loved ones have to witness what they have to go through. I do not think that we can get away from that. We know that large numbers of dying people—not just those who have an assisted death—feel that they are a burden. That does not mean that we should take away the option.

**Alyson Thomson:** In no jurisdiction is the feeling of being a burden an eligibility criterion. The eligibility criteria in the bill relate to terminal illness and mental capacity. For their peace of mind, people want to know that, if their suffering becomes unbearable, they will have some choice and control.

In the United States, for example, about a third of people who apply for an assisted death and can access the medication do not go on to use it, because their fear of suffering is unfounded and they do not experience it. I think that, if people were accessing assisted dying because they felt like a burden, you would see that figure decrease, and most people would go on to use the medication. However, that is not the case; the motivation involves other issues to do with quality of life and people’s feelings about what they wish to be able to do that they cannot, rather than any perception of being a burden.

**Fraser Sutherland:** Another thing to remember is that it is more commonly found that people are often being coerced out of the decision that they have made for themselves, even though they have a settled will. There is quite strong evidence from other jurisdictions, particularly Australia, that people are finding that family members or other people are putting a lot of pressure on people to opt out of an assisted death after they have already signed the documents and made that choice for themselves.

Obviously, the bill that we are discussing contains legal restrictions around coercion, which is important to include in the legislation.

One more thing to keep in mind is that, in Queensland, it has been suggested that

lawmakers make it an offence to coerce people out of a decision to opt for an assisted death. Members of the committee might want to think about that, as well.

**Professor Morgan:** This is quite a subtle issue from the Christian ethics perspective, because, of course, there is a strong doctrine about unselfishness and, if there are finite resources, some people might rightly say that they do not want to take up hospital resources or whatever, which might open them up to coercion in the sense that has been mentioned. However, it seems unlikely that anybody would go right through the assisted dying process purely for that reason, especially when you consider the requirements for there to be a first declaration, meetings with two doctors, a second declaration and then a decision at the point at which they are provided with the substance that will end their life. I find it impossible to think that anybody would go through all those steps primarily because of their sense of being a burden. Surely, they will be choosing those options because of the much bigger issues about all that they are going through in the dying process.

**Gillian Mackay:** Other than what Fraser Sutherland has just mentioned, does anyone have any suggestions for any other safeguards around coercion—in either direction—that they would like to be included in the bill?

**Dr MacDougall:** No. I think that the bill covers it.

**Gillian Mackay:** We had a private session with a group of people with learning disabilities who were concerned about coercion and were equally concerned about the need to be taken seriously if they were to decide to opt for an assisted death. Dr McDougall, could you give your perspective on how we balance having stringent safeguards around coercion and feelings of being a burden and so on with the need to take people with disabilities seriously when they make that choice?

**Dr MacDougall:** Is their concern that they would not be able to access an assisted death?

**Gillian Mackay:** They are worried that the potential for coercion has become such a big issue that people might think that all disabled people are being coerced into opting for an assisted death. If they decide that they want an assisted death, they want their feelings to be taken seriously, on their merits.

**Dr MacDougall:** It is important that an assessing doctor sees a patient on their own as well as alongside loved ones or people who are important to them. It is all about listening to them and asking what made them first think about an assisted death, and what kind of situation they envisage when they think about life becoming unbearable to the extent that they would want to avail themselves of an assisted death.

Those kinds of conversations are difficult and will take time. If the person has a learning disability, they might need some help with communication, but that help should definitely be provided by somebody who is an independent advocate rather than a family member or a close friend.

I think that, through those kinds of conversations, we are capable of detecting coercion. Seeing people with loved ones in the room gives you a feel for family dynamics as well, so we could pick up on coercion either way.

**Joe FitzPatrick:** I want to ask about the means of administration. It would be good to hear folk's thoughts on what the bill allows in terms of assistance.

In private and public sessions, and individually, we have heard from people with various disabilities that they feel that the legislation might, because they cannot use their hands or they cannot swallow, be too narrowly drawn for them to be able to access assisted dying. What are your thoughts on how we make sure that the legislation is accessible to everyone who should be able to get it, in relation to the question of terminal illness and capacity? What are your thoughts on what the legislation actually says?

**Dr MacDougall:** The bill is vague. It could be interpreted—I interpret it this way—as not restricting administration to ingestion: it does not restrict administration to oral or rectal administration. It could be that the patient uses a feeding tube and self-injects, it could be that an intravenous drip is set up and the patient has to open the drip, or it could be that technology is used to help. Last week, the committee heard from representatives of motor neurone disease patients who were particularly concerned that they would not be able to inject or do any of those things. However, some technology should be allowed whereby they could use a head switch or something else to start a machine.

The bill gives freedom to the Scottish ministers to draw up guidance that would allow all those things—but the committee might feel that secondary legislation is required for that.

**Alyson Thomson:** The bill strikes a balance between compassion and safety—safety measures are woven into the fabric of the bill. One of those measures, which is a cornerstone of the legislation, is the provision that the individual would be able to make the final decision and take the final act to self-administer medication. We have heard from Gillian MacDougall, and in Friends at the End's written submission, that there are several methods for doing that.

I would like to take the opportunity, while I am here, to tell the committee that Professor Michael Dooley, who is the director of pharmacy at Alfred Health in Victoria, Australia, and who is the leading expert on pharmacy and voluntary assisted dying in Australia, will be in Scotland in March. He is keen to meet or to provide evidence to the committee on the protocols and methods that are in use in Victoria. I think that we could learn and benefit from that experience.

**Fraser Sutherland:** Alyson Thomson touched on something really important—that the person self-administers by some method, in whatever way they can. The bill is about personal autonomy and respecting their decisions, so it is important that it is part of the process that the person effectively takes the final act, and that it is a voluntary act that they are doing themselves, rather than one that someone is doing to them. For any method that is available, it has to be the person themselves who ultimately does the act.

There are other jurisdictions in which IV options can be used, and in those cases there is a method for the patient to set that going. For people who are unable to take an oral solution, or for people who are suffering from a condition where there might be medical complications to do with swallowing, it might be more appropriate for them to have that option rather than an oral solution.

**Joe FitzPatrick:** Before you come in on that point, Professor Morgan, I have another question.

The evidence from Australia is that, in some states where physician-assisted dying is legal, it is the main means of going forward. It would be good to hear your thoughts on whether physician-assisted dying should be in our legislation or whether the rule should be that, by whatever means, the person has to finally administer. Do you think that that rule is a useful safeguard?

**Professor Morgan:** In our submission, we argue strongly that a person should be able to request reasonable assistance to consume the substance. That said, since then we have become aware of the techniques that have been mentioned, such as syringe drivers that can be set off with a movement of the eye. Maybe that is a way forward.

One of the strongest arguments in our submission is about non-discrimination. If assisted dying becomes law, it is vital that it is available to all people, rich and poor, with all kinds of limiting conditions, and so on. It is important that guidance to the bill spells out the alternative methods that might make self-administration possible. It is important that assisted dying is not limited to people who can physically lift a container—although I do not think that that is what Liam McArthur is proposing.

**Joe FitzPatrick:** The final area that we would be keen to hear your thoughts on is the suggestion from some people—I note that they are folk who oppose the bill, to be fair—that the numbers for procedures going wrong are up to 7 to 11 per cent. In those cases, do you think that a physician should be able to assist, or do you want to tell us what your thoughts are on those figures?

10:30

**Dr MacDougall:** If you read the reports from other countries, it is not the case that 7 to 11 per cent go wrong. The most recent report showed that five patients in Oregon had woken up having ingested medication but did not succeed. In Oregon, health professionals are not mandated to be in the house with the patient when they take the medication. It is a really important safeguard in our bill that a healthcare professional would have to be present. In Oregon, it is about ingesting. If the person does not swallow all the medication because it does not taste very nice, for example, it might not work. In countries where a healthcare professional is present at the time of death, there is an infinitesimally small number of complications.

**Emma Harper:** It has been interesting to hear everybody so far this morning. I remind everyone that I am still a registered nurse.

I am interested in some of the issues that have come up at committee about the process or model, including the ability of doctors to assess capacity and coercion without specialist input or training; the involvement of GPs, given the pressure on GP services; the level and experience of doctors; how the bill will prevent doctor shopping; and other issues to do with conscientious objection. I have a longer list, but I will save the time. Do the witnesses have any opinions about the process or service model as described in the bill? Do they include sufficient safeguards? Do they offer the prospect of a high-quality service?

**Alyson Thomson:** I will start. There was quite a lot there, so I will try to be as concise as I can.

Doctors routinely assess for capacity in all sorts of areas of medical practice, particularly around end-of-life decisions, so that would be no different. I know that the committee heard from the experts from Australia about the training model that is in place there, and I believe that such training would certainly upskill doctors on capacity training and coercion detection, as we touched on earlier.

Gillian MacDougall will know more, but at Dignity in Dying we have a group of health professionals who are in favour of assisted dying: a number of doctors, clinicians and nurses from across all specialties, particularly general practice, are very much in favour of the proposals, having

had to watch the suffering of their patients as they die. They would very much like to be trained and to opt in to participate.

We also know that the NHS constantly evolves to meet patients' needs, and more choice at the end of life is one of those needs. People want that choice, and the doctors whom we speak to are fully supportive of that.

The choice goes both ways, and we would also fundamentally respect any doctor who wishes not to participate and to conscientiously object.

**Dr MacDougall:** I think that you are asking whether the bill is sufficient to allow the guidance that you are looking for to be put in place. I argue that, as it is drafted, it is appropriate for a first-stage bill. You do not want to have to redo legislation every time some guidance changes. Allowing the Scottish ministers and health departments to liaise with the professionals who are involved and to draw up guidelines after such a law is enacted is appropriate.

**Emma Harper:** Last week it came up that somebody might have a terminal illness but also have what might be considered to be a mental ill-health issue; the bill talks about the person having a "mental disorder". However, somebody can have depression then get a terminal illness, too. That is the sort of thing that, down the line, should be addressed in further guidance—the bill supports the development of guidance—so that the assessment of adequate "capacity" can take into account that some people will have co-existing conditions.

**Dr MacDougall:** The bill is very good, in that it recommends referrals to either mental health specialists or a specialist who is involved with the primary condition, if there is any doubt that those things are influencing a patient's decision to have an assisted death. That is a very good safeguard.

The bill also says that not only can you refer, but you have to listen to the opinion that is given. If the assessing doctor says "This person is depressed but I'm not sure whether that is affecting their decision, so I'm going to refer them to a psychiatrist", and the psychiatrist says that is has affected the decision, the doctor must listen to that.

**Fraser Sutherland:** Emma Harper raised the issue of conscientious objections. There is already a robust system of conscientious objection in this country relating to abortion care, and the bill seeks to replicate that. I think that that is an appropriate method of ensuring that medical practitioners' views are respected while not allowing them to impact on the patient's access to services.

What would be a mistake—this is not in the bill at the moment, but it could be brought forward as an amendment—is allowing institutions to opt out. There has been a significant problem overseas with institutions opting out, particularly in Australia, and that has had an impact on patients. For example, if a patient is in hospice care and the institution says, "We're having nothing to do with assisted dying—we won't even allow people on our premises to do an assessment process", that has a massive negative impact on patients. They might have to withdraw to their home, which can have an impact on their care.

**Professor Morgan:** Our submission has a number of comments on some broad issues around access points. I stress that they are probably issues of detail for stage 2, and that we are fully supportive of the bill at stage 1, based on its broad principles, but there are a number of measures in the bill that we think might create barriers to accessing the process.

We have raised the question, for example, of whether you really need to ask for two forms of identification from the person, when we know how difficult it has been to get even one form of ID for voting, and bearing in mind that there are going to be very elderly people involved. Also, does the second declaration really need to involve quite as many steps as the first declaration, in terms of independent witnesses and the co-ordinating registered medical practitioner being involved?

There is also a question about whether section 3(2)(a), which requires that the person is

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

might be a wee bit too broad. That point has been raised in discussions about people who are simply depressed because of their terminal condition but who otherwise have capacity.

It would be helpful to look at such details at stage 2, but I stress that we think that the broad thrust of the bill is absolutely right.

**Emma Harper:** Okay. I think that that is covered.

**The Deputy Convener:** Do members have any final questions?

**Members** *indicated disagreement.*

**The Deputy Convener:** In that case, I thank the panel for coming in and answering our questions so thoroughly this morning. It is much appreciated.

I briefly suspend the meeting for a changeover of witnesses.

10:38

*Meeting suspended.*

10:50

*On resuming—*

**The Deputy Convener:** We continue our scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill with a second panel of witnesses, who are from organisations that are opposed to assisted dying. I welcome Dr Miro Griffiths, disability studies scholar at the University of Leeds, who is representing Not Dead Yet UK; Dr Gordon Macdonald, chief executive officer of Care not Killing; Michael Veitch, policy officer at Christian Action, Research and Education for Scotland; and Dr Gillian Wright, director of Our Duty of Care. Thank you all for coming. We will move straight to questions.

**Sandesh Gulhane:** I reiterate my declaration of interests as a practising NHS GP and chairman of the medical advisory group. Good morning, panel members. Do you think that there are any circumstances at all in which it would be ethically acceptable to legislate for assisted dying to occur?

**Michael Veitch (Christian Action Research And Education):** Good morning. Thank you for your question—it is a really good one. We would argue that it is inherently dangerous to legislate for assisted dying and that it cannot be made safe, by definition, so the short answer is no.

**Dr Gillian Wright (Our Duty of Care):** I represent a group of healthcare professionals who are opposed to assisted suicide. It is wrong for a doctor to take action to assist the suicide of someone, or to abet or to counsel someone to take their own life, so we are opposed in principle. It goes back to Hippocratic ethics—for thousands of years, doctors have sworn that they will do no harm and, as part of that, that they will give no poison, so it is on that basis that we are opposed. The relationship of a doctor and a patient is a privileged relationship, so stepping over that line to hasten the death or to take the life of a patient is a step that we would not counsel.

**Dr Gordon Macdonald (Care Not Killing):** The other thing to bear in mind is that human rights legislation and human rights treaties are based on the principle that the first and most fundamental human right is the right to life. The reason for that is to avoid the state, in particular, taking people's lives, apart from in the most limited of circumstances. Over time, those circumstances have become more limited within the European context. That is an important principle and, with this bill, the state, ultimately, would have that power, albeit delegated to doctors. That is important to bear in mind.

**Sandesh Gulhane:** Before we move on, can I ask, for clarity, whether you think that there any circumstances at all in which it would be ethically acceptable?

**Dr Macdonald:** I think that the answer to that is no. However, we have to make a distinction—which you will be well aware of—between a doctor or another person actively terminating or ending the life of a patient or encouraging them to do so themselves and the withdrawal of treatment where it is deemed to be burdensome, unnecessary or of no effect. There are circumstances where you have to stop treating and that may well lead to the death of the patient, but that is not actively bringing about the death of the patient.

**Dr Miro Griffiths (Not Dead Yet UK):** My view, as someone who is most interested in the implications that the bill has for disabled people's communities, is that the state has a role and a responsibility to protect disabled people, particularly because of the systemic inequalities that are faced by disabled people's communities across the country. The state therefore has a role in protecting all life associated with disabled people's communities. I think that what you are proposing is incompatible not only with disability rights, but with the principle that the state is there to protect disabled people.

**Sandesh Gulhane:** Just to be clear, it is not me who is proposing this legislative change; it is Liam McArthur.

**Dr Griffiths:** No, sorry—that is not what I meant.

**Sandesh Gulhane:** I want to ask about some evidence that we heard from the previous panel. We were told that the suicide rate among people who have terminal illnesses is 2.4 times higher than it is among the rest of the population, and that 591 people a week die in pain despite receiving the best palliative care. What is your response to those figures? What should we be doing?

**Dr Wright:** Those are salutary figures for all of us. It is really concerning that there are people with terminal illness who have suicidal thoughts.

The first aspect of that is that it is understandable that people are distressed when they are faced with a huge and life-changing decision. We know that such deaths occur at a particularly early stage—in the first year of being diagnosed with a terminal illness. I think that much more support is required, including psychological support and early palliative care. At the moment, the palliative care that is provided is too little, too late. It is common for a person to get a little bit of palliative care towards the end of their life, but not at an early stage following a diagnosis of terminal illness.

The numbers that you cited highlight the critical need for psychological support. Across the UK, there is wide variation in the palliative care psychological support that is provided to, for

example, hospices. The numbers are extremely small.

**Michael Veitch:** The figures that you have highlighted emphasise one of the dangers of the bill. The committee has already heard evidence that, if someone is given a terminal diagnosis, it is self-evident that, in the short term, their mental health will be very vulnerable—they might feel very low, depressed, anxious or suicidal. If the bill were to become law, it would be a tragedy if, as a result of that, many or some of those people—or even any of those people—opted for an assisted death. That is our fear.

Your point about palliative care underlines the fact that the answer to the concern that exists is not to legislate for assisted dying but to invest in gold-standard palliative care all across Scotland. The committee has heard substantial evidence to the effect that, in some circumstances, palliative care in Scotland is great, but many people do not get it. If someone with a terminal diagnosis opted for an assisted death because they were afraid that they would not get the care that they knew they needed, we think that that would be a tragedy as well.

**Dr Macdonald:** I add that there are only two psychologists working in palliative care in Scotland, as far as I am aware. That shows the numbers that are available.

Leaving that aside, it is not a huge surprise that people who have a terminal diagnosis might experience low mood or depression. The issue, as we know from Oregon and other jurisdictions, is that that depression goes undiagnosed or untreated, and people are not assessed in large numbers.

For example, in Oregon, only 1 per cent of people who go on to have an assisted suicide are referred for a psychiatric evaluation, but psychiatrists estimate that, in the case of anywhere between 25 per cent and 80 per cent of people with a terminal illness—the figure varies depending on which psychiatrist or psychiatric body you talk to—that will be associated with depression. Even if we take the lowest numbers, that shows that there is a huge gap between the provision of psychological and psychiatric support to people who are asking for assisted suicide and what the demand would be if such provision was properly funded and available.

11:00

**Sandesh Gulhane:** Dr Griffiths, in a previous panel on disability, we heard about the initial point that you made on the systemic issues that people with disabilities face. We also heard from those witnesses that the disabled community is united in its opposition to assisted death. However, we subsequently heard that, broadly speaking, the disabled community is—as is the rest of the general population—both for and against it. What is your opinion about that?

**Dr Griffiths:** Your question raises two issues. The first is that, as we are aware, there are mixed perspectives in disabled people's communities across the country. However, I have no evidence that any representative organisation—that is, disabled people's organisations that are run by and for disabled people, which are politically engaged in the social issues that affect disabled people—has come out in support of assisted dying.

That is a telling and significant point, because it illustrates that, when you scrape beneath the surface of the popular assumptions that are made about a disabled individual's life, you will start to understand the systemic injustices and issues that they face in accessing support, including health services and access to medical professionals, to live the life that they want to have—and could have—as their needs change over time.

It also raises a point about the way in which, as a culture, we think about the life of an individual with an impairment or a health condition, which is often seen as undesirable. As a disabled person, my view is that, if I have sufficient support—according to my needs as they progressively change over time—I can live a life that is of value and I can participate in my society. That is where we should be placing our emphasis.

I come back to the point on the role of the state. The state's role is to advocate for the idea that every life is worth living and that every person, as their needs change over time, should have sufficient support to live the life that they want to have or can have.

**Sandesh Gulhane:** Thank you. My final question is the same question that I asked the previous panel of witnesses: how do you reconcile opposition to assisted dying with reducing suffering and having respect for individuals' autonomy and dignity?

**Michael Veitch:** There are two aspects to that. First, on autonomy, for any piece of legislation that you consider as legislators or that we are examining from outside, it is obvious that consideration will involve weighing personal autonomy against the impact that the legislation will have on wider society. Our strong assertion is that the bill would have a detrimental impact on some very vulnerable people who will feel under pressure—by definition, invisible pressure—to consider an option that would not have been there before. As for any legislation, there is need to weigh autonomy against the wider impact. To

paraphrase someone, there is such a thing as society.

Could you remind me of your second point?

**Sandesh Gulhane:** It is about respecting individuals' autonomy and dignity versus the rights of vulnerable people and the opposition to assisted dying.

**Michael Veitch:** On addressing suffering, I reiterate what we said before about the need for investment in far better palliative care across Scotland. It is a tragedy for anyone to experience a more difficult death than they otherwise would were palliative care to be better.

**Dr Macdonald:** This debate is about autonomy versus public safety, but that is only a narrow and limited understanding of autonomy—that is, autonomy for a particular group of people who wish to have assisted dying. You also have to consider the autonomy of other people who might feel pressured into assisted dying or feel burdensome. Having the option available would add to that burden and pressure.

Autonomy is always limited. I was struck by the comments made by the former MSP Alison McInnes when assisted dying was most recently debated in Parliament. She said that she was opposed to it as a liberal and a humanist. One of her reasons for that was that she recognised that

"autonomy is not absolute." —[*Official Report*, 27 May 2015; c 52.]

When she put that to Patrick Harvie, he actually agreed that autonomy is not absolute.

We have to balance autonomy with other ethical principles—certainly that is the basis of medical ethics—but we also have to balance my autonomy with your autonomy and, indeed, with everybody's autonomy, not just in one area of our lives but in all aspects of our lives. That is the judgment that you will have to make as MSPs considering the bill.

**Dr Griffiths:** Your question leads me to come at this from the perspective of the contract between the individual and the state. Of course, all individuals surrender certain choices to live within the confines of society. There is no such thing as absolute choice or absolute freedom to do what you want, because of the nature of protections.

That, in turn, allows me to think about the significance of choice. Of course, we are talking about communities who do not have choice to live the life that they want or to access sufficient support, accessible housing and so on, and all of those issues will play into the consciousness of the decisions that one takes with regard to whether one's life is valuable or tolerable. Therefore, I think that the focus should be on how to address those issues before we debate whether there is such a thing as a choice for death.

**Sandesh Gulhane:** Thank you very much.

**Gillian Mackay:** Are there any specific flaws that the witnesses wish to identify in the safeguards against coercion that are set out in the bill?

**Dr Macdonald:** One of the questions that you should ask, particularly of the minister when they come before you, is how you can ensure that, if there is coercion, it can be successfully prosecuted under the relevant section of the bill. Coercion is inevitably difficult to detect and prosecute. Indeed, that is the case in life generally—we see it with cases that occasionally hit the headlines. You have to look not just at ticking some box that says, "There's a section in the bill that says coercion is a criminal offence," but at how effective the provision will be when it comes to enforcing it. I just make that comment to begin with.

Coercion is not just some subtle thing; it depends on how the system operates. One of the initial proposals was that consultations could be held via video. However, even in a very practical sense, if the doctor was not physically present with the patient, how would they know whether a coercive partner or individual was in the same room as the patient whom they were interviewing?

**Dr Wright:** I would echo that. Generally, doctors are not trained specifically to detect coercion—we pick up on these issues through our practice. I would also point you to Social Work Scotland's evidence on the assessment of coercion and its concerns about that.

This sort of consultation is quite unusual. The doctor and the patient do talk and discuss these matters, but, in a clinical situation, you would usually talk to other family members and find out whether there was other important information to consider. If you were worried about somebody at home, for example, you would find out whether others had concerns, too. One concern, therefore, is that there would be no possibility of discussing the issue of coercion with anybody else.

I urge you to be cautious about this, because we are really concerned that subtle coercive relationships will be missed by the doctor, particularly if, as it seems, this sort of contact is intended to happen in general practice. As we know, general practice contacts are short, the doctors are busy and they are distracted by other aspects. It is a very unsuitable setting for detecting such things.

**Michael Veitch:** In answer to your question, I would say that the safeguards are not sufficient and cannot be so. I suspect that explicit coercion

will, almost by definition, very often take place behind closed doors between a vulnerable individual—the person who is dying—and family members or friends. You cannot pick up on that, because it will happen away from the eyes of medics and anybody else. However, I would reiterate that our far greater concern is not that sort of explicit external coercion, which might happen in some cases, but internal coercion—that is, the internal pressure that a vulnerable person will start to feel as they worry about the financial pressure on their family in providing care for them or about the impact that they are having on the NHS at such a time.

**Dr Macdonald:** Another issue that is worth looking at is the increasing number of couples who are accessing euthanasia or assisted suicide—mainly euthanasia—in places such as the Netherlands. That raises a significant issue about who is really making the decision and on whose behalf. That is something to bear in mind.

**Dr Wright:** The Oregon data shows that an average of about 50 per cent of people cite feeling like a burden as one of the reasons—not the only reason—why they choose assisted suicide. I can imagine patients whom I looked after not wanting to be a burden on their friends, family and caregivers, and saying, "I will do that so that the money can go to my grandchildren or other people who need it more."

Unintended consequences and structural coercion are really important, and it would be difficult for you to amend the legislation in any way that would mitigate that.

**Dr Griffiths:** For me, there are two points here. One is that the safeguards will never be effective because the eligibility criteria are incredibly weak and broad in how they articulate who is eligible for what is being proposed and, therefore, in how you come to an objective opinion on what constitutes "progressive", what constitutes "advanced", what constitutes "unable to recover", and so on.

The other point is that I have seen nothing that illustrates how you would prevent, over time, having a network of medical practitioners who had become philosophically sympathetic to the principle of assisted suicide and, therefore, had become the go-to people for those seeking assisted suicide. We know from data across the globe that such provision generates a network of practitioners who are aligned with the principles; therefore, the reliability of their decision making is drawn into question.

**Gillian Mackay:** I will go back to what Dr Wright said about the feeling of being a burden. I know that, towards the end of their lives, my grandparents felt like a burden regardless, and I do not think that anything would have resolved that. When I think about whether I would want an assisted death, feeling a burden would always be part of that consideration, but it would not necessarily force my hand one way or another. It is about how we divorce those feelings of being a burden, which I think are a natural human emotion at the point of needing such care, from the question whether that feeling has coercive capacity for those who are seeking an assisted death. It is actually about how, as a clinician, you drill into that and divorce the two from each other—how you divorce that coercive impact of feeling a burden from real coercion.

You spoke about taking a whole-family look, which witnesses in a previous session suggested as well. It is about looking not only at the individual but at the wider family dynamic. Is that something that you would want to see? I acknowledge that, ideologically, you are opposed to the bill, but if it was to go ahead, would you like to see a soft-touch whole-family evaluation, to make sure that coercion was detected?

**Dr Wright:** I think that you are right. On balance, I would not support changes to the bill on ideological grounds, but I would urge you to look at the even wider context. I am interested in Wes Streeting's comments that the lack of care for people at the moment is also acting as a coercive aspect. People do not get the general practice, the palliative care and the social support that they need and that might reasonably be expected, and those are the reasons why they might feel like a burden.

We do not want people to feel that this is something that they ought to do because it is made available. It is really powerful that laws send social messages. If we, as doctors, suggest and discuss something, the patient can consider that that is something that we think is reasonable for them. In the previous meetings, the committee asked a number of witnesses about assisted dying being a medical treatment. One of the real concerns is that, if it is made legitimate and a medical treatment, so that it may be discussed—or even suggested—by a doctor, people might feel pressured, even by the doctor, to do it.

11:15

There are a lot of aspects to control and coercion—perhaps "undue influence" is a better term than coercion and more descriptive of the malign influence. Undue influence is a real problem with the bill.

**Gillian Mackay:** I go back to the question that I asked about a whole-family assessment. Do you believe that such an assessment should be done?

**Dr Wright:** I think that most consultations would benefit from hearing from family members. In

general palliative care, we find out how everybody in the family is managing.

**Dr Macdonald:** I would raise a question about that. In any other area of healthcare, we cannot insist on other members of the family being there or involving them, as there are issues of patient confidentiality for doctors. Although I agree that this matter affects not just the individual and that, as legislators and as a society, we should be concerned about the wider context, I cannot see how that could be put into law in the context of the current legislation relating to health, if the matter were to sit within healthcare.

**Emma Harper:** Dr Wright, I want to pick up on what you said about GPs working behind closed doors. I am a registered nurse and, in my experience, if somebody is given a terminal diagnosis, a multidisciplinary team of specialists will be working with them. That will include haematologists, surgeons, nurse practitioners and physiotherapists—a whole range of specialists will come into contact with the patient. If a patient makes a statement, therefore, in which they say, "I want to end this," it is not then just going be up to a GP to make a decision behind closed doors.

Quite often, in my experience, if a physician comes to speak to a patient and there is a family member at the bedside, the patient will be asked whether it is okay for the family member to stay or whether they should leave, and it is up to the patient to make that decision. It is about choice and more than one person is making a decision, so I am not sure that I agree that GPs would be working behind closed doors and making a decision in a vacuum with regard to what somebody's autonomous choice might be. I am thinking about the wider multidisciplinary team and about the decision being part of a care process.

**Dr Wright:** That is interesting, because in the text of the bill—certainly from my reading of it—there is no mention of the multidisciplinary team. That takes us to another aspect with regard to participation in assessments for assisted dying. It seems that the right of conscientious objection would be afforded only to those who directly participate. What you describe, therefore, would need to be absolutely clear in the bill. At present, it appears that it is just the two doctors who would be involved—or perhaps another healthcare professional—and who would therefore have the right to conscientious objection. From my reading of the bill, it is not made clear. If you would like a multidisciplinary team to be involved, that would need to be made explicit in the bill.

Allied healthcare professionals are really concerned about the bill. Again, I point the committee to the response from the Scottish Ambulance Service, which I thought was interesting. The SAS essentially asks what its staff should do if they are called and the patient has not died. Such practical complications are important. What do staff do if, for example, the patient has seizures and they are called, and there is a healthcare professional—perhaps a nurse—sitting with the patient? What do they do at that point? Do they transfer the patient to hospital or wait with the patient until that person dies? Those difficult practical problems are concerning.

I was also concerned when I read the report from the medical advisory group, which contains talk of "a rescue IV" being made available to the doctor. What does that mean? Does it mean that the doctor has licence to kill the patient and administer a lethal drug at that point or that the doctor has licence to sedate the patient if they are seizing? There is a real lack of clarity for healthcare professionals about what the bill would mean in practice.

In addition, there are real concerns about GPs sitting with patients, because, in any ordinary general practice, there is no scope for a GP to have an hour at lunchtime to make a proper capacity assessment, nor to sit for the rest of the afternoon with that patient. I am sure that they would be glad to spend time with patients, but there are real concerns about fitting that time into general practice.

The practicalities are troubling for many healthcare professionals.

**Elena Whitham:** I would like to explore the concept of the slippery slope, which is often spoken about. Indeed, Care Not Killing's written submission states that

"any limit other than prohibition is arbitrary and ripe for challenge."

I will ground my initial question in Scotland—I am thinking about our institutions and the way in which the bill could be enacted. Do the witnesses agree that any future expansion of the eligibility criteria for assisted dying would have to be subject to the scrutiny of the Parliament? We can perhaps start with Gordon Macdonald, as I referenced your written submission.

**Dr Macdonald:** You have to bear in mind that the Parliament is ultimately subject to the courts, because it is bound by the Scotland Act 1998 to abide by the European convention on human rights in all its legislation, so it would depend on the court judgment in relation to, for example, an article 14 or article 9 challenge—or an article 2 challenge, for that matter—on the subject of conscientious objection. That is the context.

Is it, ultimately, the Parliament making the decision? Canada gives us an example of that issue. In Canada, the Government and the Parliament chose to go further than the courts

required and not to appeal the court judgment in the Truchon case. A political decision-making process was going on there as well; nevertheless, that is the overall legal framework. With the bill, an awful lot is left to the Government and to guidance, so I am not sure that things would necessarily have to come back before the Parliament other than in the form of a changed statutory instrument, for example, which might get less scrutiny. You also have to bear in mind that a review of the legislation is built into the bill.

Our argument would be that the slippery slope is evidenced in different ways—not just through courts expanding the law, but also through court judgments doing so and through Parliaments considering legislation. In most US jurisdictions where that has happened, there have been attempts—some of them successful—to change laws through legislation in Parliament. It also happens through changes in practice, which is what we have seen in Oregon, where, initially, refusal of treatment leading to death was not considered to be terminal but it now is.

Similarly, in the wording of the Canadian legislation, which is replicated in the Scottish bill, the doctor has to be "of the opinion" that the patient qualifies. I would argue that, with the Scottish bill, not only might courts or future Parliaments—no Parliament can bind its successors—expand the guidance, but doctors might push the boundaries and expand the implementation. You got a hint of the potential for that when one of the witnesses on the earlier panel explained her interpretation of self-administration—well, that might be her interpretation, but another doctor or the court might have a different one. What do you do if a doctor pushes that boundary and the phraseology in the bill essentially gives a get-out-of-jail-free card to any doctor as long as they at least say that, in good conscience, they thought that the patient qualified?

**Elena Whitham:** Caveating everything that you have put into that answer, I took from it that the matter would have to come back in front of the Parliament should there be any changes—unless those changes came from a challenge to a court having made a decision on that basis.

**Dr Macdonald:** Another bill might be introduced or this bill might be reviewed, but you would have limited scope for discretion if an article 14 challenge were upheld in the Court of Session.

**Elena Whitham:** I would like to explore some of the articles in the European Convention on Human Rights. I have a question on article 8, which covers the right to decide how and when to die, and article 2, which you already referenced and which requires that there be suitable protections in place for vulnerable groups in any assisted dying process.

I take it that you do not think that the bill gets the balance right between those two provisions, but could you expand a little on that? You have also mentioned the provisions on conscientious objection. Does the bill get those provisions right? If the bill is to be enacted, what could be changed that would strengthen it?

**Dr Macdonald:** You cannot guarantee that no vulnerable person will have their life ended inappropriately. It is a question of how many of those deaths you are willing to accept, because it is not a fail-safe bill if it means that the state allows doctors or other individuals to end people's lives, either directly or indirectly, by writing a prescription. You need to ask yourself the question, "What is the level of risk that we are willing to take?" It is not possible to have a bill without that risk, and it clearly does have risk.

The claim is often made by those who support the bill that there is no slippery slope in other jurisdictions, which is not true. In US jurisdictions, the law has expanded, either in black law or in practice—that is, in the way that it has been implemented. I think that Aly Thomson cited Australia and said there had been no expansion there. There were certain restrictions in place when assisted dying started in Victoria, but every other state that has introduced it has passed broader laws, some of which are extremely broad. For example, in Australian Capital Territory law, it is a criminal offence for an institution such as a religious hospice to say, "We are not going to allow assisted dying on our premises."

The global picture in Australia is one of expansion, and there is pressure now to remove the restrictions in Victoria, so that doctors cannot raise the matter in order to protect patients from the sort of subtle pressures that Dr Wright has just been talking about. There is pressure in both Australia and New Zealand to remove such restrictions, because those who argued for the law are saying that they are a barrier to access.

Earlier, Fraser Sutherland claimed—I cannot remember exactly what he said—that he supported the current restriction on self-administration of medication, but, as far as I understand, that is not the position of the Humanist Society of Scotland, which supports euthanasia. I might be wrong on that point, but that is my understanding. There are already pressures in the wider body politic to expand the legislation further as soon as it is implemented.

**Elena Whitham:** When any legislation is enacted, there will always be a period of review—as you rightly pointed out, one is built into the

bill—to consider what can change as practice develops over time.

Would anybody else like to put across their thoughts about the slippery slope argument? I will hand back to the convener after that, because I am conscious of time.

**Michael Veitch:** Even in the bill as it stands, because of the real lack of clarity, there is scope for the definition of terminal illness and how self-administration would work to be interpreted very broadly, maybe even beyond the bill's policy intentions.

Putting that to one side, the evidence from the likes of the Netherlands, which was among the first jurisdictions, if not the first, to introduce assisted dying 20 years ago, or Canada, which introduced it five or six years ago, clearly demonstrates that once you concede the principle, whether it is via the courts or future Parliaments, there will be pressure over time to expand the criteria. Lord Wallace said that it

"would represent a crossing of the Rubicon from which there would be no return".

That is a really good point.

Once you concede the principle, it becomes very difficult to put it back in the bottle. Certainly, assisted dying would become normalised very quickly. There is evidence from other jurisdictions of a rapid increase in the number of people who opt for assisted dying. Alongside that, there will be an expansion of the criteria for it. We would argue that it is just not credible to claim otherwise.

11:30

**Dr Macdonald:** The point about the courts is an important one. The fact that, up until now, the courts have said that this is a matter for the Parliament does not mean that they will make the same judgment in future. Once the Parliament has accepted the principle, the question before the courts would not be whether it should be legalised, but whether the law is being implemented fairly and whether there are any discrimination issues.

You had a discussion earlier about the bill's proposed minimum age limit of 16, but why 16 and not 14 or 12? Under Gillick competency in England or its equivalent in Scotland, young people can make decisions about their own healthcare. If young people can make decisions about the treatment and drugs that they will accept, such as whether they will have chemotherapy, why could a young person not make a decision about assisted dying? As soon as you cross the Rubicon, you will open up all those questions, which the courts will have to navigate their way through.

**Dr Griffiths:** There are prominent campaigners in society who are advocating for assisted suicide. Many people would not be eligible, based on what is proposed in the legislation. It would be naive to assume that that campaigning would be suspended if the legislation were passed. Campaigning would continue, which would put pressure on the idea of broadening the criteria. One of my strongest messages to the committee is: do you want a society in which everyone has access to assisted suicide? Ultimately, that is the route that you will go down, unless you believe in exceptionalism.

Every country that is going through the process of assisted suicide or assisted dying is grappling with the question of how it can be expanded or how they can refrain from expanding it, and how they can reconcile the requests from different communities. You cannot give an individual a right: it is about collective rights for people and communities. Therefore, there will be pressure for more communities to say that they want access to this right. Culturally, as a society, the question is whether we give the right to everybody, or whether we say that it is dangerous and there are concerns about vulnerability and the way in which it positions the role of the state, and, therefore, we suspend all interest in the procedure.

**Brian Whittle:** Good morning, panel members.

I have been exploring the issue of access to palliative care, which the bill has raised, along with the fact that many people do not get the access to the palliative care that they need. The flipside is that some people receive the highest level of palliative care, yet they get to a point where the care that they receive does not alleviate their physical or psychological pain. If assisted dying is not an option, what would be available to those people?

**Dr Wright:** I am glad that we are having this discussion because it highlights the need for palliative care. Marie Curie numbers show that about one in four people does not get access to the palliative care that they need. There is certainly a sense that what they do get is often piecemeal or is provided too late. I also point you to the considered opinions of palliative medicine specialists across Scotland, particularly in respect of your second point. There is no doubt that there are some aspects of suffering that are very difficult and that there are very hard issues.

I do not know whether the committee has heard from palliative medicine specialists, but in a 2022 survey of palliative medicine doctors in Scotland on the proposal, 95 per cent said that they would not prescribe lethal medication, and 97 per cent said that they would not administer lethal medication—interestingly, with respect to your

latter point, they said that it would have no place in healthcare.

It is interesting that palliative medicine doctors see the most difficult cases yet feel that the proposal is not the right answer. There is also no doubt that the huge scope for research in palliative care is not being addressed. You may be aware of Marie Fallon's work in Edinburgh on difficult or neuropathic pain, and there is access to anaesthetic interventions in Glasgow. However, such interventions are not available to everybody throughout Scotland. There will be people who do not get key interventions because they do not have access to them.

On legislating for a community, there is always something that you can do for everybody. In relation to providing the best care and minimising the most suffering, there is no doubt that investing in palliative care would benefit everyone. It is important to listen to the palliative care doctors on how to spend that money, because it is not just about more money, but about spending money more wisely.

**Dr Macdonald:** Social care is another aspect of the issue that we do not often think about or discuss. We recently carried out an opinion poll that showed that 38 per cent of people who supported, in principle, assisted suicide—or assisted dying, because we used that terminology—would in essence move away from that support if they felt that people were accessing it because they were not going to get access to social care. We should not ignore the huge issue of social care and how we provide it for an ageing population.

**Michael Veitch:** You will have heard this from many witnesses time and again, but I reiterate the point that has been made—palliative care is not as good as it could be. To pre-empt the point that you make in your question, Mr Whittle, an awful lot of people are not getting the best care, and more could be done.

You speak about people for whom dying is difficult. I will make a slightly philosophical point, which is that we all come into the world very vulnerable and entirely dependent on the care of other people, and most of us will probably go out of the world very vulnerable and entirely dependent on other people. The message that we hope society would send to people who are dying—even those who are dying in discomfort—is that we will take care of you.

Going back to the preamble to Gillian Mackay's question to Dr Wright, that sense of feeling a burden is okay. It is okay to experience those hard thoughts at the end, but the signal that we as a society want to send is, "We will look after you," rather than, "We will facilitate an early death via lethal drugs."

**Brian Whittle:** On palliative care, based on the evidence that we have heard, there will be people who have witnessed loved ones in extraordinary pain at the end of life, asking for help. Because you are against the bill, you are saying that that help would not be forthcoming, which is extraordinarily difficult for the individual to hear—and for families who are not able to help to hear, as our overwhelming feeling and desire is to help our loved ones.

If palliative care, in the end, cannot alleviate physical pain or psychological pain, what do you do?

**Dr Wright:** We can always do something. We have heard many distressing stories, and we absolutely need to respond to them, but there is much more that we could be doing as a community. A district nurse told me that the problem is not that we do not know what to do, or that it is beyond us; the problem is that we do not have enough syringe drivers. I am concerned when I hear the many stories of families who have experienced distressing deaths, because there is preventative care. I am concerned when I hear that there are things that could have been done if the person had been seen by a specialist, or if, as you mention, they had had a multidisciplinary team around them.

I am aware that there are many failures of care but it is not a case of asking people to thole it, as you might be implying. There is so much that we can do that is not being done. Michael Veitch is right in that sense.

As a community, how do we respond to those who are distressed and dying? You might be aware that there are 126 specialist palliative care doctors in Scotland, which is fewer than there are members of the Scottish Parliament. Imagine one specialist doctor for each of your constituencies or regional areas—they are big areas to cover. How long does it take if somebody has particularly difficult pain and should see the consultant? That kind of service provision is hugely lacking at the moment.

We are also hearing about corridor care. This is not just about hospice care. The definition of terminal illness, or advanced progressive disease, would apply to advanced respiratory disease, advanced liver disease, advanced heart disease, as well as advanced cancer and advanced neurological disease. If the legislation simply took in those who were in the last year of their life, it would apply to about a quarter of the people who are in our Scottish hospitals.

I appreciate what you are saying about difficult and exceptional cases, Mr Whittle, and we must

not forget them. We absolutely must get the right resources to them and their families. However, the bill covers a big issue that affects a huge number of people, not just people in hospices or specialist nurses in the community. It is at our front door; it affects the general physicians who look after people with complex and multiple morbidity. It has huge implications for the whole of medicine.

**Michael Veitch:** It goes back to the point that I started with. Our contention is that it is impossible to legislate for this safely. If I remember correctly, Dr Sarah Mills made the point to the committee that she had seen a very small number of people in the category that Mr Whittle described, but that she had seen many more people who would be in a vulnerable place where they might well feel some sort of compulsion or pressure to opt for an assisted death. Going back to my opening point, even if you concede that a small number of people might feel that their circumstances justify the legislation, many more could feel that invisible pressure or internal coercion to consider it once it is on the statute book.

We must remember that we have to respect individual autonomy. You have to do that as legislators, but you also have to consider the impact that such a radical piece of legislation would have on society as a whole, especially on many vulnerable people.

**Dr Macdonald:** Could I make an anecdotal comment on that? It is helpful to talk to the leading palliative care professors. Marie Fallon, who has just been mentioned—she is the world expert on neuropathic pain, which is the most difficult pain to address—spoke at a conference that I was at. Her comment on assisted suicide in that context was that her patients who have experienced that pain are not the ones who request assisted suicide. I found that extremely interesting. In her experience, the patients with the most difficult pain to manage are not those who are seeking assisted suicide, which suggests that what is driving this is not pain but existential suffering. That is also evidenced in the data from the Oregon Health Authority. It is about not doing the things that you used to be able to do, not enjoying life, being lonely and isolated and having feelings of being a burden. It is about those existential things.

My argument is that, as a society, we have a responsibility to address those existential sufferings in a life-affirming, positive way, rather than in a way that says that they are a legitimate reason to end your life and we will help you to do that.

**Dr Griffiths:** Listening to what has been said, I am reminded that my condition is progressive. I am unable to recover from my condition, which can cause premature death. I am in significant pain. If I want adjustments or if I want to have any sort of dialogue with medical practitioners who are familiar with my needs, I am looking at waiting for three, four, eight, 12 weeks to get an appointment to have that conversation and adjust my current therapies and interventions. Undoubtedly, when we have periods of crisis or when we have feelings that this is intolerable, I am drawn to the question of how we have organised our resources and our services, and what the relationship between practitioners and individuals is.

From my point of view, those issues could be resolved, and that is where we should focus our attention. We should prioritise those issues before we start talking about whether there is enough technology or knowledge to address the concerns of people who are in pain, people's needs and so on. Technology will change over time.

11:45

At present, however, the question that we should ask is, where is the personalised medicine and the personalised support to allow people to live the life that they can as their needs change over time, and to respond to those needs in the best ways possible, based on our current limitations in terms of technology and knowledge? That is where our focus should be.

**The Deputy Convener:** I go back to a point that was raised earlier on autonomy. Do the witnesses recognise that, for some individuals, there might be some therapeutic value and comfort in having the option of assisted dying available, even though they might ultimately not use it? Simply having the option available to them as a safeguard against their fear of pain and the progression of their condition might well provide them with some degree of comfort. Is that something that you might want to consider or reflect on?

**Dr Macdonald:** It is clear that there is a huge psychological issue involved in the whole debate. That is exemplified by the situation of Esther Rantzen. More than a year ago, she was saying publicly that she was very concerned about her situation and that she did not think that she would live to see another Christmas, but she did. The latest thing that she said publicly was that she found value in life; she gave simple examples such as planting bulbs, because she has been on some new treatment and she would see them come up.

There is a psychological issue, especially when people first get a diagnosis, but the question is what happens if they find that the treatment works better than expected. Those psychological issues might very well be addressed. The risk is that, if you make assisted dying available, people would not live to experience that—they would not live to

try a new treatment, or they would live longer than might be expected.

We have to bear in mind that doctors get prognosis right six months out from death in only 37 per cent of cases. The issue is that the public think that the doctors get it right a lot more often than that. In the whole debate, therefore, there is a disconnect between public perception of doctors' accuracy in predicting people's death and the reality. You have to ask what ability doctors have to accurately predict death. Actually, it comes down to the last six weeks of life rather than six or 12 months out.

If you start having a discussion about putting such things in legislation, that forces people's hand, and they will not live as long as they might do. In fact, I noticed that, even today, in *The Telegraph*, there is an article about 20 per cent of people who have had a six-month prognosis living for three years after that prognosis.

**Dr Wright:** There are a number of aspects to the issue. First, it shows that people have real anxieties when they are first given a terminal diagnosis. Again, that is an argument for early palliative care and support, so that people can be helped to work through those anxieties and to think about what the future holds.

The issue also highlights how—certainly in my experience—people can change their minds. In some other countries, people sometimes have the medicine at home, but I remember people coming into the hospice and saying, "I just can't go on—I just can't do this any more." It is an opportunity to explore what is difficult for them and what they are struggling with. Is it pain, lack of mobility or toileting, for instance? That is where the multidisciplinary team comes in and works through the difficulties.

Some of the concerns from professionals relate to the fact that they see people change their mind and that, through interventions that are not huge, those anxieties can be allayed in different ways. That is my concern. It highlights how much people find that time difficult and anxious. It seems that, rather than just giving them the means to take their own life, we should be able to do better than that.

**The Deputy Convener:** Are there any other comments on that?

**Dr Griffiths:** The only point that I will make, in pondering the point that you have raised, is that I think that it exacerbates many of our concerns. For example, I point to the data from disability studies scholars in Canada that shows the reasons that people give for accessing assisted suicide. When that option is available to people, they go through various processes of trying to get accessible housing and sufficient support and they grapple with cultural aspects around how to receive support and feel that they are having a dignified life and so on. If the mechanism of assisted suicide is on the table and available to them—either if it is offered or if it has to be discussed or presented as a choice—it becomes wrapped up in their decision making around whether their life is tolerable, because of the injustices that they are experiencing.

The point about having that mechanism available, even if it is to give someone comfort, allows us to recognise that many people who face injustice are presented with assisted suicide as a choice but, for them, it feels like a forced pathway to go down or trajectory to follow, because of the inequalities that they are experiencing.

**Michael Veitch:** We do not take that approach with regard to mental health. The Scottish Government and MSPs have done excellent work on the anti-suicide strategy and, clearly, suicide is very much linked to mental health. The approach is never to validate that; it is to do everything that we possibly can to assure somebody that their life is always worth living and that it is never right to take their life. It seems deeply retrograde, in terms of physical health, to validate somebody's choice by saying that there might be circumstances in which ending their life prematurely is the right thing to do.

**The Deputy Convener:** Thank you.

**David Torrance (Kirkcaldy) (SNP):** Good morning. My question is on the means of death. What concerns do the witnesses have about the substances that are used in assisted dying in other countries?

**Dr Macdonald:** There is evidence from Professor Joel Zivot, which you should have a look at, on the drugs that are used in assisted suicide deaths in Oregon, for example, which are the same as the drugs that are used in executions in the United States. Given that Professor Zivot is a campaigner against the death penalty and has had patients who were on death row, he did an autopsy on the bodies of people who had been executed and found that there was excessive fluid on the lungs. He argues that the effect of the drugs that are being used is to create pulmonary oedema and that they, in essence, lead to suffering on the part of the individuals concerned, which is one reason why he campaigns against the death penalty.

The European Union has banned the export to the United States of drugs that are used in the death penalty protocol. If the same drugs are being used in assisted suicides or euthanasia deaths, we have to ask what research has been done on that. Of course, not much research has been done, because autopsies do not often

happen in those situations, and the doctors who are involved tend to be ones who are ideologically signed up to what is happening.

**Michael Veitch:** Almost by definition, medics giving patients lethal drugs takes us into uncharted territory where comparatively few jurisdictions in the world go. To go back to Gordon Macdonald's point, I remember years ago watching a fascinating documentary presented by Michael Portillo in which he went to the United States to try to work out whether there was a compassionate or safe way to carry out the death penalty. He looked at all the different means of death, and his conclusion was that there was no such way. The same logic would appear to apply to the bill, as well.

I recall that, in the evidence session that you had with people from Australia at the start of the process, it was conceded that, in some cases, there are complications. The underlying assumption in the bill and its raison d'être seem to be that there is a guarantee that, if the process is legalised and somebody opts for it, they will have a peaceful and pain-free death. However, there is absolutely no guarantee that that would be the case.

**Dr Wright:** There is evidence on the complication rate. Generally, when you use oral drugs—drugs by mouth—there are complications. Patients can regurgitate the medicines, it can take time for them to die, and they can sometimes have seizures. The complication rate is generally quoted at about 7 per cent, so complications are not hugely common, but that rate is significant and is replicated in a number of jurisdictions.

It is important to note that that is why a number of jurisdictions opt for doctor administration, because oral administration is not guaranteed to be effective. In Canada, for example, for the very small number of people who opt for oral administration, there is a protocol for what happens if complications occur.

I understand why self-administration was chosen for the bill, because it is largely protective of the patient and voluntariness is most important. However, we have to be aware of the complication rate and the fact that self-administration might not be effective—in particular, the patient might not die.

**Dr Griffiths:** That plays into the concerns about eligibility criteria, as well. You will always find community members who will say that the proposed form of self-administration does not work for them, so alternative pathways need to be associated with administration. That will bring pressure for expansion of the criteria, based on capacity, capability and ability.

**David Torrance:** What are the witnesses' views on an attending doctor being allowed to provide assistance in circumstances in which there are complications?

**Dr Wright:** We are hugely concerned about the role of the doctor in that scenario. For example, if the patient takes the medicine and then has seizures, the bill is not clear about whether it is right for the doctor to give medicine to stop the seizures, or whether you are licensing the doctor to kill the patient in that scenario. That is the protocol in other countries. The lack of clarity is a hugely important issue.

On average, such deaths take a matter of hours, but some deaths are prolonged, so what would happen in those scenarios? Would the patient be admitted to a hospital or hospice? What would be the role of the general practitioner in that setting? Those practicalities are concerning, and there are no easy answers.

**Dr Macdonald:** It is interesting to note that, in Australia, which has a mixed model, in some states, the method is primarily self-administration, but the doctor can step in and euthanise the patient if that is not working. In other states, the method is primarily euthanasia by the doctor.

It seems to be the case that, over time, the method has moved towards euthanasia. If euthanasia is on the table as an option, the numbers are much higher—we see that particularly with Canada, compared with the US states.

The bill's proposer is, I presume, trying to strike a balance, but there is no simple solution one way or the other, and there will always be problems, whatever system you implement, unless you say, "Actually, this is just too difficult and too dangerous, so we are not going to do it", which is simple and clear.

It is not clear from the bill, the explanatory notes or the medical advisory group report what the doctor who is present does in circumstances, as has been mentioned, in which the patient does not die and is vomiting or seizing. Whatever legislation the Parliament passes has to be clear—that is a basic principle of law. If it is not clear, there will almost certainly be a judicial challenge. There have been examples of bits of legislation being struck down in the past when they have not been clear.

**Brian Whittle:** I have a question about the concern around doctors administering drugs that will end life. It strikes me that, in cases at the end of life in which increasing pain relief is being administered, it is the pain relief, such as morphine, that actually ends the person's life. How do we deal with that position?

12:00

**Dr Wright:** In modern medical palliative care, it should never be the case that our drugs cause the death. The practice is to titrate, or to increase the drugs slowly, and to do so with regard to the symptoms of the patient—that means that, as you increase, it should be in relation to the pain. There is never a sense that it is the morphine that kills the patient; it is not the intention that that be the case.

One of the guiding principles of modern palliative care is that we do not hasten death. That is upheld across palliative care in Scotland and the rest of the UK. However, I have heard a number of people say exactly what you are saying. It is important that it is not the perception of the public that palliative care hastens death, so we must explain better how we give medicines and the purpose for which we give them. It is certainly never the intention that they are given in order to kill patients.

**Brian Whittle:** I was not suggesting for one second that morphine is being administered specifically to end somebody's life. You are saying that it would not be a contributing factor, because there is a balance between pain and the concern about the level of dosage. That is all that I was suggesting.

**Dr Wright:** Morphine is not generally selected as one of the drugs to be used in assisted dying, because it is not thought to be effective. What happens is that, generally, you titrate slowly to high doses, so it is not considered to be contributing to death. It is the cancer or the respiratory disease that causes the death.

**Dr Macdonald:** As I recall, there is a paper from Canada, which has been mentioned by some of the witnesses from Canada and in other contexts, that shows that people live longer if they have palliative care than they would otherwise. I have certainly heard palliative care experts say that morphine does not kill people—basically, people do not die of morphine.

The fact that somebody has had a dose of morphine 10 minutes before they have died does not mean that the morphine killed them. The analogy that I have heard being made is that you would not say that someone who died 10 minutes after having a cup of tea had been killed by the tea. The point is that they were dying anyway—they were approaching death. The management of pain at an appropriate level is not what kills them.

The situation is slightly different in the Netherlands, where physicians intentionally administer huge doses of drugs in palliative sedation—above what would be used in the UK—and people are, in essence, allowed to die. That happens in about 25 per cent of all deaths in the Netherlands now.

It is all to do with the level of dosage and what the intent is. If the intent is to end the life of the patient, as is happening in the Netherlands, you put them to sleep and you do not wake them up again, and they slowly starve to death.

**Emma Harper:** Dr Wright, I am processing the information that you gave about whether people with chronic obstructive pulmonary disease or heart disease might be considered terminal, as might people with diabetes who struggle because they are in dialysis three times a week or have neuropathic pain or something like that. Are you suggesting that the definition of what constitutes a terminal illness diagnosis is too broad, because it might lead to persons with diabetes, COPD and heart disease being eligible?

**Dr Wright:** I imagined that it was your understanding that patients with chronic aggressive progressive disease were included.

**Emma Harper:** Not all COPD is terminal, and not all diabetes is terminal.

**Dr Wright:** Absolutely.

**Emma Harper:** I am a type 1 diabetic, and I do not consider myself terminal.

**Dr Wright:** No, but a good number of patients who are admitted to Scottish hospitals with advanced chronic obstructive airways disease or advanced breathing disease would come under the bill's definition of terminal illness, as would a significant number of patients with severe aggressive heart failure, which is a non-malignant disease.

The committee should be aware of the fact that it is a broad definition. It would include not only advanced cancers, for example, but advanced non-malignant diseases, such as respiratory disease, advanced liver disease and advanced kidney disease. You are right that not every diabetic would be covered, but a good number of diabetics with advanced kidney disease would fall into that category.

My point is that it is important that we are conscious of the fact that it is a broad definition because of the way that it has been designed.

**Emma Harper:** Again, we are talking about autonomy and choice. Dialysis is not nice to go through. I have worked with patients who have had multiple issues. If someone is suffering, work should be done with their care provider, their clinician and their family to establish what autonomy they should be afforded.

**Dr Wright:** Absolutely. I support individual choice and autonomy, but I am concerned about the option of assisted dying being proposed for a

significant number of people, when it is intended to be used for exceptional cases. I imagine that, in scope, it was intended to be used for exceptional cases, such as those that Mr Whittle described, which are particularly difficult, but I would be concerned if the committee felt that the wording was appropriate for an exceptional group, when it is our understanding that it would apply to a significant number of patients in Scottish hospitals and Scottish care.

The issue is not about which individuals are eligible, but I hope that the committee realises that the scope of the bill is significant. Is it your intention to include a large number of people in its scope or to keep assisted dying for exceptional cases, such as those that have been described?

**Emma Harper:** My understanding is that the UK bill refers to conditions that are untreatable, rather than ones that people cannot recover from, which is the language that the Scottish bill uses. Does that make a difference?

**Dr Wright:** I do not think that that word choice makes a huge difference. If something is not treatable, we would understand that the person is not going to recover. My concern is simply that you understand the sheer breadth of the scope of the bill, as it is written at present, and the impact that that would have—bearing in mind the cases that you have cited—on hospital care and general practice and across medicine as a whole.

**Emma Harper:** Some people can refuse treatment, but they might be treatable. For example, they could receive chemotherapy to extend their life for another six weeks, but they might say, "I don't want to go through that." I am trying to explore the difference in definition between untreatable and unrecoverable.

**Dr Macdonald:** I think that Liam McArthur indicated that he has said publicly—this might be in the explanatory notes—that the option of assisted dying would be for people in the last few weeks of life. The problem is that the definition does not say that. The breadth of the definition means that assisted dying could be available to someone who has two decades to live, depending on the condition that they have.

It is very hard to tie down the intent in legislation. That is the problem. It is very hard to limit it to what is claimed to be the objective, especially when there is pressure from people who do not qualify but are seeking to qualify. The difficulty with the inclusion of a prognosis, as is the case with the Westminster bill, is that, as I have mentioned, that is often inaccurate in any case, especially six months or 12 months out. That is presumably one of the reasons why such a provision is not in the bill. However, the effect of not having it is that you open up the option to all and sundry, to some degree, because people might have five years, two years or whatever to live.

The conundrum is trying to draft something that covers all those bases. In fact, you cannot really do that, which is one of the issues with such legislation.

**Emma Harper:** Thank you.

**Carol Mochan (South Scotland) (Lab):** You have already touched on the issue of assisted suicide, but do you have any comment on Office for National Statistics research that found that a diagnosis or first treatment for certain conditions was associated with an elevated rate of death from suicide? I know that you have touched on that, and that the evidence varies, but I am giving you another opportunity to talk about the issue. Are there any safeguards in the bill when it comes to giving people the ability to know that assisted death might be available to them? How would you respond to that?

**Michael Veitch:** Again, that just illustrates how vulnerable a person is—very understandably—when they get a terminal diagnosis. I go back to the fact that making this legally available, and presenting such an option to somebody in that moment, is very problematic.

I would say that there are no safeguards. I come back to the point that was made at the beginning that you cannot legislate against the pressure of internal conflict that vulnerable people will face. In that sense, there are no safeguards that can make the bill safe to proceed with.

**Dr Macdonald:** On the issue of suicide, you should look at Professor David Albert Jones's research. The argument that is being put forward is that the rate of committing suicide is higher among people who are terminally ill than it is among the general population, but, as I have said, that is not a huge surprise in view of the terminal diagnosis.

If that were a reason to change the law, one would expect that, when the law was changed, the non-assisted suicide rate would fall. However, that is not what happens; it has not happened in Oregon in the United States, and it has not happened in European jurisdictions, either. The overall suicide rate, if assisted suicides are included, goes up, but the non-assisted suicide rate does not decline. That suggests that the motivation for people committing suicide is not necessarily lack of access to assisted suicide but underlying depression or another factor.

**Dr Griffiths:** Presenting this as an option raises a concern about creating, culturally and socially, a twin-track approach, in which we say that, for those from certain backgrounds or with certain

characteristics, the state will do all that it can to facilitate and arguably accelerate their deaths, whereas, for those with other characteristics, backgrounds or experiences, the state will do all that it can to prevent them from taking their lives. That, in turn, plays into cultural assumptions around quality of life and reflections on whether life is worth living, and the rationale for saying, "My life isn't horrible", because of the way in which society has been organised.

I come back to the point that we could debate and explore the nuances of safeguards and try to grapple with questions of eligibility criteria—I come back to the previous question in that respect—but the problem is that this is a catch-22 situation. If you make things too tight, people outside the boundaries will continue to apply pressure to expand the campaign, and if you make things too broad, you will face questions about whether we as a society actually want this for everybody.

For me, the emphasis should be on providing the required resources and infrastructure to make society accessible, inclusive and participatory so that people feel that they have sufficient support to live their lives as their needs change over time, instead of our thinking about and drawing unnecessary attention to the things that we are talking about today. We should focus on the underlying foundations of inequality and marginalisation, which affect all those whom we are talking about—people in situations in which they would be exposed to assisted suicide.

**Dr Wright:** I will add a comment about the context with regard to Scottish mental health provision. The fact is that people are not able to access mental health support. We consider it realistic for them to wait 18 weeks for psychological support or treatment, but we might be providing them with assisted suicide within three or four weeks.

As Miro Griffiths has said, there is a twin-track approach in that respect, and I have real concerns about the lack of psychological support. For example, if a GP were to prescribe an antidepressant, it might take two, three or even four weeks for it to have an effect, but we might be giving people access to assisted suicide within four weeks. We need to think about the context in which we are offering this and whether we are offering mental health services that are fit for purpose.

**Carol Mochan:** Thank you.

**The Deputy Convener:** I thank the witnesses for attending the committee and for answering our questions so fully. Our next meeting will be a week today, when we will continue our stage 1 scrutiny of the Assisted Dying for Terminally Ill Adults (Scotland) Bill with evidence on law enforcement considerations, followed by an evidence-taking session with the Cabinet Secretary for Health and Social Care.

That concludes the public part of our meeting.

12:15

*Meeting continued in private until 12:34.*

Published in Edinburgh by the Scottish Parliamentary Corporate Body, the Scottish Parliament, Edinburgh, EH99 1SP

All documents are available on
the Scottish Parliament website at:

www.parliament.scot

Information on non-endorsed print suppliers
is available here:

www.parliament.scot/documents

For information on the Scottish Parliament contact
Public Information on:

Telephone: 0131 348 5000
Textphone: 0800 092 7100
Email: sp.info@parliament.scot

The Scottish Parliament
Pàrlamaid na h-Alba