HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Assisted dying/assisted suicide, HC 711

Tuesday 28 March 2023

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Watch the meeting

Members present: Steve Brine (Chair); Lucy Allan; Paul Blomfield; Paul Bristow; Chris Green; Mrs Paulette Hamilton; Rachael Maskell; James Morris.

Questions 1 - 80

Witnesses

I: Lord Falconer of Thoroton, Labour peer; Baroness Meacher, Cross-Bench peer; Baroness Finlay of Llandaff, Cross-Bench peer, Professor of Palliative Medicine, Cardiff University School of Medicine; and Baroness Hollins, Cross-Bench peer.

II: Dr Naomi Richards, Senior Lecturer in Social Science and Director of the Glasgow End of Life Studies Group, University of Glasgow; Dr Alexandra Mullock, Senior Lecturer in Healthcare Law and Co-Director of the Centre for Social Ethics and Policy, University of Manchester; and Professor Nancy Preston, Professor of Supportive and Palliative Care, University of Lancaster.

Examination of witnesses

Witnesses: Lord Falconer, Baroness Meacher, Baroness Finlay and Baroness Hollins.

Q1 **Chair:** Good morning. This is the Health and Social Care Select Committee. We are live in the Palace of Westminster, in the House of Commons. This morning is our first evidence session in our new inquiry into assisted dying/assisted suicide. It is a subject that is obviously incredibly sensitive and affects us all, which is how we die.

Some people feel incredibly strongly about there being the need for a change in the law. Some people feel incredibly strongly that there should not be a change in the law. Many people are obviously well aware that there is a debate raging on the subject, have not picked a position on it and may never do so. Our purpose is to look at all the issues and the evidence, and to do so, as we always try to do, in the most sensitive way we possibly can.

A call for evidence for the inquiry was launched at the start of December, to collect evidence of domestic and international views on the subject. To briefly set them out for those watching, the terms of reference were things ranging from the extent to which people in England and Wales have access to good palliative care, how that can be improved and whether such improvements negate some of the arguments for a change in the law to what we can learn from evidence in countries where the law has already been changed and what professional and ethical considerations are involved in allowing physicians to assist someone to end their life.

There are a number of other terms of reference, all of which are available on our website. Today's session is the first oral evidence session for our inquiry. We are going to hear from four peers who have been involved in work on this topic over many years, including those who attempted to introduce legislation in the House of Lords to change the law. On our second panel, after we take a very short break, we will hear about the current evidence base from academics with expertise in the fields of palliative care and end of life care and the experience of healthcare professionals involved in medically assisted deaths.

Let me introduce panel one: Baroness Finlay of Llandaff, Lord Falconer of Thoroton, Baroness Meacher and Baroness Hollins. Thank you so much for giving up your time and speaking to us at the very start of an incredibly high-profile inquiry. We are aware that there is huge public interest in this. The amount of evidence that we have received and the number of replies to our survey has surpassed any expectations. My Clerks are thrilled with the tens and tens of thousands of replies that we received. I place on record my thanks to them because a huge volume of work has come in to them.

Before I open up the floor to my colleagues, I want to ask each of you to speak from the heart, not discussing the law or the procedures, and to tell us why you care. I said at the start that on both sides of this some people care deeply. Why do you care so much? I will start with the former Lord Chancellor, Lord Falconer. Why do you care so much, sir?

Lord Falconer: I am like everybody else in this issue on policy. I have myself had personal involvement in somebody dying, where a point was reached when it turned out that there were weeks to go but there was nothing left except an increasing focus for the person who was dying on their inward suffering, where death was absolutely inevitable and where it was absolutely clear that assisting her to die would have been unquestionably the best course, but that was not possible. A long period went on when there was—how can I judge this—quite bad suffering for her, and quite bad suffering for those who loved her.

After that experience, which is what started my involvement, I got interested in the issue for obvious reasons. I wondered whether or not palliative care would have been better for everybody, because it should be better for everybody, and if it would make the difference. As it happened, the person to whom I have just referred was in the health service, and therefore quite high-quality care was given. There desperately needs to be an improvement in palliative care, but it is absolutely clear that improving palliative care will not resolve the needs of some people to end their life earlier in the context of a terminal illness.

There is widespread sympathy for the position that I adopt. Indeed, the law has turned itself on its head from, "It's a crime to assist somebody to commit suicide," to, "The law will not be enforced by the DPP because everybody accepts it's a nonsense of a law."

There need to be safeguards. As it happens, the assisted dying proposal, if it became law, would be the most safeguarded route to an earlier death because it is more safeguarded than withdrawing your own treatment, the hospital deciding that you are not going to be treated if you are under the care of the Court of Protection and the doctors and your family agreeing, and you can have that stopped without any intervention. It is the most safeguarded.

Where we have got with the law now is such a mess. We allow people to go to Switzerland. We allow people to be helped to go to Switzerland. We investigate their loved ones when they come back, which is a hellish experience. The law is such a mess. I don't think I have met anybody who does not think that. The law itself recognises that. I think it is time for a change.

Q2 **Chair:** Thank you very much. Baroness Hollins, why did you want to come and speak today? Why do you care so passionately about this subject?

Baroness Hollins: As a doctor, as a psychiatrist and as a legislator, I am very worried about the unintended consequences. I think no country in the world has succeeded in creating a law that actually protects people who find themselves in vulnerable situations. That is my main reason. About 5% of the world currently has access to physician-assisted suicide. That is all. It is a minority, and it is not proved to be safe, essentially. Attempts in previous private Members' Bills to make it safer have not been well received by the proponents of the legislation.

I have been an academic psychiatrist for 40 years, and in my work on death education—teaching medical students, for example—and community staff working in mental health services, all the time we found a fear of talking about death. We do not have adequate death education in our society. It is driven by fear. That is one of the big reasons. I would like to see a much more accepting conversation about death; an acceptance that it is something that is going to happen to all of us and is a normal process. The more we talk about it, the more there is the possibility that people will get the help they need when they are dying so that they can die in comfort with family and friends around them, and without all the anxiety that goes around assisted suicide.

I have been teaching in schools more recently through a charity that I set up—Books Beyond Words. It has been fabulous to begin to talk to children who have been bereaved. I think a parent dies every 20 minutes in the United Kingdom. Every class will have at least one child who has been bereaved of a parent, yet teachers are not comfortable talking about death. We have been trying to introduce ways to do that. That is really important.

As a clinician and as a researcher, I see how the lives of people I am particularly concerned about—people with learning disabilities and autistic people—are not valued, and how their own lack of confidence and their own quality of life can lead to changes in the perception of those who are caring for them. We saw it during the pandemic, when people with Down's syndrome had a six times higher death rate. A lot of that was due to "Do not resuscitate" and assumptions being made about the quality of life.

My research in the Netherlands has found that the evidence there is unusual. They actually provide case histories of people who have had euthanasia. It is normally euthanasia in the Netherlands—I think 96% of cases—because it is easier and more effective, and because the complication rate from physician-assisted suicide is so high. We did not expect to find those in the learning disability and autism community represented among those euthanised, but they were. We found 38 cases, described in our study. This will be an underestimate because they are not all described. We found 38 cases of people with learning disability and/or autism who were euthanised simply because of the symptoms of having a learning disability or autism. That is the sort of safeguard that I am concerned about. I will stop there.

Q3 **Chair:** Thank you. That is a very good setting of the scene. Baroness Meacher, you have introduced legislation on this subject. Staying away from that, because we will come on to the nuts and bolts, why are you so identified with the subject and wanting a change? Why do you care so much? What is your lived experience?

Baroness Meacher: Chair, I declare my interest as chair of Dignity in Dying at the start. I am a former social worker and a Quaker, and I suppose I have spent my life trying to listen to people's needs, trying to reduce unbearable suffering and trying to protect vulnerable people.

At the moment, some people have to choose between suicide, suffering or Switzerland. Future generations will be appalled that we have taken so long to put this right. If we think of patient autonomy, for many years polls and surveys have shown that the huge majority of British people want an assisted dying law, and 86% of disabled people want it. They want an assisted dying law for people who are terminally ill and who are mentally competent. It is very clear that that is where the support lies, both for non-disabled people and disabled people. We know that choice and some control at the end of life will bring tremendous comfort to dying people, relieving unbearable suffering.

Terminal illness brings unbearable suffering in various forms. Obviously, uncontrollable physical pain is one such form. Another is endless nausea and vomiting, maybe because of opioids and an allergy to antiemetics. Another is faecal vomiting which can recur and recur. Another is a fungating tumour, creating the most appalling odour that the patient cannot get away from. Other people do not want to come into the ward because of the odour. The patient cannot leave it. There may be a complete and utter loss of the ability to move, perhaps because of motor neurone disease. These patients, towards the end of life, are unable to swallow, to speak, to eat or to drink. They are existing; they are not living. We all want more and better palliative care—of course we do—but however good palliative care is, it will not be able to eliminate the unbearable suffering of many people.

We must protect vulnerable people. At the moment, a patient might stop eating or drinking. They stop taking their medication. They will leap off a bridge. They will try hanging themselves. There are no safeguards or regulations to check that these people are not under coercion from a near relative to shorten their life. An assisted dying Bill will introduce strong safeguards, involving two doctors, of course, and a succession of interviews with the patient to make sure that they really have a sustained wish for help to die, as well as interviews with relatives to check their motives, too. Geoff Whaley, an MND sufferer who went to Switzerland, wrote to every MP complaining of the hypocrisy and cruelty of the current law, and pleaded with MPs to change the law so that others would not have to suffer as he had suffered.

What about healthcare professionals? My daughter is a doctor. I am very conscious of the historical issues around assisted dying, for doctors and nurses in particular, but of course the medical profession has changed tremendously over recent years. The BMA and the Royal College of

Physicians, for example, were opposed. They are now neutral, having consulted their members. Why? The BMA survey was the largest-ever of doctors on this subject. It found that far more doctors were in support of assisted dying than were against it; 50% supported it and 39% were opposed.

Things have changed internationally, too. The number of states in the US that now legally have assisted dying has more than doubled in recent years. All the states of Australia and New Zealand have legalised assisted dying since 2017. Countries are on the move in Europe and, of course, in Scotland, the Isle of Man and Jersey.

Q4 **Chair:** Thank you for setting the scene in that way. Finally, Baroness Finlay, what is your experience that drives you to speak publicly on this sensitive subject?

Baroness Finlay: I declare that I am a palliative medicine physician. I have worked in the field since 1987 and I have looked after thousands and thousands of dying patients, as well as of course having my own experience of people very close to me dying.

I have had many, many conversations with people who are dying and people who are in absolute despair. I had a patient back in 1991 who was desperate for euthanasia. Four of us thought that his prognosis was three months. With great difficulty—I was there until 11 at night—I persuaded him that I would try to relieve his symptoms. He said he would give me two weeks before he killed himself. Eleven years later he phoned me because his wife was dying. She died in my care, with his children at her bedside and him in a wheelchair. He is still alive today. That is just one example of how wrong you can be. I have had many conversations with patients who said, "I never believed that I could feel so much better again." The one thing that palliative care and assisted dying have in common is that they are very poorly understood, and that is a real problem.

We have the post-Shipman effect with opioids, unfortunately. Clinicians are now reluctant to prescribe the type of dose that many patients need, so it takes a bit longer to get there. As for nausea and vomiting, I have been involved in the research. The situation now is that we can control intestinal obstruction well. The smell from fungating tumours does not happen like it used to. I saw it happen years ago, but not today. Modern medicine has changed.

I had the privilege of working in the Netherlands as a visiting professor. I went out with a GP to observe the conversations happening. It was striking how you end up going down one road, and clinical thinking about other ways of controlling symptoms becomes very difficult. That was a very good GP. I have been involved in providing education all over the world. Nowhere else has the level of palliative care education that we have, but it has only been in less than the last year. The Health and Care Act finally puts palliative care as a core part of the NHS. Until now we have not had that, and it becomes really important. I have seen patients who have been suicidal and have discussed whether or not they go to Switzerland. Actually, those requests and that suicidal ideation disappears when they get the care they need.

The last thing is that my own mother was very strongly in favour of euthanasia. When she was dying, and we thought she had six weeks to live, she was extremely angry with me that I had opposed it. Four years later she said that she was really glad, and that she had had the most incredibly rewarding time, seeing her grandson born and so on. That was just an illustration to me, but I have been on the receiving end of such conversations on many occasions.

Chair: Thank you very much. It was important at the very start of this inquiry to hear those opening statements, or lived experiences. I don't like that term, but people know what we mean. For the rest of the session we obviously need to keep our answers significantly shorter than that, because otherwise we will not let Members come in, which is what they are here to do.

Q5 **Chris Green:** Lord Falconer, what is your understanding of the change in perception the public would have of doctors or the medical profession if we introduced an assisted dying or assisted suicide Bill?

Lord Falconer: I don't think there would be any significant change in relation to it. In countries where assisted dying has become permitted—for example, in Oregon—a significant majority of doctors are willing to participate in the process. There is no evidence that that has had an impact on people's views in relation to doctors.

I think people look to their doctor when they are dying. Although I completely agree with what both Sheila and Ilora said about the fact that there is not enough discussion about death, very many people are aware that they are dying, and they look to their doctor to help them in relation to that.

Q6 **Chris Green:** Your opening comments on the experience of a friend was quite narrow in terms of how you set the scope of people who would be included. Would the practice of a law that you would perhaps favour be similarly as narrow in scope, or would it be broader? If it were broader, in five, 10 or 20 years' time what scope would there be for opening it up?

Lord Falconer: As far as I am concerned, the scope would be only those who are terminally ill. They would require a diagnosis from two doctors, and a High Court judge would have to say that it was okay to go ahead with an assisted death. The period of time I have suggested is six months. There has been debate about that. Broadly, only those who are terminally ill would be within the scope of the Assisted Dying Bill that I proposed.

Prior to the Bill that I proposed in the Lords, Lord Joffe proposed a Bill. He made it absolutely clear that he wanted to go wider, perhaps to unbearable suffering. I am incredibly opposed to unbearable suffering as the root. I am only in favour of terminal illness. Lord Joffe’s Bill was defeated two to one in the Lords. My Bill effectively got through unopposed on Second Reading. When there were votes, they were all in favour. The terminal illness scope is the one that I favour.

If you start with a terminal illness scope, history tells us, looking at other countries, that it does not expand. You can go for two routes. You can go for unbearable suffering on the one hand. This is not the only country where it has been done; it has been done in the Low Countries. Or you can go for terminal illness. Part of the way is that you help people when they are terminally ill, which is more the Oregon route, and by and large the scope does not change.

Q7 **Chris Green:** In the Low Countries or Belgium they even have assisted dying or suicide for children. Society has changed. One of the reasons why we are having this debate now, or have had a succession of debates in recent years, is because the attitudes of society have changed.

Once assisted dying becomes more commonplace and more accepted, surely there will be pressure to extend the scope. If it were to include other groups, because assisted dying across the world is still relatively new, there would be pressure to include wider groups, including children. Surely, at that point, the perception of the relationship between patient and doctor would change.

Lord Falconer: First of all, you are much better able to judge what public opinion is than I am, because I am an appointed peer. For what it is worth, my view is that the idea that in this country a perception would arise that it was okay to allow children to have an assisted death is completely for the birds. I am sure that will never happen in my lifetime, which obviously has a limited span. Going forward, it seems to me to be incredibly unlikely. My feeling about what the UK will wear is that people are in favour of terminal illness assistance, but nothing more. That is absolutely my view. That is where the Lords have got to.

Q8 **Chris Green:** Baroness Hollins, I have the same question to you on the perception of the relationship between patients and doctors. Do you think that would change initially, and would it change over time?

Baroness Hollins: Hugely. It is such a sensitive relationship. I will just give one example in the Netherlands. The mother of a friend of mine was dying. Her mother was being asked every day, “Would you like to take the drugs now?”, because the culture had changed; the assumption is that that is an option. My worry is that it is an easy way out. On a personal note—

Q9 **Chris Green:** Can we clarify that? Someone is anticipating medical treatment and they are actually given the option of assisted dying.

Baroness Hollins: Yes, basically. That is just too difficult. On a personal note, I was visiting a GP with a family member who had a terminal illness. The doctor made it clear that this was an option that they would strongly support. We changed our doctor. We did not feel comfortable being with a doctor who, even in that first conversation, was raising that as a possibility, and talking about Switzerland, for example. It was not something we wanted to hear. We wanted to know that we were going to get all the support and be directed to the right support, right at the start.

It changes things. The culture, the attitude and everything changes. It is such an important relationship. People are in a vulnerable situation, and having a life-limiting diagnosis makes you vulnerable, whoever you are.

Q10 **Chris Green:** Do you share Lord Falconer's confidence that, if it were introduced with very narrow and very clearly defined terms, it would be a sustainable position over five, 10 or 20 years?

Baroness Hollins: I cannot see how we can do that safely. We are talking about such a small number of people. If you look in any other country where it has been legalised it has changed, and that is the difficulty for me. People talk about Oregon, but Canada and the Netherlands are much more like us in their legal system and culture. It has immediately opened right up. I am particularly concerned about the extension to people with mental illness, and to disabled people, particularly people with learning disability and autism, who are so open to suggestion. It is very difficult.

Q11 **Chris Green:** I am conscious of time, but, Baroness Meacher and Baroness Finlay, would you comment on what you have heard so far?

Baroness Meacher: Baroness Hollins referred to Canada. They are an absolute outlier because, unusually, the Supreme Court in Canada opened up the issue of assisted dying through a judgment that implied a broader law. The legislature was then under pressure to introduce assisted dying. They did so in two stages: first, to limit it to terminally ill people with mental competence; and, secondly, respecting the decision and judgment of the Supreme Court.

The courts in the UK are absolutely clear. We have taken a case through the courts, so I am very conscious of it. The courts will not make a judgment on this issue. The courts in the UK are absolutely clear that it is a matter for Parliament. Parliament will pass a law on assisted dying when Parliament is ready to do so. That is absolutely crucial.

The majority of jurisdictions that have passed laws on assisted dying have done so restricting it to terminally ill people who are mentally competent. Not a single one of those jurisdictions has broadened the scope from the initial scope. That is incredibly important because that is what I believe will be the case in the UK. We are a highly disciplined country and that is the route I believe we will follow. We will have the narrow law for terminally ill people who are mentally competent, and it will remain thus.

Q12 **Chris Green:** Baroness Finlay?

Baroness Finlay: It is important to remember that defining terminal illness is extremely difficult. In the Bill that Baroness Meacher proposed, an 18-year-old with anorexia would have been eligible. A diabetic who was insulin dependent would have been eligible by refusing their treatment.

Q13 **Chris Green:** In that sense, by refusing your treatment, you then have a terminal condition. Is that right?

Baroness Finlay: Absolutely. Sadly, we know that anorexia is a potentially fatal condition even now. Even though our NHS investment has improved survival by 22% in recent years, it is still a potentially fatal illness.

You also have to remember that diagnostic error is quite common. There have been cases in Canada of people who had euthanasia but, actually, never had the illness that they were thought to have. One in 20 post-mortems in this country shows that there has been a diagnostic error. That is evidence from the Royal College of Pathologists. We know that the prognosis is just about impossible. In fact, Ray Tallis, in evidence to a previous Select Committee in the Lords, described it as a "probabilistic art". The College of GPs said that at six months it is pretty desperately hopeless being able to predict prognosis.

In terms of the law itself, I think it would only be a very short time until a challenge was brought in the courts claiming inequality, for whatever reason, if you try to put firm boundaries around it. I don't think we can ignore the Canadian experience. It has split the medical profession. In Oregon, I understood that only 2% of doctors there actually prescribe and are involved in this. To say that it is widespread is not correct.

Q14 **Chris Green:** So that I understand that, the point made before is that in Oregon there is popular support from doctors, but you are saying that in terms of those actually participating it is a far smaller group. Is the question that you might support it, but you would not participate in it?

Baroness Finlay: Yes. The BMA survey that was referred to also showed that the highest opposition was among the clinicians who deal with and look after these patients all the time, particularly in my own speciality of palliative medicine, but also in geriatric medicine, clinical oncology and renal medicine. That is where the opposition came. When you ask people, "Would you be willing to participate in the processes?", the numbers go right down. Theoretically, while they think that might be okay, when they think it through the numbers drop. The BMA did an in-depth study called ELCPAD—end-of-life care and physician-assisted dying—which is well worth reading. It showed that for the public group in that, as well as for the doctors, the more they learnt about it, the more they became cautious about it.

We have to remember the drugs that are used. Nowhere in the world have these drugs been approved by any authority for repurposing. People are completely unaware. Last week, 100 clinicians were asked, "Do you know what drugs are used?" This was in Southampton. None of them knew the doses. It is 100 tablets of barbiturate or 150 tablets of a mixture of Valium, amitriptyline and digoxin. That is an awful lot of tablets to swallow.

The other thing with euthanasia is that last year over two thirds of patients in Belgium were given a short-acting anaesthetic agent, but they were also given curare. That meant that every muscle was paralysed. They would have looked as if they were peaceful, but they were dying of asphyxia. People are unaware of that.

I will add one thing. Many years ago, I asked for somebody to do a study to see whether patients, given these cocktails in euthanasia, regained consciousness before they died. There was a study of lethal injections in executions that showed 80% of people probably regained a degree of consciousness. Nobody has undertaken that study, so we are dealing with something that is unknown. The end point is that, yes, it is death but I think we can manage death better and differently. We do not have to go down that route. You have to look at Canada because the experience there is worrying.

Lord Falconer: Could I correct two things that Baroness Finlay said? First of all, in relation to Oregon the position is that the median time to unconsciousness after ingestion of medication is five minutes, and the median time to death is 30 minutes. Nobody is reported to have regained consciousness with the medication.

Baroness Finlay: I am sorry; nine people have.

Lord Falconer: The second point is that she suggested, and I was surprised by this, that the courts could set aside a Bill that Parliament passed for assisted dying, which is completely untrue. The reason why Canada is different is because of a Charter of Rights, which allows the Supreme Court to set aside or require legislation. I defer to Ilora on all medical matters, but on legal matters that was quite a leap.

Chair: We are going to move on. Colleagues know that we will not be asking all four of you each question. We have a second panel, and we are never going to get there in daylight hours at this rate.

Q15 **Lucy Allan:** I want to ask about the ethical considerations for the medical profession. Clearly, all medical professionals want to alleviate the suffering of patients. There is now also a trend for the profession to move towards choice and autonomy in care and treatment, and putting patients at the centre of that. Baroness Hollins, do you think that there is concern for the ethical considerations around medical professionals when they are faced with the suffering of their patients and lack of clarity in the law?

Baroness Hollins: I think the law is clear at the moment. The ethical issue for the doctor is to meet the needs of the patient and, if you do not have the adequate competencies yourself, to refer to somebody who does. In this country we have the opportunity to refer to palliative care and palliative medicine. Baroness Finlay is probably more au fait with the ethics because I think she is still on the ethics committee at the BMA. You might prefer to address this to her.

Q16 **Lucy Allan:** To give it a bit more context, say, for example, a doctor was faced with a terminally ill patient who was gravely suffering, and that doctor decided to give the patient a little bit too much morphine. Is that not something that creates ethical considerations?

Baroness Hollins: I think that is a misunderstanding. People misunderstand morphine. The way that morphine is used is to titrate it. Again, it is not my specialism, but I was a GP for a number of years, and I have been a psychiatrist for a number of years. I have been involved in a lot of debates and discussions around this. I have also seen and been with family members who needed morphine at the end of their life. There is often reluctance to take it because there is an assumption that if you take too much morphine it will kill you. It is not really like that. If you keep on top of the pain, the morphine will allow you in the end to die. It is not that it kills you, but it allows you to die. My understanding is that it is the pain that keeps you in suffering, but if you take morphine the natural process of dying can take place. It is about skill and titrating the dose. Again, this is Baroness Finlay's expertise.

Baroness Finlay: I think there is a real misunderstanding. If you are in the street and you do not have pain, and you take an overdose of morphine, then, yes, you may stop breathing and that would kill you. In our patients you titrate the dose of morphine against the pain, to be below the level of toxicity. I have seen patients who have had an accidental overdose—sometimes huge, because someone got the dose wrong for whatever reason—and they just have a good sleep and wake up again afterwards. It is really difficult to kill people with morphine. That is why the mixtures used in those countries are not overdoses of morphine.

Q17 **Lucy Allan:** If a patient says to a doctor, "Please can you give me more morphine?", and the doctor thinks, "This will probably finish the patient off," is that not an ethical dilemma for that doctor? They would be outside the law but acting in accordance with the request of their suffering patient.

Baroness Finlay: Sadly, I would say that probably reflects a degree of ignorance of the way that opioids work, and how to handle them. If somebody says, "I am suffering unbearably," you must go back and find out why, diagnose what the underlying cause is and think again. Morphine is not the only way of relieving pain. There are lots of other ways as well; you may have to involve other people and get other people in. People are terrified of pain. Of course, they are. Nobody wants to be in pain. But it is not the main reason why people go for assisted suicide.

If you look at the Oregon data, the main reasons are about being a burden. Pain, or fear of pain, comes way down the list. I stress fear of pain because we do not know how many of the people had unrelieved pain. Pain is not the problem, though.

Q18 **Lucy Allan:** What about patients being able to make their own choices, and patient autonomy? You are dying and you know you have limited lifespan left, you are in pain and your family are seeing you suffer, and patient autonomy is something that the medical profession is moving towards in terms of choice and placing the patient at the heart of what is done. What sort of ethical considerations are raised by that?

Baroness Finlay: The thing about choice is that you must have information. Choice is meaningless unless it is an informed choice. You need to know what the options are and have them available.

I pointed out that we have only just incorporated palliative care as part of a requirement for NHS provision. We still have parts of the UK where it is not available, and it needs to be, but we are getting there. In terms of the patient's choice as well, you have to ask what is behind the request to end their life. What is going on?

The ONS did some work on overall suicide rates, and it was misinterpreted. What it showed is that people, given a serious life-limiting diagnosis, are at the highest risk of suicide at the time they get the bad news. Their suicidal risk drops down with time afterwards. If you look at suicide rates in countries that have gone down this road, they are all higher than us. Our suicide rate in the UK is 8.4 per 100,000. In Oregon, it is 18.3. That is not assisted suicide. Those are mostly gunshot suicides, so you do not even solve that problem.

Q19 **Lucy Allan:** We have very limited time, and I was talking about ethical considerations for the profession. Baroness Meacher, could I ask you about the ethical considerations for the profession, given that the law is unclear, as we heard Lord Falconer say? I am not clear as a lay person whether it is the doctor's responsibility, the Director of Public Prosecution's responsibility or the court's responsibility. Lord Falconer is clear that it is Parliament's responsibility. If you are a medic and you are going to expose yourself to a law that is not entirely clear, does that create ethical considerations?

Baroness Meacher: I take it that the law is clear. It is not acceptable to assist somebody to die under the current law. A doctor will know that. In my view, the ethical consideration for a doctor is that they have a patient suffering unbearably and pleading with them for help to end their suffering, and they cannot end that suffering legally. Therefore I assume that they will not do it. For me, that is the ethical dilemma under the current law that, of course, an assisted dying law would eliminate. Then, the autonomy of the patient would come to the fore. If the patient really wanted to die, and was pleading for help to die, a doctor could help that patient.

The important point is this. Ilora Finlay referred to the six months rule. In jurisdictions that have legalised assisted dying, normally people request the medication, and ultimately take it, within a week to 10 days of the predicted death. They do not take it six months ahead of time. Therefore, people are much clearer very close to death that this is, indeed, the future for this person. They will die within a week to 10 days. What it means is that in the lead-up to that period the patient knows that when they really get to the end that their suffering, whatever it is—vomiting or fungating wounds; those things do happen—and the unbearable pain can be ended by a doctor. It is that security and reassurance that is so important to people, and means that dying people have a much better end of life experience.

Added to that, of course, is the fact that doctors in jurisdictions where they have assisted dying are much more able to talk openly with a patient about the patient's problems and issues. There is a lot of evidence about that.

Q20 **Lucy Allan:** Let me bring in Lord Falconer. Keir Starmer, as Director of Public Prosecutions, made the point in a speech in 2015 that relatives will usually be acting for compassionate reasons and it would have been extremely rare that he saw, in his capacity as DPP, any prosecutions against relatives. He said that medical professionals are in a slightly different position. Would you comment on that point?

Lord Falconer: You so want to talk to somebody when you are terminally ill, and you might want to consider whether or not you want to take your own life by going to Switzerland. Ilora and the entirely admirable palliative care professionals will try to persuade you not to do so. At the moment, if you talk to a doctor in England and Wales—not Scotland—and he or she says, "Look, I heard what you say and you want to go to Switzerland," if they encourage you in any way they may end up being prosecuted under the law. They will not have the protection of the DPP's statement, which only applies to relatives.

The only assistance you can get under the mess that is the law at the moment is amateur assistance—well-motivated assistance, but amateur. My experience, having looked at this a lot since my own personal experience, is that people feel alone. They do not want to talk to their own family about taking their own life. They cannot talk to the doctor, so what they do is take their life without telling anybody. It is absolutely hellish for those who are left behind.

Chair: That is fascinating stuff. Well done, and thank you, Lucy. We will go to Rachael Maskell and then Paul Blomfield.

Q21 **Rachael Maskell:** Looking at the area of commonality, everybody wants a good death and, within that, one without fear as well. Baroness Meacher and Lord Falconer, we have heard today that difficult deaths can be addressed by palliative care; for instance, we have heard about certain tumours, vomiting and so on that can be controlled. Is it that the advances in medicine, which are forever progressing, can actually address that fundamental issue about having a good death?

Baroness Meacher: All the evidence that I have seen, and I have seen a lot of it, suggests that we all want better funded palliative care, but that that will never be able to eliminate unbearable suffering for everyone. Yes, for the majority of people that is so, but there will always be a minority of people who suffer unbearably in the ways I have indicated. Obviously, uncontrollable physical pain is just one of those forms of unbearable suffering. I suppose the one that I see as the most frightening is the complete loss of ability to move, particularly caused by motor neurone disease. I met Geoff Whaley, who went to Switzerland and to whom I referred in my opening comments. The fact is that not to be able to swallow, to speak, to eat, to drink, to scratch an itch or to deal with a pain, and not to be able to move in any way or communicate because you can no longer speak and you cannot move to signal, is a form of unbearable suffering where I believe, if a person really cannot cope, they should be assisted to end their suffering. That was the view of Geoff Whaley, which he put so strongly to every MP in this country.

Q22 **Rachael Maskell:** Could I tease out a little bit more on that issue? For instance, somebody who has a learning difficulty, or a profound disability which they have had all their life, could be in that situation. What would you say to the person with learning difficulties?

Baroness Meacher: I have worked with people with severe learning difficulties, and it is remarkable the way people can find a way of communicating if they are not paralysed. The fact is that a complete inability to move is something else—something completely different.

Q23 **Rachael Maskell:** Do you want to comment, Lord Falconer?

Lord Falconer: I have nothing to add to what Baroness Meacher said.

Q24 **Rachael Maskell:** I want to pick up with you what we have heard very powerfully today, which is the lack of a comprehensive advanced palliative care system across the country. Were that to be available, do you believe it would remove some of the fear people have about not being able to access high-quality care at the end of their life?

Lord Falconer: The better the palliative care, the better the situation would be for some people. There is a group of people who, no matter how good the palliative care was, would always find the position they find themselves in intolerable. Hospice UK said the following: “It is not in doubt that some people will have what they or their families consider to be a bad death, despite the very best care being made available across all settings.”

Everyone has their own level beyond which they may feel their quality of life has become unacceptable. Why you feel that your quality of life has become unacceptable may, in some cases, be physical restriction or pain, or it may be the lack of dignity or the lack of control that makes it impossible. I think most people who have done work in this area think that there will always be a group of people who find the prospect of what is coming, which may not be pain but lack of dignity or lack of control, unbearable going forward.

Q25 **Rachael Maskell:** I have one more question, which is to either Baroness Meacher or Lord Falconer. Is the six months from a prognosis of death with or without treatment? One of our discoveries in Oregon was that somebody could have a prognosis of six months without treatment. However, with medical intervention they could have a quality of life. We met somebody who had lived 23 years.

Lord Falconer: Six months, in the context of what is happening then—if I am not taking treatment and I only have six months to live—is six months. For example, there are lots and lots of illnesses with which, if you are treated for them, you can last forever and ever. If you are taking the treatment and are happy with that, you have an indefinite amount of time to live. You have to look at the circumstances of the individual patient.

Baroness Meacher: As I said before, people are not going to get hold of the medicine and take it until right towards the end of their life, by which time things are very clear. Doctors and everybody around the patient will be very clear about what is going to happen.

Lord Falconer: To take the anorexic example and somebody who is not eating, as it goes on, their life expectancy gets less and less because they become weaker and weaker. In those circumstances, under the separate Bills that Molly and I introduced, I would have thought it inconceivable that a High Court judge would say it was okay. That is why you have a High Court judge. You need a timing. Ilora feels tempted to say what the High Court judge would do.

Baroness Finlay: No, not at all. I was thinking that they would fall within the definition.

Lord Falconer: They would.

Baroness Finlay: And therefore it wouldn't ever go to court. A young woman with severe anorexia nervosa may well have a very poor prognosis, but if she comes out the other side—it is usually women, but sometimes men—she can go on to have a completely full life.

Lord Falconer: Yes, I agree.

Q26 **Rachael Maskell:** I want to come to the issue of withdrawal of food and fluid. Clearly, that does not lend itself to a good death. Can you talk from your experience about the indications of that? It is currently legal for a patient to choose the withdrawal of food and fluid.

Baroness Finlay: In the clinical context it is extremely rare for patients to decide that they do not want food and fluid, because that is basic care.

They must still have all care, even if they have refused all treatment. If I can go back to motor neurone disease, where patients may decide they no longer want to continue with, for instance, supported ventilation, they withdraw their consent and they are supported and looked after as they die. They are dying of the motor neurone disease that they would have died of months or weeks previously.

In terms of fluids, I think that probably the medical profession have been over-cautious about putting up, for example, subcutaneous fluids for patients at home just to keep them comfortable. It is easy to do and patients can have fluids, even if they do not want to eat. It is up to the patient. You must discuss all these things with the patient quite openly and listen to what their concerns are.

You must also ask them if there are other things that they would want to do in their time and are not able to do. I had a patient who wanted to go to Dignitas. He was absolutely adamant; it was just that he needed pain control for the journey. In that conversation, when I asked him, “Is there anything else you have always wanted to do?”, and prompted him, he told me that he had actually always wanted to go on a cruise.

I am no travel agent, but we arranged for him to go on a cruise with his wife. When he came back, weeks later, he said he had had a wonderful time. I thought he would then want to go to Dignitas. His comment was, “No, I want to go on another cruise.” He went on three cruises and then, in the middle of winter, he went to Porthcawl beach and died subsequently; it was very cold out on Porthcawl beach. You need to know what patients really want and what motivates them. You need to understand their fears. Listening is the core skill for everybody in understanding what needs to happen.

Going back to the ethical dilemma, it is about listening to what people want and weighing in the balance the harms against the benefits with the patient, listening to what they want and detecting pressures on them. We must not forget about coercive pressures or abuse. The data is that about one in five or one in six people over 65 in the UK have been affected by abuse. That data is sadly borne out from all over the world. Elder abuse is really rife. It is not picked up by clinicians. It is only picked up by clinicians when it is physical abuse, but most is financial and emotional neglect, and so on. Those are pressures on people. I have had patients whose requirements for analgesia, when they revealed that they were being abused, dropped dramatically because we were able to support them and sort out their problems.

Q27 **Rachael Maskell:** I have one more question around those difficult deaths, as I have categorised them. How advanced is medicine for dealing with every scenario of a difficult death? How could it be dealt with under palliative care to ensure that somebody did not have such a death?

Baroness Finlay: Thank you for asking that. It is really important to be clear that nothing in medicine is 100%. If you have meningitis, you will be given antibiotics, but it is not 100% that they will work. Nothing is 100%. However, access to high-quality, specialist palliative care is still inadequate around the country. We are getting there. We are more advanced than any of the other countries. It is worth remembering that Els Borst, who took the law through in the Netherlands, went on to say: "In the Netherlands we first listened to the political and societal demand in favour of euthanasia. Obviously, this was not in the proper order." It is only recently that the Netherlands is developing specialist palliative care as a discipline.

The training that people have in this country is much greater than in any of those other countries. I think you have to look at the balance. How safe is safe enough? The evidence from the other countries is that there will be some people who die when, actually, their death was based on the wrong information. The information they had in making that choice was misinformation, and that is the problem. You also have to look at what is the acceptable number of unacceptable deaths through error and decide about that, if you are making a law that allows doctors or anybody else to give lethal drugs to a patient at their request. It is a balance of harms, and we have a duty to the most vulnerable in society, not only to the most vocal in society.

Q28 **Paul Blomfield:** Baroness Hollins, you said, and I am sure we would all agree, that we need to have more mature conversations about death. Would you accept, as part of those conversations, that we would have to recognise that even the best palliative care cannot provide a good death for everybody, as Hospice UK has suggested, from what Lord Falconer said?

Baroness Hollins: There is a real difficulty because an awful lot of this is to do with fear throughout the system on both sides—patients and clinicians.

I am sorry, but my mind is full of the previous conversation about motor neurone disease and dignity, and I feel that I should say that I have a family member with motor neurone disease at the moment. What is interesting about it is that in my family we are not really afraid of what you describe as a loss of dignity. That is because 17 years ago my daughter was stabbed and paralysed. She has a high-level spinal injury. She did not speak for many months. Her life could not be more dignified. She is still paralysed, but she lives a full life. She is not afraid. In our family we are not afraid of disability because we have met it and lived with it. I have worked my life with it.

Motor neurone disease does not attract the fear that it does in some of the people who are less familiar. There is no loss of dignity in any of the things that have been described. I think fear is behind it, and fear causes pain. It is not just a physical issue. It is partly a psychological issue. Being able to sit and listen to people, and hear what their fears are, changes things.

I sat with my daughter's mother-in-law when she was dying 18 months ago. She was afraid of all sorts of things. She was afraid of taking pain relief, but when she had had the pain relief she was able to settle and reflect on her life and spend time with her family. The pain relief worked, and yet she had one of those diagnoses that everybody said is the most terrible death. She did not have a terrible death. She had a beautiful death at home.

Those psychological issues are fundamental to our understanding about death and talking about it. There are numbers of times when somebody rings me up and says, "My mother's dying; she's in pain, she's in hospital, it's terrible." I say, "Has anybody talked to her about palliative care and the fact that she is dying? Is everybody tiptoeing around the subject?" It is always, "Well, nobody likes to mention it." As soon as it is mentioned and as soon as the palliative care physician or clinician is invited to come in, things change. It is the lack of addressing the issue. Doctors are not comfortable with saying to their patient, "You are dying; how can we help you?" That is the difficulty.

Q29 **Paul Blomfield:** I am really very sorry to hear about your daughter, but that was not my question. Hospice UK, as Lord Falconer indicated, said that in their view even the very best care cannot avert a bad death for some people. Do you accept that?

Baroness Hollins: I think that is going to be true, but I don't think it is as widespread as people think. That is why I was talking about the psychological, because that is underneath an awful lot of this.

Q30 **Paul Blomfield:** Thank you very much for accepting that that is in fact the case. I want to explore with you the consequences of the current law. In this debate we often focus on change, but the current law has implications for people.

Baroness Finlay, you talked about the ONS study which showed that people with terminal illness are twice as likely to take their own life. It is estimated that that is around 650 people a year. They are lonely and often very difficult deaths. My father was one of them. He did not, as you suggested, make that decision at the point of diagnosis. He actually took that decision shortly after he had sat down with a Macmillan nurse and had been through what his last months might look like. Are you satisfied that the current legal settlement has no negative consequences for individuals who take those decisions, and indeed for their families?

Baroness Finlay: Can I say, first of all, that a suicide is a devastating event for anybody—even an attempted suicide? It raises all kinds of questions in those left behind, which are particularly difficult. Thank you for speaking openly because I think it is important that we know where people come from.

I am back to the question of balance. Sadly, and I say sadly, there will always be some people for whom carrying on is not tolerable, but the rate of other suicides in the country is not lowered. The rate of suicide among people who are dying is not lowered by having this change in the law, which is why the suicide data from countries that have changed the law becomes important. Sadly, within our lives we will not meet the needs of every single person in the population.

I go back to the question that you have to ask: "How safe is safe enough if you change the law?" You talked about 650 suicides a year. If you look at the data, even if we took the Oregon figures, which are meant to be the lowest, Emily Jackson, who has been known to be a supporter of the change in the law, gave a lecture a couple of weeks ago and her estimate is that there would be 5,800 assisted suicides in the UK, on the Oregon figures. If you look at the figures from Canada or the Netherlands, it would probably be tenfold.

You then have to look at what you want your clinical staff to do. Do you want your clinical staff to be looking after patients who are dying and working to relieve their distress, or are you going to take them away from that in order to process assisted dying and assisted suicide requests? The data from Australia suggests that it takes 60 hours of clinical time. We know that we have an enormous shortfall of clinicians in this country already, and you are going to take thousands of full-time equivalent hours out of clinical services if you put this as a clinical duty by changing the law. I am back to the question of balance. If you take people away from clinical care to assist suicide, you decrease the number of people who are there to look after people who are distressed and work to relieve their distress. I don't think anyone should underestimate the shortfall in clinicians that we have in this country.

Q31 **Paul Blomfield:** With the greatest of respect, that was not my question. My question was, do you think there are any difficult consequences from the existing law?

Baroness Finlay: There are difficult consequences for some people from every law that we have, so to say no would be very naive. There will be some people who want to go to Switzerland to kill themselves. We have people who go abroad for all kinds of activities. We do not police their activities in going abroad. We have laws in our country about how we behave towards our citizens. On balance—I am back to that—our law is safer than the evidence from countries that have changed the law.

Q32 **Paul Blomfield:** In that context, you have knowledge obviously that people go to Switzerland and other people take their own decisions to take a difficult death. The debate around a change in the law is about safeguards.

Baroness Finlay: Yes.

Q33 **Paul Blomfield:** And the worries about coercion are a factor. What are the safeguards in the current law? How do we know that people going to Switzerland have not been coerced?

Baroness Finlay: That is why the Director of Public Prosecutions' guidance—why our law was changed—was that you do not prosecute people who take their own life. That would have been completely inhumane. The dangers are of coercion and pressure. Often the Director of Public Prosecutions' cases—I cannot recall the exact numbers; I will try to get them for you if you want—have proceeded to prosecution because there was mal-intent behind the persuasion. In countries where the law has changed, that does not seem to go away either; you do not remove the ability for families to coerce somebody. The Canadian experience is of patients being offered lethal drugs. We know of the athlete who was offered euthanasia rather than a ramp for her wheelchair.

Q34 **Paul Blomfield:** Would you agree that there are no safeguards in our existing law, and the risk of coercion is a factor that needs to be taken into account, either under a new legal settlement on assisted dying or under our current situation?

Baroness Finlay: I think the safeguards in our current system are greater than the proposals we have seen on the table. We put down amendments to the Bill that Baroness Meacher put forward. We said quite openly that we wanted to tighten the so-called safeguards because we did not think they were verifiable. Nobody from the campaign side has come to discuss any of those amendments with us. There has been an accusation that they were vexatious. They were not. They were to try to make it safer in the event of that legislation passing. You have to be aware that if you are going to have safeguards, they must be things that are verifiable. The proposals that we have seen have not had verifiable safeguards in them.

Q35 **Paul Blomfield:** But there are no safeguards in the existing system.

Baroness Finlay: If you look at the way that the law has changed in other countries, because that is the basis—

Q36 **Paul Blomfield:** That was not my question.

Baroness Finlay: I know it wasn't your question, but I think you have to look at the evidence. Nowhere is there any monitoring of the consultation itself in which the discussion happens over assisted suicide or euthanasia. There was not a proposal in any of the legislation that those consultations would be monitored. The suggestion of a second doctor had nothing about the relationship between the two, nor the amount they are involved. If you are going to have safeguards, they must be ones that you can verify and can go back and audit afterwards.

Paul Blomfield: I will leave it there, but obviously my question was about safeguards under the existing system, and the sort of safeguards that you describe simply do not exist in our current legal settlement, but thank you.

Q37 **James Morris:** I am assuming that, even if we were to change the law on the basis of what Lord Falconer said, we would still have a need for a mental capacity assessment for the individual. Baroness Hollins, do you think that would put pressure on our current definition of what mental capacity is, or what the implications would be, if any?

Baroness Hollins: It is such a complicated area. I sat on the post-legislative scrutiny committee for the Mental Capacity Act 2005. There are huge difficulties with it as it stands at the moment, in that very few clinicians really seem to understand how to assess capacity. It is still not fully understood and implemented. I think it would confuse the situation further. At the moment it does not extend to decisions about an assisted death.

Q38 **James Morris:** Do you think that the law around mental capacity would need to be updated to reflect any changes that came along with a new law?

Baroness Hollins: I think it would, but it has been found to be such a complicated area. There is a big discussion about whether we should have a combined mental capacity and mental health Act to try to address some of these issues. It would be a very lengthy process to get to something in any way satisfactory. Just the difficulties of even assessing capacity for some quite simple decisions are not well managed in our system. It is a very interesting question and a very interesting area to explore, but it is not something that has a simple answer, I'm afraid.

Q39 **James Morris:** Lord Falconer, do you consider there to be impacts on mental capacity law as a result of the changes that you may propose?

Lord Falconer: The Bills that have been proposed say that the person who decides to have an assisted death has to have the capacity to make that decision. That is all the Bill says. The Mental Capacity Act says—in my view correctly—that in determining whether somebody has mental capacity you have to have regard to what sort of decision it is.

It is hard to imagine a more serious decision than whether or not you should take your own life. That is a factual decision that both doctors, in some circumstances, and the courts in other circumstances are used to addressing. It is a very serious decision, but it is one that they are capable of taking. Speaking for myself, I do not think there would be any need for a change in the law. The question is, looking at a particular person, whether he or she is in a state where he or she can make the decision as to whether to take their own life. For example, are they affected by depression? Are they affected by mental impairment that prevents it? It is a factual question. It is perfectly possible for doctors and courts to make it. Although I note what Sheila says, honestly, over quite a considerable period of time judges particularly have been capable of doing that.

Q40 **James Morris:** This is perhaps hypothetical. Baroness Finlay, in the situation that you described about a girl suffering from severe anorexia, do you think hypothetically she would be deemed to have capacity to make a decision to end her own life?

Baroness Finlay: The danger is that it depends on the ability of the clinicians making the assessment. I had the privilege of chairing the Mental Capacity Forum for six years. I have to say that it was worrying to see the inability of clinicians to assess capacity—particularly fluctuating capacity. Another group of patients where there is a real worry is where there is frontal lobe involvement in the brain, where they can appear as if they have capacity but actually they cannot understand the implications of their decision for themselves and others.

Only last week, I came across a clinical case of somebody in ICU, who appeared to have complete capacity to stop treatment. By chance, his girlfriend arrived. I won't go into the details because it is a long story, but he then decided to marry her. Afterwards, he had absolutely no recall whatsoever of any of the conversations that had taken place when he had said that he did not want to be treated. At the time his clinicians—not just one, but three of them—thought that he was absolutely crystal clear that he wanted to stop treatment, and would have stopped his ventilation, but for the chance arrival of his girlfriend.

Lord Falconer: Which indicates that the Bills are the most safeguarded route. What Ilora is talking about, quite rightly, is where people decide, maybe on bad grounds, to withdraw treatment, when there will be no safeguards whatsoever.

Baroness Finlay: The point is that when you are assessing capacity you have to go back and look and think again. The clinicians had a tiny element of doubt, which is why they did not act there and then, but decided to wait to see what happened with him, even though he appeared to have capacity. That is a big problem. It is a big problem in care homes as well, where you have people who have frontal lobe involvement.

Chair: Thank you. I am conscious that we are running behind time, but this is such important stuff. We will still attempt to finish on time. Finally in this section, Paulette Hamilton.

Q41 **Mrs Hamilton:** Good morning, ladies and gentlemen. My question is geared towards Baroness Finlay and Baroness Meacher. It is a really simple question. I am about families. I read a report that was published by Macmillan in 2017 called "No Regrets", which talked about death and said that people treated death with a little bit of a taboo, so we do not talk about it enough. It also stated that 64% of people do not talk about death at all until it is upon them. Are patients and their families given enough opportunity and support to discuss death and dying before it gets to the stage when people feel isolated and have no support, and then they take decisions like committing suicide?

Baroness Finlay: Simply, no, they do not have enough opportunity. Even clinicians are slow to refer patients to palliative care early because they are frightened of having the conversation to say that the prognosis is not good, although we have moved a lot from where we were previously.

The biggest group is children. You have already heard that every class has, on average, one child who has lost a parent or sibling and two other children who have been bereaved of somebody close to them. Yet in schools very few teachers—way below half—have any training in managing bereaved children. We do not talk about death and dying. During covid, it really came to the fore, as people suddenly became aware of the threat of death from covid and what was happening. The other problem is that even when people are bereaved, people do not talk openly and let them talk about the person who has died.

I am afraid it is a no, yet death is going to hit everybody. Nobody can escape the fact that we will all die one day. As a society, we need to decide how we can provide support and help people prepare.

Baroness Meacher: It appears that the doctors are the problem. Marie Curie showed that about 65% of dying people were able to talk to their friends and family about dying—about their concerns and so forth. A YouGov study revealed that only 16% of dying people had had a discussion with their doctor about what was going to happen as their condition worsened. It is a very serious issue for people that they feel they cannot talk to their doctor about their death and dying.

We know from the jurisdictions that have assisted dying that doctors are much more comfortable about talking with their patients about dying, about pain control and about hospice care and so on. It opens up the relationship and the conversations between patients and their doctors when the doctor knows that if things become unbearable for the patient, they can actually help them right the way through. At the moment, at the point of greatest need for the patient—when the patient cannot cope any more—the doctor is unable to help. That interferes with a doctor feeling that they can actually have those conversations.

Q42 **Mrs Hamilton:** On my last point, I would be really interested in what Lord Falconer says. Going forward, if you were to give advice, what would that advice be around educating people, talking about things a lot earlier and about the taboo you have talked about so that we do not get to the stage where all people want to do is end it all?

Lord Falconer: All three of the previous speakers have indicated that there is not enough discussion about one's death. As Ilora says, we are all going to die. You need to be much more open about the prospects of how one dies. That will have the effect, I suspect, of reducing much of the fear associated with death. The longer one has the opportunity to talk about death to clinicians who might help them, the better one will be equipped to do it.

Even if you have those conversations, for very many people there is the prospect of disability, pain, lack of control and lack of dignity. Not everybody is able to cope with the lack of dignity or control, as Sheila's family have, that comes with death. Different people have different levels of resilience. For some people, even with the best help in the world, the idea of going through a period when they are completely disabled or dependent on those who love them is unbearable. You need to have the discussion about what you can cope with because people's levels are so different.

Q43 **Mrs Hamilton:** I was going to stop there, but what you said really interests me. Where my parents come from, from the day you are born you are hearing about death. You will be living in a house with a grandmother who is probably on her journey, or someone in the family. In England, in the UK and this part of the world, we perhaps have a stiff upper lip and we don't talk about it. It is like it is on a need-to-know basis. Do you think that doing things like talking about death at an earlier stage would be more helpful? Would it help people, when they come to the last stages of their life, get to the point of no fear that was highlighted earlier? Baroness Hollins, what do you think about the points I have just made?

Baroness Hollins: Absolutely. It is such a taboo. We have to learn how to talk through the taboo. That includes death, but it also includes what you are calling dignity. I think the dignity comes in part from the comfort of sharing fear, of understanding, of seeing, of participating, of engaging, of experiencing grief and of understanding that this is part of the life cycle. Let's open the subject up. Let's talk about it.

Mrs Hamilton: That is a good way to end. Thank you.

Chair: Very good, Paulette. Baroness Finlay, Baroness Hollins, Baroness Meacher and Lord Falconer, thank you so much for your time and your honesty in opening our inquiry session so frankly. Thank you very much.

Examination of witnesses

Witnesses: Dr Richards, Dr Mullock and Professor Preston.

Chair: This is the Health and Social Care Select Committee. This is our first oral evidence session in our inquiry looking at assisted dying/assisted suicide. We have just heard from four peers of the realm, and now we have a second panel.

We have, appearing remotely, Dr Naomi Richards, who is a senior lecturer in social science and director of the Glasgow End of Life Studies Group at the University of Glasgow. Naomi specialises in death and dying, ageing and old age.

In the room, we have Dr Alexandra Mullock, a senior lecturer in healthcare law and co-director of the Centre for Social Ethics and Policy at the University of Manchester. I think in 2021 Alex was one of the legal experts to the Government of Jersey's assisted dying citizens' jury. That is very interesting to us. We also have Professor Nancy Preston, who is the professor of supportive and palliative care at the University of Lancaster. Professor Preston has a strong interest in how people make decisions about their future care. She has conducted research about AD/AS in the US, Switzerland and the Netherlands as well as exploring the experiences of British families following an assisted death overseas.

This is a really interesting panel. We are sorry to be a bit late starting but thank you very much for your patience and for your time. We will start with Chris Green.

Q44 **Chris Green:** Dr Mullock, in the deliberations over the Jersey citizens' jury there must have been a bit of discussion about the scope of people, in terms of assisted dying/assisted suicide and who might be included on that. Could you briefly highlight how that conversation went?

Dr Mullock: The jury was given quite a broad, flexible remit in deciding first whether in principle assisted dying ought to be legalised in Jersey and subsequently to decide the parameters of that. The majority of the jury decided that both physician-assisted suicide and euthanasia should be legal, and they should be available for terminally ill people and people suffering unbearably.

Q45 **Chris Green:** That is slightly broader than other areas. In terms of terminal illness, for example, would the prognosis have to be six months, so there was that kind of constraint as well?

Dr Mullock: Yes.

Q46 **Chris Green:** As I pointed out earlier, in Belgium children can also be included in the remit. Was there any discussion over that?

Dr Mullock: No, there was not. The jury heard many hours of evidence from a range of experts, including from Europe. They were made aware of the approach in Belgium, but they voted to limit eligibility to adults.

Q47 **Chris Green:** In the criteria for adults, were there groups participating in the citizens' jury who were perhaps excluded from that option—perhaps the legislation as supported or the approach as supported? Were there any groups that would have been excluded from the conclusions that were drawn?

Dr Mullock: In terms of who would not be eligible, in terms of adults?

Chris Green: Yes.

Dr Mullock: There was a capacity requirement in a similar way to the way that other jurisdictions with permissive regimes have a requirement of capacity. That was also—

Q48 **Chris Green:** That sounds to me as though it is quite a broad and open approach—perhaps broader than most jurisdictions around the world—and people were going into that very consciously, perhaps thinking it was significantly broader than Oregon and other places.

Dr Mullock: The approach that the jury voted for is certainly broader than Oregon. It is similar to the approaches in the Netherlands and Canada.

Q49 **Chris Green:** Other than going down the under-18 route, there would not be such a question from the evidence you saw over moving or expanding the range of people included.

Dr Mullock: That was not something the jury were asked to consider. They were limited to the questions about whether they thought in principle it should be lawful and, if so, who for. Children were not part of that conversation.

Q50 **Paul Bristow:** My first question is to Professor Nancy Preston from Lancaster University, my old university. Welcome. Do you think there is enough data available about access to and the provision of palliative and end of life care in England and Wales?

Professor Preston: We know there is not enough. There will not be enough until it is part of the national health service and has full funding. It is 75% funded from tombolas and things like that. What we have in the UK is much greater access for more people with different conditions. I do a lot of work in Europe, where it is mainly still for people with cancer, whereas in the UK it has expanded to people with COPD, heart failure and motor neurone disease. It is a much broader church, although people most commonly think of it as for people with cancer. We are having to develop services largely for people in the community funded outside the health service, which limits its reach.

Q51 **Paul Bristow:** If we had a much more focused and universal palliative care system, how do you think that would influence the debate around assisted dying and suicide?

Professor Preston: If you look at the Oregon case in particular, Linda Ganzini, who did a lot of the work in the States, used to refer to Oregon man. Oregon man does not want to be a burden; Oregon man was hunting, shooting, fishing, and wants to make his own choices towards the end of life. These are decisions people are making, regardless of the care they are going to receive. It is not necessarily always about poor provision of palliative care. It can be about people wanting control. That is what you hear a lot in the discussions with patients and their families.

Q52 **Paul Bristow:** How would you react to the evidence we heard earlier about burden and control? Would you accept that there is a feeling that to be—How do I put this in the most dignified way? We heard evidence earlier—certainly from Baroness Finlay, I think—that people with disabilities and those who had lost control said they did not feel that it was a burden. Everyone's experiences are different. Do you feel there is a fear of that burden and that there is contagion that people would begin to feel that they are a burden, or is that not weighed by the evidence?

Professor Preston: We have no evidence to support that that would happen. Commonly, people want to remain independent for as long as they can. I guess the concern is that that could apply to people with disabilities and other groups, and then they can feel disenfranchised in the decisions they are making. Then it gets back to coercion and control. There is nothing in our evidence to say anything about that, really.

Q53 **Mrs Hamilton:** Good morning. Professor Preston, I asked the first panel this question, and I am going to ask the question again—I am really interested because of all the brilliant work you have done. I hope you were in the room at the time. It was about the fact that there is a taboo around people talking about death and dying. It was around the fact that 64% of people think that we do not talk enough about death. The question I asked the first panel was: are patients and their families given enough opportunity and support to discuss death and dying?

Professor Preston: I will give an example of a large study we did across Europe. We had 1,100 patients. We were talking about advanced care planning and "what is the kind of care that you would want to receive at the end of your life?" Towards the end of your life, you may lose competency, so you need to have talked to someone; you need to share those decisions in advance. Most of the people who came on the study probably had a median survival of 12 weeks, so that was a really important conversation. When the doctors tried to introduce it, half the patients said, "I don't want to go there. I am in a good place right now." That meant they had not had that conversation. With half of those who said they wanted it, the families said that they were in a really good place right now.

We are trying to train people to have those conversations better. We have free online resources. One of the drivers I use is the ambulance service. If we do not have those conversations, it might feel like you do not want to upset someone and it is not a good time. A paramedic could turn up and be facing a family they have never met before, having a really difficult conversation in a very acute moment, so we need to be better about it. We know that we can make that better. We did it during covid in care homes. We trained up the care home staff to have those conversations—and families. The families responded incredibly positively to it.

Q54 **Mrs Hamilton:** Thank you for that. The next question will again be focused on you because it is around doctors. Let me start by saying that I and a number of us on the Committee had the absolute pleasure of going to Oregon. It really opened my eyes to this subject. One thing I found out while we were there was that large numbers of doctors did not want to be part of it. I think it was highlighted earlier that only 2% of doctors in Oregon actually wanted to take part in anything around assisted dying. How does the legislation on assisted dying impact on care practitioners such as nurses, doctors and others, and what support would they be given to take on this massive role?

Professor Preston: It depends on the jurisdiction. In the Netherlands, when we did research there, the doctors are very supported in the process, but even though they are very supported, one of the quotes we got was, "It's stressful killing somebody." That was somebody who carried on doing that. Some people feel okay with it. Some people feel that they can manage one or two a year. Other people say, "I can't be involved." When we did research in Switzerland, those people might not even feel able to say, "Well, there is a right to die association that you can talk to. I might not be able to have that conversation." There are real gradients of the level of involvement and the impact it can have on them.

We do not talk about the Swiss system a lot, but they promote it as almost a civil system where it has been contracted out to the right to die associations. As in a lot of countries, assisted dying does not happen in hospitals. It predominantly happens in people's homes. In the Netherlands, it is in care homes and hospices. The Swiss model is very much that it is outside the main healthcare system, with volunteer doctors. It is their passion and drive, so it is taken out of mainstream health, which removes some of the pressure on the doctors in the health service in Switzerland.

Q55 **Mrs Hamilton:** Do you feel that this country is anywhere near equipped to do anything like that?

Professor Preston: I do not know whether doctors in this country really know what it would feel like to do it. I do not think anybody does until you are faced with it. As I said, there will be a range of responses as to whether they feel able. I think Baroness Finlay mentioned the BMA report. Although there is a lot of support for it I think that in part reflects people thinking, "Well, maybe I would need it myself but I don't think I could do it myself."

Q56 **Mrs Hamilton:** That is an interesting point. Can I bring you in, Dr Mullock? As a Committee we have had evidence from all over the world, especially the places that have been highlighted such as Belgium, Oregon and the Netherlands. We have had information coming to the Committee, and the Association for Palliative Medicine has expressed concerns about people reporting information around the issue of assisted dying and medication.

While we were in Oregon, the thing that got to me was the reporting of things. I am not going to say it was a little bit slapdash because I feel that is trivialising it, but I felt that we could have had a Harold Shipman and they would not have known because it is just very databased and matter of fact after it all happens. I am not sure how much of that was really checked. Do you feel that the quality of information reported from other jurisdictions like Oregon, Belgium and the Netherlands relating to assisted suicide/assisted dying is good enough?

Dr Mullock: That is a really difficult question to answer. I cannot answer it, but I could point you to the work of some people who have done appraisals of the monitoring systems that have been put in place. One example is Professor Penny Lewis, who is now a law commissioner and has done some work on this. Her assessment is that the monitoring that is carried out is quite robust and sound, particularly in the Netherlands. If I remember correctly, over a 10-year period, 111 examples of possible breaches of the Dutch criteria were reported to prosecutors. That led to one prosecution and an acquittal.

It is really not possible because it relies on honest reporting. Potentially, there are problems and flaws in that approach but, like so many things, it is difficult to assess how robust that monitoring is.

Q57 **Mrs Hamilton:** Thank you. With all the research you have done around this area, what are your views? Do you think it is possible? You're smiling at me; I like that. Do you think it is possible to get honest reporting in this area?

Professor Preston: I think it is challenging. In the Netherlands they have a very clear reporting system, but there is an anonymous survey that is carried out either every other year or every year by the team at Erasmus. They find that, closer to the end of life, doctors are more likely to use what they call palliative sedation—a larger dose of sedation—rather than going through the euthanasia legislation. It is an anonymous survey, and it is difficult to interpret and understand. It does not mean that they are doing euthanasia, but they are reliant on going to large doses of drugs to sedate people.

We are doing a big study at the moment on sedation across Europe and trying to understand practice. Within palliative care, it is very much titrated and proportional according to the patient need, and more so in GP practices and things like that. It can be used in different ways. That would be outside the current legislation.

Mrs Hamilton: That is an excellent point at which to stop. Absolutely brilliant. Thank you, ladies.

Q58 **James Morris:** This is a very emotive subject which can polarise views, so one of the challenges that we have in this inquiry is about the nature of the evidence base that this Committee is actually looking at. If we make a policy change, it needs to be on a robust basis of evidence. So I want to ask each of you, starting with Dr Richards, what you thought the critical pieces of evidence are that the Committee should be looking at as it deliberates on this matter. Maybe you could give us one critical piece of evidence that you think is absolutely central to our deliberations.

Dr Richards: From what I have heard today, you are covering a lot of the big issues. One critical piece of evidence? I suppose, thinking about the arguments for and against that have been rehearsed in the House of Commons and the House of Lords for many decades, the big piece of evidence is whether there is abuse and whether vulnerable people are coming within the scope of any legislation in any jurisdiction. That would be the No. 1 thing for me.

Q59 **James Morris:** On that point, do you think there is robust evidence on the particular issue to do with abuse? Does that exist as a body of evidence in a coherent place?

Dr Richards: It is clear to say there is no robust evidence that there is abuse, as Professor Preston has said today already. However, it is a hard thing to research, I would say.

Q60 **James Morris:** Dr Mullock, what is the critical evidence that this Committee should be looking at if it was persuaded to change the law or look at the issue differently from the current regime?

Dr Mullock: I think probably the evidence from Oregon, which you obviously have already explored on your visit. That is really critical because the Oregon approach is the approach that is proposed under the recent Bills. It is a quite restrictive approach where only terminally ill people are eligible. There is evidence coming out of Oregon, where the numbers have remained quite low and there is no evidence of abuse, although there have been reports of some worrying examples of people with depression who are not adequately assessed. You could compare that with the evidence coming out of the Netherlands, which has a much more permissive approach and where the numbers of people choosing to die by euthanasia have grown quite a lot. About 4% of everyone who dies in the Netherlands dies by assisted dying.

Q61 **James Morris:** Sorry to interrupt, but could I ask you one question about Oregon? When we were in Oregon a claim was made that the introduction of assisted dying had "improved" palliative care in Oregon. Do you have any perspective on whether you think that is a credible claim?

Dr Mullock: It is certainly credible because, in a sense, although they are very intertwined they are also separate issues. If a jurisdiction makes a determined effort to improve palliative care, it is perfectly possible for palliative care to improve at the same time as legalising some form of assisted dying.

Q62 **James Morris:** Professor Preston, what do you think is the critical evidence base that this Committee should be considering?

Professor Preston: I think you should consider all the evidence. It is definitely a decision for parliamentarians to come to. If you were to change the law, I really recommend that you look at the impact on healthcare workers and families and ensure that they are looked after as well. The debate is often very focused on the patient and the patient's rights. We need to make sure that everybody involved is supported and looked after.

Q63 **Paul Blomfield:** We established in the first session that, wherever you are in this discussion, everybody wants to see the very best palliative care, but even the best palliative care cannot avoid a bad death for some people. Would you agree with that, Dr Richards?

Dr Richards: Yes, I would agree with that. It depends how you define what a bad death is. As was discussed in the previous session, this is not just about pain and symptom management. It is about autonomy. It is about dependency and people's identity. How people die is seen sometimes to represent something about who they are; to say something about who they are. It is really important that we do not just think it is about pain and symptom management, although it is in some cases. A bad death for some people is not dying on their own terms.

Q64 **Paul Blomfield:** Professor Preston, would you like to add to that at all?

Professor Preston: As Naomi says, if we are talking about physical symptoms, you can, on the whole, try to treat those. It is through sedation, which means that you would be losing consciousness early, similar to the way you would be having an assisted death early.

Naomi is absolutely right that for some people it is not about that. It is about continence. It is about mobility. It is about being able to make decisions for yourself. A classic example would be someone with spinal cord compression. They know what is going to happen in the future and think, "I don't want to be like that." It could take a long time before they died, but that is not where they want to be. I think it is a mixture of both. A lot of the stuff we can manage with sedation, but how people feel about themselves is different.

Q65 **Paul Blomfield:** Obviously the debate that has taken place in various jurisdictions has landed with two routes. One is about assisted dying laws for those with terminal illness, and other countries have gone further in relation to unbearable suffering. There is an argument that if we change the law in relation to terminal illness, which is where the debate is in this country, there is inevitably a slippery slope into widening the law. Is there any evidence of that from jurisdictions that have taken the route of terminal illness, Dr Mullock?

Dr Mullock: No, I do not think there is. Oregon has had the same approach and that has not expanded for quite a long time. There is evidence that if you begin with an approach that allows it for unbearable suffering caused by a severe physical condition, it is quite hard to maintain an intellectually convincing or clinical distinction between a physical illness that causes unbearable suffering and a psychiatric illness that causes unbearable suffering. That problem is removed if you have an approach of terminal illness because then it becomes about allowing people to control an imminent death rather than cutting many years off their lives.

Q66 **Paul Blomfield:** Dr Richards, do you have any views on that issue?

Dr Richards: Yes. I agree with Dr Mullock that there is no inevitable expansion, as we can see from the Oregon model, which is a model across states of the US. It is yet to be seen what will happen in Australia, New Zealand and other places that have legalised more recently and whether they will expand.

It is also a question of how we frame the expansion. The population are perhaps deciding that they may legalise for a certain group or a certain category of person. There may be widespread support for that. Other people with other kinds of illnesses and suffering will also want to have access to that mode of dying. The expansion is because it is publicly demanded. The other reason why you might have changes of criteria is that, from practical experience, people have seen what works and what does not work, and they are tweaking their system. It is not necessarily to be categorised as a negative slippery slope. That is just my addition.

I would like to say something else about the previous question. Is that allowed?

Paul Blomfield: Yes, of course.

Dr Richards: I have had time to think. The issue of bad deaths and suffering at the end of life is extremely important. In the previous session there was a lot of discussion about a case study of anorexia, which is really not what we are talking about here. In this country, 600,000 people die annually. We are talking about the meaning of dying. It is really important that we stay focused.

I think there is a lack of knowledge about what suffering entails at the end of life. We have an absence of knowledge. Palliative care professionals deal with people who are at the end of life in their day-to-day practice. They see and experience that, and they help people with their suffering. We have to ask if they are professionally inclined to look at the extent of suffering if it is going to reflect badly on what they can offer patients, or is outwith what they can offer their patients.

As a researcher, I feel that there is a real lack of evidence about the extent of suffering at the end of life. It leaves a void. For example, one of Dignity in Dying's campaign angles is to say that there is all this unmitigated suffering. Then you get palliative care organisations saying, "It's not true." Honestly, we do not know. I think this is quite important because it is not right to say that people do not need to fear dying. We can say it, but maybe they do. We do not have the evidence. Maybe they do need to fear dying. I wanted to make that point.

Q67 **Paul Blomfield:** Thank you. I have one last, very niche, question for Dr Mullock. From your experience of being involved in the citizens' jury process in Jersey, do you think that is a helpful way of engaging in this debate? Do you think it is a good process for taking things forward?

Dr Mullock: I think it is a very good process and a really good way to have democratic participation. If you are going to have a citizens' jury, or indeed a referendum, you can almost be sure that they will vote to legalise assisted dying. I think the results are very soon to be out in France from their citizens' jury. The early vote suggested that something like 75% were in favour of it. That is what happened in Jersey. In the New Zealand referendum, I think 65% of the population were in favour of physician-assisted suicide for the terminally ill. If you accept that that is almost certainly going to be the result and you are prepared to go forward on that basis, I think it is very useful.

Q68 **Rachael Maskell:** What has come out today is the importance of having information to make informed choices, but there are things that we do not talk about, and we do not gather information about, and therefore those choices are all the more difficult.

We have already heard about the reluctance of talking about death. Another area of taboo—it certainly came out in the Oregon data around dignity—is about continence. Many people have to live with incontinence—probably far more people than we realise—and that should not be an issue that people are fearful of. In gathering evidence it seems that we have a shortfall in evidence that could be helpful in decision making. I am therefore quite interested in digging into some of this.

First of all, Dr Richards, bearing in mind your speciality around older people, as well as others, we heard in the earlier session that one in five or one in six experience elder abuse. What is the evidence about people who have sought to go to Switzerland from the UK, or people who are requesting assisted suicide/assisted death, having been coerced as a result of emotional, financial or other forms of abuse?

Dr Richards: The evidence for people going to Switzerland?

Q69 **Rachael Maskell:** As an example, yes.

Dr Richards: There is none that they have been coerced.

Q70 **Rachael Maskell:** Is evidence actually gathered as to the reasons why, and is that explored?

Dr Richards: There have been interviews with researchers and with relatives and friends who return. There were interviews by the police before the DPP changed the guidance. Relatives or accompaniers were interviewed by the police. I think there has been some scrutiny, but there is no evidence that we know of.

Q71 **Rachael Maskell:** That is my big concern. It is about evidence that we know of and drilling down into whether we are asking the right questions around this to protect the most vulnerable.

Dr Richards: It is quite a tricky process to get to Switzerland. The right to die organisations have their own processes. It is not just a free-for-all. It is a regulated process over there. You have all of the barriers of travelling and the huge bureaucratic barriers of applying from the UK. Then there is going there and the bureaucratic, administrative and procedural barriers at the other end. It would take a seriously committed person to try to coerce a relative.

This is really not a question for me. It would be much more about what happens when it is lawful in your own country.

Q72 **Rachael Maskell:** Clearly, how you frame the legislation could well depend on other experiences, and to know about that process.

Professor Preston: We have done interviews, with people from Dignitas largely, who have gone to Switzerland. Naomi is right that you have to be very determined to do that. I do not think there is any evidence of coercion with them. In Switzerland, for most people it is their own choice. It is a very private decision. It is very quiet. We have had cases—not many, very few—where the family introduced the idea, and another case where the treating physician had prescribed and was happy to prescribe, but felt the patient then lacked competency, so could not have the drugs. The right to die association was going forward, and she stopped the procedure.

As we have said, is it possible for any system to have every safeguard in place? It is going to be very challenging, no matter what. You are always going to get some cases, aren't you?

Q73 **Rachael Maskell:** I want to ask about the quality of death and what evidence there is on the number of deaths where people have had what I am classifying as difficult deaths, where people have either been in pain at the end or had a very uncomfortable death. Do we know what the data is on the numbers that we are talking about there?

Professor Preston: That is not an area of my research, no.

Q74 **Rachael Maskell:** Does anyone hold that information?

Professor Preston: No.

Q75 **Rachael Maskell:** Finally, I want to ask about scrutiny of the data in different jurisdictions. One of the things that concerned many of us in Oregon was some of the data being held by their equivalent of the Department of Health. For instance, they did not scrutinise the process of people dying. They did not put the reason for death on death certificates. One of the statements that stuck in my mind was when a civil servant said that 10 people took more than six hours to die in Oregon.

When looking at the data, how do you verify the veracity of that data to ensure that the right factors are being recorded in order to analyse the real impact of somebody's death experience in those jurisdictions? Is there anything?

Dr Mullock: No.

Rachael Maskell: That shows further evidence of lack of information.

Chair: Interesting in itself.

Q76 **Lucy Allan:** Dr Richards, I have a question about some of the research that you have undertaken in jurisdictions where assisted dying is lawful on the co-existence of palliative care and assisted dying. How do they work together? Does it impact on the quality of palliative care? I think we heard earlier that somehow it was detrimental to palliative care. Can you have assisted dying and palliative care co-existing successfully?

Dr Richards: I am glad you asked me that question. I just want to say, in response to the previous question, that I do not really look at monitoring. However, a lot of jurisdictions have passed legislation, and they all have different monitoring systems. If you do not like the Oregon monitoring system, look to the Australian monitoring system. The law in the state of Victoria in Australia is considered the strictest and most conservative in the world. I am sure they have quite developed monitoring systems. That is something that is potentially remediable.

On the question about the relationship, what we discovered was that across the jurisdictions that have legalised there is very little research conducted. About 16 studies came within our scoping review of the literature. It is varied and contested across different jurisdictions. In Belgium, it is considered integral and synergistic. Assisted dying was proposed by palliative care in that, so they were behind the legislation. Switzerland is the civil model, so palliative care professionals are not really trained in how to deal with requests. Oregon is quite variable. In some institutions it works alongside. Some institutions conscientiously object.

Since our scoping review in 2019, there is really interesting literature coming through from Australia and Canada. Palliative care umbrella organisations in jurisdictions that have legalised will maintain their opposition. There is a fundamental principle neither to hasten nor to postpone death. That is the operating principle.

In many cases it is down to individual professionals to decide whether they want to be involved or not, because it is a legal right. There are all of those grey areas. What palliative care professionals specifically have to face is that it is now unavoidable that they will be asked by their patients, “Will you help me?” They have a legal right to ask, and they have a legal duty to refer if they do not want to be involved themselves. They are in an interactional space now, where they are dealing with these requests.

It is not true to say that all palliative care providers are conscientiously objecting. It is just not the case. It causes deep reflection and negotiation of values, responsibilities and relationships. There is self-examination of what motivates you to be in palliative care in the first place. Some people are embracing it. Some people are continuing to conscientiously object. It is a whole variety. It is a spectrum. It is certainly not a master narrative of incompatibility.

I was at a meeting last week where the palliative care organisation of Canada said that assisted dying is an existential threat to palliative care, but it is not the case. Palliative care continues to operate and thrive in jurisdictions where it has been legalised. If we had done a systematic review of the literature and found a whole load of evidence of panic and deterioration of palliative care, the evidence would be there. I will stop there.

Q77 **Lucy Allan:** That is very helpful; thank you very much. Dr Mullock, would you comment on what Lord Falconer told us this morning about current England law in this area? He said it is a mess. With your legal background, could you comment with your views on whether it is a mess?

Dr Mullock: I agree with Lord Falconer. I think Rachael asked about evidence of coercion in relation to people travelling to Switzerland. There is no evidence. What happens is that the police investigate following the return of the family member or friend who assisted the person who has died. There have been no prosecutions. Of course, that does not mean that there necessarily should not have been, but in so far as there is retrospective investigation after the person who has died is no longer here, it is very difficult to establish what motivated those assisting.

I think Lord Falconer was right. At the moment people feel abandoned and very frightened. They may seek an assisted death abroad. It is also very expensive. As well as the bureaucratic burden and the enormous effort to arrange it, it costs something along the lines of £10,000. Many people could not afford to take that route. They might otherwise choose to take their own life by suicide in the jurisdiction, usually without help and in circumstances that can be very difficult or distressing, and they might fail.

At the moment, although you could argue—as I am sure Baroness Finlay and Baroness Hollins would—that people are prevented, and so are saved by the ban, in reality not everybody is saved. Some people who are vulnerable will go to Switzerland. Others, who are very vulnerable, will die by suicide. Other people will simply have to face the natural death that is coming for them and in circumstances that might be very difficult.

Q78 **Lucy Allan:** From the medical perspective, is there a lack of clarity if you are a medical professional in terms of how you respond to a patient who is requesting assistance?

Dr Mullock: The General Medical Council has produced ethical guidance to help clinicians to find the balance between talking to patients and helping patients, but not encouraging or assisting them towards suicide. There is some guidance, but it is incredibly difficult for healthcare professionals to navigate that. It is also very difficult in the palliative care context, where a person might be asking for a hastened death. There are fears that have come about in recent years—partly as a result of Harold Shipman—with the way that that area of care has been scrutinised, for example, with the Liverpool care pathway. I think clinicians are probably very worried about stepping over the line.

Q79 **Chair:** Finally from me, I started the session today by asking the four peers about their lived experience and their personal reasons. I asked, "Why do you care so much?" Obviously, many of us have experienced the deaths of people close to us. Professor Preston, you have spoken about the least researched and perhaps the most poorly understood area, which is how families experience death when an assisted death or hastened death is involved as opposed to the normal course of life. We have seen what you have sent us in written evidence on this, but in oral evidence what are your reflections on that dynamic?

Professor Preston: I think it is complex. For the families, in some ways it is easier. They can care for the person, and they know when the end date is going to be. Often, waiting for someone to die can be quite difficult because you do not know when it is going to happen. On the other side, there is the secrecy. Normally, when you are going through something like a death in the home, in the family, you would be talking to everybody about it. You would be sharing and getting support.

Often—I am talking particularly about the Swiss data—they do not want other people to have those conversations with them. It is really hard work to have that conversation when you are already in quite a difficult place. They hold it with one or two people. The person who is enabling and helping is actually on their own quite badly in this. After the death, there is secrecy and taboo, so they may not even tell the family what had happened, or they may tell the family and then the rest of the family say, "Why did no one talk to me about this? I feel disenfranchised from it." I think that is why we need to make sure that we have a system where families are involved. Families in the UK from Dignitas would rarely go to a hospice for bereavement support because they would be very concerned about being investigated.

Q80 **Chair:** Finally, Dr Mullock, you may wish to offer some thoughts on this with respect to your involvement in the Jersey citizens' jury. Ultimately, we can talk about the mechanics of it. We can talk about palliative care. We can talk about the drugs involved and the families' responses, but there is a Rubicon to be crossed before we get into all of that. That is effectively the moral argument: do we believe that we should involve ourselves in people's deaths? I wondered what your reflections were on that. From being involved in Jersey, is there any research that you have done around that?

Dr Mullock: As I say, I was quite surprised by the outcome of the citizens' jury in Jersey. They had many hours of very balanced evidence from campaigners, religious groups and doctors. They heard evidence about the law in lawful jurisdictions. I was very surprised that they decided they wanted to take quite a permissive, liberal approach, based on the concerns that they had heard. That is not my position. I feel quite worried about what has happened in some places like Canada and the Netherlands.

In terms of my research, I did a PhD on assisted dying as part of a project on the impact of the criminal law in healthcare ethics and practice many years ago. That started this area being one of my areas of research. I have looked at the human rights arguments and the key cases such as Nicklinson. I have looked at conscientious objection and the way that the law could protect healthcare professionals from being compelled. More recently, I have looked at conceptions of vulnerability to assisted dying.

I think the approach taken in Oregon, New Zealand and Victoria probably provides a compromise with a liberal approach, in which there are dangers to people who are not necessarily going to die soon anyway. That is why I think it ought to be limited to terminally ill people.

Chair: Thank you so much for giving evidence, Dr Richards down the line, and Dr Mullock and Professor Preston in the room. I am sorry we slightly overran, but I really appreciate your candour and your time. Thank you for giving evidence this morning.