

PARLIAMENTARY DEBATES

HOUSE OF COMMONS
OFFICIAL REPORT
GENERAL COMMITTEES

Public Bill Committee

TERMINALLY ILL ADULTS (END OF LIFE) BILL

Seventh Sitting

Thursday 30 January 2025

(Afternoon)

CONTENTS

Examination of witnesses.

Adjourned till Tuesday 11 February at twenty-five minutes past

Nine o'clock.

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

not later than

Monday 3 February 2025

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The Committee consisted of the following Members:

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

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

Witnesses

Dr Amanda Ward, independent academic and legal adviser on assisted dying internationally

Professor Gareth Owen, professor of psychological medicine, ethics and law, honorary consultant psychiatrist, South London and Maudsley NHS Foundation Trust

Professor Laura Hoyano, professor of law and senior research fellow, Wadham College, Oxford University

Professor Nancy Preston, associate dean for research and co-director of the International Observatory on End of Life Care, Lancaster University

Dr Naomi Richards, director of End of Life Studies Group, University of Glasgow

Claire Williams, head of pharmacovigilance and regulatory services, NorthWest EHealth; DipHE adult nursing; MSc pharmacovigilance; and chair, Greater Manchester Central Research Ethics Committee

Liz Reed

Pat Malone

Julie Thienpont

Dan Scorer, head of policy, information and advice, Mencap

Professor Emyr Lewis, emeritus professor, Aberystwyth University

Dr Michael Mulholland, honorary secretary, Royal College of General Practitioners

Dr Annabel Price, member of the faculty of liaison psychiatry at the Royal College of Psychiatrists; past chair and past vice chair, Royal College of Psychiatrists

Public Bill Committee

Thursday 30 January 2025

(Afternoon)

[CAROLYN HARRIS *in the Chair*]

Terminally Ill Adults (End of Life) Bill

Examination of Witnesses

Dr Ward, Professor Owen and Professor Hoyano gave evidence.

1 pm

The Chair: We will now hear oral evidence from three witnesses: Dr Amanda Ward, who holds a master's and a PhD and is the legal adviser to the Scottish Parliament on proposed legislation changes; Professor Gareth Owen, who is a professor of psychological medicine, ethics and law and an honorary consultant psychiatrist at South London and Maudsley NHS foundation trust; and Professor Laura Hoyano, emeritus professor of law at Wadham College, University of Oxford. Before I call the first Member to ask a question, I remind all Members that questions should be limited to matters within the scope of the Bill. May I ask the panel to introduce themselves?

Dr Ward: I am Dr Amanda Ward. You have already introduced me, but I have been involved with law reform in this space for 13 years. I am also a member of the Law Society of Scotland's health and medical law committee. I moved to Queensland 18 months ago and took up a research fellowship at the Queensland University of Technology. I am representing myself in an independent capacity today.

Professor Hoyano: Good morning. I am Laura Hoyano; I am a professor of law at the University of Oxford, where I have taught medical law and ethics for many years, as well as human rights. I was a barrister in Canada for a decade, where I practised medical law and human rights law among other things; I am currently a practising barrister at the Bar of England and Wales.

Professor Owen: Hello. I am Gareth Owen; I am professor of psychological medicine, ethics and law at King's College London and am part of the complex life and death decisions group there. I am a consultant psychiatrist at King's College London, a general medical hospital at which I am a liaison psychiatrist working with adults over the age of 65.

The Chair: We must stick to the timing of the sittings resolution, as decided by the Committee. We have a long list of people who want to ask questions, so it will be one question with one answer; if Members could indicate who they would like to answer, that would be helpful.

Before we proceed, Dr Tidball has a declaration of interest to make.

Dr Marie Tidball (Penistone and Stocksbridge) (Lab): I just want to make sure that it is on the record that I have been taught by Professor Hoyano; indeed, well before I was elected, she was a colleague at work.

The Chair: Thank you.

Q286 Jack Abbott (Ipswich) (Lab/Co-op): Professor Owen, you have talked extensively about the complexity of the Bill. I think it fair to say that our previous witnesses this week believe that the simplest safeguards are the safest. I stress that the simplest does not necessarily mean the weakest; it means a straightforward plan. Do you agree with the points that the chief medical officer and others have made about simplicity? Where do you stand on that, and on the broader point about complexity?

Professor Owen: I am somewhat reminded of the old adage that for every complex problem there is a simple solution that is false. We are dealing with complexity here—I think we have to accept that—but complex law or poor law will not provide good safeguards. If you step back and think about what the Bill is really about, at its simplest, it is about the decisional right to end one's own life in terminal illness.

Associated with that is the concept of mental capacity. I have had over 20 years of research interest in mental capacity. When I look at the issues relating to mental capacity with the Bill, they are complex, but the other important point to understand is that they are very novel. We are in uncharted territory with respect to mental capacity, which is very much at the hub of the Bill.

Q287 Daniel Francis (Bexleyheath and Crayford) (Lab): To elaborate on that point, Professor Owen, the Mental Capacity Act 2005 sets out the principles that a person must be assumed to have capacity, that a person cannot be treated as lacking capacity unless all practicable steps have been taken to support them and that a person cannot be treated as lacking capacity merely because their decision is unwise. Is it those issues that are causing you concern about capacity, or is it something else?

Professor Owen: It is a bit more fundamental than that, actually. If you look at how mental capacity features in the Bill, the test or the concept that clause 1 rightly invites us to consider—rightly, I think—is the capacity to decide to end one's own life. The Mental Capacity Act comes in at clause 3.

I have looked at mental capacity a lot in research, and there is no experience of the decision to end one's own life. It is outside the experience of the Mental Capacity Act, the Court of Protection, the associated research and practitioners on the ground. The reference to the Mental Capacity Act in clause 3 puts you into an area where there is no experience of the central capacity question under consideration. It is very important that Parliament be clear-eyed about that. I can talk about the Mental Capacity Act in detail if you like, but that is the main point that I want to make.

Daniel Francis: The Chair may cut you off, but I am happy for you to continue if she allows it.

The Chair: It is one question, one answer. I call Danny Kruger.

Q288 Danny Kruger (East Wiltshire) (Con): Professor Hoyano, what do you think about the indemnity against civil liability in the Bill? Do you think it is appropriate to indemnify all doctors, even if they have made a

woefully bad diagnosis, botched a prescription or, in some cases, actually caused some harm? Do you think it is appropriate that they be excluded from civil liability?

Professor Hoyano: I always have a problem when tort liability is ruled out by legislation. I think that the accountability of medical professionals, and indeed all medical practitioners in private practice, lies at the heart of how our national health service works, so I have a difficulty with that. I would have to ask Ms Leadbeater whether this is correct, but perhaps the intention was to ensure that members of the family who, for example, were against assisted dying in principle, would not be able to bring an action that could be vexatious against a doctor who had complied with the legislation and should therefore not be troubled with that type of litigation. It might be that that provision could be refined.

Q289 Lewis Atkinson (Sunderland Central) (Lab): Professor Hoyano, the Bill would establish offences relating to coercion, pressure and so on. In the processes set out, there are a number of checkpoints, for want of a better term, at which a person seeking assisted dying may talk to doctors or others. What are your observations on how the criminal construct of offences is linked to the different opportunities for an individual seeking assisted dying to have conversations? In your view, is it likely to lead to the identification of those offences? How does that contrast with some of the considerations at the moment, where people are withdrawing treatment in a life or death situation, for example?

Professor Hoyano: It is interesting that a number of Members of Parliament who are practising physicians pointed out in the debate that they have to evaluate freedom of decision making and absence of coercion in many different medical contexts. I point particularly to the withdrawal of medical treatment at the request of the patient, even if that will inevitably lead to death. It is considered to be a fundamental human right that lies at the heart of medical law that a patient has personal autonomy to decide what to do with their body and whether or not to accept medical treatment, provided that they have the capacity to do so and are acting without coercion from external sources. Doctors have to make those assessments all the time.

I suggest that it is perhaps a convenient fallacy to say that pulling the plug on a respirator or stopping artificial nutrition and hydration is a negative act, whereas giving a patient a syringe to end their own life is a positive act. I realise that with the Tony Bland case it was convenient to say that, but there is no doubt that most people on the street would say that pulling the plug on a respirator is a positive act, and yet doctors and nurses are required to do that every day in the NHS, because that is the patient's autonomy. If there is any question about either coercion or capacity, the Court of Protection steps in and has the jurisdiction to make those decisions.

The Court of Protection should, I believe, be the court that is supervising this, not the High Court. Three levels of judges sit in the Court of Protection; I suggest that a High Court judge be specified, which would mean a statutory amendment to extend the jurisdiction of the Court of Protection. The Court of Protection makes decisions every day on whether a patient has the mental capacity to make decisions about their own medical treatment. It is accustomed to doing that, and one aspect of that analysis is whether the patient is being coerced externally.

Generally speaking, when a patient says, "I don't want to be on a respirator any longer; I know I'm going to die," we do not ask questions. As I understand it, it is not part of the protocol to say, "Are you doing this because you are worried about being a burden on the NHS?", because their personal autonomy is the overriding principle governing medical decision making in relation to the patient. I hope that that answers your question.

Q290 Sojan Joseph (Ashford) (Lab): Professor Owen, written evidence from the Royal College of Psychiatrists states that 65% of psychiatrists

"are not confident that consent can act as an adequate safeguard". On mental capacity, it says:

"These decisions are opinions with a margin of error and are time specific. A person's capacity can change".

What is your view?

Professor Owen: That is important evidence, because it comes from a body of practitioners who are very used to doing mental capacity assessments. I think that the vast majority of that sample were consultant psychiatrists, so the pool, as it were, was one of considerable experience. That conveys questionable confidence in the consent processes, of which mental capacity is part, in relation to the decision to end one's life. It is significant evidence about the confidence that is out there among experienced practitioners.

It is true that psychiatrists—liaison psychiatrists particularly; I have had experience with this myself, clinically and in relation to Court of Protection matters—will be involved with assessing capacity to make decisions to refuse life-sustaining treatment. Those decisions can be quite vexed and can go to the court, and the court can struggle with them.

An important question for the Committee is the distinction—or the similarity and difference, but I think that there are key differences—between the decision to refuse a treatment that is life-sustaining, of which the Court of Protection does have experience, and the decision to decide to end one's own life. They are conceptually different decisions. I can outline some of the similarities and the differences now, but it might be helpful to take submissions specifically on that question, because it is very important and I think that there is some confusion about it. If you would find it helpful, the complex life and death decisions group could write a statement to elaborate on some of the issues. In summary, I think that that evidence from the Royal College of Psychiatrists is significant, in terms of the confidence.

Q291 Sarah Green (Chesham and Amersham) (LD): Dr Ward, I am keen to hear about your work on the Bill in the Scottish Parliament and about how best practice in other jurisdictions has informed the legislation that is currently going through Holyrood. How has it influenced and informed that draft?

Dr Ward: I was the adviser on the previous Bill in Scotland as well, under Margo MacDonald MSP and Patrick Harvie MSP. That was in session 4 of our Parliament; we then did not have a Bill in session 5, which is when we set up things like the cross-party working group on end-of-life choices and I did the PhD. Luckily, we saw a domino effect internationally in session 5;

there were various jurisdictions legislating for it. When we came to draft this legislation in 2021, in session 6 of the Parliament, we had decades of data that we had not had when Margo made her first attempt back in 2010.

With the Assisted Dying for Terminally Ill Adults (Scotland) Bill, we have been working with international experts since 2021, and we have had various consultation processes. It is currently with the Health Committee of the Scottish Parliament. We set up a medical advisory group, chaired by Dr Sandesh Gulhane MSP: a group of almost a dozen practitioners in palliative care, mental health experts, geriatricians and other interested stakeholders. It produced a report for us on the medicinal aspects of the Bill.

That has been a four-year process. I understand that concerns have been voiced in this Committee that things have proceeded at pace, but I would argue that you are not pioneers. There is 20 or 30 years' worth of data, which we have drawn on in Scotland, and there is four years' worth of work in Scotland that this Committee and this Parliament could look to.

I would also make the point that the data is peer-reviewed and evidence-based. You really have to trust your international colleagues. The data is from Government bodies, from Health Departments, from independent academic peer-reviewed work and from independent review boards. We are now looking at fact rather than at falsehoods or concerns, as we were back in 2010.

Q292 Dr Neil Shastri-Hurst (Solihull West and Shirley) (Con): Clause 9(3)(b) would permit an assessing clinician to refer to a psychiatrist if they have concerns about the assessment of capacity. Some have suggested that in fact all patients who are seeking a voluntary assisted death should be assessed by a psychiatrist. Professor Owen, in terms of workforce capability and capacity, is it reasonably practicable to have a consultant psychiatrist assessing each and every one of these patients?

Professor Owen: I think the answer to that is “Probably not,” given the current workforce. Another relevant point is that even if you were to insert into the Bill a very clear requirement for a consultant psychiatrist to be involved if there were concerns about mental health, what would happen in practice would be very different. You can see this in Oregon, whose law has a requirement for, essentially, a psychiatric referral in the case of mental health concern. Those referrals basically occur in less than 5% of cases; I think it is similar in California. Even if you put it in law, there is the question whether it will happen in practice. On the data, it does not. I think that that is a relevant consideration.

Q293 Kit Malthouse (North West Hampshire) (Con): Professor Hoyano, I am interested to explore your views on the third layer. I understand your view about the Court of Protection, but we have heard in previous evidence, not least from eminent members of your profession, that the Spanish model of a panel of experts might be an option worth examining. In those circumstances, what is your view of the investigatory processes, either for that or for the Court of Protection, or the type of evidence that might need to be adduced? What could be specified in the legislation as a requirement on those people involved in the process?

Professor Hoyano: I have to say that I have real concerns, as a practising barrister, about how the provisions as currently drafted could work in terms of judicial oversight. There are a number of unusual functions, if I can express it that way, being attributed to the court. I need first of all to stress that the High Court's family division, and the Court of Protection, regularly engage with life and death matters, but they are doing so in the context of an adversarial and not an inquisitorial system. However, since the 19th century we have had the invaluable institution of the Official Solicitor, who has investigatory powers or functions and who serves in court as an *amicus curiae*—a friend of the court—to assist the court in understanding where the issues lie and in calling witnesses. I do not think that it is feasible at all, in our current system, to have the court call witnesses or question them directly until they have been examined and cross-examined, if appropriate; the court can then put in questions and ask for clarification, as would happen normally now.

If we are to have a judicial oversight function as opposed to a panel of experts—to be honest, I think we already have the panel of experts: the doctors who are already involved in the different stages leading up to the final stage—the easiest approach would be for the investigatory function to be assigned to the office of the Official Solicitor, preferably with an individual who has expertise in this field and will be able to get experience by dealing with these cases. I point out that Lord Justice Munby himself—Sir James Munby, as he now is—represented the Official Solicitor in the seminal case on termination of life support, the Tony Bland case. We have a lot of experience in that area, in dealing with end-of-life decision making with the Official Solicitor, but I think that that role needs to be built into the legislation with very specific tasks set out, including an investigatory function.

The other current difficulty is that it is not clear at all what the procedure would be. With great respect to the drafters of the Bill, I have never before seen such a delegation of the most essential procedural structures entirely to rules of court in terms of practice directions or rules of practice; we do not do it in the family division and we do not do it in the Court of Protection. Exactly what has to happen needs to be set out.

It strikes me that the intention may be for the court to, in effect, certify that all the procedures have been correctly followed at the preliminary stages. What is not entirely clear is whether the court itself is required to investigate whether the criteria are satisfied. It reads like that, but I am not sure whether it is supposed to be a review function or a primary decision-making function.

This becomes even more difficult because of the way in which the Court of Appeal's functions are ascribed. The Court of Appeal does not have power to summon witnesses; the Court of Appeal does not have power to question witnesses. In the criminal division, which is where I am primarily practising now, the court can hear expert evidence *de bene esse* in order to determine whether it should send a case back for a retrial on the basis of newly discovered evidence that was not originally available, but that evidence will be called by the defence. The defence will be putting the evidence in, the Crown will cross-examine and the court will ask any additional questions it wants to, but to have an original jurisdiction—in effect, what we call a trial *de novo*: a trial all over

again—in the Court of Appeal is wholly inappropriate to an appellate jurisdiction. That needs to be completely rethought.

There is also a difficulty in that the right to appeal is very lopsided: only a patient can appeal a denial, not anyone else. If anyone has concerns about the probity and thoroughness of the preliminary stages, or thinks that the High Court judge sitting in the Court of Protection has made an error of law or has failed to follow the procedures, that needs to be reviewed by the Court of Appeal. We need an even-handed approach.

I can understand the motivation of not wanting busybody people, as happened in one case in Canada in which a wife had a religious objection to assisted dying, and yet there was no doubt that the husband had satisfied all the criteria. She went all the way to the Nova Scotia Court of Appeal because of her religious objections; it turned out that religion was a source of great dissension in the marriage anyway, but her church was egging her on. I know that you do not want that kind of situation, but I believe that this legislation has to be completely even-handed for it to work and for the system to acquire public respect.

Q294 Dr Simon Opher (Stroud) (Lab): My question is directed to Amanda and Laura. There is a lot of natural concern about coercion with the Bill. We recognise that it is a difficult thing to assess. Would either of you change the wording of the Bill to make coercion less likely?

Dr Ward: Which clause are we looking at?

Dr Opher: Now you're asking. Let me check.

Dr Ward: In the interests of time, let me say that I moved to Queensland a year and a half ago, as I mentioned at the beginning, and took up an academic fellowship at the Australian Centre for Health Law Research. That university was tasked by the Government states of Victoria, Western Australia and Queensland with developing the training for assisted dying implementation there. The modules in that training very specifically go through coercion, how you detect coercion, how you discuss it with patients and cultural considerations around it. They cover everything from capacity to the administration of drugs. They are very robust training modules that healthcare practitioners must satisfy at a pass rate of 90%. We rely heavily on the training to make sure that coercion protection is in place.

Dr Opher: It was clause 26, sorry.

Professor Hoyano: Under the Canadian system, the provinces each have a college of physicians and surgeons. However, what has happened is that everyone has worked collaboratively across all 12 jurisdictions, plus the federal Government. We now have the Canadian MAiD—medical assistance in dying—curriculum, which was developed by the Canadian Association of MAiD Assessors and Providers in consultation with experts from across the country. It is providing a comprehensive, bilingual, nationally accredited training programme that is evidence-based and is based on the learning that has happened in Canada since the legislation was first enacted.

There is also a model practice standard for MAiD and a companion document, “Advice to the Profession”, which all the medical colleges have signed up to. It helps practitioners to align their practice with the official

guidance and assists health professional regulatory authorities to ensure that the public is protected. Coercion lies at the heart of these documents.

The regulations for the monitoring of medical assistance in dying require—and this is something else that I suggest be changed—that in Canada there has to be an annual report from the federal Government, which is very granular in detail, from right across the country. It happens at least once a year; there was one year in which we had two reports going into all the details. On coercion, we know that in 2023, when they examined the reasons for ineligibility, there were 41 cases across the country in which the physicians determined that the person had not made a voluntary request without external pressure, and it was therefore declined. We need to know what is happening out there, and I do not think that a report every five years is going to help. We need to enlist all the medical professions involved in signing up to very detailed codes of practice, but we also need the training that Amanda has referred to as essential.

The last point that I would make is that McGill University is launching a national palliative care hub that is available to any practitioner in the country and from which they can receive guidance and support with helping and advising patients who are receiving palliative care. One of the options is, if the patient desires it, how to deal with these requests.

Dr Ward: Now that I have had a look at clause 26, may I answer the Member's question? I think it is a very well drafted provision, and it is very similar to what we have in Scotland. In particular, I know we are concerned about people being coerced into assisted dying, but internationally it is actually the converse. Some jurisdictions are considering putting provisions in their Bill because family members are trying to put undue pressure on others not to make an assisted dying decision.

On my understanding of the reporting in Kim's Bill, it is just not a five-year review: the Registrar General, the chief medical officer and the Secretary of State are involved. Again, I commend the Member in charge for the reporting procedures being very robust in the Bill.

Q295 Kim Leadbeater (Spennings Valley) (Lab): For clarity, Dr Ward, you are right that clause 34 requests that the chief medical officer submits an annual report. You clearly have many years of experience in this subject. For you, what does best practice look like when it comes to assisted dying, end of life choice and end of life care? That is what we are all aiming for in our deliberations. How do we keep it patient-centred?

I notice that you have also spoken a lot about misinformation; how do we tackle that? How do we make sure we are dealing with facts rather than speculation? In particular, how do we provide reassurance to marginalised communities and people with disabilities, who are understandably nervous about this change in the law? When it comes to safeguards and protections, what does best practice look like?

Dr Ward: To take your last point first, we must involve them in the process and have an open dialogue with them. That means not just in the consultation process, when you are considering passing legislation, but when you have your implementation taskforce, on which you must make sure you have representation from across all the stakeholders involved, including people with disabilities and people with terminal illnesses.

I would point to the fact that best practice is about balancing the autonomy, dignity and compassion that the Bill aims to achieve by giving people the option of assisted dying, while also protecting vulnerable people who feel that there are worries and concerns. However, having worked in this area for 13 years and seen people who would really benefit from having this option, and living now in a jurisdiction that has it, I would point out that some of the most vulnerable people I have seen are the terminally ill who want and need this choice. It is about taking a holistic and evidenced-based approach.

You as a Committee will hear from the great and the good across the board, and I am pleased that the Committee is taking account of lived experience, because that is very important to inform the decision-making process. It is about making sure that we are going to the source of evidence and using peer-reviewed data and Government data. Again, as I said earlier, you really need to trust your international colleagues who have gone before you on this. We need to consider what the Bill does versus inaccurate perceptions of or speculations on what it might do. The task here is to consider what is in front of you, not what might happen down the road.

Q296 Tom Gordon (Harrogate and Knaresborough) (LD): Dr Ward, I think the point about a holistic and evidence-based approach is critical. In the work that you did in the Scottish example you gave, how was the terminal illness definition arrived at? How are you capturing those people who are vulnerable and want to have an assisted death, but might end up limited in their scope and ability to access it?

Dr Ward: Look: assisted dying is the same as any other healthcare choice. It is always going to be limited. We are not going to reach everyone that we absolutely would want to. There are people who want to have this option and this choice who will not qualify under a terminal illness definition, but we have to draw the line somewhere. We looked at international evidence from Commonwealth countries that are very closely linked to Scotland and the UK. We drew the line with the definition that the person has an advanced progressive illness from which they are unable to recover and that will cause their premature death. For us, that demands the support of Members of Parliament in Scotland and the support of the public.

I really stress the fact that each jurisdiction has to legislate according to its own constitutional, societal, legal and cultural considerations, which is what we have done in Scotland. That is the definition that is working for us now. Previously, there were more liberal attempts that did not gain the support of the House. We believe that we have arrived at a situation that is very similar to the definition of terminal illness here in Westminster, and that is both safe and compassionate but also draws the line so that people who should not be able to access this do not.

Q297 Naz Shah (Bradford West) (Lab): Professor Owen, yesterday Professor Allan House gave evidence and talked about capacity and coercion, and I want to pick up on some of the concerns. In all four of the jurisdictions that collect data on the issue—Oregon, Canada, Western Australia and Washington—between 35% and 59% of people cite being a burden as a reason

for assisted dying. What do you think is the level of confidence of psychiatrists to assess capacity and consent reliably? What would your concerns be, if any?

Professor Owen: This is an essential question. I work clinically in the over-65 age group, where there is a lot of terminal illness, some of it in the last six months. You have to understand the population. The population is typically over 65 and frail. There can be a terminal illness, very typically with comorbidity. That comorbidity is often mental health comorbidity. Depression is at rates of 20% or thereabouts. Delirium and cognitive impairment is very common and often not picked up. There is patchy safeguarding, patchy access to social care and, as I know you have been hearing, patchy access to palliative care.

That is the ordinary person in the NHS. I know people who select into assisted dying are not necessarily that mean person, so to speak, but that is just a picture of what it looks like for me when I go to work. That is where one starts. Now think about burden. Well, this is a group that do feel very burdened. You might think some of that is excessive; some of it maybe is natural, given the life stage. So it is a mixed picture.

When it comes to pressure and coercion, I know you have been grappling with this a lot as a Committee, and I know there have been some amendments that address this. We have talked about clause 26 particularly in relation to this. Of course, when it comes back to the training question, you can take evidence on the state of safeguarding and how people are really able to assess coercive control, domestic violence and so on.

I would like to draw attention to something else that I am not sure has come so much to the attention of the Committee, which is not the offences or the criminal side of this; it is the common or garden capacity assessment side of it. This relates really to clause 1. It is the issue of how you deal with interpersonal pressures on somebody in a situation where there may be a mental health problem and there may not even be a diagnosis. You might be talking about a kind of cognitive impairment that has not reached the threshold for a diagnosis of dementia; you might be talking about a kind of mood problem or an anxiety problem that is sub-clinical; or you might be talking about a level of intelligence that is not clinically a learning disability. But it is there and it is interacting with a form of pressure within a family, let us say, which is often not malign in its intentions, but it exists. It is a very overvalued relationship, for example, with a strong sense of loyalty to somebody, or an enmeshment, for example.

What you have are situations where there is an impairment and also an interpersonal pressure. They interact and they amplify each other. That can have an important consequence in terms of the functional ability of mental capacity. Outside of the assisted dying context, when you look at that in the Court of Protection, which has been struggling with quite a lot of cases like this, that phenomenon of interaction that I am talking about between interpersonal pressure and impairment is recognised. It struggles with it. I have been involved in some research to try to structure the understanding of it, but it is not at the point where it is a kind of training manual that you can lift down from the shelf and roll out across the workforce. It is much more in a kind of research and development phase.

So it is important to draw attention to pressure not necessarily as malign in its intention, but which nevertheless operates in these situations and can have a subtle impact on the functional test of decision-making capacity. To bring us back to what the decision-making capacity is that we are talking about, it is the decision to end one's own life.

Q298 Bambos Charalambous (Southgate and Wood Green) (Lab): Dr Ward and Professor Hoyano, we heard yesterday evidence about the interplay between assisted dying, the Equality Act 2010 and the European convention on human rights. Should amendments be made to the Bill to deal with those issues? What are your thoughts about the interaction between those pieces of legislation and the Bill?

Dr Ward: I heard the session yesterday and would agree with the comments that were made there, particularly around proportionality. Article 2 is an absolute right—the right to life—whereas article 8 is a qualified right. Again, it is about that balancing act. The courts have been very clear that we need to protect vulnerable people, and I feel strongly that the Bill straddles that very well by giving choice but in a very limited set of circumstances.

On the Equality Act, there have been some claims made—this happened in Scotland—that the definition of disability in the Equality Act would cover people who are terminally ill. That that is not my reading of it, and that position is widely shared by the people advising us in Scotland on the legal capacity. That is all I have to say.

Professor Hoyano: I would only point out to the Committee that the common law entrenched the human rights of the patient a long time before the Human Rights Act 1998. We must remember that we do not just have to look at the European convention and Strasbourg. The common law has been very active in entrenching fundamental principles of the rights of the patient, particularly their autonomy in decision making regarding their own body, since long before the HRA.

The Chair: Time allows us to ask more questions. Three people have indicated that they wish to come in. I will start with Danny Kruger.

Q299 Danny Kruger: It is great to hear about the case for common law over the Human Rights Act. Yesterday we heard about parliamentary sovereignty. This is a tremendous process we are having here.

Professor Hoyano said that the person in the street would not see the difference between a patient requesting to die by the withdrawal of treatment versus the active administration of fatal drugs, whereas I think you said, Professor Owen, that you did see a profound difference between that decision on the part of the patient and also, presumably, the act on the part of the medical professional, in the case of either the withdrawal of treatment or the administration of fatal medication. You said that you would be happy to draw that out; could you do so?

Professor Owen: Yes. I am happy to try now, but also to do it further with some written submissions if that would be helpful, because it is such an important point. First, for the man on the street, or the person on the

bus, one thing to remember—this comes out in the public opinion polling—is that when you ask about assisted dying, some people think that that is access to palliative care. There is a degree of misconceptions that are out there in the public that are important to bear in mind.

On the distinction between the decision around the refusal of life-sustaining treatment and the decision regarding assisted dying, what are the similarities? Well, they are both about life and death. What are the differences? One is a refusal; one is a request. One is traditionally considered to be about bodily integrity—it is the so-called shield of the person, or the patient, against the intervention on the body that is being made by the medical profession. You are giving the patient an important right, which is a shield-like right. That contrasts with a request for assisted dying, which is a request. You are involving other people in an act that is an act of ending one's life. That is not something that the medical profession has been comfortable with, going back thousands of years.

So you can discern a number of differences. Could you reduce those differences to one thing and one thing only, and be particularly precise about it? Probably not. I think you are talking about differences that cluster and group, and which we overall accept as a difference of kind.

The other issue here that is important is intention. When you are assessing somebody's decision to refuse a life-sustaining treatment, the doctor there does not have the intention to end a person's life. That would be a concerning intention were it there—and sometimes it is looked for, actually, if it is disputed. But of course, when a doctor is involved with a process where somebody is seeking assistance in the ending of their life, it is quite difficult to say that the doctor does not have an intention to end life.

One could go on with a discussion of the differences, but the similarity is that we are talking about life and death.

Q300 Kim Leadbeater: This has been an incredibly helpful panel, so thank you for all your expertise.

Let me come back to the content of the Bill, and to some of your points, Professor Owen. In terms of capacity and coercion, I think we are absolutely having these really important conversations. What concerns me a little bit, though, is whether we are saying we are not confident that two doctors, potentially a psychiatrist and an oncologist, and a judge can make assessments of capacity and coercion between them. What does that mean for things that are happening at the moment? We have talked about the withdrawal of end of life treatment and those things; those assessments must be being done now, all the time, but at the moment there is no legal framework around that. Surely, putting a legal framework around that and having all those multidisciplinary people involved has got to be a positive thing. Professor Hoyano, I would appreciate your thoughts on that.

Professor Hoyano: As I say, whereas I completely respect Professor Owen's expertise in this as a psychiatrist, for me as a lawyer the question of capacity is a yes or no, necessarily. But capacity is always determined by the Court of Protection in respect of the decision that must be made by the person concerned: do they have the capacity to do it?

When we are talking about a determination of capacity, and also about coercion—which of course is part of capacity in a sense, because capacity is the autonomy of decision making—you are going to be having a very focused inquiry. It is not an inquiry into whether a person has capacity to manage their financial affairs. I probably do not have that capacity, but on something like this I would have capacity. It is important to recognise that it is a yes or no question, which the law has to draw and does draw, depending on the expertise of psychiatrists like Professor Owen, but also forming its own judgment from its own experience, which is why I think the Court of Protection really is the place where this should be.

There is one aspect of the Bill that worries me a lot, and that is the number of people who will be excluded by the provision that the medication must be self-administered. This would mean that Tony Nicklinson, who went all the way to the House of Lords to try to get the right to die, could not have it under this Bill, because he was paralysed. He was a tetraplegic, basically—he was paralysed from the neck down, with limited movement of his head, from a stroke. He lived for seven years with that condition and he would not have been able to self-administer. In fact, when he was denied by the House of Lords—anyone who has seen the Channel 4 programme will have watched him wail in despair—he refused all nutrition and hydration from that point until he died. That was the death he did not want, and I think we need to recognise that there are problems like that. In 2023 in Canada, across the entire country, only five patients opted to self-administer the medication—only five. Even when patients were capable of doing it, they wanted the doctor to do it instead, so let us remember that as well, please.

Dr Ward: Can I make a quick point about self-administration? This is something that in Scotland we looked into in great detail. In Scotland, we chose self-administration specifically because it does not just include ingestion or swallowing. There is a range of ways in which you can self-administer the medication, and I am happy to provide that information to the Committee if that would be helpful.

Q301 Lewis Atkinson: Professor Owen, can I probe a little more something that you raised before—the interaction of potential impairment, potential family dynamics and so on in a way that is not malign, but that you think is a consideration? We have heard some evidence in the course of this week about whether there would be any benefit from a more multidisciplinary approach that could make a more rounded, psychosocial assessment of someone's situation. That would be less about the clear test of whether there is capacity under the Mental Capacity Act and more about the wider considerations of those interactions. I just wonder whether the inclusion of, say, social workers or mental health professionals as part of a multidisciplinary approach would give you any reassurance on those points that you made.

Professor Owen: Good question. On the point about that interaction issue, it is not just me picking it up; it is the courts and the Court of Protection particularly. If you are interested, it is footnote (11) in the written submission from the Complex Life and Death Decisions group. The point that you make is well taken from my point of view. You have two doctors, essentially, doing the assessment. Some doctors can be very good at assessing social circumstances; some are not so good.

I think it would be preferable to try to get a law that gets sight of social circumstances; one way of doing that may be to insert a requirement that a suitably experienced social worker is involved, so that there is some sensitivity to those contextual, relational, interpersonal effects, which, as I know you are aware, can be very subtle. A lot of these things are extremely difficult to pick up. They are easy to miss and, even when you are aware of them, there can be dilemmas about what to do with them.

Professor Hoyano: Might I add a postscript to that? A model that we could consider in this context is CAF/CASS—the Children and Family Court Advisory and Support Service—in the family courts. It is a body of experts—civil servants, in effect—but they are independent and they are accustomed to dealing with specific context with social workers, for example. They investigate what should happen to a child in public law or private law proceedings. It occurs to me that something like that—a report from an equivalent body to the solicitor's office, which I mentioned before—could be a very good way of building that in, because I completely agree that social workers are likely to be more professionally attuned, by virtue of their training and experience, to looking at the wider context.

The Chair: We have two more minutes for questions and answers.

Q302 Dr Opher: Another hon. Member has asked my question, but I have another. We heard yesterday about domestic violence and elder abuse. Does the legislation need to be tightened around that type of area—the coercion of older people into taking their lives early, potentially for financial benefit?

Dr Ward: That picks up on the previous question, which my learned colleagues answered. Good legislation sets a baseline and a legal framework. You can take a kitchen sink approach to legislation, and you will end up with something that is completely unworkable in practice. There is an awful lot that guidance needs to pick up and should pick up. I understand that only certain things are appropriate for secondary legislation, but you should not try to legislate for every eventuality in a Bill.

On my reading of the Bill, there is nothing that prevents a multidisciplinary team from being involved with this. The Bill sets the baseline: there must be a minimum of two doctors. What happens in practice—and this should be picked up in guidance and secondary legislation—should be developed in conjunction with professional bodies: clinicians, allied health and social work. They are the appropriate people to develop that guidance, not legislators. I would say, “Be cautious about how much you put on the face of the Bill, because you might end up with something that is unworkable.”

The Chair: I call Naz Shah to ask the final question.

Q303 Naz Shah: Professor Owen, to follow up on the interaction that Mr Atkinson talked about, where are the gaps in research right now?

Professor Owen: There are a lot of gaps. Take that point as I intend it—I do not say it as a downer on this project; I say it because it is true. There are just a lot of gaps. We are going into uncharted territory, so you might think it would be good to have more of a map before we

start. This is one area where there are evidentiary gaps. It is not clear how those sorts of interactions should be assessed, what sorts of threshold should be set or what kind of training should be available. There has been a lot of talk about training; training is all very well and good, but you need to know what the point and purpose of the training is. The training has to be valid before you can roll it out. There are lots of gaps here.

That relates to the question of mental capacity assessment. It is often said, “Why are we worried about mental capacity? We have so much experience of doing it in health and social care contexts; we have the Mental Capacity Act, the Court of Protection and all this experience.” We do, and that extremely important work has been done since the parliamentary discussions you had about the Mental Capacity Act all those years ago. In some areas, it is being done reasonably well: in relation to treatment and care residents’ decisions, one can talk about a body of professionals who understand the concepts, can do the assessments and can achieve, at least when trained, good levels of agreement, so you can get the system to work.

But in areas of decision making where the decision itself is unsettled or conceptually much more profound or novel—I would suggest that the decision to end one’s own life has those characteristics—you cannot expect there to be such levels of reliability. That can be shown empirically in other areas where the decision making is unsettled. The question of how well capacity assessment works is actually matter-specific. That should not surprise us, because the whole concept of mental capacity is that it is matter-specific. That is the whole functional idea of mental capacity. The matter here is of the decision making to end one’s own life.

The Chair: That brings us to the end of the allocated time for the Committee to ask questions. I thank the witnesses on behalf of the Committee for their evidence.

Examination of Witnesses

Professor Preston, Dr Richards and Claire Williams gave evidence.

2 pm

Q304 The Chair: We will now hear oral evidence from Professor Nancy Preston, professor of supportive and palliative care at Lancaster University; Dr Naomi Richards, director of the end-of-life studies group at the University of Glasgow; and Claire Williams, head of the pharmacovigilance and regulatory services for NorthWest EHealth, who is joining us via Zoom. We have until 3 pm. Could the witnesses introduce themselves for the record?

Professor Preston: Hello. I am Nancy Preston, professor of supportive and palliative care and co-director of the international observatory on end-of-life care at Lancaster University. I am the co-lead for the European Association for Palliative Care taskforce, where we try to prepare guidelines for clinicians in countries where there is permissive legislation on assisted dying to help people whether they are involved or not involved.

Dr Richards: Hello. I am Dr Naomi Richards. I am a senior lecturer at the University of Glasgow, and director of the end-of-life studies group there, which is a research and teaching group.

Claire Williams: Hello. I am Claire Williams and I am chair of the Greater Manchester research ethics committee. My background is one of nursing, but my focus for many years has been on ethical decision making in clinical research. That work inspired the proposal that I submitted. As you are aware, the proposal outlines a committee-based model for decision making in assisted dying cases, offering an alternative framework to that which places sole responsibility on a High Court judge. I believe that approach is far too narrow for such a complex and sensitive matter, and it is simply too much to expect one person to carry that burden alone. The proposal really shifts responsibility from that one individual judge to a panel of professionals, ensuring that decisions are made collectively with robust safeguards in place.

The Chair: I ask colleagues to ask one question, indicating who you wish to answer. If there is time at the end, I will open the floor for further questions.

Q305 Sean Woodcock (Banbury) (Lab): My question is for Claire Williams, about the drugs that are used in the various jurisdictions and how that interplays with your view on whether this law comes into place. What are your views on the drugs that would be put forward for assisted dying?

Claire Williams: I am not familiar per se with the types of drugs that will be used for assisted dying cases. In terms of my experience in research ethics, we make life and death decisions on a daily basis and decide whether we would offer patients the opportunity to take very experimental drugs. That is particularly difficult when dealing with terminally ill patients. What is so beneficial with using a committee-based model is that those decisions can be made collectively—decisions that are very similar and have real parallels in terms of ensuring that patients have fully consented, that they have capacity and that there is no coercion involved in recruiting them to clinical trial. That is how I see those parallels and how I feel assisted dying cases should be considered.

Q306 Jack Abbott: Professor Preston, you have extensive research into palliative and end-of-life care. It would be really helpful for the Committee if you could describe some of the underlying motivations about why people come to the decisions they do when choosing end-of-life care, and how you feel assisted dying would sit as an available option for those making those decisions, if it was available.

Professor Preston: The decision to go into palliative care is often made more by a clinical team, recommending that there be changes in the goals of care and what we are to aiming do. There are two big European studies looking at that at the moment, in chronic obstructive pulmonary disease and cancer. It is about trying to get triggers so that those changes in care can happen, because people cannot make decisions unless they are informed and they are aware.

Equally, when it comes to assisted dying, we have done interviews with bereaved families and healthcare workers in the United States, the Netherlands and Switzerland, and also with British families who access assisted dying through Dignitas. We hear from the family members that it is something they have really thought about for a long time. It might come to a crunch point where they know they are potentially

going to lose capacity, they are potentially going to lose the abilities that are important to them—although for someone else, losing them may not be an issue.

That is when people start to seek help. They usually first seek help from one or two family members. There is often secrecy around that, because you do not want everyone talking about it. It is quite exhausting to talk about. It is a decision you have made. Then they seek help from healthcare professionals, and that is where they get a varied response depending on who they access. It is a bit of a lottery, because it only a minority of doctors will be willing to do this. That is where the challenge comes in.

Q307 Dr Shastri-Hurst: Professor Preston, in your written submission, you effectively propose reversing the presumption of capacity that is set out in the Mental Capacity Act. Could you go into a little more detail about that and the reasons behind that proposal?

Professor Preston: The submission was with my colleague, Professor Suzanne Ost, who is a professor of law, and that very much came from Suzanne.

I think the aim is to have that bit of extra concern, so that we do not presume capacity, but instead almost presume that there is not capacity. It would be a bit like if you go to A&E with a child and they have a fracture. The presumption there is to ask, “How did this happen?” and “Do we need to rule anything out?”, rather than just assuming “Well, they have just fallen over” and that things are exactly as said. There is an element of that, where we are not presuming capacity, but are actually going into it and switching it around within the training to ask, “Do they have capacity?”. I think that would be a change within the Mental Capacity Act.

Q308 Lewis Atkinson: Dr Richards, in the light of your research, could you say a little bit more about the weight that individuals dying place on the importance of autonomy and how that is weighed up against other considerations around safeguarding and so on?

Dr Richards: There are two things that I would like to say about this. The first is that it is individually specific, which probably will not come as a shock to you. The evidence shows that the people who request assisted dying are people who have a particular preference for control in their life, and they have had this preference across their life, so it is part of their identity. In that sense, it is a personal preference as opposed to a deficit in palliative care, which is what we hear a lot about.

The second thing is that, with regards to autonomy, proponents of assisted dying are very keen to emphasise that this is an autonomous decision, which it is, and would have to be by virtue of the law. However, that does not mean that families, loved ones and close social relations are not really embedded in that decision making. It is important to think of autonomy as relational rather than as an isolated making a decision not in relation to others. It is also important to think about the impacts on the family when you are thinking about the guidelines that would go along with any legislation.

Q309 Danny Kruger: This is a question for Claire Williams. It was interesting that you said you were not aware of what drugs might be used in assisted dying. We obviously do not yet know what will be proposed here if

we pass this law. There are lots of different combinations of drugs used in other jurisdictions, and we do not know much about them. I think that is fair to say.

What we do know is that there is a combination. In two thirds of deaths in Belgium, I think, and in the United States, where I have visited, the first drug that is used is an anaesthetic, and then there is a paralysing agent. A paralytic drug is introduced, which often gives the impression that the patient is having a peaceful death, but we do not actually know what is going on beneath the surface. I am afraid to say that, from studies into people who have been on death row who have been legally executed, there is often evidence of brain trauma. Can you speak to this at all? We know that in a minority of cases real complications occur—it often takes a very long time for the patient to die, and there is vomiting and all sorts of distress. How can we improve what we know about the actual process of dying, and how can we reduce these terrible complications?

Claire Williams: I can only apologise, because I am here to give evidence about a model for collective decision making rather than about my experience with regard to these drugs. As you say, the potential side effects and prolonged deaths are something we will need to consider for these cases. We need to take evidence from other countries that have had this experiences. Apologies, but I cannot comment on this particular aspect.

Q310 Kit Malthouse: My question is to Dr Richards. Obviously health service medics are dealing with end-of-life situations at the moment—they are withdrawing treatment or declining to give treatment if they think it is futile. In those circumstances there are a set of safeguards. How do those safeguards compare with the safeguards in the Bill? From your research, do you think there is any adjustment required to the safeguards we have at the moment?

Dr Richards: Assisted dying is quite categorically different from the end-of-life scenarios you are talking about there, so you would expect a very different set of safeguards. It is a misunderstanding to think that assisted dying is of a piece with other life-ending decisions. It is really something quite different and requires a different framework.

Q311 Dr Tidball: My question is to Dr Richards, although if Claire Williams has anything to add, it would be really helpful. We have heard evidence from overseas about the value of doctors being able to have holistic discussions about end-of-life choices under an assisted dying law. What research is there on patient experiences in those jurisdictions, in particular the evidence around quantifying the experience of dignity and respect in end-of-life choice making where assisted dying is available?

Dr Richards: Quantifying dignity or respect—

Dr Tidball: Or real-life examples?

Dr Richards: So the question is: what is the evidence on trying to find out about this interactional space where you are asking about people’s motivations? Is that right?

Q312 Dr Tidball: There are two elements to my question. The first element is talking through the available evidence on how those holistic processes work in countries

that have assisted dying. Secondly, we have heard a lot about choice from witnesses across the last two days, but a lot of the consideration about choice is about enabling patients to arrive at greater dignity and respect in their death, so it would be useful if you could reflect on any evidence around that.

Dr Richards: By holistic processes, I assume you mean the multidisciplinary team conversations that we talked about in the previous session.

Dr Tidball: Yes.

Dr Richards: Maybe Nancy knows the evidence on that. Talking about gaps in research, I am an anthropologist, so I am interested in the discourse and the conversations that are happening, and I think there is a lack of evidence about that. We have a lot of evidence where it is tick boxes, for example, about motivations and procedure being following. We have less qualitative, in-depth, interactional evidence about that kind of holistic decision making.

Professor Preston: We have done some research where we interviewed doctors and healthcare workers who have had those conversations. The majority decide against it, but they are still having those conversations. We also heard the experience of the bereaved family, and what it was like to have those conversations. On the whole, the conversation is predominantly about palliative care—“Can we do something different? How can we meet and assess your needs?”

In some cases, the doctors in palliative care, particularly in Switzerland, certainly would never suggest assisted dying, but if the patient asks for it, they equally do not advise them how to get an assisted death. In some cases they said they sort of consciously blocked the conversation, so that the person timed out and could not have it. The emphasis is perhaps the other way in places like the Netherlands and Belgium, where it has been around longer and is much more integrated into other services, such as care homes and palliative care, as part of a holistic assessment.

I remember visiting a team in the Netherlands, and when they got a new patient they said, “We assess them for their preferences about whether they want to die, about resuscitation, about advance care planning and about euthanasia.” My jaw dropped; I was British—this was illegal. They do it in such a natural way. They said, “We need to plan that for them, because we need to understand what is right for them.” They are not suggesting it—they are just trying to take it on board. I would say that the predominance of the conversation is about palliative care, but if the patient wants the assisted death, they either might assist—which is rare—or suggest how they go to a right-to-die association. But more likely they will still tell them how palliative care can help.

Q313 Naz Shah: Professor Preston, in your written evidence to the Committee, you said that Parliament should:

“Consider whether there should be a stated exception to the usual presumption of capacity under the Mental Capacity Act 2005 in the Bill.”

What kind of standard do you think Parliament should consider adopting instead of the use of the Mental Capacity Act, and why do you think that?

Professor Preston: Again, this came from my colleague Suzanne Ost, who is a professor of law. As Naomi said, this is something very different from choosing to consent to an operation or even a research study. This is finite—it is a finite decision, so therefore the assessment should be a bit more. What I will say about mental capacity is that we had a PhD student who assessed mental capacity decisions by hospice care staff—particularly doctors, but also a lot of the nursing team who were making the decisions. She was a lawyer, and her conclusion was that it was incredibly well assessed. That was in terms of safeguarding—so, when people were going back to what we might consider unsafe homes—but that is what the person wanted, because their life was that unsafe home. I am talking about social deprivation and things like that. The people in this particular team were very good at assessing that and applying the Mental Capacity Act, according to her research.

Q314 Rachel Hopkins (Luton South and South Bedfordshire) (Lab): Claire, you mentioned multidisciplinary teams and decision making. We have heard in a couple of other evidence sessions from palliative care social workers, nurse practitioners and the Royal College of Nursing about the multidisciplinary approach in care. What are your thoughts on the ultimate approval as set out in the Bill being a doctor, another doctor and then a legal okay at the end? Would a more multidisciplinary approach to approval have stronger outcomes or better safeguards?

Claire Williams: I absolutely agree that a panel/committee approach would have better safeguarding for patients, because the decision is being made collectively with legal expertise and with other healthcare professionals—that might be palliative—or ethicists like myself. It is having that collective view, ensuring that everybody is happy and that that is exactly what the patient wants. I believe it should be a committee/panel-based approach for the final decision. As I said before, expecting a High Court judge—just one individual—to make that decision alone is hugely burdensome and not an approach that we should be taking.

Q315 Tom Gordon: Professor Preston, we have heard from a wide range of different people from different jurisdictions. What we have heard and the evidence suggest that where we see assisted dying as an option, we tend to see improvements in palliative care. Do you have any comment on that and how we could better integrate into giving people that choice? You talked earlier about different routes and different systems in countries where it might sit outside the healthcare setting. Would that limit the choice and hinder people’s ability? How do you see that having a play in this?

Professor Preston: There is a bigger and bigger conversation in a lot of these countries, including the Netherlands and Switzerland, that this is not about healthcare. I know that sounds a really strange thing, but it is about self-determination and a life choice. I remember someone saying to me, “Well, you wouldn’t check who I’m marrying.” They feel it is such a personal choice. I think patients do bring this up. They bring it up all the time now. Studies in Spain have shown that if a patient has a desire for hastened death, the best thing you should do is explore that desire. Why do they have that desire? How can we help you? Are there other needs we can meet? Most people will not want to then

go ahead and have an assisted death. This is a minority of people. Could you remind me of the rest of your question?

Tom Gordon: If you have systems where assisted death is offered outside the healthcare setting, as in some of the countries around the world that you have mentioned, how does that limit people's access to it? Do you think that has an impact?

Professor Preston: I think it almost enhances their access to it. At the moment, they get lost in the system. They are usually trying to find these two magical doctors—in a lot of countries, you still have to find those two doctors. Most doctors, even if they approve of the idea of assisted dying, do not want to be part of it. They might assess, but they might not prescribe. They might prescribe, but they would not administer. Trying to find those doctors to do it is really quite challenging. That is what we get back from the bereaved family interviews. How do you navigate a system where you cannot access the people you need to get to? People go doctor shopping—they are going to multiple doctors until they get the right answer.

If you keep it safer, outside of healthcare, people can talk to their doctor—they will mainly talk to their nurses, because they are the ones who do end-of-life care predominantly—and they can say, “Actually, that is not something we can do, but if you want to see, we have a stand with information about it. This is the service you can go through.” It is the same with the GP—things like that. I think it might actually make it easier for people to navigate. That is where I came to the idea of keeping it outside. It is a supportive way for patients and families because, on top of all this, they are dying. They are having a really difficult time and we are trying to get them to navigate services that are incredibly difficult when you are trying to find two doctors.

Just finally, on top of that, it is quite secret who does this. Doctors do not want to tell people. I have had people who do this—who might just assess and may not prescribe or administer—and they do not want people to know in palliative care because it does not go well for them. They are concerned that people will not like it. I do research in this area, and some people think that means that I am trying to push for assisted dying. I am not; I have a neutral stance. I will say things pro; I will say things against. But it is quite difficult for people involved. There is a bit of a taboo—there is a secrecy. It makes it even harder to say in the Bill, “Recommend another doctor.” It will be a challenge to find that person.

Dr Richards: May I add something? The evidence suggests that one of the implementation challenges with assisted dying is finding doctors willing to participate—consciously participate—in this practice. However, I think what you are asking there is about a more Swiss model of assisted dying. There is a reason that the Swiss model of assisted dying has stayed in Switzerland and gone nowhere else—it has not transferred or translated to other jurisdictions, because of its uniqueness and the practical challenges of disentangling it from a healthcare system.

It is important to recognise that, but we are also talking a little about disentangling assisted dying from palliative care. It is important to recognise that the majority of people who request assisted dying—who

receive assisted dying—are within palliative care. They are already in that, as I am sure you have heard already. To disentangle assisted dying from the specialist communication around end of life would seem to be a self-inflicted problem of design, in my view, because it is safest being held there by the experts for those who want to get involved in it. It is safest being held in the healthcare system. As I say, there is a reason why the Swiss model is the only model where that happens outside a healthcare system. That is localised to Switzerland.

Q316 Dr Opher: I would just like to ask Claire about medication—not specifically the drugs and everything, but clause 18, “Provision of assistance”. We have heard that in Australia the medication is left with the patient, whereas under this legislation the co-ordinating doctor brings the medication to the house or the place where the patient wants to end their life. Do you feel, having seen the Bill, that that is safe, or do we need to amend it in any way?

Claire Williams: Again, those safeguards would need to be in place. There would be concerns if they were not actually giving the drug to the patient, and seeing the patient take the medication. Yes, robust safeguards would need to be in place.

Dr Opher: May I ask a further question, Mrs Harris?

The Chair: Could you make it a supplementary? I want to get Kim Leadbeater in, and then we can come back to it.

Dr Opher: Certainly.

Q317 Kim Leadbeater: We have heard a lot from witnesses this week about safeguarding. That is something I am keen to pursue. The Bill has a significant number of safeguards already, but is there anything else that you think we could add? I think all on the Bill Committee are interested in hearing such ideas. In particular, we are thinking about how we can protect people, such as people from disadvantaged backgrounds, older people—Dr Richards, I think you have experience of working with older people—people from a range of different backgrounds, and people with disabilities, so that we keep the Bill very much focused on the people it is designed to help, who are terminally ill people with less than six months to live, while addressing more of the broader concerns about some of the inequalities in society.

Professor Preston: In covid, we did research in care homes, and there was real concern about “do not resuscitate” orders and emergency care plans that were blanketed across the care homes. Care home staff were traumatised by that, so there are real issues. We know that there are real issues day to day in how people are treated within the NHS. I think it is unconscious—I do not think people are intending it—but we know that people are treated differently and that different things are done. That is partly why we think a system outside that would protect them, because then you are not within the healthcare team that is treating you and giving you advice about such things, whereas if you are having to opt into a system where you have to do something more, they will not feel like it. That does not happen in the hospital. It is about trust.

One of the issues in Switzerland—I must just add, the same Swiss system is being adopted in Germany and Austria, which already has a panel—is that they are trying to protect these people by keeping it one step removed, so that people do not feel that they are trying to be persuaded to an assisted death. Most hospitals in Switzerland will not allow assisted dying to occur, because they do not want a lack of trust in their patient group. Instead, they will sometimes allow the right-to-die associations in to do this and there are just a few hospitals that allow their staff to do it. It is all about trust.

Kim Leadbeater: That is really helpful.

Dr Richards: I do not think there is any evidence that there is a loss of trust in doctors post legalisation—I just wanted to add that.

As I said in response to the earlier question, this is a categorically new thing that would be coming into society, which would cause cultural change in how we approach, think about and anticipate dying. It is a big deal—I know you all know that. Accompanying it, therefore, there needs to be really sensitive information delivery that is appropriate across society and that will alert people to this. In particular, if you are going to have a system where doctors are not allowed to raise it with patients, people need to know about it. That is one thing.

Reducing people's fears is also important. I mean, there are so many misconceptions about assisted dying, even among people who have spent quite a lot of time reading about it and researching it. It is a very simple thing, but the discourse in society has been going on for so long that there is a lot of misunderstanding.

Q318 Kim Leadbeater: Can you give an example? What do you mean by that?

Dr Richards: Misunderstandings of what it is? Fundamentally, that it is not based on the principle of autonomy and that it is something that can be done to you, without your consent. You would not want the general public to think that. At a very basic level, it is understanding that assisted dying—the very phenomenon that that term encapsulates—is a phenomenon that starts with the patient. It is a request made by the patient because of their subjective assessment of their quality of life as they are dying. At a very fundamental level, you would want to communicate that to the public. It is a huge piece of work to have to create an informational context that is variegated according to the starting position of people's knowledge base around it, and to bring in something that does not scare the public and so they see it as something that can be positive.

In jurisdictions that have legalised, even post-legalisation there continue to be elements that resist it. However, you start to see positive stories of the kind of ceremonial aspects that can come when you can time death. There is a whole cultural piece around new rites—new rites around dying that are being created when people choose to have an assisted death, and the new dying time or space that is opened up there, as well as the intentional actions that can happen from people's social groups. Post-legalisation, it is not just fear—I think you get a balance of stories coming through—but it is something that you need to attend to.

Q319 Liz Saville Roberts (Dwyfor Meirionnydd) (PC): There was one thing I wanted to ask about, but it led me to another question, which is to Dr Naomi Richards. It seems that much of what we are discussing assumes that being patient-centric is intrinsic and runs day to day through medical culture. Is that actually the case in your experience? If not, is there something within the culture that needs to change to become more patient-centric in order to enable autonomy?

Dr Richards: I think you probably know the answer is that it is not patient-centric. In Marie Curie's "Better End of Life Report 2024", which was a representational survey with bereaved relatives, a third of people did not think that their relative even knew that they were dying. We still have a long way to go in communicating to people that they are in a terminal phase, so that they can find whatever residual value is in that period of time for themselves and their family. So, no, definitely not, but that is what we are striving for. I am sure that that is what all healthcare professionals are striving for.

In terms of assisted dying, it would be so explicit. It is categorically different from other kinds of conversations that are much more open-ended, like goals of care conversations at end of life. This is really quite specific, to the extent that you can actually give doctors a form of words to use, because their request for this procedure needs to be so categorical and there needs to be no ambiguity around that.

In a way, this conversation about assisted dying is actually different because it is very up front, it has to be very categorical and it has to be documented. In that sense, it is extremely patient-centric, and there would be no using euphemisms, which happens in end-of-life care, when what doctors think they have told their patients they do not hear. They have heard something else, because euphemisms change according to—well, you do not even have to go so far as to talk about different communities or cultural groups; they change from one person to another. I think this would require quite specific language. It would bring things into a much less ambiguous kind of territory.

Q320 Juliet Campbell (Broxtowe) (Lab): My question is to Professor Preston. I will go back to something you said in your last answer, when we talked about how people are treated, and the differences and inequalities across society but also within our healthcare systems and how things are done. This was highlighted specifically during the pandemic. How do you think these inequalities will undermine the principles of the Bill?

Professor Preston: I think it is about having that additional consideration. When additional consideration for, perhaps, social deprivation or about people from minority groups is in the training and is at the forefront of people's thinking, they can address it.

I will give you an example. We did a study looking at access to palliative care. I know you have heard a lot about there being a postcode lottery and things like that. One of our areas is one of the most deprived coastal communities in the country, and yet it had equal access for people across all areas of society, because they brought in people to target anyone from those socially deprived areas.

Equally, at the beginning of the first wave of the pandemic, at one of the big London hospitals, we analysed the data because we were concerned about

access to palliative care services. Were people accessing it during the pandemic? We also looked by ethnicity. What we found was that not only during the pandemic, but pre-pandemic, if you were non-white, it took—I don't know—three or five days longer to get that referral.

We had an idea that from some of the research we had done on social deprivation, people are making assumptions. It is not about people making horrible decisions, but they are making assumptions: "Oh, they will have a big family—the family will look after them. This will happen or that will happen."

The nurse consultant, Claude Chidiac, went in and did training for the staff and said, "Don't assume that just because people come from an Afro-Caribbean family that they have got this big family." Within a year, when the second wave happened, the difference had gone. It can be at the forefront of training and you can make people really think about it. I would say—I think someone said it yesterday—that there is almost an inverse inequality, because I think those families and those communities will be really trying to protect people from even thinking about going for it.

Q321 Daniel Francis: My question is to Claire Williams and follows on from Dr Opher's question. Clause 18(9) says that once the person has self-administered the approved substance, the doctor must stay with them until they have died, or until it has been determined by the co-ordinating doctor that the procedure has failed. We know from overseas that, in a very small number of cases, the procedure may take three or four days, so clearly the doctor cannot stay with them the whole time. Subsection (10) says that the doctor need not be in the same room as the person to whom the assistance is provided. I want to understand how that could be strengthened in terms of safeguarding. The clause says that the doctor must stay with them but, first, it is clearly not practical for the doctor to stay with them for a number of days, and, secondly, it goes on to say that the doctor need not be in the same room.

Claire Williams: Again, I can only apologise, as my evidence is about a committee-based, panel approach to decision making rather than what happens at that point of end of life. I do not know whether somebody else is able to come in.

Professor Preston: I can take that if you want.

Daniel Francis: Thank you, Professor Preston. Sorry—if you agree, Mrs Harris.

The Chair: I wondered who was chairing for a moment.

Professor Preston: We raised that concern about doctors staying with people for prolonged periods of time. I think it will come down to what "self-administered" means. In our written evidence, we said that, in Switzerland, that has increasingly meant setting up an intravenous drip and the patient opens the port. In that case, you are talking about different drugs and it would be much speedier. But we have data on oral ingestion from Oregon, and I think 30% of cases took an hour to die. Most of us know that in the NHS, an hour with a doctor will be pretty unlikely, even if they are in another room. Most assisted deaths across the world occur in a home or a nursing home, so you do not have doctors there—we are not talking about GPs being out for prolonged periods of time. The method of administration may change that as well.

The other thing is that doctors are not used to being with patients at the end of life—it is nurses and healthcare assistants. So you are actually bringing in a new role for them to be with someone as they die. I am not saying that they have not had that experience, but they are not the traditional healthcare workers who are at the bedside. Again, that would need to be accounted for in the training so that they are more used to being around people who are at the end of life. They will have had some experience, but it is very much in the realm of healthcare assistants and nurses.

The Chair: I call Simon Opher.

Dr Opher: I think that my question has been covered by my hon. Friend the Member for Bexleyheath and Crayford. I just wanted to be sure that we were secure if the doctor was not in the room, but that has been answered.

Q322 Naz Shah: My question is to Dr Richards. I will get to where I need to get to, so bear with me. You talk about this being a very explicit conversation, but I would argue that that is not entirely true. We are talking about a set of doctors who will have opted in to have that conversation; not all doctors will do that. We have also had evidence from people suggesting that doctors and lots of other people would leave hospice care if assisted death was provided on the NHS. Yesterday, we had care providers telling us that if people engaged in providing voluntary assisted death, they would leave those hospices. So it is not quite as explicit as what you are suggesting, is it?

Dr Richards: It would have to be. Those examples that you have just given would not mean that it was not an explicit conversation.

Naz Shah: But it is not, because—

The Chair: Order. One question, one answer. I call Danny Kruger.

Q323 Danny Kruger: Professor Preston, I wonder what you think about this idea of a panel instead of the High Court judge. A lot of Members who voted for the Bill on Second Reading did so partly on the basis that there would be that judicial stage. Although we can all recognise the value of having more expertise involved, the role of the judge is essentially adversarial in principle, and the public would expect it to be. They would be hearing arguments and taking evidence. Do you think that the Bill would be safe without that? Secondly, do you not agree that, as we heard earlier from a law professor, the right of appeal should be in both directions? There should be the right of appeal against an approval as well as against a denial?

Professor Preston: I think we suggested a panel. I submitted some evidence after the last Select Committee inquiry about a panel that could operate outside. Lots of the reasons I gave were about helping to navigate, helping to identify doctors and helping to support people who feel vulnerable within the NHS.

What increasingly came out from the idea of a judge is the question of what exactly their role is and the fact that there is no right of appeal. However, if you had a

panel, that would give a much more thorough understanding of what is happening. The additional safeguard is that the panel could say there needs to be a palliative care consultation. You would have to be sure the doctors who are doing it are, based on their register, qualified to have a palliative care conversation so that all options have been explored.

My fear is about if we do not specify what training is or what these people's expertise is. Most doctors do not know too much about palliative care or what the options are. You do not need to see a palliative care doctor, as a palliative care nurse can talk you through it, but the additional power of that panel is that it could be answerable to the court or some other sort of assisted dying tribunal.

Q324 Lewis Atkinson: I have a question for Dr Richards. I note from your biography that you have done work studying the phenomenon of old age rational suicide. I noted your comments before about research suggesting that people who seek assisted death have got particular, strong preferences for control and agency at the end of life. We know there are around 650 people with terminal illnesses who take their own lives every year at the moment. I wonder, particularly given your work on old age suicide, what would be your assessment on how assisted dying becoming an option here in the UK might affect those statistics.

Dr Richards: The Bill covers terminal illness only. It includes people with six months left to live, so it would not include the phenomenon of old age rational suicide, which is where you want to end your own life for reasons of the accumulated losses of old age, or because you feel you have lived a completed life. This really relates to people who are in what is called the fourth age of life. It is a social and cultural phenomenon that there are people in the fourth age of life who want to wrap things up on their own terms, but this is a separate phenomenon to people who are in a natural dying phase of life and want to accelerate that. It is different.

After you legalise assisted dying for terminally ill people, you will still get older people taking their own life. The highest demographic for completed suicides is people over the age of 70. It is a phenomenon around the world, but it is a qualitatively different phenomenon to people in a natural dying phase. If we look at the data on who requests assisted dying, it is people who want control and agency, and they may even have thought about it as a mode of dying that they want to access before they even had a terminal illness. They might have always imagined that, but that is in conjunction with various forms of suffering that they will be experiencing. It is not just personal preference; they are also suffering, and suffering is very multi-faceted and multi-dimensional at end of life. It has various different components, not just physical.

The Chair: Before we move to the next panel, is there anyone else who has pressing questions, or would you prefer to have a five-minute comfort break?

Q325 Naz Shah: Dr Richards, you were talking about elderly people in particular. We have heard evidence, particularly yesterday, about young women under 40 where terminal illness was deemed legislatively applicable

to anorexia. It appears that that is quite a phenomenon. When we talk about the explicit conversation that you are suggesting, I would argue that it is not necessarily clear cut. Do you agree that there would be a risk there when it comes to people with anorexia?

Dr Richards: I do not really understand why the case of terminal anorexia would be different to any other case in terms of the conversation. It would be necessary to have a very explicit conversation with somebody requesting assisted death; it does not matter what their illness is.

On the issue of anorexia, the numbers are really tiny. In the Oregon model, which is what is in the Bill, you are talking about one or two people in the history of assisted dying. It is a very minor issue to get focused on. I have seen so much about this in the press and being discussed here. If you are very concerned about terminal anorexia, I am sure you could do some tinkering with the Bill so that people would not be eligible for assisted dying, but in terms of the empirical data in jurisdictions that have legalised the Oregon model, which is what this is, there are one or two cases.

This should not be given a huge amount of time, because it is a distraction from the fact that really we are talking about a new mode of dying, which is a cultural response. Just as palliative care is a cultural response to suffering at the end of life, so is assisted dying. It is a different track; it is offering something different. Different types of people will want to go for that. It is a response to the protracted dying trajectory that we see now, which is new. In the history of human dying, we have never taken so long to die before. There has never been so much medical intervention at the end of life, and assisted dying is a cultural response to that. To get fixated on the two people with terminal anorexia who have accessed assisted dying in the States is a bit of a red herring.

The Chair: Thank you.

Q326 Kim Leadbeater: I have a very quick question. Professor Preston, you talked about nurses. Again, feeding into this multidisciplinary approach, one thing I am really clear about is that we must have the best training in the world around those end-of-life conversations and end-of-life choice. Do you have any thoughts about what that training could look like or what the important components of that would be? I am interested to know.

Professor Preston: We have heard lots of evidence about training schemes around the world. To be honest, I think they are still developing, but we can look at the good elements of those and at what has and has not been evaluated. We can do it almost like action research, where you are learning as you go, and we can improve the training as we go.

Most people do not die under palliative care. This Bill will affect general care; it will affect specialist care, but not in palliative care. We need to train those people as well, because they will be having a lot of these conversations. We are doing that training now, which is about how we talk to someone in a compassionate way. How do you help people to understand that they can be involved in the decision making? What might the goals of care for you be, and what might a goals-of-care conversation look like?

We have lots of this training already. Palliative care has huge expertise in this with advanced care planning and the rest of it, so it is about getting some of that incorporated. It is not just about saying, “This is what an assisted death would look like. This is how it would process.” It must be more than that, and we need to help people to explore their end-of-life choices. How do you want to die? Do you want to die at home? Do you want the cat on the bed? It is about all those things that are really important to people, but we must have that conversation and explore them, and it is quite hard to get clinicians to have those conversations. There will be a special group of people who can manage this; they will need training and support.

The Chair: I thank the witnesses on behalf of the Committee. We will suspend until 3 pm, which gives us six minutes.

2.54 pm

Sitting suspended.

Examination of Witnesses

Liz Reed, Pat Malone and Julie Thienpont gave evidence.

3 pm

Q327 The Chair: We will now hear oral evidence from families with relevant experience. On the panel, we have Liz Reed, Pat Malone, and Julie Thienpont, who is appearing via Zoom. I am afraid we have lost her for the time being, but we are trying to get her back. Could those on the panel introduce themselves?

Pat Malone: My name is Pat Malone, and three members of my family died in dreadful circumstances, two of them by suicide, and I think the circumstances of their deaths would be useful for the Committee to know before any decisions are made.

Liz Reed: I am Liz Reed. My brother had an assisted death in a hospice in Queensland, Australia. Their law is very similar to the Bill—the assessments, the focus on coercion—so I am here to share how the law works in practice for a dying person and their family.

The Chair: Julie’s Zoom link is still down, so I will start with Kit Malthouse.

Q328 Kit Malthouse: Thanks very much, Mrs Harris, and welcome, everyone. Liz, you and I have met before. I am very conscious that during the last couple of days of evidence, we have heard from all sorts of people but not actually from anybody with a terminal illness or somebody who has been through the experience that you have been through—so, welcome. Over the last two or three days, we have heard quite a lot about the complexity of the issue that we are dealing with, but we also heard right at the start that we have to balance that with simplicity, access and speed. From your experience of the two methods in Australia and Switzerland, do you think that there is something to be learned from those systems about that balance?

Pat Malone: I am not familiar with the situation in Australia. The two suicides in my family were outwith the law, and the third death I was going to talk about was a natural death—we would call it a natural death—so I am sorry but I cannot make a comparison.

Liz Reed: The system in Australia is, as I said, quite similar to what is being proposed here. It felt like throughout that process for my brother, Rob, it was really caring and respectful. He was able to change his mind, which he did, in terms of dates and when it would happen. His views and the views of his family were also taken into account and, through the process, he was treated like a person with autonomy whose choices were being respected.

Q329 The Chair: Thank you. I can see that our third guest, Julie Thienpont, has appeared on screen. Welcome, Julie. Would you like to say a few words before we continue?

Julie Thienpont: I am Julie Thienpont, and my husband and I were living in Spain at the time. My husband was diagnosed with mesothelioma and given three months left to live, so he opted for assisted dying. It was quite a rigorous process in Spain. It only came into law there in 2021, and he was one of the very first people in the south of Spain to take the opportunity of assisted dying.

Q330 Tom Gordon: Thank you all for coming here and sharing your personal experiences. I think it really adds to this, and it is why we are all here. My question is about access, which is one of the conversations surrounding the Bill, and how, if we do not legislate now, we might not see another debate or Bill brought forward for potentially a decade or longer. What are your views on that? I think some people see it as a point from which we either will progress or will not. Do you feel that this needs to be a continuing conversation, particularly with regard to palliative care and the experiences that your loved ones might have had in that system?

Liz Reed: As I said, my brother died in a hospice in Australia, where the hospices are extremely well funded, and the care he received was sensational. The team and the staff in that hospice made the time he had in there. Obviously, it was not amazing, because he was dying, but for a really difficult situation, it was comfortable for his family, and he had young children. You could not fault the care and access to the medication. We as a family, after he died, went back to the hospice to say, “This was changing for us and for him.”

But it did not change what was happening to my brother. He went from a hospital to a hospice, and he had a date planned for his death. He then actually changed his mind and extended it, because it was better than being in a hospital and the hospice care was great, but he still landed at the same point of saying, “This is not living.” It was not what he wanted, and not what he wanted. From a personal perspective, when he was diagnosed, we said, “You’ve got to come home.” But actually, I think, “Oh my God, what would have happened to him? How long would he have had to go on? How long would his children have had to watch him?” He was only 39 and his children were young, and they did not have to—they still remember their dad. For him, for his wife and for our family, I would not change anything.

Q331 Lewis Atkinson: Pat, if the Bill, as it is currently drafted, had been in place in your family’s situation, what difference would that have made to your family’s experience?

Pat Malone: In all three cases, it would have improved their lives and their deaths. My father died at the age of 85 from pancreatic cancer. He asked me to help him kill himself while he was in hospital in the last three or four weeks of his life. Obviously, I was not able to do so. He suggested that I put poison in his water, which I had no idea how to action. I spoke to his consultant and asked whether he could do anything to hasten his end, and he said, “No, no, no, I can’t.” After that, he lasted another three weeks and he had a horrendous death. It has scarred our family to this day.

My brother contracted the same disease, pancreatic cancer, and having seen my father die, he—having gone to six doctors and asked them whether they could help him end his life; he was under home hospice palliative care at that time—contrived his own suicide. Unfortunately, he asked his wife to sit and hold his hand while he died, as a result of which there was a police investigation into collusion. She and her daughter, who was also in the house at the time, were not cleared for eight months, during which they were interviewed repeatedly about anomalies and what they did or did not know. It was absolutely unconscionable to pile that on top of their grief, at a time when they had just lost their father and husband.

My sister’s death, having seen those two deaths, was much easier. She got motor neurone disease and was not really suffering in the way that my father and brother had been. She knew that her end was going to be as a live brain in a dead body, and that was the horror that she faced. From the beginning, she was fixed on going to Dignitas, which she did. It was not easy because, after the example of my brother’s family, she would not allow anybody in her family to have anything to do with the arrangements that she had to make, which were quite complicated and became ever more difficult for her. First, she could not drive a car any more and was going around on a mobility scooter, gathering endless documents and having all the tests that you need to have. Ultimately, she said, “This is my golden ticket.” When she was accepted by Dignitas, she said that it was the greatest relief of her life. She said, “I know I am not going to get cancer or dementia. I’m going to die painlessly at a time and place of my choosing.”

That is exactly what she did, but she died 1,000 miles from home. She should have died in her house with her family, and her dogs on the bed. She should not have been denied that. Had this Bill been enacted in her time, it would have been a much easier operation. The problem with this legislation mainly is that it is so long overdue. There are people now who are in that position. You may think our family is star crossed because we have had three deaths like that, but I think we are just a normal family. It is happening all the time. Chris Whitty talked on Monday about how we should not rush into this. We are not rushing into it; we are at the back of the queue, really.

Q332 Rachel Hopkins: Thank you all for sharing your family stories today. It is really moving. Julie, I want to ask about your experience in Spain and how you found that particular process in comparison with what we have in the Bill. How did it work? What was positive or difficult for you?

Julie Thienpont: Guido had decided right from the word go, even before he got sick, that that was the way he would want to end his life, if there was a possibility

of it. He was from Belgium originally, so he expressed a wish that if ever he needed it, he would like to go back there.

The law in Spain is very similar to the Bill, which I have read through countless times. There are a lot of similarities. There were very rigorous checks. It involved much paperwork, counselling and family liaison. The difference was that it went before a board, so it was a panel that would allow or not allow the decision—it was not decided in a court. That would be the main difference, but the process was rigorous. It was slightly difficult for me, because although I can speak Spanish, the terminology was frequently more difficult, so they very kindly translated for me. They explained everything: what would happen and how it would happen, if it happened. It was a big celebration for Guy when he was actually granted this. They also told us that he could change his mind after he had made the decision, should he wish to. He did once. It was me who asked him to do that, because I did not feel he was sick enough, which sounds a bit silly, I know.

He was an intensely private person. The palliative care in the part of Spain where we were is excellent, but it was quite irrelevant for him because he had already expressed that he wanted to die at home. We lived up a mountain; we were quite remote. Being such a private person, he never wanted to be in a situation where somebody else had to see him in any vulnerable situations, especially with personal hygiene and so on—even me, although I was able to help him in many ways. I had to do a lot of procedures for him, after being trained to do so, but he was more than happy with the situation of having assisted dying once it was granted. He did not need any other sort of care, although we still had a nurse coming every few days and the family doctor came up at least once a week. That does not sound much, but he did not want her any more often than that.

Q333 Danny Kruger: This is a question for Mr Malone. May I say how greatly I sympathise with what you have been through? I am very sorry to be fighting against you in this matter. I really can imagine how that feels. Thank you for what you said. I just want to ask about your sister’s experience. On the eligibility question, is it your belief that she would have qualified for an assisted death under the Bill, with the six-month terminal illness criterion? To follow up on that, do you think we should expand the scope to include people with motor neurone disease who might not fall within the six months?

Pat Malone: She would not qualify, because there was no telling how long she would live as a live brain in a dead body, as she said. It could have been months or even years, so she would not qualify in any case under this Bill. However, you have moved mountains to get to this point, so the last thing in the world I want to do is pile more requirements on the Bill. I would like to see some stuff stripped out of it, actually, to make it easier, but I am not going to ask for that because we desperately need to get away from the status quo. This Bill gets us away from the status quo.

Q334 Naz Shah: Thank you very much for coming today and sharing your stories. I have two questions. Julie, you said that you had family liaison and counselling. How long did that go on for? This Bill does not have that requirement, so do you think it is something that we should put in it?

Julie Thienpont: Maybe I said “counselling”, but it was not a session of counselling. It was somebody asking my opinion to check that I was 100% behind Guy. His son also did that by proxy—via us—because he was in a different part of Spain. They wanted to ensure that he had talked it over with family members. It was not hastened along, because he had been given a short life span, so it did not take terribly long. He had to wait about three weeks before the initial ball started rolling, and then two weeks later a family doctor and nurses from the hospital came round for form filling, reading through, translating and signatures, and again another two weeks after that. Each time, I believe it went before a panel. We did not, but the paperwork had to go before a panel. They were left in no uncertain terms that that was the way he wanted to end his life.

It was a very peaceful, serene and beautiful death, as opposed to what it would have been like. He was able to speak to his relatives in Australia, his brothers in Belgium and other family members, and I was able to hold his hand. Guy had always been a bit of an old cowboy, and he always said that he wanted to die with his boots on. I am proud to say that that is what he did. At the end, we were holding hands, and I said to him, “Don’t be afraid.” He said, “I’m not afraid,” and he winked at me just before he closed his eyes.

On the process, perhaps I should have said that it was intravenous, so he had a drip in each arm. It was quite a quick process—maybe 10 to 15 minutes, which I thought was quite quick—but we had had lots of time that morning, you know. It was a beautiful end—the wink especially. I am left with very good memories of such a peaceful death, which was going to happen regardless. He was at peace with it, so that helped me.

Q335 Naz Shah: Thank you very much for sharing such personal experiences. Liz, you talked about your brother, and going over, and how peaceful it was for you. We have heard lots of witnesses talking about people who have felt like a burden. I am glad that was not the case with your brother’s death. Would you support adding more safeguards to the Bill to make sure that we protect those who are at risk from coercion and who might not have capacity?

Liz Reed: I understand the big focus on coercion. It is very similar in Australia. The difference between the Queensland Bill, specifically, and the Bill proposed here is that, in the Queensland Bill, coercion is punishable both ways: you can be punished for trying to coerce someone into an assisted death but also for trying to change their mind the other way. Those safeguards are in place because you hear anecdotally from practitioners that, broadly, people are being coerced out of this.

In our experience, the day before my brother died our mum said to him, “Are you sure?” She was not trying to coerce him, but was she trying to make him go on longer? Absolutely. That is her son, and that is completely natural and normal. She did not want to see him die. His response was, “This isn’t living.”

Naz Shah: Thank you very much.

Pat Malone: As far as my brother and sister were concerned, there was no check for coercion. There needs to be, as in the Bill, but there are many more safeguards in the Bill than there are now. The people who are contemplating suicide now have no safeguards at all.

Q336 Dr Opher: Liz, you spoke about excellent palliative care. What were the reasons, do you think, that your brother wanted to end his life? It did not sound as though he was particularly depressed.

Liz Reed: No, he absolutely was not depressed.

Dr Opher: And he was having excellent palliative care, so what was in his mind, do you think? Why did he decide on that option?

Liz Reed: He knew he was dying. He was diagnosed in October 2022. Just to be clear, in the period before his health started to really deteriorate, he had a great time. He went fishing, he went to the beach—it was like an advert for Australia, how great his time was. He quit his job, he was with his young sons, and he had a lovely time. But his treatment stopped working. He had had every treatment and, even though he was on the pathway and had started the voluntary assisted dying process, he was still having immunotherapy. He wanted to live. His family wanted him to live. But he got to the point where he knew he was absolutely not going to live, and that it was a matter of time. He said that he was afraid not of dying, but of dying in an awful way. He was worried his lungs were filling up with fluid. He thought he might have a heart attack. He was afraid of that happening; he was not afraid of dying. He was not depressed but he knew what was coming. He felt, in his own words, “I’m just sitting here waiting to die.”

He had had experience of a friend whose wife had died, and she got so bad that her young son could not visit her any more because it was too frightening for him. My brother’s children will remember who he was: this big, 6-foot-6, rugby-playing, fun dad. He got to choose: “Actually, I’m ill enough, I’m frightened of what might come down, which I know is going to happen anyway, and I choose now.”

Q337 Kim Leadbeater: Thank you to the three of you for coming here this afternoon and telling your stories. I know how hard it is to tell your story over and over again. I think it is important to reflect on the fact that we have had a lot of talk this week about amendments, clauses and various other technical details, but this is the reality of the subject. Thank you so much for sharing your stories.

Liz and Julie, I am interested to know whether you think any aspects of the processes that you went through in Australia and in Spain could have been done better or improved. Is there anything from your experiences that we could learn from to enhance what we are trying to do here?

I also have a question for all three of you—and Pat, goodness me, to come here and tell your story after everything you have been through is unbelievably brave, so thank you. What impact did these different types of death have on your grief and on bereavement? We are talking about different types of death, so I think it will be helpful to think what that looks like for people.

Julie Thienpont: It is a very good question, because I think it did impact my grief. There is not anything that I would change, for definite, about that, but I think I mentioned that I had not tried to talk Guy out of it the first time around, but I did say, “Don’t be so hasty, because you’re not as sick as you could be.” He was still getting up and dressed every day and managing pain, so we had that discussion. On the only day that I ever

knew him to stay in bed a little bit longer, I knew he was thinking about phoning to say that he was ready, and he called me to him and said, “Come and sit with me. I want to ask you two things.” The main one relevant to this is: “Don’t try and talk me out of it this time. I’ve made the decision. Don’t try and talk me out of it, because I don’t want you to be impacted in that way.” The second one was to “be strong”.

Both those things have impacted my grief, because I was so strong for 12 whole months and I just thought, “Yes, we’ve gone through that. It’s been great, and”—not “great”. Sorry, I am using the wrong terminology, but for me, it was so good to know that he died so peacefully and he was at peace with himself. That happened and I thought, “Right, now I’ve got to do the ‘be strong’ bit,” so I did that. I did want to talk him out of it again, but I did not, and I was very strong, and then all of a sudden, one day, grief did start to creep in, obviously. Suddenly I thought, “Hang on, he’s not coming back.” That is a normal grieving process, but it held off a little while.

The pathway that the grief I experienced took was that every day I had a different memory of us sitting somewhere, being somewhere or doing something. During the last months that we had together, knowing that he was going to die—sorry to sound like a bit of a romantic—our love intensified so much. You know that everything you do, it is probably going to be the last time you do it. It is almost like an unbreakable bond between you: you are both in this situation together and you are going to get through it, you are going to be strong, and you are going to be there for each other. I think that carried me so far, because those four months that he lived were the best four months, in the sense of our closeness and how supportive and caring we were for each other. It makes me smile now. When I think of his passing, I smile. Yes, I do get upset and I miss him a big lot, but I smile because everything worked out the way he wanted it to.

Kim Leadbeater: Thank you so much.

Pat Malone: My experience with my father was entirely different. My daughter, who was seven at the time, reminded me recently, when I was putting my thoughts together for this, that in his last weeks she had visited him, and I had taken her into a side room and told her not to expect to see the grandpa that she knew, because he was very, very ill and he did not look anything like she would expect. She said she was very thankful that I did that, because she was stunned and shocked when she saw him. He was like a 1,000-year-old corpse, he was moving, and his eyes were yellow, and that is how she remembers him—she does not remember any of the good times. My sister, who lived close by, was with him most of the time, and she just sat by his bed and prayed for his heart to stop.

We were all shell-shocked when he did finally die. As I say, that informed the decisions that were made about suicide by my sister and brother. Had he been a farm animal, we would have been prosecuted for causing unnecessary suffering, but he was a man so he was not entitled to that sort of consideration. I remember him in that horrible ward breathing his last. The only time he moved in the last days was to cough up blood. For a man who had asked to be relieved of that burden, who had asked for an act of mercy, a week before, and it had been denied him—I cannot understand how anybody would deny a dying man a deliverance.

When my brother died, he and my sister-in-law had been together since they were 11 years old. He was only 53, so they had already known each other for 40 years. She had shared his suffering while he was being driven around the country looking for diagnoses and, ultimately, looking for doctors who would help him commit suicide. His weight had gone from 18 stone to 8 stone, and he was bright yellow as well. He was suffering all the time and she was suffering with him. She was relieved as well as grieving when he actually died—and then the police were at the door. The investigation went on until his inquest eight months later. The police were as helpful and sensitive as they could possibly be. Vicky got the impression that they wanted her to give the wrong answer—when they said, “Did you know what he was going to do?” she said, “Yes, I did”; to “Could you have stopped him?” she said, “Yes, he was weak as a kitten”; and to “Could you have resuscitated him?” she said “Yes,” because she had had some nursing training, and so on—and with every answer they just collapsed a little bit more.

Ultimately, at the inquest there was an anomaly in his suicide note. It was written in two different colours of ink, and the police investigated whether it could have been written at different times, possibly by different people. Giving evidence at his inquest, the police said that they thought his pen had run out—there was a squiggle at the top where it changed from black to blue—and they said that they were not proceeding with any idea that there had been positive involvement in his suicide.

I have a note of the transcript of what the coroner said, which reads: “I don’t want to make any more of this than I absolutely have to. I simply record therefore that Michael Malone took his own life. He did so quite deliberately and having made appropriate preparations, and so it’s not a case of my saying that he did so while the balance of his mind was disturbed, because it clearly was not. It was a decision that he took and I have every sympathy with that decision in so far as a coroner is allowed to say that.”

The police were very sympathetic. The coroner was very sympathetic. Danny Kruger is very sympathetic. But sympathy only goes so far, and I am glad that this Committee is now looking at exactly the people who matter first in this issue, who cannot be here to talk for themselves.

Liz Reed: In answer to the first point, about anything we would change or do differently, I think actually my brother’s case was dealt with really well and there were checks and balances along the whole way: “Does he meet the eligibility criteria?”—obviously—“but also, does he want to?” His wife was involved in the process with him, and he was checked constantly. A doctor administered for him, and he had met him already. He knew him and had a rapport with him. He had a few jokes with him at the end. So from that perspective, I do not think so. It is slightly different in Australia, in that it does not have to have a High Court judge, so the process feels a bit more streamlined than it is here, and maybe the access would be slightly different because of that.

In terms of the grief, I think anyone that knows someone who has been through a terminal illness knows that there is a level of anticipatory grief that comes with that—the waking up every morning thinking, “Has it

been tonight? What happens next? What's today?" Because when someone is in the final stages of their life, which my brother was, there is always something every day: "Oh, he's got to have fluid drained from his heart today," or, "Oh, this has happened." There is always something, so that grief starts coming on before the person has even died.

The day my brother died we sat outside in the courtyard and had a glass of champagne. He chose a Bob Dylan song that he wanted to die to. It was extremely peaceful. It was seconds. And he got to say all the things, have all the conversations, speak to our parents—that sort of real American "closure". That is what he got, and we were not sitting around thinking, "I wish I'd said this. I missed it," or, "I was off doing something with the kids." We were all there: my mum, my dad, me, his wife. We sat there and held his hand—and what a gift.

Q338 Sarah Olney (Richmond Park) (LD): Thank you all for coming today and for sharing these really personal recollections. I have one question, but to both Liz and Julie, if that is okay. According to the notes that I have here—apologies if I have got this wrong—in both your brother's situation and your husband's situation, it was administered by the doctor. The Bill proposes that the person who has made the choice about ending their life should self-administer a solution. I am really sorry if this causes you any distress, but, on reflection, do you think that a self-administration regime would have made a difference?

Liz Reed: I do not think so, no. I do not think it would have changed his mind. I am someone who is real squeamish, so I probably would not want to, because of how I feel about all that kind of stuff, but it would not have changed anything for him—no, absolutely not. But I think there is a comfort in having a doctor there administering that, "This is going to go as it should," and there is a calm that comes with that.

Julie Thienpont: Guy being intensely private, as I mentioned before, he would have preferred less people around him at the time. There were two nurses, the family doctor and the administering doctor. They prepared the scene and put the drips in—they had to put one in each arm—and they had to be there in order to witness the whole thing. He would have preferred to have been able to do it himself, but I do not think the fact that it was administered by somebody else impacted in a negative way for him.

The Chair: Pat, I think you wanted to say something.

Pat Malone: Yes. My sister died under the Swiss method, which meant self-administering a cup. She had motor neurone disease, and she was slowly losing the use of her limbs. She went earlier than she needed to because she wanted to be sure that she would be able to swallow and lift her arm. She could probably have put it off for some months—an indeterminate period—but she died before she needed to in order to be sure that she could self-administer.

Q339 Sarah Olney: The Chair has given me permission to ask a very quick follow-up, Pat, since you mentioned that. I am really sorry to ask this, but do you think that if it had been administered by a doctor, she would have chosen to live for a little longer?

Pat Malone: I cannot speak for her, but there were many, many problems. Bizarrely, the last package of documents that she sent to Dignitas got caught up in the postal strike, and they were all irreplaceable original documents. I do not know if you remember, but around that time—this was the winter of 2022-23—there was a postal strike, and it particularly affected international mail. For nine weeks, the documents were held up in a sorting office, and they could not find them. She was getting more and more concerned, because her horror was that she would miss that deadline. In actual fact, Dignitas agreed that in the final analysis she could hand carry the last of the documents she needed when she came to Switzerland, and she was still able, but her horror when she thought she was going to miss the bus was quite palpable. Yes, if a doctor had been able to do it, she might well have chosen that option.

Sarah Olney: Thank you for answering that.

Q340 Dr Opher: I have been fascinated by this discussion, so thank you all. It strikes me that we have spent a number of days looking at the other end of this, if you like—coercion and capacity and that sort of thing—but I am concerned that we had a judge with Parkinson's who would not be allowed through this, like your sister with MND. I just think we should consider as a Committee whether we need to make any amendments on these things, and also on self-administration. I wondered whether you thought we should widen the Act. I presume you have read some of it, at least.

Pat Malone: As I mentioned to Mr Kruger, I am loath to meddle in any way with the Bill. I think that as it is the Bill is the best we can do at this time.

The Chair: Order. I am going to let you continue, but that question is out of scope. Is there anything else you want to say, Mr Malone?

Pat Malone: I have said that as far as meddling with the Bill is concerned, I would like to see it pass as it is without too much delay.

Q341 Lewis Atkinson: I have a question for Mr Malone. The Bill as drafted talks about the commencement period and how quickly it would commence in the UK if Parliament passed it. There have been some suggestions that we should delay the commencement in order for improvements to palliative care or other such things to be made. Could you speak to your experience on that and give your opinion?

Pat Malone: I think that both my sister and brother had more than adequate palliative care. My sister, particularly—she was taken under the wing of the Macmillan nurses, even though she did not have cancer, and they were absolutely marvellous. Her GP was brilliant as well: behind her all the way for the whole year. She could not really have done it without her.

The NHS was excellent. In fact, my sister was used as a diagnostic tool, or diagnostic test, by NHS surgeons who were teaching medical students. She would be put in front of medical students and they would be asked what was wrong with her. Given that MND is normally associated with young men with brain trauma and so forth, it encouraged them to widen their appreciation of these diseases. It meant that she met NHS specialists at

a particular level. She really wanted for nothing. She had a stairlift put in her house in short order. She had the mobility scooters and all the gimcracks that you have in your bathroom to help you get out of the bath and so forth. Above all, from the Macmillan nurses in Blyth, she had moral support. These are no-nonsense people who will walk through a wall if there is something that you need, and that is wonderful to have.

So there was no palliative care issue with my sister. She never needed any pain control. She had everything she needed. It did not change her mind one bit. I would like to see palliative care divorced from the idea of assisted dying. What she needed was assistance to die. What my brother needed was assistance to die. Palliative care was a side issue. It obviously comes into it, but if you could look at assisted dying on its own, I think that would be useful.

The Chair: Are there any more questions?

Julie Thienpont: Would it be okay if I said something?

The Chair: Of course. Please do.

Julie Thienpont: This is hearsay, of course. I live in Guernsey now. It is a small island, so we know a lot of people. A lot of people know each other. I had something published in the Guernsey press fairly recently. A friend of mine had a relative in the local hospice, which is excellent—it is absolutely beautiful and the palliative care and the teams are second to none. However, her relative who was in there saw the newspaper and said, “Oh, my goodness! I wish this Bill would come to pass here. I wish it would have been in time for me.” He said, “I am getting excellent treatment, but I am sitting here waiting to die. My family are coming every day to watch me wait to die.” He lived for five more days and he actually expressed that even though his care was excellent, he really wanted to die sooner on his own terms.

Q342 Kit Malthouse: We have heard a lot in evidence over the last two or three days about how the doctor should approach the initial conversation and whether doctors should be allowed to initiate a conversation about assisted dying. I realise that each of you has experienced this at second hand, but could you talk a bit about how those conversations were handled? Do you have a view about the ability of doctors, if this Bill should pass, to raise assisted dying as an option for people facing this kind of decision? Liz, could you talk about the experience in Australia?

Liz Reed: Rob’s experience was that this law only came in in Queensland in January 2023, post his diagnosis. But it was an issue that had been in the press; he knew it was coming in and from diagnosis he thought it was something he might consider, and so he approached his doctor with that.

In terms of my view on whether doctors should bring this up—we are coming from a position of privilege where we have access to media; he knew this was going on, and I am sure there will be plenty of people who do not know. I do not really know, to be honest, where I sit on that. For our family and for my brother, it was absolutely the right thing to do. I cannot really answer.

Pat Malone: Some regulation and some guidance would not go amiss. My sister had fantastic support from her GP. She did a lot of extra work to meet the

requirements of Dignitas, and my brother had exactly the opposite. When he went to his GP, for a long time he was told, “Oh, it’s just indigestion. Try Gaviscon.” Even when he went to his GP, in the light of his understanding of my father’s death, to say, “I think I’ve got pancreatic cancer,” his GP said, “No, it’s not—it’s just indigestion,” and so forth. It would not have mattered; an early diagnosis would have made no difference at all. But the GP was not very helpful and did not want to get involved.

When my brother died, my sister-in-law called the GP and the GP called the police. Before my brother was cold, the investigation started. If there was some way you could say to doctors, “This is what you can do, and this is what you can’t do. If you do not want to get involved, leave it to somebody who does because there are plenty of people who will”, and if that could be quantified somehow by a code of conduct—perhaps among the doctors, rather than in the Bill—that would be very useful.

Q343 Kit Malthouse: Julie, you said that you got to a point where Guy said to you that he had made his mind up. Had he made his mind up after conversations with doctors about what his options were?

Julie Thienpont: No. He made up his mind long before he was even sick. He felt that his mother had quite a traumatic passing, and said that she expressed a view that, had it been an option, she would have taken it. He had said from then, “That is the way I want to die. I want to die that way. I don’t want to be lingering in a bed, whether I am in pain or not. I don’t want that to happen.” That may not be something that I would choose, but that was his absolute choice—I have no doubt whatsoever. He said that to the team who had been looking after him when he first broached the subject, and I think they first of all thought he was not terribly serious. Then, when they realised he was, he said, “It’s my life, it’s my death—I want to choose.” I think that is what it is all about: allowing people that option to choose.

Q344 Kim Leadbeater: I wonder if you have been on your own journeys around your personal views on assisted dying and choice at the end of life. I have spoken to lots and lots of people about this, and anybody who has had experiences similar to yours are very clear that the law needs to change. People who have not been as close to this issue as you have often hold a different view.

Prior to your personal experience, you might have had a different view or friends and family who had different views. For me, speaking to people who have had the experiences you have had, it becomes very clear that we have problems with the law as it stands, or the lack of the law as it stands. Would anybody like to share their own journey about that?

Pat Malone: From my standpoint, I did not give it a lot of thought until it started impacting on the family. But I understood exactly why my sister and my brother committed suicide. I would hope that this Bill could be enacted when my time comes.

Liz Reed: I had not given it a huge amount of thought; I am relatively young. I suppose if I was asked at the time I would have said, “Yes, sounds fine,” but I

think I had also grossly misunderstood what it would mean for someone to go to Dignitas. There is a flippant comment that goes around—I can remember my dad saying it: “Oh, I’ll just go to Switzerland.” It is just not that easy. People I know and have met, like Pat, have had family members go to Dignitas, and it is actually a deeply traumatising experience. People’s lives are cut much shorter, they cannot enjoy their time and so on. I absolutely agree that I had not given it much thought.

I remember, on the day my brother died, getting back to where we were staying; I sat there and thought, “What would have happened to him?” I wrote to my MP, to say, “Hello, I am just wondering what would have happened, out of interest.” That is how I got involved. Had he been here, what would have happened to him and how long would he have had to limp on? You hear enough stories of people begging to die at the end of their lives, and I am really thankful that he did not have to.

The Chair: May I offer all three of you the collective condolences of everybody on the Committee? I thank you for your bravery in attending today and for speaking to us. Thank you very much.

Hon. Members: Hear, hear.

Examination of Witnesses

Dan Scorer, Professor Lewis, Dr Mulholland and Dr Price gave evidence.

3.54 pm

The Chair: We will now hear oral evidence from Professor Emyr Lewis, emeritus professor at the department of law and criminology at Aberystwyth University; Dr Michael Mulholland, honorary secretary at the Royal College of General Practitioners; Dr Annabel Price, from the Royal College of Psychiatrists; and Dan Scorer, head of policy, public affairs, information and advice at Mencap. Could you please introduce yourselves, so that we know who you are before you start giving evidence?

Dan Scorer: Hi. I am Dan Scorer from Mencap, the learning disability charity. We work across England, Wales and Northern Ireland. We support 4,000 people with a learning disability with their care and support needs, as well as providing information and advice services across the three countries. We also campaign for better support for people with a learning disability, and their families, across health, social care, employment, social security and cost of living.

Dr Mulholland: Hi. I am Michael Mulholland. I am a GP in Buckinghamshire and the honorary secretary of the Royal College of General Practitioners, the professional membership body for general practitioners. We have 54,000 members across the UK.

Our current position as a college is that we oppose a change in the law regarding terminally ill adults; that was ratified by our council in 2020 when we last had a survey of the membership. Seeing that there were changes in the legislative landscape across the UK in 2023, our council asked for a group to be convened to look at where our college should be going. We created a committee that looked at that and created a list of principles, which I will be referring to in any evidence I give today. In our

council, we are currently undergoing a review of what our position should be. We have a membership survey that is live at present, and we will be bringing that to our council in March this year to decide the college’s position.

Professor Lewis: Hello, I am Emyr Lewis. I am a lawyer from Aberystwyth University, and I am here to talk about the legal and constitutional aspects relating to Wales that arise from the Bill.

Dr Price: Good afternoon. My name is Dr Annabel Price. I am here representing the Royal College of Psychiatrists, a professional medical body responsible for supporting psychiatrists through their careers, from training through to retirement, and I represent 21,000 members.

I am an old-age liaison psychiatrist, working in a general hospital setting. I also provide psychiatry input to my local hospice, and I teach palliative care at the University of Cambridge. I have a research background in mental health at the end of life, and particularly mental capacity for terminally ill adults requesting assisted dying.

The Chair: Thank you. Liz Saville Roberts, Danny Kruger has kindly forfeited a question in order for you to have two, so I will call you first.

Q345 Liz Saville Roberts: Thank you very much to Mr Kruger, and to you, Chair.

Professor Lewis, I am glad to say that the Committee appreciates that scrutiny is necessary for Wales-related aspects of this private Member’s Bill. What are the risks of insufficient scrutiny?

Professor Lewis: Because this is a private Member’s Bill, it will not have gone through the process, which a Government Bill would have done, of having discussion between Governments as to how this might be sorted out. That impacts on Wales. So it is really important to have a session that focuses, albeit briefly, on Wales. I am grateful to the Committee.

This is an England and Wales Bill because certain criminal offences are matters on which the Senedd in Cardiff cannot legislate, and that includes offences that relate to suicide. However, apart from that, the impact of the Bill on devolved matters, if it became law, would be substantial—on the health service in Wales, on social services in Wales and on Welsh society generally. It is important that you take account of that. Indeed, certain aspects of the Bill seem to me to require a legislative consent motion to respect the Sewel convention.

Q346 Liz Saville Roberts: Could you expand somewhat on which aspects those are?

Professor Lewis: As I am sure you are aware, the Parliament here in London can legislate about anything at all—absolutely anything. However, where the power to legislate is given to the devolved legislatures, the Sewel convention states—in the Government of Wales Act, in section 176, I think—that the Parliament in London will “not normally legislate with regard to devolved matters”.

That is what is said. Therefore, there are certain aspects of this Bill—I will give you brief detail on that—that, in my opinion, relate to devolved matters. The first is clause 32. This is a very broad clause that would give the Secretary of State very broad powers for the implementation of the Bill within the NHS, including within the NHS in

Wales. It seems to me unarguable that that is a matter both on which the Welsh Government ought to be consulted and which would require legislative consent from the Senedd.

The second is a cluster of clauses that impose specific functions on Welsh Ministers and on the chief medical officer for Wales. They are clauses 31, 33 and 34. Once more, from a formal perspective, they seem to require a legislative consent motion, so it seems to me that some thought needs to be given as to how that might happen in the context of a private Member's Bill.

Q347 Sarah Green: To follow up on what you just said about legislative consent, in October of last year, the Senedd voted against Julie Morgan's assisted dying motion. In your opinion, what implications does that have for the Bill and its progress?

Professor Lewis: A motion was put forward by Julie Morgan that was supported by three or four Members of the Senedd, which was broadly in support not of this specific Bill, but of the purpose of this Bill, and it was defeated, as you say, after a full debate on the Floor of the Senedd. Formally, legally and constitutionally, that is of no consequence, because it was not a legislative consent motion, and of course, as I said earlier, this Parliament is able to do what it likes. It could totally disregard that. Whether that would be a prudent or an appropriate thing to do, or even what one might describe as a constitutionally appropriate thing to do, is another matter.

I think it reinforces the point that there is a significance in making sure that scrutiny of the Bill has a Welsh focus. You might consider, for example, making different provision in Wales. How do you respect what was a democratic vote in the Senedd in Cardiff? Well, you might consider having different commencement provisions—I am not advocating this, it is just an example of what you might do. Commencement of the Bill in Wales might happen in a different way, on the assumption it was passed. You might put that in the hands of Welsh Ministers and the Senedd, just as an example.

Q348 The Minister of State, Ministry of Justice (Sarah Sackman): To be clear, I am here as a Government Minister on this Committee, and the Government are entirely neutral on the Bill, so we do not take a position on the substance of the issues you have raised. Clearly, the draft Bill is intended to apply in both England and Wales, as you say, and your note is extremely helpful in highlighting some of those issues that will need to be worked out. As a Government, we will work closely with the Welsh Government to assess the legalities and practicalities of any potential changes to the law.

You have highlighted in particular the distinctions between health law, which is a devolved matter, and the law on suicide, which currently is not devolved. On the first page of your written evidence, you draw out clauses 32, 31, 33 and 34 in particular as issues that we should focus on in ironing out those legalities. Is there anything else you want to add to that that you think that we as a Government should focus on in our work consulting with the Senedd?

Professor Lewis: I think it is important that both Governments understand how the implementation of what will be a pretty radical change in the law will happen

on the ground within the health service and among those who are responsible for delivering social services. I am thinking of issues such as adult safeguarding, which in Wales has its own specific law and is slightly different from the arrangements in England. There are those kinds of nuances between the two territories, and I think it would be prudent to focus on them.

I also think it is wise to bear in mind that Wales has certain statutory bodies whose interests might extend to the Bill. For example, there is the Older People's Commissioner for Wales, in particular; there is the Future Generations Commissioner for Wales as well. I think it is important that there is some forum, some scope, for those people also to be involved in how this is shaped.

Q349 Sarah Olney: Dr Price, I am really glad that we are able to have the Royal College of Psychiatrists in front of us today; thank you for making the time. I want to ask you about paragraph 11 of your written evidence, which states that it is the royal college's view that the Mental Capacity Act

“is not sufficient for the purposes of this Bill.”

Could you expand a little on that and, if you feel able, make some recommendations as to what you think could be sufficient?

Dr Price: Thank you. In answering this, I will also refer back to Professor Gareth Owen's oral submission, thinking about the purpose that the Mental Capacity Act was drawn up for and the fact that decisions about the ending of life were not one of the originally designed functions of it. We would need to think carefully about how that would then translate into a decision that was specifically about the capacity to end one's life.

We also need to think about how that would work in practice. When we are thinking about capacity assessments, it is usually related to a treatment or a choice about a treatment or about somebody's life—for example, changing residence. Psychiatrists and doctors and actually lots of professionals are very used to those sorts of decisions and have gathered a lot of knowledge, expertise and experience around it. This particular decision is something that in this country we do not have knowledge, expertise and experience in, and we therefore need to think about how that would look in practice.

As for advice to the Committee about what that might look like, I think that we need to gather what evidence we have—it is actually very thin—from other jurisdictions that think about capacity as part of this process. I am thinking about my PhD: I visited Oregon and talked to practitioners who were directly involved in these sorts of assessments. They described the process, but they are not using the Mental Capacity Act as their framework. They described a very interpersonal process, which relied on a relationship with the patient, and the better a patient was known, the more a gut feeling-type assessment was used. We need to think here about whether that would be a sufficient conversation to have.

One of the things that I have thought quite a lot about is how we can really understand the workings of a mental capacity assessment, and one of the best ways we can do that is to see who is not permitted to access assisted suicide because of a lack of capacity and what that assessment showed. We do not have data because the assessments for people who were not permitted to

do it are not published; we cannot read them, so if this becomes legislation, one of the suggestions that I would have—it is supported by the Royal College of Psychiatrists—is to, with patients' consent, record capacity assessments to see whether they meet the standard that is necessary. I think it is important to set out the standard necessary and the components needed to be confident about a mental capacity assessment. That will help with standards, but will also help with training, because this is new territory for psychiatry, for medicine, and to be able to think about consistency and reliability, training needs to actually see a transparency in capacity assessments.

Q350 Dr Tidball: This is a question for Dan Scorer. I have worked with a learning disability charity, My Life My Choice. I have done a lot of work with that charity on self-advocacy in the context of healthcare, so I am really keen to hear from you. We know there are excellent initiatives that focus on supporting people with learning disabilities to engage with advanced care planning, so that their preferences at the end of life can be respected. I just wondered whether you could share some lessons learned, particularly in relation to giving people with learning disabilities a voice and an opportunity to talk about what matters to them at the end of life, and say, as part of that, what we could incorporate into the regulations that are being developed as part of the Bill.

Dan Scorer: There are two key concerns I will touch on. One was covered just at the end of the last session, with the question about preliminary discussions, and that is certainly a key area that we have concern about, about how that initial conversation is initiated and structured. For us, that really leads into a conversation around rights to advocacy. It would be extremely concerning if people with a learning disability who were terminally ill were not fully prepared and supported for that discussion.

For us, this links into the experiences that we had during the pandemic, which were touched on in yesterday's evidence session by Dr Griffiths and others. We had people with a learning disability who were being consulted by medical professionals about “do not resuscitate” or “do not treat” decisions, and they were not being properly prepared for or supported in those discussions. Indeed, in one of our own care services, we had someone we support who was called up by a GP and asked whether she would want the kiss of life. The GP was trying to explain it to her excessively and she said, “No, of course not. I would not want to be kissed by someone I do not know.” Potentially, a “do not attempt CPR” notice was put in place. That example just shows the importance of preparing and supporting people for such discussions, so we want to see a right to advocacy included within the Bill to support people considering their end-of-life options.

Also, building on the previous question about the adequacy of the Mental Capacity Act, there is a question about the adequacy of training, awareness and compliance with that Act now. That is a huge issue that has been addressed, for example, through the Oliver McGowan mandatory training on learning disability and autism, which is rolling out across the NHS and social care services at the moment. However, in addition to the MCA, we also need to make sure that clinicians fully understand the Equality Act and the NHS accessible information standard about rights to information and support for disabled patients.

On clause 5, on training, we want to see much more specificity about the level of training that clinicians would have around the Mental Capacity Act and to make sure that they are fully aware of their responsibilities to make reasonable adjustments for patients, and to support them with understanding their choices around end-of-life care, which could include assisted dying.

Q351 Sojan Joseph: I want to come to you, Michael. The Royal College of Psychiatrists has given a written statement, which says:

“Mental disorders, such as depression, are more common in people nearing the end of their life. Delirium is more common... Hopelessness is a common symptom of depression... And people's capacity and consent can be affected when they are going through this condition.”

In the last few days, we have heard much evidence that expressed concern about capacity assessment and that said, as Dan mentioned, there should be an advocacy service available. Rather than having the current model of two doctors and the court, if we have a panel with experts on it who can consider psychosocial assessment and capacity, would that make the Bill stronger, with more safeguarding being introduced to it?

Dr Mulholland: Sorry—can I check whether that was a question for me at the Royal College of GPs or a question for the Royal College of Psychiatrists, because I think that statement was in their evidence?

Sojan Joseph: The evidence is from the Royal College of Psychiatrists, but anybody can answer the question.

Dr Mulholland: As GPs, we feel that we need a stand-alone service to take people through this process for assisted dying. We do not feel that the GP is in a place to make an assessment of capacity for this process. That is beyond anything that any of us have ever trained in or understood, and it will need people who are trained in assessing capacity at that point. As GPs, we are very used to assessing whether somebody has the capacity to take a course of antibiotics or to be referred for something that we understand, but this is an issue that will require a much deeper level—the Royal College of Psychiatrists has probably thought more on that level about the next steps.

Dr Price: Yes; to refer back to the written evidence, if we think about people with palliative care needs towards the end of life—so the people who would qualify under this Bill—around 20% will have diagnosable depression, around 10% will have a wish to hasten death, and around 4% will have a more persistent wish to hasten death. Those wishes may not be expressed unless they are assessed for. One of the things that I would do in my clinical practice would be to look for treatable mental disorder in people who express a wish to hasten death.

I do not do that alone. You asked about a panel. When I am thinking about the needs of people who are nearing the end of life, and I work with people nearing the end of life most weeks of my working life, I work in a multidisciplinary team. My own small team comprises doctors, nurses and occupational therapists, but I work closely with social workers, the safeguarding lead, chaplains and all my medical and surgical colleagues to make good decisions about my patients in a biological, psychological and social way. Not all difficulties that are psychological can be fixed with a psychiatric intervention.

We would advocate as a college, and I would suggest as a clinician, that good decisions about our patients' needs are made in a multidisciplinary way. That should be considered in the model of how to meet people's needs in whatever way they present, but particularly for people who have difficulties and are suffering in a way that makes them feel that they do not want to continue living.

The Chair: In the interests of time, to allow everybody to ask their question, will Members indicate which of the panel members they would like to answer so that only one gives an answer? That allows everybody to get in.

Q352 Tom Gordon: We have had a lot of conversations and taken a lot of evidence over the last few days about a gag clause to prohibit medical professionals raising assisted dying as part of the options at end of life. We have heard from different states and jurisdictions on whether or not that is something that they had. Broadly speaking, the consensus was that it did not seem to work. Dr Mulholland or Dr Price, I wondered if you had any comment on that.

Dr Mulholland: That is something we have been thinking about carefully at the RCGP. Part of our normal discussion will often open it up for patients to lead discussions around their end of life. We see there could be potential restrictions for that clinical consultation with a gag order. We very much follow the opinion I heard from Dr Green from the British Medical Association earlier in the week. We go along with that.

We are very protective of our relationship as GPs, and want to give patients the options that they might want to choose for themselves. We are not usually pushing anyone to any decision, but supporting them through their end-of-life journey. We would want to protect that in whatever way, so we therefore feel that a service we can signpost to would be the most appropriate thing as the next step.

Dr Price: As a psychiatrist and as a representative of the psychiatric profession, it is noted in the Bill that mental disorder is a specific exclusion. It is very unlikely that a psychiatrist would suggest or bring up assisted dying in a conversation.

I think a concern allied to that is people with mental disorder who request assisted dying from their psychiatrist. It may be clear to all that they do not meet eligibility criteria for that, but it is not absolutely clear in the Bill, as it is written, to what extent a psychiatrist would have to comply with a wish for that person to progress to that first assessment. There is quite a lot involved in getting to that first official assessment, such as making a declaration and providing identification. A psychiatrist might therefore have to be involved to quite an extent in supporting that person to get there if that is their right and their wish, even though it may be clear to all that they do not meet eligibility criteria if that is the primary reason for their asking to end their life.

Q353 Jack Abbott: My question is also for you, Dr Price. The Royal College of Psychiatrists has been really clear in its statement that we as parliamentarians have to consider the outstanding questions about a person's capacity to decide to end their own life, and

whether it can be reliably assessed, and you particularly cite the implications for those with mental disorders, intellectual disabilities and neurodevelopmental conditions. Do you believe that anyone requesting assisted dying should be assessed automatically by a psychiatrist, or that certain criteria should have to be met for a psychiatric assessment to be undertaken?

Dr Price: If I take you to thinking about what an assessment of capacity would normally look like, if we think about clinical practice, a psychiatrist would normally get involved in an assessment of capacity if the decision maker was unclear about whether that person could make a decision. The psychiatrist's role in that capacity assessment would be to look for the presence of mental disorder, and at whether mental disorder was likely to be impacting on that person's decision making. They would advise the decision maker, and the decision maker would then have the clinical role of thinking about that information and assessing capacity with that in mind.

Psychiatrists sometimes assess capacity and make the determination, but it is usually about psychiatric intervention and issues that are within their area of clinical expertise, such as care and treatment, capacity assessment around the Mental Health Act 1983 and whether somebody is able to consent to their treatment. In the Bill, I am not absolutely clear whether the psychiatrist is considered to be a primary decision maker on whether somebody should be eligible based on capacity, or whether their role is to advise the decision maker, who would be the primary doctor or one of two doctors.

Should a psychiatrist be involved in every case? If there is a view that psychiatric disorders should be assessed for, and ideally diagnosed or ruled out, in every case, a psychiatrist might have a role. If they are seen as an expert support to the primary decision maker, that decision maker would need to decide whether a psychiatrist was needed in every case. We know from Oregon over the years that psychiatrists were involved very frequently at the beginning of the process, and now they are involved by request in around 3% of completed assisted dying cases. We do not have data on what the involvement is across all requests.

Q354 Dr Opher: Conveniently, my question follows on from that. On our first day of evidence, we had Chris Whitty, the chief medical officer, saying that when you are assessing capacity, the vast majority either clearly have capacity or clearly do not, and there is a small section in the middle. Michael, would you say that a role of a GP would be to inform those definite yeses and definite noes, and then they would perhaps not have the skills for the intermediate ones? I am just suggesting that.

Dr Mulholland: As GPs, we can assess capacity. In this situation, the college's position would be that we feel the GP should not be part of the assisted dying service, so we would see a standalone service that we can signpost our patients to. The GP role may go on to a different route afterwards, and it may be part of other things with palliative care and looking after the families. We think that some GPs may want to be involved and take that step, but we know from our membership surveys that we have had at least 40% of members in the past who would absolutely not want to have any part in that.

Similar to other services, such as termination of pregnancy, we think that the best option would probably be that the GP could signpost to an information service, such as something like what the BMA suggested the other day. They would not have to do anything more than that, and they would not withhold any option from the patient. We could discuss that these things exist, but we would not be doing that capacity assessment. Obviously, to give patients information about what they are going to, as you know, we would assess their capacity to take that information in, retain it and do the right thing with it for them. We would be doing that level of capacity assessment, but not further on in the process, where you are assessing whether a patient is able to make a final decision. I think Chris Whitty referred to the various levels of capacity. As the decision gets more difficult and complex, you want a greater understanding with the patient that they really know the implications of what is going on, and we just would not be doing that in general practice.

Q355 Daniel Francis: My question is to Dan Scorer. In the Mental Capacity Act 2005, the definition of “capacity” means that many people with a learning disability are presumed to have capacity. We have heard comments from others on the panel, and I am trying to understand whether you feel that the existing provisions in that Act would cover those with a learning disability or whether you would need that greater advocacy, as you discussed, or something different from the Act. Do you have any comments on the fact that family members—lifelong carers, in many cases—would have no requirement, under the Bill or the Act, to be involved in the decision or to comment on their family member’s capacity?

Dan Scorer: The Mental Capacity Act starts from the principle of presuming capacity. The question would be whether, when someone who is terminally ill puts themselves forward for assisted dying, doubts start to emerge about whether they actually have the ability to make that decision in terms of whether they can understand, retain or weigh the information and communicate their intentions.

As I mentioned earlier, our concern is how those discussions around assisted dying are initiated. For many people with a learning disability who are terminally ill and in an incredibly vulnerable position, doctors are very important and influential figures. Having a doctor come to you and say, “What do you think about assisted dying—is that something you might want to consider?” could move them towards or into potentially accepting a course of action that they had never considered before.

That is why I was saying that it is about having advocacy support around that discussion and, as you were saying, about the role of families. Individuals should be able to choose who supports them with those discussions, whether it is friends or family members or an independent advocate—that would probably be our preference—who is specifically trained to support people with a learning disability who are considering their end-of-life options.

There is a lot that could be done in addition to what is in the Bill already to potentially much better support people who are considering end-of-life options and to have other professionals who could input into multidisciplinary discussions, potentially around capacity assessment.

Q356 Kim Leadbeater: I take that on board fully, so thank you for those helpful comments. In terms of capacity assessment, point 12 in the feedback and the written evidence from the Royal College of Psychiatrists mentions having multiple opportunities to assess capacity. To provide reassurance on that, those are in the Bill—I think there are four or five opportunities to assess capacity.

My question relates to point 15 in your written evidence, around the Human Tissue Authority. This is a model I looked at in terms of the decision making on coercion and capacity around people involved in organ donation. Can you tell me a little about that, and whether you think that there are parallels? It is a very serious decision, so we are in that territory. This is about what that looks like and what the role of psychiatrists is. We have talked a little about this already, but if we were to take this multidisciplinary approach, which I think is really powerful, what should the role of psychiatrists be?

Dr Price: On the role of an oversight group, one of the risks with individual practitioners doing these sorts of assessments is that they may do it once or twice in their career. What we know is likely to happen is that a smaller number of practitioners will do lots of assessments and build up individual expertise. However, it might be that a particular practitioner does this only for a patient who they know, or only a few times. Therefore, in terms of building up through repetition the sort of expertise that somebody such as me might have in the mental healthcare of an older person—thousands of patients over a couple of decades—an external group that understands the standards and the process should be able to scrutinise things at the time.

There are a number of bodies that do that not just for organ donation, but across lots of different services. We have them for liaison psychiatry, and they might have them for electroconvulsive therapy services, for example. They are not extraordinary or unusual, but they ensure that there is some consistency and reliability and that the assessments are of a standard. Scrutinising assessments after somebody has completed the process is useful for everybody who comes afterwards; it may not ensure that the quality was there for that individual. That would be the rationale for that sort of approach. Forgive me, but would you ask me the second part of your question again?

Q357 Kim Leadbeater: I think you have answered it, but it was whether there was any specific detail about the Human Tissue Authority, how it operates and what that looks like.

Dr Price: I do not have lots of individual experience with that group, because I do not work within a specific service. But it is an example of a model that is in operation, and hopefully I have described the sorts of characteristics and why they are there.

Q358 Dr Shastri-Hurst: My question is directed to Dr Mulholland. Thank you to the Royal College of General Practitioners for the helpful written evidence. I want to pick up on something in it, which is summarised in paragraph 6 but gone into in more detail in paragraph 7, and that is around the refusal of practitioners to engage in the assisted dying process. I note the wording that has been used by the Royal College, which is that GPs and

any other healthcare professionals can refuse “on any ground”. That is distinct from the Abortion Act 1967, which in section 4(1) sets out that it can be a conscientious objection. Can you explain why you have decided to take what appears to be a broader expansion of that definition, and why you have chosen that particular wording?

Dr Mulholland: We are aware that we have a range of views in RCGP across general practitioners. Some of them have very strong views for or against based on moral grounds, and some of those are based on religious grounds—traditional conscientious objection grounds. But others do not want to take part in assisted dying just because they do not want to; they do not feel it is part of what being a GP is, or part of what they trained for.

In discussion with colleagues today, someone shared with me that for 35 years they have spent their time trying to extend the life of patients—that has been our role—and to help them towards the end of life. It is a philosophical change if they start to think about whether the patient’s life should end earlier. There are some colleagues who may decide that for those reasons, they do not want to take part in this. There will be others who very definitely do. We have that range, so we feel that a doctor or a health professional should have the right not to take part on any ground, and that should be protected—they should not feel the obligation to do something that they do not feel is within their wishes.

Q359 Naz Shah: My question is to Dr Price. We heard yesterday from Professor House and this afternoon from Professor Owen, who were talking about capacity and coercion. They also talked about how different people’s life experiences impact their ability and their state of mind, and the lack of research or evidence in that area—the courts are grappling with those issues at the moment. Is there any evidence about the effect on patients’ mental health when they have a diagnosis of a terminal or serious physical illness?

Dr Price: There is a lot of research evidence around depression in people with palliative care needs and people nearing the end of life. We know that depression is common, and across a number of studies it is at around 20%—much more common than in the general population. We know that depression is strongly associated with a wish to hasten death, and that if depression is found and treated in that group of patients, there will be significant change in the wish to hasten death.

There are a number of associations other than depression with a wish to hasten death, and they include difficult symptom experience, poor functional status—needing a lot of help with things—and being socially isolated. Those are really key ones. They also include a sense of loss of dignity and feeling like a burden on others. These things can all come together to make life feel very unbearable. We know that there is also an overlap between a wish to hasten death, which is a response to suffering, and feeling that one is better off dead, ending one’s own life or harming oneself. I was involved in a study where we asked people both the wording of “a wish to hasten death” and the suicide question from the PHQ9, which is a depression screening tool. Those who had a wish to hasten death were 18 times more likely to

also feel suicidal, according to the psychiatric definition, than people who did not have a wish to hasten death. There is a strong association.

Q360 Lewis Atkinson: My question is for Dr Price as well, please. We heard in the week from the chief medical officer earlier, who said that he was “relieved” that this Act based capacity on the Mental Capacity Act, noting that it already provides that

“the more serious the decision, the greater the level of capacity”—*[Official Report, Terminally Ill Adults (End of Life) Public Bill Committee, 28 January 2025; c. 30, Q3.]*

and that it is used in tens, if not hundreds, of life and death cases in the NHS every week. The example he gave was someone refusing blood products that they would need to continue their life. In the light of that, I suppose I am a bit confused about your evidence saying that the MCA is not suitable for life or death decisions of this type. Do you think the MCA is not fit for purpose for those current life or death decisions that are being made, or is there something about the life or death decisions that would be made in an assisted dying context that makes that different?

Dr Price: The assumption that the Mental Capacity Act can translate neatly into this specific decision without a really clear sense of what that would look like in clinical practice is something that needs more careful thought.

I was involved in research in this area, and one of the things that I did was to scrutinise the concept of capacity as discussed in a number of forums—for example, the Commission on Assisted Dying, discussions in the House of Lords, and also interviews with doctors in England and Wales and in Oregon. There is a broad sense of what capacity is. For some, it is a very tight, cognitive definition that would mean that in practice, in assisted dying, most people would be found to be capacitous. Those who advocate a much broader sense of what capacity is—these can be contained within the framework of the Mental Capacity Act—would advocate a much broader sense of what that is, thinking about values and the person’s life experience and making more judgments, really, about that person’s life in a general sense.

What I do not think we have really pinned down is what concept of capacity is operating in the thoughts behind this Bill. Is it enough to say that we will essentially refer to the Mental Capacity Act, or do we need to be more specific about what is capacity for this decision? Is it sufficient to say, “We will refer out”, or do we need it on the face of the Bill so that anybody assessing capacity for this decision knows exactly what they should be doing and exactly how they should be having that conversation? Even though you may be operating within a legal framework, I think that the actual conversation—the actual content—will vary across practitioners. Is that good enough? Is that sufficient? Is that a good enough standard? When I do a capacity assessment, I have in mind that it may be appealed against—that is somebody’s right—and it should be available for scrutiny by a court. Essentially, that is the standard we are looking for, so it needs to be clear where the standard lies.

Q361 Kit Malthouse: I also want to explore this issue of capacity a little further with Dr Price, because I share my colleague’s slight confusion.

[Kit Malthouse]

You talked about a percentage who wish to hasten death. The people we are talking about are facing death in any event within a foreseeable period, and they may be contemplating a death that is not pleasant. Some of the characteristics you talked about are presumably to be expected and may not necessarily interfere with their ability to make rational decisions in what they believe is their own best interest. In those circumstances, I do not understand why the Mental Capacity Act would not apply. I understand that you may be coming at it from a practitioner point of view, but if I make a decision to decline treatment to hasten my own death, I am not sure I would necessarily see that as qualitatively different, from the point of view of my own capacity, from saying, “I know I am going to die in three months’ time and I would like you to assist me to die slightly earlier.” Why are the two qualitatively different, from an MCA point of view? At the moment, one would be dealt with through the MCA, but you are saying the second would not necessarily be.

Dr Price: You are equating a refusal of treatment, in capacity terms, to hastening death by assisted dying. If those two things are equated, in terms of the gravity and the quality of the decision, the Mental Capacity Act may well be sufficient, but there are differences. There are differences in the information that the person would need and what they would need to understand. They would need to be able to understand the impact of the substance they are taking and what the likely positives and negatives of that are—all of those things.

The informed consent process is different from a refusal of treatment, and the informed consent process feeds into the capacity assessment. This is an area where we need to think carefully about whether the processes of the Mental Capacity Act, as it stands, map neatly enough on to that decision to make it workable.

Q362 Rachel Hopkins: Dr Mulholland, I want to push a little on where you were saying the royal college sits on the ability of members to say that they would not want to participate in assisted dying, if it came through, and on your written evidence saying that you would like to see a separate body. Given that many GPs are already very much involved in the care of their patients and will often be doing a lot of palliative care themselves, particularly around medications, and given that the Bill is about terminally ill adults with a diagnosis of six months left to live, do you mean that all GPs would stop at that six months and it would go over to an independent body, or are you saying that those GPs who want to continue that care could do so but that those who do not want to be involved in a potential route to assisted dying would step out? I would like a little clarity on that, given the person-centred care that so many GPs do so well.

Dr Mulholland: The shape of the service is not set out in the Bill. We would say that GPs need to have a space where they can step away from it: that is the key point that we want to get across. For those who want to take part, it may be that they decide to do it, but it would have to sit outside the core general medical services that we provide at the moment. This is an additional thing; this is not part of our core job. We think that a separate service—it may not just be GPs; there may be lots of different practitioners and health professionals involved

—would sit better with that. You could then assess the capacity and assess those other parts that are so important and are in the Bill at the later stages.

The GP may have a role, but that would be very much up to the individual GP to decide. It would not be set out that they should be taking part. They would then probably be part of this additional service to which the others who are not taking part could signpost. We just want to make sure that there is that clear space.

The Chair: As we have time, I call Danny Kruger.

Q363 Danny Kruger: Following straight on from that, do you imagine it to be an NHS-funded service if it is outside core general practice? If so, what might the implications be for resourcing, assuming that it was funded out of general NHS resources? In the practical terms of the Bill, what do you think of the provision that the co-ordinating doctor must remain present with the person until they die, bearing in mind that that might take some hours? I am interested in your view on the implications for resourcing the service.

Dr Mulholland: Fortunately, that is not the RCGP’s bit, but I think we would be very much concerned. In our principles, we were clear that we thought that there should be no reduction in core services in general practice, nor should there be any reduction, if the Bill goes through, in funding to palliative care services, which we know are often struggling as well. This should therefore be additionally funded. Whether it occurs in the NHS is not our decision, but we would be very concerned about health inequalities creeping into any part of the health service. We are aware of the differential that occurs in lots of things—life expectancy has come out again in recent reports between different parts of the country and people who live with different levels of poverty. If the Bill comes through, we will want to make sure that there is not a differential in who is able to access it. Whether that says that it should be NHS or private I am not sure, but that needs to be considered as part of whatever comes out of this.

Q364 Dr Opher: I would like to go back to the point about depression, because it is common. In the general population, 20% are on antidepressants—on SSRIs. GPs diagnose the vast majority of depressions. Dr Mulholland, what are your thoughts on whether checking for demonstrable depression should be a standard part of the assessment before you refer people into the service? The idea of getting a psychiatrist who wanted assisted dying to see every case, given how difficult it is to see a psychiatrist in the NHS at present, would really limit the service.

Dr Mulholland: We see a lot of people with mood disorders of different types and of different severities. Many people with depression who are treated with antidepressants carry out full-functioning jobs and lives because of the treatment that they have and because their depression is not of that severity. If someone had very severe depression and we were accessing our psychiatric colleagues, that would be a different decision, and perhaps it is not something that would happen at that point. Most people with depression, anxiety and other mental health problems would have capacity, because we would presume it under the Mental Capacity Act, so it is not necessarily an obstruction to people being referred for anything.

Q365 Kim Leadbeater: I will stay in the same territory, if I can. The Bill includes, very clearly, an opt-in model for doctors. I took that from the BMA, which was very clear on that, and I think it is very important. My slight concern, on which I would like you to expand, is about the removal of assisted dying from the holistic approach to end-of-life care and conversations that GPs have all the time—as do other healthcare professionals, including nurses, as we have heard this week. Where this works well in other jurisdictions is where it is integrated and where we talk about palliative care, we talk about decision making and we talk about choices. I would appreciate your thoughts on that concern.

On capacity, just to reflect on the previous panel, my view is that psychiatric assessment would not be necessary in every case. We have heard from three families this afternoon; we can probably all agree that there was a clear wish from those individuals that this was the choice they wanted to make. I agree with the colleague who said that there will be a percentage of people; that is why I think referral to a psychiatrist is important in those cases. Have you any more thoughts on that, Dr Mulholland?

Dr Mulholland: As GPs, yes, holistic care is what we do—whole-person, biopsychosocial care. If we got into an end-of-life discussion with a patient and they expressed a wish to go through a route of assisted dying, should that be legal, that might still be part of a discussion that we would have with them. It is the active part of the process. The BMA referred to the word “refer”—referring to a colleague, for those who did not want to do it. We agree that signposting is a better process.

We would not want to be out of the patient’s life. It is very difficult to be out of a patient’s life, but it may be that we are not part of that particular aspect of their care. It is the same when we refer to surgeons and hospitals; they have an episode of care elsewhere. This would be another episode that someone might be undertaking for that person. We will still have the families that we are part of; we will still be caring for them as well. We do not see them leaving general practice or general practitioners, but the assisted dying part of their health journey, or death journey, would perhaps be outside some people’s experience or expertise. You would need experts and people trained in it to be doing it, and not necessarily every GP.

Dr Price: No matter what somebody’s reason is for entering the process or what the outcome is, we are very clear that anybody should be able to access really good evidence-based care so that this should not in any way derail, deflect or make people not think about really good care. People should get really thorough assessments, have the right professionals involved in their care and have treatment where they need it and would benefit from it. All the quality that we have and all the guidelines that we work to should still be adhered to. We should still be providing all of the other good-quality care that we can. It is important not to bypass that and not to take shortcuts because they have made that decision.

The Chair: There are three people left who want to ask questions, so can I beg for brevity?

Q366 Naz Shah: Under clause 4(2), doctors would be allowed to raise the issue of assisted dying with a patient, unprompted. Dr Rachel Clarke gave evidence to this Committee that, in some circumstances,

“The very act of raising assisted dying in that way will make that vulnerable patient think, ‘God, is this doctor telling me that my life is not worth living any more?’”—[*Official Report, Terminally Ill Adults (End of Life) Public Bill Committee*, 28 January 2025; c. 75, Q93.]

We heard from Dr Jamilla Hussain yesterday. She talked about mistrust of the NHS, particularly post-covid, where people had DNRs attached to them—disabled people and people of ethnic minority backgrounds in particular. Dan, are you concerned about the potential impact on people with learning disabilities?

Dan Scorer: Yes. One of the first things that I said earlier was about how the initiation of that first conversation is potentially an extremely risky and dangerous moment for people with a learning disability who are terminally ill. Your question is absolutely spot on, from the point of view that it could be highly suggestive and push people on a course that they may not want to go down. That is why I am suggesting that that initial conversation has to be incredibly well supported and structured.

There should, in our view, be an advocate who is supporting the person and preparing them for that discussion. Under the principles of the Mental Capacity Act 2005, the person should have accessible information in advance of that discussion so that they are fully informed about all their rights in terms of treatment options at end of life. That discussion with a clinician should not be taking place until the person has been able to consider that information and have support from an advocate, so when the conversation does happen the person is fully informed and has had time to think about what their wishes might be. That would reduce the risk, which is absolutely there, that people could take the initiation of that discussion as a statement, “This is what you should do.” We absolutely do not want people to be in that position. We want strong safeguards and support in place if the Bill becomes law.

Q367 Dr Tidball: Dan, I am really keen that we ensure that if the Bill passes, the voices of disabled people are continually involved in understanding its impact, particularly on the issue that you have just raised. Earlier, we heard evidence about implementation taskforces that are used in other jurisdictions. I am considering tabling an amendment on an advisory council. How might we ensure that the voices of people with learning disabilities can be included in such a body?

Dan Scorer: There are a couple of things that I would like to say in response. One is about clause 31, on guidance from chief medical officers. Immediately, I would say that people with a learning disability should be involved in the development of that guidance from chief medical officers. That guidance will be key to many of the issues that we have discussed.

Clause 35 is about the review of the Act. The lived experience of people is absolutely vital to that. The Bill says that it will be five years until we have that review. Our view is that that is far too long. If the Bill becomes law and if there are really serious issues and discrimination taking place against people, we will want to know that a lot earlier than in five years’ time, and we will want action to be taken. Our suggestion is that review should be earlier. We would want to see strong representation from patient groups across that, as well as from people who have been involved in the process, such as family

members, advocates and clinicians, to make sure that if serious issues are being raised, they can be picked up early and addressed.

Q368 Lewis Atkinson: It is late, and I am far from being an expert on Welsh devolution, but I want to ask Professor Lewis a question, not least because we have not come to him for a little while.

Although it is not my area, I absolutely note the concerns and the discussion about respecting the democratic will of the Senedd in these matters. Would you suggest any potential avenues in the Bill to incorporate an element of positive affirmation by the Senedd, or its consent? What do you suggest we look at?

Professor Lewis: Formally, there is a need in any event for a legislative consent motion in relation to the specific bits I mentioned earlier, I have suggested one potential avenue, which is that the Senedd and Welsh Government take on responsibility for whether and when the Act commences in Wales. Another option might be to do a thorough “think once, think twice, think Wales” review to see to what extent other functions of the Secretary of State might be better exercised in Wales by the Welsh Ministers. That is a non-exhaustive list, but I hope it helps.

Q369 Naz Shah: Dr Price, you talked in your earlier evidence about depression. One Committee member suggested that 20% of people were on antidepressants; actually, the factual position is that 10% to 11% of the adults in this country are on antidepressant medication, according to the latest statistics. To be clear, are you saying that people who are depressed are more likely to ask for or go down the road of assisted dying?

Dr Price: The evidence that we have from research—this is in populations who would fulfil the criteria in terms of terminal illness—is that the prevalence of depression is around 20%. That is across a number of populations. It is associated with a wish to hasten death. Depression might impact upon that person’s decision making; I am not saying that it absolutely would, but it might. Also, treatment might change their view. We know that there is a strong association, for example, between pain and a wish to hasten death. Unresolved physical symptoms make people want to die, and when that pain is better, people no longer feel that way.

That is borne out in my clinical practice. We will get urgent referrals to see somebody who wants to die and who they are very concerned about. Then the pain is under control: we see them that day or the next day and they say, “Do you know what? The pain’s better. I don’t feel like that any more.” When we think about symptoms, we need to think carefully about what is treatable and what is remediable. That may be about psychiatric interventions, but it is often about a biological, psychological and social approach.

The Chair: May I thank the panel for giving evidence today? We really appreciate your attendance.

Daniel Francis: On a point of order, Mrs Harris. Yesterday, we heard evidence about the impact of the Bill on different groups with protected characteristics, including age, disability, race and sexual orientation. We heard from the EHRC, an arm’s length body of the Government, that it strongly recommends that a full

impact assessment, a human rights assessment and a delegated powers memorandum be undertaken before the Committee begins line-by-line scrutiny.

We have also heard from witnesses about the impact that the Bill will have on disabled people, from Disability Rights UK and others, on black and minority ethnic people, from Dr Jamilla Hussain, from LGBT people, from Baroness Falkner, and on those from a low-income background, from Sam Royston of Marie Curie. We heard from Dr Sarah Cox and Dr Jamilla Hussain that evidence from their work shows that this Bill has a higher probability of pushing minority groups further away from seeking healthcare, while inequality pre-exists. As observed through the pandemic and from available data, minority groups do not always trust that their interests will be best represented in institutions that would enable the facilitation of someone’s death, should this Bill become law.

I therefore believe that on the basis of that advice, so as not to inadvertently widen health inequalities through Bill, it is essential to have health impact assessments. I appreciate that an equality impact assessment will be produced for Report stage, it will not be available for detailed line-by-line scrutiny. When we agreed the timetable for line-by-line scrutiny last Tuesday, we were not aware that this assessment would be produced, given it was first reported to the House during the money resolution last Wednesday. There is a risk that there will be a bigger impact on people with protected characteristics, and this will not be understood fully until the Government have produced the equality impact assessment. As things stand, that means that we will move into line-by-line scrutiny of the Bill on 11 February without a full understanding from the assessment of the impact of the Bill.

I am therefore minded to request a short Adjournment of the Committee so that, as advised, we can receive the assessments before we progress to line-by-line scrutiny. Please will you advise me, Mrs Harris, how I could secure such a motion to adjourn the Committee until we are in receipt of the evidence, as advised by the witnesses yesterday?

Sarah Sackman: Further to that point of order, Mrs Harris. I want to clarify the Government’s position. As the Committee knows, the Government are neutral on the Bill, but once the Committee has concluded its work and prior to Report, we are committed to publishing the ECHR memorandum, a delegated powers memorandum, the economic impact assessment that was committed to during the money resolution debate, and an assessment of the equalities impact of the Bill. In terms of the timing, it is necessary that the impacts that are assessed be of the Bill as it is brought forward. If the Bill is liable to change via amendments proposed by members of this Committee, it is important that we know what it is that we are assessing the impact of. That is why the proposed timing is to publish the impact assessment at that stage. The point is that before Members of the House come to a vote on Report and Third Reading, they will all have before them the impact assessment in respect of equalities and all those other aspects of the Bill.

Danny Kruger: On a point of order, Mrs Harris.

The Chair: I am going to proceed now. I thank the hon. Member for Bexleyheath and Crayford for notice of his point of order. I am sure that the Member in

charge and the Government have heard his points. If he wishes to look at procedural options, he should consult the Clerks in the Public Bill Office.

That brings us to the end of today's sitting. The Committee will meet at 9.25 am on Tuesday 11 February to begin line-by-line consideration.

Ordered, That further consideration be now adjourned.
—(*Bambos Charalambous.*)

5.2 pm

Adjourned till Tuesday 11 February at twenty-five minutes past Nine o'clock.

