HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Assisted dying/assisted suicide, HC 711

Tuesday 4 July 2023

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Watch the meeting

Members present: Steve Brine (Chair); Paul Blomfield; Chris Green; Rachael Maskell; James Morris.

Questions 237 - 300

Witnesses

I: Dr Paul Perkins, Chief Medical Director, Sue Ryder; Dr Matthew Doré, Honorary Secretary, Association for Palliative Medicine of Great Britain and Ireland; and Jonathan Ellis, Director of Policy, Advocacy & Clinical Programmes, Hospice UK.

II: Helen Whately MP, Minister of State, Department of Health and Social Care; and Professor Stephen Powis, National Medical Director, NHS England.

Examination of witnesses

Witnesses: Dr Perkins, Dr Doré and Jonathan Ellis.

Q237 **Chair:** Good morning. This is the Health and Social Care Committee live from the Palace of Westminster in London and our fifth oral evidence session for our assisted dying/assisted suicide inquiry, which, as our guests and viewers will know, is of huge interest. There is huge public interest and huge parliamentary interest. This morning we are looking at the provision of, and access to, palliative and end of life care in England.

When we move on to our second panel at about 10.45, we will hear from the Minister and NHS England's national medical director. Before that we have Dr Paul Perkins, who is the chief medical director at Sue Ryder; Dr Matthew Doré, who is honorary secretary at the Association for Palliative Medicine of Great Britain and Ireland; and Jonathan Ellis, the director of policy, advocacy and clinical programmes at Hospice UK.

Thank you very much for joining us. We are grateful to you for giving up your time. I am sure you are aware of how much work we have already done on this inquiry. You have seen some of the coverage of it. You may even have read some of the transcripts from the evidence sessions that we have had here. We have also visited the United States. We have been to Oregon, the first state in the US that legalised medically assisted dying.

What we want to explore with you is end of life medicine. Mr Ellis, where would you rate palliative care in England today if you had to land it somewhere between nought to 10? Would you say that it is higher than five or lower than five? Where would you land it?

Jonathan Ellis: That is a very good question. I think I would land it higher than five, certainly. Internationally, the UK is frequently rated as among the best in the world in its provision of palliative and end of life care. However, that is not to say that everything is perfect. We know that there are huge inequalities. There are huge gaps and unmet needs that exist within our communities. The one thing that we cannot do is be complacent about the quality and availability of that provision.

Q238 **Chair:** Dr Doré, where would you land it? Would you say that we are in a good place in England?

Dr Doré: Historically, we have a very good history of it, but I do not think we are in a good place. We have a population in England and Wales of 58 million; that is 10 million who are over 65 and it is going to increase to 16 million by 2037 according to ONS figures. That is going to be a 60% increase in workload, essentially, to transfer to palliative care.

We have evidence from Fliss Murtagh's paper showing that 69% to 82% of patients are going to need specialist palliative care. We have a diminishing workforce who are really struggling. On top of that, it is predominantly funded by the charitable sector. One third is commissioned by the state; two thirds, as my esteemed colleague from Sue Ryder will

say, is charitably funded. By the way, the workforce report just last week does not even mention the charitable medical workforce at all. We have acceptance of a charitably funded sector that is going to breed an element of inequality because it is charitably funded. It is feeding for its charitable donations as opposed to a state funded-system, which I think we all really want.

Q239 **Chair:** Following that, to what extent do you feel—or maybe you don't—that it is not in a very good place, to quote you? To what extent do you feel that that drives the agenda of those who would like to see a change in the law around medically assisted dying?

Dr Doré: It is bonkers that we are talking about having an assisted dying/assisted suicide Bill that would be 100% commissioned and funded by the NHS when we leave the palliative care sector to be funded by the charitable sector. That is the state essentially endorsing death while not funding and paying for palliative care.

To phrase it another way, I think the main proponents of this are regarding choice: my body, my choice. I know that you know the law a lot better than I do, but my understanding of the law is that there is individual autonomy versus public safety. For example, when I flew here I could not open the door to the aeroplane. I cannot choose to do that because it kills everyone else. That is the same reason why we have speed limits. We have a 30 mph speed limit because it is the individual autonomy of driving a car versus public safety in the street. If you are driving at 100 mph, you get arrested because you are a risk to other people. The main argument I would put forward to the esteemed Committee regarding assisted dying/assisted suicide is that it is a public safety issue. If you legalise it, you risk the wider majority of the population.

If it pleases you guys, I would love to bring the historical precedence behind that. The historical precedence, I believe, is in capital punishment. As you know, that was abolished in 1973 based on the fact that there were errors. We hung people who were subsequently proved to be innocent. That was with a full judicial process. There were judges, juries and beyond reasonable doubt and months of deliberation. Despite that we got it wrong.

What we are talking about here is two doctors making that choice so many weeks apart—two doctors who do not have access to all the things that judges and juries have to make their decision. You could say that it is their choice, but diagnosis is uncertain. We have a spate of MND diagnoses that are wrong. Prognosis, as is very well documented, is uncertain. Autonomy is relational; it is who you have around you. We know that one in five have hidden elder abuse. We know these numbers.

Essentially, we have a situation in which you are going to advocate, and there will be, incorrect deaths. My question to you guys is: how many incorrect deaths justify the fact of the right to pre-emptively kill yourself

early? The APM position, by the way, is that we are against this in healthcare, and certainly in palliative care.

Q240 **Chair:** Thank you for that. Dr Perkins, can we hear from you finally in these opening exchanges? By all means tell us whether you think we are in a good place, a bad place or a middling place, but to what extent is it just a moral question that people do not wish to extend their life or extend into palliative care? They wish to exercise the choice to find the exit door. We have heard from plenty of people who have said that to us. In our roundtables and anecdotally talking to constituents, I have heard that said to me many times. To what extent is good or bad palliative care driving this debate?

Dr Perkins: I work for Sue Ryder. We are a national charity. We have seven specialist palliative care centres, four neurological centres and a national bereavement service. We are not campaigning for or against assisted dying. We are passionate about good palliative care for patients and their families. It is such an important time in people's lives.

As for giving a score as a nation, I think it depends where you are. If you are lucky enough to be in a hospice, it is a nine. The care is fantastic. The CQC ratings for hospices are very good. If you are in some parts of the country or in some hospitals, you are going to get a low score. The care is patchy.

One of the big stresses for patients and families is in the middle of the night when they have pain and are distressed. They call for a district nurse and for advice. In Marie Curie research last year 27% of the country does not have a dedicated advice line, where you can get through to someone sensible. You end up calling 111 perhaps and an ambulance comes and takes someone to A&E. Then someone ends up dying in A&E, which is not what you want.

I can tell you a story about my mother. My mother died of covid and dementia in a care home. A couple of years before she died, she fell and banged her head. The care home rang me and said, "She is on blood-thinning medication, she has banged her head and has to go to hospital." My mum was a very clever woman. She was a headmistress and had been a teacher. She would have hated anything to extend her life. She would not want to go to hospital. I said to the care home, "Please don't take her to hospital." They said, "No, we have to." I spoke to the paramedics and said, "Please don't take her to hospital." They said, "No, we have to." I called the on-call GP and said, "Please don't take her to hospital." He said, "No, we have to." I said, "I am a palliative care consultant. Please. I am advising people about these kinds of things all the time." He said, "It's not a palliative care case."

We have to do so much better at educating people about palliative care and end of life issues. I knew that if my mum went to hospital and had a head scan, even if there was a bleed, there was no way a neurosurgeon was going to do anything about it. It was completely pointless. Palliative

care improves people's quality of life and can stop pointless interventions like that happening, if we were just better resourced.

Chair: Fascinating. I wish you would all say what you think. Thank you. Those were really good opening exchanges. I will bring in Chris Green.

Q241 **Chris Green:** Mr Ellis, most funding for hospices comes from charity donations rather than national health service commissioning. Do you think that the current balance is right? I think about a third comes from the national health service. Can you also comment on the patchy nature around the United Kingdom of hospice coverage?

Jonathan Ellis: Absolutely. I would say very simply, no, I don't think the mix is right. Hospices, as Dr Doré said, rely on charity donations for the vast majority of the care that they provide—fun runs, charity fundraising and bake sales to fund what, in any reasonable perspective, is a core healthcare service. It is care for some of the most vulnerable people at the most vulnerable point in their life.

Q242 **Chris Green:** If it is not a third or thereabouts, what should it be?

Jonathan Ellis: The right question to ask is, what is the mix of services that we need to meet the needs in the population? Most people who die each year will never come anywhere near a specialist palliative care service for lots of different reasons. Most people who die will be supported by their GP, by private care, by their family or by their loved ones. They are very often the people who miss out on expert intervention and could benefit hugely from that expert intervention.

I believe that what we need to do is increase the size of the pie that is available to meet those needs in our populations. I point to this example. Picture a person with complex palliative care needs. There is a fundamental inequality at the moment. How that care is resourced depends entirely on where that person happens to be. If the person is receiving their care in a hospital bed, of course it is 100% funded through our taxpayer-funded healthcare system. If that person happens to be receiving their care in a care home bed and has assets, the chances are that they will probably have to sell their home to pay for that care. If they are receiving their care in a hospice bed or in a hospice-at-home service, they are reliant on charitable giving. There is a much bigger question about the priority that we, as a health and care system, are placing on an essential and core part of the health and care service.

Q243 **Chris Green:** When I talk to local hospices near me, they quite like their independence. If they were wholly or largely run by or funded by the national health service, they feel that they would be more restricted in what they could do and how they would operate. How important do you think those concerns are?

Jonathan Ellis: That is a very understandable perspective. There is enormous benefit and value from the charitable contribution. There is the ability to innovate and experiment. In fact, the whole basis of the hospice

model when it was first envisaged by Dame Cecily Saunders, the founder of the modern hospice movement, was to fix dying outside the NHS and then put it back. The bit we have never done is the putting back and the mainstreaming of good care at the end of life throughout the health and care system.

Q244 **Chris Green:** What is your understanding at the moment? We have the integrated care system and the integrated care boards. With the hospice movement not being part of the national health service, and with funding pressures on the national health service, the systems do not quite recognise or support the hospices because they are going to look after themselves—the NHS—before they look after those guys over there.

Jonathan Ellis: That is a characterisation I would definitely recognise. There is enormous variation around the country in the priority that is given to hospice and palliative care in integrated care boards, and the resources that are therefore made available. As Dr Doré mentioned, we had the workforce plan published last week. It spoke exclusively about the NHS workforce and completely ignored the enormous workforce that exists in the voluntary sector, particularly in voluntary hospices, who are an essential part of helping the NHS deliver the very best care in those communities.

There is enormous variation among integrated care boards. There is enormously variable commissioning quality by the NHS of hospice services. I think there is much more that we need to see Government do to reduce those inequalities and to mainstream hospice and palliative care services.

Q245 **Chris Green:** Can I ask Dr Doré and then Dr Perkins briefly about the relationship between the hospice movement and the national health service. Should it be closer? Should it be more integrated? Do you see any dangers with that?

Dr Doré: It should be more integrated. There should be more money poured into it. If you think about it logically, we fund birth in the NHS. We fund loads of things that not everyone gets. Not everyone gets an eye problem—ophthalmology—and not everyone gets diabetes, but this is tax and dying; everyone dies. Why are we ignoring that area? I know it is a difficult area to talk about but, yes, it is fundamentally part of life.

Dr Perkins: I have a comment about ICBs and funding. Our experience of ICBs is that they have reduced uplifts that were promised. They have converted money from last year into a down payment for this year, or they have not increased funding for Sue Ryder hospices. Integration with the NHS is crucial, but I am constantly surprised that as a society it is okay for us to have to sell second-hand cardigans to be able to look after seriously ill people. If people thought that you had to sell second-hand cardigans for their cancer surgery, I don't think that would be acceptable, but for some reason it is okay.

Q246 **Chair:** This is fascinating. Several of you have made the point about the charity workforce being completely absent from the workforce plan. When it came out last Friday, did you Ctrl-F and search the words to see whether it was in there? Was Hospice UK consulted in the preparation of the workforce plan? It has had a very long gestation, as you know, and it has been very much the NHS's plan. Maybe that is the problem, because you are not in the NHS. Did you find yourself consulted on it?

Jonathan Ellis: We certainly had some very positive conversations with officials who were working on the development of the plan. Chair, you are right that the difficulty is that it was always envisaged as a plan for the NHS workforce, but the workforce who are providing not just palliative and end of life care but health and care across our communities is much more varied. We have 40,000 nurses working in hospice services. We have staff working in care homes and in community services. All of these people are providing essential support to care for people at the end of life. The absence of recognition of those is a very serious problem when we are also facing exactly the same workforce pressures.

Q247 **Chair:** They are part of the ecosystem, aren't they?

Jonathan Ellis: Absolutely.

Q248 **Chair:** Following Mr Green's point about the hospices movement having a view on state funding, I know that the air ambulance sector would say that they cherish their independence from state funding, because it can be very unreliable. I know that part of the sector likes that, but that is not to say they do not want certainty for the portion that they do get. This Committee has pushed the Secretary of State very hard on the children's hospice grant, which I am sure you know has been a point of contest over recent weeks. We are still concerned about where it is going to be distributed through ICBs.

Dr Perkins: It is a constant stressor for the hospice sector. How do we keep funding our staff? How do we keep looking after patients and families? While there might be some hospices in some parts of the country where they are able to raise much more money—perhaps they have a better-off population—for a lot of the sector it is a constant stressor. Unless hospices are better supported, you will get hospices shutting.

Chair: This is a great start. Thank you for that.

Q249 **Rachael Maskell:** Thank you for being here this morning. I have a few questions that have emerged during the inquiry, and some that I have personally around dealing with difficult deaths. We have often heard throughout the inquiry that palliative care can be the solve-all, but also cannot be the solve-all. I want to delve into that a little bit more. Can palliative care prevent all suffering at the end of life? Where are its limitations?

Dr Perkins: We would sit here sounding incredibly arrogant if we were saying that we could get rid of all suffering. Even when you have a

patient who says they are very comfortable and their symptoms are well controlled, they are still leaving the people they love. Nothing that we can do in medicine is going to change that.

Our job is about making deaths as good as they can be and supporting families into bereavement. I have been a consultant for a long time, and I have looked after lots of patients. Sometimes I will be looking after people who have what I would consider intolerable symptoms, but they do not feel like that. They want to carry on and have more treatment. I see other people whose symptoms really are not that bad, in my view—who knows how I am going to feel when I am the one in that bed?—yet for them their life is intolerable, and they would like it to be ended.

Q250 **Rachael Maskell:** Jonathan Ellis.

Jonathan Ellis: There is quite a helpful concept in hospice and palliative care of total pain, recognising that pain is much more than physical. It can be physical, social, psychological or spiritual. I completely agree with Dr Perkins that it would be totally inappropriate for us to suggest or even imply that hospice and palliative care services can somehow address all pain in all circumstances. For me, the basic fact that we have so many people currently who are entirely missing out on interventions that can help improve their quality of life, and hopefully their quality of death, is a very big problem that we need to solve.

Q251 **Rachael Maskell:** Dr Doré, going through some of the scenarios that have been put to us at our roundtables and in our inquiry, people have raised their fear of pain or of vomiting, perhaps vomiting faeces or blood. We have also had mental anxiety raised. First, can these be avoided? Secondly, where is the research and funding needed around palliative care to provide even better outcomes?

Dr Doré: I will address the word "suffering" first. The pretext of that question is not killing the sufferer. It is like taking this room and saying, "I don't want it green," so you knock it down rather than repainting it. There is a pretext in the question that alleviating suffering is helping the sufferer.

There are more than just physical symptoms. By and large, physical symptoms are almost predominantly controlled. It is the wider stuff—the social, psychological and spiritual aspects—which is much more distressing and harder. The undercurrent of what you are asking is whether assisted suicide could alleviate those things and act as a pretext along with palliative care. I would strongly advocate no within healthcare, because the ethoses contradict.

The ethos of palliative care through alleviating suffering is that you imbue a value and worth and safety upon that person. That is what people say when they come into the hospice. They say, "I feel safe." We imbue that value. That is what Cecily Saunders was talking about when she said, "Make you as much you as possible." It is doing that.

There could be a whisper in someone's ear that maybe it is not worth living or, "What value are you bringing to this family?", which is what has happened in MAID in Canada, as we have seen. There are the social circumstances. They cannot get a chair lift. There are disabilities. "You're not worth it." The contradiction of the ethos is there. What happens then is that palliative care becomes subservient to assisted suicide and the ethos. It shrinks or certainly stays stagnant where it is. By the way, although there is no normal suicide, non-assisted suicide either stays the same or goes up. In Oregon it increased by 20% to 30% because you have imbued in the culture—as a correlation rather than causation—that there are circumstances in which it is not worth living.

My question to you is: where does suicide prevention begin and promoting suicide end? That is the situation you have. To answer your original question very specifically, there are bad deaths. Anecdotally, the poor deaths I see are the people who want to live; they have young children, and they want to live. They are not the ones who would request this legislation.

Q252 **Rachael Maskell:** I want to move on. You mentioned Canada and their assisted suicide/assisted dying. They are moving to look at mental health as well. We know that many people experience extreme mental anxiety. What provision could palliative care provide for people in that mental state, where they are determined to take the course of suicide, as opposed to providing that value, worth and safety ethos in wider healthcare?

Dr Doré: My answer is, yes, to prevent that is exactly that—to imbue the value that you are important. It is to imbue safety; "Come here, we will look after you." We have spent 50 years trying to remove the misconception that we bump people off—that we kill people in palliative care. It does not happen. People are afraid to go into a hospice because of the lingering thought that you go in and you do not come out. That is not true. There is a 50% discharge.

To go back to your original question, depression is awful. It is a proper, clinical diagnosis along with all the other mental disorders. How do you prevent it? Proper psychological and psychiatry support, drugs of course, but also imbuing that culture. You must know that laws are more than just rules. They send cultural messages. That is what I am trying to imbue: safety, value and suicide prevention.

Q253 **Rachael Maskell:** Dr Perkins, I said to my constituent that I would ask our panel on palliative care this question. Their mother had CJD. As a result of that, she lost all communication, mobility and the ability to eat or drink. She was being supported with food and fluid. That food and fluid was withdrawn. Clearly, it was a very difficult process as they waited for their mother to die. Is the withdrawal of food and fluid appropriate? It is seen as withdrawal of treatment, but it can be incredibly difficult to witness, and indeed for the patient. Is that really within the sphere of the values that we have just been talking about?

Dr Perkins: I have looked after patients with that condition and supported families. It is a horrible illness, yes. Our job is to do the best for patients and families within a moral and ethical framework. You have to work out what is in a patient's best interests. I am guessing that that patient did not have capacity, so I would talk to the family about what they think the patient would want us to do in that position.

The Mental Capacity Act is clear that you have to continue to offer food and fluid, but giving artificial hydration is a medical intervention and it can legally be withdrawn. What is very important when you are talking to families is saying, "This is a medical decision." You do not want families feeling guilty that they are the ones having to make the decision. It is a medical decision, "but it would be very helpful to know from you what you think your loved one would want." If they were to say, "I don't think that my loved one would want this life prolonged assiduously," you might consider withdrawing hydration.

You mentioned research. We are a centre for a randomised control trial at the moment looking at the role of hydration at the end of life. It is a very important issue for families. They worry whether a patient should have a drip or not have a drip. That is a really important question for us to answer. Hopefully, in the next year or two, we will know whether drips, subcutaneous or intravenously, lead to people being more or less comfortable.

Q254 **Rachael Maskell:** I have a final question for Jonathan Ellis. One of the things that I have witnessed as a clinician is the process of death. How does ensuring that people have good palliative care—we have heard the values of that—help families with the bereavement process, as opposed to what we have perhaps witnessed with a disruption in the life process, through assisted dying/assisted suicide?

Jonathan Ellis: I think families and the people important to a patient are just as important in hospice and palliative care as the patient themselves. The support that is provided to loved ones is absolutely central, whether that is pre-bereavement support, helping people to prepare for the fact that the person who is so important to them is going to die, or providing the very best quality of care to the patient themselves. It is a very holistic and people-centred approach. It is talking to people and the people who are important to them. As Dr Perkins says, it is listening to what is important to them and then doing our very best to achieve that.

Q255 **Rachael Maskell:** Dr Perkins or Dr Doré, do you have anything to add to that? Surely death is a process and not an event in that context.

Dr Doré: It definitely is a process. I guess the palliative care ethos is living until you die. Our role is to let nature take its course, but control what nature throws at us. When we are withdrawing treatment, we are returning to the natural course of events. You have a legal right to withdraw anything. Food and drink are slightly different. I have never

actually seen it, despite quite a lot of years doing this. As a human right, we never stop it being available.

In terms of withdrawing treatment such as chemotherapy or even antibiotics, you cannot go to the doctor and demand antibiotics. It is a clinical decision. As in my earlier analogy, it is your up to 30 mph speed limit. You can withdraw any treatment. If you don't want chemo, you don't have it. There are many advocates of assisted suicide who have had the opportunity to withdraw treatment but have not done so and wanted someone to actively kill them.

It is not illegal to die. No one is forcing treatment on you. In terms of research, there is research for specialist palliative care. Temel and Biddle are fantastic papers. They show that palliative care, although that is not our aim, extends life, reduces hospital admissions and increases the quality of life. I am sure that you have the data there. It is very clear.

Q256 **Rachael Maskell:** Finally, Dr Perkins.

Dr Perkins: I have listened to the evidence all through the sessions. It is fascinating, and I would not like to be in your shoes having to make these decisions about how the law is going to change, but there are some things that I think should be said.

There is the emphasis that palliative care is all about people who are dying. We are about life. We are about helping patients to have the best quality of life possible until they die, and supporting their families. The WHO definition is about life-threatening illnesses. Palliative care can be needed early in someone's illness. You do not need to be dying to need palliative care. It is a cause of great distress to me and my colleagues when we see patients who absolutely need to be in the hospice, but will not come in because they are so afraid of what it is going to be like. When we do persuade them to come in they say, "Oh, this is so much better than I thought it was going to be. I wish I had come here sooner." We have patients who will not see my community colleagues because they are so scared of what palliative care means. We know that the palliative care clinicians will be able to help their symptoms and give them a better quality of life.

As Dr Doré said—this is really important—everyone thinks that the only way out of a hospice is in a box. Just under half the patients who come into my hospice in Cheltenham go home or to a care home, and the average length of stay is 10 days. We need to try to improve death literacy. People do not know as much as they should about facing illnesses and the fact that we are all going to die.

Q257 **Chair:** It is interesting. We spoke to the Canadians online as one of our sessions. I don't know if you saw that session. Professor Dugdale spoke to us. Which one of you would like to respond to what she said? I am going to quote it. "There are so many stories coming out of Canada right now. It has made me become more vocal on the subject. Many

colleagues in Canada say that it used to be that if a patient said, 'Doc, I just don't want to go on any more,' you would then sit down with the patient and say, 'What do you mean you don't want to go on any more? Do you want to be discharged? You don't want more cancer treatment? What do you mean by that? Are you depressed? Do we need to get a psychiatrist in here? What is going on?' Now there is almost a reflex, 'Let's just call the MAID team.'" MAID stands for medically assisted dying. What would be your response to that, Mr Ellis?

Jonathan Ellis: I think there are some lessons from history in this country that we can look to for some of the things that we will need to be very cautious about. If you recall, when the Liverpool care pathway was first introduced it was designed to be a mechanism by which we could improve the quality of end of life care given to people outside specialist palliative care settings, particularly in hospitals. It went wrong because the investment was not made in the workforce. The investment was not made in supporting staff, clinical teams or the people working in high-pressure environments in hospitals or, to Dr Perkins's point, in educating the death literacy of the wider population. It inevitably became a very destructive and very damaging tick-box exercise. We can look at the history in this country for some of the things that we will need to consider very cautiously and carefully in terms of unintended consequences, potentially, of making any change in this very sensitive area of health policy.

Q258 **Chair:** Dr Doré, do you recognise that quote?

Dr Doré: Yes. I think of the DNACPR scandal during covid, which we are going to hear about in the inquiry. The Mental Capacity Act has not been fully implemented yet. We know about elder abuse. I wish I did not have to state this, but I think there will be a governmental apology in Canada in years to come regarding this. There is a massive scandal coming our way.

I find it terrifying, to be honest with you. It is recurrent. If you make assisted suicide a medical treatment, the arguments of equality break through. All the safeguards subsequently become potential things to slide. If it is a medical treatment, why are you denying a medical treatment to a 17-year-old as opposed to an 18-year-old? Why are you not offering a medical treatment to someone who does not have a life-limiting condition? Why are you not offering a medical treatment to someone who does not have capacity? All of the supposed safeguards potentially become easily surmountable barriers in legislation. They break down. That is what happens on the basis of equality of access to a medical treatment.

Q259 **James Morris:** A previous incarnation of this Committee, back in 2004, said that health inequalities in this area "are compounded in that services are disproportionately needed in areas of so-called deprivation and disproportionately present in areas of social affluence." That was back in 2004. Has anything changed in the last 20 years?

Dr Perkins: I think that we need the commissioners to step up and commission the services where they are needed. I am very proud of some of the work we have done at Sue Ryder. We have an innovative project in our hospice in Peterborough. We talked to members of the local community about our services and learnt about what they need. We are trying to improve some of the death literacy. For example, those communities did not realise that we had services that came out of the hospice and were able to give hospice at home to people. We are now going to replicate that across all our centres. It is beholden on us as hospices to try to get our message across better to communities, but, as was mentioned earlier about some hospices that perhaps do not need NHS funding, these will be in affluent places. So often charities have popped up because affluent people have said, "Oh, we could do with one of those." Where you need them are in places with less resource.

Q260 **James Morris:** Mr Ellis.

Jonathan Ellis: There are enormous structural inequalities in the way that hospice and palliative care is provided and organised, in exactly the same way as there are inequalities in the wider health and care system. We can look at geographical inequalities—the inverse care law principle, that those with the greatest need are the ones who will least likely access it. There are also diagnostic inequalities. We know that it is still the case that people with a non-malignant condition are less likely to access specialist palliative care, regardless of the level of their need. We know that there are inequalities in patient characteristics. Some of the most excluded communities in society generally are also some of the most excluded communities in access to hospice and palliative care.

The fundamental core responsibility of integrated care boards, given their legal duty to provide a comprehensive healthcare system across their population, is to recognise and take active steps to address those inequalities not just in relation to hospice and palliative care but across the wider health and care system. I see within the hospice care system enormous efforts being made to proactively address inequalities in the system.

Q261 **James Morris:** On the point you made about integrated care boards, have you as a sector had a voice on your integrated care board in putting the case?

Jonathan Ellis: It is a very mixed picture. I certainly know of hospices that are very well connected and well integrated into their local ICB system. There are others that find it very difficult to get palliative and end of life care on to the agenda and have a voice in those conversations. There is a huge opportunity with the new duty that the Health and Care Act introduced to ICBs in their responsibility around meeting palliative care needs within their population to really ensure that that is happening. One of the questions in urgent need of an answer is, "What is the mechanism by which we will ensure that that is being delivered?"

Q262 **James Morris:** Dr Doré.

Dr Doré: The Health and Care Bill, with Baroness Finlay's amendment, does not say "specialist palliative care" but "palliative care". One of the questions was generalist versus specialist palliative care. I want to address that, if that is okay.

This is a model throughout medicine. A cardiologist specialises in the heart and GPs are not generalists in cardiology. No one calls them that; they call them generalists. For some reason we make the distinction in palliative care between specialist palliative care and generalist palliative care, when actually that model is ubiquitous across the entirety of the health service. You need both. By gum, there should be more funding for primary care—for the district nurses and GPs—but that does not replace the need, and I would not be doing my job if I did not say this, for specialist palliative care. As I said, Fliss Murtagh's paper shows that the need for specialist palliative care is really high, in conjunction with the generalists. The generalists—the GPs—do the antihypertensors; they do the blood pressure tablets, but when something goes wrong they refer to the cardiologist. It is the same with palliative care. ICBs just funding GPs doing palliative care does not solve the problem.

Q263 **James Morris:** I think this has been mentioned in exchanges already. When we went to Oregon, those who had been promoting the change to the law in Oregon made the suggestion that since the introduction of assisted dying in Oregon, palliative care had improved. There had been a correlation between offering assisted dying and an improved palliative care system. What do you make of that assertion, Dr Perkins?

Dr Perkins: I have no reason to disbelieve the evidence you were given. Anything that helps palliative care improve in this country is great. My concern would be, if we look at the Association of Palliative Medicine evidence and the Royal College of Physicians' surveys of people who work in palliative medicine, that the palliative medicine workforce in this country are not in favour of assisted dying. It may be difficult to find people in palliative medicine who want to work alongside that system. We already have a problem with staffing in our hospices with the funding, as we have discussed already. You may find that you have people who are leaving the specialty if the law changes, unless it is completely detached from medicine altogether.

Q264 **James Morris:** Mr Ellis.

Jonathan Ellis: I am no expert on the situation in Oregon. For me, the most important question is what the measure or metric is for improving palliative and end of life care. Is it about access? Is it about quality? Is it about sustainability and cost, or the complex interplay of those three things? The most important test for me is whether it is delivering more care to more people. Are more people getting access to the care and support that they need?

Q265 **James Morris:** Dr Doré, is it possible that the reason why, in this

country, people are advocating a change in the law is, in a sense—exploiting is probably not the right word—a reflection of the fact that the palliative care system is still very fragmented? We have talked about regional inequalities and access. For people who want to advocate a change in the law, this gives them an opportunity to do so. If we had a palliative care system that was perfect, where there weren't regional inequalities, where there weren't access problems to palliative care and where there was a respect for the values that you described, and that the NHS was commissioning services appropriately, there would not be a space for the advocacy of assisted dying. That is just a hypothesis.

Dr Doré: The reason there is inequality is essentially because of the funding model we have, which we have discussed. It is the one third, two thirds thing. Whether it would remove the speculative requirement and people advocating it, my guess would be no. Why do people want assisted suicide? That is the very fundamental question. Interestingly, in all the jurisdictions, including Oregon, there is no follow-up or monitoring of the decision in the room pre-death. There is some monitoring. It is inadequate post death. There is no "why". I mean that. "Why is that person requesting this?"

You are quite right that we kind of know some of those things. If we are talking about Oregon, 54% think that they are a burden; 7% have financial concerns and less than 30% are concerned about pain. It is not that they have pain. We don't know; it does not differentiate. If 54% of people believe themselves to be a burden, imagine the scenario, which I believe has happened in Canada. An elderly lady does not want to go to a nursing home. Rather than pay for the nursing home through their house, they want to give their house to the kids. There is an internal motivation to get assisted suicide because they want to give it to their kids. Is that the society we want?

Chair: We are running a little bit late. The Minister is waiting outside, but we will finish with Paul in the next 10 minutes and then move to the next panel.

Q266 **Paul Blomfield:** Following on from that point, Dr Doré, you acknowledged that a minority of people in palliative care nevertheless have a bad death. We talked earlier about what that bad death might look like. Rachael mentioned pain, acute nausea, terminal haemorrhaging, fungating wounds and people drowning through fluids produced in their own lungs. Do you think that might be a factor in people wanting to end their lives earlier?

Dr Doré: When I think of older people who have asked me for assisted suicide, and they have, they are worried about those things. It is not an actuality. They are fearful of those things.

Q267 **Paul Blomfield:** You say it is not an actuality. Are you saying that nobody suffers those things?

Dr Doré: I think those things are very rare. The people who are advocating something pre-emptive are fearful of those things, but that does not mean they are going to happen. For the vast majority of people, when you look at them and care for them, you say, "Look, you are important. I hear you. We are going to address the fear that you have a fungating wound." This is a fear of something or other. We want to work through that. You say, "Look, let's work through it." The desire for assisted suicide disappears. It is about living, as my colleagues have said, until you die, and letting nature take its course.

Q268 **Paul Blomfield:** Do you accept that some people, faced with those, albeit rare, awful outcomes might have different values from yours and might make a different choice? You talk about respect. Shouldn't there be respect for that choice?

Dr Doré: My argument against that is that it creates a public safety concern. With all the other aspects of it, as I talked about with the speed limits, how can you safeguard more widely against people like the old lady not wanting to sell her house to facilitate that? We have just heard how poorly funded palliative care is.

Q269 **Paul Blomfield:** I think we all agree with that. Can I ask about safeguards? We talked about the withdrawal of treatment earlier. Your association has guidelines on the withdrawal of assisted ventilation at the request of a patient with motor neurone disease. Those guidelines say that, when evaluating that request, doctors should ensure "there is no coercion, nor is the decision driven by mistaken kindness to the family." Can you explain to me how doctors make that decision?

Dr Doré: It is the argument regarding withdrawal of treatment rather than demanding that someone kill you. Withdrawing treatment is the patient's right.

Q270 **Paul Blomfield:** Yes, but I am asking you about the guidelines. You say that there has to be a regulatory framework within which these rights are exercised. You produced those guidelines. They say that doctors need to ensure that there has been "no coercion, nor is the decision driven by mistaken kindness to the family." How do they make that judgment?

Dr Doré: I am not aware of those particular guidelines, in all honesty.

Q271 **Paul Blomfield:** They are produced by your association, aren't they? You don't know; fine. Let me move to a different question.

We are looking at other jurisdictions, and you have mentioned other jurisdictions. In a previous evidence session about the Netherlands, we were told that 5% of deaths involve euthanasia and 25% of deaths involve palliative sedation. Do you have any data on the number of deaths involving palliative sedation in this country?

Dr Doré: I am glad you brought this up. Palliative sedation, as a European term, is very different from what we do in the UK. You are right that there were 44,000 palliative sedations in the Netherlands. That is

with the intention of killing, and it is not even monitored. They put you to sleep with unproportional doses. Here, we titrate the doses of medicines to the symptoms. There is a very different ethos behind it, although the terms are the same.

Q272 **Paul Blomfield:** The question though, with respect, is whether you have data on the number of deaths involved in palliative sedation. You have made some assertions, which may or may not be correct.

Dr Doré: It doesn't happen, so we don't have data.

Q273 **Paul Blomfield:** That conflicts with evidence we heard earlier in the inquiry.

Dr Doré: The words are used in the same way, but the unproportional nature of the drugs in Europe is very different from the practice here. They are very different.

Q274 **Paul Blomfield:** Do you deny the existence of palliative sedation at all in this country?

Dr Doré: It depends what definition you are using. If you are using the European definition, where they use unproportional doses, that is not what is happening here. In palliative sedation, where we are titrating to agitation, for the terminal agitated patient, we follow the patient, very closely monitoring and titrating the drug to solve the symptoms.

Q275 **Paul Blomfield:** You have actually moved to the point of my question. Could you talk about what kind of monitoring and oversight there is in that situation where palliative sedation is used?

Dr Doré: As in the UK kind of terminal agitation? There are guidelines as well. The PCF is the most commonly used one, where we escalate through the drugs. We go through levomepromazine, midazolam, hyoscine hydrobromide and phenobarbitone. There is an escalation plan proportional to the nature of the symptoms existing.

Dr Perkins: Could I add something on that?

Paul Blomfield: Of course.

Dr Perkins: I think we are in a good position in this country, in that often our teams work as teams. What you do not want is a Shipman scenario, where a single clinician is working and looking after patients. We have teams who peer review what is happening. Also, we have the medical examiner. It is not everywhere yet, but that is an independent scrutiny of death certification and what has happened to a patient before a death has been certified. If we want to start collecting data like that, a good way to do it would be through the medical examiner system.

Q276 **Paul Blomfield:** I have one last question for Mr Ellis. During the inquiry we received evidence that in the absence of safeguarded choice some dying people take matters into their own hands, either by travelling overseas for an assisted death or by ending their own life in this country.

Today, actually, is the 12th anniversary of my father doing exactly that. Has Hospice UK been made aware of any cases of dying people ending their own life in hospices?

Jonathan Ellis: I am not aware of any instances of that happening.

Q277 **Paul Blomfield:** Do you think it might be worth exploring that further and gathering whether there is that evidence. One of the concerns we are exploring as an inquiry is the absence of choice. We are looking at the safeguards that might be there for a change in the law. The absence of an assisted dying option leads people to take desperate measures. It often leads people to take their life prematurely because they want to exercise control while they still can. Has there been any consideration of that, or do you think it might be worth looking at?

Jonathan Ellis: In exploring the safeguards that might be needed if this change was to be made, I think it is fundamental to understand what the nature of those safeguards might be.

Q278 **Paul Blomfield:** And exploring the consequences of there being no change?

Jonathan Ellis: Yes, absolutely. That is a very understandable and very legitimate question to ask.

Chair: Thank you so much for your time. We really appreciate it. Dr Matthew Doré, Jonathan Ellis and Dr Paul Perkins, thank you.

Examination of witnesses

Witnesses: Helen Whately and Professor Powis.

Q279 **Chair:** We are talking about assisted dying/assisted suicide. We have been talking to the hospice movement and Sue Ryder in our first panel. Obviously, it is a very challenging and sensitive area of discussion.

I am pleased to say that we are now joined by Helen Whately, Minister of State at the Department of Health and Social Care, who is responsible for the area of palliative medicine, and Professor Stephen Powis, the national medical director of NHS England. We have seen him on television a lot in recent days as the NHS workforce plan was published. Thank you both for coming. I am sorry we are a bit late, but we will crack on.

Minister, in their submission to the inquiry, Sue Ryder, who were just here, said that demand for palliative care services will rise quite significantly from about 245,000 people in 2021-22 to just under 380,000 in 2030-31. The Association of Palliative Medicine, who were also here, say that access to palliative care is inadequate in England and Wales. As you know, the Health and Care Act 2022 introduced a statutory requirement on our new integrated care boards to provide access to palliative and end of life care. How would you characterise the provision of palliative and end of life care in England today?

Helen Whately: Thank you for asking me to come and speak to this session. I welcome having a conversation about such an important topic. Palliative and end of life care is a topic that we do not necessarily talk about enough in a health system which, understandably, is mainly focused on saving people's lives. Actually, experience of death really matters, both for anyone facing death—we know it will come to us all—and for family, friends and loved ones. I feel very strongly about how much that matters, and therefore making sure that we have good palliative and end of life care available to all when they need it. I also take the view that we should try to talk more and have more conversations about end of life and what living well and dying well look like, as a society as well as a system.

To answer your question about, essentially, the state of our end of life and palliative care system in England at the moment, I am sure the Committee knows that around half a million people die each year in England, of whom a substantial share but not all will receive palliative and end of life care. The majority of that care is provided by the NHS, but hospices play a really important role in our system.

As a country overall, I would say that we have a good story to tell on palliative and end of life care. There are various international surveys and studies that look at how England compares to other countries. We do well, including being first of 81 different countries in a recent study in the *Journal of Pain Management*. We look to the CQC—the Care Quality Commission—to assure us about the quality of palliative and end of life care. They assess care of the dying as good or outstanding in 88% of settings. Hospices have a 94% rating by the CQC as good or outstanding. If we look at the national audit of care at the end of life for the last year, the vast majority of hospitals—99%—have access to a specialist palliative care team. The majority of that is 24/7, and a significant proportion of that care and support is available face to face; for instance, 74% of families and carers report the care as good, excellent or outstanding. There is a positive story to tell.

Against that, not for a minute do I think that is enough. As Minister with oversight for end of life care, the areas of concern would be in variation and inequality of access to care, knowing that potentially more people could benefit from palliative care. As is acknowledged in NHS England's statutory guidance to integrated care boards, there is variation in underserved populations. That is flagged as something to address, including variation in access to care out of hours.

These would be my areas for focus. I am sure we will go into this, but there are three ways where I see we will work to make the system better at supporting people. The first is raising the focus in our health system on palliative and end of life care through the statutory duty in the Health and Care Act 2022 and how that passes through to local NHS organisations and integrated care boards in their duties to commission end of life care and address the inequality that I mentioned.

Secondly, it is in the approach that NHS England is taking nationally with seven regional strategic clinical leads and clinical networks to raise quality and access and share good practice across end of life care. Thirdly, there is the overall investment we are making in the workforce, particularly the generalist workforce, recognising that most people will be cared for at end of life by their GP, community nurses or staff in the acute trust. Our investment in the workforce is both in skills and confidence in care towards end of life and, as announced in the long-term workforce plan, increasing the numbers in our future healthcare workforce.

Q280 **Chair:** I have here the long-term workforce plan. Our first panel were all saying that it does not mention the charitable workforce. In annex A, which lists the 40 organisations that NHS England worked with in drawing up the workforce plan, there is no mention of the charitable workforce. Was that a mistake? Was it deliberate? What are your reflections on that?

Helen Whately: My reflection on the workforce plan overall is that it has set out to model and predict the workforce that we need going out 15 years, which is something that has not been done historically. It is a big step to do that and it is not straightforward by any stretch of the imagination to look at both the scale and the shape of the workforce that the health system will need in the future.

Something that is really significant in the long-term workforce plan is the shift in the proportion of the workforce to be in community settings as well as in primary care. That is a really important reflection on the direction of travel of healthcare overall, where we want to care for more people out of hospital, but it is also very relevant to palliative and end of life care, which will be increasingly delivered out of hospital. Community healthcare trusts do very important work on this. During the 15 years' period of the plan, the plan envisages the community workforce doubling and increasing as a proportion of the overall workforce from 30% to 37% of that workforce. I think that is a really significant shift to draw attention to. I recognise that the workforce plan does not go into specific numbers of staff by specialties. That is for future work and a subsequent stage. At the moment, it is about the overall shape and professions.

Q281 **Chair:** That makes sense. Professor Powis, was our first panel accurate in their reading of the workforce plan in terms of it taking account of the charitable sector workforce?

Professor Powis: In fact, as you said, Chair, we consulted and worked with a large number of stakeholders, and charities—the Richmond Group, for instance—are listed there. Of course, you can always do more and there are always more people to talk to. As the Minister said, this is the first step. There will be ongoing engagement.

It was never intended to go to specialty condition level. This was always going to be a high-level plan at professional group level. I think the point is that by expanding the number of doctors and medical school places,

the number of nurses through nurse training and the range of other professionals in the plan, that expansion of the overall workforce will by necessity mean that there will be an expansion of the various specialties that underpin the workforce as a whole.

That is the next stage of work. We were very clear to our stakeholders, including the royal colleges, that that would not be in the plan. It will be in the subsequent work and there is a commitment to do that. Obviously, we published the plan last Friday, which was a momentous day for all the reasons that the Minister has mentioned. On Monday—yesterday—we were hard at work on the next phase, which is working on the implementation of it. As I said on Friday, it is a challenge but it will be doable. Of course, the other big commitment—again, an ask from the Treasury but one we support—is to refresh it every two years so that it stays very relevant to advances in medicines and changes in the overall workforce.

Chair: I do not want to hog it, so I will bring in colleagues. Rachael Maskell is going to come in now and will probably continue the ICS conversation that I started with the Minister and the support available to them to deliver their new statutory responsibilities.

Q282 **Rachael Maskell:** Minister, we have obviously heard about the workforce plan and the ambition of that. However, palliative care is a very specialist area of medicine which requires specific training as well as skills in not only medicine and nursing but other professions. Will there be an ambition to set out a palliative care plan in the light of what you have already highlighted—the inequalities within the system and many of the challenges which exist in the system?

Helen Whately: The approach that we are taking to raise the focus on palliative and end of life care in the system is very much through the structure of integrated care boards, the local NHS organisations and their duty to commission palliative and end of life care. It is really important to me to work with those structures, which we created. The fact that the Health and Care Act spells out specifically the importance of their commissioning palliative and end of life care is very important.

There is then NHS England's statutory guidance saying what that duty actually means, including the importance of improving equity of access and outcomes, especially for underserved populations, to palliative and end of life care, and a set of other things for ICBs to focus on, including the workforce, commissioning for all ages and a whole system approach. I draw the Committee's attention to a particular document because it is very important. It is called "Ambitions for Palliative and End of Life Care", and is known as the ambitions framework. It is a really good document that involved 34 organisations which came together to set out what we want from our palliative and end of life care system. That is one of the things for ICBs to draw on as they commission as well.

As of last week, ICBs were submitting their joint forward strategic plans setting out how they are going to commission to meet their statutory duties, including palliative care. NHS England is now doing the work of going through those plans and being assured that they will meet those statutory duties. I see the role of ICBs as really important in addressing variation and making sure that our communities have the palliative and end of life care that they need, supported by the work that NHS England is doing with the seven regional clinical leads.

On the training side, coming to your angle about the workforce question, steps are already being taken to raise skills in palliative and end of life care, recognising its importance. You have both the specialist and the generalist workforce in this. You have a specialist workforce of over 700 doctors, of whom around 400 are consultants who are specialists in palliative and end of life medicine. You have nurses who are trained with a special interest in palliative and end of life care. There is also the generalist workforce where, for instance, palliative and end of life care is included in the curriculum for GP trainees and nurses. Last year, Health Education England launched an e-learning module available to a very wide workforce, including social care and the voluntary sector, to raise skills more widely in palliative and end of life care. It is very important to recognise the need for the generalist workforce to be confident in supporting people towards the end of their life, crucially supported by a specialist workforce as well.

Q283 **Rachael Maskell:** Thank you. I hope you listened to the previous session we held. You would have heard a very different perspective from the palliative care specialists we had before us in that evidence session. I hope there will be much learning from that session about how that perspective should move forward, because palliative care is very poorly understood. It reflects more your comments than the reality of what is required within palliative care medicine, moving forwards. I think there is a lot of learning for Government.

I would be interested, Professor Powis, in your setting out how you go about this huge gap of understanding between what is required and how we have a premium palliative care service and the paucity of service we have today, albeit one of the best in the world, but it still has a long way to travel.

Professor Powis: Obviously, the Minister has outlined some of the steps that we are taking. The first thing to say is that we welcome being here today. Palliative and end of life care is a real focus of the work at NHS England. There is a real commitment to improve access and the quality of provision. Clearly, it is something that we do not do alone. As you know, we work in partnership, as do ICBs obviously, with the voluntary sector. That will continue.

The Minister has highlighted some of the things that we have been doing, even before the recent Act, which put this on a statutory footing. We have had a five-year framework which we developed in partnership with

the national palliative and end of life care partnership. We have issued statutory guidance, which has already been mentioned, to integrated care boards. We have seven strategic clinical networks as part of end of life care that are supporting ICBs. As the Minister just said, we have asked all 42 ICBs to submit their forward-looking plans for the provision and commissioning of palliative and end of life care. I can confirm that all 42 have indeed submitted. The deadline was the end of last week. Clearly, we have not had time to go through them in detail, so I cannot give you a sense of what is in there.

Helen Whately: There will be a specific focus on palliative care within that.

Professor Powis: Yes, but I expect there will be variation in those plans. That is the first thing to say. Obviously, the purpose of getting those plans in is to look at the strength of the plans and the variation, and to provide support to those ICBs that we feel are further behind on it. There is a lot that we are doing. Unfortunately, I cannot give you the granular detail of those plans yet, but I would be very happy to do so once we have had the chance to analyse them.

Q284 **Rachael Maskell:** A last question from me. ICBs had to make efficiency savings, or cuts, in their budget. We heard powerfully earlier that the way we are funding palliative care is by selling second-hand cardigans, as opposed to really investing in the end of life process. What steps is the Department taking to look at how we fund? It is not just passing it over to ICBs because this is talking about a new responsibility of properly funding palliative care across the service.

Helen Whately: If you look at our funding for the health system as a whole, there is no question: we are making hugely substantial investments in our national health service. This year the budget for the NHS is over £150 billion. That is a 20% increase in cash terms since 2019 and a 13% increase in real terms. The autumn statement—

Q285 **Rachael Maskell:** Could you just focus on the hospice situation?

Helen Whately: I will come down to that. That is the funding that is then distributed to our integrated care boards, who then commission services to meet the needs of their population. We have set up a system where we have 42 local NHS organisations that have the responsibility of understanding the health needs of their populations, using resources to support that. I think that is a really important structure. It is early days for that structure. We have had conversations about that before, but we will do our best to support the structure to succeed. ICBs also clearly have the statutory duty to commission palliative and end of life care. That is the funding flow.

The majority of palliative and end of life care is provided by NHS organisations. Hospices play an important part. We estimate that around £6 billion a year is spent by the NHS on palliative and end of life care. Hospice UK tells us that the hospice budget is around £1.6 billion a year.

That gives you some sense of the quantum of funding going into palliative and end of life care across the NHS and hospices.

As I say, I think a substantial amount of funding is going into the national health service and it has been increasing. In the autumn statement the NHS got an extra £3.3 billion for this year and the next to support funding the growing costs of healthcare. That in turn goes to ICBs for them to then meet the needs of their population. The majority of that palliative care will be met through NHS organisations. Hospices often also have a relationship with the local NHS, and some care is commissioned for hospices to provide. It is funded that way through the NHS.

I would say it is a strength of our system that hospices also fundraise and are hugely valued by their local communities. That also provides some funding to enable some of the truly phenomenal palliative and end of life care that hospices provide. I have experienced it through my family, and I have visited hospices as well. I see what they do, and it is fabulous. It is a strength of our model that we have hospices doing this fantastic job alongside the NHS playing its part in end of life and palliative care.

Q286 **Rachael Maskell:** That does not really answer my question. Again, I respectfully ask you to listen to the session earlier. Many of the challenges in the system are because of that funding model and what you have described, as opposed to really putting up front the importance of palliative care, who delivers it and how it is delivered. Continuing that model, we know that several hospices are already under significant financial stress. Indeed, we heard in the earlier evidence session that they may have to close. There has to be another approach if value is placed on palliative care and those statutory duties can be fulfilled.

Professor Powis: There is the £2.4 billion of extra funding that was announced on Friday as part of the long-term workforce plan. Of course, the staff of the NHS and other organisations are fundamental to delivering end of life and palliative care. That expansion in the workforce, as I said earlier, will have a beneficial effect over time.

On the particular point of next steps, the final chapter of the long-term workforce plan is the "Next steps" chapter. Paragraph 21 gives a specific commitment to working "with system leaders, employers and stakeholders…to gather better data on specialist staff and establish clearer demand signals" around particular specialties. We have that commitment to working at a more granular level, including with the palliative care sector, on understanding the specific workforce challenges and planning for those.

Q287 **Chair:** I was trying to find your next steps section at that point.

Professor Powis: It is chapter 5, page 106.

Q288 **James Morris:** We have touched on the issue of inequalities of access to good-quality palliative care. If you go back to May 2016, the Care Quality Commission published a review into inequalities in this area and identified

some of the main barriers. They said it included poor communication from staff, inequalities in accessing good care, staff awareness and non-collaborative working. Do you think the situation has improved since 2016 in improved access and quality access to palliative care, Minister?

Helen Whately: One of the things in the statutory guidance from NHS England to integrated care boards on their commissioning duty for palliative and end of life care specifically says: "There is currently variation locally in access to high quality, personalised palliative and end of life care services. ICSs have a responsibility to ensure action is taken to improve equity of access and outcomes for"—palliative and end of life care—" specifically for underserved populations."

While I do not have a comparative data point to the one that you gave just then, what I can say is that the variation and challenges in access for some populations is clearly recognised, and recognised very up front, by NHS England. One of the priorities for integrated care boards as they commission and oversee palliative care in their geographies is exactly to address the problem of inequality in access, therefore raising the access and better meeting the need for palliative care in their populations.

Q289 **James Morris:** Professor Powis, I suppose this is a values-based question. You have outlined quite a lot of the things that have been done to address the inequality in access issue, but these issues have been around for a long time. I quoted a report in the previous session from a previous incarnation of this Committee, which talked about health inequalities being compounded because services are disproportionately not available in areas of social deprivation. That was back in 2004. Do you think we have an appropriate way, ironically, of treating death with respect in our health system?

Professor Powis: Yes, but I think there is much to do. There is a lot of variability. There is a real and clear need to focus on health inequalities. That is a particular focus for us at NHS England, which we have accelerated post pandemic. You will be aware of the Core20PLUS5 programme which helps ICBs and local systems to particularly focus on areas of deprivation and health inequality. That is working with palliative care teams and is open to palliative care services to work with them. Population health data is really important in understanding inequalities. Many ICBs are working hard on their population health strategies. OHID is providing additional data to ICSs as well.

Q290 **James Morris:** What I am asking is a slightly more direct question. Is one of the reasons that it has taken 20 years or so, from the previous report, something about the attitude and values of NHS commissioning which, in a sense, undervalues end of life? It has not been a priority in our health system and continues not to be a priority.

Professor Powis: I don't think that is quite fair. It has certainly been a priority for us. If you look back at the long-term plan five years ago, it

was definitely a priority in the long-term plan. That is not to say that there is not variability in provision, access and equality.

As you know, the CQC did a report post pandemic. One of the things they commented on was the quality of the conversation around advanced care planning. Yes, there is more work to be done. We are working on that in partnership with professional bodies, including the colleges, but I agree that there is more work to be done. I think people recognise that this is an incredibly important part of our provision of care.

Q291 **James Morris:** Minister, do you think we need to have a better quality of conversation about death?

Helen Whately: I wanted to come in, as you could probably see, on exactly that. The conversations are really important. Advanced care plans are produced through the conversation. The need for the step to have an advanced care plan can trigger a conversation. It is helpful and important.

We are seeing increasing numbers of people having advanced care plans. At the moment, GPs have around 280,000 people on the palliative care register. We are seeing progress. Conversations are happening on advanced care planning, but we need to continue to prioritise that and focus on it, because it can lead to making sure somebody has the treatment that they want and avoid having treatment that they do not want, and they are more likely to be able to die in the place where they and their family would like them to. In its own right, having the conversation is really important.

Related to that is the work that we are doing on our major conditions strategy at the moment. One of the things that we heard from stakeholders in that, particularly patient representatives and family groups, is how important they feel it is that the strategy encompasses palliative and end of life care. Of course, it is important that we talk about prevention, diagnosis and treatment, but actually we know from patients and their families that they really want us, as a system, to make sure we are thinking all the way through to palliative and end of life care. Clearly, we are responding to that in the work that we are doing on that strategy and the work in the interim report. That probably reflects a wider and growing understanding about the importance of—

Q292 **James Morris:** In terms of the values point, one of the previous witnesses said that he found it odd that societally we find it acceptable that hospices were funded by the sale of second-hand jumpers. From the point of view of raising money, if that was the case for cancer services, there would be public outrage. Do you see that as an issue around the way we treat end of life care and the way it is thought about in society? Does he make a good point?

Helen Whately: As I responded to Rachael a moment ago, we should recognise that a lot of end of life and palliative care is provided through

the national health service and funded through national health service funding. Yes, a substantial amount of care is also provided through hospices, and some hospice funding is through the national health service and commissioned. Some of it is through the fantastic support from donations, whether those are legacies, people making substantial donations or from shops and the other ways that hospices raise money. I think we should say that is a good thing and not be critical of it. Let's not forget that a large amount of funding for palliative and end of life care is through the national health service and our taxpayer-funded system.

Q293 **Paul Blomfield:** Perhaps I could move to a different area. Obviously, our inquiry is looking at palliative care in the context of also exploring a change in the law to facilitate assisted dying. I appreciate at the outset that the Government have no official view and that they are neutral. I just want to explore what thinking is going on around the issue.

There clearly is considerable public support around the world. Different countries are adopting different approaches. Some are facilitating law change in relation to terminal illness, and some in relation to terminal illness and unbearable suffering. Is there any thinking going on at all about what a law might look like should we begin to address it? I am not seeking a view on the issue.

Helen Whately: I recognise what you are saying about different countries taking different views. Clearly, I follow that as a parliamentarian and a Member of Parliament representing my constituents, quite apart from my ministerial role. You will be well aware—you alluded to it—that the Government's position is that this is a debate to be led by Parliament. A change to the law in this sensitive area would be something for Parliament to decide. It is an issue of conscience for individual Members of Parliament. If the will of Parliament is that the law on assisted dying should change, then Government would not stand in its way. That is the Government position on the question.

Q294 **Paul Blomfield:** Thank you very much. I will come back to that in just a moment. Among the jurisdictions that are moving down this path are three within the UK: Scotland, Isle of Man and Jersey. Is any thinking going on about how the Government would respond if assisted dying, as is anticipated, becomes legal within UK jurisdictions?

Helen Whately: We observe and watch what is going on in other countries, and clearly, very importantly, within other parts of the United Kingdom. We should watch as those proposals progress in those other areas.

Q295 **Paul Blomfield:** What I am asking is: have there been any discussions within Government about the implications of a UK jurisdiction adopting a law facilitating assisted dying—any discussions at all?

Helen Whately: I have personally not been part of a discussion along those lines. I cannot speak for other discussions that may have happened.

Q296 **Paul Blomfield:** Can I come back to your point about the will of Parliament? We both know that while the Government might be neutral, the will of Parliament cannot be facilitated without the Government finding parliamentary time for legislation to be properly considered. That has been the case on other issues of conscience such as abortion and other questions. Do you think it would be right, should there be a majority opinion in Parliament that we should properly consider the issue, that Government should find time for that debate to take place?

Helen Whately: I recall back in 2015, shortly after I had been elected, that we debated a private Member's Bill about assisted dying. There was a substantial debate at the time. I remember the day very well. We know that at the time Parliament voted very clearly against assisted dying at that point. What I can do is reiterate the Government position, which is that should the will of Parliament change, the Government will not stand in its way, but Parliament needs to take that step.

Q297 **Paul Blomfield:** There is a difference between not standing in its way and enabling proper debate. I remember the debate in 2015, too. It was very clear, but had that been carried it would still have stalled had the Government not found time for there to be proper consideration. I just wonder whether you felt that was something that would be appropriate.

Helen Whately: You are asking me a hypothetical question which, at the moment, I cannot give you a different answer to.

Chair: That is one for the Whips, I am sure, through the usual channels if it were to be passed on a Second Reading.

There are a couple of things, finally. We heard earlier, in our first panel, about investment in palliative care versus, presumably, the investment that the NHS would have to make in providing medically assisted dying. If we were to have a change in the law, Professor Powis, has any modelling work been done in NHS England about where that cost would come from?

Professor Powis: Not that I am aware of. This is a policy area that I do not think it appropriate for NHS England to get involved in. Obviously, as we have just discussed, it is a matter for Parliament. If Parliament so wished and directed NHS England, through Government, of course that is something we would need to consider.

Q298 **Chair:** It is a matter for Parliament in making the moral decision to cross that Rubicon, but if we were to be faced with such legislation it would be perfectly reasonable for Members of Parliament to come to NHS England and say, "How would you facilitate such a change if we were to give it the green light?" We would have to be in that knowledge base before we made that decision. No, is the answer to any work being done on that.

Professor Powis: As far as I am aware, it is not work that we have done.

Q299 **Chair:** The Minister confirmed a couple of weeks ago that the children's

hospice grant would continue from April 2024, which is good for the children's hospices, including Naomi House & Jacksplace in my constituency. We as a Select Committee wrote to the Secretary of State because they are concerned and anxious about the distribution mechanism for that grant being changed from where it is at the moment in the regional structure to within ICBs. Can either of you comment on that? What is your intention, Minister?

Helen Whately: I am well aware of those concerns. I have spoken to NHS England colleagues about them. I know that they are considering the distribution mechanism and we will be communicating about that in due course.

Q300 **Chair:** Have you spoken to Together for Short Lives?

Helen Whately: I have had conversations with Together for Short Lives, yes.

Chair: We would ask that you continue those conversations and take note of that. It is obviously of great concern. Yes, they do not get all of their funding from the state, but they obviously need certainty on what they do get and that it is coming, which you have given. They also need to know how it is coming.

Unless colleagues have any other points to make—I think everybody has had a roll of the dice—we are very grateful to you both for coming in. Minister Helen Whately, thank you very much. Professor Stephen Powis, we hope to see you very shortly for your next return to the Palace of Westminster. Thank you for your evidence this morning.