Choice at the end of life

Event transcript




Event transcript
Took place on June 21st, 2024

Centre

Sponsored by
CAMPAIGN FOR DIGNITY IN DYING.

Contents

Event panel

Baroness Meacher

Crossbench Member of the House of Lords

Baroness Meacher is a Crossbench Member of the House of Lords and is Chair of Dignity in Dying. She introduced the 2021 Assisted Dying Bill to Parliament, which received widespread support across Parliament.

Professor Sir Sam Everington

Former Vice President of the British Medical Association

Sam has been a GP in Tower Hamlets since 1989 at the Bromley by Bow Centre and previously chaired Tower Hamlets Clinical Commissioning Group. He is a former Vice President of the British Medical Association, and was a trustee of the Kings Fund.

Dr Alex Allinson MHK

Member of the House of Keys and Minister for the Treasury

Alex is an independent Member of the House of Keys and is the Minister for the Treasury. He proposed the recent bill on assisted dying within the Isle of Man, which later became law.

Cllr Will Barber–Taylor

Former Deputy Director

Will was our Deputy Director and now serves as a Councillor. He hosts the Debated Podcast and the Not A Day For Soundbites Podcast. Will was previously the Digital Campaigns & Media Officer for Generation Rent.

About Centre

We are an independent non-profit foundation and cross-party think tank. Our mission is to rebuild the centre ground and to create a more centrist and moderate politics. We support better public services and a strong economy inspired by policies from the Nordic countries.

To achieve these goals, we work with people from across the UK and party politics. This includes engaging with politicians and our networks, which include academia, politics, and law.

Our work includes creating new conversations by hosting events and conducting interviews. We also produce new policy ideas to better inform debate, publish papers, and release articles. We aim to build consensus, shape public opinion, and work with policymakers to change policy.

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This event was sponsored by Dignity in Dying, which is a national not-for-profit campaign and membership organisation campaigning for change across the UK. Dignity in Dying believes everybody has the right to a good death, including the option of assisted dying for terminally ill, mentally competent adults.

This event was commissioned for £1,500. We retained editorial control over the transcript, and we signed a contract with Dignity in Dying setting out the full terms. The invoice, contract, and general information on transparency can be found on our "Transparency" page in the footer of our website.

We also approached Dignity in Dying about this event as a result of our shared position on this issue. Payment for this transcript was also received before this project began.

All policy proposals are our own or those of the panel or audience and do not necessarily reflect those of Dignity in Dying.

Commissioned by

CAMPAIGN FOR DIGNITY IN DYING.

Event summary

This discussion focused on the debate over assisted dying in the UK, exploring previous legislative attempts and how international examples could guide future reform. Speakers noted widespread public support and the need to gain further support from MPs. They agreed that greater education and engagement with MPs, alongside open public debate, are essential to move the issue forward and to ensure any future bill reflects both compassion and robust safeguards.

The conversation examined the impact of current laws, which criminalise assistance in dying, on patients and families. Participants described the fear and isolation this creates, often forcing people to travel abroad or take desperate measures. They emphasised the need for a legal framework that allows informed, compassionate decisions at the end of life, supported by safeguards such as medical oversight and independent assessments.

Speakers also discussed the relationship between assisted dying and palliative care, agreeing that both can and should coexist. Evidence from abroad was cited to show that legalisation can improve palliative care funding and patient choice. The discussion concluded that carefully designed legislation, combining robust protections with respect for personal autonomy, could align the UK with international best practice and ensure dignity and compassion at the end of life.

Transcript

Will Barber-Taylor: Thank you for coming along to this event. My name is Will Barber-Taylor, and I am the Deputy Director responsible for outreach at Centre Think Tank. I run Centre Think Tank events and the interview series in conversation. Centre Think Tank aims to rebuild the centre ground and to create a more centrist and moderate politics. We are a non-profit foundation and are both a think tank and a pressure group. Our goal is to support strong public services and a strong economy similar to the Nordic model. To achieve this, we work with people from across party politics and the UK.

Today, in this event, we will be discussing assisted dying and the continued debate within the UK on the issue. It will cover previous attempts to change the law, how other countries have changed their laws, and the future of law change within the UK.

In the first half of this event, we will be asking the panel a series of questions about assisted dying and how the law could be changed. The second half of the event will allow members of our audience to ask questions to our panel members on the issue. If you do have any questions, make sure to put them in the Q&A section at the bottom of your screens, and please include your organisation and position if applicable. I will also explain, before the Question and Answer section begins, how to ask questions directly to our panel.

We have Baroness Meacher, a crossbench member of the House of Lords and chair of Dignity in Dying. Baroness Meacher introduced the 2021 Assisted Dying Bill to Parliament, which received widespread support across Parliament. We also have Professor Sir Sam Everington, former Vice President of the British Medical Association and a GP in Tower Hamlets. And last and certainly not least, Dr Alex Allinson, MHK member of the House of Keys and Minister for the Treasury. He proposed the recent bill on assisted dying within the Isle of Man, which is going through the House of Keys as we speak.

So I would like to thank Dignity in Dying for sponsoring this event and for all you do related to the cause of assisted dying.
The first question I would like to ask is, there have been numerous attempts to change the law on assisted dying within the UK. Why do you think previous attempts at law change have not succeeded? And what lessons can we learn from these attempts? Baroness Meacher, if you could respond to that first.

Baroness Meacher: I think quite a lot of work needs to be done, and perhaps has not been adequately done with MPs specifically. There is huge support for assisted dying across the country, more than 75%. But MPs do not necessarily understand the issue. So I think there is work to do on that. That is my feeling.

Will Barber-Taylor: Alex, on the same question, what is your response? What do you feel? Why have previous attempts not succeeded, and what can we learn from these attempts?

Dr Alex Allinson: I think, as Baroness Meacher said, that there has been a degree of indifference from politicians about assisted dying. It has not been on any manifesto that I can think of in terms of each party; it has not been very much at the forefront of party politics. And so it needs to be accelerated up the agenda. I think some of the work that people like Esther Rantzen have done brings the human face of the dying to the forefront and has gained a huge amount of traction.

I think also what we need to acknowledge is the opposition to assisted dying, which is often on religious, moral or ethical grounds. And that is quite an organised opposition, which has been very successful in terms of sidelining and preventing various private members' bills coming through, both in Westminster and also on the Isle of Man. I am bringing through a private members' bill. I am the third politician on the Isle of Man who has tried to do it for over 20 years. And even now, I am being accused of rushing things. It is a subject that has been debated quite extensively over several decades. And actually, what politicians are trying to do is respond to the public appetite for assisted dying constructively.

We have to acknowledge that there are people who oppose it. That is fine in a democratic system, but that does need to be countered by the great weight of evidence we have now got from around the world about how you can provide for assisted dying within a well-regulated legal framework.

Will Barber-Taylor: Just on that point, Alex, I would just like to follow up with you, Baroness Meacher, on rushing things. What Alex just mentioned is the idea that people think is something that is being rushed. Where do you think this argument comes from? Why do you think it is used so often?

Baroness Meacher: Well, it is very, very difficult to think of it in any way rational. I suppose if you do not want something and the thing keeps coming up, that is a fact because the popular support for it is so enormous that there is pressure on those of us who represent, for example, Dignity in Dying to raise it and try to get it through parliament. I suppose, and rush is obviously the wrong word, but certainly a sense of pressure. I do understand that the opposition is bound to feel that.

Will Barber-Taylor: Absolutely. Turning to our next question, as the law currently stands, assisted or encouraging someone to access assisted dying is illegal. What impact does this law have on people seeking assisted dying and their family and friends within the UK? Sam, if I could turn to you first for your response to that question.

Professor Sir Sam Everington: So I think it is tragic, and I speak as a barrister and a GP. The reality is, although there are very few prosecutions of loving and caring relations, that is what we are dealing with here: it is the fear of it. When somebody chooses to go through assisted dying, the last thing they want to do is leave behind any burden on those people they love and adore. And to me, it is absolutely tragic and needs to be changed. It is a completely unfair burden on those people left behind.

As a GP, I just know the vital importance of the relationships being around people in those last few days. One of the shames of this country is 47 % of people with terminal illness are dying in a hospital. We know that it can be significantly reduced. I have never come across anyone except a chief exec of a hospital who wanted to die in their hospital. It is just not what you want. You would choose to be surrounded by your loved ones in your community, in your home, and that is what we should be helping people with.

Instead, it is not just the insufficient palliative care as an issue, but actually, why are people dying in hospitals? There is a really big issue here about care for those you love if you are choosing to go through an assisted dying process. And that cloud sits on their head; even though the chance of being prosecuted is low, it is the fear of it, which is entirely appropriate.

Will Barber-Taylor: Alex, what is your response to the same question in terms of the impact you think that it has?

Dr Alex Allinson: Yeah, I completely agree with Sam. I think it was Keir Starmer who, originally, when he was Director of Public Prosecutions, helped clarify that people would not be prosecuted. But they are still investigated often, and so they still have to give evidence to the police. I think more than that, the current law stifles honesty and the right conversations at a time of death, either from people with their GP or their doctors, because doctors are put in a very difficult position, although the GMC have changed their advice to doctors.

There is very much the feeling, I think, amongst my colleagues that this is something we should not be talking about in case we get a complaint against us afterwards, or we say the wrong thing, and we are seen to be aiding and abetting. So it is this silence that is inflicted by the legislation we have at the moment. And we are also more than aware of evidence from the Office for National Statistics in terms of the suicide rates, unfortunately, amongst those with terminal illness. People are taking things into their own hands. They are making a judgment for themselves that they want to be in control of how and when they die. But they are doing that again in complete silence, not talking to their relatives, not being able to talk to their healthcare providers. And that is stifling debate and the honesty that I think a lot of people want. One of the real compulsions for doctors nowadays is to listen to their patients. And by having these legal barriers, we are stifling those conversations.

Will Barber-Taylor: On that same question, Baroness Meacher. As Chair of Dignity in Dying, I will have encountered a lot of people who have been affected by this, the relatives. Could you just tell us what kind of effect you have seen people who have been affected by the law have had?

Baroness Meacher: We know that six and a half thousand terminally ill people, every year, try to take their own lives. And of course, if you try to take your own life and you fail, which is what happens to these six and a half thousand people a year, you will very likely end up a good deal worse off than you were before, suffering greatly. If you throw yourself on a bridge and you do not die, my goodness, you have got problems and so on. So you have got all those people.

You also have 650 terminally ill people who take their own lives every year because they cannot have an assisted death with their loved ones around them. So the consequences are quite appalling. And also, the number of people joining Dignitas has increased by 80% in the last decade. So the demand for assisted death is growing all the time. And yet, people cannot get the help they need in this country. And so they go off abroad, and they spend £10,000. And they will not likely take a nearest relative or loved one with them, because that person might then be prosecuted when they return from Switzerland. So the consequences of this law, banning and making assisted death unlawful, are truly appalling.

Will Barber-Taylor: Right now, the UK has a struggling palliative care system, and some worry that assisted dying may be used as a crutch for a failing system. With other countries passing legislation, is there international evidence for these issues, and do you think this concern is something which could be addressed? Sam, if you could respond to this first, please.

Professor Sir Sam Everington: Palliative care is a massive problem in this country. In the East End of London, we have a really good service. We run virtual wards from the community in every practice, which proactively manage all our patients with terminal illness. So a terminally ill patient of mine will get my mobile phone; they can text me, they can ring me at any time. It is a very personalised service. Why is that not there across the country? And that is massively supportive of individuals, and also their families, who are often very frightened about the idea of actually supporting somebody at home. If they hold their hand in reality and virtually through the process, their bereavement is substantially reduced. And I often sit there after a loved one has died and say on behalf of the person who has died, "You have given me the best gift in life, and that is a good death." And we know the bereavement is significantly reduced below that.

There is a massive problem with the palliative care issue, which people are not addressing and some very simple solutions. And sometimes, actually, some of the palliative care system is not doing it. It is very much based in hospices and does not always understand the important role of GPs. But actually, we are talking now about a scenario where people are very close to death. And palliative care in some of these situations just does not have anything to offer them, both in terms of their mental and physical pain. To me, there has to be that option available for individuals. And the argument that palliative care can always, always resolve that distress is just not valid.

Will Barber-Taylor: On that same question, Baroness Meacher, of palliative care and assisted dying being generally used as a crutch for the palliative care system, what are your thoughts on that? And are there any international comparisons that you think can be used in terms of the argument relating to the UK?

Baroness Meacher: Yes, well, I think it is very important to have the international experience because there are countries where assisted dying has been introduced, where palliative care has then been better funded and is better able to support people. So it is not a matter of either/or, either good palliative care or assisted dying. We need both.

As Sam Everington said, the fact is that palliative care cannot eliminate all forms of suffering, things like the respiratory problems, all sorts of problems that palliative care finds quite difficult, I think, to handle effectively. You absolutely need assisted dying alongside palliative care. But in my view, the international experience suggests that palliative care is not in any way threatened if assisted dying is introduced; in fact, it can be the opposite. People then become more aware of the end of life and more aware of the importance, if at all possible, to provide palliative care and support people in those last stages of life, so that they perhaps do not need an assisted death. So that is certainly what I am picking up from around the world.

Will Barber-Taylor: And of course, some concerns that changing the law may leave people at risk of coercion or feeling that they are a burden. How do we ensure that legislation provides better protections than the current law? Alex, if you could provide your response to that first.

Dr Alex Allinson: Yeah, certainly. To follow up on the previous question, assisted dying is an end-of-life choice. It does not distract from palliative care. In many ways, it is an additional choice alongside palliative care. But we know that there are some people who, for whatever reason, either cannot or do not want to access traditional hospice care and hospice support, and I think assisted dying gives them that right.

In terms of coercion and people feeling as though they are being forced into assisted dying, again, I think this is one of these myths that opponents of assisted dying put out, that the dangers of assisted dying are so great that we should never introduce it. When you look at some of the research that has been done in Oregon, when people are asked what their main concerns are when they are approaching death, the concerns about being a burden are there, just over half of people, but that is not their main reason for having this or asking for an assisted death. I think when you have been independent your whole life or even after some serious illness, as you approach your death, you want to leave this world but also leave your family with the memories they should have of you and not of seeing you incapable and unable to do things for yourself. So that risk of coercion, that risk of people being forced into having an assisted death, I do not think is particularly valid.

However, in terms of legislation, I think the key to this is having legislation worded so that people can access assisted dying if they have capacity, if they are competent, if they are an adult, if they are facing an imminent death within six months, which is the usual proposal, although in our draft bill we have extended that to 12 months now, and then they are seen by medical professionals who validate their decision. Doctors are involved in various safeguarding issues almost daily now, around children, domestic abuse, and elder abuse, so I think we are in a good position to be able to judge whether someone is being pressured into asking for an assisted death. Interviewing them independently, having two doctors see them independently, and having that open and honest conversation to explore their reasons is right and introduces the safeguards necessary to provide a safe and dignified choice at the end of life.

Will Barber-Taylor: Absolutely. Baroness Meacher, on that same question, given concerns that people raise about coercion and people feeling that they are a burden, how do we ensure that legislation gives people the kind of protection that they need?

Baroness Meacher: Well, I think if you could say at the moment that there is no protection, the idea of the legislation is to require the two doctors not only to interview the person seeking an assisted death, but also to interview the closest relatives to ensure that the motives of those people are pure and that they are not putting pressure on the patient. So I believe that with legislation with those safeguards, people will be a great deal safer than they are today. So in that sense, I do not worry about it, actually.

Will Barber-Taylor: I am about to ask the final question to the panel. If you are a member of the audience and would like to ask a question, there are two ways you can do it. If you would like me to read out the question, then simply click the Question and Answer button and type in your question there. For these, please include your organisation and position if applicable. If you would like to ask your question directly, then raise your virtual hand, which will appear as a hand icon at the bottom of your screen.

To move on to the final question. We have touched on international comparisons a little bit, and we know that there are a range of countries and states that have implemented assisted dying legislation for the terminally ill and mentally competent adults, with laws similar to those proposed in the UK already in place. Are these other systems safe, or do they have any issues? Sam, if you could respond to that first, please.

Professor Sir Sam Everington: I think the biggest problem is the perception of problems. And I say that as a GP. So I am at the Royal College of GPs today, and it is the only college and organisation that has taken a position a few years ago, admittedly, against assisted dying. And then I brought a motion which said, "Look, it is coming now in several parts of the UK. If we continue with that rigid position, we do not get involved in addressing the concerns of everyone, those people who are for, against, or neutral." And actually, I won that debate, and that was a massive process. But what I learned through that process is understandable fears that GPs have. They are the family doctor. And so I understand their fears completely. A lot of it is perception. But it is really important that they are taken through the journey of understanding their role and that their role is positive.

Some of them even came with the idea that they would be forced to do it themselves. It is an extraordinary idea. Whereas, I think we all feel that what you need are real experts. And in a sense, I would often say you need somebody independent. Personally, as a GP, I might advise somebody, signpost them, support them through the process. But at the end of the day, if I were doing the process, that would be, to me, an enormous conflict of interest and would be difficult.

It is those sorts of questions that a lot of GPs had, which I think led them a few years ago to express a feeling against. Interestingly, this time in the debate, I think they are much closer to the perspective that it is almost not an issue whether they are for or against it. They should not even be asked that question on one level. It is the question for the public, and the public is overwhelmingly saying they support it.

The issue for the GPs is what their role is in the whole process in supporting an individual patient and their family to the best of their abilities. And that is what I think they want to learn and hear about. Yes, there is a lot of fear-mongering that goes on out there. And that is what they have heard, but they have not heard the other side of the story and the practicalities of what it would mean for them as a GP.

Will Barber-Taylor: On that same question, Baroness Meacher, regarding the other systems that are in place around the world on assisted dying, do you feel that they are safe, and is there anything you feel the UK can learn from them?

Baroness Meacher: It seems to me remarkable that assisted dying is very prevalent as a legal system. 30 jurisdictions now have a form of assisted dying, and 70 % of those have the form that we want in the UK, limited to terminal illness and mentally competent people.

There is no autocracy or a whole lot of criticism against those systems. I think that is what is important because if there were problems, if there were abuses, my goodness, you would hear about them. So in that sense, I feel we just have a lot that we can learn from the many jurisdictions that already have the system that we very much want to introduce into this country. They have been doing it for many years. As we know, Oregon has had assisted dying for terminally ill people who are mentally competent for 27 years. Lots of other US states have similar systems, the whole of Australia, New Zealand, and so on, and several European countries, so there is a great wealth of experience from which we can learn. And frankly, I do not know whether the others would agree. I am not aware of significant criticisms and complaints, and worries that I am not. It seems to me it is working well.

Will Barber-Taylor: We are now going to move on to the question and answer session of the event, where you can put your questions to the members of the panel. As I say, there are already a few questions that have been asked. This can either be a question following on from something a member of the panel has said or a new question about assisted dying legislation.

I will start with the first question, which is from Janice Long, and Janice asks the Dignity in Dying campaign for assisted dying for the terminally ill. My Death My Decision wants assisted dying to be extended for unbearable suffering. The criteria for that are unclear. Will that make it easier for the anti-campaign to stop legislation? If Baroness Meacher could respond to that question, please?

Baroness Meacher: I would be very worried about assisted dying being extended to people who are not terminal but who are suffering unbearably because of the disability lobby. I am in the House of Lords with people like Baroness Grey-Thompson, who is fiercely concerned about assisted dying because she feels it is going to undervalue the lives of disabled people. And I think if you had assisted dying available to people who are not even terminally ill, these people, the disabled lobby, as I call them, would feel incredibly threatened. So I think it is a step too far, which I just do not feel I could support.

Will Barber-Taylor: Would either of the other members of the panel like to respond to that question at all?

Dr Alex Allinson: In terms of the Isle of Man, we have looked at, in terms of the draft legislation, expanding to unbearable suffering. One of the issues with that is the very diagnosis of that. It can be very subjective. And we have seen in other jurisdictions, particularly in terms of the Netherlands and Belgium, and also recently in Canada, where their legislation has been broadened due to the Supreme Court, that it ends up encompassing more and more people. And then questions have been asked by both the medical and their parliamentarians about whether this is the exact intention of the legislation.

Whilst I can completely understand that some people have chronic conditions that produce unbearable suffering, from an assisted dying point of view, if we are going to have safe and effective legislation, we have to have quite firm parameters around that. I think the essence of having it restricted to terminal illness is very sensible. The opponents of assisted dying will always talk about what they see as a slippery slope towards eugenics. I do not think there is any evidence that that has happened anywhere in the world, even with quite progressive systems, since they include unbearable suffering. But it is still a concern, and I think to address that by having quite well-worded legislation, by limiting it to terminal illness. That is certainly the best way for the Isle of Man, but I would also advocate for the United Kingdom to pursue it.

Will Barber-Taylor: Sam, would you like to respond to that question?

Professor Sir Sam Everington: I think there is nothing else to add. I agree with Molly and Alex.

Will Barber-Taylor: The next question is from Anne Cullen, who is a research lead for the UK Association of Palliative Care Social Workers. Anne asks, as you all know, many people in palliative care services are anxious that legalising assisted dying would lead to less funding for palliative car,,e and there is also opposition from some groups of disability activists who fear that they or their relatives will be pressured to end their lives because their quality of life seems poor to others and is not valued and respected.

As an organisation, we have taken a neutral stance on assisted dying, but would like to suggest that it might help to allay some fears if there was a role for social workers akin to that of approved mental health professionals who would make an independent assessment and ensure that people were able to make an informed decision based on being clear about their rights and can access any services that could alleviate the suffering this is leading to them to feel that they want to die and then support them and their loved ones if they choose an assisted death. Alex, would you like to respond to that first?

Dr Alex Allinson: We have talked a little bit about what is seen as conflicts with palliative care. In terms of the hospice movement, palliative care, I have the greatest respect for them. On the Isle of Man, we do have a very good palliative care system and a very accomplished hospice here, but there are still those people who, for whatever reason, do not find that it satisfies their desires and their suffering.

Now, in terms of all the legislation we are bringing through, we have been quite clear with the wording of the legislation that when somebody applies for an assisted death, they have to be told all the various options available to them, including palliative care options. Whether or not they take those up is up to them; it is their choice, but it is the responsibility of the assessing healthcare professionals to go through all the options with them so that they are aware of the entire range of assistance that can be provided, including social assistance, social care, and the full works.

I think that is very important. It is not a binary decision that you either have palliative care or assisted death, and one therefore rules the other out. I would like to see in the future that assisted dying is seen as very much an adjunct to decent patient-centred palliative care. And, some of the initial evidence from New Zealand where some of the hospices there have adopted assisted dying and worked with their staff and brought them along with this, have shown really promising results in terms of opening up the range of options to patients themselves, but also including as many staff there who want to be included in this with conscientious objection, obviously, but that would encompass healthcare workers, but also social care workers as well.

Will Barber-Taylor: Sam, do you have a response to this?

Professor Sir Sam Everington: Yeah, I think there are two points. Part of it is, so what am I doing as a GP? And I am very supportive of assisted dying, but also passionate about good palliative care. Things go hand in hand. It is the same value set, which is around wanting to care for people and particularly give them the care that they deserve and should have actually had in their last few months.

I think the second thing is, when I said I gave them my mobile phone, we have a multi-disciplinary team that supports them. I am just part of that team. We have social prescribers. Whether it is that they need a nice bed or their cat needs feeding, whatever it is. Our team has been doing that in the East End of London for over 10 years. So, it is not just social workers. It is a whole multidisciplinary team that you need to support these patients because you never quite know what the need is going to be, what really matters to them. We often talk in social prescribing terms about actually, but what is the matter with somebody is far less important than what matters to them. So it is an incredibly personalised approach. And part of that personalised approach to me is a social prescriber, a social worker, that whole team supporting that patient and their family, but also the assisted dying. That has to be part of what is on offer.

Will Barber-Taylor: Baroness Meacher, do you have a response to Anne's question?

Baroness Meacher: Well, I think Alex and Sam have answered it extremely well. The important thing is that those of us who support assisted dying want the best possible palliative care for everyone. And it is only when the best possible palliative care is not providing a good enough life for somebody, and they really want to die, that we need to support them in their choice to take that step and to bring things to an end. The important thing is that the patient is in control at all times and they are given support for their wishes.

Will Barber-Taylor: Absolutely. The next question is from Cindy, who asks: Are there any professional ethical dilemmas to consider with assisted dying? Who would like to tackle that one first?

Dr Alex Allinson: I would be quite happy to kick off. There is a huge range of possible dilemmas, which is why I think you need to have properly worded legislation and why you need to make certain before you introduce an assisted dying provision that you have done all the right consultation, education and training. Most jurisdictions that brought this in have taken at least a year, if not 18 months, to lay that groundwork there.

Part of that is to deal with some of the apprehensions that medical professionals have over assisted dying and normalise it, but also give people the tools and the skills to provide for it. So we have talked a little bit about choice and people having access to palliative care.

One of the things that Scotland did relatively early in terms of their private members' bill was set up a consultative committee with medical professionals to talk about this, even before they got their bill started. What I would like to see on the Isle of Man is once our bill does get royal assent, we can then, we can get two doctors together, say, "What is the best way of applying this law? How can we structure the right framework to provide for assisted dying", which would, as Sam has said, involve a multidisciplinary team so that everyone can have those discussions with a patient and provide that level of assurance?

There is education to be done for the general public about what assisted dying is and what it is not, but there is also a large amount of work that needs to be done with doctors, nurses, pharmacists, social workers, other people who work in the healthcare sector, particularly those who are looking after people who are dying, to give them the right tools and skills to be able to advise others on assisted dying.

If they do not want to take part in it, I completely respect that, but they should at least have the knowledge and the ability to counsel people about the choices that they have. As Sam has said, creating an expert team of people who have the right skills and training to provide for assisted dying is absolutely the right way forward. Some of the ethical dilemmas can be overcome as long as you have the right legislation to deal with it, you have the right guidance, both in terms of the General Medical Council and, British Medical Association Ethics Committee to do it, but also that you are certain that you have the right capacity assessment for people, you have got to make sure you have got the right diagnosis for that person, and then you can listen to them and have that honest conversation.

Will Barber-Taylor: Sam, what is your response to the question regarding professional ethical dilemmas?

Professor Sir Sam Everington: I have been a GP for 35 years, and when I started, there was no internet. So I was the encyclopedia. It is completely different with patients now, rightly so, they have googled their problems, and they come in, and quite often they know more than I.

So, what is my role as a GP in this modern world? And the answer is to help people make choices because, actually, when you are terminally ill or very close to death, there is a big fear; you are afraid, it is a bit like childbirth. All these things in medicine will induce enormous fear in patients, and then making the decision is quite tough because even when I am ill, I lose my logicality.

Actually, a gentle support and helping them through those choices is really important from somebody they trust. It is not forcing them to choose any direction whatsoever. That is important; the old days of that patronising doctor, hopefully gone. Your role is to focus on what matters to them and help them make the best choice they can in the circumstances. Life is never clear-cut. There is no right or wrong choice, often I find in medicine and for patients, but it is helping people navigate the process of how that knowledge and information comes to the best choice for them and their families. Because somebody who is dying, the thing they leave behind is their family. And it is the most important thing in life, for most people, is their family.

Will Barber-Taylor: I would like to move on to Nathan's question from Nathan Stillwell, who is an assisted dying campaigner at Humanists UK. Nathan asks, Multiple sclerosis is not a terminal condition. Someone with MS could be in extreme pain and suffering from a condition they know is only going to get worse. But they would not have had an assisted death under the bills proposed by Parliament in the past. Why should someone with a terminal condition be allowed a dignified end, while someone with a non-terminal condition, multiple sclerosis, Parkinson's, locked-in syndrome, and soon be forced to endure suffering? Now, who would like to respond to that first?

Baroness Meacher: The main problem, as I understand it, with multiple sclerosis is a great deal of pain because of the seizure aspect of it. And the fact is, we do have good pain control. So I think my feeling is that if I had multiple sclerosis, I would prefer to have very good pain control, rather than to have my life terminated. It depends on the individual, it depends on the extent to which that pain really is controlled and so on. But there is a difference between somebody who is terminally ill, where death is inevitable, and somebody where that is not the case.

Will Barber-Taylor: Sam, if you could respond first.

Professor Sir Sam Everington: Yeah, so I think this is a really difficult ethical dilemma because I believe passionately in patient choice. I am not there to tell people what to do. It is their lives, it is their body, it is their families. And I am just there to support them and help them in any way I can. And so there is part of me that completely understands the argument of saying, well, it is their choice to end their life. And the last thing you want them doing then is being forced to go abroad, or go down the pathway of suicide, which some of them are likely to do.

I think from earlier discussions, there is something about taking this in steps. And I think the first step is around the terminal illness. And then this might come in time. But it is a massive ethical dilemma for me on this, because I just believe so strongly in people's autonomy and their right to make choices in their lives. If they are of a complete sound mind and it is not just a kind of temporary depression or whatever, in which case what they need is a lot of help and support. So this is a really difficult question for us.

Dr Alex Allinson: I completely understand Nathan's question, and I also have a lot of sympathy with Humanists UK and their campaign. We are coming back to the whole idea of unbearable suffering and the subjective nature of it. Assisted dying as brought out in most of the United States, the American states, is about terminal illness. And certainly, the draft bills that have been proposed in the United Kingdom are all about terminal illness.

I suppose it is that fundamental difference between shortening somebody's life, which you may do if you bring forward assisted dying for unbearable suffering, and shortening a person's death, which is what you are doing when you are dealing with a terminal illness. Somebody is dying, and what you are trying to do is shorten that death process and give somebody that autonomy around it.

Part of my role as a politician is achieving a well-drafted piece of legislation that is safe in providing for assisted diving provision. And I think that whilst we have discussed unbearable suffering and bringing that in for non-terminal illnesses that still have devastating effects on the people who suffer from them, I do not think that, certainly at the moment, we are ready to take that step, certainly in the British Isles. Whether that would develop later on is up to Parliament. I think part of my job is achieving the achievable. I think assisted dying legislation, when you strictly limit it to terminal illness, is achievable and possible. I think broadening that out at the moment has quite a few inherent difficulties. I do not think that our parliament is ready for that. Although our parliament is lagging behind the general population on these issues.

Will Barber-Taylor: I would now like to turn to Gillian McDougall's question. Gillian is a recently retired ENT surgeon, a supporter of assisted dying. And Gillian asks regarding one of the previous points: how detailed do the panel think the legislation would need to be? Can we just legalise the idea but leave the details of the GP role, for example, to guidance once the law is changed? Or would GPs feel better if it were legally specified? I think I would like to turn to you, Alex, first, if I may.

Dr Alex Allinson: So our bill and most of the bills which have gone to the House of Lords are relatively brief. When you look at some of the Australian legislation, particularly in the State of Victoria, it is quite a substantial bit of legislation which puts in primary legislation an awful lot of details.

What is going through our parliament at the moment is very much an enabling bill which decriminalises the ability for somebody to end their own life and then sets up a structure in terms of how they apply for assisted death. Now, what we also have is the ability and the compulsion on our Department of Health and Social Care to bring forward regulations, and I think the regulations are very important in terms of trying to make sure that we have the legislative framework for doctors and other people to work within.

The key to that also is the amount of guidance that is needed, and regulations and guidance should come about through detailed negotiation and discussion with all those people involved in assisted dying, and by having them in secondary legislation allows them to develop as the knowledge base increases, as well, and further define and refine how we go forward over the next couple of years.

What our legislation will do is provide that legal framework. You will need secondary legislation in terms of how you assess people. You are almost like a tool book for people to work through this. There will need to be guidance and policies outside of legislation to allow people to have that confidence in doing the right thing. And also from a GMC perspective, that they are working within their capacity and within their knowledge base.

Will Barber-Taylor: Baroness Meacher, on that same question, how explicit do you think that the role of GPs would need to be?

Baroness Meacher: I would be quite concerned if the primary legislation were rather limited and a lot of detail were left to regulations and guidance, because what would be very alarming would be if an assisted dying law were introduced and implemented without absolute clarity about issues like the safeguards and the centrality of the patient. I would want the key features of an assisted dying system to be within that primary legislation to make sure that no one had an assisted death before everything was in place.

Professor Sir Sam Everington: I think to myself, there are certain features here. I think people need to feel that, whether you are a professional or an individual going through assisted dying, or a family member, the law will protect them in the process. And therefore, that needs to be a level of detail. I think Alex made the point earlier on, which is important. It is the guidance you almost need to be getting on with now, which is where the reason I argued for the RCGP to get involved, because that can often surface issues which legislation needs to deal with. So the guidance is almost the final bit, which is how a professional or a member of the family or an individual is going to go, how it is going to look, and how it is going to be supported. And so it needs to come hand in hand. So what we mustn't have is the legislation first, and then let us go and do the guidance later on. Let us do these hand in hand at the same time.

Baroness Meacher: Yes, you must have everything in place.

Will Barber-Taylor: We are coming towards the end of the event, but we do have time for one final question from Sylvia Lewin. Baroness Meacher mentioned the need for involving members of parliament so that they will understand the importance of bringing in change. In 2015, the MPs admitted that they did not know anything about the proposed bill. What would the panellists suggest doing to improve this situation? Alex, if you could start.

Dr Alex Allinson: Since then, we have had a committee in Westminster look at and take evidence on assisted dying, evidence from right around the world as well as within the British Isles. And I think that has gathered a huge amount of information there. People who do not like the idea of assisted dying will always oppose it. That is fine, that is their right. But in terms of parliamentarians, I think it is looking at what other jurisdictions are doing, but also listening to their own constituents.

There have been very successful campaigns recently by groups like Dignity in Dying and My Death, My Decision, in terms of bringing out the human story of assisted dying, because some of the strongest proponents of assisted dying are people who have witnessed a bad death themselves, of friends or relatives. And so from a parliamentary point of view, I think it is down to individual people lobbying their MPs, saying, “Look, this is important for me, and this is why. This is why if we can change the law, we can improve lives, but also improve those individuals’ deaths.”

As Sam said, for everybody who dies, they leave a lasting memory in their family and friends of their death. And one of the most rewarding things as a doctor is to enable somebody to have a good death and leave those positive memories, rather than very negative ones of seeing somebody suffering unnecessarily.

Will Barber-Taylor: Baroness Meacher, you might be able to respond to this question about assisted dying in terms of the knowledge of MPs.

Baroness Meacher: The crucial thing is personal experience. Every MP has around 60,000 constituents. Amongst those people, there will be those who have had terrible experiences of a loved one dying. We want those constituents to get in touch with their MPs and get across to the MP how incredibly important it is that people avoid terrible deaths, and assisted dying being legalised is the best way of doing that. So yes, it is down to that, down to constituents talking to their MPs.

Will Barber-Taylor: Sam, and if you could provide the final word.

Professor Sir Sam Everington: One of the things I have done over the years around social prescribing is that we have a very unusual health centre where we have had different projects, cafés, gardening therapy, you name it. And it is a holistic approach to healthcare. And one of the things I have learned over the years is that you can produce lots of paperwork: articles, business cases, all of those things, but there is nothing that beats coming down to the coalface and meeting and talking to people. And Molly has talked about that in terms of meeting people who are going through the process. And it is that personal experience.

Even if somebody is really against assisted dying, they must talk to people who are going through it. So that is what I would say most of all is, and MPs are really good at doing this, because of all their constituents, they are really like GPs. They run very similar surgeries. And so I would implore them to go and meet people who are in favour and opposed, so they have an in-depth understanding of what they are going to have to vote on sooner or later.

Will Barber-Taylor: So this is the end of the event. Thank you so much to everyone who came along to it and asked questions. I would like to thank our panel, Baroness Meacher, Professor Sir Sam Everington, and Dr Alex Allinson, for their answers and the discussion about this very important issue. I would also like to thank Dignity in Dying, which has sponsored this event and made it possible. Thank you, everyone, for coming, and I hope you have enjoyed the event.

Baroness Meacher: Thanks a lot.

Note: This event has been edited for grammar, clarity, and flow. The original recording is the final and definitive version.

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Transcript uploaded

October 19th, 2025

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