HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Assisted dying/assisted suicide, HC 711

Tuesday 6 June 2023

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Watch the meeting

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

Questions 141 - 180

Witnesses

I: Professor Irene Tuffrey-Wijne, Professor of Intellectual Disability and Palliative Care, Kingston University, London; Professor Jan L Bernheim, Oncologist and Emeritus Professor of Medicine and Medical Ethics, End-of-Life Care Research Group, Vrije Universiteit Brussel; and Professor Rutger Jan van der Gaag, Professor of Psychosomatic Medicine and Psychotherapy, Emeritus Professor of Psychiatry and former President of the Royal Dutch Medical Association.

II: Professor James Downar, Professor and Head, Division of Palliative Care, University of Ottawa, Canada; Professor Trudo Lemmens, Professor and Scholl Chair in Health Law and Policy, Faculty of Law, University of Toronto, Canada; and Dr Scott Kim, Adjunct Professor of Psychiatry, University of Michigan, and Senior Investigator, Department of Bioethics, National Institutes of Health, USA.

Written evidence from witnesses:

- [Add names of witnesses and hyperlink to submissions]

Examination of witnesses

Witnesses: Professor Tuffrey-Wijne, Professor Bernheim and Professor Van der Gaag.

Q141 **Chair:** Good morning. This is the Health and Social Care Committee, live from the Palace of Westminster in London. This is the Committee's third oral evidence session for our inquiry into assisted dying/assisted suicide. This is a cross-party Committee. Members of the House of Commons in this Committee will hear from witnesses in jurisdictions where individuals are eligible at the moment due to "unbearable suffering, including, but not restricted to, suffering related to a terminal illness."

The first panel, which I shall introduce forthwith, comprises witnesses and experts in Belgium and the Netherlands. The second panel, which we will move on to at 10.30 sharp, contains witnesses from Canada or with expertise in Canada. We are going to look at the monitoring of cases in these jurisdictions, eligibility criteria, safeguards, capacity assessments and, of course, the role of palliative and end-of-life care.

Before we get started, do any members in the room have any interests that they wish to declare? That was a no, for the record.

Let's introduce our first panel of guests. We have Professor Irene Tuffrey-Wijne, who is professor of intellectual disability and palliative care at Kingston University in London; Professor Jan Bernheim, who is an oncologist and emeritus professor of medicine and medical ethics in the End-of-Life Care Research Group in Brussels; and Professor Rutger van der Gaag, professor of psychosomatic medicine and psychotherapy, emeritus professor of psychiatry and former president of the Royal Dutch Medical Association. Thank you so much for joining us. Obviously you are online, but we have a loud and clear connection to you. We are really grateful for your time.

If we might start with you, Professor Van der Gaag, can you give us a sense of how this debate came about in your country? Why do you think that you were such early adopters of legislation in this field?

Professor Van der Gaag: Thank you very much, Chair. I trained as a GP in 1976. Every week we had discussions among colleagues in the region. I was serving in a small village outside Utrecht. Every week we had cases where we discussed how to palliate the suffering of terminal patients. Oftentimes we offered patients the means to terminate their life, but no one ever used that. We were always very afraid of what might happen if the word were spread that we were offering patients the possibility of terminating their life as their suffering was unbearable and there was no prospect of recovery.

I had the same experience when I served for 12 years in the department of oncology of the Wilhelmina Kinderziekenhuis in Utrecht, where, with the accordance of the regents, I offered care to youngsters who were terminally ill with cancer for which, at that point in time, there was no solution. They were all afraid that they would suffocate or suffer unbearably. I consoled them by saying that I would be there all the time. None of them died with any assistance, but I postponed holidays and weekends to make sure that I was at their bed once a day, or even more often.

Among physicians in the Netherlands, there was always a sense of tension because they were afraid of being prosecuted if they were reported to the police. Els Borst, who was my supervisor when I was a medical student, became Minister of Health after having been my boss at the University Medical Centre in Utrecht. She was the one who, at the strong request of the Royal Dutch Medical Association, passed the Termination of Life on Request and Assisted Suicide (Review Procedures) Act back in 2002.

I must say that, as president of the royal college of medicine in the Netherlands, I had a hard time in the WMA—the World Medical Association—and elsewhere explaining why I thought that the Act, which I have never used myself because I have always been there for my patients giving palliative assistance, was so important. It was important for safeguarding the doctors, but it was especially important for respecting the autonomy of the patients. What I think is most important is that it is a system with checks and balances. In our country, 170,000 people died in 2022; 8,720 died with assistance under the terms of the termination of life Act and 44,000 died under palliative sedation at home. We do not know how many died in hospitals and nursing homes with palliative terminal sedation; there are no checks and balances.

For me, it is essential that citizens are respected, that the self-determination and autonomy of citizens is crucial, that citizens have safeguards and that there are checks and balances. Although I understand fully the need for palliative care, which I have provided all my life, and the possibility of terminal sedation, and I have the utmost respect for my colleagues and the nurses in our country, I do not know whether the 44,000 people who died from terminal palliative sedation last year in our country did so because they wanted it or because other pressures pushed the doctors to terminate their life.

That is the reason why I strongly advocate having a law, although I myself, as a person, have never been able to give terminal palliative sedation or assisted suicide because it is against my moral principles. I have always assisted the thousands of people whom I have helped to die without any medical measures, but I think that, as a respectful country, we should have respect for the autonomy of our fellow citizens, we should safeguard our doctors and nurses, and there should be a system of checks and balances to make sure that the will of the patient is respected by all means.

Q142 **Chair:** Thank you. That is a very powerful first answer. You personally would never administer such assistance because, as you said, it is against your principles, but you believe in having it. That would make you quite unusual, if I may say so, given some of the evidence that we have heard.

Professor Van der Gaag: I am very unusual.

Chair: We all are, sir.

Professor Van der Gaag: I have given palliative sedation and done my very best not to make people suffer unduly, but I could not myself inject a lethal substance into another individual. Having said that, I respect those who do it. I respect especially our legislation. We have an Act. We know that 0.1% of the cases are not duly done according to the law.

Q143 **Chair:** Thank you for that as a starter. Bearing in mind the time, could we keep answers relatively brief? Professor Bernheim, why do you think that the Netherlands and Belgium were such early adopters of policy in this area? What is it in the psyche of your country that makes it different from, say, the UK? *[Interruption.]*

Professor Bernheim: I am sorry. I will be right back.

Chair: Okay. The phone has gone. Such is Zoom. We are right back in 2020.

Professor Tuffrey-Wijne, I will put the same question to you. Why do you think that your country was such an early adopter of a change in the law in this area?

Professor Tuffrey-Wijne: Thank you for that question. First, I want to explain that I grew up, lived and was trained as a nurse in the Netherlands, but I have lived and worked in the UK all my adult life. I have no professional direct experience of assisted dying, so that is a difficult question for me to answer.

There are two things that I can say. One is that the Netherlands did not have a well-developed palliative care profession, as a specialism, when that law became law—unlike the UK, which, I would say, had a far more advanced palliative care specialism. The other thing is that it is always difficult to weigh up the ethical considerations of autonomy and doing no harm. How countries interpret and strike a balance between those two things is different in different countries. What I know of my own culture is that in the Netherlands there is possibly a much stronger emphasis on autonomy and having rights, as an individual, to make your own choices and decisions. I am concerned, though, that that might be in conflict with doing no harm. We may well come to that in further questions.

Chair: I feel that we might. Professor Bernheim, welcome back. To conclude that question, why such early adopters in your country? What is it?

Professor Bernheim: I think it is compassion. I worked as an oncologist at the Cancer Institute in Brussels, which is similar to the Royal Marsden in your country. That was in the late ’70s and the ’80s. We had British expats among our patients. They said, nicely, that they trusted that we were reasonable oncologists, which was probably true, but we were no good at end-of-life care. I am talking about the late ’70s and early ’80s. They asked us to go and have a look at hospice palliative care in the UK, which we did, with nurses and colleagues. We liked most of what we saw, and we introduced it in Belgium. I think that we were the first palliative care unit on the continent, outside the UK. They were called continuing care communities.

The inspiration was, of course, compassion and good medical practice, but in those days, as before and as in the UK—to a small extent, I know—we also got requests for assisted dying. The last thing that we wanted to do was to be obliged to honour such requests for lack of good palliative care—good preventive measures for the request. Palliative care was introduced in Belgium for two reasons: first, on its own merits, undoubtedly; and secondly, to make the honouring of requests for assisted dying ethically acceptable. That is what happened.

Palliative care was quite well developed in Belgium. Incidentally, it is very important to note that it is demand-driven. It is not funded by budget; it is fee for service. In other words, it has been growing by 10% every year since about the turn of the century. Interestingly, the number of cases of assisted dying has increased in parallel with that. I am pleased with that. In Belgium, palliative care and assisted dying go hand in hand. They are, you might say, bedfellows.

Chair: Let’s move on. I am going to bring in other colleagues who are in the room, starting with Paul Blomfield.

Q144 **Paul Blomfield:** One of the issues that we are keen to explore in terms of law change is the question of safeguards. The question is raised in relation to any new law in the UK. Equally, there is a question of safeguards in relation to the current law. Professor Van der Gaag has made some fairly powerful points on palliative sedation and the lack of safeguards in that area. Obviously, palliative sedation is legal. Professor Tuffrey-Wijne, do you think that there are sufficient safeguards in current UK law to protect people?

Professor Tuffrey-Wijne: I think there are. The intention of palliative care is to make people comfortable—to relieve suffering. The intention is not to bring about death. That is quite a clear principle. Sometimes giving people sedatives or increased doses of pain relief may bring about death sooner, partly because it relaxes people into being able to die, but it is not the purpose of what you are doing. In my view, palliative sedation does not have the intention of bringing about the patient’s death. It is about making the patient comfortable. That is quite a fundamental difference in principle. British law is quite clear. You cannot intentionally bring about a patient’s death. I think that the answer is yes, there are sufficient safeguards.

Q145 **Paul Blomfield:** The law is clear; you cannot intentionally bring about death, but what you describe is that palliative sedation shortens lives. Clearly, assisted dying also shortens lives, but by choice. We also have the situation where people in this country travel to Switzerland to seek assisted death. Do you think that there are safeguards in our law to prevent coercion in those sorts of circumstances?

Professor Tuffrey-Wijne: I am interested to know what you mean by coercion. I don't quite understand what you are asking there.

Q146 **Paul Blomfield:** Let me clarify the question. Those who resist law change say that one of their primary concerns is that people may be coerced into seeking premature death. What we are trying to explore is how far that might happen under the existing legal settlement in the UK.

Professor Tuffrey-Wijne: Maybe coercion is the wrong word there. I don't believe that anybody would say, "I think you should die. This is a good choice for you."

What I have seen is this. My subject area is around disability and end-of-life care, so I have done extensive study of the case reports coming out from the euthanasia review committees in the Netherlands on assisted dying, particularly for people with learning disabilities and autism. I have seen from those case reports from the Netherlands that there is something about understanding or knowing what the alternatives are. If palliative care is not well developed and assisted dying is an option that is available and on the table, and people know that it is an option, it becomes much more difficult to consider the alternatives.

For people with disabilities, in particular, there is an underlying unconscious bias from society that disability and dependence are difficult to live with. That is where the word coercion may come in. It is too strong a word, I think. It is not actively coercing people, but the implicit message may be that death is preferable to life in their situation.

Q147 **Paul Blomfield:** Can I move on to Professor Bernheim with the same essential question? Do you think that law change has added more scrutiny and oversight to end-of-life practices in the Netherlands?

Professor Bernheim: In Belgium?

Paul Blomfield: In Belgium. I am sorry.

Professor Bernheim: Undoubtedly. A couple of particularities of my country are that it is probably the country where the end of life has been studied most intensively. The study group I belong to is 70 people strong. There are dozens and dozens of studies and publications, so we have exact answers to your question.

Before the law in 2002, there were three times more cases of assisted dying without explicit requests than with explicit requests. That was before the law. They were all illegal, but it happened. That was studied quite extensively. Yes, with absolutely no trace of a doubt, scrutiny of the end of life has very much improved since the law. It is legal and obligatory. Now the number of unrequested endings of life has become very small. When we studied those cases—with Dr Downar, incidentally, who is to be your witness from Canada—we found that in all cases they were really continuous deep sedation that the doctor, for some reason, had got into the assisted dying/euthanasia series.

I say wholeheartedly that, in my view, peer scrutiny is the most important safeguard. It has been very effective. There have been a few prosecutions brought about by scrutiny. There was also one brought about by the Control and Evaluation Commission, which is the federal organisation to which all cases must be reported. The answer is wholeheartedly yes. There is much more control, much more scrutiny, much more awareness and much more compassion.

Q148 **Paul Blomfield:** I see that Professor Van der Gaag wants to come in on that point. Given that I have not given him the opportunity in my questioning yet, let me take him.

Professor Van der Gaag: I would like to say one thing about palliative care. Then I will come to the scrutiny. My father died in 1985 in the UK. They lived in Wimbledon, and they had wonderful palliative care from the Macmillan nurses, which was non-existent in our country at that time. I completely agree that palliative care lagged behind on the continent for a long time and that the UK had an exemplary palliative care system at that time. I am very grateful for that.

When it comes to scrutiny, one of the very interesting things is that in 2015 we got something called the end-of-life clinic. I was president of the Royal Dutch Medical Association, and we were all very much afraid that some coercion or facilitating of the legislation would be in place due to that so-called clinic. In the first year, more than 700 people applied to that clinic. Nearly all of them were psychiatric patients. In our law, there is no differentiation between physical suffering and psychological and existential suffering. As a psychiatrist, I was very concerned that many of those people would qualify for assisted dying. At the end of the day, 14 of the nearly 700 were helped. Those were dramatic cases where, when I reviewed the cases, I really thought that there was no other way out.

My question was, what happened to the other 686 people? We went to see them. None of them committed suicide. All of them had a feeling of release. For the first time, they had been really heard by two independent doctors. They had had long conversations with nurses. The whole process of checks and balances had given them new perspectives.

When we talk about checks and balances, it is not only about looking at whether the scrutiny has been optimal for those who qualify but, especially, about the other people. As a specialist in autism, having worked in that field from 1980, I know many cases of patients I brought into the process who did not get assisted dying. The problem is that many psychiatric patients hear all the time, "Oh, you have suicidal ideations. It’s all your mental disorder,” whereas their suffering is sometimes unbearable. They have been admitted to psychiatric wards 20 or 30 times—over and over again. There is no perspective in their life. When we have a procedure for these people to talk to their own psychiatrist and two independent psychiatrists, and an independent doctor reviews their case, they feel comforted, even when they are rejected. I think that is an act of compassion, not only assisting but hearing people and really taking their autonomy seriously.

Paul Blomfield: That is a really helpful point. I would like to pursue it further, but I think I have run out of time.

Chair: Yes. Maybe we will come back, if we need to. Chris Green is next.

Q149 **Chris Green:** Professor Tuffrey-Wijne, the debate in the United Kingdom when we discuss assisted dying/assisted suicide normally opens up with the statement that it would be very limited in scope. Initially, it would be limited to people who have a terminal illness, perhaps with an expectation of six months left in life. Why is the situation in the Netherlands so much broader than the debate suggests that it would be in the United Kingdom?

Professor Tuffrey-Wijne: In the Netherlands, the criteria are around unbearable suffering without prospect of improvement. I know that in a number of other countries there is a requirement to have a limited prognosis, of six months or 12 months. In a way, it is not particularly logical. It is quite difficult to know what somebody’s prognosis is. There will always be people at the edges of that who will think, “That is not fair. Why can’t I have it?” There is no actual logic in having a cut-off point of six months or 12 months. The criteria have also always included the fact that somebody has to be suffering, and have unbearable suffering. In a way, there is no particular logic around a limited prognosis. That makes it quite difficult, because then you have to think about what unbearable suffering is and what people’s prospects of improvement are. Those are very difficult issues to assess.

I want to make a very quick point about the previous question, on scrutiny, and the very low percentage of cases in the Netherlands that have been found not to have met the criteria. That may well be because, of the six due care criteria in the Netherlands, four are around unbearable suffering, its being voluntary and the person having capacity, and two are procedural: have you consulted an independent physician, and did you use the appropriate drugs for the ending of life?

Procedural criteria are the only ones that you can assess afterwards to see whether they were correctly followed. Almost all of the very low percentage of cases that failed are on that. The committees are not able to assess in retrospect whether the patient’s suffering was unbearable and there was no prospect of improvement, because the patient has died. It seems like a very solid safeguard, but it is quite difficult to assess and scrutinise afterwards.

Chris Green: I want to follow up on a different question, but Professor Van der Gaag has a comment.

Professor Van der Gaag: Yes. There is even one more criterion in terms of procedure; there has to be a written will. That is the starting point and then the others come along too. Some people who do not have a written will do not qualify for the procedure when they are terminally ill. That is a matter of concern. I agree with Professor Tuffrey that the procedural criteria have little to do with unbearable suffering.

Q150 **Chris Green:** Thank you. Professor Tuffrey, often when the subject is discussed in the United Kingdom it is around people who have cancer or a clear life-limiting medical condition. We do not often think of it in terms of intellectual disabilities. What is the experience of that in the Netherlands?

Professor Tuffrey-Wijne: Yes, that is right. Clearly, in international human rights law, disability should not stop you. You have the same rights as everybody else. If there is an assisted dying law then, quite rightly, if you have capacity to make those decisions, you are eligible.

What I find in the case reports we studied is that people with disabilities and autism find it more difficult to weigh up information and consider alternatives. For example, a patient who had a mild learning disability was treated for a curable cancer, but then found it difficult to live with the necessary changes in her dietary habits. She had to eat lots of meals a day rather than three main meals a day, which she found very difficult. Therefore, she could not really cope with the effects of the illness and that made her life limited. If you are not eating, you will die.

It is people not being able to consider alternatives, or seeing dying as one option and then clinging on to that option as the one that they want. For example, a woman with tinnitus was told by her doctor that people learn to live with tinnitus, but she thought, “Assisted dying is an option and that’s the one I want.” She was very persistent in that request. One concern is considering the alternatives.

The other concern, and it is a real one—

Q151 **Chris Green:** On that point, it is almost that you are suggesting that, if someone is offered a menu of choices, there is parity between the different choices that are being presented. Are you suggesting that someone with an intellectual disability is not able to distinguish between those different choices? Is that the case, or not?

Professor Tuffrey-Wijne: It is difficult to consider alternatives and to apply them to your own situation. That is the experience in the Netherlands. If there is less experience or expertise around you, in your family and society, of living with illness and disability in a positive way, that becomes more difficult as a choice.

We know that healthcare and social care systems are not level playing fields. If everybody had a full range of choices, options and possibilities, clearly people should have a choice, but they do not. We know that in the UK in 2021, 49% of deaths of people with a learning disability were avoidable. That compares with 22% of deaths in the general population. People are not really being offered the same range of alternatives of treatment choices, for example, because doctors may well think that the person cannot cope. There are unconscious biases there. I am not reassured that the Dutch system provides sufficient safeguards for that kind of risk that people have.

Chris Green: Professor Bernheim, do you want to follow on from that?

Professor Bernheim: Briefly to point out that, of course, capacity is a difficult and sensitive issue. It deserves our attention. Let me point out that a problem of capacity is not considered a reason to force-feed people who refuse treatment and who die, just as inevitably as with assisted dying. There should not be two ways to measure capacity when it comes to refusing treatment, which is not denied to them, and assisted dying.

Q152 **Lucy Allan:** Before I start my questions, can I come back to the testimony of Professor Irene Tuffrey-Wijne? Did you say just now that tinnitus would be a reason for assisted dying being granted in a Benelux country?

Professor Tuffrey-Wijne: Yes.

Lucy Allan: And that has happened?

Professor Tuffrey-Wijne: Yes.

Lucy Allan: Thank you very much.

Professor Tuffrey-Wijne: It is a fear around unbearable suffering. If a patient says, "I'm suffering unbearably, and there is no prospect of improving this because my tinnitus will not be cured," it is for the patient to say whether the suffering is unbearable. Of course, you then have to have the physician agree that there is indeed unbearable suffering and no prospect of improvement. It does not have to be an incurable disease like cancer, in the Netherlands.

Q153 **Chair:** That would be a point of debate, wouldn't it, between the physician and the patient? The patient could say it was unbearable, but the physician could say it was not. Who wins?

Professor Tuffrey-Wijne: Yes, that is the difficulty. There have been reports where there has been disagreement between the independent physician that you have to consult, or the first physician says no. There have been disagreements. The scrutiny by the euthanasia review committee takes testimony from the physician who carries out the euthanasia and asks their opinion. They would be the person who has agreed with the patient that the suffering is unbearable. It is a very difficult thing. How can you say that for somebody else? It is difficult.

Q154 **Lucy Allan:** Are you saying that there are no safeguards in the Benelux countries when it comes to assisted dying?

Professor Van der Gaag: I want to make one point. There are a lot of people who have tinnitus who commit suicide. They do not ask for any assistance; they just commit suicide because it drives them mad. There are cases where people have requested assistance because of tinnitus, but I strongly oppose saying that tinnitus is something very light. There are cases, and I have seen many patients who have committed suicide because of tinnitus. There are a few people who request assisted suicide.

The suggestion was that tinnitus is something very light and should not be taken care of. I want to make that point strongly. I know of cases where, if they apply for assisted suicide, they are offered options. The testimony of Professor Tuffrey was quite offensive when it comes to the care we have for people with disabilities in our country. I agree that sometimes the capacity means that they do not qualify for assisted suicide, but I strongly advocate that we have a wonderful system, that people with disabilities are well taken care of in our country and are positively approached. I really object to the image that in the Netherlands people with disabilities have no other choice than to ask for assisted suicide.

Lucy Allan: I am going to bring in Professor Bernheim on that point.

Professor Bernheim: I would like to add that Belgium and the Netherlands—not by accident, I think—happen to have the most developed palliative care services in Europe. Another important point is that in Belgium the law was possible partly also because confidence of the public in the medical profession is very high. It even rose to 95% or so after the law; confidence in the medical profession increased after the passing of the euthanasia law. Yes, palliative care services are good. There are still things left to be desired—quite so—but they are well developed in Belgium.

As far as I can see, the only place where palliative care services are largely charity is the UK, which is not the case in the Netherlands and Belgium. They are national health services.

Q155 **Lucy Allan:** On that exact point, has the legalising of assisted dying improved the provision of palliative care or reduced the availability of palliative care?

Professor Bernheim: Palliative care has expenditure. There is no such thing as a budget for palliative care in Belgium because it is fee for service; it is demand-driven, not supply-driven. It is part of national health insurance. Palliative care expenditure has increased every year since the law by about 10%, which is a lot more than the expenditure for the rest of healthcare, which is about 2% every year. Yes, the law has boosted palliative care in Belgium tremendously. I know that it is similar in the Netherlands.

Lucy Allan: Professor Van der Gaag?

Professor Van der Gaag: I just want to say that, as I stated, when my father passed in 1985 there was no real palliative care in the Netherlands. Since the turn of this century, it has advanced tremendously. I think we have a very good palliative care system in England as well.

Q156 **Lucy Allan:** Given your lived experience, can I ask you about the relationship between patients and healthcare providers? How has the introduction of legalised assisted dying impacted on the relationship between patients, healthcare providers and, of course, families as well?

Professor Van der Gaag: That is a very difficult question. The main change is that over the past 20 or 25 years there has been tremendous patient emancipation: 20 or 30 years ago people just believed what the doctor said, and in very few cases were there second opinions, but nowadays the patient comes with the Google of his or her disease, and the doctor is often taken by surprise because the patient knows more than the doctor does. I think there has been a tremendous change in the relationship between the doctor and the patient. That means that our patients are more assertive when it comes to the end of life.

I must say that one of the points we have is that you have to have a written will. I have a written will. One of the things that is very underestimated is what happens to you when you become ill. When you become ill, you change. Many people in our country think, “If I get cancer or dementia, I want to have assisted dying.” One of the other safeguards is that you have to reiterate your will. You have to write it down in the first instance. When I think of the criteria that people I know have written down, what often happens is that they request assisted suicide much later than they had anticipated when they were healthy.

It is one of my concerns that a lot of people think that death does not belong to life. Death is the only certainty we have, but somehow it has been banned from the public debate. As Professor Tuffrey was saying, everyone is working hard to safeguard life and I think we are missing a lot of opportunities to respect the last phase that people go through in their life. Sometimes we must say that the fact that we have legislation in place should, on one hand, be a safeguard and, on the other hand, an encouragement to skip a phase that is very vital not only to the person but to all the family.

Lucy Allan: Professor Bernheim, do you want to add to that?

Professor Bernheim: Yes. Germane to this is the thought that I have practised assisted dying several times in the presence of a minister of religion, a priest, after the last rites took place. Let me be clear. Research has shown that spiritual palliative care and spiritual aid in dying is three times more frequent in the case of assisted dying than in the case of conventional death. That is one of the studies we did in Belgium.

If you are going to be serious about the spiritual experience of death, by all means do not oppose assisted dying. Alas, too many deaths are in isolation during the night with no mental or spiritual preparation. In the case of assisted dying, it is a ceremony. It takes place mostly in the home of the patient, sometimes after the last rites. Death then becomes part of life, and it is also a spiritual experience. That is the case for a number of my colleagues who practise it. For them, it is a transcendental experience to help their patients with assisted dying.

Q157 **Chair:** There are a couple of things, and then I am very happy for any colleagues who want to complete questions to come back in. I said at the very start that we were going to probe the monitoring of cases. I am not sure who wants to take this, so stick your hand up as I am asking it.

In the Netherlands, doctors "must"—underlined—report the death to the municipal coroner, who informs the regional review committees. In Belgium, doctors "should" report the death to the federal control and evaluation commission. In 2021 there were 7,666 notifications of euthanasia in the Netherlands. In 2021 there were 2,699 cases of assisted dying reported in Belgium. Why do you think that difference between "must" and "should" is so obvious?

Professor Bernheim: The first thing is that Belgium is a lot smaller, not in surface but in population. It is about 11 million, whereas I believe the Netherlands is about 17 million. That is one thing.

The other thing is that, yes, the prevalence of assisted dying is a little bit lower in Belgium than in the Netherlands. In 2022, there were almost 3,000 cases for 100,000 deaths, which means that about 3% of deaths were by assisted dying, but there were 15% deaths by palliative sedation or continuous deep sedation, without safeguards. I am afraid that, oftentimes, that was without any request by the patient.

Q158 **Chair:** Finally from me, and this is probably for you, Professor Van der Gaag, in the Netherlands children aged 12 to 16 are eligible with parental consent. The Government approved plans in 2020 to extend it to children aged from one to 12 years with parental consent. I would be interested in your view on the so-called slippery slope. Separately from the Act, euthanasia of infants under one year is permitted with parental consent and is regulated through the Groningen protocol. Could you address the slippery slope thesis and explain to us what that protocol is, please?

Professor Van der Gaag: There are two different things. The first thing is that the Groningen protocol refers to children who are not viable and are in neonatal intensive care units, where the child is kept in life but there is no possibility to terminate the ventilation, although everyone knows that the child cannot live or survive without ventilation assistance and would not develop. That is an act that refers to very disabled children who would not have survived if, at the first moment after delivery, neonatal intensive care had not been put in place. It was to help parents and doctors take the decision to stop ventilation.

In our country, children aged 12-plus are allowed to speak in all legal cases. I refuse the word "euthanasia", but I think the termination of life on request Act holds true for them too, especially in cases of cancer where the suffering is unbearable and unfortunately there are no prospects for recovery. In that case, our legislation makes it possible for parents and children to be heard and for the protocol to be followed. I think that is, as Professor Bernheim expressed, an act of compassion.

The problem, of course, is: why not then apply it to cases between one and 12 years under the same criteria? Obviously, there we have a legal problem that I cannot address, but from a human point of view, why would you refuse? These children get palliative care, but should they suffer unbearably for as long as necessary? There is no legislation at this point.

Chair: Bearing in mind that we are coming towards our 10.30 stop on this, we have a paediatric care doctor as a member of the Committee. Dr Caroline Johnson wants to pick up on the thread that I have started with you, Professor.

Q159 **Dr Johnson:** I want to clarify the point the Chair asked you about the protocols as regard to children under the age of one. In the UK, we see a distinction: when children who are receiving mechanical ventilation have that ventilation stopped because it is felt that the child's prognosis is very poor and/or that they would die without ventilation, that is seen as a withdrawal of active care, moving to palliative treatment. That is not the same as active euthanasia or actively ending somebody's life by simply removing something that keeps them going. Are you saying that that is as far as it goes in your country too, or are you saying that people would be able to actively euthanise a baby?

Professor Van der Gaag: No. The Groningen protocol is exactly as you say. It is withdrawing care in those cases. There is no active termination.

Chair: Finally, I promised that Mr Blomfield could come back for a second turn.

Q160 **Paul Blomfield:** This is on the issue of what leads people to seek assisted dying. A lot of attention, in relation to both Belgium and the Netherlands, has been around mental illness, but the numbers that we have been given as a Committee suggest that the overwhelming number of people taking assisted dying as an option breaks down to two thirds cancer and largely other physical illness. Mental illness is too small to register in the Netherlands, and it is less than 1% in Belgium. Is that a fair reflection of the situation?

Professor Van der Gaag: Absolutely. In 2022, there were 8,720 cases of assisted dying in the Netherlands, with 288 in dementia, 282 of which were in the early phase when the patient was able to express his will. There were only six cases in prolonged dementia and 115 psychiatric cases, compared with nearly 6,000 other cases.

Paul Blomfield: Professor Bernheim, do you want to come in?

Professor Bernheim: It is about the same thing in Belgium. In Belgium, since the law changed in 2015, there have been six cases of minors receiving assisted dying—six cases. They are not negligible, but this should not be overblown as a concern.

Q161 **Paul Blomfield:** Thank you very much. I have a final question for Professor Tuffrey-Wijne. You wrote in a blog that you thought that decisions on euthanasia "should only be open to those with a high degree of mental capacity", and that for "a life-or-death decision such as this, the bar for capacity should be set high." If we were to change the law in the UK, how would you set that bar? What are the eligibility criteria and safeguards that you think would give the right balance between people's right to choice and protection?

Professor Tuffrey-Wijne: There are four criteria that are used: the Appelbaum criteria. The person has to understand—clearly you have to give somebody real information, in a way that people can understand, about all the options on the table—and then the person has to be able to apply that to their own situation, appreciate the significance and weigh up the options, using reasoning and logic. How much people can understand is not a black and white thing. It is a continuum but, of course, whether or not you have capacity is a yes or no decision. Where you make that decision matters.

It is very difficult to assess. It is very difficult to know that for sure, but I would say that if two or three physicians assess somebody's capacity and disagree with each other, you should not proceed with the euthanasia, because there is a question. That is what I mean. I am not sure whether the bar is always set high enough. There are a number of case reports where there has been disagreement, yet the euthanasia went ahead. I think there needs to be more involvement of more people—psychiatrists and doctors, and also families. That is not very clear from the case reports. It may well be that they are involved. Of course it is the patient who matters, but a patient does not live in isolation. It is a very complex thing, and it needs more research and looking into where and how that is set.

Paul Blomfield: Professor Bernheim, do you want to come in very briefly? We have a couple of minutes left.

Professor Bernheim: Yes. I think that the family, mainly for emotional and coherence reasons, must be informed and must have a say if necessary. I recommend students to relay the wishes of the family to the patient, but it is for the patient to decide. Bringing in the family as judges is a terrible burden on the family and brings in the possibility of coercion, which is really unbearable.

Professor Tuffrey-Wijne: I am not saying that families could be brought in as judges, but that their opinions should be part of the decision. It is not just the patient.

Professor Bernheim: Of course.

Professor Van der Gaag: We have to be careful. If the family is in favour and the patient is against, I would listen carefully to the patient. On the other hand, what Professor Tuffrey was saying about the criteria is exactly what is happening. For instance, the Netherlands Catholic association requested that two independent psychiatrists should see people with mental disorders, and in cases where there is doubt the attendant doctor often calls on a third specialist. We see in the case reviews that scrutiny is in place. Judging someone's capacity is very difficult. I agree with Professor Tuffrey that someone with a learning disability might be very susceptible, so you have to be very careful. If there is any doubt about the capacity to decide, in our country there is no way you can proceed.

Chair: Thank you very much. We are going to leave it there. We could talk all day; it would be lovely to talk to you in the room, but I think we have coped very well with the technology being such as it is. Professor Irene Tuffrey-Wijne, Professor Jan Bernheim and Professor Van der Gaag, thank you so much for your time.

Examination of witnesses

Witnesses: Professor Downar, Professor Lemmens and Dr Kim.

Q162 **Chair:** This is the Health and Social Care Select Committee's third session on assisted dying/assisted suicide. We have just had our first panel from the Netherlands and Belgium; we are now jumping across the pond to Canada.

We are joined by Professor James Downar, who is professor and head of the division of palliative care at the University of Ottawa; Professor Trudo Lemmens, professor and Scholl chair in health law and policy at the faculty of law at the University of Toronto; and Dr Scott Kim, adjunct professor of psychiatry at the University of Michigan and a senior investigator in the department of bioethics, National Institutes of Health, USA.

Dr Kim, you wanted to put something on the record in respect of your giving evidence to us today. Please go ahead.

Dr Kim: Yes. I work for the US Government, but I want to make it very clear that today I am giving my own expert opinion and I do not represent the views of anybody else.

Q163 **Chair:** Thank you very much. As you know, we do not have legalised assisted dying/assisted suicide in this country. We are holding an inquiry to inform Parliament. The courts here have been crystal clear that this is a decision for Parliament. Hopefully, our work will inform a future Parliament and future parliamentarians if/when they are faced with that decision.

You have had the law in Canada for a while now. Professor Downar, what message, through this Committee, would you give people in this country as to where we sit versus where you sit right now? Do you perceive us to be in the dark ages?

Professor Downar: Absolutely not. I do not think that any country should look down on any other country on this issue. In general, we have reached a point in development as a society where many countries are in a position to legalise safely medical assistance in dying for people with serious and incurable illness who have intolerable suffering. It is something that you can offer people and that they can choose to take or not to take. I think a number of jurisdictions have shown that it can be safely implemented as part of a comprehensive suite of end-of-life care options for people.

Chair: Professor Lemmens, the same question to you—give us your opening thoughts, please.

Professor Lemmens: I would say that Canada is a warning sign for countries that contemplate legalising medical assistance in dying or assisted suicide and euthanasia. We have a system that started off in response to the typical more exceptional cases of suffering, where there was a perceived need to allow euthanasia and assisted suicide in the case of a person with a degenerative disease approaching their natural death.

For various reasons it has rapidly expanded from a system that focused on an already broad end-of-life context in response to a Supreme Court case to, I would say, the most open-ended system in the world. We see the offer of physician ending of life, which is the large majority of cases—the overwhelming majority of cases. We have nearly no cases of assisted suicide. It has transformed into a system of life ending by medical professionals and has, in some way, become a first-line therapy. What I mean by that is that it is accessible largely on demand in very broad circumstances in response to suffering associated with medical illness or a disability more broadly. I would say that it is also the most rapidly expanding system in the world.

Q164 **Chair:** I am going to come right back to you on that, so hold that thought. Hold it lightly.

Dr Kim, following up on the first question I asked, your colleague has just said that Canada is a warning sign to the rest of the world. Do you agree?

Dr Kim: I think, on the whole, I would agree with that. I would say that the process that you have embarked on with this inquiry is very impressive. It is a very careful, bipartisan, open-ended, evidence-based inquiry, which involves a fair treatment of input that I think is very good.

In that process, looking very closely at Canada will be useful. I will be very brief. If you want to see an example of the most radically medicalised system of providing assisted dying, Canada would be a very good example. By that I mean that it combines, in terms of eligibility, something fairly close to almost a pure autonomy model, but the mechanism by which it implements it throughout the country is a well-established medical network. I would not say that it is a warning sign because it is the most open-ended. There are other countries with more open-ended laws. What is most sobering about the Canadian system to me is the combination of very open eligibility that is implemented through a well-networked framework of medicalisation. I am sure that we will go into details.

Q165 **Chair:** You can be sure of that. Going back to you, Professor Lemmens, although it was legalised last year, the eligibility criteria for accessing medically assisted dying in Canada, do not yet cover those who request it due to suffering caused by mental illness, but obviously the intention was there. I am just trying to understand—and then I will come to you, Professor Downar—why you think that implementation has been delayed twice.

Professor Lemmens: There are a couple of reasons. First of all, the Supreme Court decision itself did not deal with mental illness. The law came about and focused on the broad end-of-life context, which obviously did not exclude people approaching their natural death who suffer from a mental illness, but it did exclude them because of the restriction to end of life generally in people who suffer from mental illness who are not in the process of dying. They are suffering from a mental illness that has to be addressed.

When the law was expanded in that end-of-life context there was already very serious opposition by all Canadian disability organisations. There was a lot of pushback by health advocacy groups. The Minister of Justice himself, when he introduced the expanded Bill in Parliament, indicated that he agreed that there were unique challenges for legalising the need for medically assisted dying for mental illness and that, therefore, they would not move forward at this stage.

It got into the legislation under a sunshine provision as the result of a Senate amendment. The Senate, as you know, is your House of Lords. The Senate amendment introduced that, but because of the pushback that certainly came from the mental health communities and suicide prevention organisations, there was an agreement that they would take two years to design appropriate safeguards. That was recently expanded by another year.

Q166 **Chair:** Professor Downar, what is your view on that? Is it a certainty or still in question?

Professor Downar: I will take a step back for a second and refer more broadly to the question of non-terminal illness. One of the messages that has come out, unfortunately, is that people have tried to create the impression that the courts did not intend the law to apply to non-terminal illnesses.

MAID was decriminalised in Canada as a result of the Carter decision by the Supreme Court. Kay Carter herself was suffering from a condition called spinal stenosis, which can definitely become incurable and quite severe, but I do not think anybody would ever consider it a terminal illness. If you are saying that the Supreme Court intended to limit MAID to terminal illnesses, you are essentially saying that you think the Supreme Court did not want the Carter decision to apply to Carter, which is obviously not correct. In reality, and this was upheld in the courts in a subsequent challenge, in the Truchon decision, the court said once again that nobody ever intended the Carter decision to be limited to terminal illness. As stated, the Carter decision did not specifically exclude mental illness.

The delays that have happened are the result of a number of delays in the legislature to set up adequate training and other supports. Parliament has actually started to use its time well. There has been the passing of various benefits, including a national disability benefit and increased funding for palliative care and other supports. I think that is the reason for the delay. It is prudent.

Yes, there are definitely some very unique challenges to implementing MAID for mental illness, but I want to emphasise that the non-terminal cases in Canada are also exceedingly rare. In the first year, it was only 2% of all MAID cases. The same number of Canadians received non-terminal MAID as are struck by lightning.

Professor Lemmens: Could I briefly respond?

Chair: Yes, please.

Professor Lemmens: As a law professor I would not want to respond to the claim that the Carter decision focused on Kay Carter. The reality is that the Carter decision was particularly focusing on Ms Taylor. There are constitutional reasons why I cannot go into the details here, but Ms Taylor was suffering from ALS and the Supreme Court explicitly stated that it restricted its reasons to the circumstances of the case. I am not saying that it explicitly stated that the case of Kay Carter was not at stake, but it actually focused on the circumstances of the case in front of the court, which was the case of Ms Taylor.

Other cases have come since. There was one lower court decision in the Quebec Superior Court, but that is a lower court decision. The Supreme Court never ruled on the circumstances relating to mental illness. It explicitly stated in its reasons that it was not looking at cases of mental illness like those in Belgium which were brought to its attention.

Chair: Finally, Dr Kim.

Dr Kim: I want to address the point about non-terminal illness cases being exceedingly rare, and to point out that from 2021 it was about 2%, but of course there was a 90-day waiting period, plus it did not get implemented until March.

However, the reasonably foreseeable death criterion has always been interpreted so broadly that it includes many cases that many people would not see as terminal illness. That is one of the reasons why you are able to say that they are so rare. In fact, there have been legal cases challenging the RFD criterion in which the people who brought the case were found to be eligible, given the prevailing broad interpretive standards of end of life that allowed them to qualify. I remember Dr Downar testifying at the Truchon trial; he was surprised that challenging the RFD was even brought up, because he thought the plaintiffs could qualify. You have to understand the details of how this has been implemented at ground level to get a sense of what the practice is really like.

Q167 **James Morris:** Picking up on the discussion about mental illness as part of this equation, I have a question for Professor Downar. If we were to accept, hypothetically for a moment, that assisted dying for people who have a mental health diagnosis is legitimate, what are the limits to how we may define somebody who presents with a mental health condition and wants to go down the assisted dying route?

Professor Downar: Thank you for the question. I am happy to talk about this, just as long as we recognise that it really does not represent about 98% of MAID practice in Canada.

When it comes to mental illness, the paradigm from the Supreme Court very clearly stated that it applied to any serious and incurable condition with intolerable suffering for people who had reached an advanced state of irreversible decline and capability. The criteria established by the court, which are now encoded in law, certainly would not apply very broadly to anyone presenting, for example, to the emergency department with acute suicidality or an acute mental health crisis. None of those individuals would be eligible for MAID under the Canadian paradigm as it exists. Certainly, a number of guidance documents have been produced recently to try to help people assess when someone has reached the point of having an incurable mental illness.

It is obviously a contentious issue. To be clear, among the psychiatric community in Canada, polls indicate that roughly half of Canadian psychiatrists agree that there definitely are cases of mental illness that they would consider incurable. The Canadian Psychiatric Association has been quite clear that people should not be considered to lack decisional capacity just because they have incurable mental illness, or a mental illness.

Broadly, you are applying exactly the same paradigm. For somebody to have reached the point where they have an advanced state of irreversible decline and capability, and what would truly be considered an incurable mental health condition, is quite rare. Again, we can look to Belgium and the Netherlands for their experience of this.

Q168 **James Morris:** I accept that the rarity point is slightly irrelevant to the discussion. If, as others have said, the existing law is being interpreted in a fairly broad and open way, doesn't that potentially lead to a slippery slope where we are opening up assisted dying to a whole range of potential mental health conditions? Your definition of something that is an incurable mental health condition is itself a pretty contested definition, from the point of view of psychiatric interpretation. A lot of the interpretation and the definitions are pretty loose. Isn't that quite dangerous?

Professor Downar: I don't think there is 100% agreement on the issue whenever you ask questions about whether something is truly incurable. I have been in situations with people who had quite advanced cancer. There was somebody around thinking, "Well, maybe if we tried this, it could still be cured." You get to the point of how far down the list of potential therapies you have to go, and how much somebody has to endure before you are willing to concede that it is actually incurable—to the degree that we can tell that anything is incurable. The experience—

Q169 **James Morris:** Sorry to interrupt, but somebody could present the case that "I have been suffering from depression all my life; it is incurable; therefore, I want to access assisted dying."

Professor Downar: No current document written would accept that explanation alone. You can only define curability and incurability in terms of things that have been tried and would have been tried. There isn't a standard of care for treating depression, but there are a number of different approaches. I think everybody accepts that in order to be considered incurable you would have had to undergo a number of different treatment attempts, and essentially to have found them to be ineffective. The suffering will have had to have gone on for a very long period of time.

James Morris: Dr Kim?

Dr Kim: This is a very complicated issue and we could spend a long time talking about it. However, I want to point out that the focus on incurable and so forth makes it somehow seem like Canada has this objective and rigorous system. In effect, it is the following.

I believe one of the reasons why mental illness MAID has been delayed is because the committee that was charged with coming up with safeguards published a report that did not have any safeguards. It refused to define the kinds of things that most doctors would consider. For example, the Dutch Psychiatric Association has published what would be objective standards for a reasonable kind of package of treatment that would be standard for a person for a given disorder.

The key point is that under Canadian law, the fact that a person may have a chronic illness and refuse an effective treatment—if they can say, "Look, I've tried others and I don't want to do it"—or, more importantly, that they lack access to standard treatment, does not matter. They can still be eligible as long as the doctor makes the patient attest that they have "considered" the treatments that have been mentioned. That is very different from the standard practice even in the Netherlands, where it is a last resort option. It does not have to be a last resort option in Canada.

What that means is that a person can refuse effective treatment and have lack of access to effective treatment, yet be legally eligible in a medical culture that sees legal eligibility as creating a medical obligation to provide it. When you combine those things, it is a very dangerous situation, in my view. I think Dr Downar repeatedly says that this is going to be rare and so forth. In the Netherlands, about 5% to 10% of mental illness-based euthanasias are granted. The vast majority are found ineligible. The No. 1 reason why they are found ineligible is that they did not meet the irremediability criterion. In Canada that would be irrelevant. I think to say that it is going to be rare is not a factual statement.

James Morris: Professor Lemmens, do you want to come in?

Professor Lemmens: Briefly, to add that with respect to the legal context it is true that Canada has a unique system in the sense that, like Belgium and the Netherlands, there is an emphasis on the need to provide access, which results in part from the Carter case and the fact it was a Supreme Court case, where the court emphasised the right to have access to some form of life-ending procedure and re-emphasised the right to refuse treatment.

In the end-of-life context, that intuitively makes sense. Anybody will agree that when they are approaching death, it is quite common for people to say, "Well, do I want to go through an additional session of treatment? I've had enough." In that context, we emphasise that the right to refuse treatment makes sense, but it has been transformed now outside the end-of-life context. When you contrast that with Belgium and the Netherlands, where the doctor's approach and the legal obligation on the doctor is "I, as a physician, have to agree that there are no medical options left that can relieve the suffering of the patient," the Canadian context explicitly says there is no legal obligation to do so. The patient decides.

In the track 2 cases, outside the end-of-life context, there is a need to agree that the patient has seriously considered other options. There is still the requirement that patients obviously have to be suffering from a serious condition, illness or disability and to have irreversible decline of capability, but those criteria have been interpreted very broadly. We already have the case, for example, of Alan Nichols, who was brought to an emergency room because he was suicidal and subsequently received medical aid in dying. That was even before the track 2 cases.

It will really depend on the interpretation that is provided of irreversible decline of capability, which has been interpreted very broadly. You can combine that with the fact that there is an emphasis on conscientious objection. Health Canada guidelines now suggest that if people fundamentally object to providing medical assistance in dying in some cases—a physician might say, "In the mental illness context I think it is problematic to provide medical assistance in dying"—that constitutes conscientious objection, which would create a duty of effective referral.

When you combine these two things, you have a situation where you risk having a couple of very flexible physicians who believe that this is really something that should be provided and who may attract a large majority of cases. That phenomenon of physician shopping has happened in Belgium and the Netherlands, particularly in Belgium.

James Morris: Finally, Professor Downar, I think you want to come back in, and then we probably need to move on.

Professor Downar: I want to clarify a couple of points. The discussion has centred not around points of law at this point, but around points of clinical guidance. That is obviously a process that can be ongoing. Again, in developing guidance documents, this is something that involves much more than the medical community, with the participation of regulators. Again, it is not getting at the core question of what the law says.

As a point of information, I also want to state that in the case of Mr Nichols, which has been raised here, this was a gentleman who was brought to hospital with advanced frailty and not suicidality. This gentleman was actually assessed by a psychiatrist and was found to be capable of making decisions. I think that is really important. A number of cases in Canada have been misrepresented. It is important to set the record straight on some of these.

Chair: Paul Blomfield wants to pick up on one point that was made and ask a couple of other questions, and then we will go to Rachael Maskell.

Q170 **Paul Blomfield:** I want to press Dr Kim on his claim that 5% of assisted deaths in Benelux countries were as a result of mental illness. Perhaps I misheard you.

Dr Kim: Yes, you did mishear me. I said that, of all the requests for mental illness-based MAID or euthanasia, 5% were granted. In fact, only about 1% to 2% of all euthanasias in the Netherlands are mental illness-based.

Q171 **Paul Blomfield:** We have just heard from a panel of both supporters and critics who would concur with that and say the number is barely recordable in the Netherlands and below 1% in Belgium.

Dr Kim: No, that is incorrect. It is about 2% in the Netherlands. Belgium had a slight decline after a very public controversial case which went to court. Up to that point it was rising as well. Yes, it is in the 1% to 2% range, but growing. I think that should be added.

My point was simply that in the Netherlands it remains small because there is an objective criterion that a doctor has to apply. In Canada there is not that kind of backstop or safeguard of requiring an expert doctor's opinion, being given the power to say, "Look, I don't think you're eligible because there are other options that are very good that you don't want." In Canada, a person can still be eligible even if a doctor thinks that. That was the point I was making.

Paul Blomfield: Thank you. I will pause there and come back later, if I may, Chair.

Q172 **Rachael Maskell:** Thank you ever so much for joining us today. I want to look at the options to patients at a point when they are seeking solutions. My understanding is that around 30% of patients will have access to palliative care and many more could benefit from that. How much are the options for patients explored before being advised around assisted dying/assisted suicide in Canada, Professor Downar?

Professor Downar: Thank you very much for the question. The statistic of 30% is often thrown around in the Canadian context, but it is actually not accurate. We have no means of measuring access per se. There is no metric for access. We can tell you what people received and what they did not receive, and we can tell you who is getting MAID and who is not getting MAID. That much I can tell you.

What we know is that approximately, according to a Canadian report that was just released, about 60% of Canadians receive some form of palliative care before they die. That represents almost a 10% increase in the past five years. I underscore that point. Since legalising MAID, the use of palliative care has risen by almost 10% across the board of the population, which is almost certainly the fastest rate of growth of palliative care in Canadian history. That occurred as a result of very substantial investments in home care services and physicians. Despite the pandemic and the staff disruption of the pandemic, we still probably had the strongest growth of palliative care in history. It was probably between two and three times the rate of cases of MAID being provided.

We also know that the vast majority of people who receive medical assistance in dying are people with cancer. We know that almost 80% or 90% of people with cancer receive palliative care before they die. There is a very high concentration of the practice of MAID in populations that have the highest provision of palliative care. Again, this happens across the board. Certainly, people have expressed concern that maybe people are being driven to MAID because they do not have access to palliative care. First of all, Canadian federal reporting makes it very clear that 80%-plus of people who receive MAID also receive palliative care services and 98% had access. Certainly, we see that pan out in more objective data on who is actually getting MAID. The populations with the worst access to palliative care also have the lowest rates of MAID.

Q173 **Rachael Maskell:** Thank you. Can I put a similar question to you, Dr Scott Kim? Is there equality of access to palliative care in the same way that there is to assisted dying/assisted suicide?

Dr Kim: I don't practise in Canada, so I cannot speak from practice experience, but I confirm what Dr Downar said. The 2021 report, which is publicly available from Health Canada, states that a high-80s percentage of people who needed palliative care received it before MAID. That is about the extent of personal knowledge I have.

Q174 **Rachael Maskell:** Trudo Lemmens, when we made our visit to Oregon, one of the things that was presented to us was that assisted dying/assisted suicide was available to individuals on Medicare where, perhaps, cancer drugs were not available. Is there equality of access to the provision of all forms of healthcare that could sustain life or could indeed bring an improvement to somebody's situation for a period or a longer term?

Professor Lemmens: Yes. There are two things. First, with respect to access to palliative care, it is true that the Health Canada report states that 81% of people who received MAID received palliative care, but still 16.8% did not receive palliative care. If you look for the numbers about what they received, there is no information. I am sure that Dr Downar will agree with that. We do not know exactly what the quality of care is, of course. What is particularly striking is that close to 40% actually received palliative care for less than one month. I would leave it up to palliative care specialists, but many may have objections about claiming that that clearly shows they have sufficient palliative care.

In the 2021 numbers for disability support, again there is an indication that 43% of the 10,000 people who received MAID needed disability support; 87% received it. That means that there were 4,300 needing it, but it still means that 559 people needed disability support and did not receive it. Whatever those figures mean, we do not have much information about it. These are important things to keep in mind.

With respect to access to care more generally, we have a fairly decent healthcare system. People often do not realise that the Canadian system has serious limitations; for example, outside hospitals drugs are not covered. There are some exceptions. This is, on a provincial level, regulated quite well in Quebec but not in all provinces. There are problems with accessing adequate care. There are problems with accessing adequate disability support. Even the Federal Minister of the Government who introduced track 2, outside the end-of-life context, has conceded that it is often easier, even with the 90-day reflection period or evaluation period, to have access to MAID than to have access to very important disability support.

There is a tension around whether we are focusing too much on providing access to medical assistance in dying. Even in the province of Quebec, where they have introduced their own legislation, which explicitly connected medical assistance in dying with palliative care, there is a realisation that there are challenges in providing access to adequate palliative care in some cases.

Q175 **Rachael Maskell:** Is there any evidence or research which looks at how it determines people's choices for MAID if they do not have the access to comprehensive and high-quality social care or palliative care?

Professor Lemmens: There are some studies. Again, Dr Downar has done a study on the availability of palliative care, so he may want to comment on that. If you look at the Health Canada report, one of the things that raises a red flag for me is the reasons why people identified that they were suffering unbearably, which is the basis for asking for medical assistance in dying. You see that a very significant number of people asked for access to MAID because—I am looking at my numbers—they suffered from pain or feared that they might suffer from pain. It is a very significant number of people—more than 50%. If that is the case, it is a concern to me that we see unbearable suffering as a reason for providing MAID, but being identified as one of the important reasons why people say they suffer unbearably. We know that adequate pain relief will solve most of the cases in the healthcare context of people enduring or suffering from pain.

Q176 **Rachael Maskell:** Thank you for your response. Professor Downar, I see that you want to come back in. Do you believe that there could be stronger safeguards put in place in the legislation?

Professor Downar: Thank you very much for the question. I want to correct a couple of points that have been made. First of all, I am not sure where anyone is getting the idea that in the Canadian system drugs are not available outside hospital. The Canadian system absolutely covers particularly palliative care outside hospital. We send people home with very advanced technologies to deliver medications at home. All of it is covered by the Government. I am not sure where that perception comes from.

On the availability of disability support, again about 96% either did not need support or had the support that they needed, according to the Health Canada report. Again, I would love it if that number were 100%, but it is hard to argue that it is driving MAID to any degree. It is important to understand that the populations that are requesting and receiving MAID are predominantly from cancer groups and very much not from the non-cancer and frailty groups. Patients with cancer typically have much lower support needs than individuals with non-cancer illness and frailty, so they often do not require very substantial supports as they approach the end of life. They do at the very end, but at the time that MAID requests are made their needs are substantially lower.

The other thing you need to know about the people who receive MAID is that the statistics routinely show, in all jurisdictions, that they come from the much more affluent and well-supported ends of society in terms of family structure and living arrangements. The people who are receiving MAID are the least likely to need such supports and the most likely to have them in the form of family supports and finances. If we are thinking that unmet support needs may be driving this, you would expect to see exactly the opposite. That is all objective data. There is nothing subjective in that data.

I want to emphasise the point about the rationale for which people are requesting MAID. It is very rarely due to uncontrolled physical symptoms. It is almost exclusively due to existential distress and simply the fact that people have lost the ability to do the things that, in their opinion, give their life meaning. These are things for which even the best palliative care has very little, if anything, to offer.

As a palliative care provider, I like to think I am pretty good at my job. We all try our best, but I do not think that any field of medicine can justifiably claim that we can treat everything we see. We cannot. There are limits to what we can do. They are thankfully rare—it is only about 3% or 4% of people who receive MAID. If you are asking about what other things can be put in, you might want to tie benchmarked funding support for hospice systems or funding to improve research, so that we can develop newer treatments to give people more options for how they might want to treat their suffering. Those are all great ideas, but I really emphasise that, based on the data we have in front of us, there is very little reason to believe that any amount of MAID, or any substantial amount of MAID, is being driven by unmet support needs.

Q177 **Rachael Maskell:** Dr Scott Kim, can you also address the issue around whether there are sufficient safeguards in the system? What further safeguards would you want to see?

Dr Kim: I want to add something to what Dr Downar said. It is true that if you have very limited terminal illness only, in assisted dying the characteristics of people that Dr Downar mentions are probably true. I agree that there has not been evidence of widespread abuse or things like that. There are reports of worrisome cases, but not a big population of abuse. That is precisely because the decision on how one wants to die and how one wants to manage one's death versus whether one should go on living when one is not dying are very different human decisions.

It is important to keep that in mind when we talk about this. There is a sense in which because we use the common term "assisted dying" or "assisted death"—MAID—we tend to group all of that in one. Common sense and evidence tell us that these are very different decisions. To the extent that we are trying to make these general statements—do they get safeguards and so forth—we should think very differently. We need a looser definition of "reasonably foreseeable death". I believe that is the case in Canada.

It is indisputable that a person with a chronic illness who has made the clear intent to take steps to end their life by refusing to eat or drink would, even prior to the new law, have qualified for MAID. To the extent that it is a broad interpretation, plus including people who are not dying in the broader sense that we are talking about, you create a new set of vulnerabilities. If we just think about who the people are who are faced with the question, "Should I go on living even though I'm not dying?", these are folks who have many misfortunes that we traditionally think, as a society, we should connect with, engage with and support. That is a different kind of framework. To the extent that that is not provided, it is what worries me most about the Canadian system. For all those people who are struggling, not immediately at the end of life but in the longer term—a big proportion of what is happening—it is precisely that question.

To the question whether there are sufficient guards, I do not believe there are safeguards that could fix the problem, because of the law itself. I am going to conform to what Dr Downar suggested and stick with the law. The law itself says that this does not have to be the last resort, which means that a person could genuinely lack access to disability services and out-patient psychiatric treatment, which is common in Canada. Those people would still qualify. I think that is a very disturbing societal norm that is being practised. It is very difficult to think of safeguards that could overcome that structural, legal framework, which basically says, in effect, "Well, providing MAID to end your life is another treatment alternative we can offer you if you can't have these others."

Q178 **Rachael Maskell:** Thank you. Trudo Lemmens, you have one minute to come back.

Professor Lemmens: Very briefly. I have the numbers here in front of me. Nearly 58% of people explicitly say that a fear of pain or a fear of lack of control of pain is the basis for their unbearable suffering. I would say that that is a worrisome indication.

The second thing, in response to Dr Kim, is that I confirm that one of the concerns for people like me who supported the initial legislation is that originally there was a denial of the fact that we had cases of people who were asking for MAID because they lacked adequate support. There is now an explicit admission by some of the strong advocates for broader access to MAID that these cases are happening, but that they are a solution to a situation that is worse. It has been defended as a form of harm reduction to offer MAID when people do not have adequate access to social support and care. That is a serious concern.

I will share with the Committee some information about the Canadian system. I am not saying that there is no access to medicines outside the hospital. I may have been misinterpreted, or mis-stated that. As a matter of principle, the Canadian legislation does not provide an obligation for provinces to offer medicines outside the hospital context. As I mentioned, in Quebec and other provinces it is dealt with in different ways, but there are problems with accessing some forms of medicines. I can share that information with the Committee.

I can also share information about the Alan Nichols case, where Dr Downar suggested that I gave misinformation which was inadequate. I certainly did not intend to say that Mr Nichols was brought to the emergency room because he was suicidal, but he was diagnosed as suicidal in the emergency room and still received MAID a little more than a month later.

Chair: Thank you. You are being very helpful, and we appreciate that. Mr Blomfield gets the final word on this panel.

Q179 **Paul Blomfield:** I want to follow up on Dr Kim's last point. I would be grateful if you clarifed my understanding of your comment that your main concern about the Canadian system is the lack of precision in the term "reasonably foreseeable", which is in contrast with other jurisdictions where terminal illness is defined more clearly. Is that correct?

Dr Kim: It is certainly one of my concerns, but it is not my top concern. My top concern is to convey a message that, as I said at the beginning, the Canadian system represents currently the most extreme form of medicalised assisted dying. By that I mean the eligibility criteria, because at the end of the day the person requesting it could refuse an effective treatment or lack access to standard treatment and still be legally eligible. That is the first point.

The second point is this. Dr Downar said that this is guidance, so I will call it guidance. The Canadian Government have given millions of dollars to an organisation to train Canadian doctors how to do MAID. They say that MAID is a medically effective treatment. The provision of MAID is a new field of medicine. In fact, the Health Canada report recognises that functionally it is a medical specialty for some people; in other words, it is their full-time job. It is seen as a treatment on a par with other standard treatments because it is not a last-resort option. The law permits a practice where there is no medical standard which can say, "Look, medically you have alternatives, and you should not get MAID." That is not there. Even when the person persists in it, you can say, "Oh, this is a medical treatment. It's not what you wanted, but it's a medically effective treatment." When you combine those two, it is a very aggressive medical delivery system of euthanasia. We know it is 99.99%. It is heavily medicalised.

I will give one symbolic difference with even a place like the Netherlands, which is also a very liberal regime. There, most cases are also euthanasia, and few are self-ingestion. However, the rate at which people self-ingest in Canada versus the Netherlands is really remarkable. In Netherlands, you might have 1:15 or one out of 40 people who choose to self-ingest. In Canada it is less than one in 1,000. I think that is symbolic: it is emblematic of how aggressively medicalised the expectations are. That is not just guidance; it is part of what the Government are doing with the training groups.

Paul Blomfield: Thank you very much. That went somewhat beyond the point of clarification.

Dr Kim: Sorry!

Q180 **Paul Blomfield:** Professor Downar, Dr Kim has made points about people choosing MAID because of the unavailability of other support and treatment. I know that this is something you have written about. Would you like to reflect on that point?

Professor Downar: There definitely are issues of access to services in parts of this country—that is absolutely true. I simply state that what we know of the individuals who are receiving MAID is that 96% received or had good access to disability supports and 98% received or had access to palliative care supports. That is not just a self-report; it was corroborated by coroners' reports in Ontario for the first 3,000 cases. I published work on that. It is important to distinguish that while there are access issues broadly in Canada, in the UK and in the US—this is a very true statement—those access issues do not seem like they are driving MAID decisions to any substantial degree at all. I would love to see those numbers be 100% instead of 98%, but to focus on that as the issue is to miss the point.

I want to draw out a couple of points about the idea of its being last resort. I don't think that MAID has often been taken as a first resort; I think that is a bit of a misconception. I do not think, frankly, that the practice in Canada and the Netherlands is all that different. We do not force people anywhere in the world to undergo every conceivable form of treatment before we offer them palliative care. If somebody chooses to stop chemotherapy or dialysis, or if they are chronically on a ventilator and choose to stop it, we can offer other therapies, but we do not force them to receive them.

One of the important rationales in the Carter decision was that. It was essentially trying to treat people who are not dependent on life support, for example, the same as we might if they were on life support and able to make those decisions. It is important to have those alternatives offered to people. It is always good to improve services. Disability services, support services, income and secure housing—all those things drive mortality to a huge degree. We should definitely improve those things across the board, because they account for tens of thousands of deaths every single year. Will they make much of a dent in MAID? I think that that is almost certainly not going to be the case, simply because of the people who we know are receiving MAID.

Paul Blomfield: Thank you very much indeed. I think we have probably run out of time.

Chair: We probably have, yes. Professor Downar, Professor Lemmens and Dr Kim, thank you so much for giving evidence to us this morning. We really appreciate your time, and your getting up and speaking to us at 5.30 in the morning in your time. At least it is now 6.30 for you—time for breakfast.

We will continue this inquiry. We will be going to Switzerland next and talking to people there. Don't forget that we also have plenty of other work going on around our prevention and cancer inquiries, and much more besides. That's it for today.