Joint Committee on Assisted Dying debate -Tuesday, 14 Nov 2023

Protecting Vulnerable Individuals from Coercion: Discussion

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An Cathaoirleach

Apologies have been received from Deputy Troy and Senator Hoey.

Parliamentary privilege is considered to apply to the utterances of members participating online in a committee meeting when their participation is from within the parliamentary precincts. There can be no assurances in relation to participation online from outside the parliamentary precincts and members should be mindful of this when contributing. This committee discusses dying, including suicide. Support information can be found on the committee's web page.

Our first agenda item is to show two short video submissions from Mr. Brendan Clarke. Mr. Clarke was invited to appear before the committee but, very sadly, died before this was possible.

On behalf of committee members and the secretariat, I would like to extend our sincere condolences to his family. We are grateful that he was able to share his experience with us. I ask that the video would be shown. I again thank the family for helping this to happen.

We have a technical problem with the sound. In the absence of the video, we will have to move on to the next item on the agenda. We will go back to the video when the sound problem has been resolved.

I welcome the witnesses who are here today to discuss the topic of protecting vulnerable individuals from coercion. From the College of Psychiatrists of Ireland we have Dr. Siobhán McHale, Dr. Eric Kelleher, Dr. Anita Ambikapathy; from the National Suicide Research Foundation we have Dr. Eve Griffin, chief executive officer, and Professor Ella Arensman, chief scientist, and Dr. Léopold Vanbellingen, research fellow with the European Institute of Bioethics. We are very grateful to them for coming here today to share their knowledge with the committee.

The format for this meeting is that members will ask questions after the witnesses have given their opening statements. A member can ask an individual witness a question or address a question to all the witnesses more generally. I ask in advance that all the witnesses would keep their opening statements to the agreed five minutes. They will see the clocks throughout the room. They have five minutes for their opening statement. There will be a further seven minutes shared between members and witnesses for questions and answers. They will see the clock ticking down all the time. I invite Dr. McHale to please give her opening statement.

Dr. Siobhán McHale

I thank the Cathaoirleach and committee members for inviting us here today. I am a consultant liaison psychiatrist in Dublin. My colleague, Dr. Eric Kelleher, is a consultant liaison psychiatrist in Cork. My colleague, Dr. Anita Ambikapathy, is a consultant in intellectual disability in Dublin. In addition, I am a special visitor appointed by the Decision Support Service, within the Assisted Decision-Making (Capacity) Act 2015. Dr. Kelleher, Dr. Ambikapathy and I are High Court appointed ward of court office medical visitors, with regard to specialist training and provision of capacity expertise in complex clinical cases or cases involving the courts. We are here representing the College of Psychiatrists of Ireland.

There are many challenges to consider, as have been thoughtfully presented to the committee over the time of its work. Our college paper, which members will all have, is clear in its outline and detail of our main concerns, and so we will focus in on some key areas which we hope will add to the discussion.

First, we are in agreement that the status quo, where we know that an important minority of patients are not receiving the optimal level of specialist palliative care and psychosocial support to allow them to die with dignity, cannot continue. The answer to this is not to end our patients' lives, but rather is to interrogate each and every incident of concern, to clarify relevant contributing factors, and to provide the appropriate evidence-based interventions ranging from improved pain control to family support. Where there is no access to the appropriate intervention, or there is a lack of evidence for these, then we must target our energies and resources in these areas.

In Ireland as internationally, we know there is an unequal distribution of palliative care services, a dearth of psychological and psychiatric supports available to people with challenging health journeys and insufficient research in end-of-life care, with most ethics proposals explicitly excluding patients at end of life from research. Addressing these deficiencies is the necessary next step, not to enable ending the lives of terminally ill people as a way to avoid these challenges. We can do better.

Second, as psychiatrists we believe it is not possible to clearly differentiate between suicidal patients and patients who request assisted dying.

Suicidal people are human beings who cannot see any alternatives to ending their present or predicted future suffering other than by ending their lives. The work of the National Office for Suicide Prevention, NOSP, and Connecting for Life: Ireland's National Strategy to Reduce Suicide are key, with people with chronic illness designated as a priority group requiring targeted approaches to reduce suicidal behaviour and improve mental health outcomes.

NOSP has referred to the potential for assisted dying to undermine the fundamental principles that suicide is preventable, and that interventions that are proven effective in suicide prevention should take precedence across our health system. As psychiatrists, this is at the core of our work. So, we engage with and support more than 12,000 people who present to our emergency departments each year with suicidal actions or thoughts. We then go to the ward to see inpatients with cancer or motor neurone disease who will often have additional challenges such as addiction or a history of trauma. We also engage and support these patients to find ways to alleviate their present suffering or fear of future suffering, including those patients who cannot see any alternative to ending their lives. This can only happen if patients and their families have access to good quality palliative care, mental health, social work and disability services. Far too often they do not. The view of our college is that we need to find a better way to substitute for these deficiencies than by offering assisted dying.

Third, we emphasise the impossibility of separating physical and mental disorders. Our long-standing splitting of illness into real, medically and socially validated physical conditions such as cancer or diabetes, and poormoral-fibre, pull-your-socks-up mental health disorders has persisted, despite our advancing neuroscientific knowledge. We do not include the dynamic nature of trauma; external events, past, present and future; and social support, on how our brain functions as a central computer in managing our immune and hormonal systems, as well as our central nervous system. This is integral to an integrated physical and emotional response to illness and to response to treatment.

Fourth, autonomy and decisional capacity, and the cornerstone of any decision being voluntary and well considered are highly complex for people with autistic spectrum disorder or with intellectual disability and can be difficult to assess. Attempting to establish an absolute right to bodily autonomy by legalising assisted dying may undermine other individual and group rights, and by creating one class of people for whom life is expendable, that particular view may be extended by society to all groups possessing such attributes, such as permanently disabled people.

Finally, with regard to the question of whether one person's choice of assisted dying will have an impact on another who does not so choose, we would say that the introduction of assisted dying legislation means that every person has to then choose it as a potential option or not for their end-of-life care. No person is an island.

In conclusion, we want to acknowledge the public service task that this committee, both collectively and as individuals, is faced with here in considering this radical change to our legal system and the direction of our society. It will take great wisdom and courage to find the balance for not just those who have clearly heard voices, but the unheard voices whispering from the future. Our college believes there is another way, and that Ireland can bring great leadership for others to follow.

An Cathaoirleach

I thank Dr. McHale. I invite Dr. Eve Griffin to give her opening statement please.

Dr. Eve Griffin

On behalf of myself and my colleague, Professor Ella Arensman, I thank the committee for the invitation to contribute to this morning's meeting. The National Suicide Research Foundation is an independent research organisation and our mission is to provide a body of reliable knowledge, from a multidisciplinary perspective, on the risk and protective factors associated with suicidal behaviour. As part of the invitation to participate in this session, we have prepared a discussion paper on considerations for suicide prevention, research and policy development in the context of exploring legislating for assisted dying in Ireland.

Based on our review of the international literature, we have identified the following key findings.

Even though an increasing number of countries have introduced legislation to facilitate assisted dying for people with physical health conditions and, in more recent years for people with mental health conditions, there is limited information about the implementation of legislation and the procedures involved. Based on the available research, there is no consistent evidence that rates of suicide change as a result, with no study reporting a decrease in suicide rates as a result of such provisions. However, research in this area is significantly hampered by the lack of reliable data on deaths both by assisted dying and by suicide and the involvement of a small number of countries.

The profile of individuals who die via assisted dying seems to be distinct from those who die by suicide. Those who die by assisted dying are generally older and are more likely to be female. However, some potential risk factors are shared by both groups, including living alone, having no children, and not identifying as being religious. Furthermore, the prevalence of psychiatric comorbidities in individuals who die by assisted dying is difficult to establish, with reported proportions ranging from 3% to 39%. It is likely that the prevalence of mental health conditions such as depression are under-reported and undiagnosed in people who request assisted dying.

There is very little research on the relationship between suicide risk and terminal or chronic illness. International research shows that the risk of suicide in this group is highest in the first six months following a diagnosis. Our research has found that 57% of people who died by suicide had been diagnosed with a physical illness. Furthermore, 72% of people deemed to have engaged in high risk self-harm had experienced chronic physical pain in the past year. In addition, the motives related to suicidal acts are wide-ranging.

Systematic and independent research is also lacking on the safeguarding processes within frameworks for implementing assisted dying legislation, which may negatively impact on patients experiencing psychiatric conditions, in particular.

Considering these key points, there are five important recommendations for research and policy. First and foremost, as a foundation focused on suicide prevention, we strongly advocate for investment in the development and implementation of evidence-based psychotherapeutic interventions for people recently diagnosed with a chronic or terminal illness and for older adults. There should be continued and increased targeted funding to reduce health inequalities and to optimise standardised access to health and mental health services. We advocate for clarification regarding the role of mental health professionals in the assessment of patient competency and decision-making capacity. Given the lack of reliable data on deaths, if a change in Irish legislation was to occur around assisted dying, it should be accompanied by a comprehensive data recording system, in order to reliably monitor trends in both assisted dying and suicide at a national level. There is a lack of evidence regarding the effectiveness and standardisation of safeguards in the process of assisted dying. It is difficult to identify what safeguards

would be deemed sufficient, based on the international experience and where responsibility lies in determining adherence to safeguards.

Dr. Léopold Vanbellingen

I am a doctor of law at the University of Leuven and I work as research fellow at the European Institute of Bioethics. Our institute is an independent research centre based in Brussels. Over the past 20 years, the European Institute of Bioethics has developed expertise on the impact of assisted death laws on the protection of vulnerable people in society, particularly in the Belgian and Dutch contexts. Our major observation is that despite their alleged safeguards, each of these national laws rapidly tends to pose a threat to the lives of vulnerable people.

We can identify at least three categories of victims of this threat, elderly people who are dependent, people suffering from mental illness and healthcare practitioners. The first illustration of this trend is the elderly and the concept of polypathologies.

This category now accounts for almost one fifth of officially reported euthanasia in Belgium, for example. Among these pathologies, the Belgian federal control committee mentions impaired eyesight, hearing problems, walking disorders, and incontinence. Although none of these conditions is a serious or terminal disease, patients are nevertheless considered eligible for assisted death because of their suffering, which is related to the "loss of autonomy" or "social exclusion". From the very beginning, the euthanasia control committees in Belgium, the Netherlands and Canada considered that the criterion of suffering should be assessed subjectively, that what the patient says about his or her suffering should be considered as binding on the doctor, regardless of whether the patient's pain could actually be relieved, for example, by palliative care.

A second illustration of this trend is assisted death for mental illness. In Belgium, in particular, there has been a constant increase in euthanasia of patients suffering from depression or other psychiatric conditions such as autism. I will mention one such person: Shanti De Corte. Shanti was a young Belgian woman suffering from depression. She was also one of the victims of the March 2016 terrorist attacks at Brussels airport. Shanti was already suffering from depression before that attack but obviously things did not improve after it. Two doctors eventually agreed to end her life. In May 2022, Shanti died by euthanasia at the age of 23. The problem here, once again, is the subjective approach followed by every country that has permitted assisted death. This makes it virtually impossible to reconcile suicide prevention with the practice of euthanasia.

The third and last example of the threat to vulnerable people is the impact of euthanasia laws on healthcare professionals. In theory, each of these laws protects healthcare professionals who conscientiously object to participating in euthanasia but what we see in practice is that the individualistic and subjective nature of assisted dying leads to implicit or explicit forms of pressure on doctors and nurses to agree to be involved in the practice of euthanasia. One example is the latest amendment to the Belgian euthanasia law which aims to force every hospital or nursing home to accept the practice of euthanasia within their walls. This trend is rapidly leading to healthcare practitioners becoming increasingly vulnerable as they are forced to work in an environment where they are asked to do two completely contradictory tasks, namely caring for some patients on the one hand and taking the lives of others on the other hand.

In conclusion, what we see is that in every western country that has decriminalized euthanasia, the combination of a subjective and individualistic approach leads to a gradual extension of the law to situations that were not considered eligible initially. This particularly affects vulnerable groups including the elderly who are tired of living, young people who suffer from mental illness, and ultimately, any person in a vulnerable situation who, at some point, considers that his or her life may not be worth living.

Deputy Gino Kenny

My first question is for the College of Psychiatrists of Ireland. Dr. McHale said in her opening statement that there is a minority of patients who are not receiving the optimal level of specialist care. I invite her to elaborate on that.

Dr. Siobhán McHale

We aware in Ireland that there is inequity in accessibility of services across different areas of the country. In those areas, we know that some patients are not getting access to the appropriate services to which patients in other areas have access. It is a problem across our society with regard to disability, psychiatric and palliative care services in particular. There are inequities that are less significant across medical or surgical services, whereby people can move across different areas and be referred to different areas for services.

Deputy Gino Kenny

That would be psychosocial support. Would it be an absence of that as well?

Dr. Siobhán McHale

Psychosocial support is an umbrella term to cover mental health services, social services, financial supports, and disability services, etc.

Deputy Gino Kenny

With all due respect to the witnesses, I think it is unhelpful to conflate the issue of assisted dying with the issue of suicide. I have stated this from the very start. I do not think it is helpful to the debate. Are there any circumstances where the College of Psychiatrists of Ireland could see

where somebody is coming to the end of their life, they have a terminal diagnosis, and they could in that situation avail of assisted dying? Is the College of Psychiatrists of Ireland saying there is a blanket ban?

Dr. Siobhán McHale

It is similar to working with people in very challenging situations who are suicidal and can only see that they either live as they are or they end their life. What we suggest is that there is another way to approach and address this. The lack of information we have about people's experience at the end of life is significant. We say, similar to our colleagues in the NSRF who have particular expertise in research and the quality of research in these areas, and that is an area-----

Deputy Gino Kenny

Surely there is a difference between somebody who is coming to the end of their life. Of course, somebody could be extremely traumatised and depressed about their diagnosis but surely there has to be a difference between their physical being and their mental being. Surely in that situation, where somebody is coming to the end of their life, they should have a say in how they actually die.

Dr. Siobhán McHale

My colleagues are keen to speak. The only thing I would say is that they have a say in a whole range of aspects of how they die. I will pass over to my colleague, Dr. Kelleher.

Dr. Eric Kelleher

I thank the Deputy. To come back to his earlier point, I did not get a chance to answer the first part of his question. I will use an example locally in terms of how psychosocial supports, or the lack of them, can influence behaviour. I am anonymising this because I am conscious this person or their family may be listening. I was looking after somebody who has a progressive neurological illness and lives in a very rural area of Cork. They presented with suicidal ideation and some behavioural disturbance. They were diagnosed with a progressive neurological disorder. Their wish was to continue to live in their own home. When we assess somebody - and this goes to the second part of Deputy Gino Kenny's question - who has suicidal ideation we take a biopsychosocial approach to that case, looking at the biological factors but also the psychosocial stressors. Those two influence behaviour and suicidal ideation. For this person, who was expected to live many years with a progressive neurological illness, we really struggled to get homecare supports and disability services, to actually-----

Deputy Gino Kenny

That is wrong, obviously.

Dr. Eric Kelleher

It is wrong and I agree with the Deputy, but I want to really highlight it is also the reality of what many patients we come across face and how we address the biopsychosocial needs of patients. It is not necessarily enough just to treat somebody with medication or therapy; it is about adding in all those layers of support.

Deputy Gino Kenny

I completely get that.

Dr. Eric Kelleher

I know.

Deputy Gino Kenny

I completely get that but even if those supports were in place and somebody said they did not want to go through certain periods of their life because of the diagnosis, surely in that case they have that right to say, "I want to end my life and I want to end it with the permission of the State, with the permission of the doctor, and to have my say." Even if those things were all in place, and I understand where Dr. Kelleher is coming from, surely it is the fundamental right of a person. Obviously, that has an impact on society but that is what we are trying to get at today.

Dr. Eric Kelleher

I know.

Deputy Gino Kenny

Is it the individual? Is it society? It is the collective. At that particular point, the person surely has the right to say, "I do not want to go through that certain period of my life."

Dr. Eric Kelleher

That is the principle of autonomy. Does autonomy overrule other ethical principles? I do not underestimate the importance of autonomy but I do not underestimate the challenges on healthcare providers to provide that wraparound biopsychosocial support to patients. That must be provided to patients in a reasonable manner. Some patients are happy but some are unhappy to have family members looking after them.

They would like other people to do that job. We struggle to get that. My colleague, Dr. McHale, would like to come in.

Dr. Siobhán McHale

I am struck by the information being provided by Dr. Griffin where she said that suicidal ideation in the context of illness is highest in the first six months. The process of adaptation is a key component of our humanity the ability to adapt to change. If that is highest in the first six months, and we are looking at a situation with the possibility of introducing terminal illness within six months, then we are not giving people the opportunity in relation to interventions.

Deputy Gino Kenny

I understand that. Today is the anniversary of Vicky Phelan's death. I spoke to Vicky many times before she passed away. She always said, "I am not suicidal, I do not want to die, but I do not want to die in a situation that is out of my control". There are other people in that situation. It is conflating the issue with suicide and somebody with a terminal diagnosis who may want this. That is unhelpful.

Deputy Patrick Costello

Can everyone hear me?

<u>An Cathaoirleach</u>

Perfectly, thank you.

Deputy Patrick Costello

I thank our witnesses. I will start with the College of Psychiatrists of Ireland. One of the statements is that in the view of the college is that we need to find a better way to substitute for deficiencies in end-of-life and psychosocial supports than offering assisted dying. The opening statement talked about where people are receiving suboptimal care and are not

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receiving all the supports they need. We hear loudly from many people that the support they need or want is medically-assisted dying. I agree with the sentiment that we need to improve the deficiencies in end-of-life care, but I do not see offering assisted dying as a way of papering over the cracks. Many people would see this as part of that intervention.

I want to dig into the bit where the witnesses said they believed it was not possible to clearly differentiate between suicidal patients and patients who request assisted dying. I am looking at the National Suicide Research Foundation's opening statement which said that the profile of individuals who die by means of assisted dying seems to be distinct from those who die by suicide. It said these are distinct groups. Surely we should be able to tell them apart. Is it not the case where there are patients who are clearly suicidal, and patients who request assisted dying, and there might be an area of overlap or confusion in the middle? Is that a more accurate way of describing the situation, rather than the statement the College of Psychiatrists of Ireland has made?

Dr. Siobhán McHale

I do not believe it can be divided in that way, in terms of thirds. Dr. Griffin might refer to her finding to which she spoke, that there is a significant similarity between people in terms of specific groups, for example, older women, people with terminal illnesses and people with pain. What we know is that in a situation where we have such a lack of information about the experience of people in this area, we need to find out that information. Of course, people are going to have important individual voices but, as a group, we need to be able to understand that group, but that evidence, research and information is not there.

Deputy Patrick Costello

In saying that the information and research is not there, does Dr. McHale

mean internationally?

Dr. Siobhán McHale

Yes.

Deputy Patrick Costello

We have had a lot of evidence from jurisdictions that have introduced this and have conducted their own research and have had this for a long time.

Dr. Siobhán McHale

I am referring to information about people prior to the introduction of assisted suicide and the experience of people in that situation. I am not referring to the information about people who have gone through the assisted suicide pathways or applied for it. Dr. Griffin and Dr. Arensman will have more expertise in this area.

Deputy Patrick Costello

I am concerned that the framing of much of the statement is through a lens of supporting the status quo. I am looking at the statement that it is not possible to differentiate but we see other jurisdictions internationally which are able to differentiate. I am concerned that there is a conflation here but certainly-----

Dr. Eric Kelleher

I will reply to that. I wish to highlight international data from the assisted dying process, and I have watched several of the hearings. Certainly information from Oregon is that most patients who opted for an assisted death have not been referred to a psychiatrist or, indeed, to any mental health clinician. There is actually a lack of information in that regard. We know from very large studies, and we are happy to send these on to the Deputy, that for patients who are newly diagnosed with a new cancer diagnosis, a progressive neuromuscular illness, such as motor neuron disease, end-stage COPD, that they experience increased suicidality in the first six months of that diagnosis and then the suicidality appears to downward trend. It is most unusual in the Oregon data that that is not seen. Some of that information is not recorded at all, so there are certainly gaps in the data that is gathered from Oregon. That has been highlighted in the literature and we can share that with the Deputy.

Deputy Patrick Costello

Please share that with the committee. If we are talking about an increase in suicidality for six months after diagnosis and if you are dealing with someone who seven, eight, nine, ten or 12 months later is still saying assisted death is the choice he or she wants to make, is that not differentiating himself or herself from that initial suicidality post-diagnosis?

Dr. Eric Kelleher

This is the complexity of the challenge. In the first six months, the rates are higher and then they appear to dissipate. They appear to then downward trend. Enabling this type of legislation enables it for everybody, so there may well be a select group of patients who lived autonomous lives and wish to make this choice and are free of mental illness. We all acknowledge that. However, changing the law changes it for all the people who experience suicidality in the context of a new diagnosis. It is hard if, as a society, we reframe how we view suicidal behaviour. In practice, these behaviours highlight those with chronic physical illnesses as being a priority group, as Dr. McHale and the National Office of Suicide Prevention, NOSP, highlighted. What happens to that in the context of a legal change? Do we start to normalise these types of experiences for people and expose more people to vulnerability? That is the great challenge here.

Deputy David Cullinane

I welcome the witnesses and thank them for their expert opinion and evidence they are giving to the committee. It is important for us to clearly understand the rationale and the evidence which is being given. I will start with the College of Psychiatrists of Ireland. Some interesting statements were made, which I want to probe. I will start with the areas that I agree with, and with which I believe most of the committee members would agree.

In her opening statement, Dr. McHale noted that "an important minority of patients are not receiving the optimal level of specialist palliative care..." I think we would all agree with that. She also said that people do not always get the psychological supports that they need to help them die with dignity. We can agree with that. She stated that we need "to provide the appropriate evidence-based interventions ranging from approved pain control to family support." Again, I do not think anybody would disagree with that. She also said that "Where there is no access to the appropriate intervention, or there is a lack of evidence for these, then we must target our energies and resources in these areas." In relation to end-of-life and palliative care, I think we can all accept, as a starting point, that there is an awful lot more we can do. Reading directly from Dr. McHale's opening statement, she said that all of that should not enable "ending the lives of terminally ill people as a way to avoid these challenges..." Essentially, she is saying that if we were to propose legislation in this space, it should not be a substitute for the lack of supports in those areas. Would that be a fair assessment of what Dr. McHale is saying? I would like to get clarity on that.

Dr. Siobhán McHale

It is. I would add that we think this committee and this really important debate could actually open up an important area where we could introduce real change in how we deliver our services, rather than the processes in place at the moment which are challenged.

Deputy David Cullinane

I accept that and thank Dr. McHale for clarifying that point. She has also referred to people who do not have access to what she calls "good quality palliative care, mental health, social work and disability services." Very often, that is the problem. I might just differentiate that from some individual cases. This is where I want to get clarity on the evidence that is being presented. Certainly, we have seen some very high-profile cases involving legal challenges and I have met some of the families involved over the course my time as an Oireachtas Member. It strikes me that they did have access to good quality palliative care, and they did have strong family support, clarity of mind and clarity of purpose. Does Dr. McHale accept that there are circumstances where that is the case?

Dr. Siobhán McHale

Absolutely, yes.

Deputy David Cullinane

If that is the case, the question then is whether or not we legislate to give them the option to die at a time of their own choosing and, as they would see it, with dignity. From Dr. McHale's perspective, is it then a question of moral or ethical issues, or is it more a question of, as Dr. Kelleher mentioned which is why I wanted to come back to it, the possible implications that it might have for others? If we were to permit assisted dying through legislation in the circumstances where there is good palliative care and there is very strong family support, clarity of mind and purpose, is Dr. McHale's concern the impact that it would have on others that perhaps would not have that clarity of mind? Is that the thrust of the evidence she is presenting?

Dr. Siobhán McHale

I refer back to the Marie Fleming judgment, which reached the similar conclusion that while for some individuals this would be the right answer, there are so many challenges and so much that is unknown for society in general and particularly for the vulnerable in our society, who we are talking about today. It is not possible for us to achieve both of those things at the same time.

Deputy David Cullinane

When Dr. McHale says it is not possible, in what circumstances is it not possible? Has she seen any evidence in other jurisdictions where maybe it has worked and it is possible? I think people will understand the point that is being made and the evidence that is being presented to us to the effect that if we legislate for assisted dying and there are circumstances in which - and I think Dr. McHale agreed with it - people have all of the supports, have the clarity of mind and make a decision, there is a concern about the unintended consequences that would have on others. Are there any circumstances, from Dr. McHale's perspective, in which we would legislate to deal with and differentiate between those two areas?

Dr. Anita Ambikapathy

Perhaps I could answer. It is true that we have concerns. In lots of other jurisdictions, including Belgium and the Netherlands, we can see that it has been extended to the other groups.

They all started off with minority-type legislation which then opened up to everything. That brings us to the equality discussion we had.

Deputy David Cullinane

That is a separate point, with respect. That is a decision that was made. I am asking if it is possible to separate the two sets of circumstances to which I have referred, namely, those of the person who has clarity of mind, good quality palliative care and an illness and the others. Dr. McHale mentioned names. I did not want to mention names. As I said, I have met families and individuals who are clear on what they want to do and on their autonomy. Is it possible to separate those cases from the others? I agree with the concerns expressed by Dr. Kelleher in relation to making assisted dying more widely available and those people being given the option in those circumstances. Is it possible to differentiate between the two by way of legislation?

Dr. Anita Ambikapathy

Our view would be similar to the ruling in the Marie Fleming judgment, which was that it is not possible. Whether it would be possible, if we were to do the appropriate-----

Deputy David Cullinane

Sorry, that judgment was passed in the context of the current law.

Dr. Anita Ambikapathy

Yes.

Deputy David Cullinane

If there had been different laws in place, that judgment may well have been different.

Dr. Anita Ambikapathy

Yes, that judgment said it might be possible to-----

Deputy David Cullinane

Exactly. That is why we are here and why I have asked whether it is possible, by changing legislation, to actually achieve that very complex balance. I agree it is very complex.

Dr. Anita Ambikapathy

Our opinion is that the information is not there to allow us to do that at this time.

An Cathaoirleach

I know we are over time in the slot but in the interest of balance, we have to go to Dr. Griffin.

Dr. Eve Griffin

To come back to the earlier question on the research on the profile of both groups, what we have reported is based on international research that has been published on people who have died via assisted dying, which does show a difference between those two cohorts. What has been described and what also comes across in the research is that intersection and potential vulnerability, particularly among two cohorts of people who identified in our Connecting for Life strategy, namely, older people and those in the early days of chronic or terminal illness. From our perspective in terms of advocating for suicide prevention to be the first line of response, those are the particular risks and potential vulnerabilities that we wish to highlight, along with the need for early intervention in the days and weeks after a person receives that diagnosis and the need for those psychosocial supports to be available from the outset.

Professor Ella Arensman

I want to complement that information further by bringing in an important evidence base which has been extremely consistent in our research over the past 35 years. We have done several studies on people who survived a highly lethal act of attempted suicide. What seems to be very consistent and particular about the profile is that it features not only mental health conditions but clear comorbidities of severe physical health conditions, including cancer, chronic obstructive pulmonary disease and terminal illnesses, with mental health conditions. As was alluded to already, the risk of repeated self-harm or suicide is very high within the first three to six months following diagnosis. We have managed to interview many of those people through our research over the past 30 years. What has been very consistent in those in-depth interviews, which are sometimes three to four hours in length, is that following the survival of a highly lethal act of attempted suicide where the person has come very close to dying, the majority have reported various motives underlying the act. The majority report a wish to die, but we have not identified people who only reported a wish to die. There are always motives of having a glimmer of hope of some change, some successful intervention or another opening out of the negative cycle. In collaboration with at least six countries, including Australia, we came to defining that concept as ambivalence.

Working then with colleagues in psychiatry and psychology, we also detected there is very limited attention being paid to the complex concept of ambivalence. Our evidence shows it is highly prevalent and I would like people to take that into consideration.

Deputy Emer Higgins

Joint Committee on Assisted Dying debate - Tuesday, 14 Nov 2023

I thank our guests for being with us today and for all the work they do on a regular basis within all our communities. I am linked in with Pieta House and with many counselling services in my constituency so I am aware of the lifesaving work that psychiatrists, counsellors and NGOs do for suicide prevention. I value our guests' perspective. This has been a very unusual committee for us. There has been an awful lot of diverging viewpoints. My own perspective on this issue has shifted in and out, depending on whom I am speaking to. That is why it is so valuable for us to hear from experts in the field and from people who have practical experience.

My first question is to the representatives of College of Psychiatrists of Ireland. I have read their submission and the language in the conclusion is stark. They have spoken about this potential legislation as representing a fundamental and harmful reversal on medical care, running counter to the efforts of society in general to prevent deaths through suicide and that it may risk people dying from treatable psychological distress and mental illness. That is stark and sobering. I want to get an understanding of the background of this paper. It was done two years ago and prepared by the human rights and ethics committee before going to the college council for approval. I would like to understand the context of it within the general membership and alumni of the college. Is the report representative of the opinions of the industry?

Dr. Eric Kelleher

I can answer that question. I thank the Deputy. Our position initially came out of a submission to the Joint Committee on Justice on the Dying with Dignity Bill. That was what prompted an initial submission. It was drafted by members of the council, was approved and sent as a submission. That prompted us, as a college, to reflect on whether or not we would take a position on the issue. The college council then tasked our human rights and ethics committee to consider a college paper in this regard. A working group was established and views were gathered from two different forums. We gathered the views of the faculties within the college which represent elected members who reached out to other faculties and general adult psychiatry, liaison psychiatry and the psychiatry of old age. Views were gathered from the faculties and from the membership. The then president of the college, Dr. William Flannery, emailed the membership of the college to gather their views. All the information from members was fed back to Dr. Flannery, who anonymised it and sent in on to the human rights and ethics group committee to formulate the response. A draft position paper-----

Deputy Emer Higgins

I am sorry to interrupt, but how many people were involved or engaged with?

Dr. Eric Kelleher

The membership of the college comprises 1,200 people but for the consultant psychiatrists, the figure is somewhere around 700. The draft paper was formulated and brought back to the council, which approved it. We then had a soft launch, as they say, at our winter conference in 2021. There were many opportunities for feedback through email and at the conference. We then formally launched the position paper at the end of 2021. Between the initial submission to the justice committee on the Dying with Dignity Bill to the time of the launch the paper, it was approximately a year in formulation.

Deputy Emer Higgins

How many people engaged in that process during the year?

Dr. Eric Kelleher

Through the various faculties and membership, there were hundreds of psychiatrists. There was a variety of contributions through the faculties and

through individual emails. That information came back.

Deputy Emer Higgins

It would be great as a follow-up if Dr. Kelleher were able to provide that level of detail as to how many members were involved and engaged. That would be useful for us to know. It sounds as if an awful lot of work went into it and it was very thorough. I thank Dr. Kelleher for that explanation.

I will move to the representatives of the National Suicide Research Foundation. Their submission outlined a number of concerns around, in particular, safeguarding.

It falls short of saying that they are against assisted dying. That is fair enough if they do not want to make any judgment call on that, but if they are in a position to say whether they are for or against this in principle, now is their opportunity to do so.

Professor Ella Arensman

If we look at the overall research, in particular the research gaps that we have outlined, it is still premature to take one stand, black or white. One of the challenges where I would like to see Ireland learning from other countries is to take a more nuanced approach to the diversity of people - first of all, individuals, but possibly some subgroups. When Deputy Kenny referred to some of the cases, there is certainly scope for some flexibility and openness to discussing assisted dying with people where it is crystal clear that the quality of life cannot be reversed or changed and has been hugely impacted and there are no indications of treatable or preventable mental health conditions. However, I am touching immediately on a gap there, not only the gap in Ireland but also in countries like the Netherlands and Belgium. I would like to hear our colleague say a bit more about that.

When we look at the evolution of the developments in countries like the Netherlands and Belgium, in hindsight it always appeared too frequently that rigorous mental health assessments but also safeguarding procedures, including second opinions and third opinions, were not followed through intensively, sometimes with disastrous or close to disastrous outcomes.

Deputy Emer Higgins

Enforcement.

Professor Ella Arensman

In principle, we in the NSRF are very open to contribute and to keep contributing to the debate but a starting point could be to look at specific subgroups and to be very nuanced in terms of people's needs and being offered the extra services that they have had and then overall assessment of people's consistent wish to die in light of that very important aspect of ambivalence. This is where we have to respect people as well.

Deputy Emer Higgins

I thank Professor Arensman. I apologise if I mispronounce Dr. Vanbellingen's name. In that international context, he spoke of a case that was being looked at from the point of a loss of autonomy and that being part of the commission's decision. I am unclear as to how that can be part of it when we are talking about having the autonomy to make a decision.

Dr. Léopold Vanbellingen

The loss of autonomy is being quoted by the commission to justify that the person who suffers from polypathologies has psychological suffering. The feeling that there is a loss of autonomy is considered as one of the reasons euthanasia could be accepted in Belgium. I do not know if that is clear.

Deputy Emer Higgins

Yes. I thank Dr. Vanbellingen.

Senator Lynn Ruane

I thank the witnesses for their presentations. Initially when I first read over the submissions, a lot of my questions were for the College of Psychiatrists of Ireland but Deputy Cullinane worked out some of those threads for me so I am not going to repeat his questions other than to pick up perhaps on one sentence in the submission. The witnesses do not even need to comment but I read it so that I can contradict what is there. It states: "Addressing these deficiencies is the necessary next step, not to enable ending the lives of terminally ill people as a way to avoid these challenges." I imagine that nobody in this room or who comes before the committee is looking for an easy way out and to not address challenges. As legislators and policymakers, many of us have been working for many years on all those areas of life and I would hate to think that anybody would be seen as wanting to introduce the option to end one's life as opposed to us continuing to do our jobs in regard to health and equity in terms of those psychosocial supports. I wanted to put that on the record.

My next point is for Professor Arensman and Dr. Griffin. I am going to imagine for a moment that the only way to protect a vulnerable person is not just the status quo and that the status quo has changed. I am going to look at the fact that we are talking then about how we protect vulnerable people. We may not all agree on whether the status quo should change but let us imagine that scenario. It would not be ideal for us to leave a committee and think that it should or should not happen but to never discuss a scenario where it does happen without discussing what those safeguards could look like in practice. I say that without the witnesses saying they agree something should or should not happen. Let us just imagine that it does. In a scenario where the status quo has changed, and we are looking at competency and the ability to consent and the distinct idea between someone choosing how they die rather than someone choosing to take their own life due maybe to their living conditions, fear, or all of those other things, could the witnesses contribute on what safeguards actually look like and how we begin to protect vulnerable people in a scenario where assisted dying does exist?

Professor Ella Arensman

My colleagues, in particular Dr. Griffin, and others in the NSRF have tried to look into the future. Obviously there would be a requirement for a range of safeguards but, again, as a starting point, I would start with a positive for Ireland. Ireland is now in a position to review and look carefully at other countries where certain developments went very fast, were not always conducted or implemented with the appropriate safeguards or with certain safeguards that may not have provided optimal situations. I will give one example. The college is also aware of some case reports. We are talking about case reports, not hundreds of people, where via what in the Netherlands is referred to as a due diligence procedure, even at a second opinion a person was still assessed as being 100% confirming a wish for assisted dying and then, coincidentally, by a third opinion from a specialised psychiatrist, two of the three psychiatric diagnoses were reversed and suddenly the world looked different for that person. Different treatments were on offer and there was then a drastic shift in moving from assisted dying to living and to at least making the effort of making use of the treatment. We do not want to dwell on it but that is a dramatic case because a person in the Netherlands was apparently very close to assisted dying but with a third opinion the procedure was reversed. Already here, two opinions is not sufficient if we start looking at measuring that, Dr. Griffin and I would very much advocate reviewing those frameworks in the different countries more carefully and then seeing if there is any possibility

for a pilot situation in Ireland, certainly in reference to some of the cases that were brought up by Deputy Kenny.

Another important safeguard - Dr. Vanbellingen may be able to come in on this – for many of us working in this area is that15 years ago we would not have been able to predict that following assisted dying or euthanasia for people with physical, chronic terminal illnesses that we would be talking about an 18-year old or a 20-year old girl, boy, or young adult who for non-physical health conditions would be granted assisted dying. We do not have a lot of long-term, follow-up evidence but I am still involved with some steering groups in the Netherlands on suicide prevention efforts whereby now my colleagues in suicide prevention are concerned that there is a fallout from the narratives of these cases in terms of young people who have been granted assisted dying in that it may also accelerate suicide among young people overall.

Dr. Vanbellingen might say more about this. It immediately indicates the boundaries that must be considered.

Senator Lynn Ruane

On boundaries, creating discriminatory practices is what the issue will come down to, with people challenging the subjectivity of suffering and all those conversations that need to be had. I keep going back to the eighth amendment and the different boundaries that were created around abortion care in Ireland. There is the consideration that when something is introduced for one person, it automatically becomes an option for everyone. That does not mean everybody will choose the option, in the same way as applies to reproductive care and different types of medical and psychiatric care. If all the supports are in place, people are choosing from all the adequate supports and they are all of equal measure in terms of accessibility, one would hope there would be a much fairer and more equal access to healthcare and that end-of-life care would be more about end of life and not about 18- or 20-year-olds choosing a particular option. Of course, we may have to answer challenges to that, but all legislation is ultimately open to be challenged once any sort of discriminatory boundary is placed around who can access it.

Senator Rónán Mullen

I thank all the witnesses for attending the meeting. Dr. Kelleher spoke about exposing more people to vulnerability. As a lay, non-medical person, am I characterising his approach and that of the other witnesses fairly as one that holds that while it may be possible in theory to say there are people, and individuals have been mentioned, who are not suicidal and not affected by mental health conditions and who have a greater level of freedom to know, and clarity about, what their wishes are, it is impossible, in practice, to isolate those people through any legal or administrative measure and impossible to make the distinction between them and others who may have conditions that compromise their autonomy and, dare I say, their capacity in some ways? Is that a fair assessment of what is being said?

Dr. Eric Kelleher

It goes back to the earlier point that once the law is changed, and the evidence bears this out in most countries where it has been introduced, it becomes impossible to limit provision to just one group. There are people with terminal illnesses who are free of depression and mental illness and who would view this process as a choice. I do not think there is evidence out there to say one can identify this group safely in isolation. The gaps in data from Oregon, for example, show, I believe, that there is an underdetection of mental illness in those cohorts and, structurally, how the data are recorded reinforces that, unfortunately. This is the case even in countries, such as Australia, that have introduced this type of legislation to include many safeguards, which goes back to Senator Ruane's earlier point. I am going on with this point, which I hope Senator Mullen will permit me. There is a paper from Professor David Kissane, an Australian psychologist specialising in psycho-oncology and palliative care, in which he shares four stories of de-identified patients who had requested and-or went on to experience an assisted death. A paper describes some of Professor Kissane's findings as follows:

Another de-identified patient, was reported to have been pressured to an EAS [assisted death] by an adult child home on holidays. This caused bereavement challenges for his wife who had anticipated having longer with him. In a further case... the oncologist referred the patient to a psychiatrist, although the patient's family were encouraging the patient to request EAS. The psychiatrist diagnosed clinical depression and commenced treatment with effect.

In another case reported by Professor Kissane, an oncologist patient's symptoms were "under managed by the oncologist who became primarily focussed on the process of EAS distracting away from symptom control".

These cases really illustrate that even when a law on assisted dying is enabled for patients who are felt to have capacity, there are still enormous challenges in terms of those who go forward for the process. I am representing the College of Psychiatrists of Ireland today. As a college, we have not been convinced by the evidence from any jurisdiction that has brought in this type of legislation that it can be safely limited to just one group. Even people who go through the process are exposed to harm.

Senator Rónán Mullen

My next question is for our guests from the National Suicide Research Foundation. I was very struck by the last key point in their opening statement regarding the lack of evidence for the effectiveness and standardisation of safeguards in the process of assisted dying, with a difficulty in identifying what safeguards would be deemed sufficient. That

is almost, but perhaps not quite, saying that it is impossible to have safeguards in this situation. Much of what has been presented to us regarding a proposed change in the law is predicated on the idea that there is a cohort of people who know exactly their own mind and whose autonomy should, in effect, be absolute when it comes to this decision. One of the arguments presented is that if the law is changed, it may contribute to a lowering of suicide rates. I have seen evidence submitted by Professor David Paton of the University of Nottingham to the British parliamentary commission looking at this issue. It accords with what Dr. Anne Doherty told us last week, which is that if we total up assisted and unassisted suicide rates, there is not evidence that making provision for assisted dying ever contributes to a lowering of suicide rates, contrary to what would be claimed by advocates for a change in the law, and that there may be some cohorts, such as women with an unmet need for support for depression, who may be particularly vulnerable. If the witnesses agree with that, are they broadly of the view that a change in the law here could endanger society's efforts to combat suicidality and suicide rates?

Dr. Eve Griffin

There are two parts to this. I will speak about the evidence from the data and Professor Arensman might talk a little more about the safeguards. One of the challenges is that research in looking at trends in rates is based on population-level data. When we look at trends in rates of suicide, we are looking at what is often a very complex issue and it is very difficult to tease out why rates may fluctuate. It might be as a result of economic changes or different kinds of cohort effects within the population. Based on the research that has been conducted, we do not have strong evidence on either side. We have not seen evidence to support that if assisted dying is introduced, it will lower rates of suicide. On the other hand, we have not seen a big increase in rates of suicide in any country as a direct result of assisted dying being implemented. There are a couple of points to make in this regard. Much of the research in this area is very limited by the quality of the data. Often, deaths as a result of assisted dying or euthanasia are not reported. There may not be a requirement for mandatory reporting and, in addition, there is not an International Classification of Diseases, ICD, code internationally. We are often dealing with data of low quality and there are particular challenges in regard to suicide data. I do not think we will be saying there is evidence that provision for assisted dying contributes to a large change in rates of suicide. However, it is important that we identify potential impacts we would wish to examine if there is a change in legislation in this country, particularly in respect of what we know about the impact on vulnerable people within the population from exposure to the topic of suicide and narratives around suicide.

Senator Rónán Mullen

Is the story so far that, contrary to what was claimed, there is not evidence of a reduction? The reduction that was suggested is that those who might otherwise choose unassisted suicide, for want of a better term, would have recourse to assisted dying and, therefore, it would be a more benign experience. That does not seem to have been established.

Dr. Eve Griffin

We have not seen that. One of the issues is that it is very difficult to disaggregate the data. The data are often presented together and it is difficult to look at the detail. It is one of our key findings that further research is needed in this regard.

Senator Rónán Mullen

My friend, Deputy Gino Kenny, has said we should not think of this issue in the context of the suicide debate at all. I am characterising or paraphrasing what he said. Do the witnesses think this is an issue with which we must continue to wrestle?

Professor Ella Arensman

I fully agree with the points made by Dr. Griffin. To take one small step back, I have concerns about the overlap. I am not talking about the entire population who present with self-harm or suicidal ideation but I am greatly concerned about the group we have worked with over the last 35 years, those who undertake highly lethal acts of self-harm and come close to death but who survive by chance. It is interesting that, when you speak to these people at length after their suicidal crisis and recovery, it is not clear that they want to die. There is an ambivalence. As we have heard from the College of Psychiatrists of Ireland, in some regions, there may not be all the right approaches to support or intensive treatment linked to the physical and mental health co-morbidities. I suspect a subgroup that may apply for assisted dying might come in there.

The other point the Senator made related to suicide prevention. Ireland has come a long way and is seen by the World Health Organization as leading in some areas of suicide prevention. The Connecting for Life strategy is still en route. A lot has been achieved but a lot more needs to be done. We in the NSRF would certainly say that, if the assisted dying legislation is further developed, progressed and implemented, this should go hand in hand with continuous efforts to support and sustain all the priorities for suicide prevention. I do not want to add in more complexity but some countries have gone so far as to legislate for suicide prevention, something that has had positive impacts in reducing suicide rates.

Deputy Pa Daly

I thank everyone who has provided opening statements and given evidence today. I will ask one or two questions of Dr. Griffin. She said "Those who die by assisted dying are generally older and are more likely to be female." A number of weeks ago, we heard evidence from a psychiatrist in Cork who said that older women have a much higher rate of depression than the general population. What is the breakdown there? Where is the NSRF getting those figures? Is that standard internationally or does it differ from country to country?

Dr. Eve Griffin

It can differ but what we have included in our discussion paper is a comparison of the profiles of the cohort of people who die by suicide and those who die by assisted dying based on international data. We see that, in Ireland, more men than women die by suicide. Women account for approximately one fifth of all suicides. However, when you look at assisted dying, it is more in line with what would be seen at population level. Approximately half of those who die through assisted dying are women. There is that difference and, obviously, there is also a difference with regard to the average age with people dying through assisted dying being older. I believe the point Professor Doherty was making in the last session is that, with regard to that group of older women in particular, there are concerns that depression and suicidality are being underdiagnosed and that, as a result, there is insufficient treatment. Even though the rates of suicide and self-harm among older people in Ireland are low relative to the rest of the population, in the cohort of people who do present, we see that it is more difficult to detect suicidal intent, although the rate of such intent can be much higher. There are sometimes similarities with regard to some of the risk factors such as vulnerabilities, ongoing challenges with pain and things like social isolation and loneliness. What we have said is probably broadly in line. There are particular subgroups where there may be an overlap.

Deputy Pa Daly

In which subgroup is the overlap greatest?

Dr. Eve Griffin

There are similar factors shared across the older people group in particular.

Deputy Pa Daly

What are the differences between males and females among older people?

Dr. Eve Griffin

While women were mentioned, we did not see any particular differences between genders beyond distribution in the population.

Deputy Pa Daly

Professor Arensman mentioned ambivalence. Will she elaborate on that a little bit more?

Professor Ella Arensman

Over more than 30 years, we have conducted different types of research including interview studies with people who have survived an act of selfharm, present to the emergency department and obtain a mental health assessment. We have done some of this work in a standardised way with other countries in Europe and with Australia and one of our findings went against what we would have expected. We expected a subgroup of people who had survived a highly lethal act of self-harm to record a wish to die as their only motive. That was our hypothesis. However, that is not what came out. The same type of interview was used across all of these countries. They took place a week to three weeks after a person had survived a suicide attempt. We did not detect anybody reporting a wish to die as his or her only motive. It was always reported with temporary relief from an unbearable situation, seeking attention, to use the interviewees' own words, or self-punishment. We were struck by the finding that, while more than 80% reported death-oriented motives, it was never the only motive around the time they undertook highly lethal acts of self-harm.

This brought us to the concept of ambivalence, which, to some extent, was a surprise to us. It also appeared to be absolutely unknown to those doing the assessments in the emergency department. It is almost hard to believe that, 30 years on, we are still educating people in this construct in the training for emergency department staff, clinical nurse specialists, trainee psychiatrists and psychologists. Why is this construct so important? First, it opens up the communication and allows people to talk not only about death but about whether there is a small glimpse of light in the darkness where they have some hope that things may change. What then becomes important is the offer. Where do we see equality in the offers being made to these people? It is absolutely striking. The figures are also supported by striking cases of people who are now active in suicide prevention advocacy.

<u>Deputy Pa Daly</u>

I am going to cut Professor Arensman short because I need to ask Dr. Kelleher a question. He mentioned psychosocial supports from mental health and social services when there is a diagnosis of cancer requiring palliative care. I presume that, because of how he spells "Kelleher", he is Cork-based. There are different spellings. When people receive a serious cancer diagnosis, what psychosocial or therapeutic supports are usually made available? How quickly can such people see a psychiatrist?

Dr. Eric Kelleher

As a result of the waiting list for general outpatient psychiatry, it may be weeks to months, depending on where you are. The national clinical care programme for psycho-oncology is being brought in to address the issue. We recognise that patients with cancer have great mental health needs so they are referred to a psycho-oncologist, who will be the clinical lead for that patient group and will have a team of social workers, psychologists and nurse specialists who will support patients on their cancer journey.

Challenges can arise in the translation of the care that person might get in hospital, for example, if the person has cancer that is ongoing, in how that translates into the community setting. If we go back to the case I described earlier and the challenges there, my colleague Professor Doherty made this point as well. We have a national clinical care programme for psychooncology. We could have that type of programme for every type of chronic illness, including neurological disorders. The issue is translating the care into the community and the supports that people need. This may be ongoing psychological work or it may be very practical measures, such as someone coming in to do changing and minding. That can help somebody with their self-care.

Deputy Pa Daly

Is that where the deficiencies exist?

Dr. Eric Kelleher

There are well-documented deficiencies across the mental health service. The issue of funding for mental health and the need to increase it has been raised before. However, we do not look at that in isolation. It is a matter of how it translates into social care in the community as well and clearly deficits exist there. This is particularly the case in areas such as where I work which has an urban-rural mix.

Senator Mary Seery Kearney

I am struck by how stark the witnesses positions are. We have previously been told that we need to make sure we have the courage to be able to

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recommend the legislation for this. This morning, however, I am struck by the message that having the courage not to legislate is also important.

Regarding services in the community, I agree with the witnesses that there are well-documented deficits. At what stage do we know we have sufficient supports? Are there recommended ratios of practitioners to population? Is there ever a way of calculating that, at a certain point, it is safe because there is a balance, or do we merely measure it in terms of budget? I am trying to figure out when we will know that we have hit the crucial point.

Dr. Eric Kelleher

I remember, a week after we launched our position paper, driving in my car and listening to local radio. It was coming up to Christmas and patients with terminal illnesses were being directed to the emergency department because of the lack of nursing and palliative care in the community. There is clearly a certain level of basic access to care for people with palliative care needs that we need to be able to provide. As we know from everything that is happening in the health service at the moment, it is not just about having the places; it is also about having adequately supported staff to go into those places. One would expect that a basic level of care could be provided, including access to pain treatment in one's home, ideally with palliative care, and access to mental health supports in hospices. At present, this is not available in any hospice nationally.

Dr. Siobhán McHale

The psycho-oncology programme is a really good example of an area of medicine that has taken these issues on board. The funding for this comes through the national cancer control programme, not from mental health services. I know a number of colleagues who are trying to work across the boundary between psychiatry or mental health services and medical conditions to try to improve access to integrated care. This could apply to cystic fibrosis or neurological disorders or whatever groups that need to have a similar model. The outline of how it has been constructed in the national psycho-oncology programme - in acute hospitals, in the community and working across voluntary services and in HSE-funded services - is a really good model to consider.

Senator Mary Seery Kearney

I am not a professional in this area. Is there a set number of individuals who need to be employed? How do legislators predict that when such and such a level is reached the provision is a safe one?

Dr. Siobhán McHale

The psycho-oncology and perinatal mental health programmes are aligned to each of the areas. For the oncology programme, there are eight cancer centres and the paediatric centre. Each of them has a team with one consultant psychiatrist, three psychologists, three social workers and clinical nurse specialists.

There is also the funding from the cancer support services for the model in the community and how these work together very effectively. Yes, there is a very clear number of people associated with that.

Senator Mary Seery Kearney

From a cancer perspective, it is at the operative level.

Dr. Siobhán McHale

Yes.

Senator Mary Seery Kearney

At this moment in time we could be obliged to discriminate between who could access the choice to end their life based on their diagnosis.

Dr. Siobhán McHale

Undoubtedly, we have better access to information about that patient group than we do for all the other groups.

Senator Mary Seery Kearney

A narrative is emerging from this meeting and last week's meeting that seems to suggest that mental health is a determinant and that safeguards need to be imposed. This concerns me in some ways. While I welcome it and understand it, it also concerns me that people who are already vulnerable because of diagnosis or their particular level of health may be put through having to prove their mental capacity, which is contrary to a presumption of capacity. If there are undiagnosed or under-diagnosed mental health issues, how do we start thinking about that when it comes to safeguards? Indeed, is it appropriate that it becomes a determinant?

Dr. Anita Ambikapathy

In other jurisdictions it was originally and now it is not for Belgium and the Netherlands. It is not just mental health or mental illness as a whole, there are specific groups. There are special cases, specifically in the Netherlands, for example, where a young person was allowed to proceed with this purely based on their diagnosis and mental health. To say that it is simple to put that little ring fence around it is incorrect. It would be very difficult and very complex.

Senator Mary Seery Kearney

I am not talking about mental health as a reason to choose end of life. I am talking about proving mental well-being in order to have a presumption of capacity to make the decision to access whatever method of assisted dying we would put in place.

Dr. Anita Ambikapathy

Even in cases where there is legislation for which a psychiatrist is needed, much of that legislation for psychiatrists is for capacity only, that the person has the knowledge and the wherewithal to make the decision that is personal to them. It is not that they have mental illness at all. The psychiatrist is not there for a diagnosis of mental illness or to look at the biopsychosocial or any other therapeutic intervention. The psychiatrist is there to judge capacity only. Even then, we know that can go from two to three or four different opinions. That is the dilemma. Even talking about a group that has vulnerability because of their mental illness, proving the other side is proving to be quite complex in all jurisdictions that we have seen. There is no clear answer to that question.

Senator Mary Seery Kearney

I do not want a narrative to start creeping in that just because someone wants the option of assisted dying, that assumes the person has to be treated or considered as having mental health issues.

Dr. Anita Ambikapathy

Nor do we.

Senator Mary Seery Kearney

That narrative started creeping in at last week's meeting and it is here again this morning. I am not comfortable with it.

Dr. Siobhán McHale

It is a measure of the stigma. If people were told somebody was being offered another opinion in terms of medical assessment and a treatment for their condition, whether it was multiple sclerosis, or whatever, people would be delighted. However, there is stigma attached to being asked to meet a psychiatrist and the association of potentially having a treatable component of their suffering seen to is considered to be a negative. These are the challenges to how we interface with the separation between medical and psychiatric disorders.

An Cathaoirleach

Dr. Vanbellingen, because you are attending remotely, I feel you have not been involved enough. Before we go on to the next round, I want to give you a few moments to give an overview, in the interests of balance.

Dr. Léopold Vanbellingen

Let me come back to the distinction between what I would call suicidal patients and those who have clarity on their wish to die. It is true that if we look at the figures in Belgium and the Netherlands, most patients who ask for euthanasia are not suicidal, as such.

If we look at the case of elderly people who do not have a terminal illness but polypathologies, which now accounts for 18% of all euthanasia in Belgium, these patients do experience psychological suffering and they consider themselves tired of living. Are they suicidal? No, but they do suffer from mental illness.

Another specific case that my colleagues refer to is the problematic issue we now see with young people suffering from mental illness. These people are in many cases suicidal. Let me go to the Belgian commission's latest report on this issue as an example. It suggests that the case of young patients' failed suicide attempts have made the commission aware that there is another more dignified way of ending one's life. This means that euthanasia is now viewed as a more dignified alternative to suicide, especially among young people.

We need to keep in mind that all countries that legalised assisted death have this subjective approach that does not allow us to judge what the patient says about his suffering and, therefore, we cannot question what the patient says about his own suffering, including his own psychological suffering. That also explains why many doctors and psychiatrists in Belgium and the Netherlands now consider that they have to consider euthanasia as one of the options, especially when the treatments do not work as they had hoped. We recognise that there is a mental illness but we are not ready to say that these patients are not eligible for euthanasia because of this mental illness. It is also related to the principle of non-discrimination, which explains the fact that even though the law in Belgium and the Netherlands did not really change with respect to the substantive conditions and criteria, incredibly, the law is interpreted as making patients with mental illness eligible for euthanasia.

Deputy Alan Farrell

I thank the witnesses for their submissions and contributions. It has been a really interesting discussion. I have been listening intently remotely, just in case the witnesses thought I had just appeared on their screens.

My question at this stage has likely been answered. Nonetheless, I want to ask a direct question of our witnesses by surmising a particular scenario. It has been expressed at this committee on a number of occasions that if we were to legislate, we would only do so for terminal illnesses and, therefore, the issue of mental health and some of the examples that have been provided during the course of this morning's hearing would not apply. My question for our witnesses is rather simple. What is their view on that matter, notwithstanding any potential for a future Oireachtas to change the law? I am of the view that, given the international experience, this matter is coming, and it is a decision that, fortunately or unfortunately, will come in time. My opinion is that if we are asked to make a decision on this and if we choose to legislate, we should do so as best we can and, for me, that means we should do so extremely carefully and cautiously, without consideration for mental health as a ground for access to legalised assisted dying.

Do the witnesses have a view on that?

Dr. Eric Kelleher

To summarise the question, if we bring in this type of legislation, is it safe to limit it to just one patient group and exclude those with mental illness? Was that the question?

Deputy Alan Farrell

My question has more to do with what we might do. The conversation thus far and witness statements already provided to us have stated that if we are to legislate, we should not permit a person with mental health difficulties to access assisted dying. My question is what your view would be if we were to legislate only for persons with a terminal diagnosis. I could qualify it further by saying that a six-month terminal diagnosis was offered into evidence at this committee.

Dr. Eric Kelleher

My colleagues may want to come in as well. What we have really tried to convey here today is the complex interplay between the mind and the body. Even something as simple as fatigue or motivation can be a consequence of physical illness but can be also a consequence of a comorbid or co-existing mental illness. It is very difficult in clinical practice to separate out those two things. We do our best and we endeavour to do so, and we provide the wraparound supports that we can for individuals who we see in acute settings in hospitals and emergency departments and then translate that care into care in the community. However, as the evidence has shown in other jurisdictions, it is always open to challenge in terms of who we limit these groups to, and that would be a huge concern of ours.

I do not think anybody here is supporting mental illness alone as a qualifying factor; nobody is saying that and we are not saying that either. We want to highlight the high rates of co-existing mental illness and the overlap there is with those with physical illnesses. No jurisdiction has actually identified that and, as my colleague, Dr. Ambikapathy has said, we examine capacity but not co-morbid mental illness. As I said earlier, this reframes how we view patients with physical illness who express suicidal ideation, and my colleagues will want to come in on this, as will those in the National Suicide Research Foundation. Therefore, I imagine there will be a certain proportion of patients who will not get access to care because of how we as a society - because it is a societal issue, as the Deputy is highlighting - reframe somebody with a chronic illness or terminal illness who is expressing a wish to die, for whatever reason.

Dr. Siobhán McHale

To add to that, the evidence we have from stroke literature is that for patients who, for example, have a devastating loss of power down one side of their body, and who had previously been very active and independent and are now wheelchair-bound and so on, there is a process in regard to the understandability of their response in terms of distress. However, what we also know from the research evidence is that treatment of that distress, in particular the associated increased risk of depressive disorder, greatly improves a patient's rehabilitation outcomes, so it is now a routine part of post-stroke care to have that included within their management.

Deputy Alan Farrell

To respond to that, insofar as I am aware, and of course there will always be individual cases, a stroke victim is not necessarily going to have a terminal illness. My question really relates to your view on limiting access to assisted dying to terminally ill patients, not a stroke victim who has suicidal ideation.

Dr. Siobhán McHale

I did not intend that to come across as my intention. What I was implying is that the process of what is seen as the understandability of a person's response might not be considered to have an intervention other than to presume tthat is an appropriate emotional response to his or her very distressing situation.

Dr. Anita Ambikapathy

I will make two points. On the time limit, we have seen in a lot of the literature that the six-month or three-month limit with regard to how long somebody thinks they have to live is difficult in the medical field, and all of us understand that. Time limiting how quickly one will die from illness is very difficult.

The second part is more about safeguarding robustness and how, even should that happen in the time limit we talked about, all the literature internationally states that as much as safeguards have been put in to decide about capacity, severity, and the close time to a certain illness with no other therapeutical interventions, these have not been classified as being robust enough. It would be safe to say that in respect of every jurisdiction. The difficulty we are grappling with is how best to ring-fence and how best to legislate, which is where we are and why we are here. That is still being struggled with worldwide after decades and decades.

Dr. Eric Kelleher

I will not take up any more time. Deputy Farrell asked what could be done. As clinicians, we are front-facing. We work in hospitals throughout the country and members know our backgrounds. We see gaps in the services that are available to patients, and under-resourcing of mental health services, palliative care services and chronic pain services. Professor Arensman highlighted that earlier in respect of patients who did an act of self-harm and who had experienced physical pain in the previous year. There is lots more society and the health service can do to provide for patients who sit in that zone between mental and physical healthcare without necessarily having to change the law. I hope we have conveyed what the risks are internationally when the law is changed. As legislators, members may well have to acknowledge that there may be some people with treatable mental illnesses who will come through the gaps. The question then is what number is acceptable in that regard. I do not think any of us have an answer to that.

An Cathaoirleach

We will move to the next round of four-minute slots. I again ask everybody to keep an eye on the clock.

Deputy Gino Kenny

It will probably be no surprise that I support assisted dying. Our committee is here to grapple with and assess whether we can legislate for that over the coming period. It is a difficult and fundamental question to ask society and the committee. We all agree with that. There are obviously deficiencies in our health system in respect of inequalities and palliative care. It is to be hoped that will get much better over time but that should not be a barrier to legislating in future. Dr. Kelleher said that other jurisdictions have legislated for this, even if it is very limited, and it is very limited in Ireland, New Zealand and Australia, but it is quite a fallacious argument to say that once A is legislated for, then B, C and D will automatically happen. There is no evidence of that. At the end of the day, we are legislators. If we legislate for assisted dying, it is us that will have to change the law or not. There is a whole mechanism whereby things change over time. Over the past 25 or 26 years, Oregon has not essentially changed the criteria for those who can avail of assisted dying. I do not agree that somebody can avail of assisted dying on the basis of having a mental health condition, but I agree with somebody availing of assisted dying in relatively limited circumstances. That has to be teased out over time.

The argument made that if we legislate then everybody will want to die falls apart. That is not the case. People want to live. They want to live as fully as possible. However, there are certain circumstances, and we all have personal experience of this, where people do not want to go through a very complicated and painful part of their life. Who is to say that they have to? Can anybody in this room or anywhere say to me that those people have to go through that? They should not. They should have a choice regarding how that ends. That is a fundamental right for everybody, as it is for the committee to debate this issue here and beyond.

Dr. Eric Kelleher

I totally agree with the Deputy insofar as members have a huge challenge.

I commend the work of the committee. I have seen its timetables. Members are talking to the right people and are looking at what has happened around the world. I do not underestimate the seriousness of this matter and the responsibility they all hold.

I will make some comments. My colleagues may want to come in as well. We have spoken about the limitations to access to things such as palliative care and mental health services. This was raised previously. A colleague from UCC raised the issue of access to services in making autonomous choices. To be able to make a choice, people need to have access to services in the first place. For it to be truly said that people are making an autonomous choice, services, including access to care, should be available to them. We see many gaps in clinical practice where that may not necessarily be the case.

Dr. Siobhán McHale

The nub of where we are coming from is that while this is a very important area for people to consider, we cannot see a way of it being introduced with sufficient safeguards to allow protection of the vulnerable people in our society.

Deputy Gino Kenny

I disagree with that.

Senator Lynn Ruane

I agree with Deputy Kenny in that I believe there is a way to create safeguards but I also accept that sometimes, people will fall through even the strictest of safeguards. That is a conversation that needs to be acknowledged. It needs to not be denied as a reality. I understand that.

I have three questions or comments. Last week, a witness said the conversation is about two ways of dying rather than someone wanting to live or die. It is about people choosing between two different ways of dying because they are within a certain proximity to death. That resonated with me as a concept as regards end of life. I have been both unfortunate and very honoured to be with people in the last moments of their dying process. It can be a very beautiful thing. I have been honoured to witness that and be with people as they died. However, my father spent three days completely unconscious, vomiting blood from his stomach into a tea towel, whereas if he had been assisted to die three days before that, he could have died singing The Drifters with us. That is what I thought of last week. It is beyond the pain question and the suffering question. The other question is how we want that dying moment to happen, and how meaningful it can be with your loved one in still being able to recognise each other in the room as the end of life happens. There is something beautiful about that, which fits into the question around the proximity to death. If we look away from all the other conversations about different types of illnesses, cancers or mental illnesses, we can then consider what the proximity to death is and whether we can, in a very limited circumstance, allow someone to choose which way he or she dies, rather than the fact that he or she is just dying earlier for whatever reason. If we get the safeguards well enough, we can give people that choice at that moment in time, whether it is at the three-day or six-month point, although those can be abstract conversations enough in themselves.

On the issue of capacity and consent, and the fact that an assessment is not being made previous to that on whether someone has a mental health condition or diagnosis and has capacity, is the assessment of capacity rigorous enough such that it answers the previous question? If somebody is in the throes of or is experiencing a mental health diagnosis - I do not mean a mood disorder or a certain low level of depression but a very obvious mental health disorder, whether that is psychosis, schizophrenia or any sort of delusional disorder - it is to be hoped that would be picked up anyway in a consent or capacity assessment. If it is not, why not? It is then about how that assessment of capacity is made rigorous enough that it answers the previous question around where someone's mental health and ability is at.

My final question on research is for Professor Arensman and Dr. Griffin. It was probably them who mentioned suicide intervention being better in Ireland than in other countries. Now I am wondering how we can review any other country's system in isolation at all. If we look at home care, disability services, culture and attitudes and the stuff around autism, most people in Ireland would be appalled to think that anyone would be given assisted dying because they were autistic. I am wondering then how we even begin to compare a system in Ireland adequately with systems elsewhere when we have to take in culture, attitudes, understanding, awareness and all the other social supports that are in place. We nearly need to look at them all to know whether Ireland would end up in the same position where it is widened too much. Perhaps we would not widen it too much because the culture and attitudes towards particular illnesses here in Ireland are much more compassionate, empathetic and understanding. I am wondering, from a research perspective, how we begin to capture that in a much more holistic sense.

Professor Ella Arensman

On the first points that were part of the Senator's overall question, when she was talking I was reflecting. In line with what has been said by colleagues before and what our research has identified, we probably would not be discussing some of the questions we have discussed today if we were already at the stage of having integrated mental and physical healthcare and accepting it as the norm. The committee should use this opportunity to look at countries and areas where this has happened, because it would not be such a huge task or endeavour to bring in the normality of integrated mental and physical healthcare, certainly for that very important group of people with the comorbidities.

On suicide prevention, there has been an acceleration in leadership in recent years, with a lot of credit due to the HSE and the National Office for Suicide Prevention, NOSP. One of the outstanding features has been that the NOSP has not only tried to put in place a strategy, but with a clear, detailed implementation plan and independent monitoring and evaluation. That type of template, completely tailored to a pilot model of assisted dying for a specific group, would at least come close to safeguards and good practice, which we have clearly missed in the early years in some of the countries we have discussed here. That is possible and feasible, but it requires very vigorous planning and reviews of the dos and don'ts in other countries.

Senator Rónán Mullen

Up to today, I thought that one of the arguments or concerns was that if we legislated for assisted dying in whatever form on limited grounds, then the argument might be made on equality grounds as to why it cannot be accessed for disability reasons or, indeed, for mental health-related reasons. That is a strong problem to be considered. What I am taking away from today, and I ask the witnesses to correct me if I am wrong, is that if even if we do not legislate on those grounds, it is possible, as Dr. Kelleher said, that some people with underlying, treatable mental health illness would fall through the cracks. In other words, we would have a situation where assisted dying is available on mental health grounds, provided there is also a coexisting terminal illness, depending on the limitation that is put on it. My colleague, Senator Seery Kearney, has effectively spoken of the undesirability of attempting to screen people for mental illness conditions. The witnesses have also spoken about the difficulty of doing it anyway, even if it was socially conscionable to engage in such screening. To me, that points to a lot of difficulties that we, as a committee, have not really had a chance to consider to date to any significant degree.

As doctors, I would like to ask the witnesses the following question. If the committee went ahead and recommended a change in the law and the opening, however slight, of a possibility of State-supported assisted suicide or indeed euthanasia, should doctors be involved in that event? Also, what do the witnesses say to the argument that is out there that doctors are just being paternalistic doctors in telling people how to live their lives when

they are clear in their own minds about they want? What are the witnesses' views on that?

I have a question for Dr. Vanbellingen, but perhaps the witnesses might respond to those questions first.

Dr. Siobhán McHale

Apologies, but I am trying to remember the first question.

Senator Rónán Mullen

Should doctors be involved?

Dr. Siobhán McHale

That is a question that has been debated, and there have been publications in relation to that in some medical journals. I know that my palliative care colleagues have views about it, and ask why a doctor would need to be involved in this process. There are processes that could be considered as an alternative way of administrating the intervention without requiring a doctor's involvement. What is the Senator's second question?

Senator Rónán Mullen

It is on the allegation of paternalism, when people who are settled in their mind as to what they want.

Dr. Siobhán McHale

What we would be looking at comes from our expertise in the area of illnesses. Comorbid illnesses have been talked about. We routinely understand comorbid illnesses such as high blood pressure, stroke and renal failure. On how we include depression or anxiety as additional comorbid illnesses that are very common in people with or without physical conditions, and ensuring that people have the right to that treatment separate from it being considered as an opinion, we are looking at the science.

Senator Rónán Mullen

My colleague and friend, Senator Ruane, mentioned Ireland's abortion law as an example of where limits or margins are put in place. People have different views on that particular issue. People can comment as they wish but I am not asking them to comment on their attitude to Ireland's abortion law. What I do see is an increase in numbers and a lot of controversy about the position of those who, for medical or professional reasons, believe they should not go this route. I am conscious that whatever about abortion, it would seem to me that there are a lot of hospices in this country and in other countries that would have grave difficulty and would not see it as a professionally good thing to do to be involved in any kind of assisted dying. They would see it as going against the good care of a person. What is the prognosis for such institutions in the event of a change in the law, in the view of Dr. Vanbellingen and the other doctors? Obviously, there is some limited scope for a freedom of conscience opt-out for an individual, but how does it work for institutions? That is something that is on my mind.

Dr. Léopold Vanbellingen

Taking the example of Belgium, in 2002 when the law was adopted, the legislature guaranteed that health institutions would not be forced to apply euthanasia within their walls because the law was supposed to be a law of flexibility that offers a choice to people and does not force them to do things. Quickly, because of this individualistic approach that really focuses on the relationship between the patient and the doctor, the legislature eventually considered that as it is an individual choice, we could not, as an institution, refuse to apply what was decided by the parliament.

What makes things complicated now is that in Belgium, and in the Netherlands and Canada, if I want to work as a doctor or nurse in palliative care in a hospice or a nursing home and I do not want to be asked to be involved in euthanasia, I do not have any place to work because of this law that now forces every health institution to agree to apply the euthanasia law.

Dr. Anita Ambikapathy

Going back before the institution argument, psychiatrists in other jurisdictions have been involved in the earlier part - not necessarily in the end-of-life part - of making that decision. They have been involved in the capacity argument about whether the person has the ability to make that decision voluntarily and coherently.

In other jurisdictions psychiatrists have been involved. We are here to show that we are sometimes dragged into this argument, willingly or unwillingly, to be the person who makes that decision about whether this person can make that decision. That is quite a huge responsibility. We all know that decision-making can change from being time-specific to issue-specific to tiredness to pain. It is a complex argument to have consistent capacity issues. That is one of the reasons we wanted to be here; we wanted to explain that the capacity discussion is a vital piece of this.

<u>Deputy Pa Daly</u>

I do not have any more questions. I thank all of the witnesses for bringing us further along on the journey. We all know there may be unintended consequences but we can hardly say the consequences are unforeseeable. A lot of clarity has been provided on that and on the level of services. That is important. In my community, while there is excellent palliative care in Kerry, some of the other services may not be as strong. That is something to be taken into consideration.

An Cathaoirleach

We are going back to the first item on the agenda, which is to show two short video submissions from Mr. Brendan Clarke. Mr. Clarke was invited to appear before the committee but he sadly died before this was possible. On behalf of the committee members and the secretariat, I again extend our sincere condolences to his family and thank his family for allowing us to do this. Each one of us is grateful to his family. We had a technical difficulty earlier so, hopefully, that has been corrected.

The joint committee viewed an audiovisual presentation.

An Cathaoirleach

We should be able to hear the presentation. We will not continue with it. We will have it better set up for our next meeting where we will all have headphones or something. We will have to abandon it until the next day. Out of respect to the family, I want this to be done properly and we are not doing it justice.

I thank all of our witnesses, including Dr. McHale, Dr. Griffin and Dr. Vanbellingen for being with us. I thank them most sincerely for taking the time to come here. It is very is much appreciated. We cannot do our work without their expertise and we are truly grateful to them for giving us that expertise. Their questions and answers are very helpful to us in doing the job of work is ahead of us.

The joint committee adjourned at 1.14 p.m. until 10.30 a.m. on Tuesday, 21 November 2023.

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