

Written evidence submitted Professor Bronwyn Parry and Dr Sally Eales (ADY0479)

Summary

Between 2016 and 2021 we interviewed a total of 58 dying people, bereaved loved ones and healthcare professionals on the impact of the current blanket ban on assisted dying. The aim of this work was to better understand the views and experiences of these groups, insights that were lacking in the existing literature.

Findings from the interviews were subsequently used by Dignity in Dying to inform three reports, which we recommend the Committee reads in full: *The True Cost: How the UK outsources death to Dignitas*, *The Inescapable Truth: How 17 people a day will suffer as they die*ⁱⁱ and *Last Resort: The hidden truth about how dying people take their own lives in the UK*ⁱⁱⁱ.

We conducted the interviews as independent qualitative researchers without in-depth knowledge of the assisted dying debate. The interviews were semi-structured but largely led by the interviewees, who welcomed an opportunity to share what they had witnessed and experienced.

Our interviews found extensive evidence that the current ban on assisted dying prevents dying people, their loved ones and doctors from having open and honest conversations about dying. This often forces people to suffer unbearably against their wishes at the end of their lives. As a consequence, some people try to exercise control over their deaths by travelling abroad for an assisted death, or take their own lives at home in this country, often in violent, lonely circumstances that we found very disturbing.

Our findings illustrate serious failings in the current law apropos its ability to provide compassionate choice to dying people or sufficient safeguards to protect them. The injustice of this status quo was further highlighted by interviewees' knowledge of jurisdictions around the world that have modernised their legal frameworks around end-of-life choice. In short, the deeper we dug into the realities of the current law, the more apparent it became just how inadequate it is.

Below we highlight a number of key themes emerging from our interviewees relevant to the Committee's inquiry, using direct quotes to illustrate them. These quotes have been edited for clarity. This list of themes is by no means exhaustive and we would welcome the opportunity to provide further oral evidence.

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To what extent do people in England and Wales have access to good palliative care? How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

Palliative care and unbearable suffering

In regards to palliative care, two things became clear from our research. First, that those who support assisted death also support palliative care access for all. Many of the interviewees had first-hand experience of providing or receiving palliative care to an excellent standard. Second, that nobody believed that improvements to palliative care services would negate the need for a safeguarded assisted dying law as the issues that confront some patients simply cannot be addressed via improved palliative care, as palliative care practitioners themselves noted:

“There are people who are in intractable pain, whose pain we can’t deal with adequately and that may be because they really have such complex physical pain issues that we can’t find the right combination of drugs or the side-effects are too great.” Palliative care nurse

“She was very positive, she was very stoic. She had palliative care in the house but then at the end of September she developed gangrene in one of her hands, which they said was due to the cancer and vascular problems. She was in excruciating pain.”

Interviewees detailed symptoms that could not be relieved even with the best possible care:

“One of the most distressed patients I have ever seen in my life was a man who had had a penile cancer. His penis had been removed and he was left with a big open hole directly into his bladder. He was a very gentle person. He was so ashamed and he would cry. He was begging to have his life ended because he just hated it and he had lived for months in that condition. He was begging to have his life ended because it had absolutely no meaning. He was also in pain, but that was not the main thing; it was the utter degradation. I felt so helpless. We could do nothing about that.” Palliative care consultant

“Nausea and vomiting is usually controllable, but sometimes it isn’t and it’s terrible for people, really terrible. They’re just feeling awful all the time, even if their physical pain may be gone. Of course when you’ve got all those symptoms, I think for a lot of people it’s difficult to distinguish one from the other; they all blur into just feeling awful, really awful.”

“I have seen people who have got vomiting towards the end of life because they have partial bowel obstruction. They are able to take some sips of water. They are able to take a cup of tea, but an hour later it comes back accompanied by faeces. They are actually vomiting up their faeces.”

Travelling abroad for an assisted death

We interviewed people who were planning to travel abroad for an assisted death, and people who have accompanied loved ones to facilities in Switzerland that provide assisted dying services. These confirmed that palliative care cannot always address intractable end of life pain.

“We had a meeting in hospital. It was one of those meetings where there were two doctors, consultants, a Macmillan nurse. It was one of the rooms where they have flowers... ‘There’s

nothing we can do. It's wrapped around an artery, and I just couldn't get it out. It's going to become quite painful, but we can give you palliative support.' I came out of this meeting and went online to Dignitas, and got their form, and sent in an application to join them. That was almost immediately."

The logistics of planning an assisted death abroad left people feeling isolated due to a lack of support, and many needed help from others to navigate the process – something that is illegal. However, the majority of people we interviewed were willing to break the law to help their loved one achieve a pain free death. There was a clear sense that the State and healthcare system were abandoning people by failing to help them achieve this end.

"You do all this without any support from any of the care systems. If you were dying in Switzerland now, there would be a whole care system in place through the state and through volunteer organisations as well. When you do this in the UK you do it completely on your own."

"She got the information pack through. There was a big form that came with it. You had to give a lot of information. She couldn't cope with doing it, she was exhausted and really struggling with breathing, but also mentally she'd just found out she was going to die a really horrible, slow death. I offered. I said to her, 'Can I help you do it?' She said, 'Please, please do, I don't think I can sort this out on my own."

"Somebody would have had to help her with the paperwork, with the appointments... But I didn't really care at that point. When it's the most important person in your life, you don't really care".

"She said, 'Well, I don't want you being prosecuted. I worry about what will happen afterwards,' and I was like, 'Look, I don't care; if I get prosecuted, that's fine. I'll deal with it. I would do anything to help you achieve the death that you want.'"

Even though relatives were willing to break the law, the threat of prosecution made dying people feel anxious that their decision would have serious consequences for their loved ones.

"My daughters might get prosecuted. I'm very concerned. How am I to know that they won't come off the plane at this end and, you know...? They said they don't care, that they want to do it, they want to be with me... They're three very strong women."

We also identified inconsistencies in how healthcare professionals support people who wish to have an assisted death abroad, ranging from refusing to supply medical reports, to offering advice, to actively participating in making arrangements. There is undoubtedly a postcode lottery in this country when it comes to people's access to end-of-life options.

"Her doctor's surgery couldn't have been better. They actually allowed me to fax her medical notes to Dignitas from their office. They were fantastic, absolutely brilliant. They made no charge and they let me sit in the office and fax everything from there. I was surprised they allowed me to do it."

Another interviewee, however, described the experience of her husband, Paul, who was denied access by his GP to the same documents he needed to arrange his assisted death in Switzerland.

“He did speak to his GP, who he’s been with for a very, very, very long time. In the appointment he didn’t ask his advice. Paul was very decisive and he’d made up his mind about this, so he went to his doctor and asked for a letter outlining his condition and the prognosis, at which point the doctor said, ‘Look, what’s it for?’ Paul said, ‘I’d rather not say,’ and the doctor said, ‘Whatever it is, you can tell me.’ So Paul did and at that point the doctor said, ‘No, I can’t give it to you. I need to seek legal advice.’ He spoke to the surgery’s lawyers, who said, ‘Under no circumstances give this man a letter.’

He was distraught, absolutely distraught because he felt that the decision had been taken out of his hands and he couldn’t have the ending that he wanted. To see him so distraught at not being able to do it, that was awful.”

The interviewee went on to describe how Paul died.

“He felt like he couldn’t breathe, so he was gasping for breath. He shot up out of the bed and collapsed, and that’s when he was gurgling. He was wild eyed and petrified and flailing around, and that’s a horrible memory to have. It was horrific and about the furthest you could get from the nice, peaceful death that he’d wanted for himself.

I remember the palliative care worker holding his hand and saying, ‘Don’t stress,’ because he was so anxious. He was having panic attacks, saying, ‘I’m going to be in so much pain. I’m already in pain and it’s getting worse.’ She was holding his hands, ‘Trust us. We’ll make sure that you’re not in pain.’ And they didn’t deliver on that. At all. He was in a lot of pain and he suffered unnecessarily.”

Inconsistent practice means that choice at the end of life is a possibility for some dying people but not for others. We also uncovered the financial cost and complexity of travelling abroad for an assisted death. This gives rise to grave inequalities:

“The first thing I’d like to say here is that this is a class thing. I’m middle-class but Bob was a working-class bloke. I know my way around the system, he wasn’t confident, he found it frustrating and instead of getting things done, he just got frustrated and angry with it. I’m afraid you have to smooth your way around, it’s not very pleasant but it has to be done.”

Given the lack of an assisted dying law in this country dying people travel to Switzerland earlier than they want to, to ensure they were well enough to make the journey overseas. People believe the current law is thus leading to premature deaths and robbing people of time with their loved ones in their final months and weeks.

“The best way I could describe that feeling is if you leave it too late, you’re trapped. I want to reach a stage where I say, ‘look, this isn’t an enjoyment anymore.’ But there’s no way I’m going to end up trapped.”

“If it had been here in our own home, we would have had far more time together. He would not have been so anxious as he was. He was oh so anxious about it all.”

“He looked into going to Dignitas, seriously looked into going to Switzerland, that was an option. But he realised very quickly that if he went down that road he’d probably have to die a lot sooner

than otherwise would have been necessary had some sort of assisted dying plan been in place here. And that's just so cruel."

Desperate measures

While we had some knowledge of the fact that people travel to Switzerland for an assisted death prior to conducting our research, we had not anticipated encountering cases where dying people had taken their own life by a range of highly distressing and violent means. It is our view that the Committee can enhance the assisted dying debate by increasing awareness of such cases. A GP we interviewed was still traumatised by the experience of one of his patients:

"I had the privilege of working in General Practice part-time for 32 years. One afternoon an old sea dog came to see me, a leather brown, weather beaten, rather bedraggled fellow. He said, 'I've got a swollen leg, what's the problem?' I very quickly came to the conclusion that the swelling in his leg was due to some horrible metastatic disease.

A couple of weeks later he came back and he said, 'Look, I've been thinking, can you tell me how to take my own life?' I was worried about being complicit with his death and being charged with manslaughter. I said, 'I'm terribly sorry, I want to be able to help you, but I can't.' This was an informed decision he'd come to. He wanted to end his own life in a dignified manner.

A few weeks later after morning surgery I was doing something before going out on my afternoon visits when I heard a bit of a commotion in the waiting area. His wife, uncharacteristically, was almost hysterical and the staff were having a hard job trying to pacify her. She said she'd been shopping, she'd just come back, her husband's car was parked outside the house, which was odd because he'd gone out for the day. She sensed something terrible. She went into the house. She went to the hall, opened the door into the sitting room and... Sorry...

He'd shot himself.

She had to live with that for the rest of her life, poor lady. Because of my inability, my cowardliness, whatever, to help him. He decided to have the most obscene, cruel, violent death imaginable because he didn't want to have the indignity of suffering any longer for what was likely to be a fairly torrid last few months.

I've had to live with that for the rest of my life too. I felt as though I'd completely let this fellow down and I was directly the cause of his violent death, which will forever be in my memory. And his poor widow... She continued to see me but I think she moved. She had to move, she couldn't live in that house."

All of the dying people we interviewed who attempted to end their life and survived, tried again.

"He decided to stop treatment. He came home and it was shortly after that he made his first attempt at taking his life. I was in the kitchen and heard a thump from upstairs. I thought he'd dropped something or he'd tripped, you know, in a weakened state. I got upstairs and there was a lot of blood. He'd cut his throat and wrists. The wrists were superficial, but the one on the neck was more serious. My first thought was that he'd haemorrhaged because that's the progress of

this particular form of cancer; it strangles you because the tumour has grown so big or it crushes the carotid.

I immediately called 999, they arrived in droves, including a helicopter that landed in our local park should he need to be taken the hospital. They stabilised him and he was taken to the Royal London. He was stitched up and kept in there for about a week. He was moved from the general ward into a psychiatric ward. From that psychiatric ward he was moved into a crisis centre and they really didn't know what to do with him to be quite frank. He had a panic attack there. During that time I saw him twice. I saw him two days before he did take his life.

Another relative related the end of life experience of her dying son:

A couple of policemen knocked at the door, and I thought, 'Well what are you here for?' having contacted him half an hour or so before. They said, 'We're very sorry but your son's been killed.' One of the side roads to the hospital has a junction with a major road. A witness saw him run into the second lane, where he was hit by an HGV."

The experiences we share cover only a fraction of the full range of challenging circumstances that patients and their carers face in the absence of a safeguarded assisted dying law. Our work builds understanding of different perspectives in this debate that have historically been rendered invisible. We would encourage the Committee to examine these perspectives in detail and take note of the failures in the current law they expose. However, our primary recommendation is that the Committee acknowledge that taking no action in regards to the current situation – as Westminster has to date – represents an active and deliberate choice that will give rise to further acute suffering by the dying. We do not comment on the rights or wrongs of that decision here, our intention is simply to help document the implications of that decision.

ⁱ https://cdn.dignityindying.org.uk/wp-content/uploads/DiD_True_Cost_report_FINAL_WEB.pdf

ⁱⁱ https://www.dignityindying.org.uk/wp-content/uploads/DiD_Inescapable_Truth_WEB.pdf

ⁱⁱⁱ <https://www.dignityindying.org.uk/wp-content/uploads/Last-Resort-Dignity-in-Dying-Oct-2021.pdf>

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