

My name is Nancy Preston and I am a Professor of Supportive and Palliative Care and I conduct research about both assisted dying and palliative care. I have a neutral stance on the debate.

Much of the debate around assisted dying focuses on whether it is right or wrong, needed or not. As your committee makes clear it is also crucial to think about how provision for assisted dying might operate.

There is a natural assumption by the public that assisted dying will be integrated into healthcare systems. However, from our research in the Netherlands, the US and Switzerland where this is permitted, we know this is rarely the case, with most assisted deaths occurring at home. This is in part because institutions do not want to be associated with the practice for fear of damaging trust with their patients. Even in the US, where the Oregon system is often championed as the preferred model, hospices with religious affiliations do not allow assisted dying on their premises and tell staff they cannot discuss it with patients even if the patient ask. Staff struggle with this. In interviews we conducted in the US, staff talked about patients who went on to kill themselves by storing up medications or shooting themselves. Even when patients had applied and been granted MAiD, they found the cost of medication prohibitively expensive as pharmaceutical companies are reluctant to have their name associated with an assisted dying.

There is also potential impact on health care staff themselves who assist. As one doctor who supported and helped patients gain an assisted death in the Netherlands said – ‘It’s stressful to kill somebody’. They managed this by limiting the number of cases they did each year. Others moved away from practice areas such as palliative or elderly care to reduce the requests they received. This is challenging for healthcare systems if health care workers choose other specialities for fear of being asked about assisting a death. For others the toll seems less severe.

Often physician acts are carried out by volunteer doctors from right to die associations. These are people who have chosen to support assisted death, who feel less dissonance about performing the act. While they don’t have a long-standing relationship with the patient and family, they are there to enable the assisted death.

Because of the reluctance of health care staff to be involved in assisted deaths, it can make it difficult for patients and families to navigate the system. Even if a doctor supports assisted dying, it doesn’t mean they are willing to assist, indeed most don’t. In some of our research doctors told us they actively discourage patients from having an assisted death and openly admit they will keep the decision-making procedure going so long that the request is no longer necessary as the patient is no longer fit enough to make the request.

The impact of trying and potentially failing to navigate the system on the patient and family is further compounded by this being a relatively secret event. Patients seem to ruminate on the decision and then choose to share their desire for an assisted death with just one or two

people. These people are then asked to maintain secrecy about the patient's decision. It can be isolating for these family members as they can't draw upon a wider group of friends or contacts to help them. However, our research suggests most family members are pleased they respected the decision of their loved one. The family would have been happy to support them to die naturally but this isn't what the patient wanted. For the patient to be in control was of utmost importance at a time when they are losing control.

Because of this secrecy, other family members may only find out after the death that it was an assisted death. It is hard to find these people to interview but they express sadness that they weren't involved in the decision making. However, these conversations are potentially exhausting for the patient, so they seem to only share on a need-to-know basis.

To help overcome some of these issues various people have written about a system for assisted death operating outside of the healthcare system. A panel could make a

judgement based upon medical reports. One of these reports should include a palliative care consultation where alternatives could be discussed. All applications would be recorded in advance which would act as a safeguard for subsequent monitoring. In most other countries any assessment of legality is only after the death which is too late. A similar system was introduced to Austria last year. Similarly in Switzerland assisted dying is predominantly outside of health care with a large role played by the right to die associations. Oregon isn't the only model the committee should consider.

Keeping assisted dying practices outside of health care could potentially smooth the process for patients and families and also protects health care workers. It would allow for greater scrutiny both before and after the death. Importantly this means all cases can be assessed to see if due process was followed.