

Professor Stephen Duckworth

At the age of 21 I broke my neck in an accident and am completely paralysed from the neck down. Since then I qualified as a doctor gained a PhD in Disability and Equality Politics and an MSc in Rehabilitation Studies. I am presenting my views but not purporting to represent the views of any organisations that I'm currently involved in.

From 1981, the time of my accident, until 2010 I was fervently opposed to assisted dying. I then joined the Commission on Assisted Dying chaired by Lord Charlie Faulkner. On the basis of the evidence that we heard over 12 months, specific commissioned research and visits to 4 locations delivering assisted dying around the world, I change my mind.

I now believe that the opportunity to celebrate our life, to say goodbye to the people we love, and to slip away peacefully on our own terms, avoiding unnecessary pain and suffering – is that not how all of us would want to go?

This was the picture painted so movingly by Alice Snape in *The Independent* Newspaper in 2022, as she described travelling abroad to attend a final goodbye party for a dear family friend. This friend was suffering in agony from advanced multiple sclerosis and had opted to die with assistance from a doctor rather than endure a painful end.

I have been an electric wheelchair user for 40 years and enjoyed the choice and control over my life that disability activists campaigned for, year after year. Yet some of those activists, who have considerable influence, are now arguing that I should be denied that choice and control at one of life's most important events, the dying process.

I am not terminally ill, but one day I may be. I am not scared to die but I want choice and control over how I manage that dying process. While over 206 million people live in places with some form of legislation that enables assistance to die, it is not an option in this country. The UK and

Ireland uphold a blanket ban on assisted dying, despite 84 per cent of the public supporting this option being made available for terminally ill people. Support for this type of law is similarly high among disabled people. I am proudly among that number and believe that a safe, compassionate assisted dying law is long overdue.

I know that transparent, safeguarded assisted dying legislation and protections for disabled people can co-exist and work effectively, and there is international evidence to prove it. In Oregon, for example, a tightly-restricted assisted dying law has been in place for over 23 years. Disability Rights Oregon claims it has never received a complaint of abuse or attempted abuse under the Oregon Death with Dignity Act.

Meanwhile, it has provided choice and compassion to a great many dying Oregonians and the legislation has worked so effectively that it has since been replicated in states across the US, Australia and now New Zealand. This is the model that I and many others believe is right for Ireland and the UK, too.

I also recognise that the current law contains far more risks for potentially vulnerable people, and that includes me and millions of other disabled people. The reality is that prohibiting assisted dying does not make it go away and there are currently no workable safeguards to protect disabled people. It simply forces dying people to suffer against their wishes or resort to unimaginable actions to control their deaths – often in secret, without the possibility of open conversation or exploration of other potentially beneficial options.

Currently, for those few terminally ill people who can afford it and somehow manage to escape, there is Dignitas in Switzerland – but this involves putting their loved ones at risk of prosecution for their involvement, travelling to a foreign country, and often dying before they are ready.

For those without the funds, some may be able to refuse treatment that is keeping them alive and be sedated while their disease consumes them, or while they starve or suffocate. But this can involve a drawn-out death, with no guarantee that suffering can be relieved, and it is not an option for all illnesses.

The only choice remaining is to take matters into their own hands. These deaths are often violent and painful, can involve multiple attempts, and cause untold devastation to those left behind. The doctrine of double effect caused by continuous deep sedation with opiates used at home and in many palliative care settings, essentially renders the patient unconscious until they die from respiratory failure, there is no ethical difference between this and assisted dying.

Politicians need to fully understand how the current law is operating if they are to make informed decisions about what is right for our country and citizens. That includes understanding the views of diverse groups – most importantly dying people and their loved ones, but also healthcare professionals, the police, and disabled people.

Personal choice, autonomy and control are values that many disabled people hold dear. But claims by a vocal minority that all disabled people are opposed to a change in the law – as if we are a single, homogenous group – have caught many politicians' attention.

The status quo on assisted dying is not sustainable. In 2018 in England Mavis, 80, helped husband Dennis, 81, overdose in pursuit of an assisted death to escape his suffering from terminal cancer. Mavis also overdosed and was hospitalised. Dennis died. Mavis was imprisoned for 30 hours still wearing her hospital gown. She endured an 18 month court case, whilst grieving for Dennis, until found innocent. After Dennis's death, 5000 miles away in Oregon, Frankie, and Charlie, married for 66 years, died peacefully in their sleep. Frankie, 88, had unbearable heart disease and Charlie had prostate cancer. They were dying, but they

were able to take control by the legislation, so they took their medicine and died.

A study published in January 2021 in the UK on the views of disability rights organisations on assisted dying revealed only 4 per cent have an official position against a change in the law. Claiming that this is a widely held opinion among disabled people and the organisations that support or represent us risks stifling debate and creating a toxic environment where those who are supportive of assisted dying feel unable to express their views openly.

Other jurisdictions around the world have had a civil, thorough debate, examined the evidence, and concluded that changing the law on assisted dying is the right thing to do. The UK and Ireland are increasingly the outliers.