

## Written evidence submitted by Anne-Marie Irwin (ADY0309)

My name is Anne-Marie Irwin. I qualified as a solicitor at a national law firm in 2009, and in 2020 became a founding Partner of Rook Irwin Sweeney LLP, recognised in Chambers & Partners legal directory as ‘a renowned public law and human rights firm.’ I have acted in many of the leading public law and human rights cases of the last decade and I am ranked highly in Legal 500 and Chambers & Partners for Administrative and Public Law.

In 2017 and 2018 I acted for Noel Conway in an application for judicial review, seeking a declaration that s.2(1) of the Suicide Act 1961, which prohibits assisted dying, was incompatible with his right to a private and family life under the Human Rights Act 1998 and Article 8 of the European Convention on Human Rights. Noel called for a change in the law to allow terminally ill, mentally competent adults the option of an assisted death, subject to approval by two independent doctors and a High Court judge.

Noel had a terminal diagnosis of motor-neurone disease and wanted the option of an assisted death at the end of his life. He had a loving family and excellent care, provided by the NHS, at home. He was a former academic and lecturer, and he explained to me how important it was for him to be able to exercise his autonomy at the end of his life, and how aggrieved he felt that the State could interfere in a decision which was so personal to him. He explained that he wanted to change the law to allow him, and other terminally ill people, to have *“the right to die peacefully, with dignity and on our own terms.”*

Noel was increasingly reliant on a ventilator to breathe, and although he had the option of refusing ventilation to hasten his death, there was significant uncertainty about how long this would take, and about the experience Noel would have, which inevitably caused him anxiety. Following the High Court judgment, he explained that *“there is no way of knowing how long it would take me to die if I did this, or whether my suffering could be fully relieved. To me, this is not choice – this is cruelty.”*

He explained to me that, if he had the option of an assisted death at the end of his life, he would be able to live the remainder of his life with a sense of control and certainty. He was no longer able to travel to Switzerland for assistance and he was clear that he did not wish to put any member of his family *“at risk of prosecution by asking for their help here at home”*.

Although the High Court and Court of Appeal rejected the claim, both Courts accepted, having heard legal submissions, that they had jurisdiction to hear the claim. Following the Court of Appeal judgment, Noel explained that

*“This illness has already taken away my ability to breathe independently and I am now almost completely immobile. I know it will also rob me of my life, and I have accepted that. But what I cannot accept are the options I am faced with under the current law.*

*“I am told that I can choose between letting nature take its course until I am completely unable to move or communicate; hastening my death by removing my ventilator with no guarantee my suffering can be completely relieved; attempting to end my own life at home in potentially painful and traumatic circumstances; or making the arduous and expensive journey to Dignitas and risking prosecution for any loved ones who accompany me.*

*“It is barbaric to force me to decide between these unacceptable options.”*

Although the Supreme Court refused to grant permission to appeal, Lady Hale recognised, in her reasons, that assisted dying is *“an issue of transcendent public importance”* and *“touches us all”*.

Noel ultimately chose to remove his ventilation to bring about his death. In his final statement, he explained that *“this is not something I would have chosen but I feel that I have no alternative to ending my life without pain and suffering.”* His wife explained that he died “peacefully”, but that *“the uncertainty over how long this would take for Noel and what he might experience presented us all with considerable anxiety.”*

I am aware of other terminally ill patients whose family have agreed to support them to travel outside of the UK for an assisted death. In addition to the stress and grief they feel regarding the loss of their loved one, they must also consider the risk of prosecution. Despite the guidance issued by the Director of Public Prosecutions, the outcome of a police investigation cannot be predicted. They have reported living in fear of prosecution and/or undergoing the intense stress of an investigation, include police questioning and a lengthy wait for a prosecution decision, when they are grieving their loved one.

I carefully considered a significant amount of evidence during Noel’s case, including evidence of the impact of assisted dying in countries where it is legal, from personal accounts to more formal, statistical evidence. I believe that allowing safeguarded patient choice at the end of life is both compassionate and in accordance with the principles of autonomy and respect for a person’s private life. I hope the committee will take this opportunity to recommend a change in the law.

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