

Twenty years after John's death

by Lesley Close, England

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In March 2001, at the age of 53, my brother John Close was diagnosed with Motor Neurone Disease, and by the Autumn of 2002 he was a wheelchair user who needed full-time care. In late January 2003 John saw a BBC News item about Reg Crew's trip from his home in Liverpool to "DIGNITAS – To live with dignity – To die with dignity", a Swiss non-profit organisation. Reg also had MND and John showed me the story then, after I had read it, typed (his voice had gone some time earlier) *That's how I'd like to go when my time comes*. I immediately understood why John wanted an assisted death – it would give him a death which was peaceful and dignified.

John signed up for membership, submitted a formal application with medical and other evidence and subsequently received a "provisional green light". On Monday 26th May 2003 we took an early morning flight to Zurich. John took a small bag with him, and I have it to this day: it contains the clothes in which he died.

After meeting Ludwig Minelli, attorney-at-law and founder of DIGNITAS, and going through the paperwork, we went to the office of the doctor who had reviewed John's application for assistance to die. He and John were initially alone, with John's communicator device allowing him to answer questions. When I was called to join them, the doctor asked me about John's medical history and his family left at home (there was only our mother) and he made sure that I understood what John was about to do.

And then the doctor said something that for him was perfectly compatible with the Hippocratic oath. He said: *My main duty as a doctor is to preserve life but, here in Switzerland I have an extra duty. I will perform that duty for you, Mr Close, and write the prescription to help you to die*. And with that he left the room. The silence which fell wasn't just due to John's lack of speech – it was the expression of a profound sense that the end of John's suffering was not far away now. Because I was with John as he died, I have the lasting comfort of knowing that he didn't suffer. I have an abiding memory of him smiling, just minutes before his life ended. Of course, John's death was sad but my grief at losing him was tempered by the control he had over the way he died.

John achieved the peaceful and dignified death he wanted but the fact that John's death took place in Switzerland meant that that was the only peaceful part of a difficult experience. The journey was hard for all sorts of reasons. Above all, it was physically very difficult for John: he had to stop eating the day before travelling (to avoid needing to empty his bowels on the journey); he drank very little after waking at 04:30 that day (to avoid using his urine bottle on the plane); he had to endure being manhandled into and out of his plane seat by the ground crew more like a 'thing' than a human being. In addition, he needed to travel before he completely lost the ability to communicate or to do anything for himself: assisted dying under Swiss law means the person needs to be able to self-administer the lethal medication. And then there was the fact that our frail and elderly mother could not be with her beloved son for she too was a wheelchair user.

I also had to prepare myself for the risk of prosecution when I got home. Although ending one's own life has not been a crime in the UK since the 1961 Suicide Act was passed, assisting someone's suicide remains a crime, even if it is within the framework of the legal procedure in Switzerland. Helping John to arrange his assisted death in Switzerland or accompanying him there could be interpreted as 'assistance with suicide' in the UK.

May 26th 2023 marks the twentieth anniversary of John's death. Over that time, I have seen the British public attitude toward assisted dying change from discomfort and embarrassment to

acceptance and understanding. The subject is often referred to in comedy, a sure sign that assisted dying is becoming part of the fabric of society – we tend to laugh at things we find a bit uncomfortable as a way of working out how to incorporate them into our lives.

I have seen almost twenty years' worth of mounting evidence that the law must change. I have become aware of the huge toll that the current law takes on dying people and their families. I have met many people whose terminally ill loved ones took their lives, dying alone in the UK because they could not – or did not want to – travel to Switzerland. I have heard harrowing stories of intolerable, irremediable suffering in hospices and learned that palliative care cannot solve all the problems that surround death. Others have described how a cynical doctor, opposed to assisted dying but claiming to act in their patient's best interests, used the doctrine of double effect to end their loved one's life at the time of the *doctor's* choosing by administering a massive dose of sedative which led to unconsciousness and, ultimately, death.

Someone who is dying should always be front and centre of the discussion about the end of their life and people should be given the autonomy they deserve to take their own decisions about the manner and timing of their death – something which the European Court of Human Rights acknowledged to be a human right in 2011, in a case brought by DIGNITAS. One day British society will look back and wonder why we let so many people endure needless suffering, why it took us so long to grasp the nettle – as we did with slavery, abortion, gay marriage – and make this country a better place to live and die. To date, over 500 Brits have gone to DIGNITAS but Westminster has still not moved to resolve this issue of one-way traffic in the way a clear majority of the public wishes.

Over the last twenty years I have witnessed many important debates on assisted dying in the British Parliament and have met many of the MPs and Peers who support changing the law. I have rejoiced when politicians engage with the issue and have listened as Members of both Houses spoke movingly, relating personal experiences of how our broken law failed their family members and friends. I have debated the issue of assisted dying with many of its most fierce opponents. And I have seen many encouraging signs that change *will* come one day. The first glimmer of hope was Lord Joffe's Bill, introduced not long after John died. The Commission on Assisted Dying, which visited DIGNITAS (as had the Committee vetting Lord Joffe's Bill), was tremendously encouraging, as are moves to change the law in Jersey and the Isle of Man. The Scottish Parliament has seen some shining examples of the public campaign moving inside a legislative chamber, thanks to Margo McDonald and Liam McArthur among others.

But Westminster continues to drag its feet on the issue. Rob Marris won the chance to introduce a debate on the issue in 2015, a session that lasted almost a whole day. Some MPs spoke in support of the Bill but far too many simply repeated time-worn untruths about slippery slopes and others took the opportunity to overstate the benefits their local hospice could offer to dying constituents, benefits which (they suggested) obviated the need for assisted dying. Lord Falconer's Bill set up some good rules by which a future law could operate, including the need for a judge to make the final decision on any request for an assisted death, but the parliamentary session ended before his bill could become law. The British political position on assisted dying is, essentially, very little further forward than it was when John died.

DIGNITAS is a marvellous organisation, but Britain should not be outsourcing choice at the end of life by relying on the option of assisted dying in Switzerland. Instead, we should be learning from the experience of other countries. Three Commonwealth countries, Canada, Australia and New Zealand, have changed the law to permit mentally competent, terminally ill adults who are suffering intolerably to have the right to ask for help to die while Oregon, whose law changed several years before John died, is often held up as a shining example of compassion in action. Belgium, The

Netherlands, Luxembourg, Spain, Germany, Austria, Italy, Colombia have also legalised assisted dying. Those civilised places have changed their laws but their societies still function, and vulnerable citizens are protected.

Changing the law would not bring about more deaths, but it would reduce the amount of unnecessary and undignified suffering that dying people endure as well as the risk and dire consequences of failed do-it-yourself suicide attempts. It would mean fewer people having to travel to Switzerland earlier because they need bodily and psychological strength to do so, like John. I hope British law will change before another twenty years have passed: when that day comes, I will finally unpack the bag John took on his one-way journey twenty years ago.

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