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LOVE AND A GOOD DEATH

Daily Telegraph, Sydney

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Zoe Coyle could not hold her mother's hand as she died.
Today she wants to be sure no other family has to bear the same grief

Story ZOE COYLE

Zoe Coyle's terminally ill mother euthanised herself. Devastated that assisted dying was not accessible to patients in Australia who desperately wanted it, Zoe became an advocate for euthanasia law and the right to die. That experience has now inspired her deeply moving debut novel *Where The Light Gets In*, about a mother who asks her daughter to help her die. This is Zoe's story ...

Twenty years ago, my mother took her own life. She didn't commit suicide; she euthanised herself, and there is a difference. Suicides want to end their lives, people who euthanise want to end their

pain and suffering.

It all started when a colleague accused her of being drunk at work because her speech had begun to slur and her balance was off. She wasn't a drunk, but she knew something was wrong, and in time so did her doctors, but they struggled to know exactly what.

They tried operating and put a shunt in her head to drain off brain fluid, but that didn't help. More doctors were seen, and finally, there was a correct diagnosis.

Progressive supranuclear palsy. It attacks the brain cells and impairs mental and motor functions. The prognosis was terminal, and it would be a painful, slow and degrading death.

Already she had a constant searing band of pain circling her skull. She told me it felt like a hot metal strap being cranked more tightly around her head each day.

Her eyelids were thickening, making it difficult to read and, in time, would make it near impossible for her to open them at all. My mother would end up in high-dependence care, unable to move or swallow. She would need a tube down her throat to feed her so she would be unable to speak.

As a nurse, and in the face of her prognosis, she was calm. And adamant she did not intend to let the disease rob her of her autonomy and dignity. She didn't want to die, but she didn't want to suffer unduly either. Due to her type of illness, she didn't qualify to travel to Switzerland to die at Dignitas. And 20 years ago, it was not available or legal to euthanise in Australia. So she had to take matters into her own hands.

She read books and went to talks about euthanasia. She put her life in order and her plan in place. Over time as anticipated, her condition deteriorated further. She had to stop work, couldn't drive or write anymore. She fell often and choked when she ate or drank.

Her intention to euthanise never wavered, but the laws were clear.

If anyone helped her die, they would go to jail for murder. Even counselling someone how to die was a crime. Just knowing they would do it and not attempting to stop them was not allowed. Legally, therefore, the only option was that my mother would need to be alone when she ended her life.

She got to a point where living in her own home was too difficult, so she decided it was time. It turns out killing yourself is hard, even with medical training. My mother wore a Do Not Resuscitate sign, but she was discovered,



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whisked off to hospital and revived.

I sat by her bed as she regained consciousness, and never in my life have I seen someone so desperately sad. Even now, all these years later, to think of her distress at still being alive makes me need to suppress a scream.

She wanted to get discharged from the hospital as quickly as possible to try again.

Time was a factor because the window of her physical capacity was closing every day. The hospital policy was that if you tried to end your life, you were considered a psychiatric patient, and they wanted to refer her to that unit.

My mother was not mentally unwell; she was not depressed; she simply knew the quality of life available was not what she wanted.

The staff suggested palliative care, but my mother could potentially live on deteriorating for years. If forced to stay in hospital system, she stated she would refuse food and drink, but that wouldn't work as they'd have force fed her through a tube.

So my mother was desperate to get home, which she did manage, and three weeks later, she successfully killed herself.

I was not with her. I can't begin to tell you how much I wish I had been, and that we as a family had been offered the choice to have support during this very worst time of our lives.

It took me close to a decade to recover from her death. Of course, to have a beloved parent die is always distressing. Still, the nature of her death is what made my grief almost insurmountable.

And when I say the nature of her death, please understand me, I'm very proud of her courage. I respect and understand her choice; what created the damage were the laws that prevented us from being there for her, being together, being a family.

Now five of our six states have passed a Voluntarily Assisted Dying bill. Between the time the law is passed and when it is available to use is about 18 months. Medics need training, protocols, and safeguards put in place and learned. This is very serious business after all.

The VAD bill is currently up for debate in NSW's Upper House. Last time, in 2017, it failed by one vote, so I am hoping it will pass, as I'm sure is every other family with a story like mine. Not for our families, but for yours, should you ever need this kind of help.

I understand people's fears that assisted dying is murder. I don't see it like that. I see it as offering compassion and care to someone who needs help and love. I also understand how some people are concerned these laws will be abused, allowing vulnerable people to be

manipulated by family or the system to their deaths, but the process of applying for an

assisted death is hugely rigorous and is meticulously designed to protect against abuse.

A patient must request VAD three times and be assessed by two independent medical practitioners. Also, to qualify, the person must be over 18, be an Australian resident, have decision-making capacity, be acting voluntarily and without coercion. They must have a disease, illness or medical condition that is advanced, incurable and will cause death within six months or 12 months for a person with a neurodegenerative disorder like my mum's. Also that their medical condition is causing suffering that cannot be relieved in a manner that the person finds tolerable.

Others say palliative care can manage any and all pain. That is not true. As heroic as those institutions are, and I have volunteered in one, sometimes people, despite the best medical care, have dreadful, protracted and painful deaths. Terrible for the patient but also horrifying for their families that sit by powerlessly watching on.

I've talked to families who had a loved one die in the assisted way, and their experience is the opposite of my mother's and mine. They use words like beautiful, dignified, loving, sacred. They talk about how grateful they are. I am happy for them and relieved they didn't have to go through what we went through. The words I would use are the opposite of theirs: harrowing, lonely and traumatic.

There is, of course, another way, and this VAD law enables it. It's fundamentally about kindness, compassion and empowerment. ■

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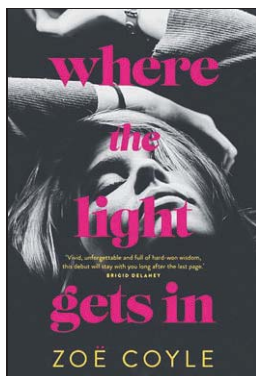
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Where The Light Gets In,
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Zoe Coyle, left, became a euthanasia advocate and an author after the devastating death of her mother.