

# The right to die

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Pablo Cánepa was a normal, healthy 35-year-old Uruguayan. Handsome and extroverted, he was a talented graphic designer who loved to host barbecues with his girlfriend and was fanatical about Nacional, a local football team. Taking a shower in March 2022, he suddenly felt dizzy. He thought little of it.

But within four months he was trapped in his own body; his brain had lost almost all control of his muscles. As a kid, he loved to draw. Now he cannot sit, feed himself or control his bladder and bowels, let alone hold a pencil. His 75-year-old mother must change his sodden nappies. His mind is lucid. He knows exactly what has happened — what he has lost—but even his eyes do not work; he sees double. Speaking is exhausting. For three years he has been lying staring at the ceiling, unable to move his limbs to relieve the stiffness and pain, his muscles withering. Trapped, he suffers panic attacks. He has been denied even a clear diagnosis. All the doctors can tell him with certainty is that he has irreversible brain damage with no known cause. Pablo wants to die. He has said so repeatedly since early 2023. But under Uruguayan law no one can help him to do so.

That could soon change. On August 13th Uruguay's lower house passed a law with a thumping majority to legalise assisted dying. The Senate, where a similar bill got stuck in 2022, is widely expected this time to follow suit. Legal assisted dying would continue Uruguay's long liberal tradition and put it among a handful of countries in the world to have legal marijuana, gay marriage and assisted dying. For Pablo, the law cannot come soon enough.

In Colombia and Ecuador assisted dying was decriminalised after court battles. Cuba recently declared it legal, too. None of these countries has a comprehensive law to regulate it, so its application is often very limited. Colombia is the most advanced but even there it is bafflingly complicated. Uruguay would be the first country in Latin America to pass a

comprehensive law legalising assisted dying that would make it widely available. Advocates in Chile, where an assisted-dying bill is stuck in the Senate, are watching closely.

The law that Uruguay's lower house passed is strikingly liberal, more so than a current effort in Britain, where assisted dying would be limited to those with a terminal illness who will anyway die within six months. Uruguay's bill imposes no such time limits. Moreover, it is open to people with an incurable illness that generates unbearable suffering, even if it is not terminal. That applies crucially to Pablo, whose disease is torture but not terminal.

Uruguay's bill still has constraints. Mental conditions such as depression are not explicitly ruled out but patients need at least two doctors to determine that they are psychologically fit to make the choice. Minors are excluded. So are directives whereby people who are in good health can leave instructions to be helped to die in the future, should they become so ill that they are unable to communicate.

Opposition to the law comes chiefly from the religious. Daniel Sturla, the archbishop of Montevideo, the capital, worries that, together with legal abortion, assisted dying is creating a "culture of death". He warns of "a mindset where life is disposable and where there are lives worth living and lives not worth living". Some argue that palliative care renders assisted dying unnecessary by reducing patients' suffering as they near the end. Others add that palliative sedation, which some doctors in Uruguay apply to relieve suffering and, in effect, to marginally hasten death at the very last moments, already does enough.

### **We shouldn't have to wait**

The frustration of the Cánepa family with such objections is palpable. Pablo's brother Eduardo lists a slew of Uruguayan organisations and politicians campaigning against the law. "They claim to be empathetic toward life ... but it is only in the abstract," he says, his voice cracking with emotion. "None of them has called us, none of them has sent us a message to see if we need something, to see if they can help—absolutely nothing."

Palliative care is more widely available in Uruguay than in most of Latin America. But for Pablo in practice it means two visits of perhaps 30 minutes a week, even though he has both state help and private insurance. Palliative care is undoubtedly necessary, but is not a substitute for assisted dying, argues his brother Eduardo. Indeed in Canada, he notes, the vast majority of people who choose an assisted death also receive palliative care.

Florencia Salgueiro, a leading campaigner for assisted dying in Uruguay, has first-hand experience of the limits of palliative sedation. Her grandfather and uncle died of a neurodegenerative disease. Then it got her father, who died aged 57 in 2020 after a torturous last few months. Doctors obediently followed the law, apologetically rebuffing his requests to be helped to die sooner through palliative sedation.

History and public opinion may favour the Cánepas but they remain cautious. “I want to see it approved before I believe,” says Eduardo. How will he feel if it is? “Relieved,” he replies. “I don’t want people to die. I want people to be able to choose.”