

## **An elaboration on my point about the inadequacy of the current laws around end-of-life, namely in relation to the doctrine of double effect**

As a background, drugs like opiates, barbiturates and benzodiazepines treat the symptoms of dying like pain and panic and, in Amahl's case, the sensation of breathlessness, but do so by simply tricking the brain in not responding to the body's alarm systems. This is useful of course, however, they have the side effect of depressing breathing and accelerating death.

As a result, the "doctrine of double effect" is used in our current law in, what seems to me, a weak attempt to accommodate for the fact that we cannot treat suffering without, as a side effect, shortening life. It saves doctors from prosecution by doing their job, which is important, but it defies logic. We could, instead, simply accept the reality of palliation, that we can't treat suffering without shortening life.

The doctrine of double effect is based on a 13<sup>th</sup> century philosophy by Thomas Aquinas. He theorised that an action (in this case by doctors) is ethically acceptable if "only the good effect is intended, and a bad effect is merely foreseen". That is, 8 centuries ago, when treatments were rudimentary, it was accepted to not prosecute doctors for acts of bodily harm that they could, in fact, foresee, because they didn't "intend" to do it. I understand why the two acts needed to be separated in the past, but I think we are suitably informed and educated these days to accept that the actions are inseparable and an unavoidable part of palliation. Also, we can surely agree that doctors shouldn't be prosecuted for normal palliation. Not because they aren't responsible for their "foreseen" actions (which is illogical) but simply because it is impossible to avoid.

Amahl wanted to continue the ventilation (having air pushed into his lungs) with a minimum amount of background morphine for as long as possible. That way he could maintain his alertness AND breathe (the technology has improved on the mask) as well as continuing to enjoy watching his daughter, play chess, engage with his friends and family, and complete his biographical stories and birthday cards for his daughter. The four things he still really enjoyed and that gave him quality of life.

Then, he wanted just to die quickly when either the breathlessness was too great or he lost his ability to twitch his index finger on the left hand in order to activate the switch that allowed him to communicate. He wanted to say goodbye and go, and not drift in and out of consciousness watching his

distressed family suffer with the uncertainty. I just felt strongly that there was nothing wrong with that. I really wanted to do that for the person I loved which is why I felt so wronged by the law. Why was that up to me only, why was I abandoned by palliative care in doing that, and why was I haunted by this one woman who was scrutinising my every move because she thought I was an unethical human being?

Earlier on in the disease, in order to make Amahl's end-of-life care look more typical, it was suggested to us several times that Amahl spend more time off his mask with larger amounts of morphine. That would give the appearance of eventually dying in his sleep, within the scope of the doctrine of double effect. Because that wasn't Amahl's wish, I got the impression it was very tricky for palliative care to navigate his end-of-life care. We were told a couple of times that it was easier in the past because the masks were so uncomfortable.

To their credit they accommodated Amahl's wish for some time, and I believe that palliative care is extremely valuable in end-of life care up to a point. But when it came to the crunch, it depends who you get. Our physician was aggressively anti-VAD and so she took control away from us. I wanted for the control to be put back in Amahl's hands so that we could form a healthy relationship with palliative care, Amahl could get the respect he deserved for his brave journey and so that the responsibility was not given to me. Far from sidelining palliative care, I wish I was able to work with them by being able to talk frankly about death without playing a ridiculous game of which one of us is willing to go to jail to do the right thing for Amahl. Given how vulnerable these patients are, of course it is currently up to the carer and the person who loves them to deal with that crippling responsibility and fear. How different my experience would have been if I wasn't alone in that. I would have been able to preserve so much more of my resilience in dealing with what happened, be a better mother for my daughter through it all and avoid at least part of the PTSD that followed. Most importantly, Amahl could have talked to us about it and not spend his last days arguing for what he saw as his right.