

Dying Is Much More Difficult Than You'd Think: A Death By Dehydration

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Perm J 2017;21:16-148

E-pub: 03/30/2017

<https://doi.org/10.7812/TPP/16-148>

The e-mail from Lieke arrived in the afternoon:

A lot has been happening over quite some time in terms of my health. Unfortunately the new painkillers work brilliantly as such, but I just reacted badly and they produced all the side effects you can think of ... Since I have been unable to keep any food down since last Saturday, I decided to put forward the plan I had for finally using "death by dehydration" so started that [two days ago].

This shouldn't be how it ends, I thought. Withering away from lack of fluids seemed a truly awful way to die, as I imagined a dying that was protracted, uncomfortable, and painful.¹ I e-mailed Lieke back without alluding to my dismay about what she was undertaking, and then spoke with her on the phone. Although her decision to stop drinking came seemingly out of the blue, she had in fact been contemplating this for some time.

I'd first met Lieke more than 10 years earlier, when she attended a community education course on ethical issues in contemporary medicine that I was running through the university. She was in her 70s, friendly, down to earth, intelligent, and fiercely independent. One of the many topics in the course focused on physician-assisted death.¹ As a class, we explored the topic from different perspectives—the patient, the physician, and the broader social and legal contexts. She contributed to the discussions and was able to diffuse potential conflicts by presenting various arguments, playing devil's advocate, running sound analogies, and gently pushing people out of their comfort zones to think beyond the status quo. I admired her intelligence and enjoyed having her in the class.

Lieke was clear that she supported a physician either directly ending a competent patient's life at their explicit request (euthanasia), or supplying competent patients with the means to end their own lives at their explicit request (physician aid-in-dying).¹

We stayed in touch once the course finished, meeting every few months for lunch. This was often a bowl of vegetable soup from produce from her garden; flowers in a vase were never far from sight. When she left Auckland to live closer to friends on the coast, I sent her some red tulip bulbs as a reminder of our lunches and her connection to The Netherlands.

When you are comfortable talking about physician-assisted dying, it doesn't seem strange to consider what you would want (or not want) for yourself were life to become unbearable at the end. Over lunch, Lieke and I spoke of different scenarios, discussing what was important to us and what we might want for ourselves in such situations. Having some control over the decision-making process at the end of life, and indeed the manner in which one would die, was important to us both. She was clear that she would

not want her life to be maintained if there was no possibility of a return to a reasonable quality of life, and she reminded me of her advance care directive that among other things refused CPR. We had previously discussed an article that showed people's understanding of the success rates of CPR were strongly influenced by TV shows and that often they were unrealistic.² Because Lieke had been a member of an organization that advised members on how to access sodium pentobarbital overseas, I assumed she had access to a lethal dose of the medication.

After Lieke left Auckland, we kept in touch by e-mail and phone and met once or twice a year when she travelled to the city for concerts and exhibitions. Her health began to decline when heart problems required a hospital stay. Good clinical management gave her relief from pain, but ultimately her deterioration necessitated changes to her life. No longer able to drive, having difficulty sleeping because of pain, and struggling with the adverse effects of analgesics, Lieke made the decision to move to a retirement village. For someone so independent and capable, this move was hard for her to accept. It was around this time that Lieke began to consider and explore the option of refusing fluids.

A year later, Lieke's unstable arrhythmia became difficult to manage clinically and she subsequently developed ischemic leg pain caused by advanced arterial disease. Arterial blockage was not amenable to stenting, and amputation was not an option she was prepared to consider.

Then she stopped drinking all fluids. Staff in the retirement village, a palliative care physician friend, her general practitioner (GP), and her friends were supportive of her decision to stop fluids and assured Lieke they would do everything possible to keep her comfortable and at home. Although she had no family in New Zealand, she was in regular contact with her sister-in-law overseas, who also supported her decision. Hospice services were involved in supporting her throughout the dying process.

Because the practices of euthanasia and physician aid-in-dying are illegal in New Zealand,³ the decision to stop drinking was one of the few legal options open to Lieke that respected her right to exercise control over her own body.⁴ Around the time Lieke was dying, a young woman sought clarification from the New Zealand High Court regarding interpretation of the law and physician-assisted death.⁵ Lecretia Seales, the young woman, had been diagnosed with an aggressive brain tumor and wanted to know if her GP could assist her in dying without fear of prosecution. One of her concerns was that even if she had the means to end her life, she may have to put those plans into place earlier than she wanted to ensure the kind of death she sought. Having certainty that her GP could legally

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assist her meant she may live longer because she didn't have to worry about the window of opportunity permanently^b closing.^{c5} Lieke had also worried about when her window of opportunity would close, perhaps resulting in a situation where she would be unable to ensure the kind of death she wanted.

Now that she had stopped drinking, Lieke communicated with friends by e-mail because her dry mouth had made talking difficult. The physical toll: "I'm sleeping well and not having to get up to pee. Little saliva left in my mouth," and emotional toll: "It's a long process. I'm so humbled by this loving support from everyone" were evident. So too was her sense of humor: "sugar free gum is marvellous," "I can't die before I finish this book." My assumption that Lieke had access to sodium pentobarbital was quashed: "If I'd had [sodium pentobarbital] in my cupboard, it may have given me a little more time. That is the key. If you know there is a way out, you can focus on what life has to offer. You can balance the pain and suffering because if it gets to that point, you can end it."

In those last days she was constantly surrounded by caring people who didn't leave her side. She impressed upon her friends the value of hospice and of the joy of life: "Get as much out of life as you can." The dying process was pain free but arduous—it took a long time and required a strong and determined resolve. She wrote, "The process is much more difficult than you'd think. It's not an easy alternative."

Lieke died nine days after she stopped drinking fluids. Although her death was pain free and she was surrounded by love and support during those final days, she desired a different kind of death: one in which she was legally permitted to request and discuss an assisted death with her GP. The fact that she made a decision to stop drinking, and persevered with that decision until the end, shows her determination and courage in wanting a choice at the end of life. Lieke's dying by dehydration was not the painful, protracted process I imagined. The reality was she was comfortable and pain free, supported and cared for, until she died. But it was a difficult dying for her because she was a very private person who grieved for the many losses she had endured during the previous two years. It was not the kind of dying she wanted for herself.

I have wondered since Lieke died if the option of an assisted death may have given her more time. Perhaps she may have seen her tulip bulbs emerge from the ground one last time. ❖

^a Despite my unease at the practice, evidence suggests dying in such a manner can be a good death as evidenced by nurses. See: Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delorit MA. Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med* 2003 Jul 24;349(4):359-65. DOI: <https://doi.org/10.1056/NEJMsa035086>.

^b By this I mean that she was still able to exercise control over any decisions that needed to be made. Once she was unable to make decisions because of her situation, she would be subject to the decisions of others (the window had closed).

^c Lecretia Seales died on June 5, 2015. Her death came hours after Justice Collins delivered his ruling that Ms Seales' physician would not be "acting lawfully if she administered a fatal drug to Ms Seales within the terms sought. Nor can I declare that it would be lawful for Ms Seales' [physician] to provide her with a fatal drug knowing that Ms Seales intended to use that drug to end her own life and did so."⁵

Disclosure Statement

Dr Malpas is a member of the End-of-Life Choice Voluntary Euthanasia Society of New Zealand Inc. The author(s) have no other conflicts of interest to disclose.

Acknowledgements

I would like to thank Lieke's good friends for assisting me with details of her final days. I would also like to thank the five anonymous reviewers for their constructive and helpful comments, which resulted in a more polished piece of work.

How to Cite this Article

Malpas PJ. Dying is much more difficult than you'd think: A death by dehydration. *Perm J* 2017;21:16-148. DOI: <https://doi.org/10.7812/TPP/16-148>.

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Exits

Death hath ten thousand several doors
For men to take their exits.

— *The Duchess of Malfi*, John Webster, 1580-1634, English Jacobean dramatist