
Bioethics Outlook

Plunkett Centre for Ethics

Australian Catholic University,
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Felicity

We begin with the story of an individual human life marred by mental illness. It is a tender and honest eulogy given by the sister of the woman whose death was the result of an accident. For privacy reasons, the names of persons and places have been changed. We are honoured to have been given permission to publish it. It is a moving account of what it is to love one's sister. In addition, because it evokes so much of what it means to live with mental illness, it is instructive.

Felicity was three years older, so my memories of her growing up are mediated through the eyes of a younger sibling. I think of myself as having had a happy childhood, and I believe her experience was the same. We lived in a house in Brighton with a large, rambling garden where we played together for hours on end. We swam at Brighton Beach, and did family road-trips over the summer holidays, north to the Queensland coast or into the bush. My parents were enthusiastic travellers, and we spent my father's sabbatical years abroad, living in the United States and England, where Felicity and I both spent time at school, driving through Europe over the summer in an old white Triumph. It became clear early on that Felicity had an exceptional intellect, and she won a scholarship to go to a renowned high school where she excelled, eventually becoming Dux of the school.

In this issue

- *We consider the terms 'doctor-assisted dying' and 'doctor-assisted suicide', asking which is more accurate in the case of Victoria's 'voluntary assisted dying' legislation.*
 - *We finish by raising a question about the proper relation of politics to ethics.*
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I have often asked myself whether, in hindsight, there were signs as Felicity grew up of the psychological difficulties that would follow her for most of her life. Certainly she was shy and somewhat awkward at school and struggled to make close friends, but many people have that experience and are able to leave it behind them. I think those who knew her at that time would remember her only as gentle and sensitive, more quiet than outgoing, but smart, thoughtful and interested in the world.

With her Year 12 marks, that were among the top in the State, she was awarded a prestigious National Undergraduate Scholarship, and went to University interstate to study History and Asian Studies. She moved into a residential college to live. I remember visiting her there with my parents and receiving letters that she wrote to me about her life at university. It all began well and she seemed happy, excited by the new phase of her life. Just this week, I've received an email from a woman who was Felicity's friend at this time, and who heard of her death through a mutual friend of ours. Although she hadn't seen Felicity for 40 years, she said that she remembers her vividly because Felicity was so interesting and smart, and such good company when she was feeling well. By the end of her second year at University, though, things were starting to unravel. Communication with the family became less frequent and was no longer cheerful and optimistic. She announced that she was giving up her scholarship to return to Melbourne, and she moved into the residential college where I was living at the time. But she was already becoming remote and difficult to reach. I learnt later that she had been seeing a psychiatrist for much of this time and was already on medication. Things came to a head at the end of her third year of university, when she was just 21. She experienced the first of many acute episodes of psychosis and was scheduled into the psychiatric ward of a teaching hospital.

If Felicity had been born 30 years later, her life might have been very different, but for a young person diagnosed with schizophrenia in 1979, the options were grim. The medications available were crude and had debilitating side-effects. Electroconvulsive therapy was used indiscriminately. Psychiatric wards, particularly those for involuntary patients, were overwhelmingly bleak. They were designed to keep mentally ill patients away from and invisible to the community, rather than to support them to be integrated back into it, and were filled with lost and confused souls wandering the corridors.

This became Felicity's life for most of her 20s. She bounced from psychiatric hospitals to half-way houses and back again, always heavily medicated and without any meaningful social support. She lived in various temporary accommodations intended to be a transition back into independent life, but without any friends or anything really to do, it wasn't a happy existence. She had a brief period of respite when she was able to return to University and finish her degree, but it was short-lived. She arrived back on my parents' doorstep from college one day unannounced, because I think she knew she was heading for another

downward spiral, and the revolving door in and out of psychiatric hospitals began all over again. Over a period of years, she was in no fewer than seven different hospitals, sometimes for months on end. I visited her when I could but hated doing so, and doubt that my visits were much help.

And then, in the middle of all this, my father was diagnosed with a brain tumour and died after 18 months of unsuccessful surgery and radiotherapy. I have only a hazy memory of what was happening with Felicity during this time. The burdens that my mother was carrying, with both of them so ill in different ways, must have been overwhelming. But she continued throughout to search for some new psychologist or therapy program that might help Felicity, refusing to accept that the right diagnosis had been made or that the treatment Felicity had already received was the limit of what was available. After my father died, my mother decided that she would bring Felicity back to live with her at home, unmedicated, in the hope that this might somehow give her the opportunity to heal herself. My mother's intentions were admirable, born of her determination not to give up hope, but they were deeply misguided. These were dark years for Felicity. Without medication, she became mute as she withdrew further from the world, never leaving the house. While my mother continued to hold out hope that some internal transformation could still take place, Felicity sank deeper into her own confused and agitated reality.

The turning point came in 2000, when Felicity was again scheduled into hospital – for the last time – and began treatment with a new anti-psychotic medication. For the first time in years, her personality started to emerge just a little, and a new chapter of her life began. I believe the last 20 years of her life were her happiest. She moved back home with my mother and the two of them re-built a relationship of sorts. It was a rather strange co-dependent relationship, with each of them intermittently belligerent towards the other, but there was also genuine companionship between them, and Felicity at last found some stability. She didn't have friends of her own, but she was happy to spend time with my mother's friends when they visited, and there was a rhythm to her life centred on the two of them having lunch together every day, usually in the garden. She didn't go out much, but that was by choice, and when I could persuade her to come with me to a film or out for coffee, I think she enjoyed it. She saw my daughters grow up, and followed their progress closely always asking about and remembering what they were doing.

She monitored the birthdays of everyone in her extended circle with great zeal, and took on herself the role of ensuring that every birthday was remembered and celebrated appropriately. Dates were circled on the calendar, reminder notes left on the kitchen bench, and birthday presents wrapped and put aside weeks in advance. And because Felicity never shopped, she had to have a more inventive approach to present giving. Stray packets of biscuits or tea from the kitchen were often wrapped up and presented as gifts, or well-thumbed books from the bookshelf, complete with Felicity's rather eccentric hand-

written annotations. My mother was sometimes startled to see various precious objects of hers emerge from Felicity's wrapping paper during birthday or Christmas celebrations, and I would have to smuggle them back to her later. These celebrations, modest as they were, were an important ritual for Felicity that marked out her life and her connections with the small circle of people around her.

In the two years that Felicity lived in the house by herself after my mother moved into full-time care, she showed remarkable, and for me unexpected, adaptability in adjusting to her new circumstances. She developed a life of simple routines that I believe gave her pleasure – feeding the cats, reading the newspaper every morning (and she could tell you every detail of what she had read), pottering around the house, sitting in the sun in the garden. She seemed very content spending most of her days in her own company and I don't believe she was lonely. In her own way, she tried to nurture the relationships that she had with those around her. When I came to visit her, she would greet me with a big smile and a kiss and would prepare tea for us both on a carefully laid out tray. She loved our girls, and was starting to develop real relationships with them independently of me. She loved Penny, her carer, and her gentle presence in the house, and the Tai Chi classes they did together in the park at the end of the street. She loved going with Sunny, her other carer, to the art gallery or the Botanical Gardens and would recount to me every detail of these outings. She had a special and enduring relationship with her GP, Sue, who provided thoughtful and devoted support to Felicity and was a central presence in her life for more than 20 years, with weekly visits, going for walks or out for coffee.

She maintained an intellectual life of sorts, albeit focused on a few, somewhat obsessive and specialised areas of interest. David Attenborough's nature shows and documentaries on India were a staple for many years, although Sunny had recently had great success introducing her to Harry Potter and Jane Austen films. She would browse through the many books in the house, probably not reading them cover to cover but copying out verses of poetry or making her own quirky notes about some topic that had caught her fancy – Islamic religious beliefs or still more on India. Her love of art was real and deep. I took her last year to see the magnificent Lady and the Unicorn tapestries when they were on display at the gallery, and she spent more than an hour in the room, engrossed in examining every detail which she could then recount. We had a tradition that each time I travelled, I would bring her an exhibition catalogue from a gallery overseas, and she would sometimes surprise me months later with some observation about one of the paintings she had seen in them.

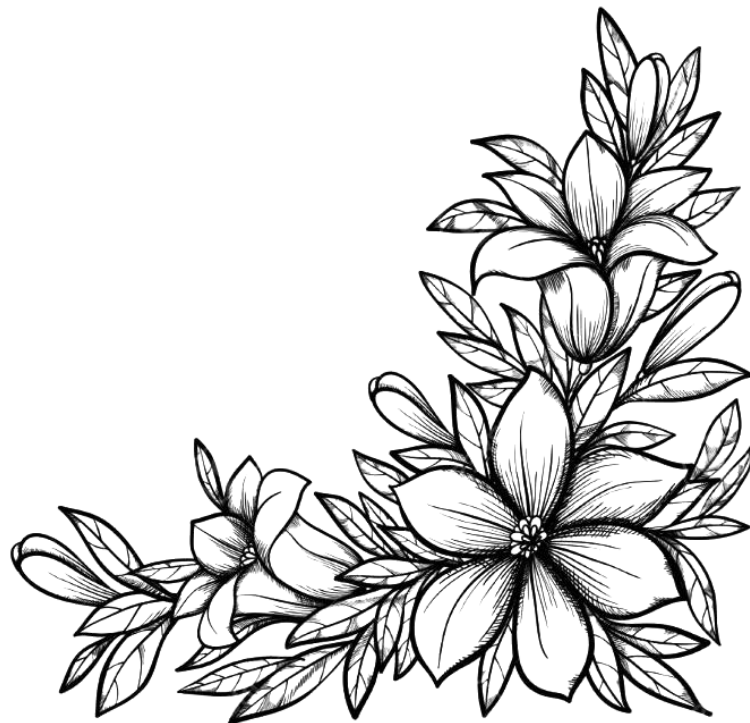
At the end of one of my visits to Felicity in February this year, she gave me a sealed envelope as I was leaving with my name on it. When I got home and opened the envelope, I found inside it – inscribed in Felicity's beautiful copperplate handwriting – a Happy Valentine's Day card. It was such a sweet gesture, typical of Felicity, but also immeasurably sad because she had no-one else to give a Valentine's Day card to.

When I went back to the house last week after Felicity died, I found in her bedroom a pile of her diaries for the last few years. I knew that she had kept a diary because at the beginning of each year, she would ask me diffidently (again because she didn't shop) if I could buy her a new diary – it always had to be a Collins diary, a day to a page. But it was only last week that I read her diaries for the first time - and they aren't easy to read. What they show is that Felicity lived in two worlds. There was the everyday domestic world that is described in her diaries in touching and poignant detail – who came to visit her that day, what they ate for lunch, what she watched on TV. But then there was the world inside her head, also chronicled in painful detail day after day. The diaries reveal a confused and distressing inner world, full of disturbing thoughts, often angry or fearful, with obsessive incantations of crazy mantras or stories of people doing bad things. Felicity kept this inner world deeply hidden from those around her. I had believed that the symptoms of her psychosis had receded over time, and it has been shocking to me to discover from her diaries that they were still ever present. Did Felicity find these thoughts as distressing as I do now, or did she just accept them as part of what was normal for her? I really don't know. Would I have done anything differently if I'd been aware of everything that was swirling around in her head? Probably not, but I still would have liked to know.

Reading Felicity's diaries, I'm struck by two things – the resilience required of her just to continue to function in the world with these agitated and confused thoughts always in her head, and how essentially alone she was as she battled with these thoughts. It's perhaps one of the ultimate cruelties of mental illness that it takes the person into a world that is different from ours, and that try as we might, we can never fully understand.

Since Felicity died, I've spent a lot of time trying to make sense of her life. I think that to do so requires multiple narratives. One narrative is the tragedy of that gentle, shy and astonishingly intelligent teenager whose bright future was stolen from her by mental illness. But there are other narratives that need to be recognised as well. Within the limitations that were placed on her, I believe Felicity did manage to craft a life that had meaning for her, even though we will probably never know exactly what that meaning was. She certainly made choices about what she did or didn't want to do, and she made connections with other people to the extent she was able to. To this day, I don't know what she made of the fact that her life wasn't the same as that of most other people. She never manifested any frustration or disappointment, and certainly never complained about anything. Perhaps the challenges of managing the world inside her head didn't leave space for anything else. But I'd like to believe that the apparent contentment we saw much of the time was part of the narrative of her life as well, and that in her own way, she had come to terms with what the reality of her life had turned out to be.

Many of you know how much I've worried in recent times about how Felicity would manage when it eventually became necessary to sell the house and find a new home for her. The house in Brighton was her world, and I'm not sure she could have begun to imagine life anywhere else - away from the beautiful view, the garden and her much loved cats. In the end, it seems she took things into her own hands by making sure that she wouldn't have to leave. Her death was certainly premature, but it was quick and painless, and took place in the home that had become her sanctuary. And the fact that it was her brain that began to die first means, I hope, that the turmoil that raged in her head for much of her life was quelled and she experienced some peace before she died.



Doctor-assisted *dying* or Doctor-assisted *suicide*?

Many of the features of Victoria's 'Voluntary Assisted Dying' Act, to come into force on 19th June, will mirror those which were put in place in Canada when its 'Medical Assistance in Dying' Act was passed some years ago. For me, a most striking moment at a recent "Implementation Workshop" in Melbourne was the audible intake of breath when Dirk Huyer, the Chief Coroner for Ontario, reported that some Canadians thought that MAiD should be called 'medical assistance in suicide'.

It is not surprising that this term is as unwelcome here in Victoria as it is in Canada. Advocates for Victoria's legislation do not want the new practice to be associated with suicide. In this regard, a recent exchange between Arthur Caplan and Farr Curlin is instructive.

Arthur Caplan: *'Here in the United States, what we've dealt with is physician-assisted dying, meaning that proponents in Oregon, California, Vermont, and Washington State say that they're going to restrict this to the dying. They're going to die anyway; we aren't going to bring about death—people are going to die. We look over at the Netherlands and at Belgium, we see physician-assisted suicide. They're not dying; they're suffering in some way. Horrible suffering is the claim. Do you think that if we go on the path that we're on, with some states allowing physician-assisted dying, that it's inevitable that we wind up with physician-assisted suicide and the more controversial baggage that it carries?'*

Farr Curlin: *'I don't agree with the distinction you draw between assisted suicide and assisted dying. Suicide has traditionally been understood as an act taken by an individual with the express purpose of ending their life. I grant that when a person has a prognosis that is quite short, it seems more understandable or more acceptable than if they are [merely] losing some of their eyesight [or] they are 30 years old and are going to live another 50 years. Although you might have a more defensible suicide and a less defensible*

suicide, they are both suicide. They are both cases where the person is acting to cause their death. That's their intention. If they fail to die, they will have failed in doing what they set out to do. So, we have assisted suicide in Oregon. We have assisted suicide now in California and in Washington and Vermont.¹

Whether one is in favour, or against, the Victorian legislation, one ought at least to try to be careful and accurate about how one describes what one is doing. For along with all the other ethically-relevant dimensions of our acts – history, intention, motive, situation and consequences, etc – the ethical ‘kind’ or ‘category’ to which the act belongs is morally relevant.² Indeed it is arguably the most important feature of sound moral reflection on what we are doing.

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¹ *The exchange can be found at:* <https://tmc.divinity.duke.edu/newspeople/farr-curlin-on-physician-assisted-dying/> accessed 26.4.19

² John Quilter. Common sense ethics: Do theories clarify or distort our ethical outlook? *Bioethics Outlook*, 27, 3. September 2013

Inverting Medical Ethics to Suit Politics

Bernadette Tobin

Daniel Sulmasy, a Catholic medical doctor and philosopher who works at Georgetown University in Washington DC, once invited us to consider the following scenario.³

Imagine, he said, that the majority of a population believed that female genital mutilation (so-called 'female circumcision') should be available to those who seek it. Suppose that, as a consequence, the parliament in that jurisdiction legalised this 'service' under certain conditions.

Would it be legitimate for the government to compel all publicly-funded hospitals to provide the service?

Or, if a publicly-funded institution had an ethical *objection* to providing the service, would it be legitimate for the government to compel the hospital's doctors to *refer* those who seek the service to colleagues who would be willing to provide it?

Sulmasy's 'thought experiment' came to mind recently when the Labour Party announced that, were it to win the federal election, it would use federal funds to exert pressure on all public hospitals to provide abortions.

Two days later, the ALP backed off, and made reassuring noises. 'Obviously, not every hospital provides every medical procedure - for example, not every hospital does brain surgery or heart surgery. That's the same for terminations', said an official for the Party's health spokeswoman.⁴

So the claim, that with public funding comes an expectation that every public hospital will provide every available procedure, is in truth little more than a slogan, one which obscures the very different reasons why a particular hospital might not conduct certain procedures.

³ Reprinted from *The Catholic Weekly*, 25 April, 2019

⁴ ALP abortion reform excludes Catholic hospitals. *The Age*, 8th March 2019

It's true that Catholic hospitals do not provide abortions, that is, 'procedures, treatments or medications whose primary purpose or sole immediate effect is to terminate the life of a foetus or of an embryo before or after implantation'.

I quote that definition from our *Code of Ethics* for two reasons. First, because the definition is accompanied by an explanation for this part of the institutional ethic of Catholic hospitals, that is, that 'Such procedures ... involve the direct and deliberate killing of an innocent human life in the earliest stages of development.'

Second, because the definition helps to distinguish deliberate terminations from other procedures with which they are sometimes confused, that is, emergency procedures needed to save the life of the mother or her baby or both.

Doctors in Catholic hospitals which act in accordance with the *Code of Ethics* may legitimately attempt to cure a serious pathological condition of a pregnant woman in circumstances in which the intervention cannot be safely postponed until after the baby is viable. In that circumstance, the doctor foresees, but does not intend, the death of the baby. So, let's set aside the furphy that Catholic hospitals don't provide needed treatment in emergency circumstances.

This 'storm in an election teacup' nonetheless has significance in Victoria. In 2017 the Victorian Government legalized what it confusingly labelled 'voluntary assisted dying' (VAD). On 19th June, in a little less than two months, the legislation will come into effect.

Of course, when their patients are dying, the much-loved Catholic hospitals in Victoria assist their patients to die in comfort and with dignity. That is precisely what they are doing when they provide palliative medicine and care! But they do not and will not assist them to end their own lives by issuing prescriptions for lethal drugs nor intentionally end their patients' lives by administering lethal injections (which is what the label 'voluntary assisted dying' actually refers to!).



Professor Daniel Sulmasy

The Victorian *legislation* protects conscientious objection on the part of individual practitioners: they cannot be forced to provide information or support for VAD, nor to assess a person for VAD, nor to supply or give the 'medication' for VAD.

In addition, the Victorian Health Department has backed up the reassurances made by the parliamentarians over and over again in the debates which preceded the passing of the Bill,

that health *services* will not be forced to participate in the provision of the procedures. Indeed, the Health Department acknowledges that one reason why a health service might decide not to participate in the provision of this procedure is that it does not align ‘with the values of the health service’.⁵

In passing, let us note the cruel if not bizarre irony that health professionals in Victoria are now said to “conscientiously object” when they are simply following the traditional Hippocratic ethic of doing no harm to their patients!

In recognizing that doctor-assisted suicide (so-called ‘voluntary assisted dying’) may not align with the ‘values of a health service’, the Victorian Health Department implies that *institutions* as well as individuals have consciences. Which raises the question: How should we understand the nature of conscience?

In this regard, a remark of the unambivalently pro-choice feminist Naomi Wolf is worth recalling. She once said that it is more truthful to speak of a woman’s decision to have an abortion not as an ‘intensely personal choice’ (which, as she pointed out, makes it sound like the woman is deciding on a carpet!), but as a genuinely grave decision about right and wrong.⁶

That is instructive. In a truly conscientious decision a person tries to get a decision right, tries to grasp the truth of what is right or wrong in their situation.

Clearly, individuals have consciences. What about institutions?

Sulmasy implies that they do. That’s why he invited us to consider his thought experiment about female genital mutilation.⁷

Indeed, we should not marginalise those – individuals or institutions – who reject female mutilation by calling them ‘conscientious objectors’. Rather we should applaud them for holding to the truth. So too with those Victorians who, against the spirit of the times, reject doctor-assisted suicide.

⁵ <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/health-practitioners>; accessed 16th March 2019

⁶ Naomi Wolf. Our bodies, our souls: rethinking pro-choice rhetoric. *New Republic*, 16 October 1995

⁷ Daniel P. Sulmasy. What is conscience and why is respect for it so important? *Theory Med Bioethics* (2008) 29: 135-149

THEOLOGY AND
PHILOSOPHY

ACU Luminaries Series

2019 Plunkett Lecture

**To thine own self
be true. Reflections
on authenticity,
citizenship and
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This annual lecture is hosted by the Plunkett Centre for Ethics (a joint centre of ACU, St Vincent's Health Network and Calvary Health Care).

Presenter

Professor Julian Hughes
RICE Professor of Old Age
Psychiatry
University of Bristol

Date

Thursday 15 August 2019

Time

5.30pm to 7.30pm
Refreshments to follow
lecture

Venue

Function Room,
Level 4, St Vincent's Clinic,
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For more information and to register for this event

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