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Seeing the Self: the moral goals of service provision in the mental health sector

Jeanette Kennett
Steve Matthews

Several years back a Senate Select Committee on Mental Health was appointed to enquire into mental health services in Australia. The committee received over five hundred submissions from individual patients, carers and mental health workers, as well as a range of professional bodies with direct and ancillary input into mental health services.¹ Following this the Mental Health Council of Australia released its own report "Not for Service: Experiences of Injustice and Despair in Mental Health Care in Australia" which drew extensively on the personal stories of those with mental illness and their families. The senate submissions and the MHCA report paint an almost unremittingly bleak and disturbing picture of mental health care in this country and raise, directly and indirectly, substantial ethical issues regarding the status and treatment of the mentally ill and their families. Stories of despair, distress, treatment denial and delay, unsympathetic and damaging treatment and social exclusion are the norm. Although mental health issues have recently received some attention in the mainstream, and a boost in recent funding, there has not, by any stretch, been a global shift in resources devoted to mental health care in Australia. Everyone agrees that more in the way of resources needs to be provided to a system which is plainly not coping with the demands upon it, but they do not agree on much more than that.

In this issue

Steve Matthews and Jeanette Kennett offer an ethical framework for the care of people with mental illness. Andrew McGee suggests one way of understanding what is wrong with a recently-advanced argument in favour of infanticide. Bernadette Tobin speaks of the need to recover our sense of our mortality.

And yet, funding and resourcing, though critical, form one aspect of mental health service provisions. Another aspect is the culture of care. It is important to focus is on how mental health clients are viewed and treated within the system that exists to assist them. We will suggest an evaluative framework based upon a model of what we call the *good human life*. Part of our motivation for focusing on the constituents of a good and distinctively human life is to provide a cooperative model for action. We think this approach may go some way to reconciling the sometimes conflicting views and interests, made vivid in submissions to the Senate Select Committee, between various professionals, carers, and consumer groups, on vexed ethical issues such as those related to denial of treatment, involuntary detention and treatment, and patient privacy.

While a number of groups quite correctly invoke a rights framework in addressing questions of resource allocation, access to health care, and standards of treatment and support for the mentally ill, we think that this approach has some drawbacks, particularly in addressing shortcomings *within* professional practice. We don't deny the existence or importance of fundamental human rights and their usefulness particularly as a baseline and check for public policy in relation to funding and access issues. Nevertheless, rights talk within the professional and service delivery context can quickly become adversarial, leading to defensive practice and even denial of treatment.

Take, for example, the regular complaint from carers and police alike of mental health crisis teams refusing to attend and assess crisis situations. Here the mentally ill person's right to treatment, the family's

right to safety and to proper assistance in caring for their ill relative, the community's right to safety, and the worker's right to safety can conflict and in many of these cases the worker asserts their rights over those of others. The proper goals of a mental health system may well be forgotten in this heated atmosphere. An adversarial relationship between professionals and other workers, carers, and patients is unhelpful, but many of the senate submissions we saw, as well as other research available to us, suggests that an adversarial, defensive culture is endemic in acute care settings. There are other contributing factors to such a culture but an emphasis on rights is not a promising way to address it. Within professional practice and service provision we thus think it best to bypass a rights framework in favour of a cooperative one that draws on widely shared views about the constituents of a flourishing human life. This is a model which can serve as the basis for a set of principles governing practice in all mental health services.

The Elements of a Good Human Life

Valuable lives are meaningful and fulfilling. How might we measure this value? One simple way might be to add up the well-being a person experiences moment-by-moment through their life, but this would fail to properly account for those goods which we hold to be most central to a flourishing human life – these are the goods we obtain in virtue of our capacities for anticipation, planning, commitment and meaningful relationships with others. Compare a life composed only of a series of short term, but on the whole pleasant, experiences and sensations, such as might arise from eating or bathing or being massaged or

listening to nice music, with a life in which the person, say, developed enduring, happy, relationships, was a hardworking and much appreciated committee member for the local hospital, wrote a well-received biography, and pursued a passion for gardening. Although there is nothing wrong with the goods in the first life, it is plausible to think more value attaches to the second. This seems plausible even if the second contained less of the short term experiential goods that the first contained. Certainly, the second person might look back on her life with greater satisfaction. Thus, valuable lives are those in which, in addition to one's basic needs for food, shelter, and safety being met, one also has the capacity and opportunity to enjoy distinctively human goods such as marriage and parenting, friendships, education and employment, and participation in a range of cultural, sporting, religious and political activities. It is these things, our projects and relationships, which shape our life story and our sense of self, our sense of being someone who matters.

It follows from this that an overarching goal of a good society is to provide the conditions under which its members may construct and enjoy such meaningful lives. A good society, then, must support the capacity of its members for autonomy, that self-determining capacity that allows us to take on long term projects such as a career or a marriage and fulfil the associated social roles. Autonomy involves the ability to deliberate and choose in accordance with our values, to plan, and to exercise control over our actions. But critically the capacity for autonomy is not something individuals possess and exercise in grand isolation. We are socially enmeshed creatures. Most of our projects and all of our relationships are engaged in with other people and require social

structures and social support for their success. A good society will see both the well-being and autonomy of its members as ethically central.

How Mental Illness Threatens the Good Life

Mental illness, especially when left untreated, poses a significant threat, both directly and indirectly, to the goods we have described as essential to a flourishing human life. There are a variety of reasons why a person with mental illness may suffer losses of goods such as education, employment, and close relationships. Some of these different reasons can be traced to features that are particular to the different disorders. So, for example, major depressive illness severely undermines motivation; disordered thought and speech, and hallucinatory episodes in schizophrenia may make it impossible to sustain attention to a project or to work cooperatively with others. In broad terms, recurrent or chronic mental illness often means that sufferers cannot rely on their future selves being appropriately affected by their present plans and decisions. Their projects are thus derailed or given up and they lose, temporarily or even permanently, the social roles that are so important to identity and self-esteem. Their losses are compounded by the reactions of those around them who shy away from socially odd behaviour, distress, anger, or unresponsiveness. The goods of close loving relationships may thus be lost or are unattainable. The stigma of mental illness cements social rejection and exclusion. The evidence is that experiences of social rejection and stigma have a negative effect on employment prospects, quality of life, self-esteem and social functioning of the

mentally ill even after controlling for the severity of psychiatric conditions. Directly or indirectly then, the symptoms of mental illness affect sufferers' capacities to access and enjoy a good human life.

Professional Practice and Service Provision

We argue that good practice must be guided by an explicit understanding of the personal, social, and moral goods which are placed at risk in mental illness. Unfortunately the multiple and depressingly similar stories from patients, carers and even some practitioners, of inadequate, unsympathetic, and damaging treatment in public hospital acute care settings and outpatient clinics indicate deep-seated attitudinal problems within these services.

While we recognise the strain on resources in the system and the contribution this makes to the unsatisfactory experiences of patients and their families, it seems clear that additional resources alone will not be sufficient to bring about effective, humane, and respectful treatment. Part of the problem is a near exclusive focus on medication in the public system. Such a focus seems to be aimed more at dampening symptoms and controlling behaviour than promoting a return to health and recovery of the self. It is an example of pessimistic defensive practice that takes no account of the patient's views of their own needs. The Senate submissions confirm other work done on patient perceptions of the treatment they are offered, for example:

Adrian: ...they're using what they call the medical model, which is basically medication and that's

it...there's more to treating illness than medication.

Ben: I was at the mental health ward at the hospital the other day. You're enclosed in a room you can't get out of and you've got a mattress on the floor... That's not going to make you better, that's not going to help you.

Tara: There was nothing in there that them nurses did except give us medication...and your doctor, like I said, ten seconds and away you go and don't dare try to get into something because you know you're not going to get time to finish it... we don't talk about the shit that needs to be dealt with. And it's not going to be overnight.²

The plea of these patients is for some decent interpersonal contact: to be listened to, to be seen and heard. As we have argued much of the suffering of those with a mental illness is indirect and is aggravated by the attitudes of others. Attitudes matter morally and a professional culture of pessimism, detachment, defensiveness, hierarchical and punitive approaches to patients is iatrogenic. Some protagonists argue that at the heart of the mistreatment is a failure to understand and respond to the patient as a person rather than a medical object. Mental illness is in a deep sense an attack on the self and the moral goal of treatment must be to restore the self, to restore the person's human capacity to make sense of, direct, and enjoy their own life. All of us need the support and recognition of others in order to effectively exercise our autonomy and access social goods, yet it seems that in the very circumstances where autonomy is most directly under threat, that recognition and support is hardest to

come by. There needs to be a fundamental cultural change amongst clinical mental health services, and this change needs to be governed by the values that we have outlined if the harms and ethically problematic practices and attitudes identified are to be addressed.

Changing the Culture: Adopting Shared Goals, Values, and Practice Guidelines across Mental Health Settings

The major good news story that came through from the Senate submissions we viewed is of the success of the work done by non-government psycho-social rehabilitation services which adopt a recovery focus. The principles articulated in these services fit with our account of the good human life and we argue that they should be adopted by all services including acute clinical services, as guides to practice, not as mere distant ideals. They should be supported by regular training for staff, staff support, monitoring, and advice. They include:

- *Fostering optimism and a recovery focus.* Research has shown that the chances of recovery are enhanced when the patient feels that someone believes in them. Once again, attitudes matter morally.
- *Client/patient-centred:* Client-centred approaches focus on the person's strengths and on building their capacities. It is responsive to their needs. It is non-judgmental. It invites patient participation in decision-making, eschewing top-down unnecessary professional shields and barriers. It requires

humility on the part of the professional and willingness to learn from the patient. Client-centred practices support and enhance the moral values of autonomy and well-being.

- *Relationship-based:* There is recognition that the relationship between professional and client forms the basis of treatment and rehabilitation and is valuable to both parties. There is a focus on the quality of relationships and interactions. The goal is patient engagement and the development of trust which positions the patient for the work associated with recovery.

We believe that guidelines based on these *cooperative* principles, if adopted and monitored, would benefit those working in the system as much as the clients of the system. Not only would they work to promote in the client the underlying values of the good human life we have emphasised here, they almost certainly would improve the quality of appropriate moral emotions – such as care, patience, understanding – that characterise the professional-client relationship. For, associated with the guidelines for practice will be a list of *professional virtues* which those working in the field should aim to develop and embody. Appropriate *expertise, empathy, optimism, trustworthiness, and honesty* would be high on the list and should be promoted in training and staff selection.

Pessimism begets pessimism and vice-versa. If mental health workers are given the chance to get to know their patients, and if they are encouraged to see each patient as a unique individual with a particular history and relationships, with

values, aspirations, likes and dislikes, quirks, strengths and weaknesses, and if they can develop a real sense of curiosity and interest and even wonder in the whole person in front of them, then they may even come to like them to the enrichment of both parties.

How Good Practice Can Help Resolve Ethical Problems

We finish with an indication of how practice which is genuinely governed by the values and principles we have outlined could help to resolve difficult ethical issues in the mental health field. Consider the issue of involuntary treatment. At the risk of simplification there appear to be two opposed camps on this question. Those who believe it may be justified, and this includes parents desperate to secure treatment for their children and fearful for their children's lives, as well as many clinicians, claim that although in general it is accepted that adults have a right to refuse medical treatment, an exception may be made in the case of some people with mental illness. This is the case where the patient is assessed as being a danger to themselves or others and if they are not competent to make an informed autonomous decision. The right to refuse treatment arises from the more fundamental right to autonomy. Where a person's autonomy is undeveloped or impaired it might be argued that the rights autonomy gives rise to, cannot be exercised. Non-autonomous beings (e.g., animals, infants, the severely intellectually disabled) don't have the set of rights arising from autonomy, and so decisions to override autonomy in the impairment case may take their cue from this example: involuntary treatment involves a decision taken by a responsible carer or

authority in another's best interests in case they are incapable of making such decision themselves.

The case against involuntary treatment is made by some patient groups and legal services. They point out that in a free society adults are entitled to make their own decisions even when it is manifestly clear that they make bad decisions. We all know people who regularly make foolish financial or romantic or health choices; but the *right* to autonomously choose even in these foolish ways outweighs the imprudence of the choice. Why, some argue, should those with mental health problems be treated differently? In addition there are many good reasons why psychiatric patients may refuse hospitalisation and medication: for example the trauma, stigmatisation and sub-standard in-hospital care (reported in many of the submissions we saw), and the debilitating side-effects of many medications, including effects on sense of self, cognitive capacity, sexuality and presentation. Treatment refusal may thus be rational. Indeed this group goes so far as to argue that when the ill person poses a direct threat to others they should be dealt with by the police and courts rather than by the mental health system.

Where should we stand on this question? Autonomy is not an all-or-nothing matter. It comes in degrees. We should think of it as akin to a dimmer on a light switch rather than the on/off switch. Even in severe mental illness the switch is rarely completely off, so even here the person is entitled to participate and be consulted about decisions made about their care and treatment. In this respect the suggestion by one consumer advocacy group for a model of assisted decision-making for those whose decision-making capacities are impaired has some merit

and is worth developing. Nevertheless it also has its limits when dealing with acutely ill people and those without any insight into their condition. The proposal by one group, familiar to readers of Thomas Szasz, that mentally ill people who pose a danger to others or otherwise offend as a result of their illness should be dealt with by the criminal justice system rather than the health system seems profoundly unjust. There is overwhelming evidence that prisons have already become de facto psychiatric holding institutions. The ethical dilemma posed by involuntary treatment is not resolved by exchanging one kind of detention for another and imprisoning ill and vulnerable people without treatment. Rather we should turn our attention to the *kind* of treatment provided to involuntary patients and indeed to all mentally ill people. If excellent, evidence-based, respectful, caring, treatment was provided, delivered promptly and in consultation with patients, with integrated follow-up and social support, then it is plausible to suppose that the need to impose involuntary treatment would diminish.

The development of decent therapeutic relationships is itself a direct contribution to patient autonomy. This is one of the lessons from the Orygen early intervention project for those at risk of psychosis at the Royal Melbourne Hospital which highlights the benefits of a model of engagement between professionals and patients that secures patient trust in the system and so lessens the likelihood of future treatment refusal and non-compliance. If mentally ill people were offered a standard of care which conforms to the recovery principles, some of the present objections to involuntary treatment could be seen for what they are

– objections to sub-standard care and ill-treatment rather than to involuntary treatment per se. Likewise, expert sympathetic care should remove the need for seclusion in mental health settings. The submissions make it abundantly clear that forced seclusion adds to the trauma experienced by patients and is perceived and sometimes used as punishment. Where patients feel valued and listened to, where the goal of interaction is the good human life, they are less likely to behave in the disruptive ways that might seem to call for seclusion.

Conclusion

To conclude, we have suggested here a shared ethical framework for the treatment of those suffering mental illness. Here, we have pointed to the importance of having a conception of the good human life and what is needed to attain it, as playing the guiding role in what the various stakeholders should aim for throughout mental health services, both in clinical settings and in ancillary services. The model we have described here is designed to elicit an accord between the various stakeholders in order to formulate good policy and good practice for the coming years.

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Steve Matthews is a Lecturer and Researcher at the Plunkett Centre for Ethics, Australian Catholic University. Jeanette Kennett is Professor of Moral Psychology in the Philosophy Department at Macquarie University. Originally published in *Res Publica*, 2005. Reprinted by permission.

There's no good argument for infanticide

Andrew McGee

Philosophers Alberto Giubilini and Francesca Minerva have received an avalanche of abusive comments and emails following the publication of their paper on "post-birth abortion" in a recent edition of the *Journal of Medical Ethics*. The response has been despicable but it shouldn't blind us to the flaws in the authors' argument.

As the journal's editor Julian Savulescu noted, their arguments "are largely not new and have been presented repeatedly ... by the most eminent philosophers and bioethicists in the world." But the discussion has continued because it's been notoriously difficult to prove the arguments wrong.

Giubilini and Minerva's argument is stunningly simple. There is no morally relevant difference between a foetus and a newborn baby, because their capacities are relevantly similar. Neither foetus nor newborn is really capable of forming any long-term aims. Only a person can form long-term aims - and this is what differentiates persons from most other species - so neither a foetus nor a newborn are persons.

The kind of harm that consists of preventing a person from achieving their future long-term aims is especially acute. It is the seriousness of this kind of harm that explains why killing is wrong. But since neither a foetus nor a newborn are persons, they cannot be harmed in this

way. If we allow abortion on this basis, we should therefore also allow infanticide.

Even many people who believe abortion should be permitted would reject the conclusion that killing a newborn baby should likewise be permitted. The challenge is to explain why the rejection of that conclusion is not irrational. That's what I will attempt here.

The wrong of infanticide

First, we need to broaden the notion of aims so it includes immediate preferences and desires. As any mother will attest, a newborn baby has immediate preferences and desires that he or she wants satisfied, such as the need to suckle the mother's breast. Why shouldn't these shorter term desires count equally to the longer-term preferences of persons?

The problem with that response, the argument runs, is that it would apply equally to many other species that we don't think twice about killing.

For consistency's sake, it is said, we must adopt the narrower concept of person favoured by the authors, or we are guilty of speciesism (and speciesism is as bad as racism).

What makes humans different from most of the animal kingdom is precisely our capacity to form long-term aims that can be quashed. This makes us capable of suffering a kind of harm that other beings

aren't capable of suffering. That's why it can be wrong to kill humans, but permissible to kill some animals.

But if we relax this criterion to include immediate preferences and desires of infants, then we have to give up killing animals and, on some views, even some insects. This drives the authors to assert that we do no wrong to a baby if we kill it.

Is there another way of approaching the problem? I think there is. We can deny the analogy between racism and "speciesism". There is something primal and instinctive about protecting our own flesh and blood, about the emotional bonds we form with them and the value we place on their wants and needs.

The authors might say: "So what? Why is that relevant? Emotional bonds and instincts have no place in moral discussion, for how we feel about a child doesn't tell us how we ought to feel about it." But the point is that there is a limit to the kinds of practices we can meaningfully subject to moral scrutiny.

Caring for our offspring is as much a natural fact about us as walking upright, so it makes no more sense to question whether we ought to do this than it does to question whether we ought to walk upright. True, there are occasions where the mother does not bond, but this is unusual. It does not mean that care for our offspring is not a fundamental feature of our humanity.

These natural facts can serve as the basis for the erection of moral norms, such as the norm that we ought not to kill our offspring. This is unlike racism, which is nowhere near as endemic or universal in human life as the instinct to care for our offspring.

But the authors might retort: infanticide has been more widespread in human history than it is today, and is still practised in some places. This might be true, but it is misleading.

In hunter gatherer societies, infanticide was practised out of material necessity of the kind we can only imagine today. If more young were born than could be suckled, or offspring with cerebral palsy were born, what could those societies meaningfully do? The options open to us today were not available in such societies. This should not be ignored.

We also should not ignore the level of ceremony and grief that accompanied the practices, which is an acknowledgement that if things could have been otherwise, the practice would not have been engaged in. So the practice of infanticide in the past doesn't mean that the instinct to care for our offspring does not run deep in us – so deep as to be beyond question.

This instinct leads us to erect the rule that it is wrong to kill our children. It explains why we care for their wants and needs, while not valuing the wants and needs of other species in the same way.

We can therefore accept the narrow definition of person the philosophers prefer, but conclude that it isn't the only determiner of value.

The role of emotion

Philosophers are prone to over-rationalising things. The emphasis on reasoning might blind them to its limitations, leading them to neglect the important role emotions play in our moral framework.

Consider the harrowing story of Dr Brian Hoolahan, a Nowra obstetrician who repeatedly witnessed babies taken for adoption from their unwed teenage mothers moments after birth, between the 1940s and 1970s: "I remember the girls calling out 'I just want to touch my baby, please let me see my baby' and they were crying and howling and it was the most horrific thing I've ever seen in my life." (Cited in *Sydney Morning Herald*, 28 February 2012).

Faced with this testimony, it is a bit easier to see why the value of a baby's life cannot be intellectualised in the way that philosophers would have it, and why capacities are not the only thing of moral importance.

The pain, anguish and unimaginable enduring grief these mothers suffered all go to show the meaning of having a baby in human life, the central place it has in our emotional make-up. These instinctive

responses to the birth of one's child are the sources of its moral value. It is senseless to ask if these mothers really ought to be having that kind of response to their children.

Not every mother wants their child. But this doesn't mean the child is of no value. The norm we have erected, based on the instinct shared by the majority of us, means we condemn such mothers if they seriously want to kill their babies.

Perhaps if the majority of us no longer wanted our children, we would abandon the norm. But that's not how things are.

Dr Andrew McGee is a Lecturer in the Faculty of Law, Queensland University of Technology, and a member of the Faculty's Health Law Research Program. This article is a slightly modified version of an article that was originally published at "*The Conversation*" online publication. <http://theconversation.edu.au/theres-no-good-argument-for-infanticide-5672> Reprinted by Permission.



We need to talk about death

Bernadette Tobin

Dr Peter Saul, an intensivist at the John Hunter Hospital in Newcastle recently said in a Tedx talk that he toyed with the idea of suggesting that the 'occupy' movement should focus on death rather than on Wall Street!¹

As he pointed out on that occasion, sudden death is now rare, and even death after a 'terminal illness' happens mostly to young people. Most of us will die at an old age, after gradual organ failure or as a result of the gradual dwindling of our capacities.

Medical successes of the last half century mean that, for very many of us, death will come after we have lost the capacity to talk to our doctors and to those who care for us about what we would want provided to us by way of medical treatment. And in an affluent country like Australia, where virtually everyone has access to advanced medical treatment, this will be a problem for most of us.

In fact those of us who die in hospital will do so after a decision has been made *not* to do something. That decision-making imposes great burdens, not only on the health care professionals (trained to save lives!) but also on the relatives who are consulted. Increasing numbers of us have no relatives to contribute to that decision making process, and because the decision making process is so stressful families are often unable to agree amongst themselves as to what it is best to do.

So we need to reclaim death, and to initiate conversations in our families about what we would want done for us as we approach death. The most valuable thing we can do is to identify the person we'd like to speak for us, should we become unable to speak for ourselves.

I recently heard of an elderly woman who had chosen her adult son rather than her elderly husband: 'Mum knew that you would not be able to let her go', the son gently told his father when the time came.

We also need to talk to the person we choose to speak on our behalf *so that he or she is strengthened for the task*. For it often comes as an onerous responsibility, especially these days when people so often think that "I want everything done for Mum (to prolong her life)" is the most effective way they can show their fidelity to that person.

As death approaches, indeed as frailty and disability set in, caregivers need to be confident that they are neither over-treating nor under-treating the people in their care. So they need to be able to talk to the person for whom they are caring or, more often, someone who can speak on behalf of that person. Prof Jane Ingham, of the Cunningham Centre for Palliative Care at Sacred Heart Hospice in Sydney, says: 'I need to be able to talk to *someone* I know the patient trusted.'

So identifying the person we'd like to speak for us, and talking to that person about what matters to us, what our

priorities and anxieties are, is something that we all need to do. In fact, I think we have a responsibility to have those conversations, a responsibility to the members of our family and to the community which makes such an array of treatments and forms of care available to us.

What about writing so-called 'living wills'? This is an alternative, and better than nothing. But it's now nearly ten years since the publication of a paper in the US which proved (conclusively, in my view) that written instructions simply don't work: few people have them; few people can predict their actual preferences accurately; few people can articulate their preferences clearly; and 'living wills' are often not available when they are needed.²

In addition, written instructions are not self explanatory; they need interpretation. The course of illness is unpredictable and a doctor needs to be free to provide good

care in the actual circumstances of a patient's illness as well as when unanticipated circumstances arise. Written instructions can tie a doctor's hands, privileging past wishes over the provision of reasonable care. So I say: let's not go for the bureaucratic solution of filling out yet more little bits of paper. Let's go for the human and humane solution: reclaiming death and death talk. The better we become at this, the more confident we can be about approaching death, our own and that of our relatives.

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Bernadette Tobin is director of the Plunkett Centre for Ethics, a joint centre of St Vincents & Mater Health Sydney and Australian Catholic University. Originally published in *The Health Advocate* June Issue 2012. Reprinted by Permission.

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The Plunkett Centre is a centre of Australian Catholic University and
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Tel: (02) 8382 2869

Fax: +61 2 9361 0975

Email: plunkett@plunkett.acu.edu.au

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Plunkett Centre for Ethics

St Vincent's Hospital

Victoria Street

Darlinghurst NSW 2010

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