
Bioethics Outlook

Plunkett Centre for Ethics

A joint centre of Australian Catholic University, St Vincent's Health Australia (Sydney)
and Calvary Healthcare

Volume 29, No 1 March, 2018

Daniel Sulmasy

Visiting Scholar at the Plunkett Centre

Daniel Sulmasy was recently Visiting Scholar at the Plunkett Centre. Professor Sulmasy, MD, PhD, is Senior Research Scholar and Andre Hellegers Professor of Biomedical Ethics with co-appointments in the Departments of Philosophy and Medicine at Georgetown. He also holds appointments at the Kennedy Institute of Ethics and at the Pellegrino Centre for Clinical Bioethics. In addition, he continues to practice medicine part time.

Dr Sulmasy's research interests encompass both theoretical and empirical investigations of the ethics of end-of-life decision-making, ethics education, and spirituality in medicine. He has done extensive work on the role of intention in medical action, especially as it relates to the rule of double effect and the distinction between killing and allowing to die. He has also made significant contributions to the philosophy of medicine and ground-breaking work on the logic of diagnostic and therapeutic reasoning. His work in spirituality is focused primarily on the spiritual dimensions of the practice of medicine. His empirical studies have explored topics such as decision-making by surrogates on behalf of patients who are nearing death, and informed consent for biomedical research.

In this issue

We sketch the various talks given by Daniel Sulmasy in his recent capacity as Visiting Scholar at the Plunkett Centre.

We publish Bernadette Tobin's submission to the 'Review of the adequacy of the protection of religious freedom in Australian laws'.

We outline new research to be conducted by Dr Steve Matthews and Dr Jeanette Kennett on how the moral agency and identity of people with dementia can best be respected.

Dr Sulmasy has served on numerous governmental advisory committees, and was appointed to the Presidential Commission for the Study of Bioethical Problems by President Obama in April 2010.

During his time in Sydney, Dr Sulmasy undertook a substantial program of teaching and engagement with fellow doctors and philosophers and with medical students.

How to analyse an ethics case

His first appointment was conducted under the auspices of the Clinical School at St Vincent's: he lectured on the subject 'How to analyse an ethics case' to the first year medical students at the University of Notre Dame. The lecture amplified the philosophical basis of such analysis, and then showed the medical students how that basis was relevant to day to day medical practice and could be applied in that context. He did this through the analysis of a case raising challenging ethical issues. The specific case involved a pregnant 15 year old Jehovah's Witness girl seriously injured in a motor vehicle accident, whose life was in danger and who was refusing a blood transfusion.

Through lively interaction with the students, Professor Sulmasy led the class to see how complex an in-depth ethical analysis needed to be and that while there were guiding principles the decisions that needed to be taken were complex and not straightforward. The lessons of his approach, especially about the need to take into account unavoidable uncertainty and complexity, should stay with these medical students throughout their professional lives as doctors.

Donation after Circulatory Death

At St Vincent's Hospital, Dr Sulmasy conducted Hospital Grand Rounds on the subject 'Organ Donation after Circulatory Death: Rationale, Justification and Cautions'. He canvassed the ethical issues associated with both donation and transplantation. Though these topics are related, they raise distinct issues.

Dr Sulmasy explained the three traditional ways of organs being made available by donation for transplantation (after so-called 'brain death', after so-called 'circulatory death' and from part or whole paired organs from live donors). He noted the recent return to an older way of donation: donation after 'circulatory death' where a decision has been made to cease life-prolonging support for a person – because continued treatment would be either futile (not genuinely therapeutic) or overly-burdensome – and the person's heart stops beating.¹ He summarized the ethical justifications for organ donation: the obligation to do good for the rest of the society ('beneficence') and the desirability of cultivating charitable giving to others and of altruistic putting others' interests ahead of one's own. And then he sketched a range

¹ In passing he alluded to the unethical practice found in the Netherlands of 'doing euthanasia' and then taking the organs. He commented that 'we ought not to engage in vivisection'.

of ethical concerns associated with donation including the distinction between the role of the Intensivist and that of the Transplant Physician or Surgeon (the decision to withdraw life-support must be independent of the decision to donate), the possibility of coercion, the importance of being certain about what the person wanted, the need for excellent palliative care, the timing of the declaration of death, certitude in the determination of death, the range of procedures which might be done before death to preserve the organs, and the rare but known phenomenon of survival after ventilator withdrawal. As he said, all of these concerns have to be balanced against the desire to help those with organ failure.

Dr Sulmasy then went on to discuss to discuss the ethics of transplantation.

- Mereology, the understanding of the relations between parts and wholes, is an important foundational idea. Though parts have their own metabolism, the life of a part (eg the heart) is not the same as the life of the whole. In death, the person ceases to exist as a unified whole. (This is significant given that an organ (for example, the heart) might cease to work in one person but be reactivated in another.)
- Different kinds of consent (active first person, anticipatory, valid surrogate consent) need to be distinguished and validated (and the proposal that consent might be presumed evaluated).
- Even though it is more important to be ‘certain’ about what the person would have wanted than what the family now wants, nonetheless family well being needs to be attended to.² The need for certitude regarding the ‘irreversibility’ of death requires an understanding of what it means to be certain in this context.
- The practice in the United States of some Transplant Surgeons wanting to ‘push the envelope’ with respect to pre-mortem procedures (which arises from a beneficent desire to benefit others) necessitates the working out of a sound way of distinguishing between ethical and unethical pre-mortem procedures. Dr Sulmasy argued that the test is: does a proposed pre-mortem procedure put the patient at risk?

He concluded by saying donation after ‘circulatory death’ is in principle justifiable and noble and that the real ethical challenges lie not in the ‘whether’ but in the ‘how’. The devil, he said, is in the details!

Frailty, Futility and Advance Care Planning

‘Frailty, Futility and Advance Care Planning’ was the theme of Dr Sulmasy’s interactive session with the Anaesthetists and their Surgeon and Intensivist colleagues at the hospital. In an informal discussion of a number of challenging cases, he recommended ways in which these three professional specialties might talk to each other about the appropriate treatment and care of patients they share. Everyone wants to find ways of improving patient care and avoiding treatment that is likely to be ineffective as a therapy or overly-burdensome to the patient. And everyone wants to find better ways of communicating with patients and their families.

² In New York, even though the family cannot override the patient’s written consent, transplant surgeons refuse to act in the face of family opposition.

The ethics of deactivating implanted cardiac devices

At his session with the Cardiologists, Dr Sulmasy's topic was 'Within you/without you: the ethics of deactivating implanted cardiac devices'. In this talk Dr Sulmasy addressed the current recognition that, as their patients age and suffer from worsening cardiac-related disorders and other terminal illnesses, cardiologists will increasingly have requests from patients or their families requesting deactivation of these wonderfully life-sustaining devices. As he argued, the ethical questions raise the broader set of questions about both the distinction between killing and allowing to die and the distinction between ethical and unethical cases of allowing to die. *All* killing of patients by doctors is wrong, and *some* allowing patients to die is morally permissible.

But in the case of these devices, further complex evaluation is required. Consider LVADs ('left ventricular assist devices'). Some think that turning off a ventilator is 'allowing to die' and therefore is sometimes permissible but that turning off a LVAD is killing and thus ought never be permitted. Dr Sulmasy argued that, though LVADs take over the function of the organ, they are not part of the patient (they involve external batteries, maintenance and dependence and they are not physiologically integrated into the person's body) and their deactivation is not killing. The central question is, whether, in a particular case, deactivation is morally permissible.³

Should we take away Hippocrates' Licence?

On Thursday 22nd March, Daniel Sulmasy delivered the Annual Plunkett Lecture entitled 'Should we take away Hippocrates' Licence? Professionalism, Conscience and Toleration in a Good Society'. In this lecture, he addressed the current claim that every doctor must perform every legally-permitted and medically-sanctioned intervention that he or she is qualified to perform upon a patient's request.

In order to show why he thinks this claim is unconvincing, Dr Sulmasy set out a series of 'conceptual clarifications' of the key concepts employed in the literature: conscience, conscientious action, professional judgment, conscientious objection, conscience clauses, civil disobedience and tolerance.

Conscience is often misunderstood as a little voice that 'tells' us what to do. Rather it is a two-fold commitment: to have and to hold fundamental moral principles and to act according to those principles. Of course, we have a duty to form our consciences appropriately: to take due diligence, to know the moral rules and to act on correct information. (Nonetheless, an erring conscience binds!)

³ Sulmasy, DP. 'Killing and allowing to die: another look', *J Law Med Ethics*, 1998; 26: 55-64

We need persons of conscience in all walks of life, but certainly in health care. Patients need to be able to trust their doctors, whose decisions have an inescapable moral (and not simply technical) dimension. Indeed the professional judgment of a doctor is informed by the internal morality of medicine: medicine is oriented to the good of the patient and ought to be undertaken conscientiously (that is, not influenced by financial or other personal gain or by such vices as laziness). Given the uniqueness of each patient's situation, wide discretion is necessary for the doctor. Practitioners will differ and insistence on uniformity would be counter-productive (which explains why good doctors bristle at the requirement to follow algorithms in their practice!).

In medicine there is widespread conscientious practice and, so far at least, no evident need for formal processes to assess conscientious objection (as exist in the military). Someone asks for a procedure. A doctor says "I don't do that procedure", and the person finds someone else. Thus do citizens respectfully work out their differences.

Tolerance for difference is not the belief that there are no right or wrong answers in ethics, but the belief that we care enough to argue precisely because we do believe there are correct answers to ethical questions. True pluralism is mutual respect for differences in our ethical views.

Should tolerance for difference be unlimited? No. Views or practices that are destructive to society go beyond the proper limits of tolerance. That said, doctors should be free not to participate in practices that are legally permitted. Neither the state nor the market should encroach too far on professional autonomy and, within the profession, there should be a wide berth for individual practices. It's good for doctors and for their patients that doctors argue with each other and so sharpen their professional judgment. It's good for doctors and their patients that doctors are able to specialize and limit the scope of their practice.

If the principle were that every doctor must perform every legally permitted and medically sanctioned procedure that they are qualified to perform upon patient request, then surgeons would not be free to refuse surgery simply on the basis of their assessments and tolerance for risk, Obstetricians and Gynaecologists would not be free to refuse to perform sex-selection abortions, Obstetricians and Gynaecologists would not be free to refuse to perform 'female genital mutilation' in nations where this is legal, and surgeons would not be free to refuse to perform plastic surgery on individuals like the "Bird Man" who wishes to look more like a bird.

Should tolerance be unlimited in medicine? No, but the bar for compelling behaviour should be set high. Sulmasy set out three criteria which would justify compelling behaviour:

- (1) the doctor's refusal would entail immediate risk of serious illness, injury or death;
- (2) the doctor's refusal is based on pure characteristics of the person and not on his or her attitude to a behaviour or practice (for instance, a doctor who refuses to perform

necessary surgery for a person just because that person is a member of the Klu Klux Klan); and

- (3) the doctor's refusal pertains to a *refraining from* action (ie, a higher standard is needed to compel someone *to do* something than to compel someone to *refrain from doing something*: so for example, compelling every doctor to *prescribe medical marijuana upon request* would be much harder to justify than compelling every doctor *to refrain from prescribing LSD*).

In summary, a good society will permit its doctors wide discretionary space in the matter of their professional judgments.

The last low whispers of our dead: thoughts on palliative sedation.

Dr Sulmasy's final talk was given at the 'work in progress' seminar of the School of Philosophy at Australian Catholic University.

Starting from the fact that about 15% of patients at the end of life are now being sedated (which is a far cry from Dame Cecily Saunders' view that it may be necessary to sedate a small percentage of the dying whose symptoms of pain are refractory), Dr Sulmasy analysed three putative 'justifications' for the practice of dissociating people from their consciousness at the end of life. In short he supported one of these justification (so-called 'double effect sedation') but opposed two (so-called 'proportionate palliative sedation' and so-called 'sedation to death'). This work will become part of a book on the philosophy of medicine was he is currently writing.⁴

To conclude

We were delighted to have Dr Sulmasy, and his wife Lois, with us for the two weeks. The Australian Jesuit Peter Steele once pointed out that original meaning of the word 'doctor' is 'teacher': Dan Sulmasy is a wonderful teacher!

⁴ Daniel Sulmasy is the author or editor of six books:

The Healer's Calling (1997), *Methods in Medical Ethics* (2001; 2nd ed. 2010),

The Rebirth of the Clinic (2006),

A Balm for Gilead (2006),

Safe Passage: A Global Spiritual Sourcebook for Care at the End of Life (2013), and

Francis the Leper: Faith, Medicine, Theology, and Science (2014).

He also serves as editor-in-chief of the journal *Theoretical Medicine and Bioethics*.

Religious Freedom Review

A submission from director of Plunkett Centre

I understand that the Panel is to examine and report on whether Australian law (Commonwealth, State and Territory) adequately protects the human right to freedom of religion. Examining whether specific Australian laws adequately protect this right involves assessing these laws against a general principle or standard or rule or 'instrument'.⁵

My submission sets out what I think the standard/principle/rule/instrument should be in a society which is deeply pluralist about religious belief, a society in which very many citizens take atheism or agnosticism as their default positions. Identifying this principle is a fundamental matter for the Panel to determine. It is more important than its determination about any specific law since it should inform its determinations about all laws.

The key to understanding the right to religious freedom is that freedom of religion should be understood not as a 'liberty right' but as an 'immunity from coercion'.

Religious freedom entails an immunity, of individuals and groups, from coercion in respect of religious belief and all those expressions of religious belief that are compatible with laws motivated exclusively by concern to uphold just public order.

This way of understanding the relation of religion to the state is found in the following documents, considered not merely as 'positive law' but as embodying an essentially political-philosophical idea:

(a) The US Constitution's First Amendment's protection of '*the free exercise of religion*';

(b) The European Convention of Human Rights Article 9 (1)'s guarantee that '*Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance*' (subject to the considerations of public order spelled out by Article 9 (2)); and

(c) The Second Vatican Council's Declaration on Religious Liberty which closely tracks the identification of the right to religious freedom in the European Convention but

⁵ In outlining this principle I draw on the work of John Finnis, in particular from his essay 'Religion and State' in *Collected Essays*, Vol 5, OUP, 2011

which more clearly identifies it as an immunity, of individuals and groups, in respect of religious belief, and all those expressions of religious belief, or other acts of putting one's religious belief into practice, that are compatible with laws motivated exclusively by concern to uphold just public order. Section 7 of this Declaration explains 'just public order' as respecting the rights of others, public peace and public morality.

On this view of the right to religious freedom, it follows that governments have the negative duty not to coerce religious acts unless these threaten the rights of others, public peace and public morality.

There is much in this principle that requires careful consideration, particularly its application in particular circumstances.⁶

That said, perhaps the element most likely to be debated is the idea that there is such a thing as 'public morality', and that ordinary Australians recognize any such thing. I submit that there is such a thing and that Australians do recognize it. Consider, for example, someone who chooses to urinate on the steps of a Parliament House. Or a couple who choose to have sexual relations in the same location. We can anticipate public disapproval on the grounds (which may not be made explicit) that these acts offend against public morality. This shows, I suggest, that ordinary Australians, implicitly if not explicitly, recognize and employ a distinction between private and public morality, and that they take protection of the latter at least to be an element of 'just public order'.

So I submit that, in order to determine whether Australian law adequately protects the human right to freedom of religion, the test to be applied is:

Does the law infringe the immunity from coercion that individuals and groups (should) have, when their expression of religious belief does *not* violate the rights of others, public peace or public morality? If it does so infringe that immunity, then the law violates the right to freedom of religion.

I am not able to make a general assessment of whether Australian law (Commonwealth, State and Territory) adequately protects the human right to freedom of religion.

However it seems clear that, if the Catholic Archbishop of Hobart's publicising of his church's endorsement of the traditional view of marriage, specifically that it is between a man and a woman, ran afoul of a Tasmanian law, then it is reasonable to conclude that that law constitutes a violation of his freedom of religion.

⁶ There is also controversy about what it means to call something a 'human right'. I take it that specifying the claim to a 'human right' involves three things: (1) the class of persons who has the right, (2) the interest of theirs that they have the right to respect for, and (3) the persons who have the duty of respect for that interest and the kind of choice that is required of them to fulfill that duty. So for example: (1) people who live within a jurisdiction, (2) have the right to protection of their lives, (3) by the state.

Whatever one's view of marriage, *publicising* the traditional view of marriage as between a man and a woman does not violate just public order. That is, though some may find that view of marriage not in accordance with their own view of marriage or distasteful, or false, or 'offensive', etc, *publicising* that view does not infringe the rights of others, public peace or public morality.

The objection to this view is that the Archbishop's publicising his church's endorsement of a traditional view of marriage violates another person's 'right' not to be offended. The state does have an interest in ensuring that offensive language does not undermine public order. On the other hand none of the documents referred to in (6) recognize a stand-alone 'right' not to be offended. Indeed I submit that there is no basic human right as a 'right not to be offended'. Basic human rights mainly concern safety, including safety from coercion.

There is much more to say about the proper relation between religion and the state. For instance, the state has a duty not to make subscribing to a particular religion a prerequisite for public offices or benefits, a duty not to seek to direct any religion by claiming a power to appoint its office-holders, etc.

And there is much more to say about religion. For instance, it should not be presumed that religion is to be contrasted with reason; it should not be presumed that no religious claim can add anything to what is established in moral or political philosophy, in natural or social sciences or social theory; etc.

All I have tried to do in this short submission is to propose a reasonable and reliable way of understanding the principle at the heart of the 'human right to freedom of religion'.⁷

Bernadette Tobin

⁷ It is worth noting the distinction between freedom of religion and freedom 'from' religion. The latter idea easily leads to forms of coercion in belief or practice.

Dementia, Moral Agency and Identity:

Respecting the Vulnerable

Dr Steve Matthews of the Plunkett Centre has recently embarked on a new research project entitled 'Dementia, moral agency and identity: respecting the vulnerable'. In this research he works with the philosopher Jeanette Kennett of Macquarie University. Drs Matthews and Kennett have been successful recipients of Discovery Grants from the Australian Research Council in the past: as a result their combined research has yielded ten refereed co-written articles and book chapters, a range of non peer-reviewed papers, submissions to policymakers/peak representative bodies, as well as media engagement. Their research will once again be funded by the Australian Research Council, a reliable sign of both the significance of the project and the outstanding ability of these researchers!

People with dementia face the hardship of progressive cognitive decline where negotiating everyday tasks cannot be taken for granted. In later stages of dementia basic elements of personality are lost, including even moral traits, and this affects the capacities of close others to respond to those in care as they used to.

The direct concern of Drs Matthews and Kennett is with moral questions raised by the effect of dementia on those important relationships that dementia threatens. They will focus on the moral psychology of dementia, on its effects on agency and identity, and on what can be done to maintain relationships and address impairments in this vulnerable group in a way that is both practical and respectful of their dignity.

They argue that an understanding of the ethical losses which dementia can bring will assist in the design of ethically well-informed, as well as cost-effective, supportive therapies and care. And so they will examine the threat dementia poses to agency/selfhood in ways that will refine and test some existing philosophical accounts of personal identity, narrative agency, and vulnerability, and they will provide analyses of the impacts of dementia on those who have the condition, their families and their carers. They will then attempt to establish norms for treatments that are both beneficial to, and respectful of, the experiences of those with dementia, their loved ones, and carers, and make recommendations about policies that best accommodate a well-informed understanding of the moral losses brought by dementia.

Their research will clearly address a significant ethical and social problem. It will show that there are many valued ways in which we can, and ordinarily do, engage with each other that do not depend on particularly high levels of autonomy or moral responsibility. In particular, the research will examine whether there is a version of the participant stance available to friends, relatives and carers that is sensitive to and builds on the individual's capacities for engagement and responsiveness, is interpersonally satisfying, and avoids the undermining of the dignity of persons.

Knowing how to respond to the effects of dementia both interpersonally and institutionally crucially depends on having an ethically informed position with regard to questions of autonomy, agency and vulnerability. In particular, knowing something about the retained abilities of those with dementia ought to inform approaches to treatment and to social interaction. Drs Matthews and Kennett will draw on the conceptual framework of Hilde Lindemann when she talks of 'holding one in personhood', meaning the use of an approach to treatment that aims at construction or retention of the self. (By analogy we do this in other contexts where care is prominent, such as in raising children.)

It is noteworthy that the ordinary physical abilities, certain know-how capacities, such as those for art, music, dancing, swimming, and other skilled actions of those with dementia can remain intact through cognitive decline. The preservation of these capacities has led the researchers to notice something quite startling: when such capacities are exercised under the right circumstances, some people with dementia experience temporary periods of cognitive revival. Dr Matthews has himself discussed the achievements of music therapy for people with dementia, an approach to dementia care that places a focus on the person rather than their illness. Instead of managing and controlling the patient, this approach tends towards engagement with the person – their qualities, abilities, interests and preferences. Significantly, it connects well with the intuition that it is just too hasty to conclude, as the philosopher Ronald Dworkin concluded, that we should make treatment decisions based on the idea that the competent person pre-dementia has moral authority over their life in virtue of a principle of autonomy.

REFERENCES

- Dworkin, R. 1993. *Life's Dominion*. New York: Vintage Books.
- Kennett, Jeanette. 2007. 'Mental Disorder, Moral Agency, and the Self.' Oxford Handbook of Bioethics (ed. Bonnie Steinbeck), pp 90-114. Oxford: OUP.
- Kennett, J and Matthews, S. 2005. 'Seeing the Self: The Moral Goals of Service Provision in the Mental Health Sector'. *Res Publica*.
- Lindeman, Hilda. 2014. *Holding and Letting Go: the social practice of personal identities*. Oxford: OUP.
- Matthews, Steve. 2015. 'Dementia and the Power of Music Therapy,' *Bioethics*, 29, 573-9.
- Matthews, Steve. 2016. 'Human Vulnerability in Medical Contexts.' (with Bernadette Tobin) *Theoretical Medicine and Bioethics* 37 (1), 1-7. 2016.
- Rowe, M. A.'People with dementia who become lost.' *Am J Nurs* 2003; 103: 32-39.
- Strawson, P. 2008. *Freedom and Resentment and Other Essays*. London: Routledge.
- Wolff, J. 2009. 'Cognitive disability in a society of equals,' *Metaphilosophy*, 40, 402-415.

Calvary Healthcare joins the renewed partnership between ACU and St Vincent's Sydney

It is with pleasure that we announce both the renewal of the 'memorandum of understanding' between Australian Catholic University and St Vincent's Sydney with respect to the Plunkett Centre and the formal participation in this arrangement of Calvary Healthcare. The new arrangement is for five years, from 1st January 2018 to 31st December 2022.

The Mission of the Centre is to promote the values of compassion and fellowship, intellectual and professional excellence, and fairness and justice. Its primary focus is on the realisation of these values in the provision and allocation of health care. The Centre expresses this commitment through research, teaching and community engagement, as these are informed by the Catholic tradition.

The objectives of the Centre are to deepen and advance knowledge and understanding of the ethical standards relevant to human health and well-being, and in particular to clinical practice, medical research, business and management practices, and the allocation of healthcare resources; to offer courses in philosophical ethics and in the ethics of healthcare provision, medical research and healthcare resource allocation; to engage and where appropriate to collaborate with local, national and international bodies as they seek to respond to their intellectual and ethical needs, and to foster collaboration on ethical matters between Australian Catholic University, St Vincent's Health, Sydney and Calvary Healthcare.

The Centre fulfils these functions by conducting and promoting research, providing research training and supervision, developing and teaching courses, conducting reviews of professional practice, providing an ethics consultation service, and participating in public discussions.

Calvary Healthcare have been a long-term friend and colleague of the Plunkett Centre. The Centre has had a consultancy arrangement with Calvary, and arrangement which is strengthened and formalized by their becoming a formal partner.

Bioethics Outlook

A quarterly bulletin of the Plunkett Centre for Ethics

The Plunkett Centre is a Centre of Australian Catholic University, St Vincent's Health Australia (Sydney) and Calvary Healthcare

www.acu.edu.au/plunkettcentre/ Tel: +61 2 8382 2869 Fax: +61 2 9361 0975

Email: admin@plunkett.acu.edu.au

Subscriptions: \$99 Institution: \$55 Individuals; \$27.50 Pensioners & Students