
Bioethics Outlook

Plunkett Centre for Ethics

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

Volume 25, No 2

June 2014

***"I just need to be able to talk to someone I know
the patient trusted!"***

**Why Catholic Health Australia
has prepared a new brochure for
advance care planning**

Bernadette Tobin

Some years ago I was lucky enough to be in the audience when an experienced palliative medicine doctor introduced a group of young doctors and nurses to the best ways of responding to the challenges of providing good medical care for people who are approaching the end of their lives. It was a wonderful class. She - I'll call her Dr Jones - had an exemplary grasp both of the proper role of a doctor in taking care of her patients at the end of their lives and of the difficulties for the patients - and their families - in these circumstances. One remark she made in the course of an hour and a half's lecture has stayed with me. Dr Jones was discussing the very-frequently-encountered scenario of caring for patients when they have lost the capacity to converse with her - unresponsive patients, or unconscious patients or cognitively-impaired patients - and she said: "I just need to be able to talk to someone I know the patient trusted."

In this issue:

We have inserted a copy of Catholic Health Australia's new brochure for advance care planning, and explained why we recommend it.

And Dr Frank Brennan, palliative medicine consultant at St George and Calvary Hospitals in Sydney, reflects on what the great American journalist, H.L. Menchen, would think of palliative care.

'I just need to be able to talk to someone I know the patient trusted.' So much is hinted at in that remark. Unpacking it fully would take a lot of time and space, and would repeat much of what has often been discussed in previous issues of *Bioethics Outlook*.

For instance: Medical successes mean that many more people die having lost decision-making capacity. In developed countries, virtually everyone has access to advanced medical treatment. The power of technology is so great that these decisions affect everyone: most people who die in hospital do so after a decision has been made *not* to do something. Planning in advance is useful because the burdens of decision-making fall largely on third parties, most of whom find it very stressful. Increasing numbers of people have no family to make decisions for them as they die. And sometimes family members cannot agree on decisions.¹

On this occasion, that is, on the occasion of the publication of *Catholic Health Australia's* new brochure for advance care planning², I want to draw attention to two things: that good health care at the end of life depends in crucial part on the doctor's being able to talk things over with someone who can represent (*re-present* !) the patient to her, and that the best person for re-presenting the patient to

¹ See D. Sulmasy. 'Advance directives as an extension of the tradition of forgoing extraordinary means of care', *Bioethics Outlook*, Vol 19, No 2, June 2008. See also B. Tobin. Advance care planning: purpose, instruments, use and misuse. *Bioethics Outlook*, Vol 23, No 3, September 2012.

² The brochure is downloadable from the website of Catholic Health Australia: www.cha.org.au

the doctor is someone who was trusted by the patient.³ Let us start with the first.

Why the doctor needs to be able to talk to a trusted person

Advance care planning is needed to ensure that two things happen: that the proper goal of medical treatment is being pursued, and the means for pursuing it reflect the judgments of the patient. Of course Hippocrates was right when he said that the goal of medical treatment was 'the benefit of the patient', but it is obvious that, depending on circumstances, what actually benefits the person may be one of a number of things: preservation of life itself, cure of an illness, stabilization of the person in a satisfactory condition, relief of symptoms, improvement of the dying process, etc. So getting the objective of treatment right is the first thing that matters, but just as important is ensuring that the means for pursuing the (appropriate) objective reflects the judgment of the patient (who, by hypothesis) is now unable to talk with the doctor.

Two illustrations. For some people being pain free matters more than being lucid (so they will accept modes of treatment which ease their symptoms at the cost of their being lightly sedated), for others the maintenance of lucidity is foremost (so they will want pain relief to be titrated with that in mind). For some people spending the last part of their lives at home with family is their first priority (so they may be prepared to forgo treatments available only in hospital), whereas others are content to leave that decision up to the family itself.

If the doctor is unable to talk to the person about whose care such decisions need to be

made, she needs to be able to talk to someone who can inform her of what mattered to the patient, what the patient 'would have wanted', to enable her to make good decisions about the patient's medical treatment.

However, many people do not realize that there is always someone authorized by law to have this conversation with the doctor. Indeed, this comes as a shock to some people, in particular to those who have thought that, unless they had specifically appointed someone to undertake this role, the doctor doesn't have to talk to anyone! Some people think that, unless they have purposefully and officially appointed someone to have their 'medical power of attorney', then no one has the authority to speak on their behalf. Other people assume that their family, or their 'next of kin', will fulfil that role. Others again just have no clear idea!

So it is worth noting that, in each state and territory in Australia, the law automatically gives someone the authority to speak on your behalf, to represent you, to *re-present* you, should you become unable to do so yourself.

Two questions arise. Do you know who that person is? Is that person the one you'd trust to speak on your behalf?

Do you know who your (automatic) representative is?

To find that out, you need to know the method by which the law has identified that person and, since that varies from state to state, you need to know the law in your own state or territory. To give an example. In New South Wales, the law requires the doctor who wishes to provide treatment for you (when you are not able to decide for yourself) to talk

with and obtain consent from the person it calls your 'person responsible'. The law then sets out a hierarchy of people who automatically fulfil that role. If you have appointed a 'guardian' (or if a guardian has been appointed for you by the Guardianship Board) and that person has been given the medical consent function, then that's the person. If you have no such 'guardian', then your spouse (including de facto spouse or same sex partner who has a close and continuing relationship with you) fulfils the role. If you have no such spouse or partner, then the carer or person who arranges care regularly for you and is unpaid fulfils the role. And if you have no such person, then a close friend or relative can fulfil the role.

This, as I say, is how things work in New South Wales. Each state has its own set of arrangements. You need to find out the arrangement which obtain in your own state or territory.

Is your (automatic) representative the person you'd trust to talk to the doctor?

Given that the law automatically authorizes someone to re-present you to the doctor, it is important that that person be the person you would trust to fulfil that role.

Generally, this is unproblematic.

If you have gone to the trouble of appointing a guardian with medical consent function, then it will be obvious that you want your doctor to speak with that person. (I heard of a woman who, because she thought it would be just too onerous a responsibility for her husband, appointed her adult son instead. When the time came, the son explained to his

father: ‘Dad, she knew you would find it just too hard to let her go.’) If you have not done so, then it is reasonable for the doctor to assume that she may talk with your spouse, etc. Nonetheless, this is worth checking out: that the person you would trust the doctors to talk to about your medical treatment towards the end of your life is the person who has that authority automatically: if they are two different people, then you need to formalize the appointment of the trusted person of your choice as your guardian with power to make medical decisions.

Your trusted person needs help

Once you have ensured that the person who is your representative is the person you would trust to talk on your behalf, then it is important that you make sure that that person is well-informed about your beliefs and priorities, about your ‘wishes’. For your trusted person needs some guidance from you, in advance, to make it easier for him or her to give advice to the doctors, make decisions on your behalf, etc. He or she needs to understand what you would have wanted. And that will not be easy unless you have given that person some help.

This is where *Catholic Health Australia’s* new brochure comes into its own. It prompts the right kind of discussion to have *now* with your trusted person and it leaves the trusted person with the right kind of guidance for making decisions in the future. It gives that person the clues they will need to make decisions which are faithful to you, and it gives them those clues without rigidly binding them to ‘directions’ which may not be appropriate in the actual circumstances in

which they have to make decisions. It gives them the kind of flexibility they will need if they are to help the doctor make decisions which are appropriate to the proper goals of medicine as well as true to your wishes.

And so.

In this edition of *Bioethics Outlook* we have included a copy of *Catholic Health Australia’s* new brochure.

Remember that it has been designed to encourage you to help the person you trust to speak to the doctors on your behalf should you become unable to speak for yourself. It has been designed to ensure that, should it not be possible for the doctor to elicit your beliefs, priorities, wishes about medical treatment at the end of your life directly from you, then it will be possible for the doctor to talk to someone you trusted enough to prepare for this responsibility.

This may well be one of your last opportunities for generosity, for realizing how hard this may be for your spouse, your children or your friends, and so giving them some help in advance.

I recommend to you *Catholic Health Australia’s* new brochure.⁴ For as Dr Jones said:

‘I just need to be able to talk to someone I know the patient trusted.’



⁴ For the sake of transparency, I should add that I had a hand in its development.

Bring on the Angels – H.L. Mencken, Death and Palliative Care

Frank Brennan

If H. L. Mencken were alive today, he would pass his polymath eyes over the world and, perhaps sooner than later, rest on the profession of medicine. Those eyes, trained in satire, would pause irresistibly over such practices as liposuction and vitamin infusions. Finally, after scanning the specialties, his eyes would come to settle on Palliative Care.

It would intrigue Mencken that doctors specialize in this area. Not because it would appal him. The opposite would be true. Mencken, the great journalist and writer, who for decades taunted the comfortable and the complacent in American life, would applaud Palliative care. He would admire its origins, the tenacity of its founders, its sweep of interest from the physical to the spiritual, and its annoying habit of reminding the rest of the medical profession that all humans are ultimately mortal. Mencken, the truth teller, the *fool* in *Lear*, the missile-launcher of words, the brilliant curmudgeon would love Palliative Care.

Henry Louis Mencken was born in 1880 and died in 1956. He was the most famous newspaper columnist of his time. Genial, sceptical and formidable. His essays ranged over culture, politics, religion, the

law, medicine and literature. He admired Emerson, Whitman and Poe.

He despised cant in all its forms. His accounts of the fourth-yearly ritual of the nominating conventions for presidential candidates were classics of insight, clarity and humour. One admirer said: *Mencken was 'a man to whom the English language was green pasture to romp in.'*ⁱ

Romp in it he did. He once described New York City as 'that third-rate Babylon,' defined a Judge as 'a law student who marks his own examination –papers' and Puritanism as 'the haunting fear that someone, somewhere, may be happy. One of his many life-long rules was 'Never accept a drink by day, or refuse one by night.'

Little escaped the attention of the sage of Baltimore. Including death and the prospect or otherwise of an after-life. At the very time American society was becoming enamoured of medical advances, promising to hold back death, Mencken wrote about it openly. Characteristically, in his essay *Exeunt Omnes*,ⁱⁱ he approached the subject from an almost playful angle: *Go to any public library and look under 'Death: Human' in the card index, and you will be surprised to find how few books there are on the subject.*ⁱⁱ

He described, 'after much weariness', discovering one book that encyclopaedically documented various theories, thoughts, literature, and art on the subject of death. Mencken is impressed but not satisfied: *One idea, however, I did not find in it: the conception of death as the last and worst of all the practical jokes played upon all mortals by the gods. That idea apparently never occurred to the Greeks, who thought of almost everything else, but nevertheless it has an ingratiating plausibility.*ⁱⁱ

Mencken points out the distinction between the noble death of myth and the reality: *The hardest thing about death is not that men die tragically, but that most of them die ridiculously. If it were possible for all of us to make our exits at great moments, swiftly, cleanly, decorously, and in fine attitudes, then the experience would be something to face heroically and with high and beautiful words. But we commonly go off in no such gorgeous, poetical way. Instead, we die in raucous prose – of arteriosclerosis, of diabetes, of toxemia, of a noisome perforation of the ileocecal region of carcinoma of the liver.*ⁱⁱ

Mencken also points out that deaths from chronic conditions have a preliminary phase of change and deterioration: *The human tendency to make death dramatic and heroic has little evidence in the facts.....A man does not die quickly or brilliantly like a lightning stroke; he passes out by inches, hesitating and, one may almost add, gingerly.....*ⁱⁱ

Mencken found another book. It stated that death was acidosis. He paraphrased the author: *He said that death was caused by the failure of the organism to maintain the alkalinity necessary to its normal functioning.*ⁱⁱ

Mencken received this revelation with delight: *...in the absence of any proofs or any argument to the contrary I accepted this notion forthwith and have cherished it ever since. I thus think of death as a sort of deleterious fermentation, like that which goes on in a bottle of Chateau Margaux when it becomes corked. Life is a struggle, not against sin, not against the Money Power, not against malicious animal magnetism, but against hydrogen ions.*ⁱⁱ

Having pondered the topic and fortified by the experts Mencken describes the process of dying: *.....the abdominal acidosis sneaks upon us, gradually paralysing the adrenals, flabbergasting the thyroid, crippling the poor old liver, and throwing its fog upon the brain. We pass into the blank unconsciousness of infancy and the into the blank unconsciousness of the prenatal state and finally into the state of undifferentiated protoplasm..... the dying man doesn't struggle and he isn't afraid, As his alkalis give out he succumbs to a blest stupidity. His mind fogs. His will power vanishes. He submits decently. He scarcely gives a damn.*ⁱⁱ

Naturally, Mencken's death was completely different. At the age of 68 he suffered a stroke. He lay in hospital. A friend described him, semiconscious, raising up in an oxygen tent to say 'Bring on the angels'. Cruelly, for this gifted man of letters and ideas, the stroke left him unable to read. For 7 years he lived a twilight existence. He slowly tried to relearn to read but was not able. A fellow journalist said 'He could see and he could talk, pretty much as he had always talked, with sass and pungency and scornful humour.'ⁱ

As a child, he discovered a love of literature – through *Huckleberry Finn* – but lost any faith handed down to him. From that time, he was

a nonbeliever. Near the end of his life, he was challenged by a friend about his atheism and asked what he would do if, upon dying, he discovered there was an after-life. Mencken replied that if he did indeed 'fetch up beside the Twelve Apostles, I should simply say to them: Gentleman, I was wrong.'

On the night of January 28, 1956, H.L. Mencken bade his brother good night and went to bed. He turned on the radio to listen to his beloved classical music. It was a programme of Beethoven, Bach and Mozart. Famously, he once summed up the work of Johann Sebastian Bach in the single metaphor: 'Genesis 1;1'. Later that night, he died in his sleep. In his will he asked for a simple funeral with no 'whooping and heaving'. His family and friends complied.

H.L. Mencken and Palliative Care

In his writing, Mencken was never iconoclastic for its own sake. He was acerbic but never destructive. His motivations were less to ravage than illuminate. He looked at ideology, pomposity and hypocrisy as worthy of healthy investigation. Similarly, from its inception, the discipline of Palliative Care dared to look at 2 very uncomfortable truths – that the fundamental needs of patients with life – limiting illnesses and their families were not being adequately met and that those needs extended beyond the physical to the emotional and spiritual. If one commences with the premise that the sole role of medicine is to cure and preserve life, Palliative Care stood from inception with an altogether different view. The iconoclasm of Palliative Care was intrinsic to its foundation. Palliative Care, like Mencken, looks upon death with clear eyes. It begins with a simple premise – all humans are mortal. From that premise it moves to a simple question – if death is

inevitable, how is the period leading up to and including death to be dealt with? If death is altogether human rather than mythical, what is the appropriate human response to its challenges? If the response is nihilism or abandonment then suffering is compounded by inaction. If the response is a concentrated, holistic approach to all the needs of patients and families, then some measure of good is restored. Yes, we all die. But, if care is performed meticulously, dignity can trump suffering.

The other aspect of Mencken's insight is his recognition of the duality of death – that death can be both tragic and absurd. All health professionals recognize this truth. The most delicately constructed preparation for death can be interrupted by the unexpected, the humorous, or the bizarre. We are human beings all the way until our death and, as such, are subject to all the vagaries of our personalities and idiosyncrasies. Equally, the endless variations of the physical nature of death constantly challenges the routine and the predictable. No death is predicable. All deaths are unique.

Whether tragic or absurd, or both, death is universal. H. L. Mencken, in his writings and his own death, can teach us important lessons. Whether patients face the triumph of hydrogen ions or the faces of the Twelve Apostles, each will do it in their own way. The science of death is one thing. The spirit of death is altogether broader.

This article was first published in Am J Hosp Palliat Care, December 2011 vol. 28 no. 8 573-575. It is reprinted with permission.

Footnotes

- 1 Cooke, A. *Talk about America 1951-1968*, New York, NY, Penguin Books, 1968:113
- 2 *Smart Set*, December 1919. In: Cooke A, ed. *The Vintage Mencken*. New York, NY: Vintage Books; 1956.

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