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Ethics in the Context of Age, Dementia and Palliative Care

This is an edited record of the presentation given by 2013 Senior Australian of the Year Professor Ian Maddocks at the Centre's conference held on palliative care on 3 October 2013. Professor Maddocks reflects on the challenges which ageing brings – challenges which we face as individuals, as health professionals, and as a society. There is wisdom which comes only from generous commitment and long experience. Many people recognised that wisdom in this presentation.

Thank you very much for inviting me to this conference. I have found palliative care meetings to be different from other meetings. People are moved and inspired by the opportunity to work with people who are facing terminal illness. It seems to evoke a friendly and serious atmosphere of sharing. I sense that happening here.

What is Ethics?

Ethics was not much discussed when I was a medical student, 60 years ago. When, 50 years ago, I asked a family practitioner to raise, with students in Papua, issues of importance for a private practitioner, he could cheerfully say: "Then there's ethics. Ethics is easy. Leave the sheilas alone and don't rubbish your mates: that's all you need to know about ethics."

He was reflecting *mores*, agreed customary behaviour, which is quite different from Ethics. At that time it was a fair representation of the *mores* of the Medical Profession: to ensure that doctors stayed within the law, and kept the reputation of the profession safe. Has it changed? Perhaps only slowly.

About 40 years ago, Davis McCaughey, first Moderator of the Uniting Church of Australia, delivered a sermon considering medical ethics. He drew on a quotation from Dickens in *Bleak House*, but for his purpose, changed 'lawyers' and 'clients' to 'doctors' and 'patients', so that the passage became: "let patients in hospitals once clearly perceive that the grand principle of medical care is to make business for doctors at their expense, and surely they will cease to grumble." Perhaps we should ask, therefore, whether greed as a guiding principle has infiltrated the Medical Profession.

Common teaching about ethics considers the headings set down in the left two columns of Table 1 (on page 2). I have added an additional column, with three words that seem to me to embody the meaning of these ethical concerns in human terms:

I am suggesting that ethics is primarily about a relationship between people that embodies trust and

respect. Palliative Care promotes 'Patient-Centred' or 'Person-Centred' Care which affirms the same values. Another term, suggested by Thomas Kitwood, pioneer in dementia care, is 'Presence'. Being 'present' with a patient means attending with a knowledge and respect that fosters a trusting relationship. That is more important than Rules and Guidelines. It is constructed with sympathy, interest and concern for the totality of that individual, an understanding of that person's history, culture, context, relationships, fears and hopes.

How Relationships Change Us

Relationship creates something different from the sum of individual parts participating separately.

The interdependence of the many parts of creation is a theme of Process Theology. It might be illustrated at the simplest level: 'I experience the tree; the tree experiences me.' I enjoy its shade, the freshness of its foliage; the tree also experiences me: I compress the ground over its superficial roots; I breathe carbon dioxide into its atmosphere.

The Patient *with the* doctor is different from each apart – the behaviour of both will change. Patients change when in hospital, which is a strange environment, one where they are subjected to special talk: 'Hop up here, dear; hop down now' (as Polly Toynbee described in her book

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ETHICAL PRINCIPLE	CONTENT	COMMENT
Autonomy	Consent, Rights, Information	Relationship, Respect, Trust
Beneficence	Outcome, Doing good	Relationship, Respect, Trust
Non-Malevolence	Do no harm	Relationship, Respect, Trust
Justice	Equity, Fairness	Relationship, Respect, Trust
Fidelity	Keeping Promises	Relationship, Respect, Trust
Veracity	Communication, Telling Truth	Relationship, Respect, Trust
Confidentiality	Keeping Secrets	Relationship, Respect, Trust
Privacy	Dignity	Relationship, Respect, Trust

Table 1: Rephrasing Common Ethical Principles in Human Terms

Hospital). It is helpful if staff experience being patients. In *The Beatitudes*, an Arizona care home for dementia, staff are invited to experience being bathed, teeth brushed, sitting in wet diaper – feeling what a patient feels.¹

Relationship requires time, and time has become a very precious thing. We're living in a world where time has changed. It used to come in big pieces. Once we actually read books; now we read abstracts. We used to have long conversations. We used to express ourselves in letters; now you'll be sending text messages. Time is now measured in tiny little pieces, and tiny pieces of time are not appropriate for building relationship. That needs space and time. And that constitutes a reflection on the nature of evidence. We're very much into evidence-based care. Evidence is commonly based on things you can measure – that can be reduced to numbers, put down in a single sentence, or a couple of words. But the evidence needed about a patient is their whole story: it's very difficult to encompass in a single paragraph.

Stephen Leader, in a recent comment in the MJA, under the heading *Love in the time of Cancer*, bravely wrote of love as an important component of care: “We should not balk at exploring the meaning of love as a sustaining motive in our care — manifest through our professional activity — in this age.”² I look for evidence that love has attended the care we offer: it will be a challenge to measure, but it can be felt.

Relationship between two things creates something which is different from either of them. Both of them change. And when the patient is with the doctor, each of them changes.

Suffering-Centred Care

Pacientia: Suffering (from the Latin root *pati* = to suffer) is the origin of many of the words important in care, such as: patient, passion, patience. We might recast palliative care’s favourite phrase ‘Patient-centred’ as ‘Suffering-centred’. A healer needs to consider the many latent depths of suffering. Ethical practice will reach into those depths to assist or relieve suffering, and will recognize that it is unethical to allow unnecessary suffering.

There has been litigation in the United States challenging

doctors who have failed to treat pain properly. If we have not treated suffering well, we are not doing our job.

Toby Minyintiri Baker is an Ngangkari (traditional healer) in the APY Lands in South Australia. Aboriginal communities know about suffering; their suffering has extended from the time of the invasion of their country. Toby works with his own people, using his healing hands with understandings from past millennia to relieve suffering among his people, and to prepare them for going on to conventional health care, strengthened by the spiritual power of his traditional insights.

It is a real challenge to work with somebody who comes out of a completely different culture. Our understanding of Aboriginal culture and people remains extraordinarily poor.

One of the things that my wife Diana and I were able to do in Papua New Guinea was move to live in a village outside Port Moresby for six years so that we could achieve a better understanding of the world from a Papuan point of view.

Ethical Issues for Society

There are several ethical issues currently prominent:

- The use of the social media where people share much personal information, and some individuals share images or messages that show no respect.
- The use of the Electronic Health Record, and how to keep it safe. Your Health Record in the wrong hands could be a problem. For example, insurance companies might use this information to increase your premium.
- Government surveillance: all the material being gathered into data bases: what are they going to use it for? They're looking for terrorists - but they are also looking at me and you.
- The question of refusal to submit to public health programmes such as immunisations, and whether that right of autonomy may stand when it can affect others.
- Tele-health: Technology now allows two-way video that might have potential to provide surveillance of elderly persons living alone. But there is also potential for all kinds of problems, I think. You

remember George Orwell's *1984*? 'Big Brother' could look in on you and keep you under his control.

- We live with the imperative of what's possible, doing things because we *can* do them. I sometimes say to students: "If you send a patient to a surgeon, he's going to operate, because that's what surgeons do." And as new things to do are invented, they involve more expense for individuals or for society – there seems no end.
- Requirements for recording consent have become more stringent. Defense against litigation, a real problem in the United States, is mounting here. Fear of litigation distorts thinking, and focuses on recording everything, taking us away from the patient.

Attitudes to Ageing

There are issues relating to ageing that have ethical dimensions:

- Traditional veneration of age is being eroded; while devaluing of the aged is becoming widespread.
- The demographic realities of increasing aged populations are well recognised, but there's little action or consideration for how their needs will be met.
- Changes in the patterns of illness of elderly persons presents us with multiple chronic diseases needing a lot of drugs and a lot of care, very costly for everybody.
- The question of responsibility for what is happening to us as we age: whether it's our responsibility or somebody else's to look after us.
- The writing of Advanced Directives as a necessary preparation by individuals and families for potential future crises.
- The great enthusiasm for assisted suicide among certain groups of the elderly. They seek its availability so it could be available if they want it.

Traditional societies valued the aged. In our six years in Papua New Guinea we made elderly friends who were important people in the village. Igo Ovia knew all the old stories. It is a verbal culture; he had its oral history absolutely together, and out it comes in full unhesitating cadence, on and on, and it's just lovely to listen to. Those legends told of what really mattered in the village. Guba Rahobada was a great fisherman, and he could stand on Taurama Peak tell the canoes: "Go that way, the fish are there." He knew. And Legu Tom, lifting a large tuna from the net, recalls the story that about eight generations back a Pari woman called Igua Vaina gave birth to five tuna fish. She was by the water so she released them into the sea and they would come back to feed at her breast every day. Her husband could see that something had happened: she was no longer big. He followed her one day, saw the fish come when she called them by breaking a stick. So he went after, broke a stick, took one of the fish home and cooked it. Igua came back from the garden and said, "What's that you're cooking?" He said, "Oh, fish." She said, "That's one of my children." He said,

"Well, why didn't you tell me?"

And so she went back to the sea and she called the fish again and she said, "Go out into the open water and only come back if men make a net who have not slept with their wives, then they may take the tuna." And so, to harvest the fish, Pari men knew they must keep the taboos, do it properly. Then the tuna would swim into the net, and be lifted out. I saw this happening. But now it's all gone. Along with the loss of old rituals, the old people have lost importance, because the songs they knew and the rituals they undertook don't have any importance in the modern city.

Responsibility for the Costs of Care

Our population structure is changing, raising the question of who will provide the finance and the physical support care for the huge numbers of elderly that can be predicted.

Many mature-aged people cannot afford health insurance, and the health care costs that they are asked to underwrite are burdensome for them. Is paying for illness a public or individual responsibility? Some will say, "It's your own business; society shouldn't be expected to provide health care for you." We are lucky to have the Government support we receive in Australia.

To put it another way: who owns your illness? How much do you handle it yourself, how much to hand over to a professional? Our elderly population absorbs quite a large amount of health care costs. And some people say, "Well, this is not really fair. They've had their time." If discounting age, you may also wish to discount people with dementia or people from a different minority group. Some people ask: Do they really deserve all that cost?

... I've written some things for my own family. It says, I want to stay at home if possible. And if you can find the funds to make sure I am able to stay at home, do that; but if you can't or it goes on too long, you can put me into a nursing home.

Some people see Advanced Directives as paternalistic, encouraging people to write out instructions future for care. Review of the life situation and decision-making of someone coming towards the end of life, is a continuing process: you've got to be there, available ready to respond, because things change. You will need to recast what your hopes are for yourself.

I've written some things for my own family. It says, if I'm competent, I want to make my own decisions, but I will share them with you all. If I'm not competent, I want you to do these things for me, and I've written down what I feel I want. I want to stay at home if possible. And if you can find the funds to make sure I am able to stay at home, do that; but if you can't or it goes on too long, you can put me into a nursing home. It might change: for example, I might get a disease that looks as though it's killing me, but then I get better. That is hard to anticipate, and

sometimes causes quite a lot of trouble. One person admitted to Daw House Hospice clearly was dying, but got better. We said, "Look, I think you could go home" - but the kids had sold the house already.

In 1984, Governor Richard Lamm of Colorado said to the aged, "You've got a duty to die and get out of the way. Let the other society, our kids, build a reasonable life."³ And Daniel Callahan, the ethicist at the Hastings Center, wrote a book called *Setting Limits* back in the 1980s.⁴ There are arguments for getting the aged out of the way: "They've had a good time. They should retire gracefully. It costs a lot to keep them alive. And they're an emotional and physical burden."

... We have a personal responsibility to prepare for a healthy old age giving attention to a healthy diet, regular exercise and social engagement. At the same time we must accept that to live and die is a fundamental mark of the human condition ...

Daniel Callahan wrote a later editorial which was a little more restrained, but he says – and I think he's right – that justice and unrestrained progress are no longer compatible because we are inventing so many new ways of doing things that are quite expensive - like the new drugs for cancer - and only the wealthy will be able to afford them. He suggested that the goal of reducing mortality - of giving people a longer life - is a very inadequate goal, and palliative care opens a way for a better balance between life and death, between curing and caring.⁵

Ethical Issues for Ageing Individuals

We have a personal responsibility to prepare for a healthy old age giving attention to a healthy diet, regular exercise and social engagement. At the same time we must accept that to live and die is a fundamental mark of the human condition. A palliative approach will affirm a hope for what St Francis of Assisi called "most kind and gentle death." In conversations with those people who are facing final days, we are faced by our own acceptance of death, how far we are prepared to say, "I will be ready. I will try to be ready." There's a personal ethic as well as a public ethic: the idea of dealing with one's own ageing, taking responsibility, being prepared to change.

"Don't send me to a nursing home" is a common elderly wish. I want to say to my family that if that seems to be the sensible thing, well, for goodness' sake, send me to a nursing home. Many people will want to defer decision-making: "I don't need that yet! I'm not ready for that" A willingness to accept dependence and the need for help is appropriate, but many will bargain; deny change; extract a promise, "Never to put me into a nursing home."

Who decides? There's a lot of range of possibility of who can participate in decision-making in crisis situations. We have the patient, the family, the doctor, the team, the lawyer, and finally the court if no

consensus can be reached. And of course it is a process much influenced by the culture you come from. There are cultures in which the eldest son is going to make all decisions. Culture also influences how it's told to you. And of course individual competence will influence who decides.

How important is consent? Well, it used to be hardly at all: the doctor just did what he wanted to do. Now we are required to provide copious information, but I contend that giving the patient a handout with pages of the things that could go wrong with the drug that you've been prescribed or the procedure you face is not the same as having the right conversation within a respectful relationship. Information just written down is frightening sometimes. It is not helpful to give too much information: "Look, I didn't take that drug because I read all the things it could do to me."

Whose fault is it, if the patient fails to follow instructions? In a study from the Institute of Medicine in the United States, people with limited literacy skills had difficulty. 26% didn't understand when their next appointment was; 42% didn't know what 'Take on an empty stomach' means; and 78% were worried about all the warnings on the prescription information that they were given. So we need to come back to relationship and communication, and communication includes respect of where the patient is, what the patient's competence is, what the patient's background is, what the patient's supports are.

Autonomy needs many qualifications when considering how much you can rely on a patient to make a proper decision for themselves, but it's what we aim for.

Issues of Justice

Medicine has considerable justice issues. Australia spends a huge budget on anti-cancer drugs – and often an expensive treatment offers no more than two to three months' survival. What is that worth compared with palliative care? What's its clinical value? What's its dollar value: how much is this going to cost? What's its social value - in terms of what it does for the community's attitudes and so on? Can we offer equity of access? Is it really necessary? Justice issues also apply in palliative care, which began concerned primarily with deaths from cancer. Now we have to now think much more broadly, extending our concern into all areas of need, particularly in aged care.

Autonomy and Coping

I like this quotation from Ivan Illich:

Man's consciously lived fragility, individuality and relatedness make the experience of pain, of sickness and of death an integral part of his life. The ability to cope with this trio autonomously is fundamental to his health.⁶

Illich applauded the individual's autonomous ability to cope, to have control in the face of threat and disaster. I

claim that control is a central component of health. One of the things I recognized in the village was that people knew that if I couldn't make a patient better, it must be due to sorcery. And they knew what to do with sorcery. They had control in that situation. I came to recognize that to know what to do is very important in maintaining your health - to understand your illness as well as possible, to know whom to approach, to know where you can get care for your needs. We do not give that enough significance in our care of people - we should offer them better opportunities to control their situation themselves.

That sense of control must extend beyond the purely physical issues of illness. Arthur Kleinman, a neurologist-cum-sociologist followed doctors around and looked at their behaviour and their words in treatment situations. And he talked with patients about the meaning of illness: what does it mean for you to be ill? He suggested that a focus on the meaning of illness:

may even liberate sufferers and practitioners from the oppressive iron cage imposed by a too intensely morbid preoccupation with painful bodily processes and a too technically narrow and therefore dehumanizing vision of treatment.⁷

Issues in Palliative Care

Palliative care is a bit different from other areas of health care. Autonomy is diminished; it is not always clear what will be best in this situation, because there are inconsistencies and changes through the course of the illness. The family may have their own ideas, not always the patient's ideas, and it may be unclear what is the right thing to do. In team work, there is a risk of sharing secrets that can erode confidentiality. Some of the private things that have come up in discussion may be ventilated by a team member to show how close they are with the patient.

Other palliative care issues include:

- The question of truth telling, especially where the family say, "Well, don't tell him."

I like this quotation from Edmund Burke about telling the truth:

*Falsehood and delusion are allowed in no case whatsoever, but as in the exercise of all virtues, there is an economy of the truth. It is a sort of temperance, by which a man speaks truth with measure, that he may speak it longer.*⁸

Don't load patients with the whole truth, all at once. "How much do you want to know?" and "Wait: there's more to be said. We'll come back to this." I think that's quite a good principle in terms of telling the truth.

- The various procedures that we could do or not do, depending on what the patient wants, where the patient's at, how close to death they are, and so on. It's a judgment.

One example is whether giving fluids is going to be useful or not. Dr Joanne Lynne is an ethicist in the United States. She wrote:

When a patient with advanced dementia refuses to eat, that person is dying. Artificial measures, particularly if offered in uncomfortable ways, are entirely inappropriate.

If you're demented and you refuse to eat, you're dying. Accept it! So if the patient is from the Mediterranean area, and the family says, "If he doesn't eat, he'll die," you say, "He's dying. He's dying. He doesn't need to eat."

- Whether it's necessary to move in and treat a particular discomfort or infection.

Sir William Osler talked about pneumonia as the old man's friend:

Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short and not often painful illness, the old man escapes those cold degradations of decay so distressing to himself and his friends.⁹

- Whether sedation will make dying faster or just more comfortable.

... I am suggesting that ethics is primarily about a relationship between people that embodies trust and respect. That is more important than Rules and Guidelines. It is constructed with sympathy, interest and concern for the totality of that individual, an understanding of that person's history, culture, context, relationships, fears and hopes ...

- How to assess pain in the unresponsive patient or the demented patient.

Jenny Abbey has looked at how you might assess pain in dementia, and has developed an assessment tool that is quite useful. Those who are bathing the patient, feeding the patient, turning the patient, are the ones who can give the best assessment. The doctor standing at the end of the bedside can't do this. The doctor must talk with the staff, enhance their confidence in reporting, interact with those who are closely involved in care. Part of the joy of palliative care is working alongside staff who are doing the bedside work. The nurses will say, "This is why I did nursing. I love this work." And it's really lovely to be there together - the patient, the family, the nurse and me.

- The question of writing orders of 'Not For Resuscitation.'

Back in about the late 1980s, a meeting in the Flinders Medical Centre was discussing resuscitation. At that time, to avoid futile resuscitation you wrote in the

notes: 'Not for 4111.' 4111 was the number to bring the resuscitation cart. And I had this flash of insight, and I said to the meeting, "Look, this is ridiculous. This is a coded message written by a doctor. We've got to do better than this." And I made up a template of good palliative care orders, and it would go something like this:

I have discussed the situation of patient XX with him, with family members PP, YY & ZZ, and with staff members QQ, RR & SS. We have agreed that management shall be directed to the provision of good palliative care, with emphasis on dignity and comfort, and that in the event of further deterioration, resuscitation measures will be inappropriate.

There is an open, combined, cooperative written statement in the notes. And we're heading towards that. We still don't try to get everybody onside. We talk to the patient or the family, and then we write down: 'Comfort care only; don't resuscitate; and so forth.' I think we can still do better. And certainly, stop using codes.

- Advance Directives and advance care planning.

Looking ahead and sharing options and hopes is not limited to palliative care; it is something for everyone to give thought to, and the sooner, the better.

- The whole question of prognosis: "How long have I got, Doctor?"

I never try to give people a figure. I say, "Just hang in. We'll ask again. See how it goes. I can't tell you: I'm always wrong."

Euthanasia

The issue of voluntary assisted suicide remains topical.

There are difficulties in writing legislation, in giving clarity to matters such as:

- Whether an illness is 'terminal';
- Whether a discomfort is 'unbearable';
- Whether treatment for depression is necessary;
- How long the individual is expected to live;
- Whether the individual is competent to make a major decision;
- Whether there is pressure from the family;
- The doctor's intention when a prescription for comfort *might* accelerate death.

The examples from The Netherlands and Switzerland need understanding. I am unhappy about the option of flying off Switzerland and having your euthanasia overnight as a human right. Philip Nitschke is still active and I expect that legislation will continue to be actively pursued. Nitschke gets some very enthusiastic responses from cheerful and cheering old people. He is entertaining, and he tells them how they can do it for themselves, and they like to know this. Virtually all of

them will do nothing about it. But his message, widely supported is, "It should be available."

I see a considerable risk that the demands of our aged care population who are not getting good care may well keep pushing a demand for euthanasia legislation. If in fact you are a very needy, aged person in an aged care situation which is not going well, family may well say, "This is ridiculous. We've got to get out of this." I understand that. We must advocate for much better care in aged care: euthanasia is no answer for poor care.

Issues for Health Professionals

Those who work in aged care and palliative care face these professional issues:

- Coping with not having clear answers. That's very much part of palliative care; we live with uncertainty in our work with our patients. We cannot be sure just what tomorrow or the next week is going to be like.
- Being clear about our own values, and to know something about our own sense of conscience, what values we would want to be recognized for espousing.
- And of course there are always behind us legal issues related to death certification, but legislation in recent decades has cleared the way for confidence in offering comfort care even if it risks a hastening of death.

Palliative care tends increasingly to search for evidence to guide its management, and does not enough, I think, rely sufficiently on the intuitive relationship that we have with our patients. Albert Einstein made a comment relevant to evidence: "The rational mind is a faithful servant" but "the intuitive mind is a sacred gift."¹⁰ Where do we get our intuitions? What makes us know that something is right, deserves to be preserved and to be upheld?

People used to fear hell. I don't think that's very common these days. More common, perhaps is a sense of an afterlife. This is John Donne:

*One short sleep past, we shall wake eternally,
And death shall be no more; death, thou shalt die.¹¹*

I think most or many of my patients will not have the triumphalism of Donne's certainty, but a sense that "I'm going to see Mum again" is common - a vague awareness of something beyond us that we may be headed for. They don't know - nobody knows - but there is this sense of something. It's not necessarily religion. It's tucked in, as a little side effect of our culture somewhere, that we hope there is something afterwards. And this can be entirely secular.

Conscience remains important in facing uncertainty, and reports of those who have followed their conscience remain inspiring. In 1534, Sir Thomas More refused to swear to the Act of Succession and the Oath of Supremacy demanded by the King. His companions urged him to go along with them, and accept the Oath, to visit it with them, for 'fellowship'. We might say he was

being encouraged to follow *mores* – what you do with the crowd - rather than conscience.

In a representation of the time, Sir Thomas replies, “*And if I do, and you go to Heaven for following your conscience, and I go to Hell for denying mine, will you visit me, for ‘fellowship’?*” He was committed to the Tower, found guilty of treason and beheaded on 6 July 1535. His final words were: “*the King’s good servant, but God’s first.*”

For a final consideration of conscience and faith, I return to Davis McCaughey: His text for the sermon touched on earlier was Matthew 6:25: *Is not life more than food? And the body more than clothing?* In the same passage: *Which of you by being anxious can add one cubit to his span of life?*

McCaughey’s concluding words were a reassurance to those who might experience anxiety in the face of difficult ethical decisions:

Receive life from God as a gift, not a threat. Then you will be freed from anxiety. The decisions you make may be difficult, they will certainly not be simple. They need not make you anxious. For whether you make them right or wrong, or as is common among men, a mixture of right and wrong, your future and the future of the human race is in the hands of God, the Lord, with whom belongs the issues of life and death.

ENDNOTES

¹ Rebecca Mead, “The Sense of an Ending,” *The New Yorker* 20 May 2013; *The New Yorker*, http://www.newyorker.com/reporting/2013/05/20/130520fa_fact_mead?currentPage=all

² Stephen Leeder, “Love in the time of cancer,” *Medical Journal of Australia* 199, no. 9 (4 November 2013): 567.

³ “Gov. Lamm asserts elderly, if very ill, have ‘duty to die,’” *New York Times* 29 March 1984, *New York Times*, <http://www.nytimes.com/1984/03/29/us/gov-lamm-asserts-elderly-if-very-ill-have-duty-to-die.html>

⁴ Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* (Washington, D.C. Georgetown University Press, 1987).

⁵ Daniel Callahan, “Justice, Biomedical Progress and Palliative Care,” *Progress in Palliative Care* 8, no. 1 (2000): 3-4; reproduced at International Association for Hospice and Palliative Care, <http://hospicecare.com/about-iahpc/publications/ethical-issues-2/other-publications/justice-biomedical-progress-and-palliative-care/>

⁶ Ivan Illich, *Medical Nemesis: The Expropriation of Health* (New York: Pantheon Books, 1976), 107; available on-line at Scribd, <http://www.scribd.com/doc/20783309/Medical-Nemesis-The-Expropriation-of-Health-1976>

⁷ Arthur Kleinman, *The Illness Narrative: Suffering, Healing and the Human Condition* (New York: Basic Books, 1988), 9.

⁸ Edmund Burke, “First of Letters to a fellow MP,” (1796), quoted in Ian Maddocks, Bruce Brew, Heather Waddy, and Ian Williams, *Palliative Neurology* (Cambridge: Cambridge University Press, 2005), 14; on-line at <http://f3.tiera.ru/1/genesis/570-574/571000/1748b2457dea12893184141fed0e6559>

⁹ Sir William Osler, *The Principles and Practice of Medicine*, 4th ed. (New York: D. Appleton and Company, 1901), 108.

¹⁰ While this quote is often attributed to Einstein, it has not been located in any of his writings. A more likely origin for this quote is Bob Samples’ 1976 book *The Metaphoric Mind: A Celebration of Creative Consciousness*. For more on this, see “The Intuitive Mind Is a Sacred Gift and the Rational Mind Is a Faithful Servant,” Quote Investigator, <http://quoteinvestigator.com/2013/09/18/intuitive-mind/>

¹¹ This is from John Donne, “Death, Be Not Proud (Holy Sonnet X),” *Poetry Genius*, <http://poetry.rapgenius.com/John-donne-death-be-not-proud-holy-sonnet-x-lyrics#note-1808957>

by Professor Ian Maddocks ✕

Emeritus Professor Ian Maddocks AM was named 2013 Senior Australian of the Year for his pioneering and ongoing commitment to palliative care. He was Professor of Palliative Care at Flinders University 1988-1999, and after retirement has continued consulting in palliative care at the Adelaide Cancer Centre. He was in Papua New Guinea from 1961 to 1974, where he was appointed Foundation Dean, Faculty of Medicine, University of Papua New Guinea in 1971. He was a Vice-President of International Physicians for the Prevention of Nuclear War when it received the Nobel Prize for Peace in 1985.

Nine Observations about Advance Care Planning

This is an edited record of the presentation given by Revd Kevin McGovern, Director of the Caroline Chisholm Centre for Health Ethics, at the Centre’s conference on palliative care on 3 October 2013. It explores the processes, challenges and benefits of Advance Care Planning. It also argues that Advance Care Planning will change the provision of health care significantly.

1. It’s a Revolution

My first point about Advance Care Planning (ACP) is that it’s a revolution. In other words, ACP calls us to make very significant changes in the way in which health care is delivered. There will be much more consultation with patients and their families, and these conversations will be ongoing. For many people, there will be fewer medical interventions aimed at cure, and more

interventions reflecting a palliative approach that will manage symptoms and maximise quality of life. These are very significant changes. And they will affect many, many areas of health care.

It must be said that this sort of change is not easy. It’s not easy for health professionals. Health professionals have developed their own way of doing things, and ACP asks them to change these established patterns. Indeed, it also asks them to do something which takes more time

and is harder than the established practice. An experienced clinician recently observed that it “takes about one minute” simply to send a patient to intensive care, but it takes “about two and a half hours to have a proper discussion with the medical teams, the patient and the family.”¹ These are also difficult conversations which raise hard topics – topics like the limits of what health care can do, hard topics like dying and death. These changes are also not easy for health care institutions. Institutions must develop policies and effective procedures for ACP. They must provide education and training. They must develop mechanisms to store ACP information, and ensure that this information is accessible and indeed that it is actually used whenever necessary. Over time, too, institutions must continue to embed ACP within their institutional culture, so that ACP becomes standard practice. Finally, ACP is not easy for patients and for their families, because it does ask them to confront those hard truths like sickness and suffering, dying and death.

... At the heart of Advance Care Planning is facilitated decision-making. This involves a dialogue between the patient and their health professional ...

Patients and their families do not always find it easy to raise these matters with their health professionals. Even so, study after study has demonstrated that most patients and most residents in aged care facilities expect that their health professionals and carers will raise these matters with them, and that these carers and health professionals will then guide them through the process of ACP. For this reason, it is not satisfactory for a health professional or an aged care facility to wait until patients or residents raise the question of ACP. Patients and residents expect that their health professionals to take the initiative, and health professionals should strive to satisfy this legitimate expectation.

There are many advantages to ACP. A randomised clinical trial at a Melbourne hospital in 2010 demonstrated this. ACP significantly increased the percentage of patients who were very satisfied with their hospital stay. Among those who did die, it significantly increased the percentage of patients whose end-of-life wishes were both known and followed during their final illness. Those families whose loved one had undertaken ACP were also significantly more likely to be very satisfied with the process of their loved one’s dying and death. In those families whose loved one did not undertake ACP, somewhere between 15 and 30 per cent of family members in the 27 families studied experienced significant stress, serious depression or severe anxiety either as their loved one died or in the months afterwards. But in those families whose loved one did undertake ACP, there was not a single family member in the 29 families studied who experienced high levels of stress, serious depression or severe anxiety.²

What type of revolution is ACP? From the perspective of the health professional, it is a Copernican Revolution. In

the sixteenth century, Copernicus stated that the sun does not revolve around the earth, but instead that the earth revolves around the sun. Sadly, in health care, for all sorts of reasons, it can sometimes seem as if health professionals are the centre of the universe, and patients have to revolve around them. Health professionals need to get through the day, not wanting it to be too complicated. Perhaps without really realising it, they therefore expect their patients to conform to the ways that things are usually done. But ACP challenges health professionals to recognise that they are not the centre of the universe; and instead of expecting their patients to revolve around them, they must learn to revolve around their patients, their patients’ values and wishes, and what are truly their patients’ goals of care. In this respect, ACP truly is a Copernican Revolution.

2. Facilitated Decision-Making

At the heart of ACP is facilitated decision-making. This involves a dialogue between the patient and their health professional, and this process cannot really succeed unless both the patient and the health professional play their proper roles.

The process of ACP begins with the patient speaking about their current state of health, and their understanding both of their medical condition and the likely trajectory of their condition. They also speak about their values and wishes. For example, are they someone who believes that every last thing must be done to preserve life, or do they believe that treatment may be refused if it is either futile or too burdensome? Do they want treatment which might keep them alive for their granddaughter’s wedding, or do they want treatment which will keep them comfortable and allow natural death to occur? The health professional should ask questions of clarification, and offer medical and other information which the patient may not have. From all this, the patient must make decisions about their future care. Significantly, however, the health professional does not simply sit there and wait for the patient to decide. Instead, they facilitate the patient’s decision-making. This requires that they attend not only to the patient’s process of reasoning, but also to their feelings and emotions, and indeed to many other aspects of their life-situation. The health professional should not of course decide for the patient, but it is very important that they help the patient to decide. Indeed, when it is appropriate, they may even respectfully challenge some of the patient’s initial choices.

There are of course some patients who do not need the facilitation of a health professional. But most of us do need this facilitation. And most of us are more confident about our decisions if we have received the counsel and facilitation of a health professional.

As a general rule, the patient’s family or loved ones should also be present for the ACP conversation. They too have their part to play in the dialogue which is ACP.

I should also note that the conversation of ACP is

ongoing. It should be renewed at regular intervals, and also if there is a significant change either in the patient's life-situation or their medical condition. Thus, for example, the conversation about ACP should be renewed every 6 or 12 months, or if a significant person in the patient's life dies, or if the patient is readmitted into hospital or their health deteriorates.

3. Conversations and Paper

Some record of these conversations is necessary. I've called these records 'paper,' but nowadays these records are just as likely to be electronic records in a computer. Indeed, as the Personally Controlled e-Health Records become more common, many people will store their ACP records there.

My point here is to remind us of the correct balance which should exist between the conversations of ACP and the paperwork which records the conclusions from these conversations. Good forms are necessary, but we should be very clear that other things like good procedures for ACP practice and good training for staff are even more important. It would not be sufficient if a health institution simply gave an ACP form to patients or residents without any process whereby a trained health professional met with them and their family, and helped them through the process of making decisions about future care.

ACP is more than 'tick-a-box.' It is more than 'fill-in-a-form.' It is an ongoing conversation which facilitates decision-making about future care. It is important that records are available which capture the conclusions from these conversations. But the reductionistic tendency which reduces ACP to little more than these bits of paper must be resisted.

4. More about Paper

One of the questions which should be asked in an ACP conversation is this: "If in the future you were not able to make your own health decisions, is there someone you would want to speak for you?" It could be your spouse; it could be your daughter or son; it could be a trusted friend. There are forms to capture these decisions. In Victoria, one such form is the *Enduring Power of Attorney (Medical Treatment) Form*.³

There are of course many excellent reasons why someone might appoint someone other than their closest relative as their substitute decision-maker. For example, I know one man who has not appointed his wife to speak for him. He reasons that if he is dying, she is likely to be distressed enough already without having to make end-of-life decisions for him. Or again, I know another woman who recognises that substitute decision-makers sometimes have to be a bit assertive either with pushy family members or over-zealous health professionals. Because every member of her family is a bit quiet and unassertive, she has chosen an assertive friend as her substitute decision-maker. All these decisions should be recorded on an appropriate form.

What if someone has not completed one of these forms and they become unable to make their own health decisions? In these cases, Victorian law allows for the automatic appointment of a substitute decision-maker. It's really the lawmakers trying to guess. Because the person has not expressed a preference, the lawmakers try to guess the most appropriate person. The first choice is the person's spouse or domestic partner, provided that the relationship is close and ongoing. If there is no such person, the second choice is the person's unpaid carer. Victorian law then has a list of other relatives, and the order in which they should be selected.⁴

Other people want to record their values and wishes. Or they want to record either treatments which they definitely do not want, or other treatments which they definitely do want. There are many ways to record these things. One way is to ask your health professional to make a record in your medical record. Or indeed, someone could even write a handwritten message on the back of a used envelope, and this could be legally acceptable if it was appropriately dated, signed and witnessed. There are other forms which can also record these decisions. One important question is whether you want your decisions to be legally binding, or whether you want them only to guide your health professionals and substitute decision-makers. Because we can never know for sure that the future holds and what might or might not be appropriate, I think it is better as a general rule not to be too directive, and instead to trust that your team will make the right decisions for you. But I can also see that there are some situations in which a legally binding directive might be appropriate.

We are also recognising the value of forms which are specifically tailored to specific diseases. Someone with cancer may face different decisions from someone else with end-stage renal disease. Or someone who is frail and elderly may face different decisions from someone who struggles with mental health issues. There is therefore merit in trying to design forms which best capture the sorts of decisions which someone with a specific condition may have to face. In the long term, I suspect that we will have a suite of forms for a variety of conditions.

Finally, in Victoria, there is a *Refusal of Treatment Certificate*.⁵ This form is used when someone wants to refuse a certain type of treatment during their current bout of illness. Because our decisions may change, this form ceases to bind after this bout of illness passes. If the person becomes sick again, they must fill in another *Refusal of Treatment Certificate*.

5. Realistic Goals for Advance Care Planning

Some people seem to think that ACP is little more than just filling in a form. Related to this view is another view that everyone in Australia should have completed an Advance Directive saying what to do if they are ever unexpectedly either in a car accident or struck down by an unexpected illness.

This might be possible in an ideal world. In practice, however, more realistic goals need to be set. So let me offer a view of what is practical and realistic:

I suggest that we divide people into four groups, with different aims for each group. The first group is those who are in reasonable health. A realistic goal for this group is that they appoint a substitute decision-maker, and that in some way they give their substitute decision-maker some guidance as to what their values and wishes might be.

A second group is those who have developed a serious and chronic illness (e.g. diabetes, a heart condition, or dementia). It is even more important that they appoint a substitute decision-maker, and provide some guidance about their values and wishes. They should be encouraged to learn about the likely trajectory of their disease, and what this might mean for their life-plans. Is there anything on their bucket list which they should be trying to achieve as soon as possible?

There is a trigger question to identify the third group. It is this: “Would I be surprised if this person died in the next twelve months?” If the answer is no, such a person should be helped to put a number of things in place. A person in this situation does need a substitute decision-maker. They need to speak with their substitute decision-maker about their values and wishes. They need to learn about likely disease trajectories, and what these might mean. They need to reflect on their bucket list, and perhaps to try to achieve some things as soon as possible. They probably should also consider such matters as treatments which they either want or do not want, and to record these decisions perhaps even in a legally binding directive.

The final group is those for whom death is imminent, that is, people who are likely to die in the next 48 or 72 hours. By this time, we hope that the plans are already in place, and that these plans will help to guide treatment over the last days of their life.⁶

6. Challenges for Institutions

Many institutions are currently involved in developing their own approach to ACP. I am involved in ACP working groups in three health institutions. From that perspective, let me note some of the challenges which institutions face:

To be frank, the first challenge is not to feel overwhelmed. Especially at the beginning, there can seem to be many different things to do, each of which is quite demanding. I do not want to minimise the challenges, but I believe that slow and gradual progress is indeed possible in this area. Most health professionals are favourably disposed to ACP. Some are therefore ready to help as ACP programmes are developed; while many more will be very receptive when these programmes are rolled out. It is also useful to network, and to seek advice and resources from other institutions. And this is a good area for continuous quality improvement, doing what is possible now as the next step on a long-term journey of steady improvement.

What are some of the tasks? Clear and effective written policies and procedures must be developed. Regular education and training in ACP must be provided. Patients and residents must be given information about ACP, including how to access trained staff to facilitate their decision-making. There must also be processes which do not wait for patients and residents in an aged care facility to take the initiative, but which instead offer ACP to patients and all residents in a planned and ongoing way. Forms and records are also needed to record ACP decisions, along with information systems to store these records and to enable access to these records in a timely manner whenever they are needed. Is an institution able to communicate ACP information to other institutions if, for example, an aged care resident is taken to hospital? Is there a planned process of audit, as part of a planned programme of continuous quality improvement? The ultimate aim in all of this is to embed ACP within our institutions so that it simply becomes standard practice.⁷

7. Cultural Competence

In our multicultural society, there are many different standards which influence ACP:

The legal standard is that a competent person may refuse any form of medical treatment at all.

By contrast, Catholicism preserves the traditional morality which informed Western civilisation at least until a few hundred years ago. This ethic distinguishes between ordinary and extraordinary means of sustaining life, holding that people should not refuse ordinary means, but may refuse extraordinary means. Treatment is judged to be extraordinary if it is either futile or too burdensome. And treatment may be too burdensome if it is physically too painful, psychologically too distressing, socially too isolating, financially too expensive, morally unacceptable, or too distressing spiritually.⁸

Some traditions within Judaism have a profound appreciation of the value of human life. They will not permit the withholding or withdrawing of any form of life-sustaining treatment. For them, every possible intervention must be done in order to preserve human life.

Hinduism, Buddhism and some of the other dharmic religions hold that the state of mind of the dying person influences their rebirth in their next life. Because they want to be aware as death approaches, those who hold to these religions may refuse sedation and some forms of pain medication in order to remain conscious.

Jehovah’s Witnesses refuse blood transfusions. Sikhs may refuse medical treatment if it requires the shaving of any of their hair.⁹

In 2006, the National Health and Medical Research Council (NHMRC) published *Cultural Competence in Health: A guide for policy, partnerships and participation*. They defined cultural competence as “a set of congruent behaviours, attitudes, and policies that come together in a system or among professionals and enable

effective work in cross-cultural situations.”¹⁰ Because of our cultural diversity, the NHMRC insisted that cultural competency is vitally important in Australian health care.

Cultural competency is also vitally important in ACP. ACP programmes and ACP practitioners must have some understanding of the diversity which exists within this multicultural nation. More than that, as ACP practitioners we must positively value diversity. For example, we must encourage those from diverse religious traditions to contact their own religious practitioners and to seek guidance from them as they engage in ACP. Over time, too, ACP practitioners should also develop a database of religious practitioners, at least for those religious traditions which they regularly contact. This allows appropriate referral and consultation as part of the ACP process.

8. Difference Blindness and Cultural Safety

Cultural safety is defined as “an environment that is safe for people: where there is no assault, challenge or denial of their identity, of who they are and what they need.”¹¹

Some health practitioners say that they treat everyone the same. But if I am truly different, you should not treat me as if I were the same as everyone else. This failure to recognise my difference is called difference blindness. If I am different and you are blind to this, you do not provide me with a place of cultural safety. I will experience your failure to recognise my difference as an assault, challenge or denial of my very identity. And if this identity is an important part of who I am, this assault, challenge or denial can be deeply hurtful and very serious.

In the previous section, I spoke of cultural competence and of the need in ACP both to recognise and to value diversity. This section speaks to the shadow side of this reality: if ACP practitioners do not recognise and value my difference, they do not provide me with a place of cultural safety and in some ways they threaten my very identity.

9. Coming to Terms with Sickness, Dying and Death

I remind you finally that underneath all this is our fear of sickness, dying and death, and the existential challenge to come to terms with these realities. It is this fear which causes many people to resist ACP, or to think that we should do every last thing to hold back sickness, dying and death. Sadly, in far too many cases this can mean that dying people are given treatments which are extremely burdensome and which ultimately prove to be futile. On the other hand, ACP is one step on the journey of coming to terms with sickness and suffering, with dying and death.

I do not want in any way to deny that all these things are hard. Sickness is hard. Dying is hard. The approach of death can be hard too. And all these things are hard for the patient, for their family and friends, and for health

professionals too.

Even so, there are possibilities here - possibilities of a better and more abundant life. We are challenged to think of sickness and suffering, dying and death as a quest. Most of us are familiar with the narrative of the quest: a man or a woman journey to a strange land; they endure various hardships; and they discover great treasure. This time, however, the strange land is the world of sickness and suffering, of dying and death. But even so, there is treasure here too. Indeed, there are perhaps treasures to be found in this strange land which we cannot find anywhere else.¹²

As just one example of this, let me offer Philip Gould’s memoir *When I Die*. Philip Gould was diagnosed with cancer early in 2008. He died just over three and a half years later towards the end of 2011. And in his memoir, Philip wanted above all to tell us about the extraordinary possibilities of this sort of experience. For example, he wrote, “Intensity comes from knowing you will die and knowing you are dying.... Suddenly you can go for a walk in the park and have a moment of ecstasy.... I am having the closest relationships with all of my family.... I have had more moments of happiness in the last five months than in the last five years.” He continued, “I have no doubt that this pre-death period is the most important

... as Advance Care Planning practitioners we must positively value diversity ... if Advance Care Planning practitioners do not recognise and value my difference, they do not provide me with a place of cultural safety and in some ways they threaten my very identity...

and potentially the most fulfilling and most inspirational time of my life.”¹³

I should add that pastoral care practitioners have special expertise in assisting people to find meaning and purpose in their lives and to satisfy their other spiritual needs. Especially when patients face these existential challenges, pastoral care practitioners – or spiritual care practitioners, as they are sometimes called – therefore have their own special role to perform within the multidisciplinary treatment team. It is important that those of us who have other roles within the multidisciplinary team keep this in mind, and involve pastoral care practitioners as required to facilitate patients in their quest for meaning. The knowledge, attitudes and skills of pastoral care practitioners also mean that they have much to contribute to the process of ACP.

Well, the quest is on, and there are treasures hidden in this strange land of sickness and suffering, of dying and death. May Advance Care Planning help us in our quest.

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