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Advance Care Planning: purpose, instruments, use and misuse

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In 2007, Daniel Sulmasy, Nancy Dubler and I were invited to address a meeting of the Senate of the Italian Government: the Senate was then considering whether the Italian people would be well served by legislation authorizing the use of advance care plans.¹ Daniel Sulmasy argued that advance care planning is not a revolutionary idea but rather an extension of a centuries-old tradition of forgoing extraordinary means of care.² I recommended the approach to advance care planning found in Catholic Health Australia's *Guide for people considering their future health care*³ which combines (on the one hand) encouraging people over time to communicate with family, friends and health care professionals about their hopes and goals in life, their attitudes to health care, their religious commitments, and (as illness and disability occur and especially when death approaches) the things that are important to them in life, with (on the other) appointing someone to make decisions about their medical treatment should they become unable to make those decisions themselves.³ Nancy Dubler argued that two key features of good end-of-life care for people who have lost decision-making capacity are a relationship of trustful cooperation between the doctor and the person appointed by patients to make medical decisions on their behalf, and institutional support in hospitals and nursing home for that relationship.⁴

In this Issue

First, a discussion of some pros and cons of advance care planning.

Second, an interview with Don Chisholm, an outstanding Australian doctor who has long been a friend of the Plunkett Centre.

Five years later, the context of my remarks is 21st century medicine as practiced in Australia. Features of our present context include: a wide variety of advance care planning instruments recommended and used in this country; much variety in institutional support for advance care planning (including no institutional support at all); funding by the Australian Government and support from the Victorian Government for the Austin Hospital's *Respecting Patient Choices* program; understandable concern amongst Australians about *both* over-treatment and under-treatment of the seriously ill and frail elderly; the promotion of advance care planning by various bodies (including some which promote the legalization of euthanasia and assisted suicide); the publication of a National Framework for Advance Care Directives by the Australian Health Ministers' Advisory Council⁵, and, alongside the encouragement by both Catholic Health Australia and the Bishops' Conference of advance care planning, a concern amongst some Catholics about the potential for misuse or abuse of advance care planning.

In this article, I outline the purpose of advance care planning and distinguish the two kinds of instruments which may be used: the appointment of someone to speak on one's behalf and the provision of detailed set of written instructions. I set out two responses to advance care planning amongst Catholic commentators, one largely negative and the other largely positive. I then sketch the usefulness of advance care planning and the concerns that it provokes. I conclude by indicating why, though advance care planning is not a panacea for all the problems which beset medical treatment towards the end of life, I think it is worth encouraging.

Advance care planning: an explanation

At its best, advance care planning is planning for the future to ensure both that the proper goals of medical treatment inform the care of people who become unable to make decisions about their own treatment, and that the means used to seek those goals reflect the judgments of the patient.

The goals of health care include promoting health and preventing disease; saving life, curing illness, slowing the progress of a disease; relieving suffering and disability; and caring for people when they are sick, disabled, frail or elderly.⁶ The means used to pursue those goals should be therapeutic ones: that is to say, they should be oriented to the health of the patient.⁷ So, not only should healthcare professionals have a clear understanding of the purpose for which they propose an intervention (for example, to provide diagnostic or prognostic information; to save a life; to improve or maintain the patient's health by curing an illness or slowing the course of an illness or by stabilizing a patient in a reasonably satisfactory condition; to relieve pain or other symptoms of illness; to nourish and sustain a patient); they should endeavour to ensure that patients clearly understand the purposed for which an intervention is proposed. For treatments which are futile (that is, treatments which make no significant contribution to cure or improvement) or overly-burdensome (that is, the benefits hoped for do not justify the foreseeable burdens imposed) may legitimately be forgone.⁸

Advance care planning: instruments

Two main instruments can be used: a set of instructions which record in detail a person's preferences for treatment and care in the future (a 'living will'), or the appointment of a

person to whom the health care professionals can talk when the person is not able to do so himself (which appointment may itself be recorded in a written document).

It is now eight years since the publication of *'Enough: the failure of the living will'* by Angela Fagerlin and Carl Schneider⁹, in which they argued that written instructions simply fail: few people have them; few people can predict their actual preferences accurately; few people can articulate their preferences clearly; and 'living wills' are often not available when they are needed. In addition, as Catholic Health Australia notes in its *Guide for health care professionals implementing a future health care plan*¹⁰, written instructions are not self explanatory; the course of illness is unpredictable and a doctor needs to be free to provide good care in the actual circumstances of a patient's illness as well as when unanticipated circumstances arise; and written instructions can privilege past wishes over the provision of reasonable care.

So, Catholic Health Australia says, better that patients, in advance, asks someone to do the talking with the doctors when they are not able. Professor Jane Ingham, director of the Cunningham Centre for Palliative Care at Sacred Heart Hospice in Sydney, supports this. She says: 'I need to be able to talk to *someone* whom the patient trusted.' I endorse this view. But it does mean that each of us needs not only to identify such a person (or persons) in advance, but also that we need to talk to that person about what we would want in the way of treatment and what we'd expect others to do for us.

That said, there is a place for documentation: naming the person appointed to speak on one's behalf, indicating (perhaps primarily to that person) that one would want treatment which serves the then-appropriate goal(s) of medical treatment - cure, stabilization, relief

of symptoms, end-of-life comfort care, etc – that is to say, treatment which is genuinely therapeutic; indicating what interventions one would judge appropriate ('therapeutic') and inappropriate ('overly-burdensome') in the pursuit of that or those goals.

Attitudes to advance care planning

Two kinds of attitudes to advance care planning are found amongst Catholic commentators, a largely negative one and a largely positive one. I'll start with the negative one, and come back to the positive one already mentioned. Though different in emphasis, they agree on one thing: the desirability of identifying and authorizing someone to make medical judgments should a person be unable to do that himself.

A negative attitude

Six years ago Catholic Health Australia sent out a draft of its proposed guidelines on advance care planning to Catholic bioethicists in Australia and overseas. The reply of one commentator provides a good example of the negative attitude. Since her comments were intended for use by the group which was drafting the advice for Catholic Health Australia, I'll not mention her name. This is what she said, in response to a preliminary version of what ultimately became the current CHA guides:

'In general I don't think people ought to make advance directives. The draft itself mentions the problems, but, it seems to me, does not take them seriously enough. Once morally unacceptable options are excluded, sound discernment of what health care is appropriate requires taking everything into account - and one can rarely do that without being in the situation that requires a judgment to be made. The exceptions are disease processes that run a very definite course, so that the person's coming incompetence and a matter about which judgment will be needed

can be foreseen with virtual certainty. For instance, a couple came to see me some years ago. The husband had amyotrophic lateral sclerosis and was already confined to a wheelchair. They asked if it would be okay for him to accept a respirator when he needed it and then, at a later stage when he could no longer express his wishes, order it withdrawn. I thought they could, because initially the ventilator would enable him to continue doing worthwhile things, but the benefits would gradually decline and the relative burdens gradually increase. They already had learned a great deal about what they were up against and filled me in on the predicted course of degeneration. Given their evident conscientiousness, I thought he might well signal 'enough' even while still able to communicate, but that if he did not, they might well discern in advance that he should be taken home and the respirator withdrawn when it became clear to her [the wife] that he could no longer communicate. But I told them it was up to them to consider everything and to do their best to discern God's plan for them. Apart from such special cases, I don't think it is reasonable for anyone to try to discern in advance among morally acceptable options for treatment or care, and I think it is gravely wrong to encourage people to try to do that...Often there is a very wide gap between what people want, wanted, or would have wanted and what they would choose or accept if they acted upon sound moral judgments and discernments among the morally acceptable possibilities... In places the draft approves of and even encourages leaving judgments about one's care when incompetent to friends, family, and the professionals involved. In my judgment, doing that might well have been reasonable a century ago but is very imprudent today. Some professionals do not respect moral limits... Unless there is some one person who can make sound moral judgments and has the power to tell the professionals what to do and

not do, family and friends seldom will be able to get themselves together and exercise any serious influence over the professionals. So I would delete from the draft everything that gives aid and comfort to leaving decisions to friends, family, and professionals. What then should people do? If they can, they should identify and appoint as their agent with unrestricted and legally enforceable authority someone who can and who they believe will make sound moral judgments about the relevant matters or, at least, someone who will get sound moral advice so as to limit choices to those that are morally acceptable, and who will then discern well among those morally acceptable options what health care to ask for, to accept and to refuse... it seems to me that the draft's hesitations about named representatives are gravely mistaken. Not only do they need all the power the law can give them, the professionals need to be compelled ...to provide patients and their authorized representatives with the information they need to make judgments, and then either to get off the case or to do to the best of their ability what patients and their authorized representatives tell them to do...'

A positive attitude

Now for the positive. According to Daniel Sulmasy, advance care planning is an extension of the tradition for forgoing extraordinary means of treatment, a tradition which springs from four (what he calls 'natural law') principles: the dignity of the human person (which is the idea that each human being, by virtue of the mere fact of being human, has an intrinsic value, the idea which explains why medicine reaches out to the sick); the *prima facie* duty to preserve life (an idea which has several sources: self-interest, the duty of gratitude for the gift of life, and the responsibilities we have in our roles and relationships with others); the fact of finitude (the idea that human beings are finite, morally, intellectually, physically; the idea that

medicine is itself an imperfect art and that our resources – individually and collectively – are finite); and the diversity of the human (the idea that each person is unique, reacts differently to medication, has different psychological, social, economic and moral resources, etc).

The immorality of euthanasia and suicide follows: they are immoral *in the sense* that they violate the dignity of the person and undermine the duty to preserve life. The duty to preserve life is certainly limited, but it cannot be made consistent with an intention to eliminate life, one's own or that of another person.

Sulmasy makes five points about how the tradition has understood the distinction between 'extraordinary' (that is, optional) treatment and 'ordinary' (that is, obligatory) treatment.

- First, an intervention is 'extraordinary' if it is futile (that's to say, it will not work: it won't cure the patient, or reverse the condition, or appreciably forestall an imminent death, etc) or if the burdens imposed by the intervention - physically, psychologically, socially, economically, morally and spiritually - outweigh the benefits.¹¹

- Second, in the tradition, one does not focus on the intervention itself, *a priori*, but on the particular circumstances. In the circumstances of a ruptured appendix, one might require a ventilator and other things being equal the use of a ventilator would be obligatory in that circumstance. But in the case of a patient with an untreatable or widespread cancer, a ventilator might not appreciably forestall death. So even if not strictly futile, the burdens could be judged to outweigh the benefits and the use of a

ventilator in such circumstances would be optional.

- Third, in the tradition, these questions have been examined from the perspective of the patient and his duty to preserve his own life rather than from that of the doctor or that of the family. The question is: would it be reasonable for him, in *his* circumstances and in *his* judgment, to forgo the intervention.

- Fourth, wide latitude (within the bounds of reason and of the judgment of the community) has always been given in the tradition to the patient in deciding what is extraordinary, not because of any commitment to an unrestrained notion of autonomy but in recognition of the diversity of the human. That's why a patient with a lymphoma who has failed several treatments and suffered really bad side effects and has been offered another treatment might opt to have the treatment again because he is looking forward to attending his daughter's marriage. If the patient becomes unable to think or communicate, treatment decisions should be informed by what is known about his likely wishes.

- Fifth, in the tradition the family was consulted because *it was assumed* that the family would adopt the viewpoint of the patient. "Knowing our son" or "knowing my wife", these burdens are too great relative to the benefits. In this regard, the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* says: 'In the case of an incompetent patient, a decision to withhold or withdraw a treatment should only be made after the responsible doctor has judged that the treatment would be therapeutically futile or overly-burdensome. There should be discussion between the responsible doctor, the family, any legal guardian or representative and others relevant to the care of the patient. In particular, proper account

should be taken of (a) any information about what the patient would have wanted (if anything is genuinely known about that), (b) any signs as to what the patient in fact wants now, (c) the capacity of the family or others to look after the patient, (d) the views of the family and relevant others regarding the appropriateness of the proposed care, and (e) any relevant authority required by law.’ (5.16)

Usefulness

Advance care planning is useful for a variety of reasons.¹² First, medical successes mean that many more people die having lost decision-making capacity. Second, in developed countries, virtually everyone has access to advanced medical treatment so this is not a problem just for the wealthy. Third, the power of technology is so great that these decisions affect everyone: most people who die in hospital die after a decision has been made not to do something. Fourth, it is useful because the burden of decision-making falls largely on third parties, most of whom find it very stressful. Fifth, increasing numbers of people have no family to make decisions for them as they die. And, finally, it is useful because families are sometimes unable to agree on decisions.

Concerns

There are, however, legitimate concerns about advance care planning. I shall sketch two: its *de facto* promotion of a reductive theory of ethics, in particular an unrestrained notion of autonomy, and its possible association with euthanasia and assisted suicide.

A first concern is the thought that advance care planning can reinforce a reductive approach to ethical issues in medical treatment and end of life care. The tradition which distinguishes between ordinary and extraordinary means of care, examines the

matter from the perspective of the patient, asks those who know him to adopt his viewpoint and to decide what he would have wanted, etc, is very different from an approach which starts from the common law obligation to respect refusals of treatment and tries to keep that notion alive in circumstances in which the patient is no longer able to refuse. No doubt these two ideas - the notion that an intervention can be optional and the common law's notion of the obligation to respect refusals - developed hand in hand. No doubt they point in the same direction: that the decision is ultimately the patient's and not the doctor's. Nonetheless today there is a widening gap between what the tradition (on the one hand) and contemporary secular culture (on the other) hold about the 'optionality' of treatment. In the tradition it still makes sense to talk of treatment that *should be accepted* (for instance, a ventilator in the circumstances of a ruptured appendix). But, though Australian doctors no doubt still encourage patients to accept treatment that they think will likely be therapeutic for them, it would be unthinkable for any health department document to talk of treatment which *should* be accepted.

Further, even if the some of the ideas that come from the tradition of forgoing extraordinary care are mentioned in advance care planning documents, they are sometimes used in a way which is so remote from the context that originally gave them their meaning that their significance seems to have changed. In a recent article in the *Medical Journal of Australia* Bill Silvester and Karen Detering commend the wisdom in the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* for stating that, if a treatment is overly-burdensome or the burdens outweigh the benefits, the patient may legitimately forgo the treatment.¹³ But, in the Statement of Choices

document associated with the Respecting Patient Choices literature, the box concerning 'Life prolonging treatments' (ventilators, dialysis, feeding tubes, surgery) offers three choices: *I would like life prolonging treatments in order to prolong my life as long as possible, OR, I would like life prolonging treatments only if the doctors expect a reasonable outcome* (and then there is space for the person to nominate what would be a reasonable outcome for him or her), *OR, I do not want life prolonging treatments at all.*¹⁴ This set of choices focuses on interventions in themselves, *a priori*, regardless of circumstances, whereas in the tradition the judgment that an intervention would be futile is a judgment that the treatment *will not work* (it won't cure the patient, or reverse the condition, or appreciably forestall an imminent death, etc): that is to say, in the tradition, the idea that an intervention may be futile relies on the prior idea that *medicine has its own goals in the light of which interventions can be judged as therapeutic, non-therapeutic, insufficiently therapeutic*, etc. This is a subtly different idea from that which is implied in the statements 'I would want my life prolonged' and 'I would not want my life prolonged.' And, again, in the tradition the judgment that an intervention would be overly-burdensome is a judgment about an intervention-relative-to-particular-circumstances: the use of a ventilator in *these* circumstances. Only the second of the three choices hints at that proper relativity.

In addition, it is well known that organizations which promote the legalization of euthanasia and assisted suicide also tend to promote advance care planning. (See, for instance, the advice provided by Dying with Dignity NSW. It endorses the filling out of written instructions over the appointment of a person to speak on behalf of the patient or resident. It encourages the refusal of *kinds* of intervention *a priori* (antibiotics, ventilators,

etc) rather than an-intervention-in-particular-circumstances. It recommends a tick-a-box approach to refusal of interventions: 'If I am in the terminal phase of an incurable illness, I do not/do want cardiopulmonary resuscitation, assisted ventilation, artificial hydration, artificial nutrition, antibiotics (unless it is part of my palliative care).'¹⁵ Sulmasy advised the Italians that legislation to support advance care planning would have to distance itself from euthanasia. He was, of course, speaking in a country in which the Catholic church is still influential in matters of public policy even if not in the everyday lives of most ordinary Italians. But, as he said, the difference is made *explicit* in most places in the United States in which advance care planning has been given statutory support. True, the difference *is* made explicit on the website of the *Respecting Patient Choices* program but not prominently so. And the difference is not well explained: the explanation of euthanasia which is given does not make it clear that one can 'do' euthanasia by an act or an omission, by doing something or by not doing something which one ought to do.

So, if advance care planning is to be a way of ensuring that the proper *goals* of medical treatment inform the care of people who become unable to make decisions about their own treatment, and that the *means* used to seek those goals reflect the judgments of the patient, what is needed? An approach to advance care planning which reflects all the elements in the tradition of forgoing extraordinary care. An approach to advance care planning which avoids the bureaucratic solution of tick-a-box instructions and emphasizes a trustful, collaborative relationship between senior healthcare professional and the person appointed to make decisions on behalf of the patient. Institutional arrangements which support collaborative relationships between senior

healthcare professionals and authorized decision-makers. And a culture of openness to the right kinds of conversation in ordinary Australian families: there's little point in appointing someone to speak on one's behalf if we haven't talked the matter over with that person!

Conclusion

Advance care planning is certainly not a panacea for good end of life decision making. There are many other things about 21st century medical and nursing practice at the end of life that deserve our critical attention. For instance, young doctors need to *unlearn* some of what they have been taught about practice of medicine (for instance, that patients (or their families) have unrestricted autonomy to decide what treatment they receive). And they need to *learn* some aspects of the practice of medicine that they may not have been taught (for instance, how to relieve different kinds of pain and discomfort: Margot Somerville recently pointed out that there is more time devoted to teaching the techniques of pain relief in standard veterinary curricula than there is in standard medical curricula!).¹⁶ The profession needs to regain the idea of professional leadership in medicine: just as some senior doctors leave 'consenting the patient' before surgery to junior doctors, too many leave the difficult conversations about end of life care to young and inexperienced staff. And the profession needs to recognise and respond to other challenges to good end of life care found in, for example, the increasingly widespread practice of sedating patients unto death and in the loss of the notion of basic care owed to anyone regardless of his or her condition.

Nonetheless, I share the view that advance care planning can be useful in ensuring both that the proper goals of medical treatment inform the care of people who become unable

to make decisions about their own treatment, and that the means used to seek those goals reflect the judgments of those people. For this reason, I think we should promote good advance care planning and be critical of it when it falls away from this two-part standard. We should not allow it to be abused by being treated simply as a stepping stone in policy shifts towards legalizing euthanasia and assisted suicide, but rather we should work with colleagues to ensure that it is one more way in which we can recognize the intrinsic dignity of each person, particularly those who spend the last part of their lives in hospitals and nursing homes.

So, we need to talk about life, death and life-prolonging medical treatment, in particular with the person we ask to represent us when we lose the capacity to speak for ourselves. We need to document that appointment. And it may be worthwhile to make the kind of statement of our wishes with respect to future health care such as that suggested by Catholic Health Australia in its *Guide for people considering their future health care*. Indeed, a retired doctor recently pointed out that, with respect to advance care planning, there is a place for both conversation and documentation. I will finish by quoting her:

"Here in Melbourne, I have been tied up with the medical profession rather drastically for two months, and this included two weeks (post heroic surgery – not cancer) in ICU – and a DNR order (self initiated and superbly sorted out with the ICU director carefully listening and documenting my wishes, and also with consent refused for "clot busting" treatment for CVA, which was on the cards as was cardiac arrest). My Durable Power of Attorney person (all formally and expensively sorted out a year or so ago with my lawyer) was overseas and un-contactable by phone all the time I was in ICU. Two close Adelaide friends came to Melbourne to support my magnificent Melbourne contact person: the latter told me only last night that the clarity embodied in

that piece of paper (filed and transferred when I moved hospitals for another four weeks) was of real help in the difficult circumstances...There are principles at stake here. Advance Directives (and the pieces of paper which embody them) are for the sake of the patient, not the doctor or friends, however helpful clarity is to all these categories of persons. It gave me much peace of mind to have that document in place, and it may have assisted me to die in a dignified manner, if that was to be the outcome then. It is good, but secondary, that it also helped the situation for the others. After all, it is the right and responsibility of each of us as persons to take steps to shape the last phase of life, as any other phase of life, even this one day, in accord with the values we try to live by... and others have some responsibility to support our decisions and efforts, even though personal privacy may lead us to refrain from articulating much (especially our reasons) in the ordinary course of events. As you know, I am opposed to the legalization of euthanasia, even when voluntary, together with 'physician-assisted suicide', on the grounds that these are destructive ways to solve very real problems. But until the former notions are really accepted and in practice, the latter 'solutions' will continue to rumble. But that is another discussion for another day. Meanwhile I do think that it is wise to welcome carefully constructed "pieces of paper"... and encourage their incorporation into the health care system, rather than deplore their underuse.¹⁷ By the way, I am now home and have a good prognosis! I am very happy and grateful woman!"

Notes

¹ This paper is based on a talk given at the Annual Colloquium of the Australian Catholic Bioethicists Association in Melbourne in January 2012.

² Sulmasy, D. 'Advance Directives as an extension of the tradition of forgoing extraordinary means of care', *Bioethics Outlook*, Vol 19, No 2. June 2008, 1-12

³ Tobin, B. 'More talk, less paper!' *Bioethics Outlook*, Vol 19, No 3. September 2008, 1-7
<http://www.cha.org.au/images/resources/Future%20Health%20Care.pdf>

⁴ Dubler, N. 'Tell me about Mama: Facilitating end-of-life decisions.', *Bioethics Outlook*, Vol 19, No 4. December 2008, 1-8

⁵ The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. *A National Framework for Advance Care Directives*, 2011; obtainable at www.ahmac.gov.au.

⁶ *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, Basic principles, No 3.

⁷ *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 1.12

⁸ *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 1.13

⁹ Carl Schneider & Angela Fagerlin. Enough: the failure of the living will, *Hastings Center Report*, 34.2 March-April 2004, 30-42

¹⁰ In addition, as is noted in the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, 5.9, if it is not reasonably available without disproportionate hardship to patient, carers or others.

¹¹ Sulmasy, op cit.

¹² William Silvester and Karen Detering. Advance care planning and end-of-life care. *Medical Journal of Australia*, 2011, 195, (8): 435-436 .

¹³ And then there is the addition: If life prolonging treatment has been commenced I request that it be discontinued and that I receive palliative care.

¹⁴ <http://www.dwdnsw.org.au>; accessed 17th September 2012.

¹⁵ Somerville, M. Euthanasia: *Is legalizing it a good idea?* *Australian Dialogues*, Talk given at St Vincent's Hospital, Sydney, June 2011

¹⁶ See Tobin, B. 'We need to talk about death', *Bioethics Outlook*, Vol 23, No 2, June 2012, 11

¹⁷ <http://www.cha.org.au/images/submissions/Guide%20Health%20Care%20Prof.pdf>

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It's in the blood – Professor Don Chisholm reflects on his career in endocrinology and diabetes care

Professor Don Chisholm AO has been a leader in diabetes research, care and education. He was head of the Diabetes Research Program at the Garvan Institute of Medical Research in Sydney from 1978 to 2003. He was foundation director of the Diabetes Centre at St Vincent's Hospital in Sydney from 1980 to 1991. He has retired from clinical practice apart from a monthly diabetes clinic at an Aboriginal medical service in western NSW, but continues to work in diabetes research at the Garvan.

My career has centred around St Vincent's Hospital and the Garvan Institute in Sydney. After resident and registrar training at St Vincent's, I did about a year and a half of research at the Garvan in its early days and then spent almost two years at McGill University in Montreal in Canada, before returning to Australia to work at St Vincent's in Melbourne. I returned to St Vincent's in Sydney in 1978 to a position as staff endocrinologist with the recognition that I would spend a substantial portion of time in research at the Garvan.

I did my registrar training in the mid '60s when radioimmunoassays for hormones had just been invented. Endocrinology suddenly became an exciting specialty because for the first time you could measure circulating levels of hormones.

One of the most rewarding aspects of diabetes care is working in a team. The best diabetes care is patient-centred, with doctors working closely with nurse educators, dietitians and podiatrists. While teamwork has always been important,

the resources and the structure to make it happen weren't there a few decades ago. It's much better now — the emergence of diabetes centres and the establishment of the role of diabetes educators in both hospitals and community centres have been enormously important.

The advances in diabetes care during my career have been incredible. When I first started in diabetes in the late 1960s, no one dreamed patients would be able to measure their own blood sugar, and people would go blind from diabetic retinopathy as there was no effective treatment. Nowadays, as long as diabetic retinopathy is recognised at an early stage, laser treatment is highly effective. On the downside, while the advances in diabetes have been terrific, type 1 and type 2 diabetes have been increasing substantially, so unfortunately it is a growth industry.

I've always been very happy working in diabetes. Over the past couple of decades my research focus has shifted from insulin delivery and blood sugar control to insulin resistance and the pathogenesis of type 2 diabetes.

Currently, I work with a team at the Garvan and particularly Dr Jerry Greenfield, the head of the department of endocrinology at St Vincent's in Sydney, to try to understand the molecular mechanisms of insulin resistance and the development of type 2 diabetes.

There are a number of issues transforming diabetes, none of which will bear fruit straight away.

One of these is the worldwide push for lifestyle change to prevent type 2 diabetes, including state and federal activity in Australia, which is a step forward but it isn't enough. In terms of type 1 diabetes, it will become a preventable disease if we can find ways to stop the immune system attacking insulin-producing cells without hitting the immune system with a sledge hammer. One of my roles is to chair the board of the Diabetes Vaccine Development Centre, which is based at the Garvan and supported by the National Health and Medical Research Council and the Juvenile Diabetes Research Foundation International. Through the work of this centre and other research, progress will be made towards the immune prevention of diabetes in the next decade, but the full-scale prevention of type 1 diabetes will likely take another 20–30 years.

One of my most satisfying career achievements was my involvement with others in establishing the Diabetes Centre at St Vincent's in Sydney in 1980. It was not the first diabetes centre in Australia, but I believe it was the first to undertake diabetes care entirely on an ambulatory basis. Up until then, people who had newly developed type 1

diabetes or had severe complications were regularly hospitalised. The Centre's contribution to diabetes care has been further enhanced under the direction of Professor Lesley Campbell, who took over from me in 1991. On the research side, I am most proud of my involvement in the growth and development of the Diabetes Research Program at the Garvan.

When a young doctor asks me about career choices, I always urge them not to make up their mind too early. The later they decide, the better they'll know. I also urge them to find a clinical mentor who's not only a good clinician but also has good organisational and administrative skills. I had several excellent mentors, including Les Lazarus at the Garvan, and David Pennington who recruited me to St Vincent's in Melbourne in 1971.

One of my regrets is that I didn't get a PhD. In the end it didn't hold me back in my research career, but it's different these days and I recommend that young doctors interested in an academic career should get a PhD. They should also look for a research mentor who has a good track record of publications.

It's in the blood – Professor Don Chisholm reflects on his career in endocrinology and diabetes care. *MJA Careers* 20 August 2012; 197(4) p C5. © Copyright 2012. *The Medical Journal of Australia* - reproduced with permission.

Plunkett Lecture 2012

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My brain, my mind and my body *Stem cells, organ donation and end-of-life care*

Dr Andrew McGee

Lecturer, Faculty of Law
Queensland University of Technology
Member of Faculty's Health Law Research Program

Response by

Dr Steve Matthews

Senior Research Fellow
Plunkett Centre for Ethics

Thursday 25th October 2012
5.00 – 7.00 pm

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