



# VES<sup>nsw</sup> NEWSLETTER

**promoting end of life choice**

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The July members' meeting was a great success. Our guest, Prof Colleen Cartwright proved to be a witty and informative speaker. She talked about advanced care planning: what it is and why it is important. The timing of her talk was perfect for the society as VESNSW has decided it's time to update our Advance Health Care Directive (AHCD), and Prof Cartwright has generously agreed to allow use of her template. You will find it included with your newsletter. President Dr Giles Yates talks about the new directive on page 9.

And there are more excellent speakers to come! Dr Rodney Syme speaks at the end of this month, (see page 11), Prof Peter Baume at the AGM in March, and Dr Leslie Cannold In July.

The euthanasia issue came into focus in an episode of Q & A on ABC TV. Leading with an excerpt from a YouTube video, made by a dying woman, Angelique Flowers, (pleading for Prime Minister Kevin Rudd to reconsider Labor's position on euthanasia), the panel attempted to discuss voluntary euthanasia. I say attempted, because they were quite plainly out of their depth, peppering their comments with clichés: *slippery slope* et al. The panel included Maxine McKew, Robert Manne, Tony Abbott, Aly Waleed and Margaret Fitzherbert.

A show of hands in the studio audience reflected polls revealing that 80 per cent of Australians would want a medically assisted death if they were suffering from a terminal illness.

Watching the program, it became clear how unprepared for the subject the panel were. It's imperative that ongoing balanced information is provided for politicians and others, in this complex area – it's not enough that they raise their hands and say: *It's all too complex!*

Many of the VE societies and some of our members, like Bill Alcock, felt compelled to write to the panel members. Bill says: *I am an*

*eighty-three year old WW2 veteran and it would give me great peace of mind if I could get medical assistance to die in a dignified manner...I fear degeneration far more than I fear death.*

**If every member wrote to their local member of parliament, the MPs couldn't claim ignorance of the issues.**

We are heartened by society's fleeting empathy for the plight of those like Angelique Flowers, whose bravery forces us to recognise her, and her pain. Any society depends upon empathy in order for people to be able to answer the question: *What do we owe one another as members of the same society?* The success of these narratives illustrates the interplay of empathy, moral judgment, and society's sense of justice. Telling stories is a powerful way to communicate meaning and encourage behavioural change.

And we all have stories – do you have a story you'd be prepared to tell?

As Julian Barnes wrote in *Nothing to be Frightened Of*, his book about facing death: *Perhaps a sense of death is like a sense of humour... For me, death is the one appalling fact which defines life; unless you are constantly aware of it, you cannot begin to understand what life is about.*

Caren Jenning died. She had been suffering from terminal cancer, which had spread from her breasts to her bones. Convicted for her role in the manslaughter of the Alzheimer's sufferer Graeme Wylie, Caren took her life with the same drug she illegally obtained for him. In a final statement released at a conference by Exit International, Caren said her treatment during the trial "was significant in my decision to end my life". Vale Caren.

The Victorian PAD (Physician Assisted Dying) Bill was voted down 25 to 13 in a conscience vote in the Upper House. The Parliament rejected a Bill that would have permitted euthanasia for terminally ill patients. The Bill has been sent to an Upper House committee for further consideration. Dr Leslie Cannold discusses the issues involved in conscience voting on page 7.

Despite the failure of the Bill, the debate on euthanasia was lively, even swinging a few votes, and in that sense – says Monash University politics expert Dr Nick Economou – it is a return to how Parliament was envisaged before the invention of party politics. And that has to be a good thing!

# END-OF-LIFE ISSUES AND ADVANCE HEALTH CARE DIRECTIVES

## PROF COLLEEN CARTWRIGHT



Let's be very clear in our definitions of euthanasia. It is not:

- pain relief which may also have the effect of shortening life (double effect)
- respecting the patient's right to refuse further treatment
- withholding or withdrawing life support systems that have ceased to be effective or which provide no real benefit to that patient.

The World Medical Association defines euthanasia as the deliberate ending of a person's life (using drugs) at his or her request. The definition that many of my colleagues and I think is the most appropriate is:

Euthanasia is the deliberate act intended to cause the death of the patient at that patient's request for what he or she sees as being in his or her best interests.

So, it's active – it's voluntary – and it's euthanasia in its original sense – the 'good' or peaceful death. The most important word is 'intended' – that the intention is to end the person's life – not to ease pain, or anything else.

Giving pain relief which may also shorten the person's life is often referred to as the doctrine of 'double effect', because the primary intention of the action is to relieve pain. A secondary, unintended, but foreseen consequence could be the hastening of the person's death by a few hours or days. This practice is accepted by most religious and medical groups, including those who strongly oppose euthanasia. For example, the Catholic

Improvements in living conditions, health care and rapid technological developments have increased longevity and allowed people who would previously have died to be kept alive. At the last census there were over 3000 people in Australia over 100.

This extension of life through the use of ventilators and feeding tubes – challenges many practical, legal and ethical issues, particularly around end-of-life care and the extension of the dying process.

I became aware of the fear many older people have about the end stage of their lives when I was working in Queensland on a community project which I called *60 and better! You can't turn the clock back – but you can wind it up again!*

I was surprised to discover that people weren't afraid of dying. They weren't necessarily even afraid of pain. They were afraid of loss of mental faculties, loss of control and dignity, and of being a burden on families.

I heard stories about loved ones hooked up to machines to the very end, where no one could get close enough to hug them and say goodbye. One woman said to me: *Mum always said she didn't want to be resuscitated if she had a heart attack – but they wouldn't listen.* Many said: *I don't want this to happen to me!*

One man talked about his wife who was dying from bone cancer. The surgeons put a pin in her hip because she was in pain. He said to me: *I wondered why. If she was so crook, why did they do that – because it was a terrible mess and just added to her pain?* They gave her more chemotherapy and took numerous x-rays, three and four a day.

We're talking about the last few days of this woman's life. Is that any way for anyone to die?

Everyone has the right to consent or to refuse treatment – any treatment. Just because you go into hospital doesn't mean you've given up that right. You should be provided with information about what they're planning to do, be informed about any alternatives, and about what will happen if you don't take up the treatment. If you are in hospital and someone proceeds to do something to you – you can say: *Excuse me! I haven't actually consented to that procedure.* There are plenty of legal precedents to support you.

Another man felt that his specialist just couldn't accept defeat. The doctor was still trying to cure him when there wasn't any point. He was running all these tests and trying to build up hope when he knew damn well there wasn't any!

And at the end of all this are angry and bitter carers, who feel like they failed the person they loved because they weren't able to protect them.

This last story is very concerning: The man was in his late 80s early 90s with multiple problems and he decided he'd had enough, so he stopped eating and drinking. His wife recounted what happened: *When he was in hospital he wouldn't eat, he was trying to starve himself. They couldn't get him to eat. So they force-fed him. They put the tube down his nose and they tied him to the bed because he kept pulling the tubes out. He just didn't want it.*

Let me tell you if he just didn't want it – he just didn't have to have it!

Every competent person has the right to refuse any treatment – even life-saving treatment. If I tell a doctor or a nurse not to touch me and they do – I can have them for assault, both in common and statute law under the Criminal Code. If you're competent, you do not have to receive any treatment.

Many of the problems I've just outlined stem from the confusion over what is and what is not, euthanasia. This confusion leads to inadequate pain management, inappropriate use of medical technology, fear among health professionals about the legal consequences of care provision and in the end, poor doctor patient communication, and to disillusioned patients, families and carers.

Church accepts the doctrine of double effect because the first person to use the term was St Thomas Aquinas. Aquinas said: *If you must achieve a good end, and the only way you can achieve that good end is to also run the risk of a foreseen but unintended consequence, you must still achieve the good end.*

So what are we talking about here? We're talking about pain relief. It is absolutely unacceptable for anyone to be left in pain. **If I leave you with no other message today that's the message.** It is unacceptable for anyone to be left in pain, and if someone is in severe pain, they should sue their doctor – or somebody should, on their behalf. One of the best palliative care physicians I ever met, Professor Ian Maddock, said that with the right combination of medication, and the right dose at the right time, at the right frequency, there were only about 3 per cent of patients whose pain he could not adequately control so that they were comfortable, without making them unconscious. One of the difficulties is that a lot of medical practitioners have not been trained adequately in pain relief.

With the doctrine of double effect – the primary intention is to relieve pain. A secondary unintended, but foreseen consequence, may be hastening the death by a few hours or days. The irony is that death can be hastened by not giving adequate pain relief. If you leave someone in severe pain, they can suffer respiratory distress. They can suffer from severe cramping and they can die.

I experienced this first-hand when my son was in a country hospital with severe back pain. The response from his surgeon when I demanded adequate pain relief was: *I don't want to turn him into an addict.*

This surgeon was not properly trained in pain management, because I knew that if you give the right dose, at the right time, in the right amount, the pain takes up, if you like, the pain medication. The person doesn't get 'high' – and they won't become addicted.

I once said in a meeting like this: *And if they're terminally ill, would it matter anyway?* But a palliative care specialist in the audience rapped me over the knuckles and said: *They won't become addicted – we can control their pain adequately by giving them the right dose.*

A patient's right to refuse treatment is a legal and moral right possessed by every competent person. It is also a right of a non-competent person if they've written their wishes in an advance health care directive, and they've appointed someone to make their decisions for them.

This is a difficult area for some

health professionals, especially in some circumstances, such as when someone refuses a blood transfusion because of religious beliefs. When I'm giving this lecture to medical students who say: *But we could save their lives.* I reply: *Yep, you probably could, except in that person's belief system accepting a blood transfusion means they're damned for all eternity.*

You might think that refusing a blood transfusion is based on flawed thinking, but it doesn't matter what you, I, or anyone else, thinks. Provided the person is only going to affect themselves, they have that right. One of the great things about living in this country is that, by and large, we have religious freedom and tolerance. And, in fact, more people have died from accepting contaminated blood than from refusing a blood transfusion.

Withdrawing life support systems (what used to be called 'passive euthanasia') can lead to the inappropriate, continued use of invasive technology. It can prolong the dying process itself rather than prolonging the patient's life. How?

If I'm on my dying trajectory and you interrupt that process by putting in a ventilator, a peg-tube, or a dialysis machine, and, as time passes you realise that you cannot return me to any kind of quality of life – all you have done is put a roadblock in my dying.

However, you have not engaged in euthanasia if you removed those impediments to my dying, and allowed my natural dying to continue. Removal of futile treatment is good medical practice. There's one little glitch, however – there is no definition of futility in the law, but it is generally agreed that it's when burden outweighs benefit. However, the burden and benefit should only be judged from the viewpoint of the patient. If the patient thinks it is too burdensome for the benefit they're getting from the treatment, then it should be removed.

Medical practitioners are much more willing to withhold treatment in the first place than they are to withdraw it once it's started. Legally, morally, there is no difference. The same questions should be asked. What is our goal of care? What is the patient's goal of care? Will this treatment help us with that? And if it's clear that it will, then start

treatment. But if, clearly it won't, don't start treatment. But don't start treatment because you think it might.

When we did research in Queensland and in the NT we asked people: *If you were terminally ill, what do you think would cause you most distress?*

In every study, loss of mental facility came first in response to this question. But the reality is, if I've lost my mental facility and I'm terminally ill, it's probably not going to be bothering me much at all, it's probably going to be bothering everybody else around me. Loss of control came second.



## Advance Health Care Directive



Completing this form gives you the best chance of ensuring that you will not be given unwanted medical treatment at the end of life. It can also make it easier for your family and health care providers to understand and respect your wishes.

VESNSW thanks Professor Colleen Cartwright and ASLaRC for permission to reproduce this Advance Health Care Directive.

In the first study we used the term 'extreme pain' and it came in at No.3, but then the research team discussed this and agreed that nobody should be in extreme pain. If anyone is in extreme pain they should sue their doctor. So we changed it to 'physical pain' and in the second study it dropped down to No.6 and in the third study to No. 8.

Loss of control and loss of independence were top of the list, and the more items we added to the list, the further down pain went. Burden on family, loss of dignity and leaving loved ones behind, were seen as the causes of the most distress. In every study, fear of death came in last. No matter how many items we added to the list, death came last. People were not afraid of dying.

One way we can address some of our fears and concerns is to do advance health care planning. Many people think that if they have given someone enduring power of attorney then that person can make your health care decisions. This is incorrect!

Enduring power of attorney applies only to property and financial matters. It is really important to be clear about this. In the next section we're going to talk about advance health care directives, enduring guardians and about the 'person responsible'.

**Enduring guardianship.** A competent person over 18 can appoint an enduring guardian to make personal and lifestyle decisions about medical or dental treatment on their behalf, in case they lose the capacity to make those decisions for themselves. The person you appoint has to be at least 18 years of age, and is usually a trusted relative or friend.

You cannot appoint your GP or one of your doctors, or your community nurse, nor someone who provides accommodation services (such your nursing home provider), and you can't appoint a relative of these people.

You can appoint more than one person and direct how they are to make their decisions. The person you appoint has to agree to the appointment. And they should understand your wishes and be prepared to carry them out. The appointment has to be in writing and has to be in the approved form. You need to sign the form and so do the person/people you appoint. Under NSW legislation, your appointment of enduring guardian form needs to be witnessed by a solicitor, a barrister, or a registrar of the court.

**Advance health care directives.** NSW is one of the few States that don't have specific legislation covering the advance health care directive, however it is covered under common law. Under common law, if I have capacity when I have refused treatment, that holds past lack of capacity. In Australia, if we don't have case law about a specific issue, we take our case law from the UK, where there have been cases where the court said: *Yes, a competently made decision holds past loss of capacity under the common law.*

So what is an advance health care directive? It's a written document which allows a person to make their wishes for future health care known. It extends the current right of a competent person to accept, or refuse, treatment to a future time when they may not be competent. It is not a form of euthanasia. It will only allow people to ask for actions which they could legally

consent to for themselves, if they were competent to speak. It only comes into effect when the person whose advance health care directive it is, has lost the capacity to speak. This is important, because the same applies to your enduring guardian form. You can appoint someone now, but they don't have the right to make decisions while you still have capacity.

Nearly everyone we canvassed (94 per cent), said that they should be legally binding. What was interesting is that a higher percentage of health professionals than the rest of the community said that they would like to make their own advance health care directives. Why? Because they know what can happen, and they don't want it to happen to them.

When canvassing doctors and nurses, I asked: *Are there ever times that you feel*

**LET ME TELL YOU  
IF HE JUST DIDN'T  
WANT IT – HE JUST  
DIDN'T HAVE TO  
HAVE IT!**

*legally vulnerable just in carrying out your normal duties?* And about 73 per cent said yes. They shouldn't have to. They shouldn't have to work under that sort of fear. And if they are following a legal constituted advance health care directive, then they're protected.

Another question we asked was: *What might stop your patients, or what might stop you from completing an advance health care directive?* The answer: *Not knowing enough about it!*

Alarming, 63 per cent of health professionals said that people would prefer to leave the decisions to the doctor! But only 37 per cent of the community agreed with that. And 75 per cent of health care professionals said people don't want to talk about end-of-life issues. The community says otherwise. It's the health professionals who don't want to talk about dying!

Many doctors say to me: *We were never taught to talk about death and dying.*

*We talk about curing and caring.*

**We need to talk to doctors about death and dying.**

So what are some of the benefits of an advance health care directive? Alleviation of fear is the big one! Fear of loss of mental capacity, and others mentioned earlier. If I do lose my mental faculties, someone will know what I want. Advance health care directives reduce family discord over withholding or withdrawing treatment.

An advance health care directive ensures the patient's wishes are known, because it is in the patient's own words. It assists the health care provider in their decision-making and relieves family stress in times of trauma. It's the best insurance policy you can have. And advance health care directives make the best use of community resources. If you don't want expensive invasive technology, why receive unwanted and unwarranted treatment? How we make the best use of community resources is an ethical issue.

Where should you keep the advance health care directive? Not with your Will! By the time someone's looking over your Will it's too late. Have the document signed by your GP and keep a copy in his/her file. Give a copy to the person/people appointed as your enduring guardian/s. You should have a copy accessible at home. If you're going into hospital, make sure you take a copy and tell them you want it in your file and you want it noted on your current notes. This applies if you're going into an aged care facility too.

**So, what if there is no advance health care directive, no enduring guardian? Who can make the decisions?** Firstly, let me make it clear that your next-of-kin do not have the authority to make your health care decisions. Under the NSW *Guardianship Act, 1987*, the 'person responsible' starts with your enduring guardian, but if you haven't got one, then there's an order of authority, a hierarchy. If you haven't got an enduring guardian, it falls to the spouse. In NSW that includes same-sex spouse or de-facto spouse.

You may ask: *Isn't a spouse your next-of-kin?* Yes, but their authority doesn't come from being your next-of-kin, it comes from being the next in this hierarchy of decision-makers. If you haven't got a spouse, it moves to 'carer'. Carer is often a daughter or daughter-in-law. It doesn't necessarily have to be the person who's living with you. It can be whoever most often calls in to make sure that you're ok, and does your shopping etc.

Supposing you have a son (older than that caretaker daughter), who steps in and

says: *But I'm the oldest, I'm the next-of-kin, I should have the authority to make the decisions.* He has no case, because his sister has been the one who's been doing the caring. She is most likely to know what the parent wanted.

A recent case in NSW involved a woman who had three children who hardly



ever visited her. A next-door neighbour came in every morning to help her out of bed, put her washing on, and ferry her around (to the doctor, etc). When that woman lost capacity, the children started making decisions that the neighbour knew the mother wouldn't have wanted. The neighbour applied to the Guardianship Tribunal and she was deemed to be the carer, because she had the 'care' of her neighbour. She had the authority to make that woman's decisions, ahead of her three children.

Don't leave difficult decisions up to your family. If you make your own decisions in your advance health care directive, and attach it to the back of your enduring guardian form, you are taking responsibility for your life, your treatment. If you want to be sure that the person who makes your decisions is the person you want to make you decisions, appoint them.

What if you haven't got a spouse and you haven't had a carer? You have been going along fine and then you have a stroke or a heart attack. There is, under the legislation, another category following spouse and carer – 'closer relative or friend'. Imagine the possible disagreements over who's going to make decisions! Don't risk it. Appoint your own!

#### **Who defines capacity/incapacity?**

The legislation in this area (and most of the legislation in Australia), is based on the United Nations principle of 'presumption of capacity'. That is, I don't have to prove to you that I am competent. I am competent unless you can prove that I am not. The onus of proof is not on me, it is on you.

There are a couple of basic guidelines to use in order to understand whether someone is competent in this context. The person has to understand the nature and the effect of the decisions to be made; they have to be able to take in the information, contain the information, think about it and make a decision.

The person also has to be able to communicate their decision in some way, not necessarily by speaking or writing. Body language may be adequate. The first case of this kind that went to the Guardianship Tribunal in Queensland involved a man who'd been severely injured in a car accident. He couldn't speak, couldn't move his limbs, but could nod and shake his head. He'd been taken off the ventilator about three weeks previously, and didn't want to go back on. His wife, his mother, his spinal unit specialist, and his intensive care specialist all said he knew what he was doing. His sister said he didn't. She brought in two psychiatrists who also said he didn't. So the case went to the Guardianship Tribunal. The tribunal operates with the same presumption: *This man is competent, prove to us that he isn't.*

The tribunal heard from the experts and found that it was not proven that he lacked capacity. I was asked to come to the spinal unit to witness his advance health care directive. I asked him a few questions, mainly to experience how he said yes and no, (not because I needed to determine his capacity), and started to assist him through the document with the nurse and the doctor.

I asked him questions: *If your heart stops, do you want CPR? If you can't breathe properly do you want to go back on the ventilator? If you can't swallow do you want us to feed you with a tube?* We moved through the document until we arrived at a section that said 'other' (a non-generalised specific health complexity)

*What else is he facing?* I asked. They

replied: *Chest physio.* So I said: *Ask him that. Do you want chest physio?* And he said *yes.*

For a moment I thought we had an inconsistency, was he really competent? But the health professionals reassured me. He hated chest physio, but knew it made him comfortable and they had assured him they would never use it to prolong his life. That confirmed his capacity. His wife signed on his behalf, the doctor signed and I witnessed the document and he died three weeks later.

**Incapacity is not ignorance.** If you haven't been given adequate information, then that doesn't say anything about your capacity. It's not eccentricity, cultural diversity, or having different ethical views. It's communication failure! Everyone has made a bad decision at some time in their life. It doesn't necessarily say anything about their capacity. People can make decisions for good reasons, for bad reasons, for no reason. They don't have to tell you the reason. Disagreeing with your health care provider is not evidence of incapacity; in fact, sometimes I think it could be the opposite.

When going into hospital, ensure that your enduring guardian and advance health care directives go into your medical records and that an alert is put on your records and on the computer. If, when you take you forms to the hospital and they tell you that they don't recognise them, tell them they are breaking the law. Ask to speak to the legal person in their hospital. Tell them that under the *Guardianship Act* next-of-kin has no legal status.

We all need to insist that we are listened to and work for change. Appoint your enduring guardian/s and make an advance health care directive when you have the capacity.

*Prof Colleen Cartwright is Foundation Professor of Aged Services and Director of the Aged Services Learning and Research Collaboration, at Southern Cross University, Coffs Harbour. She has extensive teaching and research experience in ageing, ethics and medical decisions at the end of life, at national and international levels, with publications in major journals and a number of book chapters. She assisted with the development and implementation of the Queensland Powers of Attorney Act (1998) and the Guardianship and Administration Act (2000) and regularly runs training sessions for staff of residential aged care facilities on ethical and legal issues, including advance care planning, PEG feeding (tubes that go directly into the stomach through an incision in the skin), informed consent and capacity, as well as information sessions for community groups on advance care planning.*

## **BOB BROWN'S EUTHANASIA BILL**

Senator Bob Brown introduced the new Euthanasia Bill to amend territory legislation to restore legislative powers concerning euthanasia and to repeal the *Euthanasia Laws Act 1997*. He gave a second reading of the Bill on September 17, 2008. Debate has been adjourned. Bob Brown says: *I feel confident that this will get through the Senate and am very hopeful it will also get through the House of Representatives before Christmas.*

He is calling for the major parties to allow a conscience vote and said: *I think Kevin Rudd may be inclined that way but that's not clear yet and we have a new leader of the Opposition, Malcolm Turnbull so I'll be approaching [him], so that we have the legislation hopefully pass the Senate and then go to the House of Representatives.*

Michelle Grattan of *The Australian* believes that Senator Brown's pressure will be a test of the Prime Minister's attitude on two fronts. How willing is Rudd (personally against euthanasia) to risk such a divisive and distracting debate? And how much does he take the Greens for granted, or will he think they need to be cultivated?

The Northern Territory Chief Minister Jon Stanhope said he would not introduce any Bill to introduce euthanasia if Senator Brown's Bill was successful.

### **SOUTH AUSTRALIA**

Greens MP Mark Parnell will introduce a private member's bill in the next parliamentary session. There have been four failed attempts since 1995 to legalise voluntary euthanasia in SA. Since the last Bill was introduced to the Upper House, nine of the 22 members have changed. Mr Parnell says he is hopeful his Bill will be supported.

### **VICTORIAN (PAD) BILL**

The Physician Assisted Dying Bill, 2008 was voted down 25 to 13 in a conscience vote in the Upper House. The PAD Bill would have allowed terminally ill patients to end their lives with the help of a doctor.

The rejected Bill has been sent to an Upper House committee for further consideration.

Many of those who voted against the Bill expressed support in principle for physician assisted dying (PAD), but had specific concerns about one or other provision of the Bill. Neil Frances, President of DWDV says: *Despite the wide disparity in the vote, all the indications are that a majority of Upper House members do support PAD in principle.*

The government allowed a conscience vote on the Bill itself, but removed the conscience vote from procedural matters for Labor members, who then voted as a block to defeat the proposal to refer the Bill for

The American Medical Association adopted a new ethical policy about the practice known as 'palliative sedation'.

California approves nurse-assisted suicide. California Governor Arnold Schwarzenegger has signed into law a Bill (AB 2747) that opponents say could open the door to the eventuality of physician-assisted suicide in the nation's most populous State.

AB 2747 mandates that physicians, nurse practitioners and physician assistants provide patients diagnosed with a terminal illness – or who have been given a diagnosis of one year or less to live – with "comprehensive information and counselling regarding legal end-of-life options, as

# UPDATES



detailed consideration in committee. DWDV has called on the Victorian Premier to refer the matter to the Victorian Law Reform Commission for wide community

consultation.

Eighty-two percent of Victorians are in favour of PAD and DWDV will continue to fight for this type of legislation to enact the right to PAD.

### **WA**

On September 6, 2008 Western Australians cast their vote for the new Parliament. Stephen Walker, who stood as an Independent for a seat in the Legislative Council, included VE on his platform, but was unsuccessful in his campaign.

The election was called early – which necessitated a hasty, but focused campaign. *The Acts Amendment (Consent to Medical Treatment) Act 2006* has received the Governor's consent, but it still has to be proclaimed by the Minister before it takes effect. Ranjan Ray, President of WAVES says: *I feel that it will be proclaimed, but it may not be a priority for the Government. I have written to the Minister, but yet to receive a reply. We are keeping our fingers crossed.*

### **USA**

On November 9, 2008, Washington State constituents will vote on Initiative 1000, a ballot to allow physician assisted-dying, as Oregon does. An estimated 320,000 signatures were submitted to the Secretary of the State's office to get the initiative on the ballot.

specified".

### **INDIA**

Taking the first step towards legalising euthanasia, the Law Commission has decided to recommend to the government to allow terminally ill people to end their lives to relieve them of long suffering.

### **SPAIN**

The local government of Spain's south western region of Andalusia is preparing a pioneering euthanasia law which would allow terminally ill patients to refuse medical treatment and make it illegal to keep someone alive by artificial means.

### **CZECH REPUBLIC EUTHANASIA DRAFT BILL UP FOR REVIEW**

For the first time, the Czech Republic Parliament will discuss the possibility of giving citizens the right to have a "dignified death" by legalising active and passive euthanasia.

### **LUXEMBOURG EUTHANASIA BILL GETS SECOND READING**

The second reading of the controversial law on euthanasia is scheduled for before the end of the year in Luxembourg's parliament. If passed, it would then come into force on January 1, 2009. The news was confirmed by the Parliamentary Health Commission.

The Bill was passed by 30 votes to 26 in its first reading in February this year. The Health Commission has examined the dossier and is proposing one small, but technical change, i.e., to replace one word 'independent' by 'impartial', in referring to the involvement of another doctor, rather than the one who is treating the patient. Also, patients under the age of 18 will be excluded from the Bill.

# CONSCIENCE VOTING

“Denying another’s freedom while exercising one’s own is hypocritical” says **Dr Leslie Cannold**.



Is it ever right to use one’s freedom to deny the exact same freedom to others? What if those others are people you are sworn to serve and protect?

Such questions may not be front of mind for our State MPs, but they should be. Before the year is out, Victoria’s MPs will cast a conscience vote on Bills about physician-assisted suicide, abortion and assisted reproductive technologies (ARTs). Conscience clauses will be contained in each of these Bills.

Our understanding of the proper role of conscience in politics and health remains murky. What is conscience, why are we pledged to honour it, and what responsibilities do those who claim the right to follow theirs, have to others?

The right to act according to the dictates of our conscience is founded in the value of autonomy. Autonomy means self-rule. An autonomous person is one who is free to direct his/her life according to his/her own values. It would be hard to overestimate the role autonomy, and therefore conscience, plays in the value systems of contemporary Australian society. Our political and legal structures are grounded in the belief, to paraphrase High Court Justice McHugh, that autonomous individuals are entitled to make, and are consequently responsible for, their own choices. And our health system, in line with that of others in the Western world, has shifted

in the past few decades from the paternalistic idea that doctors know best, to the view that patients have a right to make their own informed choices about their care.

All this suggests what is true: that most learned discussions of conscience focus on the duties lawmakers and medicos have to protect the autonomy of citizens and patients. This is for good reason. Both our elected representatives and health care staff are professionals: trusted and respected members of society, with a duty of care to those they are sworn to serve and heal.

Despite this, some professionals in Victoria seem primarily concerned with their rights – when it comes to conscience – not their obligations. Some MPs, understandably pleased at the rare opportunity to shrug off party discipline, see a conscience vote as a chance to register their own value positions on the issues at hand. In the same way, conscience clauses in Bills on euthanasia, abortion and ARTs tend to spell out the entitlements of medical professionals to refuse treatment they deem morally objectionable, but are silent on their obligations to ensure patients get timely, appropriate care.

We need to get the balance right. Yes, the entitlements of MPs and medical professionals to follow the dictates of their consciences are part of the autonomy story. But if mutual obligation means anything, then political and medical professionals who assert their right to vote, or to refuse care on grounds of conscience, must take their responsibilities to foster the autonomy of those they are bound to serve — we citizens and patients — just as seriously.

They can do this by recognising that it is unconscionable for someone to defend the right to follow his/her conscience, then deny that very same right to someone else. Such moral hypocrisy is compounded when those denying the autonomy of others are professionals, and those they are

denying are the citizens or patients they are sworn to serve.

For politicians, this means thinking twice about using a conscience vote to pass a law that denies citizens the right to act on their consciences when terminally ill, facing an unplanned pregnancy, or seeking to conceive using ARTs.

For medical professionals, it means ensuring that all conscience clauses in legislation include an obligation to refer. That is, where the law articulates the right of doctors, nurses and pharmacists to refuse treatment on grounds of conscience, it must also spell out the obligations of professionals to ensure their patients’ needs are met elsewhere.

Pro-life groups continue to resist such basic demands, though medicos tend to be on-board. A recent letter to all Victorian MPs signed by a number of religious leaders spent paragraphs detailing the extensive rights of health-care workers to refuse treatment on grounds of conscience, and just one sentence tartly rejecting the idea that these providers had any obligation to refer.

In contrast, the ethical practice guidelines of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists instructs its members to “offer or arrange a further opinion and/or ongoing care with another suitable practitioner if the therapy required is in conflict with (your) personal belief/value system”.

With all rights come obligations, and the freedom to follow one’s conscience is no exception.

**WITH ALL RIGHTS  
COME OBLIGATIONS,  
AND THE FREEDOM  
TO FOLLOW ONE’S  
CONSCIENCE IS NO  
EXCEPTION.**

As members of our community, politicians and health-care workers are as entitled as the rest of us to live their lives according to their values. But because they are professionals, these rights come with significant responsibilities, responsibilities that come down to a requirement that those who act from conscience live by the golden rule: do to others as you would have them do to you. § *This article appeared in The Age (Sept 10 2008) and is reproduced here with permission of the author.*

*Dr Leslie Cannold is a medical ethicist, the author of several books and articles on reproductive autonomy and conscience, and the president of ProChoiceVic.org.au*



**B**ranch meeting  
Seventeen members and six guests attended the meeting held on August 15, 2008, which ended up, in the opinion of one member, being the "best one ever". Unexpectedly, since no confirmation of acceptance of an earlier invitation was received, the meeting was addressed by new Federal ALP Member for Robertson, Belinda Neal.

She said that she had come to say that she had had no need to get across the issues concerning our organisation, because she was blessed by a very healthy and long-lived family. However, she was keen to listen and learn, which is what she did, encouraging questions and comments, and answering where she could. She said she would be happy to respond to any letters she received from members and guests present. All those present commented that we appreciated her courage and willingness to attend our meeting.

We had another speaker, at short notice: local solicitor Robert Byrd, who came to discuss the jury's decision on the Graham Wylie case. He explained that there is no requirement for a jury to give reasons for its decision, which was to determine if Mr Wylie's death was suicide, murder or assisted suicide. The fact that they chose not to convict Mr Wylie's partner or friend of murder or assisted suicide, but manslaughter, gave some indication of their reasoning.

Mr Byrd thought that there were two issues which played a role in their decision: one was the changes to Mr Wylie's Will, the other the question of his legal capacity to give consent to his manner of dying. In the speaker's view, there were certainly grounds for the jury to make the decision they did, given the present state of law, which makes voluntary euthanasia a crime.

The meeting also heard from Bettina O'Meara who had taken on the role of convenor of Exit International members on the Central Coast. A first workshop led by Dr Nitschke was arranged for 27 September and all interested people were invited to attend the public meeting prior to the workshop.

U3A (University of the Third Age) workshops, I'd like to advise readers about the 90-minute workshops I've been holding in various venues in Gosford over the past 12 months, on *How to write your advance directive/living Will*. The information I have been able to pass on, based on VESNSW and NSW Department of Health documents, seems to have been well received and much appreciated. I encourage other VES members to consider offering such workshops in their areas, and am happy to pass on my experiences to them if they contact me.

**Next meeting**  
The final meeting for this year will be held at the Gosford Senior Citizens' Centre at 10am on Friday 19 December. Members are encouraged to bring some food or drink to share.



**I**n the ACT election of October 18, 2008, four Green MLAs were elected, thus giving them balance of power. There are seven ALP and six Liberals in an Assembly of seventeen Members.

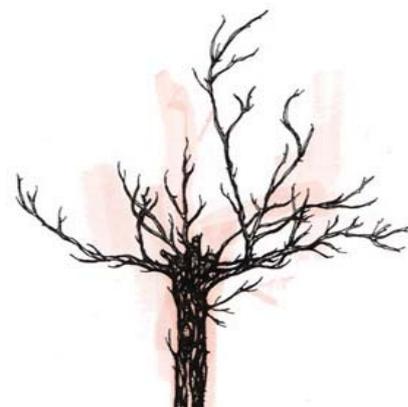
They have not yet (as at October 26) declared which other party they will support to form minority government.

They have stated that VE legislation is one of their policy objectives, so although this cannot be implemented before Senator Brown's Bill is passed, it is an encouraging development for our cause.

The AGM on 16 October was a lively meeting, with much sharing of information from web sites and other sources. This information, from within Australia and from other countries, is now so prolific that no single member or Committee can keep up with it all and we are encouraging 'corresponding' members to help us keep up-to-date and provide material for discussion.

Health Directions (known as Advance Health Care Directives in some other places) are a matter of concern to which we are giving high priority. We have contacts with other organisations interested in this matter and who share our concern to obtain national reciprocity, a stronger legal framework for recognition of such Directions, and a national data base. We would be interested in liaison with other State or Territory organisations to help make progress. One suggestion is that we might try to get it onto the agenda of a meeting of health ministers.

*The ACT Guardianship and Management of Property Act* was recently amended to extend the range of persons who can give



consent to providing medical treatment on behalf of adults who have impaired decision-making capacity. These 'Health Attorneys' can include family members, carers, and close friends. Our submission on the Amendment Bill argued for such an extension but urged also that 'Consent to Withhold or Withdraw Treatment' should be covered by similar provisions.

# ADVANCE HEALTH CARE DIRECTIVE

Dr Giles Yates  
President, VESNSW



## 'ALSO APPOINT AN ENDURING GUARDIAN....'

There is no disagreement that we have a legal right in NSW to refuse unwanted medical treatment. This right is derived from our history of judicial decisions (the common law).

This right extends to situations when we have lost the capacity to consent to, or refuse medical treatment, as long as there is a record of our wishes. There are many templates of advance health care directives (AHCDs) which can assist us to formulate our wishes as clearly as possible. However, to be useful and legally binding, the record of our wishes must be clearly established and applicable in the particular circumstances.

To be clearly established an AHCD should demonstrate that the person:

- Was informed about the alternatives and the consequences of refusing treatment
- Was completely voluntary when recording his or her wishes
- Was mentally competent to make the type of decision.

To be applicable in the circumstances, an AHCD should be general enough to cover most likely situations where it might be needed, but also particular enough to give confidence that it is applicable in the situation where it is needed.

The Voluntary Euthanasia Society of NSW was one of the first organisations in the world to recommend using advance health care directives to refuse unwanted medical

treatment.

It is now time to update, so in November 2008 we are sending out our new recommended template to all members with our this newsletter.

Existing advance health care directives on the old template are still as effective as they ever were, but we recommend that you make a new advance directive using the new template. It was written by Prof Colleen Cartwright Director of the Aged Services Learning and Research Collaboration Southern Cross University, Coffs Harbour. It is not copyright, so you may feel free to photocopy it for family or friends.

Two of the benefits of the new template are:

- it makes clearer the information that was considered when we recorded our wishes
- it covers more possible circumstances.

It is not wasted effort to sign a new AHCD because it is a good idea to renew our documents every few years. One of the uncertainties that can arise when an AHCD is needed, is that our wishes may have changed in the time since we signed it, so the more recent it is, the more persuasive it is.

VESNSW has been reminding members for some years that one of the best ways to ensure that our wishes in our AHCDs will be respected, is for us to also appoint an Enduring Guardian with the legal right to enforce our wishes. Information on appointing an Enduring Guardian can be obtained from:

<http://www.gt.nsw.gov.au/plan/enduring-guardianship.cfm>

(ACT members note: this new AHCD applies to NSW only)

## SUFFERING & CHRISTIANITY

At a mass for the sick outside the gold mosaic facade of Lourdes' Basilica of the Rosary, the pope urged the sick to remember that: *dignity never abandons the sick person. There are struggles that we cannot sustain alone, without the help of divine grace. For each person, suffering is always something alien, ...it can never be tamed.*

Mother Theresa of Calcutta not only celebrated her suffering, she taught the world's sick and dying their pain *was only the kiss of Jesus.*

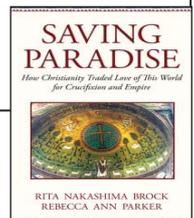
A new book, *Saving Paradise: How Christianity Traded Love of This World for Crucifixion and Empire* (Beacon Press) turns upside down the history of the Christian church's view of Jesus' crucifixion and suffering and the Church's teachings on death and euthanasia.

The book states that the early church didn't highlight Jesus' suffering, but emphasized love of this Earth, striving to make it a paradise.

That's certainly not the way Mother Teresa saw the world. She believed the anguish of the terminally ill, for whom she did not provide pain medication, was a way to *share in God's suffering and to make up for the sins of the world.*

In her charity work, Mother Teresa linked the pains and sufferings of the disabled, poor, and dying to the torture of Christ on the cross, to the point of telling lepers their disease is *a gift of God.* The lepers' redemptive suffering was *saving the world the most terrible calamities.*

**Saving Paradise:**  
How Christianity Traded Love of This World for Crucifixion and Empire  
Rita Nakashima Brock  
& Rebecca Anne Parker  
Beacon Press  
ISBN: 9780807067505  
Gleebooks and online



It paralleled a Biblical atonement sacrifice. Teresa was a devotee of the 13th-century monk, Francis of Assisi. In addition to being admired as the patron saint of animals, Francis of Assisi taught that: *perfect joy [is] to share in the suffering of the world as Christ did.*

The authors of *Saving Paradise*, Rita Nakashima Brock and Rebecca Ann Parker, judge Francis' love of suffering as an epochal downturn in the history of Christian theology.

Francis of Assisi was fuelled by a burning desire to be martyred, to be *torn limb from limb.* He brought that belief to his support of the Crusades, which aimed to convert Muslims by the sword. (cont'd p.12)

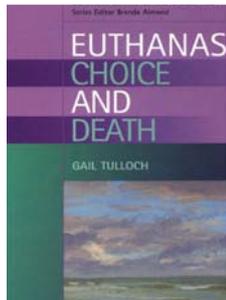
## *Euthanasia: Choice and Death*

Gail Tulloch

Edinburgh University Press

ISBN: 9780748622474

Euthanasia has become increasingly contentious as populations age, and medical and scientific advances continue



to transform and extend life. *Euthanasia - Choice and Death* examines the key philosophical arguments that have underpinned thinking and practice up till now. The centrality of

choice to our notion of the human being. The challenge of changes to our concept of death in the face of medical, scientific and technological advances. Gail Tulloch develops a concept of dignity that does not depend on religious assumptions and can promote a broad ethical consensus in a liberal democracy. Examination of landmark cases and the approaches adopted by key countries - the USA, the UK, the Netherlands and Australia - ground the book. •Dr Gail Tulloch is Adjunct Research Fellow at Griffith University.

Available from [buyaustralian.com](http://buyaustralian.com), Amazon.com, Google Books

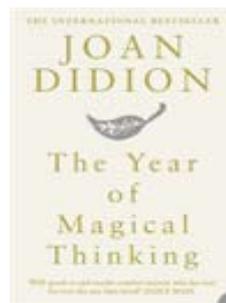
## The Year of Magical Thinking

Joan Didion

Alfred A Knopf

ISBN: 9781400043149

Several days before Christmas 2003, John Gregory Dunne and Joan Didion saw their only daughter, Quintana, fall ill. At first they thought it was flu, then pneumonia, then complete septic shock. She was put into an induced coma and placed on life support. Days later – the night before New Year's Eve – the Dunnes were just sitting down to dinner



after visiting the hospital when John suffered a massive and fatal coronary. In a second, this close, symbiotic partnership of 40 years was over. Four weeks later, their daughter pulled through. Two months after

that, arriving at LA airport, she collapsed and underwent six hours of brain surgery at UCLA Medical Center to relieve a massive

haematoma.

This powerful book is Didion's 'attempt to make sense of the weeks and then months that cut loose any fixed idea I ever had about death, about illness ... about marriage and children and memory ... about the shallowness of sanity, about life itself'. The result is an exploration of an intensely personal, yet universal experience: a portrait of a marriage, and a life, in good times and bad.

Available at good bookstores.

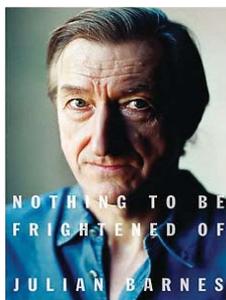
## Nothing to Be Frightened Of

Julian Barnes

Random House

ISBN: 9780224085236

Julian Barnes gives us a memoir on mortality that touches on faith and science

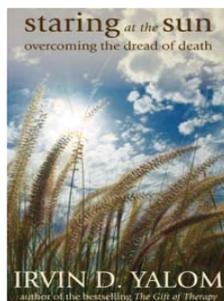


and family, as well as a rich array of exemplary figures who, over the centuries, have confronted the same questions he now poses about the most basic fact of life: its inevitable extinction.

'I don't believe in God, but I miss Him.' Julian Barnes' new book is, among many things, a family memoir, an exchange with his brother (a philosopher), a meditation on mortality and the fear of death, a celebration of art, an argument with and about God, and a homage to the French writer Jules Renard. Though he warns us that 'this is not my autobiography', the result is a tour of the mind of one of our most brilliant writers.

Available in all good bookstores.

## Staring at the Sun: overcoming the dread of death



Irvin D. Yalom  
Scribe Publications  
ISBN :  
9781921215667

Written in Irvin Yalom's inimitable story-telling style, *Staring at the Sun* is a profoundly encouraging approach to the universal issue of mortality.

In this magisterial opus, capping a lifetime of work and personal experience, Dr Yalom helps us recognise that the fear of death is at the heart of much of our day-

to-day anxiety. This reality is often brought to the surface by an 'awakening experience' — a dream, a loss (such as the death of a loved one, a divorce, or the loss of a job or home), illness, trauma, or ageing.

Once we confront our own mortality, Dr Yalom writes, we are inspired to re-arrange our priorities, communicate more deeply with those we love, appreciate more keenly the beauty of life, and increase our willingness to take the risks necessary for personal fulfillment.

This is a book with tremendous utility, including the provision of techniques for dealing with the most prevalent kinds of fears of death — especially by living in the here and now, and by embracing what Dr Yalom calls 'rippling', the influence and impact we all have that has a life beyond our own.

Available at good bookstores.

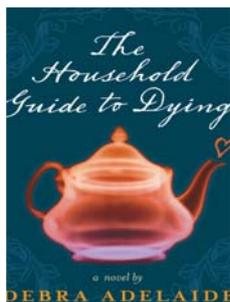
## The Household Guide to Dying

Debra Adelaide

Picador Australia

ISBN: 9780330424257

When Delia Bennet – author and domestic advice columnist – is diagnosed with cancer, she knows it's time to get her house in order. After all, she's got to secure the future for her husband, their two daughters and their five beloved chickens. But as she writes lists and makes plans, questions both large and small creep in. Should she divulge her best culinary secrets? Read her favourite novels one last time? Plan her daughters' far-off weddings?



Complicating her dilemma is the matter of the past, and a remote country town where she fled as a pregnant teenager, only to leave broken-hearted eight years later.

Researching and writing her final Household Guide, Delia is forced to confront the pieces of herself she left behind. She learns what matters is not the past but the present – that the art of dying is all about truly living.

Fresh, witty, deeply moving – and a celebration of love, family and that place we call home – this unforgettable story will surprise and delight the reader until the very last page.

Available in most bookstores.

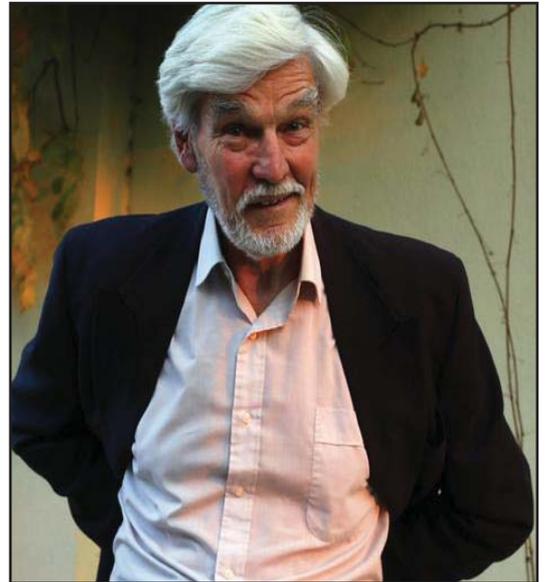
# FOR YOUR DIARY

## General Members' Meeting

When: 2.00pm Sunday 23 November 2008  
Where: SMSA 280 Pitt St Sydney  
(Sydney Mechanics' School of Arts)

## Guest Speaker: Dr Rodney Syme

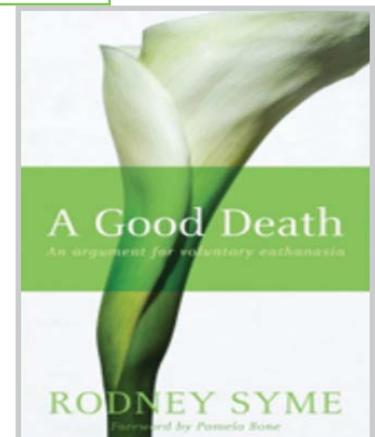
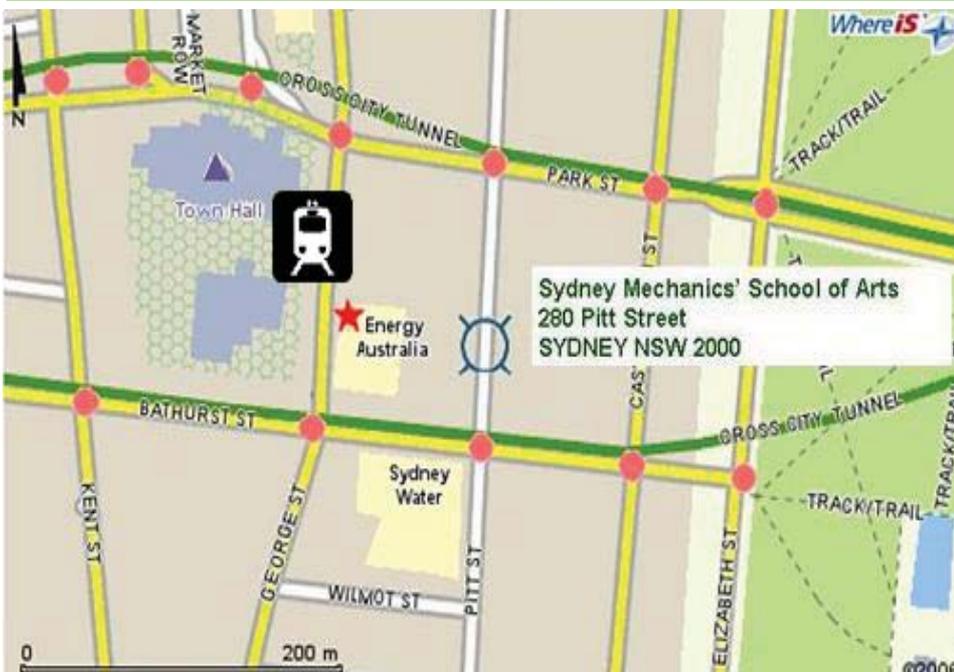
Dr Rodney Syme has been in medical practice for 45 years, primarily as a urological surgeon. He was chair of the Victorian section of the Urological Society of Australasia 1990-92, and chair of the Urology Study Group of the Cancer Council of Victoria 1992-94. He has had extensive experience with cancer patients and with people with severe spinal injuries. He has been an advocate for physician-assisted dying for nearly 20 years, and the President of Dying with Dignity Victoria for ten years.



## LESSONS FROM 'A GOOD DEATH' - THE IMPORTANCE OF LANGUAGE

Copies of *A Good Death - An Argument for voluntary euthanasia* will be available for purchase.

Win a copy of  
*A Good Death* -  
enter our raffle  
on the day!



**THE FRONT  
DOOR TO THE  
BUILDING WILL  
NOT BE OPEN  
UNTIL 1.45PM**

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(...cont'd p.9) The book's authors, both of whom are Christian, argue that the church of the first millennium never stressed that Jesus' suffering on the cross was necessary for the salvation of humanity.

They say: *It took Jesus a thousand years to die. Images of his corpse did not appear in churches until the tenth century.*

At first Brock and Parker were stunned by the dearth of crucifixion images in Mediterranean churches, especially given their importance to centuries of later doctrine, including that of Mother Teresa.

The early Christian community did not so much draw inspiration from suffering and the next world, but from earthly life and a vision of paradise. Before the 11th century, Christian imagery portrayed Jesus alive teaching and healing and living in this world.

The images were of goodness, plenty and gentleness. During their first millennium, Christians filled their sanctuaries with images of Christ ... as a shepherd, a teacher, a healer, an enthroned god; he is an infant, a youth, and a bearded elder. But he is never dead. When he appears with the cross, he stands in front of it, serene, resurrected. The world around him is ablaze with beauty. These are images of paradise — paradise in this world.

The book tackles the subversion of the Christian message -- beginning with the ninth-century Holy Roman emperor Charlemagne, who instituted the death penalty for conquered people who refused to convert.

After Charlemagne, killing, suffering and dying in the name of Christ began to represent the highest honour for Christians. By

re-emphasizing early Christians' focus on paradise, the authors are convinced they are reclaiming authentic "traditional" Christianity. It's a fascinating thesis, deserving of debate and study.

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## WEBSITE

Don't forget the VESNSW website is updated regularly and contains news stories from Australia and around the world. You can also find copies of Newsletters and book reviews as well as interesting information about the history of VE.

Access 'Fact Sheets' outlining many issues and arguments that you may find useful in your thinking.

### VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES

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### SUBSCRIPTION INFORMATION

Membership subscriptions to VESNSW are \$30 single and \$50 for a couple. Concession rates of \$18 single and \$30 couple are available for pensioners and students. Life membership costs \$550 single and \$800 for a couple.

