



VES^{nsw} NEWSLETTER

promoting end of life choice

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The big February event in Sydney was the IQ2 Debate – We Should Legalise Euthanasia. Speakers were Prof. Peter Baume, Sen. Bob Brown and Dr. Philip Nitschke (for). Dr. Maria Cigolini, Tony Abbott and Fr. Frank Brennan (against). (Frank Brennan chairs the National Human Rights Consultation Committee – more on that later). If you missed out on the debate you can watch it on our website:

www.vesnsw.org.au along with other follow-up articles by Peter Baume, *SMH* columnist Lisa Pryor, and others.

The 'for' team won the audience vote with 75 per cent in favour, 20 per cent against and 5 per cent undecided. The consensus of the 'against' camp was that they weren't *against* euthanasia - just the creation of legislation for its implementation.

Frank Brennan and Tony Abbott oppose legislation because some people are vulnerable, or are frightened of being coerced into using it.

After Frank Brennan's appearance at the Inquiry into the *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* held in Sydney I wrote: *Frank Brennan, a Jesuit priest and a law professor at the Australian Catholic University, said legal euthanasia would undermine efforts to improve health in remote indigenous communities. He used Australian Medical Association comments that some indigenous people could refuse medical treatment if voluntary euthanasia laws are reinstated in the Northern Territory, to back his argument.*

Following his thinking, we should avoid all legislation that some members of society are frightened of, or do not want. Denying someone assistance when they are suffering intolerably, because someone else is frightened, is hardly level-headed decision-making - or ethically sound.

The point is to educate the community about PAD and the safeguards that we, the VE societies, are advocating.

The members of the 'against' camp acknowledged, (and commended), those doctors who act compassionately, and provide assistance when this assistance would mean death. They justify this position using the doctrine of 'double-effect', the Catholic idea

developed by St Thomas Aquinas that where an action can be seen to have both good and bad effects, then that action is justified if the intention was good (to relieve suffering). This is their 'get out of the argument' clause. The claim that we don't need legislation because it is already happening (and working well) is an astonishing one!

There is a reinforcement of an age-old paternalism inherent in their arguments. So, it's ok for doctors to covertly assist terminally ill people to die, but it's not ok for them to act at a sufferer's request. Then it becomes a crime.

Doctors who care deeply for their patients, as many do, should not have to fear prosecution. Where there is agreement and acceptance between the sufferer and the doctor that death is preferable to ongoing distress, physician-assisted dying is an act of care and respect. A sufferer should have control over – in what must surely be the ultimate treatment – the manner in which they end their life. (See Dr Rodney Syme's comments about the doctor/patient relationship in his article: *Lessons from A Good Death: The Importance of Language*).

National Human Rights Consultation

Romaine Rutnam, convenor of the Central Coast branch would like to encourage all members to contribute a submission to the Human Rights Committee. She has been active in rallying many members to the cause. The VESNSW and the other State societies are currently working hard on their own submissions.

The recognition of a person's rights at end of life is an important contribution to the discussions. Focusing on the need to relieve profound suffering is a good place to start your own submission.

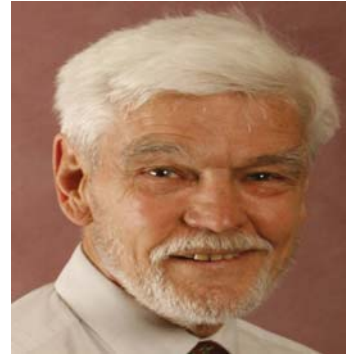
Dr Rodney Syme says in his article in this edition: *I learnt from this experience that some suffering will only end with death.*

You can send your written submission to: National Human Rights Consultation Secretariat. Attorney-General's Department Central Office. Robert Garran Offices, National Circuit, BARTON ACT 2600 **Closing date: 29 May 2009.** The committee will deliver its report to the Government by 31 August 2009.

You can call 1800 086 134 (freecall, available between 10.00am and 4.00pm) Email: humanrightsconsultation@ag.gov.au and visit the website: <https://www.humanrightsconsultation.gov.au>
Annemaree Adams, Co-ordinator

LESSONS FROM A GOOD DEATH: THE IMPORTANCE OF LANGUAGE

Dr Rodney Syme



what one is thinking and writing about, and a consistency in the use of language.

It soon became clear to me that I would have to define my subject, and also that there was no accepted definition of 'euthanasia'.

The widely-accepted Rummelink definition (the Dutch studies into end-of-life practice in the Netherlands) was designed for simply for the purpose of empirical research, so the definition was trying to sort out different ways in which doctors would be helping patients to die. That definition has been widely adopted, but in my opinion it was completely inadequate, and has harmed our advocacy, simply because it allowed euthanasia to be described as the intention to deliberately kill a patient - but without any context - and as you've seen by what I've said already, context is critical to such actions.

Colleen Cartwright, whose work I admire, addressed you recently and used this definition: 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.

Again there's no context. That definition would allow somebody who is in the middle of an acute psychotic episode, (and believes that it's in their best interests that they need to die at that particular moment), to be eligible for euthanasia, whereas later, after they had been adequately treated, they might say that was not in their best interests.

Thank you very much for the opportunity to come and talk to you, and as Giles has said, this invitation and my talk stems from the publication of my book *A Good Death*. A cause of some love and a lot of anxiety, the book had its genesis in around the year 2000 when I realised that I had had quite a significant experience in assisting people at the end of their lives.

That experience had taken place in a covert environment for over 25 years – and it was an experience not unique to me but, one which few, if any doctors, were prepared to talk about – and I felt that the journey that I'd had could be worth talking about.

At the same time I knew that I was exposing myself and my activities which were perhaps quasi-legal, to say the least, to public scrutiny, which is why the book took such a long time to come to fruition. Every time I sat in front of my computer I said: Am I being an absolute idiot? And I'll explain shortly why I didn't think so in the long run.

The second reason for writing the book was this – whilst I realised that there was a high level of support in the community for what I was doing, whilst people had a gut instinct of support in having a doctor to help them, I really felt there was a poor understanding of the context in which such assistance would be provided.

This poor understanding included not only the general public, but in my experience also doctors, journalists, bio-ethicists and philosophers. All these people, often posing as great experts, were writing about something that they have never done or never seen done. And that's like being a professor of surgery who's never operated on a patient. So I felt it would be very useful to have somebody who had been, if you like, in the front line talking about that experience.

The dialogue and ultimate transaction between a doctor and a sufferer is a unique experience, and if doctors, and those they are helping do not talk about it, there will be little understanding of what actually takes place. Of course, unless the sufferers are encouraged to record their feelings at the time, they are lost forever.

So I started recording some of my experiences before my memory dimmed, adding new stories as time went on and my experience grew. I particularly selected those patients who had recorded their own thoughts through letters to me. I particularly encouraged people I was helping to do this on a number of occasions for various reasons. Writing down one's thoughts helps to clarify, and provides a continuous record of the state-of-mind and experience of suffering. And many people needed to clarify and work through the issues. Keeping a diary can also provide a continuous record of the state-of-mind and experience of a suffering person and provide evidence of the effect of dialogue and the provision of advice and medication.

Each story gave a different context and an opportunity to develop various principles involved. As the book developed, it also became a story of my journey from a rather hesitant and fearful agent, to a more accomplished and outspoken advocate.

The book also developed into a challenge to palliative care, and although the title of the book says: An argument for euthanasia - that was the publisher's decision. I never saw the book as an argument for physician-assisted dying (PAD) or voluntary euthanasia, but I think in a way it does end up being that. Ultimately the book provides a potential challenge to the law.

The process of writing a book crystallises one's thoughts, and requires a consistent logic in

In my opinion an act of euthanasia is a palliative act. I'm speaking to you as a doctor. When a doctor carries out physician-assisted dying (which is a term which I prefer to use), because he is confronted with a person with severe and intolerable suffering, he is acting to palliate the patient's suffering.

A doctor helping such a person to end their life is acting in a palliative capacity. The doctor's primary intention is not to kill the patient – the primary intention is to relieve the suffering - even although the action that follows may result in the patient's death.

So a definition like Colleen Cartwright's and the Rummelink one may satisfy philosophers or sociologists and legal people, but it does not satisfy me as a doctor. It is totally inadequate - it does not stress that we are describing a palliative act, it has no context.

Moreover, such definitions create the view that PAD, or euthanasia by lethal injection, is something that a doctor did, rather than something a sufferer might do. The doctor is doing something, and the patient is receiving.

In my view, the responsibility of such an act lies with the individual who is suffering – it is something that they do – after being given advice about medication from the doctor.

So I developed a definition for the purpose of the book which placed the sufferer centrally as the decision-maker and actor, and the doctor as the agent.

That definition is:

That PAD is an action taken by, or at the request of, a rational fully-informed individual whose intention is to be relieved of intolerable and otherwise unrelievable suffering. And that death is hastened in a dignified manner. And you can see in that definition that the intention is the intention of the sufferer. It places the sufferer centrally in the definition. And it places the act as a palliative act.

Language is important. If we allow the definition of voluntary euthanasia or PAD to be one that says the doctor is killing their patient then that is language that flows directly into our opponents' hands. If, however, we argue that what we are talking about is a palliative act, one which is in essence no different from many other palliative acts which are carried out medically every day, then we are beginning to engage the public, and the legislators, in a very important and meaningful way.

My own experience had been contrary to that of the Netherlands, where lethal injection seemed to be the norm, but I have never used it. The experience I have had, and the stories in the book reflect this, are that it is very, very rarely necessary for a doctor to provide a patient with a lethal injection. In circumstances where a person has intolerable suffering and wants help to have it relieved, in the vast majority of circumstances, it is possible for that sufferer to do it themselves. It is only when they cannot ingest medication, because they can't swallow or absorb medication, or they're totally paralyzed or they've got no mobility, or, if they're vomiting profusely and cannot absorb the medication – these are the limited circumstances in which a person cannot take control over the end of their life.

I think it is regrettable that the Dutch developed a framework whereby lethal injection became the public image of the way that voluntary euthanasia was carried out.

The experiences that I have had over these 25 and more years, (and the stories in the book reflect this), have taught me the true nature of suffering. As a young doctor I was taught about physical illness, and like most doctors I would have seen suffering as being primarily due to pain. But it became apparent to me that pain was only a small part of the issue.

There are people with severe respiratory difficulties, struggling to breathe and people with cancer dying by inches, gradually losing weight, losing appetite, losing strength and just literally wasting away.

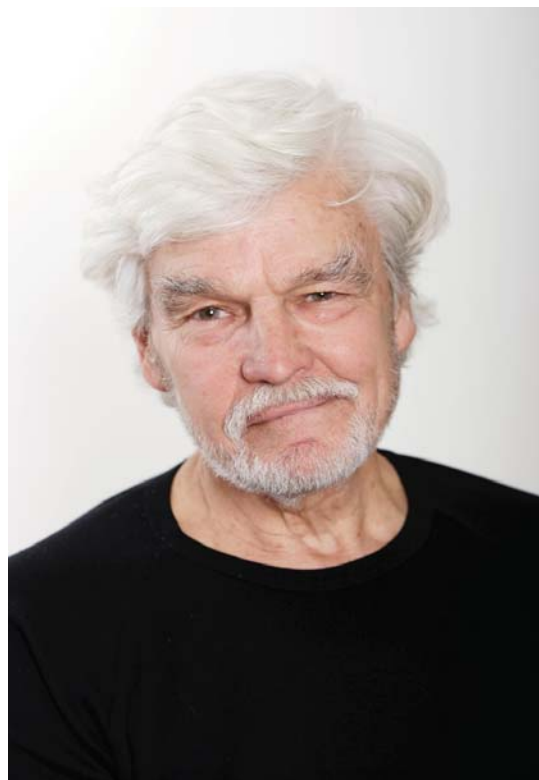
That is suffering to an extreme degree. It is not simply pain. It is not merely physical, as in breathlessness, fatigue, relentless nausea and vomiting, diarrhea and incontinence, or paralysis and loss of mobility.

But of course, these physical things that I've described are intimately involved with psychological and existential suffering. You might suffer because you've got a severe pain in your neck, but where do you feel that pain? In the mind - that's where you interpret the pain, where the suffering occurs.

People with end-of-life issues lose their sense of control about their life, the end of their life. They suffer from a loss of purpose, a loss of meaning, of being a profound burden.

All of this, wrapped up with the loss of control, adds the most profound suffering. It's not something you can measure. It's not something you can visualise. But it's there – and it's profound.

That combination of physical, emotional, physiological and existential suffering is



what is recognised in the term of 'total pain syndrome'. You can do something about some of those physical symptoms to relieve them, but not all of them. You can do nothing about the wasting that occurs with cancer – but you can do a little to alter the psychological and existential suffering that people can have.

The sufferer is fearful, has lost their sense of purpose and meaning, feel they are a profound burden. They have lost their sense of dependence, of control. All of this contributes to what palliative care calls a total pain syndrome.

But of course, much of this suffering cannot be palliated.

Each of my patients has taught me something, but I will concentrate on four particular stories.

The first patient to engage me in this issue was a woman who had cancer of the kidney which had spread into the spine. The spine had collapsed. There was partial paralysis of the leg, the bladder and the most appalling neuropathic pain due to the cancer pressing on and irritating the nerves. Her pain was like the pain you might get at the dentist if he/she inadvertently strikes a nerve in your tooth without an anesthetic – it goes from 0 – 10 in a millisecond – it's the most appalling pain you can have. And I could do nothing to relieve it.

I learnt from this experience is that some suffering will only end with death.

This embraces the concept of palliative futility. It's all very well to talk about palliative care being the answer, but there are circumstances where there is palliative futility – where there is nothing you can do in a palliative sense to alter that patient's suffering.

The next important situation was when I inadvertently came across the use of terminal sedation. I was doing some research on prostate cancer whilst following-up on a patient. This person had died in hospital. I pulled out his hospital file to find the information I wanted and discovered in the summary of the patient's history that there had been some difficulty initially in controlling the patient's symptoms, but that this had been managed and the patient had died peacefully. When I looked further into the file, I found that was stretching the truth by many, many miles.

That patient had enduring the most appalling suffering, again with a collapsed spine and paraplegic – but what I found out was that, at the end of that person's life, he had been deliberately put to sleep. By the doctors. Deliberately put to sleep without any food and fluids, without any maintenance or life-support.

This accelerated that person's death. I have no criticism of the decision to do that, but that it was done quietly, hushed up. There was no report to the Coroner, no mention in the letter to the doctor.

That patient died peacefully, deliberately obtunded. When I followed this up with the Coroner and the authorities, I found that the process of deliberately putting people into a coma and then maintaining it, was perfectly acceptable. I had discovered it by accident and I guarantee you that most of the doctors practising in Melbourne didn't know that it was going on.

Called 'terminal sedation', it has now become palliative care's answer to someone's request for a more dignified and speedy death. But that process can often take some days.

Later I had a young woman of 30 who had a brain tumour which had been operated on. She'd had radiation treatment which had been unsuccessful and she was dying slowly from this expanding tumour.

Suffering profound psychological and existential suffering, I counselled her and gave her advice and medication which would give her control over the end of her life.

She now had the means with which she could end her life. She lived on for another two and a half years. Her state of suffering

“I HAVE HAD EXPERIENCE WITH THE POLICE FROM AS FAR BACK AS 1976”

in her mind was profoundly affected (in a positive way), by having that control.

At the end of her life she did not use that medication. She died with the help of an advance health care directive which I had developed with her, and she was helped with terminal sedation.

That was a very profound experience for me because it indicated two things: if you give people control, you relieve their psychological and existential suffering, which is good palliation. The second thing was that whilst in my earlier work with people I had always been of the fear that I was breaking the law, that I was assisting in their suicide, which is against the law. But here, I saw what had happened – I gave her the medication, but she didn't use it.

What I had actually done was provide palliation. Whether she ended her life depended on her intention – not mine. And

my intention, I suddenly realised, rather dimly, had been to palliate her. I didn't actually want her to end her own life and I wasn't inciting her. My intention wasn't that she do it. My intention was to provide relief of her suffering and give her back some control. And that's what I did.

She decided in the end not to use the medication I gave her. Her intention was not to end her life. I think this is a very important lesson that we draw from that particular case.

Finally, there was the case of Steve Guest, who had esophageal cancer. He couldn't swallow, had a tube in his stomach. He was in severe pain, was wasting away to a ghost, and so, following through on that earlier case I mentioned, I decided that Steve was an absolute psychological and existential wreck and that one thing he needed for the last few weeks of his life was control. And I gave that to him. And I gave it to him for palliative reasons.

I now felt that I had an argument that I could use in defence of a doctor-provided medication which might then be used by a patient. I could argue that this was a palliative act, and so, through the media and various other ways, I made it known that I had given him control over the end of his life.

This then started a rather farcical investigation by the police and the authorities which is still going on, three and half years later. I'm having a further interview with Melbourne police next week which I'm looking forward to. [Victorian police have reopened their investigation into the 2005 death of Steve Guest. Dr Syme was interviewed on *December 10, 2008 – ed.*]

What are the lessons that I've learnt from the experiences and from writing this book?

Firstly, I think I can describe six medical 'givens', six medical facts that we can rely on:

- That dying can be associated with intolerable suffering
- Palliative care cannot relieve all such suffering
- That such suffering may only be relieved by death – the concept of 'palliative futility'
- Some patients do rationally and persistently request relief of such suffering
- Doctors have an ethical and legal duty to relieve such suffering
- And doctors have a duty to respect their patient's autonomy.

I developed the argument of advice and medication as palliative care. I begin the confrontation, which continues. I realise the full nature of the official conspiracy.

These are important principles which support me in my provision of help to patients.



I also learnt that doctors have made the law. You might think parliament makes the law – well, in medical areas, doctors have made much of the law.

It was in the 1960s that we first started to have the tools to prevent people from dying – using heart resuscitation, dialysis – all of these modern medical marvels which have saved a lot of lives – but have, nevertheless, prolonged many unnecessarily.

Doctors became very concerned – not about putting the tubes etc., in that might save someone's life – but about the event of having to remove the tube, when it was no longer working.

They became worried that if they took it out, they would be responsible for the person's death. They could be charged with murder. But because they thought it was the right thing to do for the care of the patient, they did it. And they weren't charged. And so the law was essentially created that it was appropriate for doctors to withdraw treatment, if that treatment was futile.

That terminal sedation that I talked about – where doctors quite deliberately put people to sleep, and kept them asleep with narcotic and sedative drugs without any support – no intravenous fluid, no airway support. These were clearly circumstances which could lead to a patient's death.

Did the law say that it could be done? No it didn't.

But doctors did it because they had suffering patients, and it was the only way that they could relieve their suffering. So they went ahead and did it. The law has never prosecuted a doctor for doing that, and it is now standard palliative care.

So doctors made the law by providing good,

ethical medical care, good palliation - the law went along with that.

What this essentially means is that good palliative treatment trumps the law, no matter what the law actually says in its written word. In strict terms, if a doctor was to deliberately hasten somebody's death by as little as a minute, he could be guilty of murder. But doctors do it all the time and they're not charged.

I have had experience with the police, the law and various cursory inquiries from as far back as 1976, when I was spoken to by police after I prescribed medication for a patient who took it to end their life.

Then there was the experience of 'The Melbourne Seven', where six of my colleagues and I publicly stated we'd helped people die. Again we were investigated by police, through to the medical board's cursory investigation that went nowhere. I've been interrogated by police on at least four occasions and it's always been, to my mind, a slap on the wrist with a wet fish.

And so I've come to the view that there is in fact a conspiracy, a benign conspiracy on the part of police, the Coroner, the DPP and the government not to investigate or pursue doctors who are practising good palliative medicine if it's done at the request of the patient. And if nobody makes a complaint, then no doctor is going to be actively pursued.

The fact that this conspiracy existed gave me the confidence, in the case of Steve Guest, to push the challenge to the law and try to create the precedent that the provision of medication and control for a patient could be seen as good palliation.

That would break open the fear that a doctor doing such a thing would be guilty of aiding and abetting suicide.

The process of writing the book and thinking about language led me to address the importance of language in framing debates. George Lakoff, author of the book *Don't think of an Elephant* wrote about the importance of language in politics and other areas.

How to use language to move the debate in the direction you want it to go.

In Victoria, we felt there were significant disadvantages in using the word euthanasia. It's difficult to change it – it's been in the lexicon for who knows how long, but in using it we cede territory to our opponents – they can say euthanasia is giving lethal injections - deliberate killing.

It's used to describe what the Nazis did. It's used to describe the ending of suffering of animals. It does not have a clear definition, and ultimately, we found that it was a drawback to the debate we were trying to run. And that is why we changed our name to *Dying with Dignity Victoria* and why we try to avoid using the word euthanasia at all times.

We use the phraseology of physician-assisted dying, which is more descriptive of what exactly is taking place, and it's also inclusive, because PAD can occur in a range of ways, some of which are legally and ethically accepted – such as terminal sedation. It is legitimate for doctors to assist patients to die under the appropriate circumstances, provided the intention of the doctors is to relieve suffering and the suffering is palliated effectively.

And we're not asking for anything that's not legitimate. It is much more difficult for an argument to be made against what we're asking for.

We've also adopted the position of avoiding, at all costs, the use of the word suicide. This word carries huge stigma, has all sorts of connotations in people's minds – most people think of suicide as something someone does in an irrational state of mind – but what we're talking about is not an

irrational act, but a rational one. I think it is insulting to describe someone who is at their life's end and wanting simply to pass away with some dignity and security, to say that they are committing suicide and for that to go on to their death certificate. I think it is an entirely inappropriate use of the word, and so we rejected it from our usage.

We've learnt that there is a need in everything that we do for a simple and consistent message. It's one of the reasons why we've made a lot of progress in Victoria, and we have been helped greatly by people from public relations, information technology and advertising.

We've always had a good message, but we haven't always put it coherently. We now understand that you need to develop a simple message, and then promote it over and over again.

In order to get your message through - you must stick to your song!

We're talking about changing people's minds, and to do that you need a simple, concise message. That message is about choice, control, and the maximum relief of pain and suffering.

The secondary message which we run, but in a much more *sotto voce* manner, is the inadequacy of palliative care to relieve all suffering. But we'd rather do that in response, not in attack of palliative care, because palliative care does do a lot of good things. We would not attack palliative care unless it's absolutely necessary.

However, having had our legislation fail in September, the next time it goes up, it will be absolutely necessary to tip a bucket on palliative care, and we won't hesitate to do it on that occasion.

The next platform we adopted is a change in the ideas around how people can be helped to die. Our Bill advocates allowing doctors to assist people through the provision of medication - which then the sufferer took orally. Our Bill would not allow for lethal injection. This is following along the lines of Oregon and more recently in Washington.

The reasons we argued for this position are important to the argument. If someone wants to end their life because of intolerable suffering, then that is their responsibility. It's a huge ask for them to expect a doctor to take that responsibility, and for the doctor to provide a lethal injection when the individual can do it him/herself. The doctor

should provide every support if it's possible, all the advice that's necessary, including ongoing dialogue, psychological support and medication, but ultimately it's the individual's choice and responsibility.

There is intrinsic safety in this process, in that when the doctor is in the position of delivering a lethal injection, he/she may deliver it in the wrong circumstances.

If you've got the medication, nothing's going to happen to you unless you bloody-well decide the day has come!

And so there is huge safety in placing the means in the hands of the individual - they will decide if, or when, to close the door.

And I think this sort of approach will have far greater acceptance by doctors.

Another issue which really concerns me



rather than our society (DWDV) is the one about the inadequacy of the law, and the failure of the 'double-effect' argument to be a valid one in applying the law.

The same law applies to me as a doctor in relation to end-of-life matters as it would to a vicious killer. Questions of intention, questions of consent, are not relevant in criminal law, so if you consent to me helping you to die, then that's of no concern of the law. The law looks at what my intention was in helping you to die - it doesn't take your intention into account at all. And as I've already said, I believe that it's your intention that's the important part of the equation - not mine - I am merely an agent.

And so, the whole thrust of my challenge to the law is through this question of trying to

show that the law is inadequate. If you can show that the law is inadequate, that it's not being prosecuted, that it doesn't meet the circumstances - you put the law into disrepute and into disarray, and you put additional pressure on the government to do something about it because it's completely unsatisfactory.

We can also look at ways in which we can change the law. The *modus operandi* that most people have adopted is to draft legislation, specific legislation which will allow doctors to help patients. The problem with this track is that it requires full-scale debate by the parliamentarians, many of whom are frightened of the issues. It's generally acknowledged that it is difficult to get through such legislation. One can expect that it will take time, but with persistence and the right argument we believe this will happen.

Another way in which it might occur, is by amendment of the Crimes Act in relation to the question of aiding and abetting suicide. At present all the Crimes Act says: It's a crime to aid and abet suicide. There's no context. But surely the circumstances where a doctor is dealing with a dying patient is different from any other circumstance, and so I believe that another approach that could be profitable would be to try and persuade government that an amendment of the Crimes Act would be an alternative way of dealing with the problem.

The question of challenging the current basis of the law can be effective. When you think about it, that's how the abortion law was changed. Abortion in Victoria was only just changed from a crime about six weeks ago. But the practice of abortion was allowed for 40 years prior to this, because the law was challenged, doctors were prosecuted for carrying out abortions and juries refused to convict them.

The law was brought in disrepute and eventually a judge said that, in certain circumstances, if it was done to preserve the life and health of the mother, then that was not an illegal abortion. As so, the law was changed through the courts rather than through the parliament.

Finally I want to make one comment and it's again about the use of language and it's the use of the word 'patient'. And I know I'm pushing a barrow uphill, but I object very strongly to the use of the word in the context of somebody with a terminal illness. The word patient implies somebody who is coming to see a doctor because they are

ill or want treatment. It immediately puts that person in a dependant relationship to the doctor. The doctor is the person who is sitting on high with all the information and all the power, and the patient, who is suffering, maybe at the end-of-life, may be in the weakest position they've ever been in.

In my view, that person is not the patient but a person who is suffering and they should be looked at by the doctor as somebody who is suffering. I know it's very hard to eliminate the word patient from our vocabulary – but I would argue that in relation to medical practice, instead of using the term doctor/patient relationship (the common phraseology), we should say the patient/

and have a dialogue with. If you haven't got such a doctor, for goodness sake, get one and exert your power as a person. You are paying the doctor. He/she is, in effect, your servant, don't forget that! Don't let doctors put you down – you've got rights – exert them! Sometimes you may be in a very weak position, by all means grab hold of an advocate to help you in that process – a son or daughter, whoever – somebody to come along and support you. Do not allow yourself to be patronised!

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.

Embracing Our Mortality

Dr. Lawrence J. Schneiderman
Publisher: Oxford University Press
ISBN-13: 9780195339451

While surveys show that most of us would prefer to die at home, 80 per cent of us will die in a health care facility, many hooked-up to machines and faced with tough decisions. Vivid case studies are drawn from Dr. Schneiderman's fifty-year career that illuminate the challenging medical decisions many of us have to make when we are seriously, and possibly even terminally, ill. The cases deal with patients ranging from newborns to the elderly. We discover how the wrong decision can actually increase our

pain and suffering, while adding little time, and virtually no quality, to the end of our lives. Schneiderman discusses the latest empirical research, showing

I LEARNT FROM THIS EXPERIENCE THAT SOME SUFFERING WILL ONLY END WITH DEATH.

doctor relationship – the patient being the pre-eminent person in the relationship.

And I would advise that, when you go and see your doctor – do not let yourself fall into the trap of regarding yourself as a patient. You are a person – who happens to be suffering. You have the right to be treated as a person who has rights. You have legal rights – you have the right to refuse treatment. You have the right to be effectively relieved of pain. And, if I - (and it's easy for me to say because I'm a doctor), - if I were in the position of being a sufferer, I would go to my doctor and I would say: *Look doctor, I've got a serious illness and I want to enter into a dialogue with you, and I want you not to regard me as a patient, but as a person who is suffering. And we are going to have an honest dialogue in which you treat me as an equal person – not deny me any information that I want or that I need. I do not want you to patronise me.*

By entering into such a relationship you will put yourself in a position where you are far more likely to reach the end-point that you want, than if you adopt the usual patient role, which is one of submission and powerlessness.

So if you want that to work I give that to you as my representation to you as a person. Try and change your relationship with your doctor to one of equality. To one where they are someone you can talk to,

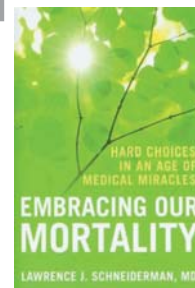
He has had extensive experience with cancer patients and with people with severe spinal injuries and he has been an advocate for physician-assisted dying for nearly 20 years, and the President of Dying with Dignity Victoria for ten years.

He is a keen birdwatcher and collects Australian stamps.

Rodney's book A Good Death: An argument for voluntary euthanasia was released this year by Melbourne University Press to great acclaim.

Rodney Syme, Vice-President of Dying with Dignity Victoria, has been elected to the World Federation Board.

the reader how to evaluate statistical claims and assess the probability that a particular course of treatment will significantly improve our medical condition. Moreover, he draws on authors such as Tolstoy and Chekov to emphasise the importance of empathy and imagination in making these crucial decisions. *Available Google Books and Oxford University Press*



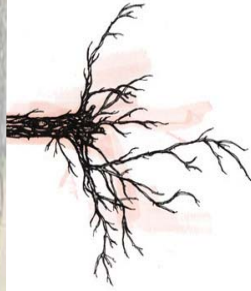
Many thanks Rhonda Taylor - Many of you may have heard the name Rhonda Taylor over the years. You may have met her at a meeting, or chatted to her over the phone.

She has decided to retire from her role as Membership Secretary. Rhonda has, in one way or another, been a valuable and important part of the society for about 20 years. She has performed many roles within VESNSW: Newsletter Editor, Coordinator, Membership Secretary, Committee member and volunteer.

On behalf of the Executive Committee of VESNSW I would like to thank Rhonda for her significant contribution to the cause of voluntary euthanasia, and wish her well in the future.

And on a personal level, I would like to thank Rhonda for her support, advice, friendship and level-headedness. She has been a great asset to me, and to the society. She is truly a VES living treasure. I will miss her very much. - Annemaree Adams





Seventeen CC members and five guests attended the last meeting for 2008 in Gosford on 19 December. Despite members coming prepared to share in the end-of-year festivities, we also managed to pass on and discuss a lot of important information before partying, in our ninety minutes together.

We heard three reports from participants at the Exit conference on *Dementia, Voluntary Euthanasia and the Law*, held in Sydney on 22 September, 2008 and two on the VESNSW Sydney meeting of 23 November, which was addressed by Dr Rodney Syme of DWDV.

There was a lot of discussion of the November VESNSW newsletter, with much praise for its content, including the book reviews, updates, and of course, the full report of Professor Colleen Cartwright's address to the July Sydney meeting.

Several members felt the length of the new advance care directive form enclosed with the newsletter, and the requirement to have it signed and witnessed by a GP and lawyer, might put members off using it in preference to other, shorter, formats.

One member said, however, that its very formality and thoroughness would be likely to assist any future campaign to have such a document gain legal status in conjunction with legislation for assisted dying.

Members shared recent newspaper clippings, including a very important one about "care receivers' limited rights" in residential aged care facilities, published in the Australian Financial Review of 10 October 2008. The October issue of the Law Society Journal titled *Lazy Euthanasia Law Makes Life Difficult For Doctors* was also mentioned, and copies taken by two members who promised to make appointments to see their respective federal MPs in Robertson (Belinda Neal) and Dobell (Craig Thomas) armed with these copies, in the new year.

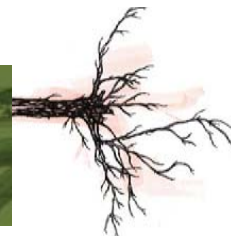
The main action item from our meeting was the following resolution: That the VESNSW committee consider putting in a collective submission to the nationwide consultations to be held by the National Human Rights Consultation Committee [NHRCC] in the early part of 2009. Our strong view is that, whatever else we say, we would like VESNSW (and we urge the committee to ask the respective State VES and DWD organisations to consider supporting this too) to urge that any charter or bill of rights that may come out of this consultation should consider the rights of the terminally ill for legalised assisted-dying services with appropriate informed consent.

Every VESNSW member capable of putting pen to paper, or emailing the NHRCC committee, should be urged to send in an individual letter or submission, in addition to the authoritative collective one of VESNSW, recognising that most local politicians count one letter/email as representing up to 10 voters.

CC members agreed to continue to lobby our local federal politicians in terms of repealing the Howard Government's draconian anti-VE legislation when we can, and our State politicians in relation to amending the NSW Crimes Act to repeal the clause about "aiding and abetting suicide", recognising the power of CC voters in the next federal and State elections, since we now live in extremely marginal (mostly) ALP electorates.

The first meeting for 2009 will be held, as usual, at the Gosford Senior Citizens' Centre, at 10am on Friday 17 April. I have invited Father Frank Brennan, chair, and all other panel members of the NHRCC, to attend if they are available.
Central Coast Branch report – Romaine Rutnam, Convenor

act branch news



Since our last report, following the ACT election, the four Greens MLAs elected to the 17-member Legislative Assembly have settled in. They decided to support the ALP to enable that party to form government, but they are playing quite an independent role in the Assembly. Voluntary euthanasia legislation is part of their policy platform. Not all ALP MLAs support such legislation, but there is some hope that, if Senator Bob Brown's Bill is passed, a narrow majority in the Assembly might support introducing such legislation in the ACT. We anxiously await a date for discussion of Senator Brown's bill in the Australian parliament.

At our next general meeting on March 19, the speaker will be Dr Kris Klugman, President of Civil Liberties Australia, whose topic will be 'Yes We Can ... Decide for Ourselves'.

We continue to be in touch with VE and similar organizations round Australia about the desirability of achieving national reciprocity for health directions/advance directives. These vary from one State or Territory to another, and do not receive reciprocal recognition throughout the country.'

UPDATES

Australia

Senator Bob Brown & Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2008

As you read this the Greens will be negotiating with the Government on the parliamentary agenda. They are hoping to have the *Restoring Territory Rights (Voluntary Euthanasia Legislation) Bill 2008* listed for debate early this year.

Now would be a good time to write and lobby senators. Mail for senators in Canberra should be addressed to: The Senate, Parliament House, Canberra ACT 2600. You can access the list of senators at: <http://www.aph.gov.au/Senate/senators/contacts/los>.

VESNSW & Exit

The Voluntary Euthanasia Society of NSW has provided strong moral and financial support to Philip Nitschke since he first started Exit. The two organisations have acknowledged a difference in emphasis: while VESNSW continues to campaign for legalisation of voluntary euthanasia with safeguards, Exit has chosen to provide information that allows people to suicide peacefully without necessarily seeking assistance.



It will take some time in NSW before we are successful in changing the law to permit voluntary euthanasia but in the interim we know that many of our members and supporters are comforted to have access to the information provided by Exit. Though the approaches of our organisations may be different, we must not forget the most important thing is to allow a release from suffering at the end of life for those who choose it.

USA

Assisted-suicide bills that are virtually identical to Oregon's law have been introduced in Hawaii, New Hampshire and Montana.

Hawaii is discussing legislation that: *Allows a terminally-ill, competent adult to get lethal*



dose of medication to end life. Prohibits mercy killings, lethal injections, and active euthanasia. Requires informed consent. Allows alternate doctor to replace attending doctor if latter declines to prescribe. Requires monitor at time of taking dose.

Washington ballot 1-1000 passed on 4th November 2008, the day of the USA Presidential election with a vote of 58 per cent to 42 per cent: a landslide in USA ballot terms. The Initiative gives Washington residents very similar rights to those in neighbouring Oregon, where terminally-ill patients may request and receive medication to die peacefully on their own terms, with a strong set of safeguards. The law becomes effective in July 2009.

One of Washington's largest hospital system providers, Providence Health and Services, will forbid physicians from helping patients die at its hospitals, nursing homes and assisted care centres. The owner of Sacred Heart Medical Center and Holy Family Hospital said: *Providence will not support physician-assisted suicide within its ministries.*

Europe

Italian coma woman Eluana Englaro dies
Eluana Englaro, the comatose woman at the centre of a euthanasia debate that has divided Italy and sparked a constitutional crisis, died at the age of 38, four days after doctors began removing her life support. The news of her death came as the upper house of Parliament began debating emergency legislation rushed out by the centre-right Government of Silvio Berlusconi.

It would have ordered medical staff to restore all nutrients. She had been in a vegetative state for 17 years after a car accident. Ms Englaro's father, Beppe Englaro, had been fighting for a decade for a dignified end to his daughter's life, in accordance with what he, and her friends have testified were her own wishes.

At his request, doctors at a clinic in Udine had stopped feeding Ms Englaro.

Italy does not allow euthanasia but patients have a right to refuse treatment.

Swedish doctors back euthanasia

Every third doctor in Sweden supports the legalisation of euthanasia, according to a new survey presented at the ongoing "Global Health in a New World" conference in Gothenburg.

35 per cent of doctors were positive to the prescription of medicines to patients with an expressed desire to kill themselves. 40 per cent were against and 25 per cent were uncertain, according to a report in *Svenska Dagbladet*. Psychiatrists and older doctors were the groups most positive to allowing euthanasia.

Dignitas under investigation

The Swiss euthanasia clinic Dignitas that has helped approximately 1,000 people to end their lives is under investigation.

Dignitas is being forced to open its accounts to prosecutors in Switzerland and disclose how much money it is receiving from its controversial business of assisting suicide.

Luxembourg to strip Duke of powers over euthanasia

Luxembourg's government plans to strip Catholic monarch Grand Duke Henri's power to sanction laws, after he signalled he would not sign a bill legalising euthanasia. Prime Minister Jean-Claude Juncker, who rushed back from an economic summit in Brussels, said his Government would seek a rewording of the constitution.

UK

Debbie Purdy, who suffers from multiple sclerosis and is confined to a wheelchair, said she was shocked after losing her legal bid to clarify the law on physician-assisted dying (PAD). She wants to travel to Dignitas with her husband at her side. Although suicide is not a crime in the UK, aiding and abetting suicide is a criminal offence, as it is in Australia.

No Prosecution for parents of Daniel James

The UK Director of Public Prosecutions has announced that it would not be in the public interest to prosecute the parents of 23-year old Daniel James. Paralyzed from the chest down following a rugby accident, Mr James had made clear his request to die: *I want to die and due to my disability I am unable to make this happen. Not a day goes by without hoping that it will be my last.*

His parents took Daniel to Dignitas in Switzerland after he had made several unsuccessful suicide attempts. His parents' efforts to talk him out of his wish to die had been unsuccessful.

In response to this case the UK Department of Public Prosecutions has determined that prosecutions will not proceed where the public interest against prosecution is strong.

Scottish MPs bill to legalise assisted suicide

Margo MacDonald, the former Nationalist MP who now sits in the Scottish parliament as an independent, will release a consultation paper next month and then table a bill at Easter, 2009 to make it legal for a doctor or close relative to help a terminally-ill person to die. MacDonald has Parkinson's disease.

The Suicide Tourist

Controversy erupted over the planned showing of *The Suicide Tourist*, which shows retired American university professor and motor neurone disease sufferer, Craig Ewert (59) in his last days, his death by ingestion of sedatives and the switching-off of his life support machine. The terminally-ill man was forced to use a mouth-operated system to switch off the machine because he had lost the use of his limbs. He died 45 minutes later with his wife of 37 years by his side.

Mrs Ewert told *The Independent* newspaper in Britain that her husband allowed a Canadian film director to record his final moments to "remove the veil" that made people reluctant to think or talk about death: *Allowing the cameras to film his last moments in Zurich was about facing the end of life honestly. This wasn't a film about him personally. He was keen to have it shown because when death is hidden and private, people don't face their fears about it.*

Dr Michael Irwin avoids prosecution

A former UN medical director questioned by police after accompanying a 75-year-old woman to the Dignitas clinic in Switzerland will not face prosecution for assisting in her suicide. The decision not to prosecute Dr Michael Irwin will be seen as further evidence that prosecutors are turning a blind eye to people who help in the planning of suicides abroad.

Dr Irwin, 77, spent more than two years under investigation and faced a maximum 14-year prison term after he admitted accompanying May Murphy, who had the severe degenerative disease multiple system atrophy, from Glasgow to Zurich.

German doctors acquitted of death

Two doctors accused of illegally helping a severely-ill British man die in 2004 have been acquitted, amid an emotional national debate on euthanasia. The pair had allowed the brother of a terminally-ill, paralysed patient to turn off his breathing apparatus in May 2004, and one of the defendants administered strong painkillers.

The British man had been paralysed since an accident in 2002 and was unable to breathe unaided. The following year, Sanders was transferred to the rehabilitation centre in Magdeburg where his condition worsened. He could barely speak and regained consciousness only for brief periods of time.

Sanders' brother Paul turned off the patient's breathing apparatus in May 2004 "with the knowledge of the chief doctor and the ward physician" and the consent of the rest of the family, prosecutors said.

Julie Walters stars in BBC drama

A Short Stay in Switzerland is inspired by the true story of Dr Anne Turner, who took her own life three years ago this week. Dr Turner had the incurable degenerative disease called progressive supranuclear palsy. She had watched her GP husband Jack die from a near-identical illness. The condition, which also affected comedian Dudley Moore, left her facing the prospect of a lingering death, unable to walk, talk or blink.

Anne travelled to the Dignitas clinic in Zurich and died on the day before her 67th birthday, taking drugs supplied to her by the doctors. She wanted her story told and was filmed by a BBC TV news crew, on the understanding the material would not be broadcast until after her death.

Dr Rodney Syme faces questioning over suicide of Steve Guest

Melbourne urologist, Dr Rodney Syme, was again interviewed by Victoria Police over the death of Steve Guest, who was suffering from cancer of the oesophagus when he died of a barbiturate overdose in 2005.

Guest became a national figure in the weeks before his death after he telephoned ABC talkback radio asking for the right to take his own life.

Dr Syme, vice-president of DWDV, was questioned at the St. Kilda Rd police complex. He believes that the police investigation has been re-opened following statements he had made in his book, *A*

Good Death, published last year, about having provided Guest with medication and advice.

He said he had answered Guest's questions about barbiturates, but that he had not incited him to take his own life.

"Steve was dying," Dr Syme said, "and I encouraged him to continue to engage with the media, as much as he was able, in order to create some purpose and meaning in the remaining days of his life, and he did this.

I found myself inevitably drawn into helping others in a range of circumstances. My conscience and my respect for other human beings would not allow otherwise."

S. Korean court backs end-of-life plea

A family's request to cease all medical assistance to a 75-year-old woman in a persistent vegetative state should be granted, a South Korean court has ruled. Seoul Western District Court ruled that the woman, identified only with the surname Kim, should be taken off life support and have her feeding tube removed as per the family's request.

S Korea: Appellate Court Rules for Passive Euthanasia

An appellate court upheld a previous landmark ruling (see above) by a lower court ordering a hospital to take a patient off life support.

The Seoul High Court sided with the family of a 76-year-old woman in a vegetative state in a legal battle for what activists call her right to die with dignity.

The appellate court said it recognizes her wish, which her family said she had expressed when conscious.

The High Court also said if medical recovery is deemed impossible for terminally-ill patients who have made clear they do not want indefinite resuscitation, their wishes should be respected.



FOR YOUR DIARY

Annual General Meeting

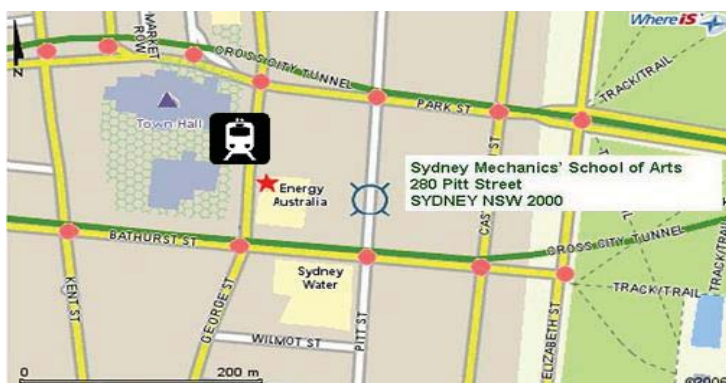
When: 2.00pm Sunday 22 March 2009

Where: SMSA 280 Pitt St Sydney
(Sydney Mechanics' School of Arts)



WE NEED LEGISLATION!

Guest Speaker: Professor Peter Baume AC



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

letters

VESNSW received a generous bequest of \$9,000 recently. Reliant on this generous support, VESNSW thanks all members for their donations and continuing support.

Dear Voluntary Euthanasia Society of NSW

Please accept the enclosed donation in memory of our parents and

He was a very early member of the VES, educating us all (including) in the humanity and compassion involved in having a clear view of the paramount importance of quality of life. They both gave us enduring guardianships and made very comprehensive advance health care directives.

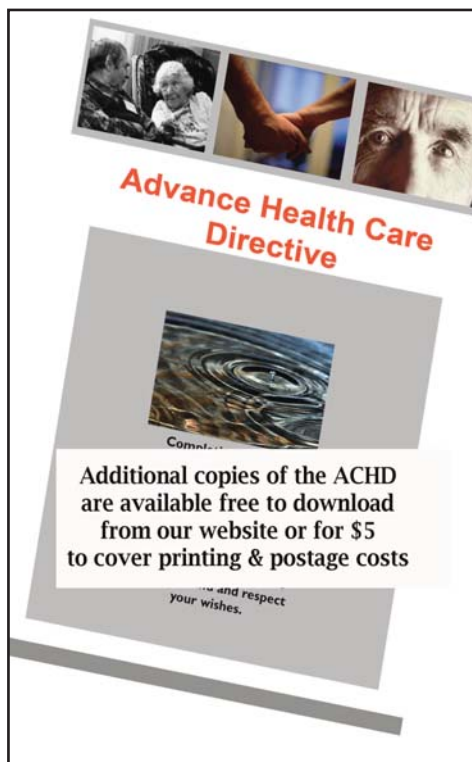
.... Your advance health care directive became necessary when he was hospitalised after a fall. We were impressed by the doctors' and hospital staffs' acceptance of his wishes and the way in which they respected his requests.

It is the work that the society does in keeping this issue in the public forum that enabled to be treated with dignity at a time when it was of the utmost importance to him to be in control of his life, and death.

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M
2009
March



Advance Health Care Directive

Additional copies of the ACHD are available free to download from our website or for \$5 to cover printing & postage costs

and respect your wishes.

VESNSW

Administration Assistant/ Membership Secretary

Required to provide support for the Co-ordinator of VESNSW. They are responsible for the provision of confidential administrative, clerical, and membership services. The position requires someone with initiative, self-motivation and the ability to communicate well with others.

Experience in database maintenance, payment and receipting functions, as well as general office administration skills are required.

A sympathetic ear, together with common sense and a sense of humour, as well as a commitment to VE principles is essential.

Please call or email Annemaree for Position Description and Duty Statement. This is a part-time position: 6-12 hrs per wk.



A bequest is one way you can help us in our campaign to change the law and educate the community

Call Annemaree on (02) 9212 4782 for a bequest form or go to our website: www.vesnsw.org.au

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.

