



# VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES (INCORPORATED)

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## NEWSLETTER

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## NORTHERN TERRITORY ACT'S 10TH ANNIVERSARY

On 25th May 2005 it was 10 years since the Northern Territory's *Rights of the Terminally Ill* Bill was passed.

However, in a move that shocked the VE movement and most other Australians, the Federal Government quickly stepped in. Led by John Howard, but supported by the opposition leader Kim Beasley, the parliament embraced the Kevin Andrews Bill that led to the demise of this world-first law.

Marshall Perron, the former Chief Minister of the Northern Territory who was the driving force behind the Rights of the Terminally Ill Act, suggested that on the 10th anniversary of the passage of the Act, all Federal politicians should reflect on the misery caused by the overturning of that compassionate legislation.

### NEW BILL

The Andrews Bill, however, was not enough for the Federal Government, and soon we are likely to have what Exit International calls 'the most draconian anti-VE legislation in the world'.

'It will soon be a criminal offence to pick up your phone to ring a friend to discuss your end of life options. The activities of Exit are set to come under intense legal attack. Never has there been such a targeted challenge to free speech and the rights of elderly and ill Australians. What is worse, NO politician from either major party is standing up against such blatant censorship.'

People who use the internet to encourage others to commit

suicide will attract fines of up to \$110,000 under the new law. People discussing methods of euthanasia over the internet could also be committing an offence. Corporations can be liable for fines up to \$550,000 and individuals \$110,000.

Philip Nitschke said the move was the equivalent of burning books. 'The big losers will be elderly people who want a viable way of ending their lives,' he said. 'Many people are isolated from good information and now the Government wants to push all this underground.'

However, Senator Ellison said the new laws were not intended to stifle debate about euthanasia. 'They will compliment existing customs regulations

prohibiting the physical importation and exportation of suicide kits and information related to those kits,' he said. 'A person engaged in genuine debate over euthanasia related law reform would not be restricted by these changes because such material would not "counsel" or "incite" suicide.'

VES NSW President Kep Enderby was one of those who spoke at the public hearing in April.

Despite the great number of submissions objecting to the proposed Bill, it is likely to be passed in the near future with only minor alterations.

For a full transcript of the hearing, log on to <http://www.aph.gov.au/hansard/senate/commttee/S8226.pdf>

## WA TO RECOGNISE LIVING WILLS

Terminally ill people will have a legally recognized right to die under new laws proposed by the State Government of Western Australia.

The move was prompted by the plight of a Rockingham family, highlighted in the West Australian, whose terminally ill 29 year old son died in March after a long battle with Huntington's disease.

Michael Spanbroek spent the final five weeks of his life unconscious and on life support despite expressing a wish to his family to be allowed to die peacefully. Attorney-General Jim McGinty said the State Government was examining British laws which enshrined 'living wills'.

These would allow adults to decide, while they are still healthy to refuse life-saving treatment if they became gravely ill.

Medical staff would not become liable for withholding or withdrawing from an incapacitated patient under the terms of the will.

WA laws are currently ambiguous because they allow patients to refuse medical treatment but doctors are not allowed to do anything that might hasten their death.

Tasmania and New South Wales are the only other States that do not have provision for living wills.

Mr McGinty said the legislation would not sanction

the taking of human life and would avoid the issue of voluntary euthanasia.

WA needed sensible laws to give people certainty when dealing with end-of-life treatment.

'If someone of sound mind has made a decision to refuse life supporting treatment if they fall into a vegetative state, then their wishes should be respected and that decision should be given legal force,' Mr McGinty said.

Australian Medical Association WA president Paul Skerritt said the proposal seems simple but it is a complex issue and legislation would have to be drafted carefully.

Michael Spanbroek's mother, Karen, said the laws would save families and carers of terminally ill patients unnecessary pain.

Mrs Spanbroek said Michael knew he would die from the disease but had not anticipated the violent seizures which left him comatose.

'Michael trusted us (to let him die peacefully) but when it came down to it we couldn't do anything because it would have been against the law, and you cannot take the law into your own hands,' she said. 'I think everyone has a right to have a choice, and if someone does not want to have a living will then no-one is going to force them.'

Source: Tiffany Laurie, *West Australian*, 14/5/05

# PHILIP NITSCHKE AND KERRI-ANNE

Thanks to the VES members who, with members of Exit International, recently turned out early in the morning to show their support for Philip Nitschke and his work, when Kerri-Anne Kennelly hosted a panel discussion on the Criminal Code Amendment (Suicide Related Material Offences) Bill 2005 on her TV show *Mornings with Kerri-Anne*.

The studio was filled to capacity to hear Senator Chris Ellison, promoter of the Bill, insisting that it would not interfere with people's ability to access information on suicide matters, but would 'protect the vulnerable'. Dr Nitschke and the audience were less than inclined to be comfortable with the senator's assurances.

## FOR YOUR DIARY

### Meetings

- **Sunday 31 July 2005, 2.30 pm** in the **Dougherty Centre**, 7 Victor Street, Chatswood. The VES is running a **workshop for members** who would like to know more about writing their own **advance directive**. The workshop will be run by Dr Giles Yates. (See back page)
- ACT Branch – enquiries on 02 6242 0066
- Central Coast - Meetings will be held on the third Friday in August (19th) and December (16th), from 10am in Meeting Room 3 at the Gosford Senior Citizens' Centre, 217 Albany Street, North Gosford (opposite William Street). Members who wish to could stay on for lunch at the food hall at the top of Gosford Town Centre (opposite to Coles – free parking up to 3 hrs with a receipt from the Centre. Contact: Romaine Rutnam, particularly if you would like a lift to and from the meetings.
- Illawarra Branch (Support Group) - For information please contact VES Illawarra Branch, PO Box 8, Keiraville NSW 2500, or phone 02 4229 2789.
- Northern Rivers Branch – Next meeting 18th July. Contact Bryan Milner on 02 6680 1961.
- Confidentiality: VESNSW does not provide information about individual members or give the membership list to any person or organisation under any circumstances.
- Email: Readers of this Newsletter are asked to help to get as many VE supporters as possible to send in their email addresses. Email is the quickest and cheapest means VESNSW has of keeping members informed. If you or your friends would like to be contacted by email please send us your email address to: [mail@vesnsw.org.au](mailto:mail@vesnsw.org.au)
- EXIT International – have a new website, <http://www.exitinternational.net> For details about their Introduction and Construction Workshops, please send an email to [info@exitinternational.net](mailto:info@exitinternational.net), fax to 08 8983 2949 or phone Kerri Dennis on 0500 831929.
- Visit the VESNSW web site at [www.vesnsw.org.au](http://www.vesnsw.org.au)

# ADVANCE CARE PLANNING AND ADVANCE CARE DIRECTIVES

**Julie Letts**, the speaker at our AGM in March, is Senior Analyst with the Policy and Clinical Policy Branch of the NSW Health Department covered topics of vital interest to all VES members.

## THE BIG PICTURE

There is an increased uptake of acute care in the elderly with an ageing demographic.

An increased likelihood of chronic illness and disability, and of dying in care.

The influence of the 'autonomy movement'.

## WHY IS ADVANCED CARE PLANNING IMPORTANT?

Most people (85%) will die after chronic illness, not a sudden event. Up to half of us are not in a position to make our own decisions when we are near death. Our family have a significant chance of not knowing our views without discussion.

A doctor who is uncertain of the person's wishes, and who has to make a decision, will often treat aggressively.

The fear of suffering is greater than the fear of death for many.

## SOME MYTHS

*MYTH1* Stopping life sustaining treatment is the same as murder or suicide, or at least not lawful.

*MYTH2* Only 'extraordinary' measures may be stopped, not 'ordinary' ones like feeding.

*MYTH3* Providing comfort measures, such as analgesia, that may hasten death is murder.

*MYTH4* No matter what my Advance Care Directive (ACD) says, doctors can do what they want.

*MYTH5* The best way to let my family know what I want is by completing a form.

*MYTH6* A relative is always the best proxy.

*MYTH7* If I change my mind, no-one will listen.

*MYTH8* A lawyer is needed to complete an ACD.

## THE LEGAL CLIMATE

Doctors deciding alone feel vulnerable.

The role of family is not clear, though opposition to treatment limitation may be supported by Courts.

Advance care directives (for refusals of treatment) made by patients are enforceable under common law in all jurisdictions.

## GLOSSARY

### ADVANCE DIRECTIVE

Document.

Written by competent adult.

Values, goals, preferences.

Applicable only when incompetent.

An instruction to health professionals or to family.

### GUARDIAN

A person with the authority to make health care decisions on behalf of an incompetent patient.

Guardianship Act 1987 (also determines 'person responsible' – consent to treatment).

Limited role in treatment withdrawal or withholding decisions ('maintain health and well-being').

### ADVANCE CARE PLANNING

Linking discussion and documentation with guardianship arrangements to make it clear what the patient prefers and who is to do the negotiating when she can't.

## ADVANCE CARE PLANNING IN NSW

It is extremely rare in all settings studied - less than 1% of acute care inpatients have any record of a conversation about preferences and less than 0.2% of nursing home residents have any documented wishes.

There is general support by the community (at least in principle).

Health Ethics Branch coordinating Working groups on End of Life Decision Making and on use of Advance Directives in 2002-4. Best practice advice 'Using ACDs' released 2004.

Pilot study underway - Hunter AHS  
- Respecting Patient Choices trial.

## OUR CONCLUSIONS

The main impact of advance care planning is in end of life settings.

While the legal effect of ACDs can be refined by legislation, this is not essential and has not been effective elsewhere in Australia.

## ADVANCE DIRECTIVES

Initiatives addressed to doctors alone are generally ineffective. If addressed to guardians they may increase congruence of surrogate decisions.

They are rarely available, even in jurisdictions where they are mandatory. Reviews are mostly about why advance directives don't work, and how we should be trying harder.

## ACD FORMS

There are lots out there with more than 35 reviewed by Working Group.

Legislation tends to produce legalistic forms. Every form has limitations so different forms are appropriate for different patient circumstance.

Advance Care Directives centre variously on Values (rejection of functional states), Goals (to live until my daughter's marriage), Preferences (intervention refusal).

## OUR CONCLUSIONS

A new 'gold standard' form would not be a 'quick fix', though best practice guidelines about completing, accessing and responding to such forms are needed.

An 'authoritative' ACD is acceptable and enforceable under common law (right to refuse

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## A TYPICAL ADVANCE CARE DIRECTIVE

To my doctors, health care team, family, and other persons concerned

Name: Helen

Address: Flat 2, Any Street, Any Town, NSW

After careful consideration and discussion with my medical advisers, I have freely and in sound mind decided that it is my express wish that if I should develop:

- *Severe* degenerative brain disease (due to Alzheimer's disease, arterial disease, or other agency).
- *Serious* brain damage as a result of stroke, injury, or other illness.
- *Advanced* terminal malignancy.
- *Severely incapacitating* disease of nerve or muscle.
- Any other condition of comparable gravity.

And, as a result suffer mental impairment such that I am unable to participate in decisions regarding my care, and my treating doctor considers that my underlying condition is irreversible, then the following points should be taken into consideration:

- In the event of cardiac arrest, regardless of the cause, I should not be given cardiopulmonary resuscitation
- With the development of any life threatening medical situation I should not be given active treatment such as antibiotics, ventilation, surgery, or blood transfusion
- Any futile treatment initiated outside the terms of this directive should be withdrawn
- If during an advanced illness I should become unable to swallow food, fluid, or medication then these should not be given to me by drip or feeding tube into intestines or vein
- I wish to have ordinary humane nursing care and the use of medical interventions only to control distressing symptoms and not merely to prolong my existence
- I consent to the use of analgesics and other measures to control distressing symptoms, regardless of the consequences for my physical health

I have discussed this document with my general practitioner, Dr Wilma Glass of Any Surgery, Any Town, Tel 12345.

I reserve the right to revoke this directive at any time.

Signed: XXX

Witness signature: I hereby witness the signing of this document by the above named in my presence. She is of sound mind, understands the implications of the document and, to the best of my knowledge, has been brought under no external pressure to sign it. I do not stand to gain from her death.

Signed: XXX      Date:

treatment) in NSW providing:

- It is specific to situation at hand
- The person was competent and free of undue influence (presumption)
- No reason to believe that those wishes are no longer current (presumption)
- Witness desirable but not legally required (unless enduring guardianship appointed)

## EFFECTIVENESS

Evidence suggests certain elements of a advance care planning program are important for success.

The role of the family is recognised and is part of an ongoing process (conversations).

Initiated by trained staff and there are education programmes. It should be easily accessed and reviewed.

Starting in acute care, out to primary care.

## THE 'VALUES STATEMENT'

### Values

● I believe I have interests even when incompetent, and that I am still a person. I would like reference to be made to things I have said, in this document and elsewhere when it comes to making decisions about my medical care.

● I am however a social being. At the time of death, I believe the people identified in this document should be involved in making decisions on my behalf, even when their decisions appear to conflict with these directives.

● Cognition is important to me. If the medical consensus is that I will lose cognition permanently (that is, I will appear not to recognise my family) then I do not wish to be kept alive.

● As far as possible, I would like to be managed at home when terminally ill. I like to be outdoors, and enjoy the sensation of sunshine.

● In case of dementia, I reject the view that I am a 'new person' – I favour the view that I am a wreckage of the old.

### Preferences

Lacking a life-threatening illness, this section is not applicable at present.

## Outcomes

As a general statement, I am not afraid of death, and do not want means to be used to sustain my life that are unlikely to work, or likely to leave me in a state of severely reduced cognition.

## Surrogates

● I wish to appoint my partner, and my friends C...and B... to jointly make decisions on my behalf.

● I request this because I believe they would act in my best interests, recognising that they may not know my preferences with any great accuracy.

● I will append a letter addressed to my guardians with detailed instructions regarding my terminal illness when that becomes manifest.

● My siblings and parents are to be listened to politely, but their advice should be ignored.

## OUR CONCLUSIONS

Advance care planning (ACDs, appointment of guardians, conversations with health care workers) can be influential, and may improve the match between expectation and experience for patients and those close to them. Using Advance Care Directives (NSW)

## Links

[http://www.health.nsw.gov.au/pubs/2004/adcare\\_directives.html](http://www.health.nsw.gov.au/pubs/2004/adcare_directives.html)

Better Health Centre – Ph 9816 0452

## TWO HELPFUL BOOKLETS TO DOWNLOAD

New Dept of Health *Guidelines for End of Life Care and Decision-Making*

<http://www.health.nsw.gov.au/pubs/2005/endlifecare.html>

*Your Future Starts Now: A Guide for the Over 50s*, a 28 page booklet published by The Benevolent Society in partnership with Public Trustee NSW, can be downloaded from the Benevolent Society's website: <http://www.bensoc.asn.au>

### **3RD EXIT INTERNATIONAL CONFERENCE**

New dates, **5-6 November 2005**, have been advised for Exit's conference to be held at the Brisbane Convention and Entertainment Centre, Southbank Brisbane.

The following sessions are provisionally scheduled:

- Tales from the Peanut (Peaceful Pill) weekend
- Too Sick to Live – Exit Clinics unveiled with MND, MS, Emphysema, Cancer
- People Power – VE as a new social movement
- VE in the media – The politics of Portrayal and Betrayal
- God's Mandate in the House – The Role of Religion in Australian Politics Today
- Law Reform vs Direct Action
- Surviving the next three years – The Future for VE with Howard

Other activities will include street actions, with a visit to Roma Street Police Headquarters, book readings and signings, and the presentation of the 2005 Bob Dent Award.

Further information and registrations form can be found on the Exit website, <http://www.exitinternational.net> or telephone 0500 831 929.

### **JUDY DENT'S LETTER TO NT NEWS**

As a member of Palliative Care NT (formerly NT Hospice and Palliative Care Association), a group that lobbied long and hard for a hospice, I welcome Dr Mark Boughey to Darwin.

However, I take exception to his assertion that euthanasia was chosen in 1995-96 because 'there weren't the services here to support people'.

This is an insult to all the dedicated staff of the Health Department's Palliative Care service whose support allowed my husband to spend his final days at home.

Nurses visited frequently and all the equipment needed for me to look after him at home was lent by the department.

Nothing was too much trouble — a request in the morning for a sheepskin to ease his back resulted in the delivery of a sheepskin that afternoon.

We may not have had a hospice then but help was certainly available. Bob chose euthanasia even though he had a lot of physical, psychological and spiritual support because he did not wish to prolong his dying.

I am pleased Dr Boughey espouses the aim of not prolonging someone's death.

As a member of the Northern Territory Voluntary Euthanasia Society, I look forward to the day the NT achieves statehood.

Our rights of the Terminally Ill Act can then be reinstated and terminally ill Territorians will again have a choice — first class palliative care at home or

in a hospice setting and euthanasia if that is what the patient desires.

Judy Dent, Tiwi

Source: *NT News*, 26.3.05

### **GUIDELINES FOR END-OF-LIFE CARE AND DECISION-MAKING**

As the end approaches for a terminally ill loved one, the last thing families want to agonise over is how much they should do to keep them alive.

But it is usually not until these final days that families are confronted with this dilemma.

To help families and medical staff with those choices, the NSW Department of Health has devised guidelines for end-of-life care and decision-making.

The guidelines state that dying patients receive the best care when those close to them know their wishes well in advance.

'Making appropriate end-of-life care decisions is dependent upon open and early communication in an environment of compassion and trust,' the Health Minister, Morris Iemma, said.

The guidelines cover care for dying children, 'do not resuscitate' orders, the distinction between euthanasia, assisted suicide and turning off life support, the use of pain-killers and sedatives, feeding through tubes and emergency treatment.

Source: *SMH*, Cosima Marriner 5.3.05

# THE LINE BETWEEN LIFE AND DEATH

Source: Gary Kalkut and Nancy Neveloff Dubler,  
*The New York Times Opinion-Editorial page, 10/5/05*

Late last month, New York's major newspapers reported that a 13-year-old boy had 'died' after he was taken off 'life support'. That assertion reflected a fundamental misunderstanding of death as defined by the laws of all 50 states. In fact, the boy had died more than a week earlier - from a severe brain infection - after transfer to the hospital where we work. In the interim, advanced medical technology supported his organs, not his life.

Death shouldn't be this hard to understand, yet it often is. According to the 1987 New York State Public Health Regulation, death occurs when either the heart or the brain irreversibly ceases to function. Before medical technology provided breathing machines, there was no meaningful distinction between brain and cardiac death. Once the brain stopped sending signals to the lungs to breathe - on account of a stroke or head injury, for example - the heart would stop within minutes. Now that machines can deliver oxygen to the lungs, however, the heart can continue to beat for days without any signal from the brain.

For centuries we understood death, whatever its cause, as the cessation of heart and lung function. A person was dead when the pulse faded, the heartbeat became inaudible and the chest ceased to rise. Brain death is harder to discern. A brain dead person whose heart and lungs are sustained by machines looks as if he's in a coma. For a family who has lost a loved one, often from an acute illness or terrible accident, it is unspeakably difficult to accept that this warm body with a heartbeat is lifeless. And yet, to imply that a brain-dead person is still alive only prolongs the loved ones' anguish. Such misunderstanding gives false hope and preys on the survivors' feelings of guilt.

The way this subject has been addressed in recent news stories could leave a person bewildered, but the facts are actually straightforward. Brain death should not be confused with a persistent vegetative state or a coma. In brain death, the entire brain

irreversibly ceases to function. Everything shuts down: the cerebral cortex, which controls higher functions, as well as the brainstem, which regulates automatic actions like heartbeat and breathing. In a persistent vegetative state, the cerebral cortex has been destroyed, leaving the person incapable of thought or memory, but the brainstem remains intact and functional. A person in a persistent vegetative state can live for years without a mechanical ventilator or other technological support. That was Terry Schiavo's situation. There was no question that she was alive. Her heart and lungs received signals from her brainstem - they didn't need machines to sustain their activity.

Then there's coma, which is just a general term for lack of responsiveness. A person can fall into a coma for any number of reasons. The coma can be temporary, as it is during general anesthesia, or permanent, as sometimes happens following injury. Only detailed neurological testing can determine the extent of brain injury or its prognosis.

The 13-year-old boy who died this April was not in a coma or a persistent vegetative state. He died of a brain infection a week before he was taken off mechanical support. The obligation of a hospital after the death of a patient is to turn its expertise toward supporting the family. After this child passed away, his family's personal tragedy was laid bare in court and in the news media, as a result of a dispute between the family's lawyer and our hospital over the continued use of a respirator.

With a better understanding of death, this could have been avoided. The dead are not kept alive on life support, and they don't die again when machines are stopped. We need to make this clear if we wish to honor the dead, protect vulnerable families and use the astonishing medical technology at our disposal to heal those whom we can actually help.

(Gary Kalkut is vice president and medical director of the Montefiore Medical Center. Nancy Neveloff Dubler is director of its division of bioethics.)

# THE MYTH OF DYING

*Ed.:* Now months old, the following article holds many truths worth revisiting. It is reproduced in full. In the weeks and months since it was written, Terri Schiavo has found peace, the Lords committee has indeed presented a positive report, the Pope has finally died and Britain has had its election.

*Friday March 25, 2005 (Good Friday)*

**Polly Toynbee, *The Guardian*(UK)**

In the cacophony of debate about insignificant things, the torture of unassisted death goes on unremarked.

Most religions have a day of the dead, and today is that day for Christians. In this most secular nation, polls show few now know what Good Friday is for, this day for sorrow, for contemplating death, loss and endings.

But here the usefulness of faith ends, for it is mainly the power of the religious lobby that forces people to die in pain and indignity due to beliefs on the nature of life and death shared by very few. For 20 years now, every poll on the subject shows that 80% of people want the right to be helped to die at a time and in a way of their own choosing. But that kind of 'choice' is not on the agenda. Or not yet.

It happens to be a good day for contemplating how we die and watch others die as the US courts finally let Terri Schiavo go. She has been 15 years a-dying in a persistent vegetative state, probably beyond pain, though not beyond reflex responses. But if there is still suffering to be had, now in her seventh slow day without water or food, the law inflicts death by slow dehydration in the name of 'ethics'. It's a shocking spectacle that could be stopped with one merciful injection. But here in our own dying rooms similar terrible ethical deaths are inflicted on British citizens every day by kindly nurses and doctors. There is a conspiracy of silence about the actual processes of death.

What kills you in the end if you have cancer or other terminal diseases? Not often the cancer itself. Nor the morphine that people innocently imagine will one day waft them away on a cloudy pillow of dreams to some opium-fuelled nirvana. What people actually die of, like Terri Schiavo, is dehydration when they can no longer swallow enough water to live - and it takes time. Enough

morphine to die quickly is very rarely administered these days. Instead, cautious doctors, extra wary after Harold Shipman, give just enough morphine to kill people by degrees. It is enough, in the very end, to render them unable to drink so they die, semi-conscious, of thirst. Hospices don't put up drips to keep people alive, but they don't give out death-dealing injections either. The legal compromise is death by dehydration or sometimes slowly and gasping for breath by morphine-induced chest infection - 'old man's friend'. That is the great unspoken truth.

The other unspoken truth is that morphine - the only existing, effective pain-relief - is a cruel drug whose main side-effect is such acute constipation that final months are spent in far greater agony from cemented bowels punctuated with bursts of uncontrollable diarrhoea than from the original disease. The indignity of bowel-obsession is no way to end up. Nor does morphine ease anxiety: on the contrary, frightening hallucinations are frequent so patients need anti-depressants as well, but those have their own side-effects. Morphine causes nausea, requiring anti-sickness medication. Nor does it take the away the terminal sense of a body crumbling and falling apart.

Many, like my mother, thought signing a living will to refuse intrusive treatment would be enough. But she, like so many others, was left begging everyone and anyone for a quick release from an intolerably drawn-out, inevitable end. It is one of the law's cruelties that a healthy person can kill themselves or an irrational person can deny themselves life-saving treatment, while the terminally ill close to death are forced to linger on beyond what they can bear.

Since I wrote about my mother's unkindly death, I have been inundated with similar stories. People often come up to me and pour out their tales of miserable deaths of horror, indignity and pain. The shock of discovering the truth about death fills people with indignation. They feel they must tell others, must give witness to what happens, aghast

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that in the great cacophony of heated debates about insignificant things, this torture still goes unremarked. Consider those who have operations while not properly anaesthetised. What happens in death may be as bad or, for all we know, worse, since no traveller returns from that bourn to tell us how it felt.

Perhaps people prefer a sanitised myth about modern dying. They hear the falsely reassuring murmurs from the religious and the BMA who claim that the best palliative care these days can take away pain and anxiety: no need for euthanasia. But in polls most doctors disagree with their own trade union. Over 80% of churchgoers, Catholic and Protestant, disagree with their church leaders. Nearly half the population say they would even go so far as to break the law and help a dying relative to die. (Though when faced with the prospect, most, like me, would probably be too cowardly to do it).

Good though palliative care can be - my mother had the NHS at its very best - its own practitioners admit they often watch people die in great mental and physical anguish.

People clutch at doctors' sleeves, begging for an injection: 'Can't you do something?' How easy it is to slip into death-like unconsciousness under an anaesthetic, gone into oblivion before you can count to five. That little death in the operating anteroom is a paradigm for how the good death could be for those who want it. Why not, the dying ask?

On April 4 the argument may progress with the publication of the report from the Lords committee on the Joffe bill on assisted dying for the terminally ill. Rumour suggests that some on this finely balanced committee, who had been opposed, were deeply moved by the evidence from 135 witnesses, thousands of submissions and their visits to the Netherlands and Oregon, where assisted dying is legal. It is rumoured minds were changed when they found their deepest fears unfounded. Numbers choosing assisted death were not rising; palliative care improved as death became an open, transparent business.

Here it is often a furtive affair, with doctors and

nurses in fear that some demented relative might accuse them, unjustly, of murder. The committee was shown death as a matter of the best clinical care, a process to be eased when people wanted it - not as the abstract debating-society topic of sound and fury. If the committee's report finds in favour, it could start a huge demand for a change in the law.

As the Pope rasps out his last breaths, his bishops are using his final suffering as a testament to the religious requirement to endure whatever quality of life God sends.

Both C of E and Catholic archbishops here will fight any attempt to change the law. Politicians have taken their cue from the churches. Only the Liberal Democrats have a policy to support it (on a free vote).

Before an election, expect no debate on anything as sensitive as this. Elections shrivel debate into an ever-narrower spectrum of issues. Death, and catastrophic climate change, will be airbrushed out. But sooner or later we all must die - and the manner of our going will matter to us very much.

## **UNITED KINGDOM**

The Select Committee on the Assisted Dying for the Terminally Ill Bill has said its Report should be debated at the earliest possible time, and has made several very helpful recommendations. This ensures that Lord Joffe's Bill will go to the House of Lords, and hopefully then to the House of Commons.

The Select Committee recognised the great suffering of some terminally ill people, and the high level of public support for changing the law. It also expressed positive views about how Oregon's physician-assisted suicide legislation works.

The Committee proposed that a future Bill on assisted dying should clearly distinguish between physician-assisted suicide (when a doctor supplies the patient with life-ending medication for the patient to take himself or herself) and medically assisted dying (when a doctor actively ends a patient's life at his or her request). This would enable Parliamentarians to choose one option even if they did not support the other.

# CENTRAL COAST BRANCH

*From Romaine Rutnam*

22 members and 8 guests attended the **15 April** meeting. Our media release *Can there be a 'Terri Schiavo' on the Central Coast?* resulted in quite a big article with photograph being published in both the Gosford and Wyong issues of the Central Coast Express Advocate. This caused many phone calls asking for information about our society, and about advance directives.

Rosemary Long, co-author of *Rest Assured - A legal guide to wills, estates and funerals*, spoke about this book, now in its 4<sup>th</sup> edition. Rosemary is a lawyer specialising in wills and estates law, daughter of one of our members, and now resident on the Central Coast and self-employed (her work telephone number is 4328 2149).

Members were invited to attend the Kerry-Anne Kennerly show on Channel 9 to support Philip Nitschke's discussion about the *Criminal Code Amendment (Suicide Related Material Offences) Bill, 2005*. Members and some guests hoped to meet their Federal members or senators to express their opposition to the Bill. One member advised that he would ask Jill Hall MP to set up an electronic petition in her office, which he has found effective in gathering quick support or opposition to proposed legislation.

The main purpose of the meeting was a full and vigorous discussion of the Terri Schiavo case in the context of Julie Lett's presentation on '*Advance Care Planning and Advance Care Directives*' at our Society's AGM. It was useful to have Rosemary Long explain that the dispute between Mrs Schiavo's husband and parents could not have occurred in NSW because the *Guardianship Act 1987 (NSW)* establishes that only her husband would be considered the 'person responsible' in such a case. (This relates to the glossary in the new NSW Health document, *Guidelines for end-of-life care and decision-making*, which was distributed at this meeting. Further free copies of this booklet, which is to be read in conjunction with the previously distributed *Using Advance Care*

*Directives*, can be obtained by ringing 9816 0452). Also included was a reading of part of a critique of NSW Health's *Guidelines*, published by Bernadette Tobin, titled 'When to withhold treatment – Terri Schiavo' and posted on [www.onlineopinion.com.au/view.asp?article=3283](http://www.onlineopinion.com.au/view.asp?article=3283)

Barbara Hasslacher, a former guest, is offering a half-day workshop on *How to Die Well*, looking at general preparations, including emotional, social, familial and societal needs. Interested people are asked to ring Barbara on 4367 4730.

The reply from Central Coast Health's Acting Director of Medical Services to my letter asking if we could convene a joint meeting on *Using Advance Care Directives* concluded 'Although your interest and desire to work with us is appreciated, we do not consider that the strategies you suggest are necessary at present.'

We had an enjoyable meeting in Gosford on **29 May** to commemorate the 10th Anniversary of the NT 'Rights of the Terminally Ill' legislation. Despite glorious weather and great surf, we attracted over 60 people.

The main speaker was Dr Charles Douglas, surgeon and Lecturer in Ethics and Health Law at the University of Newcastle, who talked on 'Legalised Voluntary Euthanasia: Arguments For and Against'. Dr Douglas, who conducted a survey in 1999 of attitudes and practices of nearly 700 Australian surgeons relating to medically assisted death, also commented on the recent publications by NSW Health, '*Using Advance Care Directives*' and '*Guidelines for end-of-life care and decision making*'. Patron of the Voluntary Euthanasia Society of NSW, Dr Peter Baume AO, responded to Dr Douglas' views, and the meeting then opened to questions and debate from the floor. Thanks to the local president of the Right to Life Association and 3 other of their supporters, we had a vigorous debate on 'Legalised Voluntary Euthanasia: arguments for and against'. A straw poll at the end showed 59 for and 4 against.

## **PRACTICAL WORKSHOP FOR VES MEMBERS ONLY**

**Advance Directives** are the topic of the moment.

They are the most immediate way we can prepare for our future medical treatment. Have you completed your own Advance Directive, ensuring that it covers the issues that are important to you? Have you talked about it with the right people and given copies of it to the right people?

Dr Giles Yates, a psychologist, a medical ethicist and VES Executive Committee member, will be running a workshop for members who would like to know more about writing their own advance directive.

This will be a practical workshop to help you work out the words to use to express your own wishes about future medical treatment. There will be plenty of opportunity to ask questions and discuss ideas.

Sunday 31 July 2005, 2.30 pm in the the Dougherty Centre, 7 Victor Street, Chatswood.

This workshop replaces the general meeting usually held in July.

## **NORTHERN RIVERS NEWS**

Our last meeting on 28 February featured the director of Palliative Care for the Northern Rivers area, Dr Joanne Doran. Dr Doran spoke eloquently of the role of palliative care but unfortunately, the numbers attending were embarrassingly low.

Undoubtedly travelling distance is a factor and a number of members are unable to attend meetings because of this factor alone. In order to assess in what direction members would like to go in the future, a questionnaire has been sent out and a good number of responses has already been received. This subject will be the main topic of our next meeting on 18 July. Also at that meeting, John Edge will demonstrate the

COGenie machine ( the carbon monoxide generator designed by Exit members ).

My programme of talks to local service clubs is continuing and at this stage, I have spoken to five Rotary Club branches, two U3A groups and the Maclean Laurel Club.

The talks always seem to be well received although there is never a queue of people wanting application forms. The exception to this was the Brunswick Valley U3A where I gave a one hour talk and gave out over 20 membership forms.

Bryan Milner

## **FROM THE A.C.T.**

The VES of NSW (ACT Branch) have conceived a way around the *Federal Government's Euthanasia Laws Act 1997*, which removed the power of the ACT and that of other territories to make 'laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life'.

They have written to the ACT Chief Minister, requesting a meeting to discuss the matter.

Their solution is to have the ACT Attorney-General to direct, at the request of the ACT Legislative Assembly, the Director of Public Prosecutions (DPP) under the *Director of Public Prosecutions Act 1990* (DPP Act) not to prosecute doctors who assist terminally ill patients with voluntary euthanasia, subject to certain conditions being met. This would have the effect of decriminalising, but not legally 'permitting', voluntary euthanasia in the ACT. In practice this means that voluntary euthanasia would still be illegal, but doctors assisting terminally ill patients according to the direction would not be prosecuted.

This matter will, of course, be followed with great interest.

## **VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES**

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### **SUBSCRIPTION AND BEQUEST INFORMATION**

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

Many loyal friends have found that a bequest is one way they can make a significant gift to further our Society's efforts to change the law and to educate the community. A bequest form is also available from the Society's office.