

President's Report AGM 2006

It is a pleasure to report to you that VESV has had a busy and effective 2005.

Some of this activity has had to do with the internal structure of VESV. Early in the year we held a committee strategy meeting which led to the establishment of effective subcommittees (strategy, finance and administration), with more work occurring in these groups and fewer formal committee meetings. During the year Max Sutherland, and later Neil Francis, joined the committee. Both have much IT and public relations expertise.

This led to the e-mailing of our newsletter. This represents significant savings for VESV and I encourage all members who can receive the newsletter in this way to do so.

The strategy meeting also led to the development of a vision/mission statement, and to renewed discussion about the effect of our name on our image in the community, and to the decision by the committee to recommend a change of name to Dying With Dignity Victoria – Promoting the right to choose. Other constitutional changes were also recommended.

Advocacy by Max Sutherland and Neil Francis has led to the development of a Dying With Dignity (DWDV) Charter, and a strategy for 2006 leading up to the State election later in the year. This election is vitally important as the changes in the Upper House election process raise the real prospect of seeing the election of Greens, Democrats and Independents. They could be the springboard to introducing private members bills.

Dying with Dignity Victoria has continued to expand the popular workshop programme, and has just revised our General Advance Directive. Mike Tinsley is another new committee member who has contacts in the retirement village industry, and he has opened doors in that area, increasing our educational role and increasing membership.

In the external arena, VESV continues to have an influence within the ALP health Policy committee. This approach was initiated by Mary Walsh and Noel Sanderson and aimed to amend the Medical Treatment Act, particularly in relation to statutory recognition of advance directives.

These amendments were unanimously supported by the health policy committee, and were finally passed by the ALP conference in December (although with some late amendments).

In 2004 VESV promoted a survey, carried out by Melbourne and Monash Universities, on the attitudes of Victorian medical practitioners to end of life issues. This is now complete and is being assessed for publication in the Medical Journal of Australia.

This will hopefully coincide with debate on these matters at the AMA national conference. Helga Kuhse and Simon Benson are working with other VE organizations on a coordinated approach.

Last year the British Medical Association agreed to a neutral position on medically assisted dying – we are hoping for the same outcome here.

Throughout 2005, various VESV members have been assisting an independent film maker with a documentary to be screened by SBS in mid 2006. It will have a significant impact on the debate. In July last year, a brave, determined and eloquent man, Steve Guest, contacted Jon Faine about his terminal illness. The resulting exchange had a profound effect on the huge radio audience.

Steve contacted me about his illness and I gave him advice regarding control over the end of his life. The homicide squad is investigating Steve's death. It is through such challenges that the inadequacies of the current law can be emphasized.

VESV has also been active in approaches to VCAT and the Medical Practitioners Board of Victoria to protect patient rights under the Medical Treatment Act, and to send corrective messages to the medical community. I thank Kitty, Sandy and Eva Cohen for their support in these efforts.

I was invited to speak about the "peaceful pill" at Philip Nitschke's conference in Brisbane, and reiterated VESV's opposition to this in principle, whilst acknowledging that it can have some political impact.

Unfortunate news just received is that the Tax Department has removed VESV's tax exempt status. Earlier in the year we had worked very hard to provide evidence of our educational and community service role in order to retain tax exemption, and this seemed to have been successful, but to no avail. It will have a detrimental effect on our financial position.

Undoubtedly, the major change has been a complete overhaul of our website by Max Sutherland and Neil Francis. The site is now first class and a powerful weapon. This would have been a very expensive exercise if done professionally. It was done professionally but at no cost, thanks to Max and Neil.

Finally, I want to thank those many people who have contributed to VESV during the year – many donors and volunteers who keep us moving forward. Our office staff, Rowena Moore and Jane Edwards, have been fantastic. Retiring from the committee this year are a number of

wonderful people who have rendered excellent advice and been tireless on our behalf – thanks to Betty Teltscher, Helga Kuhse, Belinda Morieson, Chris Momot and Simon Benson. Some will continue to advise through our sub-committees. I want to particularly thank Max Sutherland and Neil Francis for their support and encouragement. Without their help I would not have considered continuing as president.



"Amid the comfort of friends and kindness of strangers, adieu."

So wrote Pamela Bone in her final column for The Age on December 19th 2005...

Pamela, a highly respected journalist and editor for 24 years, had come back from Africa feeling awful.

She was in fact seriously ill with Multiple Myeloma, a relatively rare cancer that is treatable but incurable.

At the AGM for the newly named Dying with Dignity Victoria (DWDV) Pamela was our keynote speaker.

The way she spoke of coming to terms with the fact that she is terminally ill was inspirational and devastatingly honest. As a professional journalist, her analysis and observations regarding the current climate of the debate in favour of medically assisted dying was both balanced and personal.

While Pamela's cancer is rare, cancer itself is not. As she pointed out, one in three of us will develop the disease and one in four of those will die of it.

When first diagnosed, Pamela had treatment procedures explained to her in detail, and her options were chemotherapy and stem cell transplant.

She asked what would happen if she simply "did nothing", and the question amazed the doctor! He was silent for a moment, then replied that she'd "sink into a coma", but expressed the opinion that doing nothing would be a dumb option. This articulate and intelligent woman was surprised and annoyed to find that her doctors automatically assumed she'd go ahead with treatment.

Surrounded by her loved ones, Pamela did decide to go with the treatment option; a decision she came to

regret many times as it proceeded.

Her question to herself was, "This is terminal, so why am I putting myself through discomfort?" Had she done nothing, she reflected, she would have been dead by now and her family would have been through the grieving process.

Some eighteen months later though, Pamela is glad she's alive and on this day at least, feeling relatively well.

Pamela made the observation that we

Quoting from Pamela's final Age column:

"What I have learned in this year of illness is that legislation for assisted suicide...for the right to die at a time of one's own choosing, and to have help to do so if necessary...will and should come.

It will come because the majority of the population wants it and because those who protest so loudly every time the subject is mentioned are a minority.

To know there is a means to end life peacefully and painlessly when they want would be a great comfort to most old people.

This is a kindness that we, as a society, need to extend to ourselves."

live in a death-denying culture. On one level we all know we will die, but the mind slides away from the reality. People hastily change the subject. We now die of some medical condition... we are no longer allowed to die of old age.

Pamela was surprised by her need to feel in "control" and acted on this to the extent that she prepared her own funeral, right down to nominating which of her children would read what. She also revised her will.

She also explored the reasons why some people are drawn to work in situations requiring both great compassion and care. Is it to help others or themselves, she wondered.

One grief counsellor actually told Pamela that human suffering had a purpose, because without pain there would be no compassion. This person believed that others' pain enabled her to be kind; a conviction echoing that of Mother Theresa, about whom Pamela had written a column ten years earlier. Mother Theresa had said, "The poor exist so we may show our love and compassion". Pamela challenged the fact that Mother Theresa never asked why people were poor; never questioned the extremities of vast wealth and grinding poverty in India, and opposed the one measure that would have helped people in a practical sense...birth control.

Extrapolating from Mother Theresa and the counsellor's rationalisations, is it possible our pain exists so that Palliative Care Doctors and Nurses can show us care and compassion?

Pamela can't accept that!

She believes in the development of medically assisted dying and feels that the time is coming when it will be a reality. She is looking forward to the invention of the peaceful pill and considers that just the knowledge that one existed would be a form of palliative care in itself. The knowledge that we can leave our lives, free of pain and at a time of our own choosing, would give us a serenity we are currently denied.

Pamela spoke of the experience of death itself. In "How We Die" written in 1994 by American Dr Sherwin Nuland, the author addressed how death is defined. She believes that the idea of a "good death" is a fantasy/myth. And the "good death" myth is more prevalent today than ever. Most die badly, says Nuland.

Member of the World Federation of Right to Die Societies

PATRONS: Sir John Holland
Sir Peter Derham
Mr Julian Burnside QC
PRESIDENT: Dr Rodney Syme
V. PRESIDENT: Mr Neil Francis
SECRETARY: Ms. Alana Bourke
TREASURER: Mr Peter Foster

GENERAL COMMITTEE:
Dr Max Sutherland
Mr Mike Tinsley
Ms. Jillian Paterson
Mr Graeme Triggs

Office:
3/9B Salisbury Avenue
BLACKBURN. 3130
Office Manager:
Rowena Moore
Telephone: (03) 9877 7677
Fax: 9877 5077
Email: dwdv@dwdvictoria.org.au
Web: www.dwdvictoria.org.au

Update Editor: Shirley Clifford 9884 6085

In addressing the question of when it is OK to take one's own life, Pamela quoted Dr Nuland who says, "Rarely. It is almost always the wrong thing to do." With this exception: when suffering the unendurable infirmities of a crippling old age or the final devastation of a terminal illness.

Pamela spoke for thirty minutes and the audience were warmly appreciative of the effort it must have taken for her to bare her private thoughts, reflections and experience.

Contributed by Mary Walsh

* DWDV supports the availability of a lethal oral prescription from doctors, but not a publicly-available peaceful pill.

* Video excerpts of Pamela's talk can be viewed at www.dwdvictoria.org.au <<http://www.dwdvictoria.org.au>> and the complete speech is available for loan from our DVD library.

Dying With Dignity depends on donors and volunteers

The DWDV annual financial statements reveal that in 2005 we derived \$44,652 from membership fees and \$36,852 from donations. This is a clear illustration of how dependent we are on the generosity of our members. Donations are of all sizes and all are equally welcome. The size of the donation does not reflect the generosity of the donor...it all depends on what they are able to give. DWDV cannot thank every donor individually (actually we could but the time and cost would make it a bit self-defeating), so do so collectively.

DWDV has a policy of trying to keep our membership fee as low as possible, because many of our members are elderly and on pensions, but we encourage any who can to add a little extra by way of donation (on which we are not taxed).

DWDV also derives enormous help from a large band of volunteers who donate their time and energy to our cause. Their contributions involve helping in the office, writing for the newsletter, translating overseas journals, helping with meetings and workshops, and of course committee work. We could not survive without this dedicated effort.

Dying With Dignity AGM

The weather fiasco at the AGM prevented me from publicly recognizing all this help, so I now do so. Please keep it up. As a record 150 gathered for the 2006 AGM, ominous storm clouds also gathered. While extra seats were produced, our "parking officer" Mike Tinsley huddled under an umbrella and ushered our guest speaker into the hall.

The renowned and much loved Pamela Bone addressed the appreciative audience. Mary Walsh has provided us with a report on her address. Her talk was videoed by Neil Francis, and copies are available from the DWDV office.

The President then explained the reasons for changes to our constitution as advertised in the February newsletter, in particular, the motion to change the Society's name to Dying With Dignity Victoria, with the subtitle Promoting the right to choose. This motion was passed unanimously.

During afternoon tea alarms sounded and we were advised to evacuate the hall, as the ceiling in other parts of the building was collapsing. The remaining official business was hastily concluded outside the building, as a quorum remained.

Rodney Syme was re-elected President, Neil Francis as Vice-President, and Peter Foster as Treasurer.

Max Sutherland, Jill Paterson and Mike Tinsley make up the committee. The Treasurer's report was passed, the year resulting in a small loss of \$868. The meeting passed small increases to the annual subscription, and reappointed Ross Collier as our Auditor.

2006 will be a big year and we need every assistance you can give. Rodney Syme.

Dying With Dignity Petition

In this issue of the DWDV update there is an insert titled Petition to the Legislative Assembly of Victoria. This is one of DWDV's initiatives as we gear up to the November State election.

We urge every member to fill their petition with the signatures of friends and acquaintances. You can even take it to your shopping mall, club, sporting occasion and put it in front of strangers. The more the merrier.

If you have filled your sheet and feel you could do more, contact the office and Rowena will send you extra forms.

A few years ago, VESV carried out a similar exercise and obtained over 5,000 signatures. If every DWDV member obtained 30 signatures, we would have a petition of 50,000 to impress on our Parliament that we mean business. Dying With Dignity Victoria hopes that a number of you will have made bequests in your will to the Society. These will almost certainly be in the name of the Voluntary Euthanasia Society of Victoria, and may cite our old address in Prahran. We would remind you to change the name in the bequest, and to update the address to our new office in Blackburn.

Bequests

Those of you who have not considered making a bequest to DWDV may like to do so.

We have a brochure that gives the relevant advice and you can obtain this by contacting Rowena on 98777677.

You can also download the form from the "sign our petition" page on the web site.

Workshops

The next of our regular Workshops will be held on August 14th 2006.

At the DWDV workshops, you receive a full set of DWDV's documents to help specify your own end of life wishes.

You will also experience two and a half hours of expert tuition in how the current law applies to you, as well as how to execute the DWVD documents properly to maximise your protection, or the protection of your loved ones.

The atmosphere is friendly and informal and light refreshments are served.

After the 14th of August the new price structure for workshops will be

Members:	Pensioner \$20 Non Pensioner \$40
Non-Members:	Pensioner \$40 Non Pensioner \$80

*NOTE: The two Workshops to be held before August 14th are fully booked

**Bookings
now
open
for
Aug. 14**

“Euthanasia – Choice and Death” by Gail

Tulloch is the second book in a series entitled Contemporary Ethical Debates. The series aims to address “the most pressing ethical concerns confronting human beings at the beginning of the twenty-first century” and Tulloch’s volume certainly achieves this. It provides a relevant and informative exploration of the legal, medical and ethical issues that surround the topic of euthanasia and end of life choice.

As a lay person, with no legal or medical background, I found the first section of the book gave a very clear outline of the clinical definition of death and how the legal definitions have had to change as medical and technological advances have blurred the line that marks “end of life”.

Four forms of Euthanasia are also defined: Voluntary Active – where a lethal action is taken at the request of the patient, Voluntary Passive – where treatment is suspended, at the request of the patient, which hastens death, Involuntary Active and Involuntary Passive – which are as above, however the patient is no longer able to make the request themselves.

Chapter two discusses the “Stark Choices” that our society faces. Several cases are presented where the medical profession have faced the difficult choice of either participating in some form of euthanasia or continuing what is likely to be futile medical treatment.

At one end of the spectrum, the choice to “let” a severely deformed spina-bifida baby die is accepted, whereas the choice to take a paraplegic teenager injured in an horrific accident, off life support appears to be much less acceptable.

The question of resource allocation is also raised. In today’s society, we have the technology available to prolong the life of many, but at what cost – both in terms of financial drain on health care budgets but also in terms of the impacts on families and on society in general.

The second half of the book discusses the issues around death and dying in four countries; The USA, England, The Netherlands and Australia. This section provides practical examples of the ethical and legal dilemmas discussed in the first section. There are many examples given where legal concerns have forced individuals, families and the medical profession into desperate situations, where those wishing to die have faced a lonely and sometimes painful death and those who assist, or just wish to be present with their loved ones when they die, have faced legal prosecution and even jail.

Tulloch indicates that in most countries, the law is lagging behind the needs of the very communities these laws are designed to protect. The landmark cases presented often show that although the courts have no choice but to uphold the law, the judges often show lenience in sentencing. This in effect condones euthanasia under certain circumstances – but these circumstances are not formally defined – leaving uncertainty and ambiguity.

For me the key to the whole debate is stated towards the end of the second last chapter:

The key questions that society faces are;
Is it sometimes legitimate for a person to choose death?

If so, is this morally legitimate?

If so, should it also be legally legitimate?

If so, should the medical profession be involved?

Clearly we have the medical technology and, in most western countries, the resources to prolong life almost indefinitely – but is it morally right to do so, particularly if it is against the patient’s own wishes.

In summary, Tulloch’s book is a worthwhile read, that informs and educates and I thoroughly recommend it to anyone who wishes to increase their understanding of the important and often contentious issue of euthanasia.

book review



Sacramento:

A large majority of Californians support giving the terminally ill the option of receiving life-ending medication.

Seventy percent of all adults and 69 percent of registered voters said they believe incurably ill patients have the right to ask for and receive life-ending medication.

A smaller majority said they support allowing the terminally ill to get a lethal prescription that they could administer themselves.

“Generally speaking, Californians tend to be more open to allowing an individual to make a decision rather than having something prohibited through government fiat,” said poll director Mark DiCamillo.

He noted that the Field Poll has measured California attitudes toward euthanasia eight times in the past 27 years and found consistent support beginning in 1979, when 64 per-

cent favored the idea.

The most recent poll, conducted over the two-week period ending Feb. 26, found strong support among virtually all political, ethnic and social groups...including people who identified themselves as members of major religious organizations.

Eighty percent of Democrats said they favour giving a terminally ill person the right to take his or her life; 59 percent of Republicans said they support the idea. The poll found support among men was 73 percent; among women, 67 percent.

Sixty-five percent of Protestants said they support euthanasia, as do 64 percent of Roman Catholics. But 76 percent of people who identified themselves as born-again Christians said they opposed legalizing the option.

A bill pending in the Legislature and expected to be considered later this year would allow terminally ill adults to obtain a prescription from a doctor to end their life.

Legislation by Assembly Democrats Patty Berg of Eureka and Lloyd Levine of Van Nuys would require two physicians to evaluate a patient’s condition and medical options before the lethal drugs could be offered.

The poll found 57 percent of adults said they favour the

legislation, 34 percent said they were opposed, and 9 percent said they had no opinion.

The two lawmakers were forced to withdraw a similar bill last year because it lacked support for passage. The new bill, AB651, faces a July 7 deadline to pass out of a State Senate committee.

DiCamillo said Californians are somewhat less certain about giving people the ability to administer a lethal prescription.

"People don't want this privilege to be abused," he said. "There's much concern that an individual might do this in a cavalier manner."

Governor Arnold Schwarzenegger has not said whether he would sign the Berg-Levine bill if it gets to his desk. But the governor has said that the question of assisted suicide should be decided by the voters, not the Legislature.

Oregon

Dying With Dignity Victoria has followed the Oregon Death with Dignity Act since its inception. The Act is limited to mentally competent patients who, in the opinion of two doctors, have not more than six months to live.

The Act has been applied and researched with care. The Supreme Court ruling comes after other attempts to overthrow the Act via transfer of the control of Medical Practice from state to the Federal Government.

The Supreme Court ruled by 6:3 that Ashcroft and then Gonzales as Attorney General of the Bush administration had no special executive power to apply the Controlled Substances Act to doctors writing prescriptions for patients. Doctors had been threatened with de-registration. Around the USA doctors in palliative care became afraid to provide needed pain relief to their patients.

Meanwhile the Oregon Department of Human Services has analysed the eighth year of assisted dying under this Act. 53 Oregonians obtained a prescription from their doctor, and 38 ended their suffering by taking the medication. Their average age was 70 and 84% had cancer.

Some died without using their prescription – merely having it provided sufficient palliation. Almost all were receiving palliative care, had health insurance and were well educated. There was no evidence of abuse. It is further proof of the safety and effectiveness of this legislation.

More detailed discussion is available on the DWDV website.

France

According to a poll by TNS-Sofres for ADMD, many adults in France believe people should be allowed to die under specific circumstances; 86 per cent of respondents favour amending existing laws to allow patients in an advanced or final stage of an incurable disease to obtain medical assistance to die.

In the case of a person who is placed in a situation of dependence which he or she considers incompatible with his or her dignity, 77 per cent of respondents support doctor-assisted euthanasia.

In March 2000, France's National Ethics Committee said euthanasia may be permitted "if there is no other solution, if palliative care and pain-killers are ineffective, if all treatment or therapy has failed, (and) if there is unanimous agreement

that the situation has become intolerable." In January 2003, French nurse Christine Malevre was sentenced to 10 years in prison for the murder of six patients at the Francois-Quesnay hospital. Malevre claims to have acted out of compassion.

In November 2004, France's National Assembly endorsed legislation which legalized "passive euthanasia." This concept allows doctors to withdraw life-sustaining medication from patients, but not, for instance, to administer poisons.

The law currently makes it possible for a sick person to refuse any treatment, including food and hydration, and to be allowed to die.

On the other hand, it does not allow a sick person to be helped to die.



Please
help DWDV
minimise
costs!

DWDV Update is one of our ways of keeping members up to date with news and developments.

Printing and posting Update is a significant cost to the society, which operates on a voluntary and non-profit basis.

You can help save costs by electing to receive your own copy of Update by email rather than by post. To do so, simply email

dwdv@dwdvictoria.org.au

to request your copy of Update by email, and confirm the email address you would like it sent to.

Rowena will be delighted to add you to our growing family of internet-enabled members.

MASSIVE STROKE: Then Seven Years of Anger and Misery

My husband died in June 2001 of pneumonia – seven long years after he became imprisoned in his own body.

One week after his seventy-second birthday and riddled with arthritis, I found him collapsed on the kitchen floor curled up and making animal sounds.

My instinct was to save him of course, so I called our doctor – it was about 8 a.m. but he arrived very quickly; strangely to me, he seemed almost unwilling to send for an ambulance but how else could I save him?

Box Hill Hospital were so kind. My husband was installed in his own quiet room with drips and other apparatus. They told us he had suffered a massive stroke that affected his left side. There was little hope.

Our children were a huge support to me while he was tested for this and that.

The speech therapist found he was able to swallow food of a kind. He began to revive. Two years at the most they thought. I submitted my manifesto to please let him go. They were forced by their vows to do everything in their power to save their patients. He was moved into a men's ward to "cheer him up"!

The social worker began to talk about nursing homes. "You will never be able to manage him at home," they told me, adding "Out of the question and you must find somewhere that pleases you quite soon."

We searched for somewhere that "pleased" us. As my husband was settled in his new surroundings he began to show his anger. He found a voice and a steady stream of suitable oaths.

These weakened after a few weeks

and he gradually settled down to a silent mass of frustrated anger. But he hated the physio, hated his visitors most of the time and reduced us to tears often.

Me he hated periodically as the mood took him; he felt more secure with his carers.

Three years on and he caught a dose of flu and they "dragged" him back from the brink of death in front of us! Four years after that, and never ever flu injections, he managed to escape.

I have repented for the five years since that I did not listen to the doctor's unspoken words and just get him back into his own bed and, hopefully, let him go.

Deidre
24 February 2006

DWDV member activity

In recent newsletters we have asked members to persuade organizations to which they belong (U3A, Lions, Probus, retirement villages etc.) to arrange talks by DWDV.

There has been an excellent response – let's keep this rolling. We also asked for personal stories of distress at the end of life. Again, there have been some amazing responses.

In one instance it allowed DWDV to support a member in a complaint to the Medical Practitioners Board of Victoria regarding the lack of care her mother received. This should result in a strong message being delivered to the Victorian medical community that this abuse will not be tolerated.

Please keep these stories coming. If you feel that you or your loved one is being abused or has been, DWDV is keen to support you in a genuine complaint to the authorities.

Credit Card Details

Many of you generously make ongoing contributions via credit cards. You may need to contact the office with new details if:

1. Your card is due to expire
2. You have changed your credit card details (especially with the phasing out of Bankcard)

We would greatly appreciate your help in updating our records

Monthly meeting

The Mornington Peninsula Group of members of Dying With Dignity Victoria meet quarterly at Mt Martha House at 2pm on the first Monday of the month.

Our dates for 2006 are:

May 1

August 7

November 6

We welcome anyone interested in joining in discussions.

Contact Phone: Pat at 5974 1580



Challenge in Choice

World Federation of Right to Die Societies

16th Biennial Conference

Toronto, Ontario, September 7 to 10, 2006

The 16th Biennial World Federation Conference will take place at the Sheraton Centre in Toronto.

Guest speakers to include:

- George Felos, a nationally recognized expert in right-to-die cases, and lawyer for Terri Schaivo
- Dr Robert Buckman, a medical oncologist at the Toronto-Sunnybrook Regional Cancer Centre and a world-renowned motivational speaker
- Jocelyn Downie, Canada Research Chair in Health and Law, Dalhousie University and author of *Dying Justice: A case for Decriminalizing Euthanasia and Assisted Suicide in Canada*.
- Dr. Rob Jonquiere, CEO NVVE – Right to Die Society – The Netherlands
- Arthur Schafer, Director of the Centre for Professional and Applied Ethics, at the University of Manitoba

Presentation topics to include:

- The Truth Behind the Rhetoric – What is Working around the World and Why
- Nudging the Law – How to Move Legalized Aid-in-Dying Forward
- Effecting Social Change – Progressive Social Movements, Historical Perspective

The conference is open to all members of the public, with special rates for members of Dying with Dignity.

For further information: dbabey@dyingwithdignity.ca