

President's Report

An Age headline on May 12 said "Leader speaks out on bay, wind farms and euthanasia". The headline referred to Ted Baillieu, the recently elected leader of the Victorian Liberal Party.

In 1996, Baillieu was President of the Victorian Liberal Party and spoke passionately at the state conference of Marshal Perron's Northern Territory 'Rights of the Terminally Ill' Act.

He said then "it's compassionate, it's voluntary, it has safeguards, it's about dignity".

At that time the Patron of VESV, Sir John Holland, introduced me to Ted Baillieu, and we have remained in touch since then. It is a measure of his integrity that he did not retreat from his position, as some politicians have done, when reminded of his remarks on becoming Party leader.

It is a bonus for DWDV to have the leader of the opposition as a friend, but it does not automatically translate into Liberal Party policy.

Jeff Kennett was also a supporter of VE but was not able to do anything about it when he was in office.

As Baillieu said in his recent interview, he would not seek to make it law unless there was widespread community backing. Thus it

is up to DWDV and its supporters to impress upon him that there is support.

There are two obvious ways to do this. First by polling the electorate. Polls over the last 25 years have shown a consistently high level of support for legislative change.

The last poll was commissioned by VESV in 2002 and showed 73% support in Australia. (The support in Victoria was actually 76%.) A new poll would provide excellent evidence of that continuing support, and your committee is exploring that option.

The second initiative is through our petition. This is a practical way in which community support can be shown. I would be delighted to send 20,000 signatures to the Parliament.

The date for closing the petition is not yet set, and we may keep it open until the new Parliament sits after the election of November 25.

So please keep collecting those signatures. They have become even more important following Baillieu's announcement.

The Liberal Party has a lot of ground to make up and it may be persuaded to adopt popular policy to do so. This, of course, puts the other party under pressure.

Who knows what might happen?

Our Petition

With Ted Baillieu's announcement that he supports voluntary euthanasia but would not seek to make it law unless there was widespread community support, DWDV's petition has become very important.

In our last newsletter, we included a petition form which many members signed and returned with only one or two signatures. Thanks for that, though we need a lot more signatures.

What will make a huge difference is not only signing the petition for yourself, but collecting as many signatures as possible from friends, acquaintances, and even strangers.

Yes, strangers! I know it may not be the easiest thing in the world to approach a complete stranger and ask for their signature, but it is possible and after a while, is quite fun.

Stalwart DWDV member Mary Walsh and your President met on the steps of Flinders St Station on a cold winter morning, and engaged the public as they entered and left the station. We collected over 70 signatures in two hours.

We had no hassles, had some interesting conversations, and as I say, a lot of fun. DWDV member Anne Shepherd of Torquay has been door-knocking in her area where she has collected 72 signatures and is still going strong. Others leave the petition forms lying on the kitchen table as well, and find that most visitors willingly sign without prompting.

Any member or group of members can do this, and it is comforting to be in a group.

The railway station was a good site as people were coming and going. Federation Square would also be good, as would a football match or other sporting occasion, your supermarket entrance, or your favorite pub.

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

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Identifying DWDV T-shirts can be borrowed from the office and these make it easier for people to see where you are coming from. We found that young people and middle-aged women were particularly friendly and likely to sign. It was fun to try and predict on approaching someone whether they would be in agreement or not.

Included in this newsletter is another petition form. Please take the opportunity to completely fill it with signatures you haven't collected before. You can obtain more copies from the office or our website. If you decide on a mission, the office can also lend you clipboards and pens in addition to T-Shirts. The date for closure of the petition is not yet set.

We may wait until after the election (November 25) in order to present the signatures to the new Parliament.

So keep working hard on those signatures at least until the next newsletter in October.

We need to send a clear message to politicians that legislative reform is well overdue.

If you would like someone to accompany you on a signature gathering mission, call Rowena and we should be able to arrange this.



Mary Walsh and Rodney Syme collect petition signatures at Flinders Street Station.

House of Lords rejects Dying With Dignity bill

Sadly, the British House of Lords has rejected, by 148 votes to 100, the "Assisted dying for the Terminally Ill Bill". This Bill, modeled on Oregon's assisted suicide act, and introduced by the noted human rights lawyer Lord Joffe, was deferred to a second reading in 6 months.

The traditionally conservative British Peers and Bishops used arguments based on fear and distortion to win the day, after seven hours of impassioned debate. Lord Joffe is determined to reintroduce the bill.

DWDV Media Response Team

For some time, DWDV has had a small group of members who have been prepared to write letters to our print media in response to end of life issues that crop up from time to time. It is necessary for such responses to be rapid, and for a number to be sent on any given issue.

All major print media need to be kept under close surveillance, so that items and opportunities are not missed. Because of the need for speed, an email address is important.

DWDV is updating its media response team, and would like to hear from any member with email facility who enjoys letter writing, particularly to the media, to contact the office to join our list.

We need to know your email address, and the papers, magazines or journals that you receive regularly, and which receive letters to the editor.

End of Life Decisions: Do Advance Directives Work?

Melbourne University is running a seminar on Advance Directives on Friday 21st July. The seminar is titled *End of Life Decisions: Do Advance Directives Work?*

This seminar is an excellent opportunity to hear about current issues surrounding advance directives, medical practice and the law, and how they affect you. DWDV President Rodney Syme will be a member of the discussion panel during the seminar, and you will have a chance to ask questions.

The seminar is open to the public. Attendance is free, although an RSVP is required either by calling the University on 8344 9800 or by e-mail to mdhs-rsvp@unimelb.edu.au.

We recommend you attend if you are able!

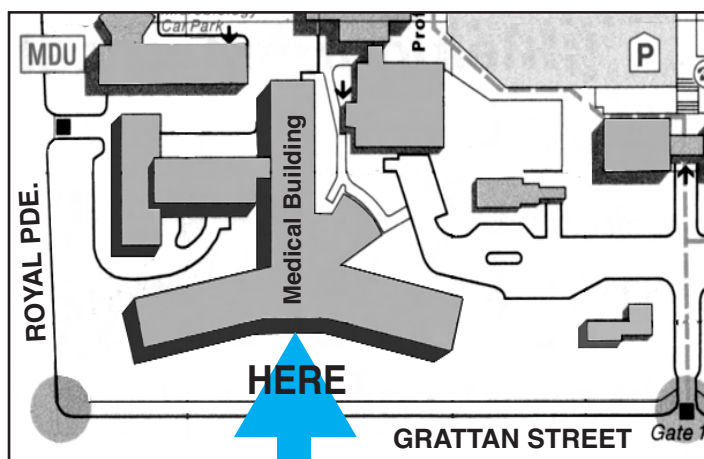
Details:

Friday 21st July, 2.00–5.00pm

Sunderland Lecture Theatre,
Ground Floor Medical Building

Corner Royal Parade and Grattan Street, Parkville.

Public transport: North Coburg Tram 19 up Elizabeth Street from Flinders Street.



E-mail - Faster! Cheaper!

At DWDV, we like to keep you informed about our activities. We send occasional updates to members with an e-mail address in between official newsletters, so that you are in the know about developments in dying with dignity.

Remember that DWDV is a not-for-profit organisation run largely by volunteers, so keeping costs down is a priority while working towards choice in dying with dignity. If you would be agreeable to receiving your newsletter only by email - if you don't already - that will save printing costs (and trees).

So, send your e-mail address to Rowena at dwdv@dwdvictoria.org.au, indicating you'd like to receive the newsletter by e-mail.

Even if you would still like to receive your newsletter in print, but have an e-mail address, do let us know what it is.

And please let Rowena know if you've changed your e-mail address, too.

Altering your Will

We have been advised that if you have made a bequest to the Voluntary Euthanasia Society of Victoria in your will, that bequest will automatically transfer to Dying With Dignity Victoria.

There is no legal need to change your will. However, to make it easy for your executor to find DWDV to forward the bequest, it would make sense to accompany the will with a separate note indicating that VESV is now DWDV, and providing the new address.

DO NOT ATTACH THE NOTE TO THE WILL IN ANY WAY (i.e. don't use a pin, paper clip, staple, etc).

The note should be an entirely separate document, though kept with the will.

You can obtain a name-change advisory form from the DWDV web site (www.dwdvictoria.org.au) under Take Action/Make a Bequest.

September Workshop Bookings now open

Bookings are now invited for the DWDV Workshop on the 18th September 2006.

At the Workshop you receive a 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 DWDV documents properly to maximise your protection, or the protection of your loved ones.

The atmosphere is friendly and informal and light refreshments are served. The July and August workshops are already sold out, so make sure to get in early for the September workshop if you'd like to attend.

Prices: Members Pensioner \$20, Non-Pensioner \$40; Non-Members Pensioner \$40, Non-Pensioner \$80.

Not on the internet?

The Internet is a wonderful communications medium...have you not been on it yet? Even if you don't have your own computer, you can get connected at the local library or Internet cafe.

DWDV is inviting expressions of interest from members for a special DWDV training session that will introduce you to computer basics and how to browse the web.

We'll also show you how to get around the DWDV web site and all the wonderful resources it contains (there'll be even more soon).

To register your interest, call the office on 9877 7677.

Final Exit DVD by Derek Humphry

Many readers will be familiar with Derek Humphry's book *Final Exit*. This book – which has successfully made the *New York Times* bestseller list – is available in many public libraries of Australia.

It gives practical advice on the dos and don'ts of self-deliverance in the case of terminal illness.

Derek Humphry has now also produced a DVD, based on the book, entitled *Final Exit on DVD – The Art of Self-Deliverance from a Terminal Illness*. On this disk, Derek Humphry stresses the value of life and makes clear that any advice contained in the disk is intended only for the terminally ill, who – after careful and rational consideration – have decided to end their own lives.

There are warnings about the unreliability and dangers of using certain drugs or methods, and practical advice is given as to how ensure a dignified death.

Like Dying With Dignity Victoria, Derek Humphry has as his ultimate goal law reform, where suffering and terminally ill patients can lawfully end their lives with the help of their doctor. This kind of help is available to patients in Derek Humphry's own State of Oregon, in the Netherlands, Belgium and Switzerland.

Unfortunately it is not yet available to most people around the world; and it is to these people that Derek Humphry addresses his DVD: to help them to achieve a peaceful end.

The DVD is spoken by Derek Humphry himself. It is full of good, sound advice and this reviewer would give it - to follow Victorian film ratings – five stars. *****

The disk is available from ERGO Euthanasia Research Organisation, 24829 Norris Lane, Junction City, Oregon 97448, USA. Cost \$US 20.00 plus shipping.

For further details, you can visit Ergo's website at www.finalexit.org.

Helga Kuhse

We remind members that DWDV does provide individual counseling. If any member is considering taking advice from the Final Exit video, a call to one of our counselors may be helpful.

my Mother's DYING

MY MOTHER'S DYING took five years and was neither the death, nor the "life" she wished for. I was sometimes with her near the beginning of those five years when she begged her very caring regional city doctor for assistance to end to her suffering. She wanted to die with dignity in her own home.

Her terminal conditions included an inoperable aortic aneurism, reactivated spinal tuberculosis, emphysema, breast cancer, and a heart that continued to beat to the tune of a relentless pace - maker until the batteries ran flat.

Eventually, lack of oxygen to the brain caused her to develop dementia.

Perhaps it was just as well.

In that final terrible twelve months she often didn't recognise even me or my father, who maintained a nightly bedside vigil at the nursing home. He had also spent most of his days with her until it came to the point she would often abuse him.

This was not my mother in life.

We were reconciled to visiting a "medical condition", who seemed to be kept alive more for the possible economic gain of the "health system" than for her own benefit or quality of life.

For us who loved her and were very familiar with her views on quality of life and the point at which death truly takes place, it was sheer torture. This was not the life my mother wanted.

And it was the death of one's worst nightmares; alone, without family or friends in a nursing home – a place my mother refused to accept as "home".

She was eighty four.

My father had earlier nursed her at home for two and a half years with the assistance of district nurses and hospice.

They were wonderful – when they were available. But often the reality of the situation was that my dad was alone in toileting her, keeping up her medications and administering pain relief. I was there as often as I was emotionally and physically able.

My mother was admitted from hospital into palliative care, having been given a week to a month to live by

both the heart specialist and the geriatrician, but when she continued to "live" she was accepted into a nursing home close to her house.

That decision to put her "into care" meant having to accept we no longer had the capacity to meet her physical and medical needs within the family.

My mother was a very forthright and vibrant woman in life. She was a great advocate for "the right to choose" in relation to euthanasia. Placing her into care felt like a kind of spiritual murder and defeat that we could no longer meet her needs, or her wish to die in her own home with dignity.

Admittedly, the nursing care itself was excellent.

I knew that had my mother been still "alive" in the true sense before her medical death, she would have wept for not having been able to move beyond confinement to bed and to the world beyond for five years.

She would have wished for the traditional extended family Christmas rituals her condition denied her. Her beloved daughter-in-law's sudden death preceded her own and on doctor's advice, she was denied knowledge and the right to grieve.

How she must have felt her daughter-in-law's unexplained absence from her very limited world.

She would have hated the loss of her beloved husband's full participation in "life" as he maintained his beside vigil during the long wait for an end to her often agonising pain and perpetual suffering, as the death of her personality preceded the death of her body.

She would have wept that her husband cried himself to sleep nightly at the loss of the wife he loved and with whom he shared sixty quality years of life.

It's as if he spent five years of dying himself at her side.

She would have wept for her children and grandchildren suspended in life perpetually alert for the phone call that brought news of the release and relief of her death. Real death.

I have grieved for five years for the mother I lost, but few friends seemed to understand where death truly began

and real life ended. As her closest friend and I finally cleared her wardrobe of the things which she once filled with life, we could not help but think of how those very things hanging unworn for five years must have been a constant reminder to my father of the life that had already been lost in so many ways.

At her funeral I spoke emphatically of the five years of her dying, and reminded some three hundred that filled the church to truly celebrate the life and vitality she once embodied and spiritually embraced. I urged those assembled that if they must mourn my mother to do so by working to make the world a better, happier place. Five years of inescapable suffering is more than enough!

When my mother was for so long denied a death, despite long-standing no-resuscitation wishes and instructions, I vowed to work towards legislative changes to permit euthanasia if the person concerned chose it for themselves.

Throughout her life she herself advocated the right to choose death with dignity, and sought it for herself.

I live with a sense that I betrayed my mother in that it was beyond us to grant her that choice. All that is left is to tell my mother's story in the hope it may lead to legal reform. It is necessary to embrace such views to celebrate my mother's perceptions of life.

Even sympathetic doctors in the country fear falling foul of the law.

There are many good doctors and nurses who profess to care; none should live in fear of the law for assisting a dignified death.

Medical intervention that seeks only to prolong life can sometimes make life itself far worse than death. That was certainly the case with what my mother and those close to her "lived" with.

All of us who seek death with dignity as a matter of personal choice need to promote legal change to ensure our rights and wishes are granted.

I firmly believe, as my mother did, that death begins when quality of life is lost, and that a person facing terminal illness, or wracked with unbearable pain should be able to define their point, company, time and place of death for themselves.

Author's name withheld