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President's Message

What an excellent AGM we had in February. For those who missed it, Bettina Arndt was our keynote speaker, and she provided a fascinating report on her experiences, and views on Physician Assisted Dying (PAD).

We also had a very successful Steve Guest Day rally on the steps of Parliament in April, with hundreds of people participating. Thank you to everyone for showing your support. A full report of the rally is inside.

DWDV also hosted a dinner for members of Parliament to launch the Exposure Draft of the new Bill, with Marshall Perron of Northern Territory fame as keynote speaker. A great success, members asked a range of probing and intelligent questions.

Now, the times they are a-changin'. First, the Premier said he would not block the passage of the *Medical Treatment (Physician Assisted Dying) Bill 2008*, unless the Government's legislative agenda was too full. Then he said the agenda was too full (is he sure?).

Later, he said the lower house would probably consider the Bill if it passed the upper house (what happened to being too full?).

The State Government claims to have a strong social agenda for Victoria, but certainly is not demonstrating it when it comes to assistance for a peaceful death for people suffering intolerably from a terminal disease.

We know from polling that a significant majority of Victorian Parliamentarians are in favour of a Physician Assisted Dying bill.

So get on with it we shall, and the exposure draft of the Bill is generating considerable debate and interest.

Already the opposition are getting very active in opposing the Bill, but we shall meet them head-on and without



reservation.

If you spot a "falsehood" made by opponents, bring it to the attention of the DWDV office and we'll make sure the record gets set straight!

Neil Francis

Get Active!

The Catholic Archbishop of Melbourne, Denis Hart, has written a letter of opposition to the *Medical Treatment (Physician Assisted Dying) Bill 2008* to every member of State Parliament. He is establishing a committee backed by the generous resources of the church to fight against our campaign.

He has also written to every Catholic priest in Victoria urging them to get their flocks to write letters of opposition to the Bill to their State representatives.

In addition, a group that calls itself *SuicideNo* (but is otherwise anonymous with no street address and no identified backers) has started publishing regular opposition bulletins to every member of State Parliament as well.

DWDV already publishes a weekly bulletin to State Parliamentarians, and your help

is needed for the PAD Bill to succeed.

With the volume of opposing mail about to become a tsunami, it is critical that *your* voice is heard too. If you have not yet written to your State members, now is the time to do so and let them know you support reform.

If you're on the Internet, you can write using our online form (www.dwdv.org.au/ContactYourPolitician.html).

Even if you don't know what electorate you live in and who your members are, our system will tell you instantly when you type in your home address.

We will also be sending information to you in the post shortly, so don't panic if you don't have access to the Internet.

The important thing is for you to get active and make sure you write and let your members know your position.

From & far near

Senator Bob Brown's Bill

A Senate committee enquiry into Bob Brown's bill to reinstate the Northern Territory *Rights of the Terminally Ill Act* was deluged with submissions both for and against. DWDV made a full submission in support of Senator Brown's bill. The enquiry continues.

Minnesota Removes Ambiguity

The state of Minnesota USA has quietly changed its law against assisting a death.

The new law now explicitly allows doctors to increase pain medication and withdraw life-support without any danger of being charged with assisting an irrational suicide. Only health-care workers as defined in Minnesota law are protected by these new provisions, not the general public.

Canadian Kept Alive

Samuel Golubchuk has been treated in the Intensive Care Unit of Winnipeg's Grace Hospital since October, where he was admitted with pneumonia and pulmonary hypertension. He moved onto a ventilator and feeding tube. Doctors later decided further treatment would be futile and ordered his life support disconnected. Golubchuk's family disagreed, saying pulling life support is

against their Orthodox Jewish religious beliefs. They took the case to court.

The courts granted an injunction, which was upheld on appeal, preventing the hospital from removing life-sustaining care from the patient. The judge ruled that the patient and his family have a right to a civil trial and ordered the hospital to not remove life support.

Luxembourg Legislates

Luxembourg lawmakers have adopted a bill legalising euthanasia, priming the Grand Duchy to become the third EU country allowing doctors to help patients end their own lives.

The parliament passed the Err/Huss bill with only a slim majority with 30 out of 59 lawmakers voting in favour. The bill, which still has to be approved in a second reading to take effect, was strongly debated. Catholic values remain firmly entrenched in Luxembourg, and the medical community was mostly against the bill.

Oregon Practise Is Stable

The 10th annual report on Oregon's *Death With Dignity Act* shows that 49 terminally ill Oregonians ended their lives last year. The new figures show a continuation of the same patterns as previous annual reports. People who

choose to end their lives this way typically are older than 55, white, insured and educated. Most had cancer and died at home under hospice care.

The report shows very moderate use and no slippery slope of the law.

Antibiotics Questioned

In a Chicago study on the use of antibiotics on Alzheimer's patients, it was suggested that antibiotics are overused in people dying of dementia diseases and should be considered more carefully because of the growing problem of drug-resistant superbugs.

"Advanced dementia is a terminal illness," said study co-author Dr Susan Mitchell, a senior scientist with the Harvard-affiliated Hebrew Senior Life Institute for Aging Research in Boston. "If we substituted 'end-stage cancer' for 'advanced dementia', I don't think people would have any problem understanding this." If the family's goal is to keep their loved one comfortable, rather than to prolong life, alternatives such as oxygen and Tylenol can help, she said.

Geelong Chapter Active

Vice-president Dr Rodney Syme spoke at the first meeting of the Geelong chapter of DWDV, an event covered in the Geelong Advertiser.

A poll in the paper that accompanied the article showed 81% of poll participants to be in favour of legalising voluntary euthanasia. While the newspaper poll was not "scientific", its result was very close to the real figure: 82%.

More news at www.dwdv.org.au/news

A Member Says...

"Yesterday I came across a letter I wrote to the last nursing home my mother went to, where I said I refused to pay their account on the basis that they did not provide her the palliative care they had promised as the basis of my decision to move her there. They immediately wrote it off, without further comment."

If *you* or a loved one haven't received the palliative or other medical care you believe you have been promised, including *maximum* palliation, contact DWDV. We may be able to help with pro-bono legal advice.

Mamma Mia!

DWDV has a fundraiser event for members and supporters to see this uplifting and hilarious movie. Tickets are just \$21 for a wonderful film plus a luncheon with like-minded people, 10:30am for an 11am screening at the Palace Cinema Balwyn on Monday 14th July.

Hot out of the studio and onto the silver screen, Mamma Mia is the global smash hit comedy that has the critics raving. It has an all-star cast including Meryl Streep, Pierce Brosnan, Julie Walters and Colin Firth.

This will be one of our most popular fundraising events ever, so post your cheque today or call the office now on 9877 7677 with your credit card details before the tickets run out!



Steve Guest Day Rally—Report



Well the weather was just perfect (unlike last year!) and the crowd was large and enthusiastic. The 2008 Steve Guest Day rally got off to a flying start.

John Guest, brother of Steve Guest in whose honour the rally is held, gave a moving account of the family's experiences of Steve feeling frustrated and helpless at first, and then relieved and relaxed once he had received advice and medication that gave him control over his end of life. His death, unlike many others, was peaceful and in the company of family.

Dr Rodney Syme, Vice President of DWDV spoke of how he had provided



advice and medication to Steve Guest, how the Coroner had taken *three years* to decide not to hold an inquest, and that he was providing advice to Peter Hammond, suffering from debilitating motor neurone disease, as well.

Mieke Hammond read out a statement from her husband Peter, who is too weak to be able to stand or talk. His message was clear; advice and control over one's end of life creates a profound reduction in suffering.

Lisa Fitzpatrick, Secretary of the Victorian Branch of the Australian Nursing Federation, spoke of the suffering that nurses see when caring for terminally ill people, and called for law reform to allow people to seek a peaceful death.

Marshall Perron, former Chief Minister of the Northern Territory and architect of the world's first *Dying With Dignity* law, spoke about that law, how its safeguards prevented abuse, and how it is not difficult to legislate for both choice and protection.

Professor David Kelly, former Chairman of the Victorian Law Reform Commission, gave a summary of the *Medical Treatment (Physician Assisted Dying) Bill 2008*, which has now been released as an exposure draft to the Victorian Parliament. He illustrated the responsibility of the Bill and its safeguards.

The Hon. Ken Smith and Colleen Hartland, members of Parliament who are sponsoring the Bill, gave personal accounts of suffering experienced by members of their own families near death, and why that had prompted them to take action on law reform.

The rally was a great success, concluding with a passionate crowd call for the Premier, Mr Brumby, to allow the Bill debate and passage through the houses—to *get on with it*.

Photos (clockwise from top): The rally, John Guest, Dr Rodney Syme, Mieke Hammond, The Hon. Ken Smith, Colleen Hartland, Prof. David Kelly, Marshall Perron, Lisa Fitzpatrick.



Getting That Paperwork In Order

So, you received those forms when you joined the Society. But have you completed them? Or are they still sitting on the desk, to be done as soon as ... Or, I'll fill them in when I get sick... and then it's too late?

Here are tips for completing three important medical documents. The documents are available free of charge to DWDV members.

Medical Enduring Power of Attorney (MEPA)

A MEPA is document that you use to appoint a person to make medical care decisions on your behalf.

1. Have you chosen an Agent who will have your best interests at heart? Does he or she have the knowledge and confidence to speak out on your behalf?
2. Have you filled out and signed the MEPA before two witnesses, one of whom is authorised by law to witness a statutory declaration?
3. Have you given copies of you MEPA to your Agent, to your doctor and to all those who treat you?
4. Have you made clear to your close family and/or friends the name of your Agent and where your MEPA document can be found?
5. Are you aware that your MEPA
 - only starts 'working' if you become too ill to take care of medical decision-making yourself?
 - is legally binding?
6. Have you discussed clearly with your Agent what decisions you want them to make on your behalf? You should repeat this process regularly.

Advance Health Care Directive (AHCD)

An AHCD allows you to document your preferences for treatment in certain situations when you are no longer able to participate in medical decision-making.

1. Do you need an AHCD? Yes, regardless of health or age. We all should make arrangements in case we suffer a sudden, unexpected catastrophic illness or accident. An AHCD is not legally binding but, increasingly, medical professionals try and carry out the patient's wishes.
2. Have you filled it in properly (ie so that it makes your wishes clear)?
3. Has your doctor signed it, to show you are of "sound mind"? This does not commit the doctor to any future action, but if the doctor is uncomfortable with the form you might get some hint as to how he or she might react in the event you become seriously ill.
4. Have you circulated copies of your AHCD to your Agent, treating doctors and close family/friends so that they know your wishes?
5. Are you concerned about dementia or your care if you move to a nursing home? DWDV has specific advance directives for these situations.

Refusal of Treatment Certificate

You can put your refusal of treatment decision in writing so that there is no chance of an error. This is a legal document. If you are suffering from a serious health condition, such as cancer, severe heart or respiratory disease, and do not want any further life preserving interventions, you can ask a doctor to complete this form.

Book Review—Bad Hair Days

Bad Hair Days by Pamela Bone, Melbourne University Press 2007.

The title of Pamela Bone's book *Bad Hair Days* refers to the loss of hair that patients suffer when undertaking chemotherapy treatment for cancer. Pamela returned from Chad (where she was covering a story for *The Age* newspaper) feeling sick. She soon became fatigued, lethargic, dehydrated and anaemic and suffered other symptoms including a bout of pneumonia. She was diagnosed as having multiple myeloma, a cancer of the bone marrow.

This book is a personal account of her confrontation with that cancer and her thoughts about ending her own life.

Pamela Bone was a long time journalist with *The Age* and the book is well written and structured. She recounts the continual tests and medications and the visits to hospital. She writes:

I was to learn what others noted, that

nearly all doctors follow a policy of not telling their patients much of the bad news unless or until they have to; what others have called 'the principle of gradual disclosure'

She ponders what it means to be brave, what courage amounts to and how one loses a sense of control when cancer singles us out from the crowd. She defends the stance she took as an *Age* leader writer when she supported the invasion of Iraq which, in hindsight, she admits was a folly. She discusses the 2004 tsunami that killed an estimated 23 000 people and how it made her feel. She discusses her atheism.

In an important insight Pamela draws attention to how the world divides when she quotes the writer David Rieff whose mother had a virulent blood cancer:

There are those who can reconcile themselves to death and those who

can't. Increasingly I've come to think that it's one of the most important ways the world divides up. Anecdotally, after all those hours I spent in doctors' outer offices and in hospital lobbies, cafeterias, and family rooms, my sense is that the loved ones of desperately ill people divide the same way.

Why does death surprise us? She asks.

She briefly discusses alternative medicine (a big business) natural therapies and the power of the mind/will in overcoming illness. All this is done in a conversational tone drawing on her thoughts and experience. She is a skeptic in regard to most things outside modern medicine. *Bad Hair Days* is a worthy contribution to the literature on dying.

Ralph Blunden

Pamela has died—see our Vale on p6.

Office Position—Part Time

We're so busy, we need more help! Rowena, Jane and Anne need a buddy to help run the office and coordinate DWDV's services to the Victorian community.

The ideal person is:

- passionate about the cause
- warm and approachable
- a good listener
- not scared of computers
- a self-starter
- able to multi-task.

Plenty of training will be provided in



Outlook, QuickBooks and office procedures, and we offer ongoing support.

The initial position is to run the Blackburn office on Fridays, with the odd hour on a monthly basis helping to set up a room for educational workshops in Kew.

If you think this sounds like something you'd love to participate in, and you could do with a little extra money, please submit your resume to the office.

We look forward to hearing from you!

Rowena Moore

Rodney Syme's Book Released

Dr Rodney Syme's book, *A Good Death: An Argument for Voluntary Euthanasia*, has just been released.

In *A Good Death* Rodney discusses some of the cases of terminal illness that he has been involved with over many decades of medical practice. He relates

considered prose.

The value of inclusiveness manifests itself in Dr Syme's attitude to those who have sought his advice over the years. He believes that the word 'patient' tends to place those seeking help into a dependent role, compromises their autonomy and places the doctor in a

dominant role. Doctors, he believes, should advise rather than direct. This is so particularly in the case of the terminally or hopelessly ill where illness is not just an affliction of the body, but of the whole person.

Dr Syme is careful to say exactly what he intends and does so with the objectivity and calm, with the thoroughness and clarity that one expects from a person not only trained

in a demanding scientific discipline, but also by an individual who has many years of hands-on experience in the sometimes harrowing processes of counselling and assisting those who are dying.

A recurring theme of Dr Syme's book is that those who want physician assistance with their dying and who are unable to get it often resort to suicide. These suicides can be very nasty affairs and include hanging, shooting, gassing, jumping from heights or in front of

trains and so on. Such desperate measures are often uncertain in outcomes and impact adversely on others in the community. Dr Syme is appalled at these alternatives as much as he is with covert practice that provides assistance but generally without counselling, without second opinions, and without openness.

This book, marked by its empathy and good sense, makes reading about death as enjoyable an experience as that topic allows. The case studies are recounted with great sensitivity. And, Rodney recognises people's courage as much as their despair. *A Good Death* provides readers with a context from which their own views about euthanasia may be formulated. Yet, it is hard to see how one might disagree with his conclusions unless one is blinded by prejudice, ignorance or belief in God as the only decision maker in how we die.

Ralph Blunden

Autographed copies of *A Good Death* are available from the DWDV office for \$32.95 posted or \$25.00 collect. Get in quickly as we have a limited number of copies and nearly 100 of them have walked out the door in a matter of days. This is a rare opportunity to acquire your own personal copy signed by Dr Rodney Syme himself!



Dr Rodney Syme autographs copies of his new book.

his early faltering, self-questioning, professionally cautious approach to those who want to end their lives. This professional hesitancy evolves into a more robust and confident public grappling with the issues that arise from his attempts to help those who are dying.

Rodney's outrage at the treatment of these people; of the overriding of their autonomy; of the paternalistic coercion involved and of the lack of rational arguments or cogent reasons for such destructive social norms is meted out in



Tragic Parkinson's Story

Six years ago my dad was diagnosed with Parkinson's disease. It was controlling his life and he tried to hide the fact from his family.

So my father took his own life by way of hanging. He tried to make the act as easy as possible on his family. He wore a calico bag over his face and left a note on the doorway before anyone entered, saying *Open with Caution*.

The police called it suicide even though there were numerous articles on euthanasia and stories found in his house, on families possibly being charged if they assist with helping or being with someone that chooses to die.

The word 'suicide' torments me. My dad wasn't depressed, he was ill.

Every day I think about the way my dad suffered in his last moments. He was a loving man that brought up four daughters. It kills me that he died alone. I wish I could have been with him. The whole family does.

It's trashed me my memories. Thoughts about my dad's suffering hurts, and the manner of his death hurts.

I wrote a few years ago to my parliament members about

voluntary euthanasia for people with a terminal illness. I was given a standard reply that really didn't answer anything, just that they couldn't pass a law because of not enough interest.

I truly believe if I had been with my father, our whole family in a humane loving manner when he choose to end his suffering, it would have made all the difference in the world.

Instead now we are left focusing on the vile way he died.

Ms Jennifer McCoy, 16th March 2008

DWDV Comment—

Jennifer's tragic story is the human face of a lack of compassionate options. Four elderly Australians commit suicide every week in undignified and often violent ways because the law does not offer an alternative that permits open discussion to be held and for loved ones to be present and say goodbye when a terminally ill sufferer chooses to die.

It's time to align the law with community expectations!

Vale—Pamela Bone

As you will know, Pamela Bone passed away recently. Pamela was a respected journalist known for taking on difficult issues and pursuing them with candour and respect. She was keynote speaker at our 2006 AGM, demonstrating her trademark thoughtfulness in an address in support of choice in dying.

Her book, *Bad Hair Days*, told her story of diagnosis with cancer, the intensive and sometimes



highly invasive treatments she endured, and the process of coming to terms with the inevitability of dying. It received critical acclaim.

In the end, Pamela did not use medication to die, but rather passed away peacefully after refusing food and water.

Her funeral service was packed to overflowing, a tribute to her warmth and popularity.

Our thoughts are with Pamela's family.

Workshops

Receive a set of documents to help specify your own end-of-life wishes. Experience two and a half hours of expert tuition in a friendly atmosphere; how the current law applies to you, as well as how to complete, witness and store the DWDV documents to maximise your protection. *"Very helpful, lucid and clear explanations of a difficult theme."*—Attendee

Workshops are held in Kew
Monday 14th July, 10am-12:30pm

Monday 8th Sept, 10am-12:30pm

Easy access by public transport

Member Pensioner: \$20

Member Non-Pensioner: \$40

Non-member Pensioner: \$40

Non-member Non-Pensioner: \$80

Reserve your place on 9877 7677 now.

Workshops fill up fast!

If you don't own

your bloody life,

what do you own?

Member comment

overheard at the AGM

Remember DWDV

DWDV relies on membership subscriptions, donations and bequests to fund its operations. We receive no funds from government.

Over recent times, we have received some wonderful bequests that have helped us achieve more than ever before.

Now that the Catholic Church is establishing a well-funded committee to fight *Physician Assisted Dying* law reform, funding is more important for success than ever.

Please do remember DWDV in your will. You can do so with the following statement:

"I GIVE AND BEQUEATH the sum of _____ [in words] (\$ _____) to DYING WITH DIGNITY VICTORIA INC of 3/9b Salisbury Avenue, Blackburn, Victoria 3130, for its general purposes."