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PAD Bill Defeated—Premier Must Act

After spirited debate in the Victorian Legislative Council which brought out both the best and the worst in our parliamentary representatives, the *Medical Treatment (Physician Assisted Dying) Bill 2008* was defeated by 25 votes to 13.

Members such as Candy Broad, Johan Scheffer, Sean Leane and Andrea Coote provided very thoughtful and thoroughly researched speeches in support of the Bill. They spoke with reason and underpinned their addresses with facts.

In contrast, members such as Peter Kavanagh, Jan Kronberg and Bob Smith rambled on in vague, emotive terms, repeatedly referring to a "slippery slope" which empirical research shows does not exist, completely ignoring the actual evidence provided by DWDV to all members in more than twenty bulletins on the subject; and contained in a significant report prepared by Parliament's own library services.

Peter Kavanagh repeatedly made the claim (including to the media) that an 18 year old with diabetes and depression would qualify to die under the Bill, which he or she certainly would not. Deliberate misinformation drove a fear campaign mounted by the usual suspects.

Despite the vote seeming like a rejection of the issue, it is not. A very significant ma-

majority of upper house members indicated their in-principle support for PAD, yet some were not able to satisfy themselves in time that the safeguards in the Bill were adequate.

Indeed, the safeguards in the Bill incorporated all the most stringent checks and balances from dying-with-dignity legislation from around the world. It was in fact a very conservative Bill.

Those who favoured PAD in principle yet finally voted against the Bill because of concerns about safeguards and other wording, recommended that there be wide community consultation to formulate a new Bill.

I agree wholeheartedly with that recommendation, and I am calling on Premier Brumby to refer the *Medical Treatment Act 1988* to the Victorian Law Reform Commission for full community consultation to guide drafting of modernised legislation.

Brumby has no grounds to object, since it was his government that referred the abortion issue to the Law Reform Commission and crafted legislation, which has passed.

The level of community support for physician assisted dying is very high just as it is for abortion, and medical practice equally is way ahead of the law yet subject to similar ambiguities. So, Mr Brumby, let's get on with it...make a referral to the Commission.

Neil Francis—President

35th Annual General Meeting Reminder

Members are cordially invited to the 35th DWDV AGM. We are back in the Northcote Town Hall where we were two meetings ago, and this time we have hired an extra super-duper sound system so that all will be crystal clear right down to the back of the hall.

We are delighted that our keynote speaker is Dr Paul Maher, palliative care specialist. A highly compassionate doctor, Maher has had a significant career as a surgeon and more recently as a palliative care specialist. He has worked in the UK as well as Australia, and in missions in Asia.

Dr Maher will outline palliative practice in Australia today, and talk especially about how to take advantage of the best that palliative care has to offer. He will also discuss the issue of dying with dignity and its relationship with palliative care. This is a rare opportunity indeed to hear from an expert in palliative medicine who is not afraid of speaking the truth...and will be able to answer audience questions, too. See you there!

Arrive early for a 2pm start Sunday 30th November, Northcote Town Hall, 189 High Street, Northcote ■ Tram 86 stop 31 ■ Train: Epping line Merri or Northcote stations (uphill walk) or Hurstbridge line Westgarth station (to catch the 86 tram) ■ Local parking available—check restrictions.



Dr Paul Maher

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Washington ballot passes

On 4th November, the day of the USA Presidential election, Washington ballot I-1000 passed with a vote of 58% to 42%: a landslide in USA ballot terms.

Initiative 1000 gives Washington residents very similar rights to those in neighbouring Oregon, where terminally ill patients may request and receive medication to die peacefully on their own terms, with a strong set of safeguards.

The Catholic church hierarchy vigorously opposed the initiative, but were out-funded and successfully countered by the Death With Dignity National Centre who championed the case for.

Washington is the second state of the USA to have such a law, and joins Liechtenstein as the most recent jurisdiction to give its citizens the right to choice at end of life.

The law becomes effective in July 2009.

The DWDV Committee decided unanimously to provide \$5,000 towards the Washington campaign to help counter opponents' efforts.

Russian man left 'no choice'

A disabled man who wrote to President Sarkozy demanding the right to die has killed himself. Rémy Salvat, 23, who had suffered from rare condition mitochondrial degenerative disease since the age of six, overdosed on prescription drugs on August 10 – just days after receiving a response.

In a letter to the president written in May he said: "I know that one day I will lose my capacities. I don't want to be forced to be trapped in a body kept alive like a prisoner."

President Sarkozy responded on August 6: "For philosophical and personal reasons, I believe that we do not have the right to end our lives voluntarily.

"However I do not want to escape my responsibilities. I would like to see talks between the patient themselves, their doctor and their family, with respect to human values to try and find the most appropriate solution in every situation."

USA doctor self-interest

Recent studies have shown that 14% of U.S. doctors, when confronted by possibly objectionable but legal medical treatments, not only would refuse to deliver such care but also would refuse to inform their patients about it or refer them to physicians who would deliver the care. That translates to about 40 million people who would receive substandard care from these physicians, who believe that their religious convictions are more important than the well-being of their patients.

Ed: One wonders what the frequency of this is in Australia.

Spanish region law mooted

The local government of Spain's south-western region of Andalusia said it was preparing a pioneering euthanasia law which would allow terminally ill patients to refuse medical treatment and make it illegal to keep someone alive by artificial means.

Under the text of the draft law, which will be put to a vote in the region's parliament, patients will have their "will and dignity" respected during the final stages of their lives.

Under the draft law, doctors who "apply useless and unjustified measures to prolong life" could face fines of between €60,000 to €1m (around \$120k to \$2m). Spain's regions have extensive powers in areas such as health and education.

Ed: In Victoria, a doctor who treats a patient against their express wishes may be prosecuted for the criminal offence of 'medical assault'.

India steps forward

The Law Commission in India recently recommended that euthanasia be legalized, subject to very strict conditions to prevent its misuse. The recommendation came on the heels of the Supreme Court itself admitting a petition requesting it to give the "Living Will" legal sanction.

The courts will have to decide between an Eastern practice in religion

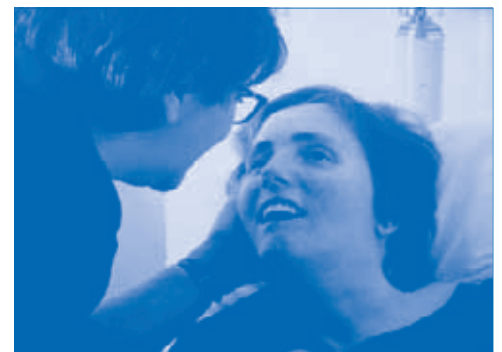
and society, and a Judeo-Christian practice. The former believes that renunciation of life is perfectly justifiable. The latter denounces this as a human interference in God's plan.

Undoubtedly, there are stories of miraculous turnarounds. But those are miracles, and should not be regarded as a norm. If a miracle were to happen, even corpses could sit up and begin life anew. Does that mean that we ban cremations and ask for preservation of the body like the pharaohs did?

The right to die is one way of coping with the predictable, without clinging to the straw that a miracle might still happen.

Catholic church interferes

Italy's Constitutional Court rejected an appeal lodged by parliament against a ruling to let doctors stop feeding a woman who has been in a coma for 16 years. Eluana Englaro, 36, has been receiving food and water artificially since January 1992 and her father has been seeking an end to the life support since 1999.



Eluana Englaro has been in a persistent vegetative state since a car accident in 1992.

In July, a Milan appeal court ruled the young woman, who has been in a vegetative state since a road accident, could be removed from life support as it had been proven that her coma was irreversible. It said that Englaro, when fully conscious, had stated her preference to die rather than being kept alive artificially. The Roman Catholic Church has made Englaro a symbol in its campaign against mercy killings and has demanded that she be kept alive.

The Constitutional Court said the appeal judges had acted within their rights, while noting that parliament has the ability to change the law if it wishes. The decision is being appealed to the Supreme Court.

PAD Bill—How They Voted

Back in October we wrote to every DWDV member with a list of their Legislative Council (upper house) representatives and how those representatives had spoken and voted on the PAD Bill. This gave everyone the opportunity to contact their own representatives to thank them for support of the Bill, or ask for an explanation of why they had opposed the Bill.

A great many members took the opportunity to write to their representatives and share their views, and there were many excellent letters.

The full report of how each Legislative Council representative acted is shown here.

Those “for” spoke and voted in favour of the PAD Bill.

Those “against some details” spoke to the Bill, indicating that they were not comfortable with one or other provision of the Bill, and voted against it, despite either explicitly or implicitly supporting PAD in principle.

Those “against in principle” largely spoke about the “slippery slope”, which has no foundation in fact: data from lawful jurisdictions show no elevated rates of physician assisted dying for the supposedly “vulnerable”. In an emotional and irrational address, Jan Kronberg (who indicated support as a candidate in the 2006 State election), compared PAD to the 1973 dystopian science fiction movie, *Soylent Green*, claiming we’d all have to have “I don’t want to die” tattooed on our foreheads to ensure we weren’t melted down into biscuits and eaten. Legislative Council President Bob Smith agreed, but DWDV believes the electorate deserves a much higher standard of representation than that shown by them.

You can easily find out which electorate you live in, and your representatives’ contact details by visiting the DWDV web site at www.dwdv.org.au and browsing to Take Action | Contact Your Politicians.

Simply enter your *home* address in the instant lookup form in Step 1. Then, select your electorate from the list in Step 2, and *voilà*, an email will be created with all the necessary recipients, ready for you to type your letter.

The issue will be back in Parliament again, so if you haven’t written already, now’s the time to get on to it.

Name	Party	Vote: PAD Bill	2006 Election Position §
<i>Eastern Metropolitan</i>			
Bruce Atkinson	Liberal	Against some details	Support
Richard Dalla-Riva	Liberal	Against some details	Declined to answer/No response
Jan Kronberg	Liberal	Against in principle	Support
Shaun Leane	Labor	For	Support
Brian Tee	Labor	Against some details	Declined to answer/No response
<i>Eastern Victoria</i>			
Philip Davis	Liberal	For	Support
Peter Hall	Nationals	For	Support--qualified
Edward O'Donohue	Liberal	For	Declined to answer/No response
Johan Scheffer	Labor	For	Support--qualified
Matt Viney	Labor	Against some details	Declined to answer/No response
<i>Northern Metropolitan</i>			
Greg Barber	Greens	For	Support
Nazih Elasmr	Labor	Against-didn't speak	Declined to answer/No response
Matthew Guy	Liberal	Did not speak/vote*	Opposed
Jenny Mikakos	Labor	Against some details	Declined to answer/No response
Theo Theophanous	Labor	Against some details	Declined to answer/No response
<i>Northern Victoria</i>			
Candy Broad	Labor	For	Support
Kaye Darveniza	Labor	Did not speak/vote^	Declined to answer/No response
Damian Drum	Nationals	Against in principle	Declined to answer/No response
Wendy Lovell	Liberal	Against some details	Support--qualified
Donna Petrovich	Liberal	Against-didn't speak	Declined to answer/No response
<i>South Eastern Metropolitan</i>			
Gavin Jennings	Labor	For	Support
Inga Peulich	Liberal	Against in principle	Opposed
Gordon Rich-Phillips	Liberal	Against some details	Support--qualified
Bob Smith	Labor	Against in principle	Opposed
Adem Somyurek	Labor	Against-didn't speak	Declined to answer/No response
<i>Southern Metropolitan</i>			
Andrea Coote	Liberal	For	Support
David Davis	Liberal	Against some details	Support
John Lenders	Labor	Against some details	Declined to answer/No response
Sue Pennicuik	Greens	For	Support--qualified
Evan Thornley	Labor	Against some details	Declined to answer/No response
<i>Western Metropolitan</i>			
Khalil Eideh	Labor	Against-didn't speak	Declined to answer/No response
Bernie Finn	Liberal	Against in principle	Opposed
Colleen Hartland	Greens	For	Support
Justin Madden	Labor	Against-didn't speak	Declined to answer/No response
Martin Pakula	Labor	Against some details	Support--qualified
<i>Western Victoria</i>			
Peter Kavanagh	DLP	Against in principle	Opposed
David Koch	Liberal	For	Support
Jaala Pulford	Labor	Against some details	Support--qualified
Gayle Tierney	Labor	For	Support--qualified
John Vogels	Liberal	Against in principle	Support

§ Response to constituent polling leading up to the 2006 Victorian State election on DWDV’s Legislative Charter, on which the physician assisted dying (PAD) Bill was based.

* Matthew Guy was absent from Parliament due to personal circumstances, but has previously articulated his in-principle opposition to physician assisted dying.

^ Kaye Darveniza was accidentally locked out of the chamber during the vote due to a very short division bell. She says she would have voted in favour of the PAD Bill.

Carol's story—inadequate pain management

My husband Alan was diagnosed with mouth cancer in early October 2004. He commenced radio therapy about six weeks later. The radio therapy was delayed on at least two occasions due to the intricacies as to where to exactly aim the treatment after the plan was drawn up and the mask was made. Whilst waiting, Alan was in extraordinary pain.

The pain started virtually immediately the diagnosis was made. Alan's last meal orally was on 14 November 2004, three weeks after diagnosis. I remember the date well; it was my 60th birthday and at my surprise party his food had to be vitamised.

The following week he was in hospital for pain management. Alan was in hospital for approximately two weeks whilst the pain management people tried a cocktail of drugs to ease his pain, mostly unsuccessfully. However he was released after two weeks with 18 pages of different medications, only to return to have a peg inserted into his stomach for feeding. By this time he was totally unable to swallow, hence all the tablets had to be crushed to go through the peg.

The pain persisted through the 35 days of radio therapy. Morphine was not at all effective with Alan despite increasing the dosage on several occasions. The only effect was that he hallucinated. The remainder of the medication seemed to work for a short time with a drug made up into a lozenge called ketamine having the most effect.

After the radiotherapy finished, he had two-weekly checkups. The pain started again. It was too early to diagnose if there were any further problems. Approximately two months later with the pain getting very severe Alan was again in hospital. The cancer had returned and it was decided that surgery was the way to go. This needless to say was a terrible experience: fourteen hours of surgery, involving removal of part of the face, neck, jaw and tongue.

Following the surgery, Alan had a heart attack. He was in intensive care for about two weeks, unable now to eat or talk, (he had a tracheotomy).

He was then transferred into a ward, where the pain management started again. Whilst in the ward, he was sent to the operating theatre again, this time for stents in the heart. He survived this, and was sent back to the ward again.

On seeing his specialist a few days later re the face and neck surgery, we were told that 44 lymph nodes were also

removed with 40 clear and 4 cancerous. Approximately a month later the tracheotomy came out. Alan was still unable to talk. In fact he never really talked again. He tried, but I was unable to understand him.

The cancer came back in early July 2005. Alan had double vision, the cancer having gone to the brain. Alan never came home from hospital.

This time he was in the worst pain ever. Nothing that they threw at him worked. I had arguments with the nursing staff, but they would only give relief every 4 hours.

After seeing his specialist and the palliative pain management team, I was finally successful in getting him pain relief as he needed it. A pic line was also inserted. I had to be at the hospital nearly 24/7 to make sure that he was not in pain.

Alan's battle was horrendous in relation to pain. It was a relief when he finally succumbed at 11.30pm on 8th August, 2005. Alan's pain and suffering was finally over.

In conclusion, I was not happy with the palliative care. I am aware that they did their best as allowable by law, but *Palliative care does not work for everyone*. Surely there has to be another answer.

Carol Clark

Dr Rodney Syme responds:

One gets the feeling that Alan became what I call a 'medical pawn': moved from one treatment to another without due consideration of the bigger picture, and without adequate time for fully informed and considered decision making. It can all happen with bewildering speed and confusion. Advice is offered by a variety of experts who see their little part of the whole, but not the whole, and with the overwhelming pressure that 'something must be done'.

The advice to have stents placed is an example. A procedure to prevent further heart problems when Alan was already dying badly from incurable cancer strikes me as extraordinary. Patients and their families are often defenseless in the face of such advice.

Knowledge of the law, of palliative care and what it can and cannot achieve, of refusal of treatment and terminal sedation are essential. Advice about these matters and about end of life decisions can be provided by DWDV counselors.

Sadly, the Alan and Carol were not DWDV members when disaster struck, so did not receive wider advice.

Olga Hilton Runs Another Successful Fundraiser

DWDV member Olga Hilton ran another November open garden fundraiser this year for several charities. It was a great success, with obliging weather, involvement of the local media, and enthusiastic crowds.

Olga reports that many people attended specifically because of the dying with dignity issue, and she made a generous donation to DWDV of \$750. To put this in perspective, this covers our annual phone bill in the provision of services to members and the community.

Thank you Olga; another sterling effort that makes an important difference to our operations!



Olga Hilton in her splendid garden
Courtesy Telegraph Express

Mexican Nembutal

At DWDV's 'meet and greet' in early October (see report back page), several members sought advice about going to Mexico to obtain Nembutal, a subject that has attracted much publicity through *EXIT International* in recent months.

We have just received a detailed update on this matter from Derek Humphry, the authority on self-help in north America.

Derek writes "There has been a deluge of publicity in recent months about the easy availability of veterinary Nembutal in Mexico. This has caused a much larger number of people than usual to travel there in search of the lethal drug for their self-deliverance from

a terminal illness should their suffering be protracted and unbearable.

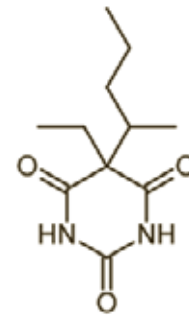
"Now, some people who are making this hunting expedition at veterinary stores are reporting that they failed entirely. Upset and angry, they are embarrassed to give details."

He describes risks of having to pay bribes to police, of increased border customs surveillance, profiteering and of drug warfare. He reports internet scams where drugs are offered at very inflated prices with no guarantee that the product will be genuine.

His conclusion is "If a person is still determined to acquire this drug because of life-threatening illness, they are best to travel to an inland Mexican city to

search. Whereas this was highly likely in the past to succeed, there is now no guarantee. Caveat emptor".

DWDV would urge caution on the part of members and reminds them that heavy penalties apply for illegally importing the drug into Australia. We strongly suggest that sufferers obtain



sound counseling advice through a call to our office on 03 9877 7677.

Rodney Syme

Nembutal is a proprietary trade name for the drug Pentobarbital.

British journal reports

In July and August 2008, a fascinating sequence of articles appeared in the British Medical Journal, the foremost medical journal in Britain. On 5th July, Iona Heath, a London GP, wrote on *Respect*, on its importance in life and medicine. While not specifically addressing end of life, her remarks have total relevance in that area.

Also on 5th July, Daniel Sokol, The Lancet's resident ethicist, wrote on *What does the law say?* He quoted DeVille - "in the interest of objectivity and consistency, the legal process, training and doctrine, and tradition have tended to downplay humanity and individuality". Sokol states that "humanity and individuality, sidelined in law, are key considerations in ethics", and that "the law often represents the lowest level of acceptable behaviour, and clinicians should surely strive for higher standards than the bare minimum".

Sokol wrote again on 2nd August on *Clarifying best interests*, and made this important observation. "Nowadays it is almost trite to say that 'best interests' is a broader term than 'medical best interests'". Good health is one value among others that may, on occasion, be offset by those others. Hence a bon vivant might accept the life shortening effects of eating full fat brie daily in exchange for the pleasure he derives from it. "Overall best interests may legitimately differ from medical best interests, and the two should not be confused".

He also cited the philosopher Ronald Dworkin who made a distinction between experiential interests and critical interests. Experiential interests concern our sensations of pain and pleasure, and we need to be cognitive and aware to express such interests. Critical interests are those things that give meaning to our lives, and may be lost even if we are unaware of it.

Finally in The Lancet of 9th August, Nicholas Christakis,

an American professor of medical sociology, penned *Too quietly into the night*, lamenting the poor state of care of dying patients. I quote him at length.

"The fact is that the everyday reality of death in the USA—and elsewhere in the developed, let alone developing world—is abysmal. Our best estimate is that 40-70% of Americans die in pain. A large minority of these have other symptoms, such as shortness of breath, nausea, or depression, that are even more distressing to patients than pain. More than 80% die in institutions. And roughly 25-55% of Americans place a significant burden on family caregivers in the course of their death.



"This reality contrasts sharply with what Americans say they want at the end of their lives, and with what the healthcare system should be able to deliver. Not surprisingly more than 90% of Americans consider a good death to include such basic elements as being free of pain and other worrisome symptoms, having the opportunity to die at home or another venue of their own choosing, being kept clean, having loved ones near by so as

not to die alone, and not burdening family members unduly. [He might have added the ability to choose when to die—it is certainly true for Australians.]

"One of the most compelling reasons for this sorry state of affairs is that those in our society who are dying constitute a particularly disempowered, even if numerous, group. It may be fashionable in medicine to think about "vulnerable populations", but it is hard to imagine a more vulnerable population than the dying, nor one that is more neglected or more invisible. We do not see marches of terminally ill people demanding recognition of their rights to more resources and more attention".

Hear, hear!

Rodney Syme

Inaugural member information session

In October, we ran our first member information session, with some thirty members attending. It provided a terrific opportunity for members to mingle and meet like-minded people, to hear a little about the history and current initiatives of DWDV, and receive advice about end-of-life choices.

Question time was lively with queries about a wide range of matters. Many stayed behind for ongoing refreshments and discussion. Said one member, "It is strange to say that I had a lovely afternoon, but I did. I certainly didn't feel strange being on my own and in fact felt very comfortable. I encourage other people to attend."

Call the office now to reserve your place for our next member information session in the new year.



Vale Sir Peter Derham

We were saddened by the recent death of one of our Patrons, Sir Peter Derham. Sir Peter was a long-time supporter of choice at the end of life.

He was a gifted businessman and philanthropist, and is often remembered for major achievements such as:

- The heritage-listed Nylex time and temperature sign on the Richmond silos.

- Promoting restoration and preservation of Mawson's Hut in Antarctica.
- Establishing the Red Hill winery estate on the Mornington peninsula.
- Sitting on a number of prominent charity boards such as the Alfred Hospital and the Breast Cancer Network.

Once described as "the champion fund-raiser of Australia" for quite a number of high-profile charity causes, Derham believed in making possible the impossible. "Never say never" was his rally cry.

He is survived by his wife of 50 years, Lady Averil, two sons, and nine grandchildren.

Our condolences go to the family.

Rodney Syme's Book — Handful Left

We have a handful of Rodney Syme's book, *A Good Death: An Argument for Voluntary Euthanasia*, left. It's a corker of a read. If you want your own autographed copy, call the office now on 9877 7677 before it's too late.

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
Next workshop February 2009
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.

"It is simplistic to argue that palliative care can remove all suffering at the end of life."

Dr Odette Spruyt, President ANZSPM
The Age, Feb 5th 2007.

Yet Spruyt remains firmly opposed to physician assisted dying. So while acknowledging that palliative care can't always help, she proposes we... just ignore suffering, or congratulate ourselves for pious sorrow?

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 very generous bequests that have helped us achieve more than ever before, including one of \$200k from the estate of Lilian Renard in September.

As we continue the fight for choice with safeguards, 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."