



Member of the
World Federation of
Right to Die Societies

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A new name

Your committee has voted to recommend a change of name to be implemented at the next Annual General Meeting. The recommended new name is:

Dying with Dignity – Victoria Promoting the right to choose

This name was arrived at following lengthy discussion and evaluation of several alternatives. Following the last newsletter, we have received a number of communications from members of which all but two have been strongly in support of the change.

Why change the name?

The committee believes the proposed new name is a more accurate descriptor of what the society stands for. The label "voluntary euthanasia" can trigger different (and often erroneous) associations. The word "euthanasia" has become linked in many minds with the WWII Holocaust and its images of gas ovens and death-camps. The powerful and negative "euthanasia" concept that has evolved overshadows "voluntary" and can result in confusion and distaste. Opponents can (and have) exploited this factor to blur and even misrepresent what we stand for.

To succeed in its objectives, it is essential that the Society must communicate very clearly with the public, the media and politicians. These groups must comprehend exactly what we stand for and what we want. Which is legal recognition of a terminally ill person's right to exercise personal choice to be able to die with dignity. Surveys consistently show that the overwhelming majority of Australians support our cause.

In investigating a name change, your committee looked at names used by similar organizations internationally. Of the 40 member organisations from 23 countries in the World Federation of Right to Die Societies, only Australia and three others (NZ, South Africa and England) retain the word "euthanasia".

A number of other organizations use some variation on "dying with dignity" (or "dignity in dying") and also often incorporate the word "right" or "rights". The committee believes that the concept of rights in the tagline is important if our cause is to resonate with younger as well as older people.

A common characteristic of younger people is the tendency to feel "bullet proof" and death is not something that resonates personally with them. But they can readily identify with, and be quite passionate about, protecting and championing the rights of others. Indeed our 2002 survey shows that by the age of 30, more than one in ten have had personal experience where a hopelessly ill close relative or friend wanted voluntary euthanasia.

So there are four key concepts contained in the new name and tagline: rights, dying, dignity and choice. No name is perfect but your committee believes that this change will enable us to be much clearer in our future communications and enable the Society to have more impact – especially with the general public. You will be asked to vote on the adoption of the new name at the next Annual General Meeting of the Society on February 25th 2005.

Max Sutherland

From The President

A time of change and a time for change

This edition of the newsletter announces significant change for VESV. First, an imminent and fundamental change is that of our name. After long debate (actually over some years) and careful study, your committee is recommending a new name for the Society, dropping the use of the word "euthanasia".

This word has come to be much misunderstood, and has a variety of meanings and uses, many negative. This has made the Society vulnerable to misrepresentation and hinders us in presenting a clear and accurate message. A second change, rather more forced on us than a choice, is a change in office location.

Third, with the advent to the committee of highly skilled communicators – Dr. Max Sutherland and Neil Francis – much of our communication with members is moving to e-mail, and our website is undergoing a major upgrade. This will lead to cost savings and increased efficiency, but more importantly, a far greater community impact.

Within the committee we have developed subcommittees or working groups to look more closely at key issues such as strategy, finance and communications.

Finally, there will be change at the top as I stand down as President at the next AGM. I have occupied this position for eleven years, and am convinced that it is in the best interests of Dying with Dignity Victoria (looking ahead) that there should be a change of leadership. I am now 70, and aware of a progressive decline in energy, memory and attention to detail that is an inevitable association of ageing. I think it is essential that we continue to evolve with vigour and new ideas. I still want to be closely involved with our activities, particularly in counselling, workshops, political advocacy and on the committee, but not in the principal role.

There will be vacancies on the committee for 2006, and I would encourage members with skills and enthusiasm to come forward to offer their time and service. Please call me on 9827 8140 if you would like to discuss this option.

Rodney Syme



VESV office to move

After more than 10 years at 70 Greville St., Prahran, VESV will be moving its office to new premises in late November. Circumstances including disagreement with our landlord about rent has made the move unavoidable.

The move will, in fact, save VESV a significant amount of rent.

Any site for an office for a state-based organization will be convenient for some but inconvenient for others. The committee regrets any inconvenience that it may cause to some members, but in fact, the office is an administration centre rather than a focal point for members.

Our new office will be at 3/9B Salisbury Avenue, Blackburn, 3130.

This is located in a small shopping area, very close to Laburnum railway station (on the Box Hill line).

The new phone number will be 9877 7677

Our Greville Street lease expires at the beginning of December, so our relocation to Blackburn will occur near the end of November.

Workshops

A VESV Workshop is scheduled for February 13th 2006 but unfortunately this is already booked out.

The date for the next one is May 15th 2006 and given the growing demand for places at our Workshops, it might be a good idea to get your name down early.

Ring Rowena at the office.

At our present office:
9521 3297 during November or at the new Blackburn office on 9877 7677 from December.

Professor Allan Kellehear,
Professor of Palliative Care at Latrobe University:
"I work to persuade anyone of the worth of staying in life as long as you feel you are able to hold on and keep breathing, to live and learn until the end. And I uphold the

principle that should you say you cannot stay one minute longer, that the law should protect your choice of dying with dignity. I am for each breath you take but recognise that the breath you take is your own and yours alone TO take. In and out, or simply out."

notice of 2006

ANNUAL GENERAL MEETING

The Annual General Meeting of the Voluntary Euthanasia Society of Victoria Inc. is to be held at the

**Community Hall
Grattan Gardens Community Centre
Grattan Road
Pahran**

on Saturday February 25th 2006

Chairperson: Dr Rodney Syme, VESV President

Guest Speaker: To be notified *Please arrive at 1.45pm for a prompt 2pm start.

Reflections from Belgium

Belgian VE President Jacqueline Herremans made the following comments last September (with slight editing).

A Belgian doctor, Raymond Mathys, was awarded the Prize for Humanism 2005 by the Humanist Association. He combined the art of medicine with the art of listening to his patient.

His interest in palliative care dates from 1997, when he set up the palliative care system in Anvers. Palliative care and euthanasia never represented contradictory ideas for him and his multi-disciplinary team, comprising not only doctors but also nurses, physiotherapists, psychologists and social workers.

Raymond Mathys, having gathered the maximum information, and having knowledge of the language of medicine, needed to teach this to his patients. Doctor and patient form the perfect team, with complementary abilities; the

competence of the doctor in the medical area, and the competence of the patient to evaluate his quality of life.

When it is a question of euthanasia, the role of the doctor is to establish, in an objective manner, the medical situation without prejudice.

As for the patient, it behoves him to say when his suffering begins to be intolerable: this is his competence. The doctor should recognize this suffering without actually giving up the contest. But the last word comes from the patient when it is a question of intolerable suffering.

A man sparing of words, Raymond Mathys is generous in listening. He must sometimes be silent to hear the words of the other.

Happily, doctors like Mathys are not unique. Every day in our country, doctors confronted by questions on ending life, try to respond, not only with the help of their technical knowledge, but also with their hearts.

Some doctors however, remain despairingly deaf. I would keep throwing this to them: it is always difficult to hear a person choose the date and hour of their death.

A feeling of failure, fear of the deed, lack of knowledge of the technique and medicines, all mix and tangle and come to disturb the communication between the patient and the doctor.

For some do not understand the art of communication. There must still be time and patience.

And it is also our own responsibility, when we are all potentially patients, to speak clearly and make ourselves heard by our doctors.

Thanks to VESV members and volunteers June Halls for translating this piece from the Belgian, and Conny Brandt for translating a related article from Flemish. If you can translate European languages, please contact Rowena at the office.

a tattoo will not help...

Members may have seen recent press coverage about a doctor who had DO NOT RESUSCITATE tattooed across his chest.

He knew the 6% odds in favour of successful resuscitation out of hospital, and at 80 years of age, he could see no point, even though he was not suffering from a terminal illness.

The truth is that it will do him no good.

If paramedics are called to someone who has collapsed in the street or at home, they are obliged to provide resuscitation. They are not doctors, so cannot make a diagnosis or assess whether treatment should or should not be given.

A tattoo, a note, or even a skilfully written advance directive will not prevent resuscitation by paramedics, although it should be effective if available to a doctor.

If you do not wish to be resuscitated if you collapse at home, you must instruct those who may find you in collapse to ring your doctor.

If he has been instructed properly that you refuse resuscitation and have completed a refusal of treatment certificate, he can then ring the ambulance, instruct the paramedics that they are NOT TO RESUSCITATE, but simply to take you to hospital for comfort care.

Jack's death...his choice

Jack Newbold is a 59 year-old retired tugboat captain who is dying of bone cancer. It's one of the most painful cancers, and he doesn't want to put his wife and 17 year-old daughter through the trauma of caring for him as he loses control over his body.

So Mr Newbold faces a wrenching choice in the coming weeks: should he fight the cancer until his last breath, or should he take a glass of a barbiturate solution prescribed by a doctor and put himself to sleep forever? He's leaning towards the latter.

"I've got less than six months to live" he said. "I don't want to linger and put my wife and family through this".

I don't know what I would do if I were Mr. Newbold, nor if I were his wife or daughter (they're both supporting him in any decision he makes). But I do believe that it should be their decision – not President Bush's.

Unfortunately, Mr Bush is fighting to overturn the Oregon Death With Dignity law, which gives Mr Newbold the option of hastening his death. Oregon voters twice passed referendums approving the law, which has been used since 1998, and it has wide support in the state.

The Bush Administration issued an order that any doctor who issued a prescription under the State Law would be prosecuted under Federal Law. Oregon won an injunction against the order, John Ashcroft lost an appeal, and now the Supreme Court will hear arguments in the Fall.

"I'm just grateful I live in the state of Oregon, where we have this option," Mr Newbold said.

"I'm just sorry the John Ashcrofts of the world want to dictate not only how you live, but also how you die. There's nothing more personal, other than childbirth, than passing on."

Mr Newbold, a Vietnam veteran and former merchant seaman, is funny and blunt, with a flair for nautical language unsuitable for a family newspaper. He started with head and neck cancer. Now cancer is spreading to his bones, disabling him and forcing him to take morphine for pain.

"By god, I want to go out on my own terms," Mr Newbold said. "I don't want someone dictating to me that I've got to lie down in some hospital bed and die in pain."

Mr Newbold has started the process of obtaining the barbiturates; two doctors must confirm that the patient has less than six months to live, and the patient must make three requests over at least 15 days.

Typically, the drug is secobarbital – the powder is removed from the capsules and mixed into water or applesauce – or pentobarbital, which comes as a liquid.

Patients typically slip into a coma five minutes after taking the medication and die within two hours.

Like many patients, Mr Newbold says that his biggest concern isn't pain so much as the loss of autonomy and dignity. That's partly why he wants the medication on hand – if he feels himself losing the self-control he has prized all his life, he can hasten the process.

"I may never use the medication," he said, "but the knowledge that you have the ability to end it gives you so much relief."

That's common – many patients who get the barbiturates do not in fact use them, but derive comfort from having the choice. Overall, 208 patients over seven years have used the law to hasten death, according to the Compassion in Dying Federation of Oregon, which helps patients work their way through the legal requirements.

When patients use the law, they typically set a date and gather family and friends around them. Those who have witnessed such a parting say it's not as morbid as it may sound.

"It's pretty weird knowing what day you're going to die, but we could plan for it," said Julie McMurchie, whose mother used the barbiturates about a week before she was expected to die naturally of lung cancer. "Two of my siblings lived out of State, and they were able to come, so we were all present.... We were all there to hug and kiss her and tell her we loved her, and she had some poetry she wanted read to her, and it was all loving and peaceful.

"I can't imagine why anybody would begrudge us that opportunity to say goodbye, and her that opportunity to have peace."

The same applies to Jack Newbold and everyone in his position. Mr Newbold faces an excruciating choice in the coming weeks, and he's got enough on his mind without the White House second-guessing him .

Back off, Mr Bush

Reprinted from the New York Times – July 2005.

Help
VESV
save costs

Our Society is a non-profit organisation funded entirely by member subscriptions and donations.

For each communication sent out to members, we incur paper, printing and postage costs. You can help the Society reduce these running costs by choosing to provide us with your email address for most communications.

If you would like to help save costs this way, please make sure we have your current email address. If you are unsure as to whether we have your current email address, simply send an email

to us at vesv@vesv.org.au. Put your name and address in the body of the email. In addition, please indicate how you would like to receive your copy of the quarterly newsletter by typing one of the following three options into the Subject field of the email:

- Newsletter by **email** only, please
 - Newsletter by **post** only, please
 - Newsletter by both **email and post**, please
- We sincerely appreciate your support.

Rodney Syme: President



from NEAR and far

France

The French have become more tolerant of euthanasia and are strongly in favour of Catholic priests being allowed to marry and the ordination of women, but remain divided on gay marriages, according to a poll carried out for Figaro magazine.

Most adults in France are still strongly attached to the role of the State in providing essential services, the TNS Sofres institute found in a sampling of "taboos".

The poll showed 81 percent in favour of the prospect of euthanasia, against 14 percent opposed and five percent who expressed no opinion.

That was a 16-point increase over the past five years in the number of those favouring mercy-killing, the magazine noted.

Some 80 percent were in favour of priests being allowed to marry and women to be ordained...both forbidden in the Roman Catholic Church... with 14 percent against in each case.

Canada

In Ottawa, MPs will be forced to take a public stand on the controversial issue of assisted suicide this Fall.

They will cast a vote on MP Francine Lalonde's Bill, which amends the Criminal Code to give sick Canadians the "right to die with dignity."

The Bill will first be debated during second reading in the Commons for one hour before MPs vote on whether to send it to a parliamentary committee for review or to trash it.

If the bill finds support from the majority of MPs after being hashed over by a committee, Bill C-407 will allow a lucid adult in extreme pain whose treatment has failed or who has a terminal illness, to be assisted in committing suicide.

According to the proposed legislation, this person must first have made "two lucid requests more than 10 days apart, expressly stating the person's free and informed wish to end their life."

Anyone assisting must have confirmation of the diagnosis from two medical practitioners and be aided by someone authorized to practise medicine.

The amendment, which Lalonde first tabled June 15th, would rewrite two sections of the Criminal Code in which assisted suicide is categorized as homicide.

The Liberal Government is not expected to back Lalonde's Bill, since private member's Bills traditionally do not find support from governing MPs.

Netherlands

The Associated Press reports that the Dutch government plans to set guidelines for when doctors may end the lives of terminally ill new-born babies with the parents' consent. Dutch pediatricians have been campaigning for regulation of a practice that has been conducted covertly on a small scale.

There are believed to be about 12 cases a year of incurably or terminally ill babies being given fatal doses of morphine.

If passed by parliament, the new guidelines will help clarify what is permissible, says pediatrician Dr Eduard Verhagen, the main author of the protocol. He added, "It's time to be honest about the unendurable suffering endured by newborns."

In addition to addressing the newborn issue, the protocol will provide a model for how the Dutch will treat other cases, such as the mentally retarded or the elderly demented.

USA

The US Supreme Court is hearing an appeal by the Bush Administration against the Oregon legislation allowing doctors to prescribe life-ending drugs to terminally-ill patients at their request.

Since Oregon passed its assisted suicide legislation in 1994, 208 people have used drugs prescribed by doctors to die.

In 2001, then Federal Attorney General John Ashcroft, a prominent

supporter of the evangelical movement, argued that doctors who prescribed drugs in these circumstances were violating federal drug laws.

Federal courts have twice ruled that Oregon has the right to pass laws on what drugs doctors could prescribe but the Bush Administration has appealed against these rulings right to the Supreme Court where the appeal will be the first major case to come before Supreme Court Justice John Roberts.

Germany

Deutsche Wele reported that the Swiss group Dignitas which helps the terminally ill to die in Switzerland proposed opening a branch in Germany. Assisted suicide is against German Law.

Roger Kusch the Justice Minister in the city state of Hamburg backed a change to the law. He said the law would require the doctor to determine that the patient was terminally ill and the patient would be required to make a notarised statement.

There was strong opposition from various sources in Kusch's own party, the Christian Democratic Union. Other opposition was from the Lutheran Church.

VESV NEEDS INTERPRETERS

Some members of our team of voluntary interpreters are currently not available.

Can you help fill the gaps? If you are fluent in another language, you could help the Society enormously by translating overseas articles and other material.

THE SEA INSIDE

Earlier this year the Spanish film "The Sea Inside" was screened internationally to critical acclaim. Many of our members were moved and inspired by this true story of poet Ramon Sampedro's fight to die on his own terms after 30 years of quadriplegia.

This wonderful (subtitled) film has now been released on DVD. This is a film you will watch more than once.

End of life stories...

Some time ago, VESV asked members to write personal stories about end of life problems they, their families or friends had suffered. Many provided information that is very powerful, and is extremely useful in persuading politicians and others that all is not well with our current law.

For example, we included such stories in our submission to the Government re the Medical Treatment Act, on Aged Care and on inequality in health care. We have used them on our website and in our Newsletter. They give a personal quality to an argument that can often seem philosophical, vague and detached from reality.

We realize that talking and writing about these experiences can be difficult, but many people find that ultimately the process is cathartic and beneficial.

Such stories can be about "good" and "bad" deaths, about lack of communication by doctors, about failure of implementation of clearly expressed wishes for effective palliative treatment or refusal of treatment, or abuse of rights under the Medical Treatment Act.

We will of course respect your wishes re publication and re anonymity or otherwise. If you have a story to tell, please send it to Rowena at our office.

Well done Dorothy!

For some years, VESV has organized a formal media group to respond rapidly to end of life issues that arise in the media.

Media group members write to the newspapers or respond to radio call-in programmes. By doing so en-masse, they ensure that there is a greater likelihood that some one's letter or comment will actually be published or heard.

Recently SBS showed an Insight documentary on the problems of ageing.

Our media group responded and long time VESV member and volunteer Dorothy Pentland was successful in Green Guide Letters.

She wrote:

"Thanks, Insight (SBS) for drawing attention to the problems of old age.

"I am 87 years old and getting closer to my demise. Your recent program on ageing, with its focus on prolonging life, made me even more worried about the time I have before me.

"Now we need to talk about celebrating a good life with a good death. We give our pets a timely and compassionate outcome out of love – why not us?"

An excellent letter. If other members would like to join this group, please contact Rowena at our office.

Comments from a palliative care professional

An experienced palliative care nurse recently made the following observations.

It is encouraging that palliative care recognizes all this suffering but a pity its vision about relieving it is limited.

"A person who is facing their own death is forced to face a series of progressive losses. ...initially, of certain physical abilities and perhaps too of mental capabilities.so that eventually many or all of the characteristics which once gave this person their identity in the world are diminished and finally extinguished.

"It is my experience that a person facing death is fre-

quently aware of this process and it is this gradual or rapid diminution of the worldly "self" which frequently triggers a deep and resonating fear.

"For what will be left when all that a person has been – their interests, their work, family possessions, their mind and their character, is no longer? What is left when the components of our worldly self are given up?

"The answer, of course, is a profoundly spiritual one and is the essential question of the great spiritual traditions."

Mendy (Meredith) Urie from Palliative Care Victoria Newsletter (Sept 2005)

Have your say

We'd like to make "Have your say" a regular feature of this newsletter.

Members are therefore invited to contribute. Below is a poem by Robert Newson:

Solomon said there's a time to die,
But he never said when it was.
So it's up to us all as time goes by
To decide for ourselves, because
If we don't, our science will keep us alive
Without purpose, or reason, or sense,
It thinks that to live is just to survive --
A perpetually dead present tense.

Death is not something to fear or to mourn.
It can well be a welcome release.
And we really all know from the day we are born,
That death is the gateway to peace.
The Ecclesiast knew, and so did Lao-tzu
That death was a cause to rejoice,
And we can know now all that they also knew --
And we all have just the same choice.