



VESV REPORT

VOLUNTARY EUTHANASIA SOCIETY OF VICTORIA INC.

Reg. No. A0006974B

Member of the World Federation of Right to Die Societies

Number 122

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Tube feeding: Medical treatment or palliative care?

A CASE currently being heard by the Victorian Supreme Court is one in which VESV has been directly involved and one which is of significant interest to all those concerned about 'dying with dignity'. The decision the Court hands down will have important ramifications for everyone involved in end-of-life care: family, doctors, nurses and nursing home carers.

Under the *Medical Treatment Act*, a patient or his agent may refuse medical treatment but may not refuse reasonable palliative care in the form of hydration and nutrition. The question before the Supreme Court is whether or not tube feeding constitutes medical treatment or palliative care.

In June 2002, VESV received a counselling call from a 70 year old man who wanted advice regarding his wife. She had been suffering from Pick's disease, a form of dementia, for 10 years. Seven years ago, at which time she was mobile and living at home, he agreed to the insertion of a stomach tube for feeding purposes.

For the past two years she has been in a nursing home and for some time has been in a vegetative state with no control of bodily functions and permanently lying in a foetal position. Unfortunately the husband had no medical enduring power of attorney, and his requests to have the tube feeding stopped were in vain. He and his family believed she was in pain and had no quality of life.

A VESV representative met with him, visited his wife in the nursing home and advised him to apply to the Victorian Civil and Administrative

Tribunal (VCAT) for guardianship of his wife so that he could make decisions regarding his wife's medical care. The case was heard in December 2002, three months after the application had been made, and it took another two months for the decision to be handed down during which time representations were made by members of Right to Life who maintained that tube feeding is a form of palliative care and should not be withdrawn. **VCAT's decision was to appoint the Public Advocate as guardian and it indicated the opinion that tube feeding constituted medical treatment and could be ceased.** Subsequently, the Public Advocate has obtained further medical and palliative care opinion and has sought a ruling from the Supreme Court.

Although this delay is frustrating for the woman's family, the care taken by the Public Advocate should result in a substantial legal

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President's message

I HAVE often contemplated and been intrigued by the reasons people join VESV. Every month there is a steady stream of new members, from all walks of life, who join without any formal advertising. We do not record the age of members, but I presume from meeting many members at our functions that most are over forty.

I know for sure that some members join when they become seriously ill, hoping, I presume, that VESV will help them at the end of their lives. It is not our purpose to assist people in a practical way to end their lives, but we do, through individual counselling and through our workshops, provide advice that may help many members with the dilemmas they face.

I also know for sure that many members join after a particularly bad experience with the death of a relative or close friend. This creates a very strong signal and impetus to try to ensure that such a catastrophe does not occur to them or to others. Sometimes it may be the report of a death of someone quite unknown to them, such as Nancy Crick or Shirley Nolan, that provides the spark.

Such events arouse emotions of anger, that society can be so callous in its disregard of human suffering, and that the powerful and influential religious hierarchies can impose their will on the majority. It can be associated with guilt that a person did not do more, or know better how to cope with such situations. Ultimately, what emerges is a heightened sense of compassion, a sense of injustice, and an innate sense that a human right is being abused.

Yet others, through their reading and thinking, develop an intellectual and compassionate interest in the issue and resolve to do something to change a cruel and senseless law. My mental image of a VE supporter is of a humanist, an atheist or liberal non-authoritarian religious person. A free thinker, with possibly an anti-authoritarian streak, a non-conformist with a strong sense of individualism. In short, a mature individual who is strong enough to confront issues of personal liberty, suffering and their own death.

Thinking of our membership, it is salutary to reflect that while 76% of Victorians support VE, only 2000 belong to VESV. It is a similar position to that of the major political parties – the great majority of the electorate vote either Labor or Liberal yet only a small fraction belong as members of either party.

VESV does provide benefits to members, but will not rest until it provides the ultimate benefit, a change in the law. To achieve this, I am reminded of President John Kennedy's famous exhortation (which I paraphrase for my purpose) – "Think not what VESV can do for you, but what you can do for VESV."

Rodney Syme

*If it were done when 'tis done, then 'twere well
 It were done quickly.*

William Shakespeare, *Macbeth*

Final EXIT (Australia) presents

Killing me Softly: Love, Death and Dying in Australia

International Voluntary Euthanasia Conference
 May 30 – June 1 - Sydney

Speakers include Prof. Peter Baume; Dick Macdonald MD, Co-ordinator of Hemlock US Caring Friends Program; Philip Nitschke; and New Zealand euthanasia activist Leslie Martin. For further information contact Christine Arthur on 08 8985 2230.

VESV seeks legal support for agents

LAST YEAR, the rights of a legally appointed agent (medical enduring power of attorney) were thwarted at a Melbourne public hospital. The agent's decision to withdraw treatment from his grandmother was ignored, and his request to complete a Refusal of Treatment Certificate was refused. VESV was advising the agent, but when the next step involved the court process, VESV was unable to help.

In addition to this specific situation, VESV is aware of other instances where hopelessly or terminally ill patients have not had adequate palliation of their suffering.

VESV is therefore entering into discussions with sympathetic lawyers who are prepared, on a *pro bono* basis, to assist members and others to pursue such matters in the courts or before the Medical Practitioners Board of Victoria.

The resultant decisions in support of the Society's platform may create important precedents which can lead to changes in medical opinion and practice. This enhances the principles of respect for autonomy and relief of suffering on which voluntary euthanasia is based.

If any member is aware of instances of apparent disregard of the *Medical Treatment Act* or of failure to provide adequate pain relief or other palliation, please contact VESV immediately.

Repeat forum on the *Medical Treatment Act*

A PUBLIC FORUM on issues surrounding the *Medical Treatment Act* is to be held on Thursday, 29 May from 1.30 – 3.30 pm in the Ashley Ricketson Centre at Caulfield General Medical Centre, 260 Kooyong Road, Caulfield. Speakers include Julian Gardner, the Public Advocate and representatives from The Alfred and Austin Hospitals. For more information telephone Valerie Kay on 9209 6394.

Tube feeding:

Medical treatment or palliative care? (Continued from Page 1)

decision which will clarify this grey area of the *Medical Treatment Act*. If it establishes that artificial feeding is medical treatment and can be refused by a competent person or by the agent or guardian of an incompetent person, it will enable medical professionals not to commence, or to cease, tube feeding when its use will only prolong indignity and suffering in dying.

The Supreme Court's decision will make it necessary to address the wider issue of palliation of suffering due to dehydration and starvation when tube feeding is withdrawn or not initiated.

Sedation to relieve **all** suffering must be clearly seen as part of the normal care of patients in

these circumstances. Although many such patients will be predominantly insensate, they are likely to be aware of pain and to allow this is unacceptable. Many palliative care experts claim that dying of dehydration is pain free, provided there is expert palliative care. This may be true if the person is very close to death, but in many of the situations where this decision is relevant, the individual is not terminally ill and will be normally hydrated.

In such circumstances death may occur over 7-14 days, and it would be inhumane to contemplate the possibility of allowing unrecognized suffering to continue for such a period without complete relief.

Advance Directive for nursing home residents

INCLUDED IN this issue of our newsletter is the new Advance Directive re treatment in a nursing home. This has been developed because many members view the prospect of entering a nursing home with distress. Sometimes there is no other alternative to this.

If this is the case, people want the maximum control over the type and extent of medical care to be provided. In this circumstance, it is essential to have an agent (enduring medical power of attorney) and a clear advance directive. With the VESV advance directive you can select the level of care you do or do not want.

Many who are now well may simply want to file this document, but others who have chronic diseases or cancer, are living alone, or could

soon be facing this question, may find comfort in completing the form. This should be done in conjunction with your G.P. Alternatively, as long as you are still competent, you can complete it on entering the nursing home.

You have a legal right to refuse any treatment that you do not want. Although this document does not have legal status, in the hands of your agent it has great value as it tells those caring for you what your wishes are.

Without such a document, people may find their lives prolonged by unwanted treatment in circumstances they might find unacceptable. An Advance Directive can be revoked or altered at any time, but any alteration must be witnessed and signed.

Your bequest to VESV will help our work

VESV'S WORK relies heavily on gifts to cover its expenses. If you would like to donate but are unable to at the present time, consider the simple step of bequeathing VESV a legacy as part of your Will.

Assuming you have a Will it may need to be updated. Are the named executors still appropriate? Have your family or financial circumstances changed?

If your present Will is in order you can leave the Society a gift by adding a Codicil, i.e. an

addition to your Will specifying your gift signed and dated by you in the presence of two adult witnesses. There is no limit to the number of Codicils that can be made to a Will but any new Codicil must record the existence of every previous Codicil.

The document is very straight forward, but to ensure it is valid you would be wise to have it prepared by your solicitor. Provided the legacy is of cash it will not attract any capital gains tax or duty to your estate. So every dollar you leave VESV will be used to change the legislation.

Attention Comedy Lovers!

Noises Off

Date: Saturday, 14 June

at 2.00 p.m.

Comedy Theatre (Exhibition Street)

VESV has a small Group Booking for a preview performance of *Noises Off* featuring a cast including **Marina Prior**. For more information and booking form see enclosed flyer.

Report on our 29th Annual General Meeting

VESV'S ANNUAL GENERAL MEETING, held on Sunday, 23 February, 2003, was attended by about 115 people.

Speakers

There were two speakers, Dr Francis Macnab, Executive Director, Cairnmillar Institute and Julian Burnside QC, VESV's newest Patron.

Dr Macnab spoke of how euthanasia is viewed in our contemporary society and why this is so. He expressed the view that a mature, or evolving, educated society sees euthanasia as a rational and sensitive proposition and practice. He explored this view and outlined the psychological and theological resistances to it.

A full transcript of his address can be found at the Society's website www.vesv.org.au. Alternatively a copy can be obtained by contacting the Society's office on 9521 3297.

Julian Burnside said he regarded voluntary euthanasia as a human rights issue, in that individuals had a right to discard or relinquish life in certain personal circumstances. He noted that justice is lost if self-respect is not protected, and self-respect is at the centre of decisions at the end of life.

He described the law of murder as a blunt instrument inappropriate for the resolution of difficult medical decisions at the end of life. Perverse jury decisions in recent years highlighted the inadequacies of the current law.

Reports

Our President, Rodney Syme, reported to the Meeting on the Society's activities throughout 2002, which he described as a "quietly productive year".

He spoke of VESV's involvement in persuading *The Age* newspaper to investigate the application of the *Medical Treatment Act* and its subsequent review by the Department of Human Services (DHS). DHS is now undertaking an educational campaign for Victorian doctors, allied health professionals and ultimately the public. He said that this is valuable but is not a fulfilment of Labor Party policy to hold an Inquiry into the *Medical Treatment Act*.

He spoke of the widely-publicised suicide of Nancy Crick, which was organized by Philip Nitschke's EXIT (Australia). Also of the suicides of a number of other hopelessly ill people, all of which illustrated the unmet needs of such people in the community. However, later in the year some not seriously ill people ended their lives (also advised by Philip Nitschke) which ultimately led to *The Age* withdrawing its support for VE law reform.

He reported that prompted by Nancy Crick's death the Society undertook a Morgan Poll of community attitudes to VE and physician-assisted suicide. This revealed 76% support for VE and 71% support for PAS in Victoria.

He reported that during the year the Society had expanded its services to members with increased individual counselling, group workshops and the development of a number of advance directives.

He said the Society needed to focus on three areas in 2003:

- Encouraging a change in the medical profession's view of VE;
- Preparation of a critique of the law in relation to end of life issues; and
- Ensuring strong political lobbying takes place with a view to a change in the law.

He asked all those present to contact their local members of Parliament, to encourage new members and to donate when and where possible.

He thanked the Committee members and the office staff for their hard work and support.

In the Treasurer's absence his report was read and accepted. He stated that the Society's funds continued to decrease and that it was important for all members to endeavour to introduce more members to the Society and to support fundraising programs where possible.

The Treasurer recommended that no increase be made to the membership fees at present.

Report on our 29th Annual General Meeting (Continued)

Election of VESV Committee

11 nominations were received for the Committee and as that number was fewer than the possible 13 permitted, each was declared elected.

2003 VESV Committee

Dr Rodney Syme - President
Mr John Anderson – Vice-President
Mr Noel Sanderson - Secretary
Ms Joanna O'Brien - Treasurer

Mr Howard Bull
Ms Janette Collier
Dr Helga Kuhse
Ms Belinda Morieson
Ms Jillian Paterson
Mrs Anna Swards
Mrs Betty Teltscher

Appointment of VESV Auditor

Rodney Syme thanked Michael O'Shaughnessy of O'Shaughnessy and Associates for acting as Auditor for the last five years. As he is unable to continue in this role Ross Collier of Ross Collier and Associates was appointed as Auditor for 2003.

VESV and Philip Nitschke

The President was asked to explain the relationship between the Society and Philip Nitschke. He stated that VESV's aims were not the same of those of Dr Nitschke or EXIT (Australia) and that each EXIT proposal or activity was reviewed by the Committee and an appropriate decision taken.

President thanked

Our President was thanked by those present for his continuing hard work on the Society's behalf.

Volunteer Help Needed

VOLUNTEERS ARE always needed to help in a number of areas. Currently we are especially seeking VESV members for two tasks:

1. Visiting members of Parliament. These visits are part of VESV's 2003 political lobbying campaign which aims for every Victorian politician to be visited at least once by a VESV member by mid-year. Information which may be useful is provided; however experience has found that **you** telling why **you** believe in voluntary euthanasia and why **you** want a change to the law is very powerful.
2. Writing articles and book reviews for this newsletter from information provided.

If you are able to help please contact Lindy at the VESV Office on 9521 3297.

Annual Membership Fees Now Due

MEMBERSHIP SUBSCRIPTIONS are now due for those members who renew annually. Please find enclosed your renewal form, which should be returned with your payment by 1 July, 2003. If no renewal form is enclosed your membership is current.