

# THE BULLETIN

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NEWSLETTER OF THE SOUTH AUSTRALIAN VOLUNTARY EUTHANASIA SOCIETY INC. (SAVES)

Vol 22 No 3 'No price is too great for the privilege of owning yourself' **November 2005**  
Rudyard Kipling

## Voluntary Euthanasia: a challenge and dilemma for Palliative Care

The Eighth Australian Palliative Care Conference, "New Horizons", was held in Sydney this year from 30<sup>th</sup> August until 2<sup>nd</sup> September. One of the themes was "New Challenges and New Dilemmas", within which voluntary euthanasia could have been most appropriately included. We applied for an exhibition booth as we did for the conference in 2003, but were once again turned away. Being convinced of the necessity for a voluntary euthanasia presence, Mary and I attended for one day, with our expenses paid most generously by NSW VES. At one of the plenary sessions I asked the following question:

*I have only been able to attend today's sessions & have been very heartened by the commitment of those working in Palliative Care & the efficacy of treatments available. It is widely acknowledged however, including by Palliative Care Australia, that even with optimal palliative care, not all people's suffering can be alleviated. Between five and ten per cent is the figure. We know that voluntary euthanasia is requested by these people as the only means of final relief. Earlier sessions today discussed the "Respecting Patient Choices" program. Do we*

*only respect those choices with which we are comfortable? Without legal choice for voluntary euthanasia what does Palliative Care propose for this minority? I ask also, respectfully, why VE hasn't been included as a topic here, with an exhibition booth of information?"*

The reply was that palliative care and voluntary euthanasia are separate, and "we don't kill our patients in palliative care"; a simplistic answer that denies the worth of people with intractable suffering, denies the reality of that suffering and leaves palliative care sorely lacking.

The Palliative Care Council of South Australia states its first objective as "To advocate for the needs, rights and interests of people who are dying and those who care for them." Palliative Care Australia's 1999 *Position Paper on Voluntary Euthanasia* acknowledges that palliative care is unable to relieve suffering in all cases and that people rationally request voluntary euthanasia.

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However, it then states the organisation's philosophical objection to voluntary euthanasia. What a dilemma! How can this be justified? This inconsistency in principle leads to an abandonment of the minority who cannot be helped. Surely Palliative Care has a duty of care to all dying patients.

Through talking with people at the conference, those who are at the beds administering palliative care, I know that some are not comfortable with the official response to voluntary euthanasia. Both they and their patients suffer because of unrealistic boundaries of care that effectively perpetuate suffering. I sincerely hope they will lead a new direction, meeting the challenge and solving the dilemma by supporting choice for voluntary euthanasia as a concept of care complementary to palliative care. If not, palliative care will be seen to be advocating only conditional compassion.

*Frances Coombe*

## **President's Report - July 2005 meeting**

SAVES President Frances Coombe welcomed invited guests, members and friends to the meeting and recounted the growing numbers of media discussions on end-of-life decision making. These included those around Terri Schiavo, Maria Korp, and Steve Guest who went public about his suffering from a terminal illness, and asking for the right to determine the time and manner of his death. The importance of advance directives was reiterated by Frances, for even though they do not yet allow choice for voluntary euthanasia, advance directives do afford a measure of control over medical procedures at the end of life.

Frances spoke about 'The Last Choice' or TLC that was set up this year by former United Nations Medical Director Michael Irwin who was also a former VES chairman. This society will operate as a benevolence network for British people seeking the assistance of Dignitas; bravely engaging in necessarily covert civil disobedience.

A Swiss government panel has recently supported assisted suicide as long as there is 'no egoistic or self-serving motives'. Dialogue with the Australian Medical Association continues in respect of adopting a neutral policy on voluntary euthanasia, in line with their neutral stance on therapeutic abortion, when they conduct a review of the *Position Statement on Care of Severely and Terminally Ill Patients* in 2006.

Frances also asked that members write to their member of Parliament on the draconian legislation passed in Federal Parliament on June 23<sup>rd</sup>, targeting suicide information via an electronic 'carriage service', meaning telephone and internet. The absurdity of the law is that the same information is legal if provided in a non-electronic manner, such as through books or face to face discussion.

Frances also advised the audience that the *Dignity in Dying Bill* has now been adjourned in the lower house until after the March 2006 state election. She then welcomed Public Advocate John Harley and Gillian Lewis Coles from the Dept of Health who both gave informative talks, and answered questions on completing advance directives under the *Guardianship Act* and the *Consent to Medical Treatment and Palliative Care Act*. The audience showed a great interest in the topic, asking many questions, both formally and informally during refreshments at the end of the meeting.

## **Emeritus Professor Graham Nerlich: SAVES new patron**

SAVES is both delighted and honoured to welcome Emeritus Professor Graham Nerlich as a patron. Professor Nerlich is Professor of Philosophy at Adelaide University, where he took his first degree of joint honours in Philosophy and English Literature, and graduate studies at Oxford University. He held a Chair of Philosophy at the University of Sydney and returned to Adelaide as Hughes Professor of Philosophy in 1974.

His interests in philosophy are quite general, but his research work has pursued the metaphysical problems of space, time and relativity theory, as well as the foundations of ethics. He has published three books and numerous academic papers. He is a Fellow of the Australian Academy of the Humanities, and also serves on several committees concerned with the ethics of scientific and medical experiments on animals.

Married to Margaret Rawlinson, Graham has three children from a former marriage. He is a keenly interested, semi-professional actor.

We welcome Graham, who along with our founding president Jim Richardson, will ensure that SAVES is well represented in pursuing its aims. Graham will be addressing the November public meeting on his chosen topic 'Leading a life'.

## **Welcome Maree**

SAVES is also delighted to welcome newest committee member Maree Day. Maree is currently an editor with SSABSA, the organisation that oversees curriculum, assessment and examinations for students

studying for the SACE. She has previously worked as a freelance editor, a representative for a publishing house, a bookseller and a business owner.

Maree was born by the sea (NSW), later moved to the mountains (Southern Highlands of NSW), and now lives on the plain. She has a son who, like Maree, has found Adelaide very much to his liking.

Maree's mother was a chemist, her sister is a rural GP; so the subjects of medical research, law and ethics have always been of interest. She thinks that some issues and rights are worth arguing for, and foresees a time when it will be inconceivable that an organisation like SAVES had to work so hard to bring about rational reform.

### ***Urgent Action***

**Members and supporters of the society are urged to write to Federal MPs expressing opposition to the *Crimes Amendment (Suicide Related Material) Offences* Bill (refer July VE Bulletin for details). See page 363 of front section of Telstra White Pages for current listing. Please write to all Senators and your own House of Representative member. Letters can be photocopied, signed put in named envelopes within a larger envelope and posted to Parliament House Canberra ACT for distribution.**

## **Launch of SAVES mobile display**

Due to the generous Arthur Cys bequest, SAVES has taken the opportunity to update the mobile display which had been in public circulation since 1988, after the launch by

SAVES first patron, the late Sir Mark Oliphant. The new light-weight construction, contemporary design and revised content will serve the society well into the future.

The display launch was held at the Adelaide Circulating Library on September 15<sup>th</sup>, with approximately sixty invited guests and members attending. SAVES is appreciative of the assistance provided by the library which had the display and other SAVES material on view to the public for one month. The Hon Dr Bob Such launched the display and the Hon Sandra Kanck also addressed the audience on her quest for law reform. Dr Such argued that those who opposed law reform felt the need to exert control over the lives of others and were statistically in the minority, albeit a powerful minority.

SAVES President Frances Coombe spoke passionately about the ongoing role of the society in lobbying for law reform over the past 23 years. Thanks to past committee member and long-standing member Gerry Versteeg, the first display was a first class construction at minimal cost.

Frances acknowledged the support of those parliamentarians who 'grasp the nettle', including Gail Gago, Duncan McFetridge, and Simon Birmingham who showed the strength of his convictions in openly supporting voluntary euthanasia legislation in the Liberal Party pre-selection. Frances also acknowledged and thanked four people who have been particularly active in the reform movement. These are Hon Sandra Kanck, state leader of the Democrats, who has introduced the *Dignity in Dying* Bills into parliament and Hon Dr Bob Such who introduced them into the Lower House. Frances also thanked Dr Roger Hunt, longest serving palliative care doctor in SA, and now Director of Western Palliative

Care Service, who has shown courage and integrity in stating his support of patient choice for voluntary euthanasia, and Dr Rosie Jones, an advocate who has participated in forums and made written submissions on the issue.

The society wishes to sincerely thank three SAVES members for their special help on the night; Jo for her luscious savouries which she prepared and provided at cost only; also Alex who donated some drinks, and, with partner Bill, gave generous time in support. Their contribution gave added pleasure as they are the daughters and son-in-law of SAVES Vice President Mary Gallnor. Helen Jones is also sincerely thanked for contributing her time and expertise as a professional photographer, taking shots of the occasion, some of which are included at the end of this bulletin.

The display will now be booked into libraries and will be used at public functions and awareness days as a valuable adjunct in achieving the society's aim.

## **British Medical Association alters stance on assisted dying**

The June 2005 Annual Representative Meeting of the British Medical Association (BMA) saw a 'landmark decision' altering BMA policy stance on voluntary euthanasia and assisted suicide from one of opposition to one of neutrality, stating that this is primarily a matter for society and parliament. 'The BMA should not oppose legislation which alters the criminal law but should press for robust safeguards both for patients, and doctors who do not wish to be involved in such procedures.' This stance may have been influenced by the growing number of hopelessly and terminally

ill British people traveling to Switzerland for assistance to die through Dignitas.

The change in British policy may have implications for the Australian Medical Association which was founded on the same principles as the British association and is due to examine its own stance on such matters in 2006.

## **'Demoralisation syndrome' and the end of life**

The term 'demoralisation syndrome' (DS) has gained currency in the psychiatric and palliative care literature in recent years (1,2). It first came to the attention of SAVES during the 2003 National Palliative Care Conference in a paper entitled '*The psychological, physical and social correlates of demoralisation in palliative care*', presented by Dr Simon Wein. While this newsletter cannot give a comprehensive discussion of the literature, there are aspects that may be of interest to the readership, especially the possible implications for end-of-life care.

The Oxford English Reference Dictionary defines 'demoralise' as 'to destroy the morale of', or 'make hopeless' (3). Demoralisation syndrome is a new psychiatric condition listed in the Diagnostic and Statistical Manual of Psychiatric Disorders (DSM-1V). Diagnostic criteria for its use are

- Symptoms of existential distress: meaningless, pointlessness, hopelessness
- Sense of pessimism, 'stuckness', helplessness, loss of motivation to cope differently
- Associated social isolation, alienation and lack of support
- Phenomena must persist for more than two weeks (13).

While DS is a separate classification to clinical depression, it is also deemed to be important in the development of a person's desire to die (4). At the heart of demoralisation are the hallmarks of existential despair (5). These are feelings that have always been understood as being part of the human condition, and understandable responses to grief and loss.

The difference between DS and clinical depression is that depression denies a person the experience of pleasure at the current moment, whereas the 'demoralised' person, while able to enjoy certain immediate pleasures, is denied any anticipatory pleasure as they regard their future as hopeless (6). It has been argued that by DS being diagnosed as a specific psychiatric condition in the terminal phase of a terminal illness there will be the opportunity for patients to be assisted in overcoming these negative emotions.

It has also been argued that it is important to regard DS as an 'abnormal state' in its severe form, for to consider it as normal minimises its clinical importance (7). This presupposes that patients who request assistance to die must be suffering from a psychiatric disorder. It is therefore considered imperative to determine whether or not severely ill patients may respond to psychological treatment, restore meaning in their lives, and reduce feelings that may lead to requests for assistance to die.

To state instead that demoralisation may arguably be a very human and understandable response to impending death is not to suggest that people no longer need psychological treatment or support, or that they simply 'accept their lot'. Patients and their families are currently regularly supported, comforted, and indeed palliated by a range of appropriate psycho-social approaches.

Supporters and opponents alike of the right to choose an assisted death generally agree that the diagnosis of *clinical depression* may influence the ability of a patient to give informed consent, including requests for assistance to die. In fact South Australian legislation proposing a change to the law to allow voluntary euthanasia in prescribed circumstances includes a safeguard of excluding people with untreated clinical depression. However, as one commentator has argued, accepting DS as a psychiatric disorder would 'pathologise' all requests for active assistance to die, including a request which persisted, despite the successful treatment of a depression which was thought to originally motivate it. A persistent request for assistance to die would remain an irrational request, implying the existence of DS (8).

The Diagnostic and Statistical Manuals, now used extensively in mental health, evolved out of a need to develop uniformity in psychiatric hospital statistics in the early 1900s. This was augmented by more comprehensive information based on a system developed by the American Armed Forces, and subsequently modified by the American Psychiatric Association (Clark et al 1995). The rationale was to facilitate clinical practice and communication; but the history of the DSMs has also been one attracting ongoing debate. For instance it has been argued that the DSM is seen to be 'pathologising' an increasing number of behaviours over time, so that rather than classifying real disorders, it is forever expanding the medicalisation of human problems (11). When considering any new diagnostic category such as DS we must

always question the broader influences at play, as 'social evolution affects medical classification and medical classifications reflect deeply held opinion, values and goals' (9).

There is no reason to suggest that the development of this new diagnosis is motivated by drug companies seeking to promote new forms of pharmacological treatments, as the proposed condition is managed by psychological interventions. It would also be churlish to imply that proponents of this new diagnostic category are not acting out of a true desire to reduce human suffering. However what cannot be overlooked is that the package of diagnostic and treatment proposals includes, implies and consequently helps to further entrench the long-standing social-moral position taken by the medical profession against assisted dying (10).

This position has supported the 'sanctity of life' doctrine founded upon the Judaeo-Christian religious heritage. What has not been questioned is whether proponents of this new diagnosis are specifically influenced by religious doctrines that are opposed to medical assistance in dying.

When every request for assistance to die can be considered irrational, what is 'defined away' is any individual's capacity and therefore right to choose voluntary euthanasia or assisted suicide. This has obvious implications for the rights and personal freedoms that are sought, but still to be realised, by nearly 80% of Australian citizens.

*Julia Anaf*

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4. op cit Kissane et al (2002) p 734
5. Parker, M (2004) 'Medicalizing meaning: demoralization syndrome and the desire to die', *Australian and New Zealand Journal of Psychiatry*; 38:765-773
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7. op cit Kissane (2002)
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12. Clark, L.A., Watson, D. & Reynolds, S. (1995) 'Diagnosis and Classification of Psychopathology: Challenges to the Current System and Future Directions'. *Annual Review of Psychology*, 46:121-153.
13. Reported in *Australian Doctor*, 27<sup>th</sup> Sept 2002

## World News

### USA

A further attempt to pass broad restrictions on the right to die, posed in a rejected senate bill, the so-called *Incapacitated Person's Legal Protection Act*, would have required that the federal courts intervene at the request of a loved one if the state court authorized or directed the withholding of life-support or nutrition where there was an alleged dispute over the patient's wishes. This would have allowed family members to obstruct the patient's wishes, leading to litigation which could last for years. Following Congressional intervention in the Schiavo case, polls show public opposition of between 70% and 80% to such intervention. Besides the push from the Christian Right for this type of legislation, there is further impetus from groups claiming to represent

people with disabilities, even though over 60% of people living with disabilities support the right to assisted dying for competent terminally ill people (Lou Harris Poll December 2001). The failure of representation is considered to be due to these 'disability' organizations having links to ultraconservative funding bodies, which funded Terri Schiavo' parents, and which also fund anti-gay and other right-wing initiatives. The voices of advocates for people with disabilities who support the right to choose are not heard.

One of these advocates is *Compassion in Dying* president Barbara Coombs Lee, a nurse and lawyer who argues 'the greatest fear of our constituents is that other people -complete strangers- will make end-of-life decisions for them. And God forbid that it is politicians.'

It is reported that Governor Schwarzenegger is 'open to the idea of a bill' to support choice in dying.

Reference: 'New Congressional Assault on the Right to Die'  
ICLA online [www.licaonline.org](http://www.licaonline.org)

### Britain

A 72-year-old man who killed his terminally ill wife in "an act of love" has avoided imprisonment. Mr Mawditt, a retired nurse, walked free after a judge ruled that a jail sentence was not appropriate. Seventy year-old Mrs Mawditt had been diagnosed with haemo-cromatosis, which leads to heart and liver failure and had left her in constant pain.

Judge Thomas Crowther said: "I cannot believe that any person who has heard what I have heard would regard a term of imprisonment as appropriate". He also stated "You will never be punished for this act, save in so far as your suffering has been a punishment in itself."

## ***The VE Bulletin - November 2005***

Deborah Annetts, chief executive of the Voluntary Euthanasia Society, said mercy killings would continue until the law was changed to give the terminally ill the right to die.

*Reference: Maxine Frith, "Man who killed terminally ill wife 'as act of love' is spared jail", The Independent Newspaper, London 3<sup>rd</sup> Sept 2005*

Also in Britain the Daily Telegraph reported that a YouGov poll has revealed huge popular backing for the legalisation of assisted suicide, with 87 per cent agreeing with the statement that people who are terminally ill "should have the right to decide when they want to die and to ask for medical assistance to help them".

More than two thirds said people should be allowed to assist the suicides of close relatives without fear of prosecution.

*Reference: Philip Johnston, Home Affairs Editor (Filed: 29/08/2005)*

### **Dignitas in Britain**

*The Independent* (UK) reports (9<sup>th</sup> October) that Zurich-based Dignitas has plans to open a branch in Britain where the society reportedly has hundreds of members. Thirty seven British citizens have sought the assistance of Dignitas when faced with intractable suffering which can only be relieved through death, but were unable to be assisted in their own country.

### **VE Campaigner 'struck off' Medical Register- vows to continue fight**

Leading voluntary euthanasia campaigner, Dr Michael Irwin who was struck off the medical register for obtaining medication with the intention to assist a terminally ill friend (also a voluntary euthanasia campaigner) end his life has vowed to continue his campaign.

Dr Irwin was chairman of the Voluntary Euthanasia Society before he stepped down after his arrest. He told the Guardian newspaper 'I felt from the start that the odds were stacked against me. But I am certain that the law will be changed and it will benefit many people within the context of good palliative care'.

Dr Irwin stated that it was rare to hear of a doctor who had a bad death and that he knew of doctors that had 'twinning' arrangements to help each other die when painful death threatened. He claimed that doctors were hypocritical if they failed to do the same for a good friend or patient requesting it. He said 'I strongly believe that the existing law on assisted suicide is unjust, and that sometimes a compassionate physician has a greater duty to a patient or close friend than their duty to the state'.

The Guardian newspaper states in the lead editorial of October 4<sup>th</sup> 'Rarely can the General Medical Council (GMC) have been given a better opportunity to demonstrate it recognises the moral dilemma facing doctors dealing with terminally ill patients than in its recent hearings on Dr Michael Irwin.. True to earlier tradition, The GMC opted for upholding hypocrisy rather than the Hippocratic Oath. This courageous medic deserved better. He should not be struck off'.

*Reference: The Guardian Sept 28 2005, October 4<sup>th</sup> 2005*

### **Germany**

Dignitas Deutschland in the city of Hanover intends to provide information on assisted suicide, according to Ludwig Minelli, general secretary of Dignitas and chairman of Dignitas Deutschland. While assisted suicide is illegal in Germany, setting up a counseling organization is not.

Dignitas is a Swiss organization which assists incurably ill people end their lives, has opened the German office amidst protest from religious and political groups.

### **Italy**

Many Italians consider that certain persons should have the right to decide when they want to die, according to a poll by Ispo Ltd. The poll question was:

*Some people have proposed to legalize euthanasia in Italy, this is, the intentional death of another person brought upon by a third party, in the event of a serious illness or severe suffering. Do you think it would be opportune to introduce a law to allow for euthanasia in Italy?*

The responses were 20% 'yes', 38% 'yes, but only in cases of severe pain for the person who is sick, 37% 'no' and 5% 'not sure'.

*Reference: (Angus Reid Global Scan) Ispo Ltd.  
Methodology: Telephone interviews to 1,002 Italian adults, conducted from Sept. 6 to Sept. 12, 2005. No margin of error was provided.*

### **Members write.**

SAVES asks that members write to their local MPs stating their views on voluntary euthanasia, and why it is that they seek a change to the law. Members Ian and Nancy Wood have given permission for the *VE Bulletin* to reproduce part of one of their letters as an example of one approach to parliamentarians:

*I refer to the Dignity in Dying Bill...I ask you to visit some people who are enduring intractable suffering from an incurable, hopeless illness. Just think how you would feel if it was someone you loved in that same position. Would you really want them to go through the same distress, because of a vote against the Dignity in Dying Bill?*

*Even the best palliative care available is not sufficient in all cases. Why should a compassionate and caring society just shrug its shoulders and say 'that's just too bad'.*

The following letter was then sent in response to what they considered an unsatisfactory reply which they were not prepared to just accept:

*Thank you for your reply to my letter regarding the Dignity in Dying Bill. Nancy and I certainly appreciate your comment that you respect our view and 'hope that you will respect mine'.*

*The only problem is that our view is that voluntary euthanasia should be a legal option in the palliative care process, and while parliament insists on retaining laws against voluntary euthanasia, **our views are not respected**, and nor are the views of around 80% of other South Australians.*

*We are only asking that it be an OPTION. No person would be obliged to use this option if it was against their individual views and opinions.*

***It is important that the issue of voluntary euthanasia is kept in high profile. One way is by wearing an eye-catching T-shirt. SAVES has these available at \$15 each in navy and red. The VE logo and the words 'voluntary euthanasia' are printed on the front and 'my life my choice' on the back. They can be worn on a variety of occasions including SAVES events. Frances wears hers shopping and receives many positive comments.***

## **SAVES Mobile Display Launch September 15th 2005**



**Top to bottom: Frances Coombe and Mary Gallnor listening to Hon Dr Bob Such  
Graham Nerlich with Margaret Rawlinson  
Invited guests and committee members**

# NOTICE OF GENERAL MEETING

Of the SA Voluntary Euthanasia Society Inc. (SAVES) at  
The Disability Information and Resource Centre (DIRC), 195 Gilles St, Adelaide.

**2.15 pm Sunday November 20th 2005**

*Guest speaker will be SAVES patron Emeritus Professor Graham Nerlich  
on the topic*

*"Leading a life"*

Tea/coffee and biscuits will be available at the conclusion of the meeting.

Bring your friends. All welcome.

Public meeting dates for 2006 will be held on April 16th, July 30th  
and November 19th: 20th November.

**\*SAVES is not able to help people end their lives\***

**A Bequest is one way to make a significant gift to further the aim of the society  
which is to achieve law reform to allow choice for voluntary euthanasia**

The appropriate wording is: "I give to the South Australian Voluntary Euthanasia Society the sum of \$..... free of duties." In the unlikely event that you wish to leave your entire estate to SAVES it would read: "I give, devise and bequest the whole of my estate to the South Australian Voluntary Euthanasia Society"

<b>Membership Fees</b> Annual Single \$20 Double \$25 Concession Annual Single \$10 Double \$14 Life Membership Single \$170 Double \$280	<b>SAVES MEMBERSHIP FORM</b> New member ( ) Renewal ( ) Date _____ Membership Fees \$ _____ Donation towards the work of SAVES \$ _____ Mr/Mrs/Ms/Miss/Other _____ Total \$ _____ Given name or initial _____ Surname _____ Address _____ _____ Postcode _____ Ph (h) _____ (w) _____	Email address if you would like to be advised of special activities _____ _____ d.o.b. (optional) _____
	<p>Please make cheque or money order payable to SAVES and send to Membership Officer, SAVES, PO Box 2151, Kent Town SA 5071.</p> <p><b>SAVES' members support the society's primary objective, which is a change in the law, so that in appropriate circumstances and with defined safeguards, death may be brought about as an option of last resort in medical practice. These circumstances include the free and informed request of the patient and the free exercise of professional medical judgement and conscience of the doctor.</b></p> <p><b>*SAVES IS NOT ABLE TO HELP PEOPLE END THEIR LIVES*.</b></p>	

Annual fees fall due on  
28<sup>th</sup> February.

## SAVES' Primary Objective:

A change to the law in South Australia so that in appropriate circumstances, and with defined safeguards, death may be brought about as an option of last resort in medical practice. These circumstances include the free and informed request of the patient and the free exercise of professional medical judgement and conscience of the doctor.



### Committee:

#### President

Frances Coombe

#### Vice Presidents

Julia Anaf

Mary Gallnor

#### Hon. Secretary

Anne Hirsch

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The VE Bulletin is published three times a year by the SA Voluntary Euthanasia Society Inc. (SAVES). Letters, articles and other material for possible publication are welcome and should be sent to *The VE Bulletin Editor, SAVES, PO Box 2151, Kent Town SA 5071.*

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**Editor: Julia Anaf**