



# VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES (INC.)

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## NEWSLETTER

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## Exploring the Euthanasia Underground

*by Dr Roger Magnusson who is senior lecturer in the Faculty of Law at the University of Sydney and co-ordinator of the Faculty's postgraduate Health Law Program.*

*This is an abridged version of his 21 July 2002 talk to VESNSW in which he explained how he became involved in researching the euthanasia underground (EU) - the term he uses for unlawful but covert assistance in dying - and a summary of his findings:*

There have been plenty of surveys about doctors and euthanasia but there has been almost no interview-based research into the ways in which they give covert assistance. That was the focus of my book *Angels of Death: Exploring the Euthanasia Underground*. [Editor's note: It is published by Melbourne University Press, 2002 and sells for \$29.95 from major bookshops or online from <http://www.mup.unimelb.edu.au>]. The book reports on 49 very detailed interviews that I carried out with doctors, nurses, community workers and one funeral director in five cities - mostly in Sydney, Melbourne, San Francisco and some in Canberra and Brisbane. I spoke to people who were involved with HIV/AIDS-related death and explored covert assisted dying in that context. I also found what I call 'euthanasia networks' - informal groupings of people who are bound together by their shared specialisation of HIV medicine or by gay friendships. This collaboration works in a number of ways: health care workers refer patients to 'activist' doctors, so if one nurse may not want to explore it they will refer a patient to

someone else. There may be collaboration in obtaining the drugs, a community worker may be working at the bedside with a GP and afterwards co-operating to conceal suspect evidence, to dispose of the body and to debrief and counsel those involved. Some people might only be willing to refer a patient to a doctor; others may prescribe drugs knowing that they are going to be used for a suicide attempt; others will chart a lethal infusion that they will leave to nurses to administer; others will give the lethal injection themselves. Some people are present at the bedside and others will be on standby in case anything goes wrong. Others will lie on the death certificate and the cremation forms so that no-one finds out what has been happening. These covert processes are well camouflaged, so it is easy to deny that they happen.

Sometimes it all goes peacefully. I spoke to a very experienced doctor who was asked by his hairdresser to provide a lethal dose of drugs for his partner who was dying of AIDS. The doctor said 'I wrote a prescription for a patient I had never seen and sent it to him in the mail. The next time I went in to get my hair cut I heard that it was the most beautiful experience that my stylist had ever had. It was Valentine's Day, they had a lovely meal with champagne, held each other and then his partner took his pills and was released'.

Well, not all deaths end as sweetly as this. Gordon, a GP, was treating a 26 year old gay man called Stephen, who had HIV/AIDS. Gordon monitored Stephen's pain and tried to assist a rapprochement between Stephen and his family who had rejected him because of his homosexuality. Stephen decided he had had enough and his friends supported his right to die but Gordon felt that the friends were conspiring in their friend's decision. Gordon assessed that Stephen might live for three more months. However, Stephen's partner managed to get other doctors to prescribe drugs for the suicide. On the agreed night, after Stephen and his friends had had dinner, Stephen took a combination of drugs and slipped into a coma. Gordon was called at around 2 am. 'I realised he is not going to survive this', says Gordon, 'he is going to be dead anyway, I might as well speed it along. I knew that if I didn't do something, they would find some other way to

do it, and I was really concerned that he didn't suffer.' But despite injecting him with every drug that he had in his doctor's bag, Stephen still breathed. Around 6 am while Gordon was in the lounge room, one of Stephen's friends went into the bedroom and



*Dr Roger Magnusson*

Gordon said he felt sure that he used a pillow to suffocate Stephen. Gordon then certified Stephen's death, a funeral director arrived and Stephen was cremated. The doctor saw himself as the victim and talked about being cajoled, assaulted and abused by Stephen's friends who were in their 20s. Gordon was an experienced GP in his late 40s who felt that Stephen had been cajoled into his suicide as a result of poor self-esteem and years of homophobic abuse. This isn't a particularly unusual story but it illustrates that the EU is characterised by the very opposite of everything associated with medical professionalism.

The medical profession is a self-regulating organisation that is characterised by specialised training that leads to unique and prestigious qualifications. Doctors are accountable to others in the profession and there is a tradition of disinterested service that involves a duty to patients and the profession. In the EU these ideals are inverted and corrupted - there is no specialised training and botched attempts are common. There is no accountability and the medical profession turns a blind eye to the practice of euthanasia by its members whose participation is shrouded in secrecy and deception.

My book has received a tremendous amount of media interest but not a single response from medical organisations. The Australian Medical Association is in the media almost daily but the AMA has taken a back seat in the euthanasia debate. Other medical groups also treat euthanasia as a hot potato and I think that is unfortunate. [Comment: 'What do

you expect them to say when it is against the law. Can they say Yes, we think this is a good idea, yes we are going to do this? They would all be prosecuted.’] **Response:** Well, I think it is pretty hard to be prosecuted but I think that a debate is a lot healthier than a non-debate and also, one of the major things I argued for in the book is that even if euthanasia remains illegal, surely there is some space for debate about how to assess patients a little more carefully than happens at the moment.

**Question:** ‘Roger, wouldn’t you think that the doctors who actually practised euthanasia, not necessarily for the gay group, would be likely to keep their heads down and do you think that this ‘Gordon’ is typical of the people you have interviewed or is he atypical?’ **Answer:** ‘No, Gordon is completely typical in my experience’.

**Question:** ‘It sounds terribly amateurish to me’.

**Answer:** ‘It is’.

**Question:** ‘Well, the cases I know of are anything but amateurish and they are not dealing with gay people’. **Answer:** ‘Yes, well all I am presenting to you is the basis of an interview-based study and there is always a counter example, but my main argument is that the Euthanasia Underground really corrupts and subverts medical professionalism. There are no norms or principles that guide involvement - in the Euthanasia Underground participation is triggered by highly idiosyncratic factors and there is evidence of casual and quite precipitative contacts, there is evidence of a complete lack of professional distance and there are some examples of euthanasia without consent. On the whole, I advocate the legalisation of euthanasia, but what is going on at the moment is a complete

*continued p4*

# FOR YOUR DIARY

## Meetings

- Psychiatrist **Dr Chris Ryan** will speak on **Why would anyone try to kill themselves?** at the next Informal Meeting which will be held at 2 pm on Sunday 24 November 2002 at the **Dougherty Centre, 7 Victor Street Chatswood.**
- **Central Coast** - The final meeting in 2002 of the Central Coast branch of VESNSW will be held on **Monday at 10 am** at the **Gosford Senior Citizens Centre, Albany Street Gosford on 2 December.** **Contact: John Doyle on (02) 4384 6676.** If you would like a lift to the August and December meetings, ring **Debbie Mastin on 4975 2732** and she may be able to help.
- The VESNSW audit has been completed and is available for inspection in the office
- **Confidentiality:** VESNSW does not provide information about individual members or give the membership list to any person or organisation under any circumstances.
- However, if you would like your name to be added to a VESNSW ‘telephone tree’ - so that members can respond quickly when VE is raised on radio talk-back sessions - please let Carmel know. The Society will provide helpful advice on how to get the message across.
- **Conference in Sydney, May 2003** - *Helping Ourselves When Governments Won’t* focuses on the delivery of services and self-help to the dying. More information in subsequent issues of the Newsletter

corruption of medical professionalism. Because euthanasia is unlawful and clandestine, every participant reinvents the wheel. There is no black book which tells you how to effectively assist the dying individual. Desperate doctors end up suffocating or strangling their patients or injecting air in a desperate attempt to get the job done. 19% of the book's anecdotes involve botched attempts.

Although there are some euthanasia recipes around, drugs like Lethobarb and Nembutal are often difficult to obtain. The degradation is very disturbing - 'It was horrible', said one doctor. 'It took 4 or 5 hours - it was like Rasputin - we just couldn't finish him off. I shooed the lover out of the room and put a pillow over his head and that seemed to work in the end'. The lack of accountability is the result of the covert nature of the procedure. There is an all permeating culture of deception. The deceit begins with the way you obtain the drugs, it permeates the planning and orchestration of the death itself and extends to the disposal of the body and all the paperwork, it permeates discussions between medical colleagues.

They care for their patients but by acting outside of a professional context they act unwisely. They fail to protect vulnerable patients and they expose themselves to the risks of blackmail and burnout. A law containing statutory safeguards would have the welcome effect of flushing these practices out into the daylight. In my study, not everyone who received assistance to die was a really good candidate for it under an appropriate euthanasia law. And one of the good things about a legalised regime is that you introduce safeguards. Others fear that legalisation will mean that exhausted patients will be confronted with killing themselves as one of the options for their care. We need to recognise the social costs of the current policy which prohibits euthanasia but connives at the unregulated practices of the EU.

A couple of weeks ago in Brisbane I met Philip Nitschke for the first time at a seminar and suggested to him half jokingly that media portrayals of him were misplaced and that really he was a bit of a conservative because, rather than turning a blind eye when doctors play God, he thinks that doctors should be called to account and should be performing euthanasia within a legislative framework which

incorporates safeguards. And he agreed. But of course, there are those in the medical profession who don't want euthanasia to be legalised even though they are quite content to play God themselves in an informal way. Doctors aren't God and they really should be regulated. Legalising euthanasia might not be acceptable to those who believe that killing is always wrong but we need to consider two other issues: we need to temper absolutist principles with mercy and we need to explore how we can best minimise harm and I believe that there is a lot of harm going on with the covert practice of euthanasia. So legalising euthanasia within a statutory context is an important argument that we should start to debate because it would respond to some of the ad hockery, some of the idiosyncratic killing. I don't trade in euphemisms. Voluntary euthanasia is about killing and some of the ad hoc killing that is going on in the EU is primitive and distressing and I hope that legalising euthanasia might balance things so that patients who have a good case for assistance in dying, can have their wishes vindicated and those who could be helped by palliative care, can be helped because what is going on at the moment is just disastrous.

**Comment:** You have based your conclusions on an extremely small sample - 49 interviews is too small to be statistically significant.

**Question:** How did you choose the people you interviewed? **Answer:** About half of my interviewees volunteered to be interviewed. I gave a number of seminars and conference papers and said I was doing this research - people would come up and press their cards into my hand, saying 'if you really want to find out what's going on, give me a ring'. About half the interviewees came that way, the other half were referrals.

**Question:** How accurate do you think were the things they were saying? **Answer:** I grilled them at some length, but I also kept their confidentiality so I wasn't able to check their story. They were telling me things that showed them in a particularly bad light and they seemed happy to do so. They were sitting on big secrets many of them, that they hadn't told anybody and they were desperate for the opportunity to talk. You can't ultimately verify

anything, but the issues that were raised in interviews were recurring themes and I don't have any reason to disbelieve them. I would ask them for detailed examples of their involvement and some of them had been involved up to 50 or 60 times.

**Question:** Are there links between the EU and what we saw in previous generations when abortion was criminalised and prohibited? **Answer:** Yes, I think there is a very close relationship between the two. When doctors stopped performing abortions a couple of years ago in Western Australia, there were almost instantly examples of backyard abortion and septicemia. It is a very good analogy. I suppose the harder question is how does society respond to things which are currently prohibited but for which there is a demand and it depends upon whether you regard euthanasia or abortion as inherently wrong or whether you think that the aim should be to minimise harm by considering the consequences.

**Question:** What is the percentage of deaths that are primarily euthanasia - eg if you have someone who is dying and a doctor performs euthanasia, gives them excess medication to relieve pain but the secondary thought is to kill the patient. Altogether, what is the percentage of death where euthanasia is the primary objective. **Answer:** There is a distinction between a situation where a patient is given pain relief which has the secondary effect of hastening their death, and cases where the primary intention of the doctor is to hasten death. I don't carry the figures around in my head. There was a 1994 study that said that up to 12% of doctors had taken active steps to hasten the death of a patient. The Kuhse/Singer 2000 study that replicated the Rummelink study in Australia found that it was up to 20%. **Interjection:** Yes, that interesting study found there were more non-voluntary euthanasia deaths in Australia (28.4%) where VE is **not** legal, compared to the 8.3% of non-voluntary cases in The Netherlands where VE is legal. [*Editor's note:* This is discussed by Associate Professor Helga Kuhse in the *VESNSW Newsletter*, no 96, March 2002, pages 4-8].

**Question:** Are you worried about abuse? **Answer:** That concerns many people and I fit uncomfortably with all sides of the debate and think that the slippery slope is something that we can't ignore. I

think that there are many people who, when they are dying and are debilitated and exhausted, want to do the best thing by their family - so I gave some weight to the fact that, particularly self-effacing people, perhaps women more than men, when they are ill are likely to consider suicide as an option and I think it is important not to nudge people.

One of the reasons that I disagree with Philip Nitschke about the Nancy Crick story is that Nancy Crick had just decided that she wasn't going to commit suicide several weeks back and then Philip Nitschke as an euthanasia advocate looked silly, because what the public sees is a photograph of him standing with his hand on the shoulder of the person who then steps back from euthanasia. **Comment:** No, that's not true - on her website Nancy said she was going to do it, but only at a time when it suited her - and she did it and there was no pressure, there was no doctor, no nurse present, she did it in the presence of 21 people. So this has to be made quite clear, that it is not true. **Answer:** I am talking about public perceptions though. I think it was a public relations disaster.

**A member of the audience commented:** 'Nancy tried palliative care and when it didn't work she came back to the idea of voluntary euthanasia. It is about her wanting to put an end to her suffering not the fact that she doesn't have cancer'. **Answer:** My point is that it is a very risky strategy to be using someone who is desperately ill for a political purpose. Now, that was no doubt her choice, but I think that it can backfire in terms of public perception. I said that to Philip. He pointed out that there are people in the VE movement who have been pushing for legal change for many years. In fact, an American journalist wrote up the Nancy Crick episode as an illustration of the wave of new activism by euthanasia advocates who are not trying to get legal change any more but are trying to force precedents. An inch at a time as it was with abortion where the police do nothing. So we claim some ground - in the case of Nancy Crick, it was the right not to die alone. Now, whether that works as a strategy and whether groups like yours will really give up on the prospect of voluntary euthanasia legislation is an interesting question.

# The Politics of Death

Extracts from an article by Dr Allan Kellehear, *Australian Humanist Magazine*, no 67, Spring 2002

The author, Professor of Palliative Care, La Trobe University, has been working in the fields of death, dying, loss and palliative care for 20 years.

Consider Euthanasia. Should we legalise it or not? Is it right or not? Yes/No; black/white; war and peace; good and evil - all the old opposites again. ... The problem of when and how to die is a personal and social problem. Dying is a personal and social experience. An example is of a woman I interviewed recently in a nursing home. Marion had lived a full 87 years as a writer, mother, journalist and local politician. Despite two hip replacements, her pelvic bones and hips had collapsed and she could no longer walk. On entering the nursing home she had lost her home, her privacy, her cat, her garden. She needed help to go to the toilet. Trapped in a total institution with women of different social class and interests and plenty of dependency, she was forced one day to endure a story-telling game organised by the staff.

Everyone tells a story about what they would do if they won a million dollars. One woman will give her money to her grandchildren; another will go to a begonia festival; another will throw a party for everyone. When Marion's turn comes, she volunteers to go to Holland and get herself euthanased. There is silence, everyone moves on. Marion is annoyed and wheels herself out of the room. The minutes - yes they keep minutes for games - merely show that Marion wants a holiday in Holland! Marion's not a palliative care case. She does not have major life-threatening illness, nor dementia. She is part of the growing number of frail-aged. She had lost everything of value to her and she wanted to die (Marion has now died of a stroke). With whose values and social experiences do you judge her request? The independent living bioethicist in his or her university or hospital

centre? The churchman whose entire religious history of based on prohibition, monoculturalism and doctrinal universalism?

If you think you can create moral conclusions about behaviours without recognition, understanding and respect for diverse social circumstances and cultures you will be seriously disappointed, and I believe, you will be a serious social menace. In a world characterised by globalisation and cosmopolitanism we can hope for the embracing of universal processes - such as democracy - but not outcomes. You can insist that the Afghans adopt democracy but you can't protest if they vote for the Taliban party as soon as they get the chance.

Marion's case and many others are serious arguments, if not for euthanasia, then for recognition of the limits of palliative care. Dying-assisted or any other kind is not simply a medical issue. The euthanasia debate is about how we should live and the role of modern citizenship in determining matters of personal autonomy.

As a palliative care professional, I oppose euthanasia as a personal choice, but I support its legislation. I will always try to talk you out of that choice. But if you could stand it no longer I would understand your wish and your act to go. I would support your autonomy because you are a free citizen and not the plaything of clinical or religious institutions. In other words, yes and no, euthanasia is not a good choice but a choice it should be, because not everyone has the same values about life. The state and individuals have always taken lives in times of peace and war. It is not uncivilised for some of us to give up our lives, because sometimes, as in war, it is necessary. The provision of choices remain the hallmark of cultural enlightenment but the task of making good choices remains the single greatest challenge to personal enlightenment. This means yes and no to euthanasia.

# Euthanasia Bid Ends in Emergency Dash to Hospital

by Julie-Anne Davies and Larissa Dubecki, *The Age*, 24 July 2002

Melbourne woman Sandy Williamson, the motor neurone disease sufferer who went public with her plan to kill herself because she said she had no recourse to lawful euthanasia in Victoria, was last night critically ill in the Alfred Hospital after an unsuccessful suicide bid. It is believed that Ms Williamson, 54, took an overdose of barbiturates on Monday evening but her family found her alive yesterday. A doctor who had treated Ms Williamson is believed to have contacted police and the ambulance service, and she was rushed to hospital.

Her sister Carmen who travelled from New York to be with Ms Williamson told *The Age* last night it appeared Ms Williamson would survive the overdose. 'She has the constitution of a Sherman tank and is hanging in there,' she said. 'This is the worst possible outcome for Sandy because she was so ready to die, this will be living hell for her if she pulls through.' She and Sandy's twin sister Sue arrived in Australia from the United States a week ago.

Euthanasia advocate Philip Nitschke, who advised Ms Williamson until recently, said it was a tragic

outcome for a woman who wanted to die peacefully. 'She has been forced to take desperate steps that have resulted in her worst fears being realised', Dr Nitschke said. 'If we had appropriate legislation in place she would not be in this terrible situation.' ... Ms Williamson told *The Age* recently she had no option but to try to take her own life. Diagnosed with motor neurone disease in September, Ms Williamson said she dreaded becoming unable to live independently. Her plight was revealed hours after a new survey revealed 73% of Victorians supported giving doctors the right to assist with voluntary euthanasia.

The Roy Morgan survey of 1,232 people in Victoria, NSW and South Australia was paid for by the Voluntary Euthanasia Society of Victoria\*. It found 70 % thought the law should be changed to allow a hopelessly ill patient seek assistance from a doctor to commit suicide. 'Hopelessly ill' was defined as a permanent and untreatable, although not terminal, illness causing intolerable suffering.

Sandy Williamson died shortly after.

\* *Editor's Note:* *The Age* should have also noted the payment was shared by VESNSW.

## Farewell to Bone Marrow Crusader

by Melissa King *The Advertiser Adelaide*, 22 July 2002

She died alone but Shirley Nolan's final farewell is shaping up as a very public event. In life, the bone marrow research crusader learnt to use the media to further her cause as she fought valiantly to save the life of her son, Anthony.

With her funeral to be held today, Ms Nolan is again drawing maximum publicity, this time for her support for the cause of voluntary euthanasia.

Ms Nolan, 60, took her life just more than a week ago to escape the symptoms of advanced Parkinson's disease.

She left letters telling of the horror her life had becoming and of her fervent wish. that her death be used to encourage politicians to support euthanasia legislation.

Her son, Anthony, died in 1979 after a bone marrow donor could not be found to cure his rare disease, the Wiscott Aldrich syndrome. Her work to found the world's first bone marrow donor registry, the Anthony Nolan Trust, has helped save thousands of lives.

# Max Bell Play Coming Next April

Article by Lisa Pryor, *Sydney Morning Herald*, 4 October 2002

In June 1996, taxi driver Max Bell put his dog and two cats to sleep and drove from Broken Hill to Darwin to take advantage of the Northern Territory's euthanasia laws. Unable to find a specialist doctor who would carry out his wishes, the terminally ill man returned to Broken Hill, where he died a few weeks later. Bell's story is now the basis of a play-in-progress by Reg Cribb, entitled *Last Cab to Darwin*, the play will star Barry Otto when it opens at the Opera House in April next year.

The play is about more than euthanasia, Cribb said. 'I was following [Max's story] when the saga was unfolding back in 1996, but the actual play we decided to base just on the mythology of

Max Bell's journey, rather than follow it by rote.' The fictionalised journey encompasses issues of reconciliation, globalisation, drought and the country-city divide. 'I love journeys because you have got to have a start and a finish and in between the drama you create becomes a metaphor for life. Obviously there are challenges trying to put a road trip onto a stage which you don't encounter when you're doing a film, so we have to be very stylistic in our approach,' he said. Despite the weighty subject matter it will be a play with humour, said its director and producer, Jeremy Sims. 'It has its serious aspects but it also has song and dance and a burlesque [feel]. Humour has always sat very closely with death.' The play is being developed with the assistance of the Opera House and a \$58,000 grant from the Australia Council.

## What Happened To Freeda Hayes?

*Euthanasia, Murder, or Act of God - The True Story Behind the Death Of Freeda Hayes* by Robin Bowles (Macmillan, \$30.00)

In August 1999, Freeda Hayes was diagnosed with an aggressive form of kidney cancer. She was 47. Dr Daryl Stephens performed a life-saving operation, giving her five precious months in which to say goodbye to family and friends. The operation also forged a special bond between Freeda and her doctor. On 4 February 2000 Freeda Hayes died in a hospice, following visits from her brother, her sister - and Dr Stephens. Freeda had been in intense pain for some weeks, and over the last few days had repeatedly asked to be allowed to die. However, hospice staff considered her sudden death suspicious and police were notified. Two months later, Dr Stephens and Freeda's

brother and sister were arrested and all three were charged with wilful murder, a charge carrying a mandatory 15 year prison sentence.

Although a committal hearing had found they had no case to answer, the Director of Public Prosecutions decided to proceed with the charges. Their nightmare had begun. Debate waged about public interest being served by charging a doctor with murder when evidence was at best, circumstantial. Pro- and anti-euthanasia lobbyists joined the argument raging over the first trial in Australia of a doctor accused of murder for 'helping' a patient to die. After a 20-month ordeal, the jury acquitted all three in ten minutes. Editor's Note: This distressing case was noted in the *VESNSW Newsletter* in July 2000, page 12 and March 2000, page 12.

# New VE Books

Three book reviews by John Langone, *New York Times*, 24 September 2002

Death and the journey toward it that is the dying have forever held fascination and fear. To some, as Seneca wrote, death is a punishment, to others a gift, and to many a favour. For those with terminal illnesses, those perceptions surface in some form. These three books deal with the ending of life from the perspective of dying patients and the people who take care of them.

Dr. Kuhl, developer of a palliative care program in Vancouver for patients with AIDS and cancer, has written an all-encompassing guide for people with a terminal illness and those who know someone who is dying. It is based on the stories of people who knew they were dying and includes their thoughts on their changing perceptions of time, what it means and how to spend it; the anguish when they first heard their terminal diagnoses; and their need to communicate with health care professionals; the effect of physical pain; and the importance of 'being touched and being in touch.'

*A Few Months to Live*, which grew out of a community project in Missoula, Montana intended to study and transform life's end and care, follows nine terminally ill people, interweaving their thoughts with those of their caregivers. The authors emphasize the complexity and the ambiguity, as well as the simplicity, of impending death, and the range of experiences among the participants. They write, 'Some know everything about their disease, some nothing; some families find closure and peace, others are at war before and after the death; some people are able to find meaning despite pain and impending death, others have difficulty.'

Interestingly, the authors found that the most feared aspects of dying - great pain, loneliness and depression - did not dominate the last days of

most of the patients studied. 'Pain and other symptoms were controlled,' they write. 'They were able to be with their families and have friends visit; and their preferences, particularly to stay at home, were honoured.' But the picture from their helpers' perspective was not as rosy. At times, the burdens for family caregivers seemed overwhelming.

Dr Quill's book is a combination of case history and an analysis of the complex clinical, ethical and policy issues that swirl about end-of-life care. Some years ago the author 'explored the boundaries' of physician-assisted suicide, helping a terminally ill woman die by giving her a prescription for a large dose of barbiturates. He was brought before a grand jury but not indicted. He wrote about the experience in *The New England Journal of Medicine*, and became 'a thoughtful and eloquent spokesman for dying patients and for the doctors who care for them,' said Dr Marcia Angell, the journal's former editor-in-chief. His book offers valuable guidelines for doctors, patients and families, discussing difficult subjects like delivering bad news, the challenges of hospice and palliative care, and the options available to dying patients.

- *What Dying People Want*, by Dr David Kuhl (Public Affairs/Perseus Books, 2002, \$45.00)

- *A Few Months to Live*, by Jana Staton, Roger Shuy and Dr Ira Byock (Georgetown University Press, 2002, \$50.00)

- *Caring for Patients at the End of Life*, by Dr Timothy E Quill (Oxford University Press, 2001, \$45.00).

*Editor's Note:* Suggest your local library buys these books: you and your community will benefit.

# Good Grief

Two helpful books are J William Worden's *Understanding Indicators of Grief*, 2nd edition (London: Routledge, 1991) and Mal McKissock's *Coping With Grief* (ABC Radio Series, 1985). Worden is a professor of psychology at the Harvard Medical School and McKissock is a palliative care and bereavement education consultant. Both authors stress the importance of recognizing that:

- It is normal and healthy to express the intense and painful emotions relating to loss
- Grieving is important for healing the wound of separation
- A bereaved person may experience a wide range of feelings
- the painful feelings will diminish with time. If they remain intense and prolonged, then professional help may be required
- a total absence of grief - when a person carries on as though nothing has happened - is not a healthy sign and also may indicate the need for professional help
- a bereaved person who has not successfully grieved is more prone to illness, both physical and psychological

In his classic study, designed for counsellors but helpful for individuals too, Worden emphasizes that death, dying and loss are difficult because they heighten awareness of our own previous and potential losses and make us aware of our mortality. Indicators of loss and grief can be grouped as follows and symptoms may include:

**Behavioural** - absent mindedness, appetite disturbance, crying, dreaming, restlessness, searching, sighing, sleep disturbance, social withdrawal, visiting old haunts; **emotional** - anger, anxiety, fatigue, guilt, helplessness, loneliness, numbness, relief, sadness, self reproach, shock, yearning and **physical** - a sense of depersonalisation, breathlessness, dry mouth,

hollow in the stomach, lack of energy, over sensitivity to noise, tightness in chest and/or throat, weakness in the muscles

Grieving takes time and some periods are particularly hard. For example; after the funeral when friends and family are no longer providing high levels of support; three months and a year after the death; at Christmases and birthdays; when the person used to come home in the evening and during mundane tasks such as seeing a favourite food at the supermarket and realizing that there is no point in buying it any more. The book also provides practical help for those who are providing support to a grieving person with tips on what to say and do and what to avoid. Try your local library for these or similar books.

**Who to call for help** (information produced by Human Services Victoria):

- **Your doctor**
- **The Centre for Grief Education (03 9545 6377)** which provides a free bereavement counselling and referral service

- **GriefLine (03 9596 7799)**

Griefline is open between 7 am and 3 pm to provide bereavement support (anonymous) and referral to other services

- **Lifeline (121 114)** Lifeline provides confidential counselling. The free service is available 24 hours a day, 365 days a year and is staffed by trained volunteers supported by professional staff

# Let the People Choose

Sandra Milne from VESQ made this plea in the *Courier Mail* on 14 September:

‘State Health Minister Wendy Edmond’s view that some people might be better off dead than having their lives extended through medical treatment has provoked a chorus of comment for her brave views. Congratulations to the Health Minister for expressing her opinion that, for many, quality of life is more important than quantity. How much of the health budget is being expended in keeping alive people who would prefer death to a miserable existence but who, because of our archaic laws, are not given the choice?’

Shirley Nolan, who established an international bone marrow registry after losing her seven-year-old son to a rare disease, wrote in her book, *A Kiss Through Glass*, of her anguish at having allowed her son’s suffering to be drawn out. ‘I felt it was both selfish and cruel to keep Anthony alive, to prolong his life of such suffering,’ she wrote 24 years ago. ‘I had now come to believe in the right to die with dignity for young and old alike.’ Does this government have the courage to conduct a

referendum on the issue of voluntary euthanasia? Why not ask the people of Queensland if they want the right to be able to make this choice?



*“If it were my car, I’d disconnect it from the battery recharger, take it home and let it die in its own garage.”*

Cartoon by Michael Maslin

## Belgium Adopts Euthanasia Law

A law decriminalising euthanasia has come into force in Belgium but patients seeking the right to die will have to wait a little longer. Parliament passed the law in May despite opposition from the Catholic Church. ‘The law became effective today but it’s not yet applicable’ [because the Health Department needed a few more days to finalise the forms that doctors practising euthanasia are required to complete. Patients wishing to end their lives must be conscious when the application is

made and repeat their request for euthanasia. Their doctor must fill in a form and consult another physician before making a final decision. Every case would be filed at a national commission, which would decide if the doctors in charge had obeyed regulations. ‘This law is very important because euthanasia exists and has been practised in secret’, said Jacqueline Herremans, president of Belgium’s Right to Die in Dignity Association. Source: *Reuters*, Brussels, 25 September 2002

# VE Around the World

## North America

The law in Canada is almost the same as in England; on July 3, a prosecution was brought in British Columbia against a grandmother for the assisted suicide of two dying people. In the US, the state of Oregon has had a physician-assisted suicide law since 1994 and implemented in 1997. Since then, more than 100 terminally ill people have taken advantage of it to hasten their deaths.

## Asia-Pacific

Japan saw medical voluntary euthanasia approved by a high court in 1962, but instances are extremely rare, seemingly because of complicated taboos on suicide, dying and death. In Australia, the Northern Territory had voluntary euthanasia and assisted suicide for nine months until federal parliament repealed the law in 1997. Only four people were able to make use of the law. It is banned in all other states and territories.

## Central and South America

Colombia's government approved medical voluntary euthanasia in 1997 but its parliament has never ratified it.

## Continental Europe

Germany has had no penalty for the action since 1751, although it rarely occurs due to a hangover taboo caused by Nazi mass murders, plus powerful contemporary church influences. Three countries authorise the assisted suicide of dying patients: Switzerland (since 1941), Belgium (since 2002) and the Netherlands, which has also allowed voluntary euthanasia since April this year, although it has been permitted by the courts since 1984. All these countries have 'residents-only' rules, except Switzerland which alone does not bar foreigners provided they are critically, terminally ill.

## Scandinavia

Although Sweden has no law specifically proscribing assisted suicide, prosecutors might – and do – charge an assister with manslaughter. In 1979, the Swedish right-to-die leader Berit Hedeby went to prison for a year for helping a man with multiple sclerosis to die. Norway has criminal sanctions against assisted suicide. Where consent is given and the reasons are compassionate,

the courts pass lighter sentences. A recent law commission voted down decriminalising assisted suicide. In Norway, a retired physician, Christian Sandsdalen, was found guilty of wilful murder in 2000. He admitted giving an overdose of morphine to a woman chronically ill after 20 years with multiple sclerosis who begged for his help. It cost him his medical licence but he was not sent to prison. Finland has nothing in its criminal code about assisted suicide. Sometimes an assister will inform the law enforcement authorities of having aided someone in dying, and provided the action is considered justified, nothing more happens.

## United Kingdom

In England and Wales, there is a possibility of up to 14 years imprisonment for anyone who assists in a suicide. Suicide itself is not a crime and has never been illegal under Scotland's laws. Whether it is criminal to help another to commit suicide has never been tested in a Scottish court.

Source: *The Bulletin*, 18 September 2002, quoting *Euthanasia Research and Guidance Organisation*

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