



# VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES (INC)

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Patron: Prof Peter Baume AO FRACP FRACGP

## NEWSLETTER

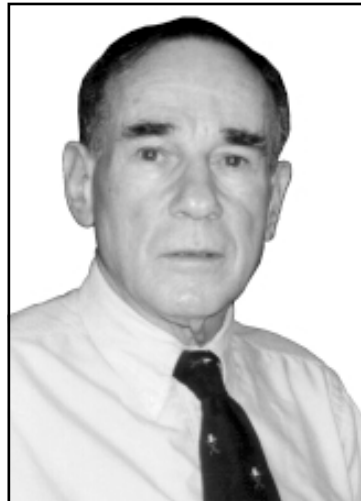
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### Compassion in Dying

by Professor Peter Goodwin



Professor Goodwin is the Medical Adviser to Compassion in Dying of Oregon and Associate Professor Emeritus at Oregon Health Services University

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*Editor's Note:* The invitation attracted so much interest that some people had to be turned away. Dr Peter Baume thanked Professor Goodwin for his rousing address and the Hon Jan Burnswood, MLC for chairing the meeting and for being our host at Parliament House. He mentioned that Dr Philip Nitschke was in the audience, describing him as a crusader who, like Professor Goodwin, had suffered abuse and all the regulatory structures which Oregon experienced and had stood up to them. Both men received a tumultuous ovation. Thank you to members who sent donations after the event. This is an abridged version of Professor Goodwin's talk:

The campaign for the right to die originated with the public. People realised that it is increasingly difficult for patients to have some control over the way they die in hospital, and for their hospital physicians to stop attempts to cure, and begin to care. Changing this is the major motivation of our movement. Ideally, we would like to die at home, surrounded by a loving family, with social supports to make us as comfortable as possible. Most of us value our personal autonomy and decide how to conduct our life - nothing

is more important than retaining that control at the end of life. In a rural practice in South Africa I gradually learnt, from my dying patients, issues that were not taught in medical school. In the States I was confronted by a much more sophisticated health care system and saw how difficult it was for dying hospital patients and their families. In about 1966, a dying patient in severe unremitting pain asked me to help him to die. It was illegal to assist this rational request and colleagues were no help. I was devastated by the outcome, and still ask why was I so ill prepared.

In 1989, when I had been on the staff at Oregon's medical school for nine years, a 39-year-old patient with pancreatic cancer came to see me with his wife - the childless couple, his parents and I discussed ways to help him die. I provided him with a large dose of morphine to drink when the time came. But on the night of his death his wife phoned me in panic because he had developed a bowel obstruction and could not absorb the morphine. She desperately wanted my help but I was afraid and did nothing. She later described the agony of his death and I still can't forgive myself. It was time to do something: I joined the Hemlock Society, which was established in the US in Oregon by Derek Humphry, and began working with a group of people brought together by a man whose wife had suffered heart disease and was immobilised by constant pain. On the day she decided to end her life, in an attempt to protect her husband from being incriminated, she banished him from the house. He returned to find her dead with a plastic bag over her head. He felt that that was an unacceptable way to die, and that something had to be done. He wanted physician aid-in-dying to be legal. There were eight of us, including three politically-savvy lawyers who were the driving force. It took us almost 18 months to write the initiative which we planned to put on the Oregon Ballot in 1994. Oregon is one of 22 states that allows citizen initiatives which make laws if they are passed. We argued about whether to allow voluntary active euthanasia. I had recently been the President of the Oregon Academy of Family Physicians and contacted about 30 of my colleagues to gauge their views. Half said they might consider providing a lethal prescription to a dying patient but none would consider directly causing a patient's death. Armed with the survey results, our group decided to exclude voluntary active euthanasia in favour of the attending physician

providing patients with a legal, but lethal prescription for them to self-administer, because we wanted to empower patients, not doctors, and because we believed that some level of support from the medical profession was essential for our success.

The Oregon law has many safeguards: the patient must be adult; an Oregon resident; dying of a terminal illness with a prognosis of six months or less and competent to make health care decisions. Patients must be acting voluntarily, not coerced by family members, the health profession or by symptoms. They must be fully informed about the ability to palliate symptoms and pain and must be aware of support services - primarily hospice care for the terminally ill at home or in hospitals. A consultant physician has to confirm that the patient is suffering from a terminal illness, is competent, is acting voluntarily, is aware of all other options and that they can retire from the process at any time and in any manner. The patient also has to be made aware that he or she has requested a lethal medication intended to cause the end of life and that there might be complications in the administration of that medication. If either physician thinks that the patient's judgement might be disturbed by mental disorder they must be referred to a psychiatrist or psychologist. The Oregon Health Division collects information about each death and publishes the statistics at the end of each year.

At the end of March 1994, there was a meeting of the Oregon Medical Association. At that meeting, two resolutions were proposed, recommending that the Oregon Medical Association actively oppose the Death with Dignity Act. Barbara Coombs Lee, a nurse practitioner and an attorney who is well-versed in the political process, helped me to write my address. I told the meeting why I was in favour of the proposed Act. An emotional debate followed, and it was subsequently decided that the Medical Association should put aside the resolutions and allow the people of Oregon to give their decision about the legislation. That was crucial to our success. By limiting the scope of the initiative we created a climate that allowed the medical profession to adopt a hands-off attitude. We still needed to get on the ballot and that involved collecting 66,000 signatures and submitting the proposed legislation to the Secretary of State for a period during which opponents could attempt to change the law. This they did! We were prepared to defend the

law because we had become realists, and knew that we had to have a professional organisation to raise funds to oppose the machinations of our opponents.

We engaged a constitutional lawyer who successfully argued our case before the Secretary of State. We established a very professional fund-raising organisation. There were four to six young people in our offices every day using our donor list of approximately 30,000. We spent almost \$1,000,000 during the campaign. I spoke to the medical profession throughout Oregon, explaining the proposed legislation, defusing inflammatory words including 'euthanasia'. That was our opponents' big word and 'killing' was their second. We worked together - we had a message and we stuck with it. As this is a populist issue we said: 'the state government, by preventing physician-assisted suicide is interfering in the most intimate time of your life! Don't let them do it - vote for us and we will keep the nose of Parliament out of your private affairs'. And in November we won by a 51 to 49 majority. We were very specific in what we wanted and we limited the goals; we ran a professional campaign; we did not antagonise the medical profession and we appealed to

## Change of Auditors

In order to meet the formal requirements for the transfer of auditors, a Resolution will be put to the members. At the meeting on 22 July 2001 members will be asked to consider, and if thought fit, pass the resolution that 'BDO Nelson Parkhill and Allworths be removed as auditors of the company'.

In the event that the motion is passed, the members will be asked to consider, and if thought fit, pass the resolution that 'Manser Tierney and Johnston be appointed as the auditors of the company.'

1 July 2001

popular sentiment. After the law was passed in 1994 our opponents immediately attacked again in the legal and the legislative arenas. They found a judge who shared their religious beliefs and did his best to prevent the law from going into effect. We had to defend ourselves, employing attorneys to represent us at the Federal District Court and ultimately the

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# FOR YOUR DIARY

## Meetings

- VESNSW Extraordinary Meeting is being called at **2 pm** on Sunday **22 July 2001** at the **Dougherty Centre, 7 Victor Street**, Chatswood to consider a change of auditors. Our guest speaker will be oncologist **Dr Fran Boyle** - her topic is **When is terminal, Terminal?**
- **Associate Professor Helga Kuhse**, Director of the Centre for Human Bioethics, will speak about **Legislation and the Situation in Belgium** at the Sunday **18 November** meeting.
- **Central Coast** - Meetings of the Central Coast branch of VESNSW will be held on Mondays at 10 am on **6 August** and **3 December** at the **Gosford Senior Citizens Centre**, Albany Street Gosford. **Contact: John Doyle on (02) 4384 6676**. If you would like a lift to these meetings, ring Debbie Mastin on 4975 2732 and she may be able to help.
- **Fee Increase** - subscriptions have not increased since 1997 and because of added costs, including the GST, from 1 January 2002, the new fees will be:

Subscriptions	Standard	Pensioner	Life
Single	\$20	\$14	\$230
Couple	\$35	\$25	\$350

Regional Court. Eventually the courts rejected all objections to the law and it was enacted just before 1997 election.

At the 1997 election our opponents went to Oregon's somewhat conservative legislature and urged that they change the law to make it useless. They couldn't decide how, so they put an initiative before the public in November 1997 asking them to revoke the law. This time we really raised the populist banner! We said, 'we warned you in 1994 that the government can't keep its nose out of your business and this proves it'. Well, in 1997 we won by 60%.

In 1994 our opponents said the proposed law would be a disaster, that it was the start of a slippery slope, that the poor and the elderly were going to be forced into an early death, that the disabled would suffer, that assisted-suicide would be provided to depressed people, that doctors would be perceived as killers, that it would destroy the patient/doctor relationship and so on. In 1997 they concentrated on one issue - that the medication proposed to be used would be a disaster: patients would take the medicine and vomit into their lungs; get lung abscesses; have seizures or become mentally impaired. They used false and distorted data from Holland. The opposition has a political agenda and they used little fibs and big lies. When they were dealing with the issues in an honourable way, I empathised with them, because they thought that this was going to lead to a disorderly society and they are very strong on order. But they lost my respect when they distorted the truth. We emphasised the truth, and the electorate rejected their distortions.

The results of the Oregon Health Division statistics from the passage of the law were completely reassuring. We have had results from 1998, 1999 and 2000 and they have been uniformly good. Those who took the medication quickly fell asleep, rapidly sank into a deep coma and most died peacefully within an

hour. Some lasted three or four hours, one died after 11 hours and one died after 24, but no patient roused from the coma. None of the opposition's concerns happened - there was no slippery slope. The number of people who took advantage of the law in 2000 were exactly the same as in 1999. The number of deaths was a tiny 27 in 1999 and 2000 - one thousandth (0.1%) of the number of patients who die in Oregon annually. But the number of patients who are reassured because of the availability of the law is very many times that number and even those patients who do not



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go through the process are very reassured if they know they can have an 'out' if they get into dire straits. Those people who used the law were terminally ill and satisfied all the requirements of the law. What ultimately drove them was the desire to die when the threads of their lives have been brought together, and the law facilitates this end.

It is a privilege to share these intimate discussions, and help patients and families to make the right decisions - sorting out problems with other members of a health care team. Interestingly, the Oregon Hospice Association eventually decided that no

hospice representative would withdraw from the care of a terminally ill patient, even if the patient has chosen aid-in-dying. Initially they were very mistrustful but when they realised we had similar motives and were working towards the same goal, it is amazing how rapidly their attitude changed.

As a result of the law the patient has been empowered. There is now much more discussion between doctor and patient. There has been a tremendous improvement in the care of the terminally ill. Now in Oregon one third of patients die in a hospital, one third die in nursing homes and one third die at home (generally 70% of patients die in hospital in the US). This is a huge step forward. Many patients are reassured, even though they don't use the legislation, knowing that they can. We know that unnecessary suicides have been prevented and we know that the disaster that used to occur when desperately ill patients took medication to kill themselves without knowing what sort to take and in what dose. These were the patients who vomited, ended in the emergency room or disabled themselves. We don't know of a single patient who has ended up in an emergency room. Dying at home has been encouraged. There have been no complications and physician involvement has increased greatly. Half the patients who have died under the Act have had their physician in attendance when they died.

Laws such as ours are for competent patients - the law cannot help those who have lost competence. So Advance Directives are of crucial importance. It is not just because you are making plans for how you are going to die, but the discussions with spouses, families and patients, lead to an awareness that may not be gained in any other way. It doesn't just help you when you die, it helps you to live. I want to emphasise the huge importance of communicating ahead of time with family members. To have some family members not understand what the dying patients wants, complicates management. Talking to your doctor is hugely important so that you can understand each other. If you haven't talked to your doctor, you are not in the minority. There was a recent study which found that, if you ask patients if they would like to discuss these issues with their physicians, 70% of elderly patients said 'yes - I really think we should discuss this with our doctor'. However, only 17% have done so. Doctors were asked - 'do you talk about issues of dying with your patient? Would you like to?' Two

thirds (67%) said 'yes', but in reality only 10% had. You need to stimulate those sorts of discussions with your physician - unless you do, they often may not have thought of the issues or be aware of your wishes.

If the reality of an assisted death is to move forward, you need a dedicated organisational nucleus. It has to be politically savvy; it has to have well-defined goals and goals that you stick to; it has to have popular appeal. The organisation must enable you to withstand the opposition effectively, and that means money. And you need a significant proportion of the medical profession to support, or at least to understand you.

In conclusion, I know that your Northern Territory law was overturned by the federal government. I also know that our Federal Government, by regulation, has the power to overturn the Oregon Death with Dignity Act. It will cost them support, but I believe they will do it. But the benefit of the law is obvious and that benefit cannot be undone. We will continue to lead a cultural shift towards acceptance of aid-in-dying as an appropriate option for a small number of terminally ill people and we will eventually prevail.

#### **QUESTIONS:**

**Q:** There are many people who are living alone who don't have the resources to die at home and will die in hospital. What about that? **A:** There is so much opposition towards this law that every institution has taken a stand. Catholic hospitals are very strong in Oregon - they will not participate and prohibit their staff from participating on hospital territory. So this answers your question in one respect. However, the largest health maintenance organisation in Oregon, the Kaiser Permanente, has a protocol whereby patients under their care can receive aid-in-dying. Staff who are adamantly opposed do not participate. At the medical school from which I have retired, there is no provision for a physician-aided death in the hospital, but there is a very active palliative care team which feels that most patients are satisfied by the care they provide. If a patient can be sent home, they are referred to physicians who will provide aid-in-dying and the out-patient pharmacy provides the prescription. My wife and I have decided that if we became permanently incompetent, neither of us wants to be kept alive and we would have to starve to death. We have asked our children if they would be prepared to come and help the surviving spouse as the other went

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through the process of dying, which might take from seven to 21 days - you can imagine what an extremely stressful situation that would be for a surviving loving spouse. They have agreed to do so. Planning ahead is essential. I think this is a difficult situation and one that Society is not yet ready to address.

**Q:** A newspaper report mentioned that 39 people obtained legal prescriptions in 2000, but only 27 died. Why is this? **A:** Well, the eight who didn't take the medication were reassured by having it. I had a patient who was reassured by the prescription and died naturally. That is a triumph. The medication has worked every time without any complications and in the case of one patient who vomited a little bit of medication, she was unconscious in five minutes and died within a half hour.

**Q:** What does 'not being coerced by your symptoms' mean? **A:** The patients would be assured that their symptoms would be adequately treated so that untreated symptoms would not coerce them into a decision to end their life. It is a safeguard to satisfy opponents who say that patients would be driven by pain and inadequate relief of suffering.

**Q:** Do people in Oregon avoid the use of the word 'euthanasia'? **A:** Yes. In fact, there are so many inflammatory words and we wished to avoid words which our opponents used, such as the word 'euthanasia', to confuse people. They talked about what happened in Holland - people were euthanised against their wishes.

**Q:** In Oregon is a plastic bag used in addition to medication? **A:** Using the assisted suicide law, it has been shown to be completely unnecessary and we do not advocate it.

**Q:** Advance Directives. What happens if you have an acute problem and go to hospital and they don't know about the Advance Directive. **A:** This occurs very frequently in the States although there is a regulation that all patients admitted to hospitals are asked whether they have an Advance Directive. In Oregon we have a form called the Physician's Orders for Life Sustaining Treatment, for use when the patient is close to death, or seriously ill, which is jointly completed by the physician and patient who decide what treatment the patient wants under specific circumstances. This form is explicit and is signed by the physician and in Oregon in an emergency and somebody panics and

calls the Emergency Medical Services team they respect that form and do what it says. This is in addition to Advance Directives and it has been very useful.

**Q:** How can you say that death will be within six months. **A:** Our opponents say that prognosis is very uncertain and how can you say that a patient has only six months to live. And opponents say 'you think they have six months to live, you give them a prescription and kiss them goodbye'. This is nonsense. In reality, the patient and the physician talk with the family and other advisers and the physician eventually prescribes the medication and then monitors the patient. You don't want them to die ahead of time but you trust them. What is imminent? Is it the next day? Well, if that is the case, then most patients will have lost competence. Is it within the next two weeks or within the next month? I think the patient makes that judgement depending on circumstances within the context of this law. The six months is the initiation of the process. Physician guidance continues, and when the patient is very close to death, that is the time that the patient usually makes the decision.

**Q:** The question is about depression and Advance Directives having been made prior to having a terminal illness. Would a psychiatrist be able to say that you are depressed and therefore not eligible even though you have thought about it years before and put your wishes down on paper. **A:** Well, if you really are dying, you are likely to be depressed. None of us really wants to die. But there is a real distinction between organic depression and 'sadness'. We are all sad at times but there is a real difference between an appropriate and an inappropriate expression of emotion.

**Q:** Has there been any impact on palliative care? **A:** Palliative care in Oregon has been dramatically improved. Every hospital in Oregon, even the small hospitals, now have palliative care teams. Ten years ago we heard nothing of palliative care teams.

**Q:** How can one be certain that an old, frail person is not being coerced by family members who might benefit in the Will? **A:** Firstly, no law can prevent evil doing. Secondly, the physician, palliative care or home care staff are intimately involved with the patient and that should be an adequate safeguard but no one can give 100% protection.

## Emergency Necklace

If you are on medication or have an illness which health professionals should know about in an emergency, you can buy a necklace from your chemist which comes with two options: a blank plate (leaving it up to you to fill in) or engraved with the words 'See Wallet'. The necklaces are small and light and cost approximately \$15.00.

The Society has supplied you with a yellow Emergency Medical Record card which you should sign and carry in your wallet. It should list relevant health information - eg, that you have a heart problem, are a diabetic, are on anti-coagulants etc - this written information is easily available to ambulance or emergency health personnel. On the back of the card is written: 'Should my brain or body be so badly damaged as to make my life intolerable, PLEASE LET MEDIE...' If you require a new or replacement card, please phone the office and we will post one out. On checking with the Ambulance Service, we were told that if such a necklace is worn, the ambulance office would take notice and look in the wallet for information.

was advocated by Thomas More in his book *Utopia*, which sparked endless debates about how seriously he meant it. More wrote:

... When people are ill, they're looked after most sympathetically, and given everything in the way of medicine or special food that could possibly assist their recovery. In the case of permanent invalids, the nurses try to make them feel better by sitting and talking to them, and do all they can to relieve their symptoms. But if, besides being incurable, the disease also causes constant excruciating pain, some priests and government officials visit the person concerned, and say something like this:

'Let's face it, you'll never be able to live a normal life. You're just a nuisance to other people and a burden to yourself - in fact you're really leading a sort of posthumous existence. So why go on feeding germs? Since your life's a misery to you, why hesitate to die? You're imprisoned in a torture-chamber - why don't you break out and escape to a better world? Or say the word, and we'll arrange for your release. It's only common sense to cut your losses. It's also an act of piety to take the advice of a priest, because he speaks for God'.

If the patient finds these arguments convincing, he either starves himself to death, or is given a soporific and put painlessly out of his misery. But this is strictly voluntary, and, if he prefers to stay alive, everyone will go on treating him as kindly as ever'.

## Euthanasia: A Recurring Utopian Dream?

John Carey, Merton Professor of English at Oxford University, has edited *The Faber Book of Utopias* (London: Faber & Faber, 1999).

In the introduction he refers to the brief period when euthanasia was legal in the Northern Territory and outlines the operation of the do-it-yourself euthanasia machine which Dr Philip Nitschke developed. Carey describes euthanasia as 'another recurrent utopian measure, recommended as long ago as the sixteenth century, and likely to become increasingly popular in the twenty-first.' In 1516 euthanasia



# End-Of-Life Issues

An abridged version of Dr Malcolm Fisher's talk at the VES Annual General Meeting on 25 March 2001



Professor Fisher is Clinical Professor, University of Sydney and Head, Intensive Therapy Unit, Royal North Shore Hospital.

In the 1990s two interesting American studies called the Support Studies, looked at people in good hospitals who were near the end of life and found that very little was known about their beliefs, that many suffered from inappropriately treated pain or received unwanted resuscitation attempts. The researchers set out to see if they could change physicians' behaviour and were constantly alerting them about examples such as patients who didn't know what was going on, did not know the treatment outcome, were in pain, or didn't wish to be resuscitated. Their efforts made absolutely no difference.

In 1981 I started running scientific meetings which talked about such issues. I heard a doctor in the US talk about different ways of using nurses' time. He agreed to come to Australia to talk about dying. I asked why he chose this topic. He said: 'Yesterday you talked about renal failure, what percentage of your patients get renal failure?' - '1%'; 'and what percentage of your patients die?' - '15%'. Yet probably 15,000 people in Australia every year die in intensive care units, and in these units, it is admitted that 80% of those people die when we are not trying to make them better. So he said - '15% of your patients die - shouldn't you know as much about dying as you do about renal failure?' His talk changed the practice of intensive care in this country, (much more so than any other talk), so we decided that one of our goals was going to be to improve the

way people died in intensive care units.

Professor Dunstan, a professor of economics in the London School of Economics, said in the early 1980s that you shouldn't judge an intensive care unit by the number of people who survive as if each death was a medical failure. You should judge it by the quality of life of those who survive, and the quality of dying of those in whose best interest it is to die and the quality of the relationships that surround each death. In 1981 we began learning new ways of talking and dealing with people and started to educate other doctors about what they could do with the tools and the laws that they have. This was a very exciting and interesting process.

What is a good death? An 86-year-old man was starting to lose his marbles and his son, realising this, came back from Hong Kong to get him into the old people's home. Before he was admitted, he wanted one last surf at Bilgola and his son took him. He changed into his wet suit, paddled out on his boogie board and caught an enormous wave which took him right into the beach where it dumped him and broke his neck. I said to his son that this was not an injury from which he can be resuscitated. Would the old man want to live on a ventilator for the rest of his days, going nuts possibly with brain damage? And his son said he wouldn't, but he was worried that if we turned the ventilator off, for the rest of his life he'd think that he'd killed his father. I said, you are the best son anyone ever had. The last thing he remembers is coming in on a great big wave and in six months he would be wearing nappies. The son thought that his father would want to be disconnected and we did that. That is a good death.

The relationships involved in each death are important. Doctors, nurses, patients, pastoral team and relatives should be on the same team because most of the time we have the same goals, we want someone alive and well, we don't want people to suffer and we don't want people sitting in a home unable to laugh, love or recognise people or keep themselves clean. Indeed, the more we empower relatives to be involved in this process, the more impressed we are as to how sensible and how dignified most Australians are in these circumstances.

How do we make a decision about whether it is



appropriate not to treat someone and why is this so difficult? A model was developed by a chaplain in Florida who said that we start at Alpha and end at Omega. In the beginning when we have everything to look forward to, it doesn't matter how much you make someone suffer, because they will forget it and there is a lot to look forward to. You don't try to make them suffer, but the dehumanising things we do in intensive care units are worth it when the goal is cure. Down the other end, it is different. Quality of life is more important than the sanctity of life. Comfort and dignity are more important than cure, particularly if the chance of a cure is remote. If you consider it that way, then for each life there comes a point where it is inappropriate to continue treatment. It has been said that the best way to turn a peaceful death into a wild death is by inappropriate intervention.

There are two parts to this. There can be mistakes in diagnosis and there are enough patients who we thought should be let die, who are still walking around to cast serious doubts on the quality of diagnosis. When we are thinking about withholding or withdrawing life support, what we really need is medical consensus. We want all the doctors involved to agree that this is the right thing to do. Only two things can dispel medical uncertainty: time and wisdom. We can keep people alive indefinitely so there is time to try and sort these things out. The second part is the quality of life issue. The patient is the person who can really tell us but in intensive care they are not usually able to. However, society seems to empower us to try to find out what that person would want and we spend many hours doing this. You have to keep reminding the family that we are talking about what the patient wants. One of the great things that came out of the voluntary euthanasia debate is that more people have discussed this but once it was not the sort of thing that Australians would talk about.

When we have worked out what the patient wants, we can do a number of things: we can give them enough drugs to make sure they are comfortable even if that shortens their life - the Double Effect. (In South Australia, this is enshrined in legislation - you may use drugs to control pain and suffering to such a degree that they may shorten life). The only real difference between many of the things we are able to

do now is that we grapple very much with the concept of non-painful suffering. If someone has, for example, Huntington's disease and can't look after themselves but they are not in pain, most doctors in this state are uncomfortable about putting them on an infusion of drugs which are essentially to treat pain. It appears to me by looking at the South Australian laws you can do this is you want to. We need to educate doctors to use the tools they have and we should try to get a NSW law about Double Effect. This is covert euthanasia because no Australian politicians are going to pass voluntary euthanasia legislation as the religious fundamentalists would descend upon them and it would cost them votes.

We can also act with 'Presumed Consent'. When a patient is on a ventilator and the family agrees that if this person knew the outcome, they wouldn't want to be on the ventilator, then we would then say OK, this is the same as if the patient was alert and had refused treatment. When I first went to North Shore Hospital death wasn't talked about. You put a blue card in patients' notes - because medico-legally it was dangerous to put 'Not For Resuscitation'. Now I believe that 80% of people who die in our hospital have a proper 'Do Not Resuscitate' order, which says 'This is what is to be withheld - this is who was involved in the discussion, this is the care to be given' and it is signed by a specialist. This change is a tremendously important attempt to stop people dying in a bad way.

Suggestions that someone should die can come from anyone and again, this is fraught with problems. It is often doctors who think the treatment is inappropriate. They discuss it and, generally they conclude that this is wrong. If you get it wrong, usually, the outcome would be that someone is going to die who shouldn't die, and we would never know - it is a self fulfilling prophecy. The patient might suggest they want to die. The first test you apply is that if someone in intensive care unit says they want to die, they probably are going to get better because it is a pretty high level of thinking. If you are comatose, you can't do that. So we then ask what are these people really saying? Are they saying, my pain is too great, are they saying I don't want to be a burden on my family, are they saying you haven't explained things to me adequately or are they saying

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my time has come. If they are saying the fourth thing, and we believe we have a duty to have them die as well as possible in an institution, with their families there, where they are cared for and treated within their ethnic and religious beliefs. There are some problems that I find particularly bad when someone we know we could make better wishes to die. One woman said she was not going on that ventilator - I asked her if she understood the consequences of that and she said she most certainly did. When she lapsed into a coma, her family then insisted that she be ventilated and we refused.

The relatives may make the suggestion. This has a lot of pitfalls too. I once had a letter from a lawyer saying that if you withdraw any form of life support from the patient, we will take you on with the full rigour of the law. What they wanted us to do was to keep this almost brain-dead person alive so that they could use it as leverage to get his son out of an overseas gaol where he was imprisoned for heroin trafficking. When the facts came from the lawyer saying this, I sent back a fax saying 'Go for it'. We heard nothing more and we took the guy off the ventilator and he died. There are also cultural issues - the Chinese believe it is absolutely wrong to tell patients they are going to die. In our culture, we believe we should provide this information and we usually do. However, a Lebanese man said if you tell my father he is going to die, your house will burn to the ground. These things are influenced by 'situation ethics'.

A nurse or pastoral worker may make suggestions about treatments. We did some studies which found that most people can get it right 80% of the time, nurses are not as good as that, but certainly when we are going to make a decision to withdraw care or to provide alternative treatment or make a patient comfortable, it must be with the nurses' and family's involvement. There are problems with so many people making suggestions. We try and do it right and most of the time we do it pretty well - overseas visitors and social workers who rotate through the Unit, believe that we have achieved something very valuable.

But there are still doctors who, I think, are not aware of what they can do within the rules (or defacto rules) we have and indeed, when we had all those euthanasia debates when Peter Baume and I

used to perform regularly on opposite sides, my mission was to try and get the public to know what could be done - if they knew what could be done, maybe they could then try and see that it got done.

Should the law have a role in all this? I have been described as one of the foremost opponents of the legalisation of voluntary euthanasia and don't believe you should legalise anything, because once you include lawyers, things becomes very difficult. This is why we should try and keep legal processes out of end-of-life care. The first reason is that end-of-life care should be a private matter between health care providers, families and patients. The second thing is because the public don't want this. We drafted a whole lot of legislation to surround end-of-life care in NSW and had a public meeting at Darling Harbour, many years ago, and every group there said we don't want lawyers, we don't want laws, we want guidelines, we want to leave it to doctors, health care workers and families. And someone asked the Solicitor-General 'Can you imagine, or is it likely that anyone who did double effect, or took someone off a ventilator would be prosecuted?' and the Solicitor General said, 'Oh no - I don't think it is likely'. The questioner then asked, 'But if they were, do you think they would be found guilty?' to which he replied, 'Oh no - I don't think so'. 'And if they were found guilty would they get other than a derisory sentence?' 'No, I can't really see that happening'. So, we don't need laws to protect doctors. [*Editor's Note: Readers might like to read 'Doctors in the Dock', Newsletter, July 1999, pages 4-5, in which Barrister-at-Law Christopher Hoy gave a very different view*].

The legal system is about winning and losing and a judge who is solely there to keep the rules. So, we should forget pushing for euthanasia laws and follow the example of South Australia to achieve your goals in almost a covert fashion. We have developed a system in the Northern Sydney Area which we call 'Elective Suicide', where someone will see us and say if this woman comes in having taken an overdose, please do not resuscitate her as she is of sound mind and she has made a decision. Under those circumstances, if that patient turned up, we would respect that decision. It is very difficult when someone has taken an overdose, not to immediately resuscitate because most people will not take another

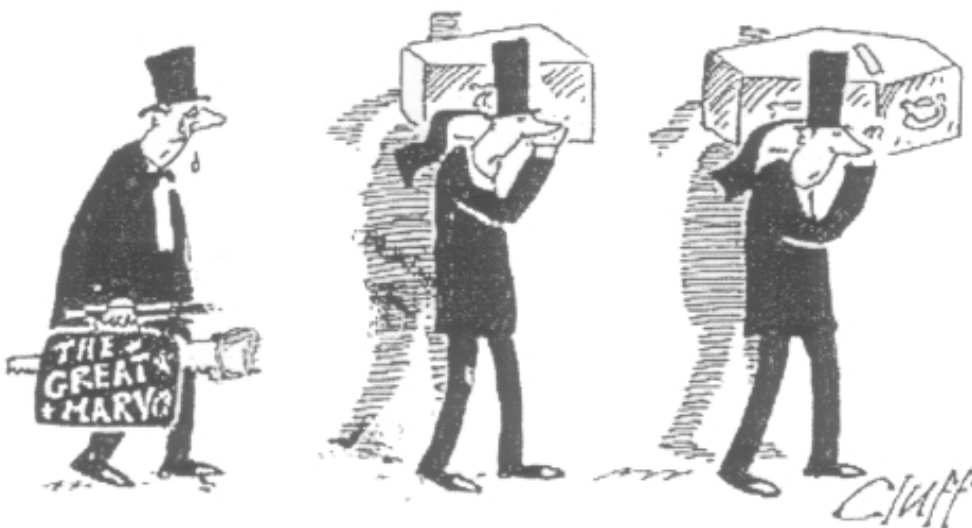
and they have things that can be treated and fixed, but even so we won't resuscitate.

I think we really need to:

a) do something like the Support Study so that we can measure what is happening to people in our hospitals to find out if the care of a dying patient is good or bad.

b) get Guidelines, and prevent people with vested interests from subverting those Guidelines, so we have something that doctors at least can use without fear or prejudice and we want to try and keep lawyers out of this process to prevent it becoming incredibly messy.

Funeral for a magician



c) and it is great if people have a Living Will [Advance Directive] or a clear-cut expression of what you want but the Living Will is still difficult and it would be nice if you could tell me what 'reasonable' means to you, because 'no reasonable chance' is something that trips us up.

### Questions and Answers

**Q.** Isn't the law already in there - the *Crimes Act 1900* - an outdated law calling it murder? Suicide is no longer a crime - what do we have to do to get rid of the law of murder in this instance? **A.** I think you would make a great leap forward if we put in the law something - and this is really new for me because I have always believed the law should stay out of it. I do think that a huge step would be to enshrine Double Effect in the law, as long as you said pain or suffering and then that virtually opens the door. No

one has to approve of euthanasia and the Right to Lifers would think that Double Effect is all right. Certainly, the Coroner has endorsed the Guidelines. On the two occasions I was in the Coroners Court, the way the patients had been looked after was in keeping with the Guidelines.

**Q.** Recently there was a survey by the NSW Department of Health reviewing the Guidelines for end-of-life decisions. How confident are you that we are going to get a satisfactory set of Guidelines?

**A.** I thought the first lot were satisfactory. It was a remarkable document - I wrote three quarters of it.

These are Interim Guidelines, we want them to be the

final ones and about a year ago, people started saying to us - leave it alone. There is a real change in consumer tolerance out there and there is going to be a large number of people who will make submissions and say that the case should be decided by a judge or this should be decided by the family and the doctors should have no say in it whatsoever. So it is going to be interesting to see what comes out. Early on I said to Craig Knowles [NSW Minister of Health] 'You've got to do something about this.'

People have got to know what they are going to get - we have to tell the public. Nothing should be covert'. And he got it on the agenda and now we have made all our submissions - I have also called up a few favours and I think I am again going to be on the committee that produces the final document and will be able to influence the outcome. What we had was all right but this may improve it. But you always worry that some special interest group will come along and Shanghai it. The palliative care people feel that this is a specialist activity which they should look after. Millions of people die every year in the world. I believe that there are skills that every doctor should try and relearn. Palliative care people should be the specialists when there is a difficult situation. That should be the goal of the guidelines and my fingers are crossed.

*continued page 12*

**Q.** I had the experience of losing my husband and during the 16 months of his illness I learnt that our palliative care system is a complete waste of time. You talk about not legalising things, but there are certain things that should be legalised - I remember on one occasion the oncologist rang Canberra to get permission for extra morphine for my husband. And they said 'No, he is on the upper limit' and the doctor had tried very hard to get permission to give him the extra. On another occasion the GP was going to give him some extra and the voluntary blue nurse said I will report you if you increase his morphine. With regard to the submissions - I found it very tricky with some of the questions. **Document A** gave one aspect and then you read **Document B** and you find that there is a little hidden twist there. They talk about having Advance Directives or Living Wills, but the bottom line was that they stated in that document that the doctor has the final say. So what if he is guided by the Church of Rome or England?... I want legalisation to know exactly where I am and some protection for the doctors.

**A.** I believe legislation will make it harder, not easier. There are two things in the document that we were very interested in and one was the bit about the doctor has the final say. I don't yet know what the right answer is about the appeal process. If you don't like what the doctor is doing, then there ought to be a right of appeal for you and I don't believe a judge is the right person. Under those circumstances, we will keep treating, we won't introduce anything more, but keep negotiating.

Another difficult issue is the phrase 'death is imminent' - how do you define 'imminent'? We said that they should leave that out altogether because in an intensive care unit once a patient is on a ventilator, death isn't imminent any more. What we are talking about is a person who wishes to die if they are in dire circumstances and it doesn't matter whether it is imminent or not and we hope they will leave that

### Alan Hamilton Carmichael Bequest

The Society gratefully acknowledges the generous bequest we received from the late Alan Carmichael. He and his deceased wife Stella were members of the Society.

out. I am not sure about the appeal process, but I know that the further negotiations move from the Unit the more difficult, public and 'likely to be stupid' it becomes and we have a patient representative to assist and help present this.

We are not going to agree on legislation, but there must be a way of getting out of these situations. One thing that the lawyers hate about the Guidelines is that the public and the doctors have made rules by proxy and that is not the way it should be done. It has to go through Parliamentary Committees. But effectively, that is what we did with the Guidelines - or covert laws - with the belief that if you worked within this framework, you would be supported and not prosecuted.

An interesting aside - two years ago in Belgium I give a lengthy talk about how to care for dying people in intensive care units. My wife came to listen for the first time. I got a standing ovation - it was all touchy-feely and as we were leaving she asked 'Do they pay you to come here and give these talks?' 'Yes', I said. She said 'That's absolutely incredible. Everything you have said is common sense and everything that all women know intuitively. Surely, what is wrong with medicine is that the men have been running it.' I think she is right.

### **VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES**

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