



VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES (INC.)

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NEWSLETTER

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Assessment and Treatment of Dementia

by Dr Susan Ogle

Extracts of her 30 November talk at the VES meeting:

Dementia is a disease of older people. There is a familial sort of Alzheimer Disease that affects people under the age of 65 and there are some unusual forms of dementia such as Huntingtons Disease, but mostly dementia affects older people and the incidence increases as we age. However, only 5% of people aged 65 are affected. By the age of 70 it increases to 10% and 20% at 85. Although 20% of those 80 and over might be affected, 80% are not - it is not an inevitable accompaniment of ageing.

So, what is an inevitable accompaniment of ageing? I alarm medical students in their twenties by saying 'your grey cells are already disintegrating'. Of course, they are - there are some changes with ageing and by the time you reach 80, some short term memory impairment is normal - you can expect some forgetfulness with ageing.

Dementia is a chronic brain disease that affects higher intellectual functioning and there are a number of different causes of dementia. The commonest form of dementia is called Alzheimers Disease but dementia is just an umbrella term. The cause of Alzheimers, one degenerative disease, is not fully known. The brain cells of Alzheimer sufferers unravel, forming what we call plaques and tangles which take up space and interfere with thinking processes.

There is some genetic element for Alzheimers Disease and those with a close relative with the disease are about two or three times more likely to get it - major head injury or boxing may also be a factor. Recent research indicates that while we thought

Alzheimers and vascular dementia were separate, we now know that hypertension - increased blood pressure - is a predisposing factor for both forms. When I treat a person with Alzheimers I look for hypertension because if you treat high blood pressure, you may delay the onset of vascular dementia and Alzheimers Disease.

A person who comes to a geriatrician for an assessment for Alzheimers Disease may have some memory loss or, in rare cases, may see imaginary people. Usually, the picture is one of slowly progressive impairment of memory and other higher functions such as planning, calculating, reading and reasoning. Those functions are coded in the top of the brain, the cortex, and there is also involvement of the frontal, peripheral, temporal and occipital cortex lobes of the brain. Alzheimers Disease is a deficiency in neuro-transmitters, particularly acetyline choline, and one of the first parts of the brain to be involved is the temporal area (involving memory) but also the parietal lobe, (involving planning). Many people come to me because of weight loss because planning, shopping, cooking and eating involves planning and co-ordinating tasks and so people lose weight, because they have forgotten (a temporal function) and can't plan (a parietal function). Another parietal lobe function is spatial, finding your way about. A good example is parking: people can get lost because they forget where they are and get muddled up about their spatial relationships.

A person with Alzheimers Disease also loses the calculation skills for financial management and paying bills on time. These impairments are so subtle initially that families, even spouses, often may not start to realise for months, even years. Another affected area is the frontal lobe which controls self discipline - insight and judgement. Somebody with Pick's Disease, which affects the frontal lobe, may be aggressive, apathetic or show inappropriate uninhibited behaviour but this change in personality might occur in late Alzheimers.

Alzheimers Disease accounts for about 50-60% of cases and Pick's Disease accounts for only 1-2%. The next most common cause of dementia is vascular, when the blood vessels supplying the brain are affected, getting smaller. It can occur in large

vessels in a person who has had a stroke, or in tiny little vessels where there may be memory and planning impairment. If somebody has had a definite weakness on one side, it is reasonably easy to pick that they have had a stroke. The changes depend upon the site and extent of the damage: tiny strokes sometimes show a picture resembling Alzheimers although the progress is not smooth. People with little strokes deteriorate progressively in step-like stages.

About 10% are a recently discovered dementia called Lewy Body Disease. British researchers in Newcastle Upon Thyme, in studies of Alzheimer patients, reviewed slides of their brains, dyed with a special stain, which showed up Lewy bodies in the basal part of the brain. They found that Lewy Body Dementia was a lot more common than they had thought and correlated these patients clinically and found that many of them also had Parkinsons Disease which is associated with movement abnormality. Younger people with Parkinsons do not usually do have dementia. Older people can get a dementia with Parkinsonism and Lewy bodies can be in the basal ganglia and also in the cortex which can cause hallucinations. Lewy Body Disease presents in a particular way not only do you have confusion and a rigid gait like Parkinsons, you also have psychotic features when you hear and see things. It is important to pick this disease up early and use antipsychotic medication. Unfortunately, one of the side effects of these drugs is that they cause Parkinsonism. People with Lewy Body Disease already have some Parkinsonism, so these drugs make them extremely rigid. There are other alternatives - the drugs that have been developed for Alzheimers Disease are quite good in Lewy Body Disease. They not only help memory, but can settle down the hallucinations and psychotic features. It is sometimes hard to pick early as some patients may develop Parkinsonism later - if you give anti-psychotic medication to a person with some confusion and psychosis, they may become very stiff making you suspect it might be Lewy Body Disease.

Some of the uncommon causes of dementia are encephalitis, hitting your head and getting internal bleeding; Thyroid Disease and deficiencies in vitamins such as B12 and Folate. Similarly, with

high calcium or low glucose - a number of metabolic abnormalities can also cause confusion. Some are reversible so it is not really a dementia, it is a delirium - acute confusion. This can affect a person with dementia or anyone who gets sick. In delirium, the main thing to look for is a treatable underlying infection or metabolic disorder, although patients with dementia do get delirium on top of their dementia

a lot more commonly.

Q: Is there any difference between the sexes?

A: Yes, women are more often likely to get dementia because they are more of them and they living longer. Men tend to get vascular dementia at a younger age - it might be stress that could be part of

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FOR YOUR DIARY

Meetings

□ **Dr Philip Nitschke** will give a talk entitled: *New Strategies for an Old Problem: Where to Now With VE?* at the Annual General Meeting, at the **Dougherty Centre, 7 Victor Street, Chatswood** at 2 pm on **Sunday 28 March 2004**. There will also be meetings on **25 July and 28 November**.

□ **Central Coast** - The results of the survey of members showed most support for Thursdays (22, over 19 for Monday), 10 am (21, over 15 for 2 pm) and Gosford (19, as against 10 each for Woy Woy and Kincumber, and 5 for Niagara). Meetings in 2004 will remain as advertised: **Thursdays 8 April, 5 August and 9 December at 10 am** at the **Gosford Senior Citizens Centre, 217 Albany Street, Gosford**. Apologies to the few regulars who can't make these times and dates. **Contact: Romaine Rutnam, 4382 6516**, if you would like a lift to and from the meetings. John Doyle, who is such a Central Coast stalwart and has been in hospital, is now making a good recovery. We're happy to say that he has started playing golf again.

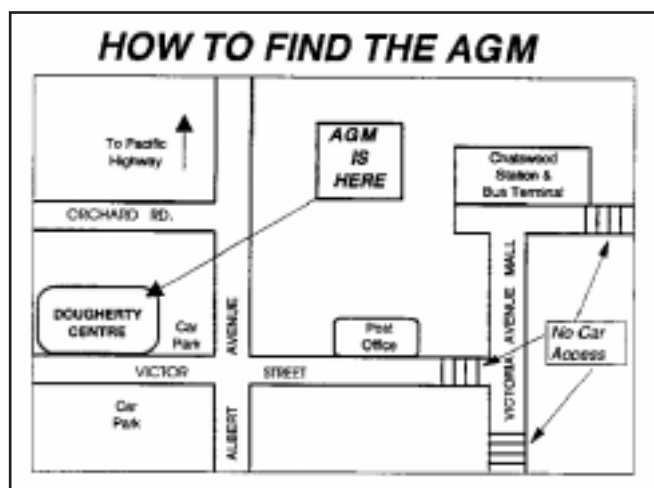
□ **Fees Increased in January 2004:** Membership subscriptions to VESNSW are now \$30 single and \$50 for a couple. Concession rates of \$18 single and \$30 for a couple are available for pensioners and students. Life memberships cost \$500 single and \$800 for a couple.

□ **Confidentiality:** VESNSW does not provide information about individual members or give the membership list to any person or organisation under any circumstances.

□ **Email:** Readers of this Newsletter are asked to help to get as many VE supporters as possible to send in their email addresses. Email is the quickest and cheapest means VES NSW has of keeping members informed. If you or friends would like to be contacted by email please send us your email address to: mail@vesnsw.org.au

□ **Exit Australia workshops:** for details please either ring Michael Griffith on 9559 7142 or send an email to exit@euthanasia.net or phone 0500-83 1929

□ visit the VESNSW web site at www.vesnsw.org.au



it and hypertension although those differences in the sexes is changing all the time.

Q: My husband had prostate cancer in the bones and he had a secondary deposit at the base of the brain and when he was given morphine he became very confused.

A: That is a good example of a delirium related to a narcotic analgesic which is morphine. People can be very sensitive to drugs and sick people are more sensitive.

Q: What about alternative remedies?

A: Vitamin E and Ginkgo are probably not any use. We are unsure about Folic Acid or Folate. In vascular dementia we treat hypertension. With Lewy Body Disease, the Arasept type drugs work in some cases and anti-psychotic can be useful to control behaviour and hallucinations and good diet, a good carer and support for the carer.

One of things that I ask when I see people is driving - I am very cautious who I let drive. There is a driving assessment place the Royal North Shore Hospital Rehabilitation Centre but with Alzheimers, one of the problems is spatial and so that really is dangerous for driving. Another problem is that most people do not have insight so that they say, I have been driving for 50 years and I am fine when they are clearly not. Sometimes we have to take away the licence for the good of everybody.

Another thing I always ask is about financial management and getting people to help with financial management. And the other thing is Wills? have they written a Will and if it is early enough I try to encourage the family and the person to get their Will up to date and ready, because later on they may have not have testamentary capacity. I presume you know Advance Directives. [Editor's note: The audience said they all had Advance Directives. Unfortunately, very few people fill in ADs and placed them appropriately - see the survey in this issue, Elderly Told to Record Medical Wishes].

Q: If a person has dementia, how useful is an Advance Directive.

A: (from Kep Enderby) Some of Australian states have statues to deal with what are called Living Wills which are really Advance Directives.

There is also an Enduring Power of Attorney but the trouble is whereas the other states have statues dealing with it, called various names, the nearest thing NSW has is the Guardianship Act which sets up the Guardianship Tribunal that gives you the power to appoint a guardian or the Guardian Tribunal can appoint someone else to be your guardian on your behalf. Common law always recognises that a person had the right to refuse treatment from a doctor. Common law contains some measure of uncertainty but it also recognises that you can say in an Advance Directive, that you don't want to have specific sorts of treatment if such and such an event occurs. But whereas the other states legislate for it and make it fairly clear, unfortunately, NSW hasn't done it yet. Doctors are may do things under a conspiracy of silence but rarely prosecuted for doing something of this sort and while this makes good sense, but it is also very vague and the law needs to be tightened up, not only directed to Advance Directives, Enduring Powers of Attorneys but also on voluntary euthanasia itself.



Dr Susan Ogle is Director, Department of Aged Care and Rehabilitation, Royal North Shore Hospital

Susan Ogle continues:

People who present early are aware that their memory is going can become very depressed - they may still have insight - some of their brain is functioning - and want to plan. That is a good time for us to plan. Sometimes it is just partial insight but you don't know how dementia is going to progress. People's quality of life when they have early dementia is variable. As a doctor, every day I must decide whether to treat, not treat, withhold treatment or to stop treatment - it can be very difficult and I don't make that sort of decision by myself. If you know that nothing is going to work when somebody is terminally ill that's a much easier decision than the

ones that are in the middle, where it depends how people think and how their families think.

Q: What about suicide and depression?

A: People do get depressed and I presume some people commit suicide but I don't know what the figures are on that.

Q: Can Alzheimers be terminal?

A: It isn't per se, but there are complications that you can get such as pressure sores chest or urinary tract infections, you may fall over and have haemorrhage or break something you may have an incidental problem and the doctor and the family may decide not to treat something.

Q: What symptoms indicate dementia?

A: People who are not eating may also not be very good at looking after themselves hair, showering, clothes and also their house. So that families have progressively have to take over prompting personal care and care of the house and eating. Or services have to come and help doing those things.

Q: How do you separate age-related memory loss from a dementia if you are living alone at home?

A: It can be very difficult. I think that once things progress it becomes obvious because a little bit of forgetfulness is really nothing much.

Q: Can the person who is dementing ask for euthanasia or can they do it themselves?

A: I doubt it. People won't be able to commit suicide when they are dementing because they don't have the ability to make a decision and to plan.

There are some drugs developed now but if they are even a little bit effective, they are worth using. There are very tight guidelines for their prescription and you have to stick to those guidelines and prove that the person responds to them or you cannot continue with them - having them on a private script is very expensive. The mainstay of treatment for dementia is support for the patient and the family, particularly the spouse or the carer who lives in and that is what I have got here. There are quite a lot of services to help families cope and people are staying at home even though they have had impaired cognitive function for quite a while.

Q: My father has vascular dementia.

A: Is there trouble with mobility? - Yes.

Strokes might affect not only the thinking areas of

the brain but also the motor movement areas, so physiotherapy is important. Are there psychotic features as well? Dementia is an organic problem - a pathology in the brain and no amount of talking helps, so that while the right environment and sympathetic handling is useful, I think an imbalance of chemicals in the brain causes those hallucinations and delusions.

Q: He is afraid he is going mad, what should I say?

A: He may be depressed. Is he crying, does he feel hopeless? Yes. We may be able to treat these symptoms with an anti-depressant and perhaps elevate his mood a bit. Is he on one? That hasn't fixed it? No. I think that he still has some insight into his dementia and it is worrying him. You have to say that you have had a few strokes, you are not as good as you used to be - reassuring comments and support are all you can give. Some residential facilities are good with activities in an environment where people can walk around and not get lost but still feel that they are free. There may be some other drug therapy, but sympathy and reassurance is the best that you can do.

Q: I wonder what provisions are made for people with dementia living on their own.

A: There are a few brochures from the Aged Care Services here which give details of dementia services. The Commonwealth government also funds community aged care packages to providing a service at home. People have to go to an aged care assessment team, which is what I run at Royal North Shore Hospital, and if you are deemed to need outreach services at home, you can have that. It provides drop-in care about seven hours a week and supplements what the family can provide. There is also dementia monitoring, a day care program at the Tom O'Neill Centre, and respite care. You can find out from an ACAT (Aged Care Assessment) team. The Commonwealth government has set up these teams throughout Australia and they will come to you at home.

Editor's note: Contact Commonwealth Carelink Centres for details about ACATs and Community Aged Care Packages (CACPs) on 1800 052 222 or phone the Commonwealth Department of Health and Ageing's Age Care Information line on 1800 500 853.

Ian Cohen's Bill Defeated

The refusal of the major parties to support Green MLC Ian Cohen's *Voluntary Euthanasia Trial (Referendum)* Bill in the NSW parliament marked a black day for the democratic process. Speaking from Darwin, Dr Philip Nitschke said that by their overwhelming rejection of a Bill which would have given the people of NSW a say in end of life decisions through referendum, the NSW Upper House has treated the people of the state with contempt. Only four members of the Upper House, the Greens and Democrats were prepared to support Ian Cohen's initiative. The other 28 members, ALP, Liberal and Independent rejected the proposal.

As news of the failure of the referendum Bill in parliament leaked out, Dr Nitschke was contacted by people who had been prepared to hang on, thinking

there was light at the end of the tunnel. It is now clear that this parliament will never address their needs and that they will need to take the necessary steps to prepare for themselves in what is a hostile and risk-filled legal environment.

Dr Nitschke flagged the initiation in NSW of greater numbers of EXIT workshops where people wanting this control will come together to manufacture and construct their own devices that will guarantee them a peaceful death at the time of their choosing. Currently there are over 150 people waiting to attend EXIT constructional workshops to be run in Sydney and Melbourne in 2004. For Information: Philip Nitschke 0407-189-339.

Source: EXIT Australia/NZ Media Release, 14 October 2003.

Green Option Lets Dead Look After the Planet From Beyond the Grave

Ashes to ashes, dust to dust. *The Book of Common Prayer* might not be seen as an environmental tract, but returning people to the ground whence they came is as good a statement on recycling as can be found anywhere.

The ultra-environmentally conscious can now practise what they preach from beyond the grave. Biodegradable coffins, made from recycled cardboard, plant materials and natural glues, can be bought over the internet for as little as \$200. Australian Eco Coffins, based in Brisbane, admits theirs is a fledgling industry averaging only about one sale a month.

Sheryn Beesley, who has run the business part-time for more than two years, says interest is higher but people find it difficult to find funeral directors who will agree to accept the biodegradable option. 'Our idea was to offer people a cheaper alternative, and the eco benefits of it were a bit of a bonus,' Ms Beesley said.

The NSW Department of Health has no problem with the receptacles. The *Public Health Regulation Act* requires a body to be placed in a coffin with a sealed lid but does not define what a coffin should be

made of. The idea came from the Natural Death Centre in England, a charity supporting people who want to die at home. It also manages 160 woodland burial grounds where people can only be buried in biodegradable coffins or shrouds and are commemorated with a tree.

'Many people say "just bury me in the backyard under the lemon tree,"' Ms Beesley said. 'But the family is often made to feel guilty if they don't spend a lot of money on a ceremony and burial.'

The Funeral Industry Council has concerns about the strength of the cardboard coffins and their ability to be refrigerated. The Funeral and Allied Industries Union of NSW says the lack of handles on the assembled cardboard coffins presents an occupational health and safety issue. An exhibition on death at the Australian Museum has been surprisingly popular. Jeannine Baker, a researcher on the exhibition, said she hoped it would encourage people not to shy away from discussing death and funerals: 'About 70% of the visitors have been women, and more older people than young.'

Source: Stephanie Peatling, Environmental Reporter, *Sydney Morning Herald*, 25 October 2003.

Elderly Told to Record

Medical Wishes

More elderly patients need to put their medical treatment wishes in writing according to a Royal Melbourne Hospital survey. The study, published on 19 December in the Royal Australasian College of Physicians' *Internal Medicine Journal*, surveyed more than 400 patients aged over 60 admitted to the emergency ward during 2001. They were asked about their knowledge of Advance Directives (AD) - legal documents outlining treatment preferences if patients are incapacitated.

While 82% of patients thought that advance directives were a good idea, only 20% had discussed the documentation with their family or doctor. A mere 8% had obtained AD documentation. Unless patient wishes about the extent or nature of medical treatment were documented, signed and witnessed they may not hold legal weight, said David Taylor, Royal Melbourne Hospital director of emergency medicine research. 'It's very important for doctors and nurses to have some sort of guidance as to what the wishes of these people are', he said. 'It protects the relatives remaining and the nurses and doctors'.

Three forms of Advance Directive are available in Victoria. Patients with a pre-existing condition, such as terminal cancer, can sign a Refusal of Treatment Certificate. An Enduring Power of Attorney (medical treatment) and Enduring Power of Guardianship allow patients to designate someone to make treatment decisions on their behalf. With the percentage of Australians aged over 65 expected to balloon from today's level of 12%, ADs would become increasingly important, said Associate Professor Taylor. 'The AD may indicate specifically the level of care desired by the patient and may avoid an unwanted, undignified resuscitation attempt. The documentation should not be confused with euthanasia, which is a conscious decision to terminate life', he said.

'With Advance Directives, the patient is not in a position to communicate with the nursing and medical staff and their relatives. They've already outlined the sort of treatment they want in a crisis'. *Source: Lucy Beaumont, The Age, 18 December 2003.*

What is a Good Death?

This question was explored in the 26 July 2003 issue of the *British Medical Journal* - the articles are available at:

<http://bmjournals.com/content/vol327/issue7408>

The *BMJ* editor, Richard Smith, commented: 'With death on my mind I read this in T E Lawrence's *Seven Pillars of Wisdom*:

She-camels ... would endure to march long after they were worn out, indeed, until they tottered with exhaustion and fell in their tracks and died: whereas the coarser males grew angry, flung themselves down when tired, and from sheer rage would die there unnecessarily.

It made me wonder whether we know whether men and women die differently?

End Crick Investigation

Letter by F G Short, in Brisbane's *Courier Mail*, 15 December 2003:

As one of the people at Nancy Crick's bedside when she ended her life peacefully and courageously in 2002, I support John Edge's complaint to the Crime and Misconduct Commission about the length of the investigation.

For 17 months we have been under suspicion of having committed a crime. What crime? A great deal of police time and money has gone into an investigation which has produced nothing of substance. What is at stake here is a simple issue of whether it is an offence to be present with a dying person (at that person's request) when he or she had decided to put an end to a life that has become insufferable. I am confident that we have done nothing morally wrong. I have no complaint against the police who seem to be embroiled in a fuzzy area of the law. It is time this was put right.

Kep Enderby on the ABC

VES(NSW) President Kep Enderby interviewed by Robyn Williams on *Ockham's Razor*, ABC Radio, 11 January 2004

Summary. Suicide and attempted suicide are no longer crimes in Australia, but voluntary euthanasia or assisted suicide is illegal. It is not a crime to ask for help in suicide, but giving this kind of help is a criminal offence. Kep Enderby QC, former Supreme Court Judge and former Attorney General argues that voluntary euthanasia should be legalized.

Robyn Williams: This is *Ockham's Razor* Number 999. It will be presented by a distinguished judge, a Federal Minister in the Government of Gough Whitlam, a person who has done much to foster debate on matters of life and death, cruelty and mercy, civil rights and their denial. He's Kep Enderby. And his subject is our right to a peaceful end.

Kep Enderby: There is much misunderstanding, sometimes mischievously created, about the meaning of euthanasia and voluntary euthanasia. The original meaning of the word 'euthanasia' was simply 'a good death'. Over the years however the meaning has been extended to take in what is sometimes referred to as 'mercy killing'.

The recent Victorian Supreme Court case of BWV, who was in an incurably deep coma being kept alive by means of a tube into her stomach, was a euthanasia 'mercy killing' type case. Her life was ended as a result of a court order made from the most compassionate of reasons. If there had not been a Victorian Medical Treatment Statute that permitted that court order to be made, it could not legally have been done. And any ending of BWV's life could, as a matter of law, have been murder.

Euthanasia and voluntary euthanasia, VE, are not the same thing. VE is different from euthanasia. It is more like suicide. Suicide and attempted suicide are no longer crimes in Australia but VE, like euthanasia, unless there is a special statutory law to permit it, and there are no such laws in Australia, is illegal. It cannot occur without a serious crime having been committed.

If VE were permitted, it would permit a competent,

adult person, seriously and incurably ill and suffering pain and distress, to ask and be given medical help so that his or her life could be ended and so free them from that pain and suffering, and permit that medical helper, if that person agreed, to give them the help needed, or if necessary do what had to be done for them.

Asking for that kind of help is not a crime. It is the giving of help or the doing of what has been asked to be done that is the crime. Depending on the circumstances, the giving of such help could be the crime of 'aiding or abetting' or of 'inciting' or 'counselling' a suicide. If the helper did what was asked to be done it would probably be murder.

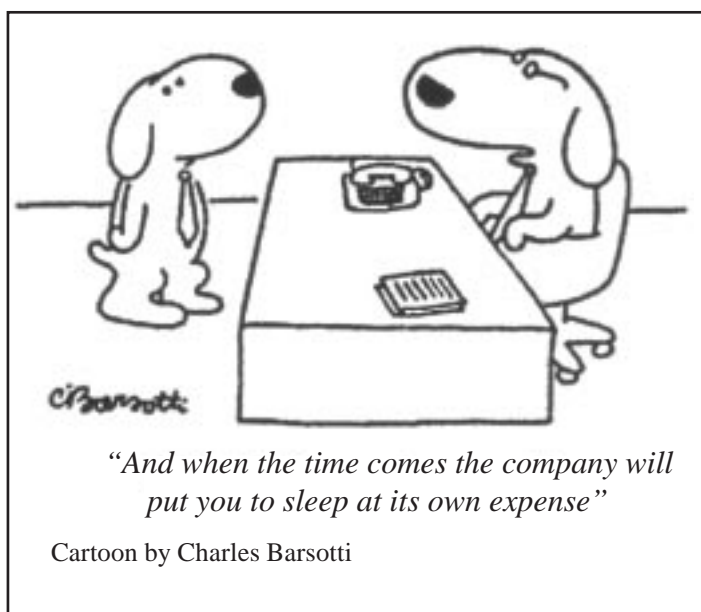
Let me tell you why I regard myself as qualified to talk about such matters and also to inform you of some of my prejudices. First, I am an atheist and I have no belief in an after life. Second, someone once said 'old age is not for the faint-hearted'.

I am nearing the end of what has been an extraordinary good and happy life. I don't want it to end, but old age can bring on serious physical and mental problems. If I ever have reason to believe that the quality of my life was going to worsen and become bad, I would see it as my right to find a way to end it, rather than have it drag on. If I ever were to do that however, without being incurably ill, I would not be a VE-type case. Mine would be more a rational suicide-type case, a type that does not happen anywhere near as often as the relatively common, ordinary emotional crisis type suicide case. Also, during my life, I have had experience of a more than usual number of suicides and attempted suicides.

A result has been that I have immersed myself in the enormous mass of literature written for and against suicide. Supporters of VE believe that in the circumstances I have described, where there is an incurable illness with associated incurable pain and suffering, that a freely made request by someone to be allowed to have their life ended, should be permitted and be complied with, and that with proper statutory safeguards, the criminality of complying with the request should be abolished. In other words, that there should be a right to die.

Although euthanasia and VE are crimes, it doesn't mean that they do not happen; they do. They occur underground, surreptitiously. The idea of fundamental human rights is an important contribution to human progress. It is a secular, humanist, concept, designed to protect and improve the value and quality of human life.

The most important human right of all of course is the right to life itself. It is the basis on which all the other rights depend. The human right that I am talking about today, a right to die, is a corollary of that right to life. Where life has no further meaning because of some incurable, painful terminal illness,



where life turns into a living suffering death, there should be a right to bring that life to an end by having a right to die.

A consequence of not having that right to die is that many who want to die endure long, painful and distressing periods of degeneration. They become totally dependent on others, often loving members of their family, usually a husband or wife or son or daughter, with problems of their own, before they are forced to die in the most miserable of circumstances.

The most common types of suicide are a consequence of some emotional, personal crisis that eventually passes, and they are essentially irrational. VE-type suicides, on the other hand, are rational and much less frequent. They result from a rationally thought out desire to escape the pain and suffering associated with an ongoing, incurable illness, something that is not going to pass.

Suicide and attempted suicide are no longer crimes in Australia. They were abrogated as crimes in New South Wales, for example in 1983. They became crimes in the first place because religious teaching taught us that they violated the sixth commandment: ‘You shall not kill’, not even yourself. Religion taught us that it was God’s prerogative to decide how and when one should die.

When they were abrogated as crimes in New South Wales, a new statutory crime was created which made it a crime to ‘aid or abet’ or ‘incite’ or ‘counsel’ a suicide or an attempted suicide. The laws in our various States and Territories, although not identical, are basically the same.

Those terms, however, ‘aid or abet’ and ‘incite or counsel’ are very uncertain, and that uncertainty can cause great distress.

About a year and a half ago, a 70-year-old Queenslander, Nancy Crick, ended her life after having gathered some friends and sympathisers around her in order to say Goodbye. Those friends later told police what had happened. Eighteen months later they still don’t know whether they are going to be charged with ‘aiding or abetting’, ‘counselling’ or ‘inciting’ her suicide or not.

A bestseller, *Final Exit*, by Dr Derek Humphrey, describes some of the ways you can kill yourself. It points strongly to a perhaps latent public demand that VE should be permitted.

Other evidence of public demand can be found in the success of Dr Phillip Nitschke’s voluntary euthanasia clinics and workshops that go around Australia attracting ever growing numbers of people, usually elderly, who want to know more about how best to end their lives, should they ever want to do so.

Public opinion polls are very supportive of VE. In February 2003, the Queensland *Sunday Mail* newspaper ran a poll with a question: Do you support voluntary euthanasia? 62.4% who answered said Yes.

One reason why the demand for VE is becoming greater is that more and more of us are living into old age with the inevitable physical and mental health problems that come with it. Statisticians tell us that the number of Australians over 65 will increase more rapidly in the next few years than it has in the recent past; that the number will double in the next 20 years, and that by the 2050s, people over 65 will

make up a third of Australia's population. The figures relating to those over 85 are even more striking. Within the next 20 years, their number will treble; we will have close to 2 million Australians over 85 in 2051.

Although great improvements have been made in palliative care and pain relief, they can only go so far. For many, quality of life can become more important than life itself.

The brutal, inescapable truth is that modern medicine and modern systems of sanitation are keeping some people alive longer than they wish. Australia's Northern Territory was the first part of the world to legalise voluntary euthanasia with its very compassionate and humane *Rights of the Terminally Ill Statute* in 1996. That Statute spelled out very carefully the circumstances in which VE could legally happen in the Northern Territory. It created a statutory regime in which a request had first to come from a competent adult suffering from an incurable, terminal illness which was causing severe pain or suffering. A medical practitioner had to examine the person concerned and advise him or her about the likely course of the illness, the available medical treatment, palliative care, counselling and psychiatric support that was available.

After being so advised the person then had to indicate a desire to put an end to their suffering by ending their life. There had then to be a mandatory seven days 'cooling off' period. After the seven days and the satisfactory fulfilment of other safeguards and the obtaining of a second medical opinion confirming the diagnosis and the prognosis, and the obtaining of a psychiatric opinion to the same effect, a second and more formalised certificate of request had to be given. There then had to be a second cooling off period of another 48 hours, and it was only after that, that the matter could go ahead. The requesting person could either do the act themselves or find a doctor who was willing to do it for them.

In 1997, however, the Federal Parliament, using its constitutional power over Territories, enacted a *Euthanasia Laws Act* that nullified the Northern Territory law. The nullifying Act did more than just nullify the Northern Territory Law.

In an extraordinary act of discrimination against Australians living in our Territories, the nullifying law took away from the Parliaments of the Territories,

mainly the Northern Territory and the ACT, the power they previously had, and which our States still have, to make laws that would permit VE. That Federal Statute thus treats Territorians as second-class citizens. It implants church dogma into Australia's constitutional arrangements and takes away from Territorians a right enjoyed by all other Australians. It should be repealed.

Since 1997, other parts of the world have followed the lead of the Northern Territory and passed laws that permit VE. The Netherlands, Belgium, Switzerland the State of Oregon in the United States of America, all now permit VE. The situations in which it is permitted differ: some are more liberal than others. In one form or another, other countries will certainly follow.

Championing voluntary euthanasia in Australia from a secular, humanistic and rationalistic point of view, are the various State and regional voluntary euthanasia societies working in co-operation with Exit Australia, an organisation led by Dr Nitschke.

Championing the opposition to VE are the churches, particularly the Roman Catholic Church, and organisations known as Right to Life Associations.

The voluntary euthanasia societies are puny in influence and power compared to the church and the Right to Life associations, but if our concept of progress is to mean anything, they must eventually succeed.

VE being a crime can produce other cruel consequences: A person wanting to die can live on in pain and discomfort for years, wanting and asking to die, until eventually a loving carer either finds a way of helping them do what has to be done, or of doing it for them.

I know of several such cases where the ongoing pressure and strain placed on all concerned has been very, very cruel. Research shows that nearly a third of persons who have helped a loved one die, often elderly persons with health problems of their own, end up committing suicide themselves. Such cruelties would not occur if VE were legalised.

Not long ago, the Leader of the Government in the Upper House of the Parliament of Western Australia, Mr Kim Chance, said, 'We don't withhold the kindness of death from an animal that is suffering. I don't see why we should withhold it from a human being.'

I can't improve on that. Mr Chance has said it all.

More UK Nurses Want to Help People Die

London's *Sunday Observer* reports up to one in three [British] nurses believe they should be allowed to help patients end their lives, according to a survey which gives an insight into changing medical attitudes towards death. In a move which is set to reignite the debate over euthanasia, a new book on medical ethics was published in November 2003, spelling out what doctors can and cannot do to help patients at the end of their lives.

Yet both carers and the public are confused about how much can be done for patients in their final days - an issue which will become more urgent as the number of people over 65 grows to eventually exceed the young. The nurses' survey shows they want more honesty about the dilemmas they face. It reveals that four out of 10 have given a pain-killer to a dying patient, knowing that it could hasten their death. One in two nurses do not feel it is unethical to administer a lethal injection at a patient's request.

A surprising 31% of the 2,700 nurses questioned by *Nursing Times* magazine said they should be allowed to assist in a patient's suicide. Most felt euthanasia should only be allowed only to the terminally ill, but 40% said it should be permitted for patients in 'extreme pain or distress.

The British Medical Association (BMA), which represents doctors, opposes euthanasia, saying its members' primary role is to preserve life, and allowing it would contaminate their relationship with patients. The BMA says doctors often feel caught between the wishes of a patient and those relatives who see death as 'a failure' and want the patient kept alive. Many medical staff want far more clarity on euthanasia, and earlier this year, cancer nurses called for a proper debate on the issue. Many of them are worried that patients are prevented from having a dignified death due to inappropriate care and because relatives sometimes refuse to accept that the patients are dying. Maura Buchanan, deputy chair of the Royal College of Nursing's council, said: 'The most rewarding part of nursing is taking the family through to a peaceful and good death. This is about how we care as a

profession and a society to help patients achieve a good death'.

A book published by the BMA in November 2003 highlights the pressure on doctors to go on giving treatment when it might be more humane to give palliative care and pain relief, and to tell patients if they are dying. Death has become 'medicalised, sanitised, and to an extent, hidden in hospital,' the book states. 'While development in some areas of medicine have saved and prolonged lives, there have also led increasingly to death being seen as a failure, often for which someone must be to blame rather than a natural, inevitable event.' Ann Somerville, a BMA ethics expert, said: 'We receive around 100 calls a week from doctors needing advice on end-of-life issues. There are some difficult areas, such as cases where relatives do not want a patient to know that they are terminally ill. The doctors have to tell them, because they have to discuss treatment and pain relief with them, and you need the patient's consent for some treatments.' Around 1,500 people a day die in the UK, mostly in hospital. Hospice beds are limited, and the National Health Service leaders want more people to be able to die in comfort at home, but this often means community teams going in to provide pain relief. There is a growing sense that there needs to be an open debate about the way patients face the end of life.

Diane Pretty, a motor neurone disease patient who went to the European Court of Human Rights to challenge the rules on euthanasia, won widespread support. She lost her case, but the House of Lords is to examine a bill on the right to die next year.

Ruth Trout, a senior nurse at the Radcliffe Infirmary in Oxford, told *Nursing Times* last week: 'I favour euthanasia because I don't like to see people suffering. Working on intensive care you know that interventions keep people alive, but keeping people alive is not necessarily the best thing for them.'

Source: Jo Revill, Health Editor, *The Observer*, 30 November 2003

Euthanasia and Assisted Suicide in 2003 Overview

From the World Medical Association (WMA):

2003 witnessed a resurgence of interest and concern about euthanasia and suicide in many parts of the world. In France the case of Vincent Humbert, a young man severely injured in a road accident, elicited widespread public and professional discussion about whether euthanasia is morally acceptable and should be legal in such situations.

In the US in May, Columbia's Constitutional Court ruled that no person can be held criminally responsible for taking the life of a terminally ill patient who has given clear authorisation to do so. Since the ruling directly contradicts current law, the court directed the country's Congress to develop procedures to 'regulate' the practice of euthanasia, leaving it up to the legislators to determine how the terminally ill who want to die may express their consent and how they should be killed.

In September the Social, Health and Family Affairs Committee of the Council of Europe Parliamentary Assembly released a report on euthanasia that asks the governments of the member states 'to collect and analyse empirical evidence about end-of-life decisions, to promote public discussion of such evidence, to promote comparative analysis of such evidence in the framework of the council of Europe, and, in the light of such evidence and public discussion, to consider whether enabling legislation should be envisaged'.

The WMA's position on euthanasia and assisted suicide is unequivocal. Its 1987 statement reads; 'Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness.' This policy, and the 1992 statement

opposing physician-assisted suicide, were reaffirmed in a resolution adopted at the Washington, DC Assembly in 2002.

In response to a report that the Code of Ethics for Belgian physicians might be changed to require participation in euthanasia, if only by referring a patient to another physician willing to perform euthanasia, in May 2003 the WMA Council passed a resolution stating:

Ethical values and legal principles are usually closely related, but ethical obligations typically exceed legal duties. In some cases, the law mandates unethical conduct. The fact that a physician has complied with the law does not necessarily mean that the physician acted ethically. When law is in conflict with medical ethics, physicians should work to change the law. In circumstances of such conflict, ethical responsibilities supersede legal obligations.

NEWSLETTER EDITOR

It is with much regret that the committee have accepted the resignation of Diana Foote as editor of our newsletter. Diana's professional commitments have become extremely hectic leaving very little time for her to devote to the newsletter.

Over the time of Diana's editorship, we have had many expressions of appreciation of the high quality of our newsletter. Thank you Diana for all the hard work you have done and congratulations on all you have achieved. You will be a hard act to follow.

Despite that, we would like to hear from those of you with the skills to take over from Diana as editor. Please contact Carmel Marjenberg in the office on 9212 4782 so a discussion with members of the committee can be organised.

VOLUNTARY EUTHANASIA SOCIETY OF NEW SOUTH WALES

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SUBSCRIPTIONS AND BEQUESTS INFORMATION

Membership subscriptions to VES NSW are \$30 single and \$50 for a couple. Concession rates of \$18 single and \$30 for a couple are available for pensioners and students. Life membership costs \$550 single and \$800 for a couple.

Many loyal friends have found that a bequest is one way they can make a significant gift to further our Society's efforts to change the law and to educate the community. A bequest form is also available from the Society's office.