

## **SUBMISSION TO JOINT SELECT COMMITTEE ON END OF LIFE ISSUES**

### **INQUIRY INTO END OF LIFE CHOICES**

**By Dr. Rodney SYME, MBBS, FRCS, FRACS**

**I am a humanist and do not bring any dogmatic or fundamental religious beliefs to this submission.**

**I graduated into medicine in 1959, a very different medical world to today. Three important changes have highlighted these last 55 years.**

**This was at the very beginning of the antibiotic era, the pharmacological explosion of effective drugs, and the technological advances in ventilation, dialysis and transplantation. These developments, combined with advances in public health, have led to a remarkable increase in life expectancy, but equally importantly, a dramatic change in how we die. Life could now be prolonged, chronic illnesses became the more common cause of death, and inevitable degenerative illnesses the cause of a high rate of placement of the frail elderly in institutional care, where they died.**

**Second, the development of palliative care followed in the 1970s and 1980s and this softened the overbearing technological approach to medicine, and to caring for the dying.**

**Third, there developed during the 1980s. and on, a sweeping change in the relationship between doctor and patient, stemming from a liberalisation of society attitudes rather than arising from within the profession. Recognition of the importance of patient autonomy and the need for open communication took place. In 1987, the Victorian AMA opposed the Medical Treatment Act – now it wholly supports it, and advance care planning.**

**But although medicine was changing radically, the law affecting doctors' actions at the end of life remained vague and uncertain – doctors have no special protection under the law despite the difficult position they occupy and the complex circumstances they face in dealing with dying patients. They have no special protection, and so their patients have no protection in achieving the care that they might want.**

**Your committee has a difficult task in dealing with an important social issue where medicine and the law collide, and government has found it easier to ignore the underlying problems than to deal with them. Because this is a matter where medical practice abuts the edges of supposed criminality, very little of what actually takes place in medical, hospital and institutional practice sees the light of day. Doctors, nurses, patients and their families refrain from commenting on end of life experiences. Your committee may find it hard to obtain factual information.**

**I have, since 1974, had what is probably a rather exceptional experience with people at the end of their lives. I have counselled, particularly in the last 25 years, well over 1800 persons about their end of life (EOL) wishes, and I have provided support, advice and medication to over 100 people to**

give them control over the end of their lives. I believe this information will be valuable to your committee, and therefore I report it.

#### PERSONS REQUESTING ASSISTANCE

All the persons requesting advice have contacted me of their own volition. The vast majority have been living in Melbourne, but some have been in regional Victoria, and some were living interstate (SA, Tasmania, NSW, Queensland and Western Australia).

#### Conditions/circumstances behind requests

- The *majority* were suffering from *cancer (malignancy)*. (30%) These can be subdivided further.
- Those who had had potentially successful treatment, were well, but wanted to have a measure of control over their future.
- Those who had failed treatment, who had spread of their cancer, and who were progressing towards, or actually having, intolerable suffering. Some of these have a terminal illness, while others have such advanced disease that they are clearly dying. These latter persons could be described as in *the terminal phase of a terminal illness*. Many were already receiving palliative care, but typically they wanted control for themselves.
- A second significant, but smaller group (14.5%) were suffering from *neurological (paralysing) diseases*, typically motor neurone disease, multiple sclerosis, Parkinson's disease (which are progressive diseases) or static conditions such as a profound stroke or quadriplegia.

These persons varied from having an *advanced incurable illness* to *the terminal phase of a terminal illness*, depending on the stage of their disease.

- A third group (20%) were frail, and usually elderly, commonly living alone, and fearful in the extreme of being placed in an aged care institution. They often have severe physical limitations such as blindness, deafness, immobility and/or incontinence, but do not have a diagnosis of a "terminal illness", other than old age.
- A fourth group (7.5%) had progressive organ failure, such as of the heart or lungs causing breathlessness and fatigue, which may run a typically episodic course with intermittent life-threatening acute episodes, or liver or kidney failure. These are examples of *advanced incurable illness*, where the illness can run a protracted and unpredictable course, with no clear end-point, but great cumulative suffering.
- A fifth group (9%) relate to dementia. They may have a deep fear of dementia, or may be in an early phase of dementia, but still competent. They desperately wish to avoid the dementia journey. Many requests are from family members caring for loved ones with more advanced dementia.

- A sixth group (6.5%) have chronic intractable pain, which may be associated with polyarthrititis (especially rheumatoid) or spinal injuries with nerve pain, and osteoporosis and degrees of spinal collapse. Immobility and unemployment are added factors. It is acknowledged that such chronic pain is exceedingly difficult to treat.
- There are a few who have chronic pain without diagnosis. This is often accompanied by depression, which itself seems not to respond to treatment. This is a very real but exceedingly difficult group.
- A seventh group (5.5%) have a depressive illness which, when directed to the proper treatment, commonly resolves.
- Occasional requests are from people with a chronic, longstanding psychiatric illness which has become unresponsive to treatment. They are beyond my competence and are referred for further expert treatment.
- Finally, there are people who are suicidal, in the commonly accepted use of that term, for a wide variety of reasons, and are directed to the appropriate care.

The committee should note that this is an analysis of *people seeking advice and assistance* from a doctor whom they have never met before, by letter, email or phone call,. Think of the level of distress which would make someone do that. What is significant is the nearly 30% of persons with problems relating to frailty, old age and dementia. People with these problems are not often considered in the usual EOL discussion about people dying in pain from cancer, which demonstrates two things. Pain is not the principal issue, and nor is cancer the predominant diagnosis which weighs on people's minds.

While the range of people seeking assistance is very broad, those people receiving active assistance is narrow, largely confined to those with cancer in the terminal phase and those with severe neurological illness, particularly motor neurone disease. Some with chronic unremitting pain have compelling stories, as do some of the old and frail, particularly the vision impaired .

#### PRINCIPLES INVOLVED IN COUNSELLING SUCH PERSONS

- All persons are treated with respect and their stories explored. Good and open communication is essential.
- The reason for their request (for advice, support, and/or medication) is deeply explored.
- The nature of their suffering is determined, and assessment made of the possibility of eliminating or diminishing it.
- Their state of mental competence and rational thinking is assessed.
- The extent of their information regarding diagnosis and treatment is explored – are they fully informed?
- Their important relationships with family and carers are determined, and improved communication encouraged. I encourage them to involve their family in discussion.
- A dialogue that continues over time is established; some of these matters clarify with exploration, and resolve.
- I have always determined to assist the person to go as far with their life as possible.

## SOME COMMON OUTCOMES

- Many people are only seen once. It is amazing how often people will say “how fantastic it was to be able to TALK to someone who would LISTEN to them and UNDERSTAND their problem”. Good open communication is essential to a good outcome. They have established a connection to someone they can trust, and they may then become comfortable and have a sense of control.
- Encouraging people to communicate their problem to their family and doctor(s) commonly leads to better relationships and better treatment.
- Maintaining an open relationship, particularly for those with chronic conditions, *advanced incurable illnesses*, with a promise of advice and medication if circumstances deteriorate drastically, is extremely valuable.
- In a small proportion of situations, suffering is truly intolerable and unrelievable, and the person is making a competent and persistent request for assistance. I have found that in this circumstance, the provision of advice and medication is of enormous palliative value. It relieves the common extreme psychological and existential suffering associated with the physical disease. This psychological relief can have further palliation on some physical symptoms, and thus quality of life is improved. It is possible that quantity of life may be enhanced, but it is difficult to prove. In some instances, the improvement in quality of life is such that the medication is not used.

It should be obvious that none of the skills utilised are exceptional – they simply involve complete honesty in communication, a willingness to talk about death and dying in a natural way, encouraging similar communication with important others, and showing a willingness to discuss or provide the means of control over the end of life.

## ASSISTANCE PROVIDED

I HAVE NEVER DELIVERED A LETHAL INJECTION TO A PATIENT.

To me, it is disappointing that the delivery of lethal injections became the primary method of assisted dying in the Netherlands, and subsequently in Belgium, and remains the method most people think of when assisted dying is discussed.

The vast majority of persons with intolerable and unrelievable suffering can take the responsibility for ending their own lives by oral means. It is only those who cannot swallow, or cannot absorb oral medication, or those so profoundly paralysed that they cannot help themselves in any way, that cannot use an oral medication.

The patient in some circumstances already has their own prescription medication which they can use. Some have obtained medications online from overseas, and some have been supplied by me.

In every case, the person with the suffering has complete control over the outcome. This is a very important control – nothing will happen unless that person is fully convinced that they are ready to die. It takes courage and maturity to make such a decision, and it is never taken lightly. These people do not want to die – they want to be relieved of their

suffering. They want to take control over their own life and death. It is their responsibility and they take it.

I have been present when some people have taken their medication, not for any other purpose than to provide reassurance. There is nothing I need to do. The patient has complete control. Such deaths typically take place in the patient's own home – they die in their own bed. I am constantly surprised by the calmness that they typically show. They can gather their family around them (some spend the whole day saying goodbye), say their last words, the medicine is swallowed, and the person drifts peacefully off to sleep in 3-4 minutes, and will die in 10-20 minutes. It is a profound experience for everyone. It can be a warm, humane and loving experience. It is a non-medicalised death. If a person cannot avoid death, then this may be a good way to go. Families experiencing such a death have far less grief than can occur in other 'not so good' circumstances.

#### **NOT A NEW WHEEL**

The committee should be aware that it is not addressing an entirely new concept. Three different approaches to voluntary assisted dying have been legally operating around the world, all carefully scrutinised and none found to be associated with abuse. They are all deeply accepted in their communities.

In *The Netherlands*, the entry point for a request for assistance is “unbearable suffering” – note, not a particular disease or its stage. The Dutch have openly practised assisted dying since 1984 (by statute law since 2001). The Belgians passed similar statute law in 2002, and this development arose from within palliative care, from the recognition that traditional palliative care was sometimes insufficient. Unfortunately, to my mind, the Dutch developed an anaesthetic approach to assistance involving lethal injection (deep sedation followed by muscle relaxant). This developed because the first doctors to assist were anaesthetists, and the Dutch guidelines stated that the doctor must be present until death occurs. This culture persists, despite the Royal Dutch Medical Association trying to move more towards oral assistance.

*The Belgians* have followed a similar path, and there, assisted dying is integrated into palliative care – an admirable and recommended situation.

Belgium has received criticism as an example of ‘the slippery slope’ through two events. The first was the euthanasia of twins who had been born totally deaf. Naturally, they became very close, as they communicated by sign language, and worked together as cobblers. In their 40s, due to the same congenital disease, they began to go blind, which meant that their sole means of communication was being lost. Remember that the Belgian legislation was based on unbearable suffering. These two highly interdependent men were now threatened with a soundless, sightless life together, for another 40 years. Unbearable suffering? A justifiable response?

The second event was to extend the age limit for requests to children with parental guidance. Does anyone think suffering from illness only starts at 18? It is well recognised by experienced paediatricians that children who suffer prolonged illness develop a maturity well beyond their years.

In *Oregon* (and presently 4 other US States), they have passed law allowing for assisted dying by oral medication – lethal injection is prohibited. This has been working well with mandatory reporting and annual assessment by the Department of Health with no evidence of abuse. It is of interest in Oregon that the entry point for a request is “terminal illness”. This is a concept which is notoriously difficult to define and medically assess. In my opinion, the Oregon model of oral assistance is optimal, but the entry point of “terminal illness” is in error. It is both too vague and too exclusive (excluding advanced incurable illness). The proposed Victorian Assisted Dying Bill has argued for terminal illness with weeks or months to live, not exceeding 12 months. This is a reasonable compromise that does not discriminate against dying people with a prolonged trajectory to death

The third model is *Switzerland*, which has voluntary assisted dying almost by accident. In the 1940s, the Swiss Parliament, having legislated that suicide was not a crime, also determined that assisting a suicide should not be a crime, unless the assistance was given for profit or personal gain. It wasn't until the 1990s that lay Dying With Dignity groups realised that they could assist intolerably suffering people using this statute. Initially, Swiss medical associations opposed doctors having any involvement, but now, such medical assistance is widely accepted. All assisted suicides are reported to authorities and studied. The Swiss Parliament has given this situation careful thought and determined that it has no need to alter these simple arrangements. The Swiss people have confirmed their support in Canton plebiscites.

It is significant to note that in none of these legislative frameworks is a mandatory psychiatric assessment required.

#### RECOMMENDATIONS TO THE COMMITTEE

- Encourage good communication and education in the community around death and dying. It should not be a taboo subject. It will happen to us all.
- Encourage general practice to make discussion about medical enduring Powers of Attorney and Advance Healthcare Directives an essential part of consultations with older patients (such as at a Seniors Health Check) – such preparations should be just as routine for older patients as discussion re immunisation is for children. Earlier discussion should take place for those who have a serious diagnosis. Patients will be saved great distress if doctors know what treatment they do or do not want well before the crisis arrives, and the health budget will save millions of dollars in avoiding unwanted treatment.
- A simple healthcare directive should be completed by all persons entering an aged-care institution. In particular, every person diagnosed with early dementia should be encouraged to complete an AHCD (while competent) to avoid prolongation of dying in the late stages of this most cruel of diseases. Examples of simple but effective directives can be provided.

- The current law applying to doctors and their patients at the end of life is vague, uncertain, and opaque – it depends on vagaries of application rather than clear statute. This does not protect doctors in providing their patients with the EOL care they want – if the doctor is not protected, his or her patient may suffer.
- I have openly indicated that I have provided information and medication to people which they may, and have, used to end their lives. Many legal people would see that as aiding and abetting suicide, a serious offence under the Crimes Act.
- I have argued a different line. The Victorian Coroner has confirmed to me that placing a patient in a deep anaesthetic coma, without food and fluids until they die, is not a reportable death – it is a natural death. It is foreseeable that such action will hasten or cause death. It is done because it is necessary to relieve suffering. It is palliation. I argue that if such foreseeable causation by injection is not illegal, then provision of oral drugs for palliation, which may have the foreseeable result of hastening death to relieve suffering should also be considered legal.
- In December 2016, VCAT upheld my appeal against imposition of restrictions on my medical registration by the Medical Board, and acknowledged that the provision of oral medication that could be ingested by a dying person to end their life had palliative effect, and that such action could be considered as equivalent to a ‘double effect’ action.

#### **THE CURRENT STATE OF LAW REGARDING END OF LIFE DECISIONS AND PRACTICE NEEDS REVIEW.**

I became a doctor to help people. This clearly involves trying to cure or ameliorate illness. Much of a doctor’s work is relieving suffering.

It is said that “doctors are healers, not killers”. When a person is dying we can no longer heal them, but we can relieve their suffering by easing their death. Sometimes their suffering will only be relieved by their death, so doctors have to be prepared to hasten death. This may become a medical necessity. If we respect our patients’ autonomy then we should listen to their wishes at the end of life – their life. We should respect how they want to die, not force a ‘model of care’ upon them. We should ease their death according to their wishes and values, not ours.

It is also said that “doctors should first do no harm”. Which is the greater harm – to relieve a person’s suffering at their request, or force them to go on suffering against their wish? Faced with this choice, I know where my duty lies.

There is no logic to insisting that everyone must go on living until their natural death regardless of the circumstances –

Many people may want to leave as the sun is setting rather than go deep into the black cold night.

It makes sense to prohibit assistance to a suicide which is irrational and of a disturbed mind, but surely there can be an exception for a rational decision to end a life of unalterable pain, suffering and distress, in a timely, peaceful and dignified way.

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