



Legislative Council

Rights Of The Terminally Ill Bill

Hansard - Extract

29/11/2001

Second Reading

The Hon. IAN COHEN [2.50 p.m.]: I move:

That this bill be now read a second time.

This bill allows a terminally ill patient with no hope of recovery, in various strictly controlled circumstances, the right to seek the assistance of a medical practitioner to help end his or her life. The tragic plight earlier this year of Norma Hall, a 72-year-old Coogee woman, a writer and mother of three, suffering terminal lung cancer with secondary cancers in her liver, bones and other organs was the driving force behind my decision to introduce this bill. As the events and circumstances surrounding Norma Hall's death unfolded, it became evident that jurisdictions in Australia are long overdue in passing voluntary euthanasia legislation. Norma, a terminally ill patient, simply wanted to die in comfort. She was not afraid of death but as an acute asthmatic she feared dying in agony and asphyxiation from the consequence of a tumour in her lung.

The bone cancer had already caused one hip bone to break. The liver cancer made her weak and nauseous, worsened by the morphine taken for pain relief. Instead of dying in comfort and at the time of her choosing, Mrs Hall's only legal option was to refuse food and drink for eight days in the hope that she would die. She hoped to be sedated so that she could avoid the worst of the suffering during those days, but she could not find a doctor who would engage in this controversial practice. The dehydration exacerbated some of her symptoms and caused her much additional physical distress. This, coupled with the pain caused by cancers, meant that Norma endured unnecessary pain and torment. When the fasting and dehydration did not work she took an overdose of prescribed drugs to end her life. It was a tragic end to an intolerable situation.

If this legislation had been passed prior to Mrs Hall's death, she would not have had to endure that final terrible week of pain and suffering. She could have had her family with her at the time of her leaving. The current law lacks compassion and mercy. It denies the right of someone who is in Mrs Hall's situation to die peacefully and in comfort and dignity, without pain and suffering. Mrs Hall and others like her should have that right. The bill seeks to give people that right.

The bill contains extremely stringent conditions and safeguards that I will outline in detail later in my speech so that honourable members have the benefit of a comprehensive assessment of the bill to provide them with adequate information on which to make an informed vote. It is based on the Northern Territory's Rights of the Terminally Ill Act 1995, which was overridden by the Commonwealth Euthanasia Laws Act in 1997. The Commonwealth Act was introduced as a private member's bill by Kevin Andrews, the Liberal member for Menzies, in 1996. The right of individuals to choose is the main reason why voluntary euthanasia should be supported. Voluntary euthanasia puts an end to the terrible suffering too often endured by terminally ill patients.

It is cruel and inhumane to compel persons to suffer when nothing can be done to relieve their suffering and when they want to end their lives. The bill allows mercy and choice. Unfortunately, for around 3 per cent to 5 per cent of the population who have a terminal illness, palliative care is simply not appropriate. Their pain cannot be controlled, or it can be controlled only by rendering them unconscious, which is known as pharmacological oblivion. Pain is not the only reason that individuals request euthanasia. Other reasons include loss of strength, loss of dignity and complete dependence on others. Even the best palliative care cannot alleviate all suffering or make an individual's situation more bearable.

Another reason to support the legislation is to preserve human dignity. Due to advances in modern medicine, many individuals find themselves facing a prolonged disintegration of their self-integrity, physically and psychologically, without any hope of a cure. Individuals in such circumstances should have the choice to avoid the suffering entailed, thereby preserving their right to dignity. They should have autonomy and self-determination. Polls consistently indicate that Australians are largely in support of voluntary euthanasia. Around the time the Northern Territory passed its voluntary euthanasia legislation, various polls found that approximately 80 per cent of the population supported the legislation.

Who has a monopoly on spirituality in society? Individuals and minorities who do not agree with the majority decision still have rights. While certain Christian and religious ethics prevent some people from taking that decision, other people have a right to make that choice. Another compelling reason to legalise voluntary euthanasia is that it is practised now, although it is not regulated. Professor Peter Baume, patron of the Voluntary Euthanasia Society of New South Wales, said on the ABC news on 23 January, around the time that Norma Hall died:

Euthanasia is common, it's practised out of sight, under wraps, no regulation, no rules, no supervision. If that's what people want, that's what they've got.

There have been various studies and reports on euthanasia. Indeed, the most recent *Medical Journal of Australia* survey of attitudes and practises based on two-thirds of surgeons in Australia regarding their intention to hasten death found a staggering one in three surgeons reported giving drugs with an intention of hastening death, often in the absence of an explicit request. The practise was pointed out in a study by Peter Baume back in 1995 in the winter edition of *New Doctor* and again in research conducted by Helga Kuhse, Peter Singer and Peter Baume that was published in the *Medical Journal of Australia* in 1997.

Just recently, there has been discussion about suicide pills and the use of plastic bags, and other contraptions being imported from overseas jurisdictions by terminally ill people wanting to terminate their lives. If this bill is passed it will alleviate the need for people to turn to such controversial and undignified methods. A few months ago at a very interesting conference on euthanasia at Broken Hill we spoke about these issues. There was overwhelming support for whatever method could be used but, at the same time, a real desire to work legislatively so that people could die with dignity without using what would be seen as backyard methods.

Oregon and the Netherlands are two places where laws relating to voluntary euthanasia have been significantly reformed. There has been a significant step forward in the Netherlands and an acknowledgment by people in that country of the concept of voluntary euthanasia. In Oregon the Death with Dignity Act legalises physician-assisted suicide. However, it does not allow a physician or other person to directly administer medication to end a patient's life. The patient must self-administer the medication.

The Oregon legislation also contains strict safeguards and conditions, and there have been no floodgates or slippery slopes in Oregon. Last year, 39 prescriptions for lethal doses were written, and 27 patients died after using prescribed medication. In 1998, 24 scripts were written and in 1999, there were 33. In 1998, 16 took the medication and in 1999, 27 patients took the medication. The legislation is working extremely well with no evidence of abuse whatsoever.

It is interesting to note from these statistics that some terminally ill individuals are obtaining medication and either are not using it or are using it at a later date. This is the so-called comfort effect where patients feel secure and comfortable knowing they have the medication and can use it at any time—for instance, when things get to the stage where they cannot stand it any more. Some individuals never use the medication but know they can if they want to. This is a great comfort.

The Netherlands has gone down the decriminalisation path rather than legalisation path. It is interesting to note that the Netherlands has been practising voluntary euthanasia in various forms for more than 20 years. Pain, degradation and the longing to die with dignity are the main reasons why patients request voluntary euthanasia in the Netherlands. In the Netherlands, euthanasia and assistance with suicide remain in the statute books as criminal offences. However, physicians who comply with all the conditions and criteria of due care will not be prosecuted. They must practise due care as set out in the law. They must also report the cause of death to the municipal coroner. Polls show that 92 per cent of Dutch people support voluntary euthanasia legislation.

The Greens support palliative care. We support extra funding for palliative care and welcome new advancements in that discipline. We support anything that will make terminally ill patients' lives more comfortable and bearable. However, for around 3 per cent to 5 per cent of the population who have a terminal illness, palliative care is simply not appropriate. This is recognised by Palliative Care Australia—the peak palliative care body—in its position statement on euthanasia of 19 March 1999. That statement:

Acknowledges that while pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care;

Recognises and respects the fact that some people rationally and consistently request deliberate ending of life;

For some people pain cannot be controlled at all or can only be controlled by rendering them unconscious. This is known as pharmacological oblivion. Pharmacological oblivion is the use of sedation to the point of unconsciousness. This is extremely undignified for the patient and very distressing for family and friends, seeing their loved ones drugged to a state of unconsciousness and remaining that way until they die of dehydration and malnutrition. Can we be absolutely confident that their minds are not active and trapped in a drugged body? Dr Rodney Syme, President of the Voluntary Euthanasia Society of Victoria, has written a paper on the issue entitled "Pharmacological Oblivion—A Critique". He argues that such treatment is acceptable because death, if it occurs, is not intended. The principle of "double effect" applies. However, he is very critical of the process, arguing:

What dignity is there in producing deliberate but fitful coma with total dependence, loss of sentience and personality and loss of other functions.

Additionally, there is a real problem with the end-of-life process. If a person is in pharmacological oblivion and he or she dies, it is impossible for the person and his or her family and friends to say goodbye to each other. The patient may die while in a drug-induced coma. This is extremely heart-rending and difficult for family and friends, as saying goodbye to a loved one about to die aids the normal grieving process. As Dr Syme points out in the conclusion to his paper on pharmacological oblivion, it has been likened to slow euthanasia, and in many respects the only distinction between pharmacological oblivion and euthanasia is the time frame in which it occurs, and the dubious matter of intent.

Quite clearly, as has been stated on many occasions, many people suffer a crescendo of pain and suffering in the final week of their illness. Under this bill, for those who choose voluntary euthanasia the crescendo of

suffering and pharmacological oblivion would no longer be necessary. This bill is based on the Northern Territory Act, which was in operation for nine months, during which time four people used it. It came into force on 1 July 1996 and was overridden on 27 March 1997. During the second reading debate on the private member's bill, the mover, the Hon. Marshall Perron, the member for Fannie Bay, said of the bill:

The law as it stands actively ensures that many doctors will not intervene to assist patients to end their suffering because of fear of legal action. This bill does no more than formalise and decriminalise a practice which occasionally occurs now but a practice for which some patients regrettably cannot find sympathetic doctors prepared to risk their careers and liberty.

This Bill is about personal choice. It does not provide carte blanche for euthanasia. It contemplates no externally imposed end of life decisions for the aged, the disabled or for anyone else. In simple language it provides mentally competent, terminally ill patients with the right to choose to shorten their agony peacefully and with dignity.

I had the pleasure of hearing Marshall Perron as a keynote speaker at a Rights of the Terminally Ill Forum that I recently cohosted with the Hon. Jan Burnswoods in the Legislative Council Chamber. Once the Northern Territory legislation was up and running it became obvious that it was an overwhelming success in terms of conditions and safeguards. This can be seen by analysing the position of Denis Burke, the previous Chief Minister of the Northern Territory. He opposed the legislation when it went through Parliament. At the time the legislation came into force he was the Attorney General and the Minister for Health, the two portfolios which administered the Act. By 11 August 1998, after the bill was overridden, he had this to say about it:

While it was in operation, I can say honestly that I thought that it was good legislation in that, once passed by this House, it survived every attack by academics and theologians. When it was finally overridden, one would have to say in all honesty that the legislation needed not one word of amendment in terms of its workability in delivering the intent of the legislature.

The conditions and safeguards contained in the Northern Territory bill are identical to those in this bill. It should be pointed out that there is no restriction on the number of safeguards that can be contained in voluntary euthanasia legislation. Every conceivable situation could be regulated by a safeguard. I say to critics of the legislation: If you have a particular concern with the legislation, I am open to amendments to rectify any problem in it. Every loophole or possible area of abuse can be regulated.

At the moment, terminally ill patients who are suffering are faced with the worst possible situation. Voluntary euthanasia is occurring in New South Wales, yet there are no safeguards. It would be far better to regulate it with adequate safeguards than to leave it unregulated and open to abuse. Experts who worked on voluntary euthanasia before and after the Northern Territory legislation, such as Marshal Perron and Dr Philip Nitschke, have said that when the legislation was passed it was as though an enormous cloud had been lifted with regard to openly discussing the issue of death and dying. Before the legislation was passed, doctors were fearful of discussing with their patients the whole issue of death and dying. It was a taboo subject. For nine months the landscape changed. Doctors could openly discuss it. Once the legislation was overridden the communication doors were closed shut again.

Debate on the issue has now moved into coffee shops, restaurants, hospices and other places. Since the legislation, people in the Northern Territory are a great deal more comfortable talking about the issue, even if doctors are not. The "vulnerable people" or "slippery slope" argument is often advanced when dealing with voluntary euthanasia. The theory is that when voluntary euthanasia is legalised, individuals who are not necessarily suffering from pain but appear to have miserable, poor quality, meaningless lives may have their life terminated. They could include the very old, the severely mentally ill, and the severely disabled.

The other issue surrounding vulnerable people is that they may feel pressure, whether real or imagined, to request an early death. Pressure may be applied by a patients' relatives, acting upon various questionable motives. Also, some individuals may feel they are a burden on their families and friends and ask for assistance to achieve voluntary euthanasia to ease the burden. The safeguards contained in my proposal would protect against this. The problem at present is lack of regulation. Voluntary euthanasia goes on behind closed doors, illegally. There is no supervision, standards or rules. Compassionate doctors who cannot bear to see their patients suffer oblige by administering drugs that intentionally speed up the death of terminally ill patients who are suffering. In doing so they run the risk of being charged with murder for intentionally hastening the death of their patients. The proposed legislation seeks to regulate a previously unregulated area to ensure that there are adequate legal safeguards. Patients will gain greater protection, not less.

An essential component of the legislation is voluntary patient consent. A patient who has a terminal illness and is suffering can request their doctor to assist them to terminate their life. No-one else can make the request. The process can only be initiated by the patient with the agreement of their doctor. Relatives and friends are prohibited from interfering in the process. Consent and voluntariness has to be raised by the first doctor, pursuant to clause 7 (1) (j), and verified by a second doctor, pursuant to clause 7 (1) (m). The legislation specifies that the medical practitioner must be:

... satisfied, on reasonable grounds, that the patient is of sound mind and that the patient's decision to end his or her life has been made freely, voluntarily and after due consideration.

Terminal illness is defined in clause 3 as:

... an illness which, in reasonable medical judgment will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in the death of the patient.

As can be seen from this definition, physical and mental disability are not grounds for requesting termination. Physically disabled people must also be suffering from a terminal illness before they can access the legislation.

Those with a mental illness or who are not competent are automatically excluded from using the legislation. Indeed, the safeguards are so stringent that it would be virtually impossible for a person to be involuntarily euthanased or for someone to request euthanasia and comply with all the procedures if they did not really want to proceed. Safeguards can always be added if a loophole in the law is found to exist. In the Northern Territory, where identical legislation operated for nine months in 1996 and 1997, there was never any criticism that the safeguards were not strong enough or that the legislation was being abused or misused. During that time only four people used the legislation. Similarly, experience in Oregon over three years disproves the claim that vulnerable people are at risk.

Another argument that is often advanced is that legalising voluntary euthanasia will lead to cost cutting and neglect of palliative care facilities, special care and treatments for the elderly, chronically or terminally ill and disabled people. Interestingly, the reverse has occurred in the Northern Territory and Oregon. The public debate on voluntary euthanasia in both places has focused attention on palliative care, resulting in more resources being directed to it.

As I said, the Greens support palliative care. We support extra funding for palliative care and welcome new initiatives in this area. We do not support cost cutting and neglect. However, we do believe that the best palliative care and voluntary euthanasia are totally compatible and can operate alongside each other. It is not our intention that voluntary euthanasia should in any way, shape or form diminish or lead to a reduction in palliative care services. Voluntary euthanasia should be available when palliative care simply does not work or works in a way that is unacceptable to the patient, for instance through pharmacological oblivion.

Voluntary euthanasia legislation is long overdue in New South Wales. It is supported by the majority of Australians. It is time that this common practice, which occurs in secret behind closed doors, is properly regulated. This bill will help those who are suffering, in agony and desperate to bring their suffering to an end. It is about alleviating individual human suffering. Those individuals have no-one to turn to under the current legal regime. Instead, sympathetic members of the medical profession or family, friends and loved ones put themselves at incredible risk to help them end their lives. This is an act of love and compassion of the highest order. If prosecuted, the helpers could be found guilty of murder. All they want to do is help their loved ones to end their intolerable suffering. It would be much better to legalise this practice so that death can be humane and dignified and so that caring and compassionate individuals do not face the threat of legal sanction.

This bill does not ask anyone to compromise his or her religious, personal or ethical beliefs. Those who oppose the legislation have no obligation to use it, but others should be allowed that basic freedom in our democracy. The bill will not, and cannot, lead to a slippery slope, as some argue. To those who argue it can, I say that they simply have not read the bill. The safeguards are so stringent that they rule out the possibility of the legislation being used on vulnerable or inappropriate individuals. I respect those who, for religious or personal reasons, oppose voluntary euthanasia, but I ask them not to impose their views and beliefs on others.

They have the right to their beliefs and choices, but others should have the right to their beliefs and choices. I ask members to support the bill so that those who wish to are allowed to exercise this right. To deny the right to access voluntary euthanasia because of religious or personal choice is to deny freedom of choice. The bill contains iron-clad safeguards so that only suffering, terminally ill patients with a strong desire who are significantly motivated to endure the rigorous process set out in the bill will be able to use them to terminate their lives. This is their right and their choice.

I shall give a brief explanation of the clauses in the bill. Clause 4 allows a patient in the course of a terminal illness who is experiencing pain, suffering or distress to an unacceptable extent to request that his or her medical practitioner assist the patient to terminate his or her life. Clause 3 deals with definitions. The clause defines key terms in the legislation. The definition of "assist" includes the possibility of the doctor administering a substance. "Health care provider" includes both institution and care-giving staff. The definition of "medical practitioner" has the effect of limiting the practitioner, and hence the power to assist, to resident doctors of New South Wales only. "Terminal illness" is defined as an illness that in reasonable medical judgment will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in the death of the patient.

Clause 5 allows a doctor to agree to a request if all of the conditions set out in clause 7 are met. Clause 6 makes it an offence to try to coerce a doctor into helping a patient to end his or her life or for anyone to prevent or threaten a doctor or anyone else for doing so or for proposing to do anything that is authorised under the Act. Clause 7 sets out all the conditions and safeguards that must be met before a medical practitioner can assist. Clause 7 (1) (a) provides that the patient must be 18 years of age or over. Clause 7 (1) (b) (i) provides that the patient must have a terminal illness. Clause 7 (1) (f) provides that the terminal illness must be causing the patient severe pain or suffering. Clause 7 (1) (g) provides that the patient must be informed by a medical practitioner of the nature of the illness, the diagnosis, the likely course of the illness, the prognosis, and the medical treatment available, including palliative care, counselling and psychiatric support.

Clause 7 (1) (b) (ii) and (iii) further provides that the treatment available to the patient will only relieve his or her pain or suffering and is acceptable to the patient. Clause 7 (1) (i) provides that the patient must consider the possible effect of his or her decision on his or her spouse or family. Clause 7 (1) (c) (i) and (d) provides that a second medical practitioner with special qualifications relating to the terminal illness of the patient must examine the patient and confirm to the patient's doctor and the patient that he or she agrees with the diagnosis and prognosis. Clause 7 (1) (c) (ii) and (e) provides that a third medical practitioner who is a psychiatrist must examine the patient to ensure that he or she is not suffering from a treatable clinical depression. Clause 7 (1) (g) and 7 (3) provide that information about palliative care options must be given to the patient by a doctor with special qualifications in palliative care. Clause 7 (1) (n) and 7 (4) provide that an interpreter must be used if any of the doctors does not share the patient's first language, particularly when the certificate of request is signed. Clause 7 (1) (h) provides that, having obtained the second medical opinion and psychiatric opinion, and having considered the palliative care, counselling and psychiatric support options, the patient must confirm to the doctor that he or she still wants assistance.

Clause 7 (1) (k), (l), (m) and (n) further provides that the patient must then wait at least seven days before signing a request form, which must also be signed in the presence of his or her medical practitioner, a second doctor and an interpreter if required. Importantly, clause 7 (1) (j) specifies that the medical practitioner must be satisfied on reasonable grounds that the patient is of sound mind and that his or her decision to end his or her life has been made freely, voluntarily and after due consideration. Clause 7 (1) (p) provides that the patient must then wait at least 48 hours before the medical assistance can be provided.

Clause 7 (1) (o) specifies that the medical practitioner must have no reason to believe that he or she, the countersigning medical practitioner, or a close relative or associate of either of them will gain a financial or other advantage as a result of the patient's death. Clause 7 (1) (q) provides that the doctor must not proceed with the assistance if at any stage the patient indicates that he or she no longer wants to end his or her life. Clause 6 (1) provides that any person who attempts to influence a doctor to assist or not assist a patient to end his or her life can be fined \$11,000, and clause 11 (1) provides that any person who improperly causes another person to sign or witness a request form may be fined \$22,000 or imprisoned for four years. Clause 8 specifies that a doctor must not assist a patient if there are palliative care options reasonably available to the patient to alleviate the patient's pain, suffering and distress to levels acceptable to the patient.

These conditions and safeguards are so strict and stringent that it will be difficult for individuals to use the legislation. People will have to be strongly motivated to jump through all the hoops placed in the way before they can use the legislation. Clause 9 provides that if a patient is unable to sign the certificate he or she may request that another person sign it on his or her behalf. This person cannot be the first doctor or the second doctor who examined the patient and confirmed the first doctor's opinion or a person who is likely to receive a financial benefit if the patient dies. This person must sign the request form in the patient's presence and in the presence of the other witnesses as required by the legislation.

Clause 10 specifies that a patient can change his or her mind regarding ending his or her life at any time. In this situation the request is no longer valid and the patient's doctor must destroy the certificate. Clause 11 makes it an offence to deceive or coerce anyone into signing the certificate. A person who offends against this provision cannot receive a financial benefit as a result of the death of a patient. Clause 12 provides that the doctor must note full details concerning the patient's request on his or her medical records, and confirm that all requirements of the Act have been met. Clauses 13 and 14 provide that following the patient's death a copy of his or her request, together with the death certificate, shall be sent to the Coroner. The death is not to be treated as unusual by virtue of the fact that the patient sought assistance.

In such circumstances the Coroner will not be compelled to hold an inquest into the death; neither will the Coroner be prevented from holding an inquest if there are other indications requiring it. Clause 14 requires relevant statistics to be tabled in each House of Parliament every year. Clause 15 allows the Coroner to report on any aspect of the operation of the Act. Clause 16 provides that doctors or health care providers are not criminally liable if they act in accordance with the legislation. Clause 17 deals with evidentiary issues, and clause 18 deals with wills and contracts. Clause 19 deals with insurance and annuity policies. Clause 20 provides that a person acting in good faith according to the Act is immune from criminal prosecution or any form of professional disciplinary action or censure. Clause 21 deals with regulations, and clause 22 specifies the nature of proceedings for offences.

I have detailed the clauses in the bill to make it clear to honourable members that the issues have been set out clearly in the legislation. The bill has the support of a number of campaigners for euthanasia and some of Australia's top medical professionals. All areas have been covered. Indeed, one criticism of the bill is that it creates too many hoops to go through for someone with a terminal condition. Essentially, the bill is a conservative bill. It allows euthanasia to take place only after many processes. The simple fact is that up to 80 per cent of the Australian community are clearly saying that they want the right to choose voluntary euthanasia if the situation presents itself at end of life.

Clearly, many people suffer greatly at end of life. If people in the community do not believe in euthanasia, there is no active coercion for anyone with a religious conviction or any other conviction to go down the path to voluntary euthanasia. I have spoken with many people who have suffered while looking after loved ones for many years; they have told me that voluntary euthanasia was the desire of the dying person. That was the desire of Norma Hall during her final days, when she was suffering terrible pain, before she died. At a meeting in Tweed Heads, at which both Dr Philip Nitschke and I spoke, many people approached me and said, "I want the comfort of having medication on hand and acknowledgement that I can use it or my family or doctor can assist me to use it at the

critical stage."

At present people who are suffering from a terminal illness, who are in great pain and distress and who are on the threshold between life and death, are forced to take their life often by rather barbaric means and in isolation without the support of their families because the legislation does not allow it. This bill is humane legislation. It is saying, "Give people the choice. Allow people to design the end of their life in a way they are comfortable with." Also, doctors should have the right to support these patients without fear of being sent to gaol, losing their livelihood and being incriminated in a most horrific crime, that is, murder. It is a basic tenet of a democratic system that we allow people, whether they are in the majority or in the minority, the right to end their life and their suffering as they see fit. I am sure members of the public would support this bill. Indeed, that has been proved time and again during a significant number of investigations.

Recently at John Hunter Hospital in Newcastle a statement was made by an overwhelming number of surgeons who admitted to having used voluntary and involuntary euthanasia in recent times. If this House keeps this issue under wraps, unofficial and unregulated, that will pose a great danger to the patient or the person who is dying and a great danger to medical practitioners who are moved by their philosophy of care to end the suffering of their patients. If this House moves to maintain that status quo, I believe that is an extremely inhumane position for this House to take.