RIGHTS OF THE TERMINALLY ILL BILL 2013

Page: 23

Bill introduced, and read a first time and ordered to be printed on motion by the Hon. Cate Faehrmann.

Second Reading

The Hon. CATE FAEHRMANN [11.06 a.m.]: I move:

> That this bill be now read a second time.

As I formally introduce the Rights of the Terminally Ill Bill 2013 I have at the forefront of my mind human suffering—the suffering that we here in this place have the power to prevent and I would strongly argue that we have a responsibility to prevent. I speak of suffering like that experienced by Angelique Flowers, who was diagnosed with aggressive and advanced colon cancer just before her thirty-first birthday. Angelique, who was an articulate softly spoken writer, learned that despite all the achievements of modern medical science and the love, support and care of her family she faced an agonising and grossly undignified death. Angelique soon discovered that the type of cancer ravaging her body meant that the pain and suffering towards the end of her life would not be alleviated in any adequate way by palliative care.

Angelique's colon cancer was cruelly aggressive. When Angelique became aware of just how she would die she realised how desperately she wanted to avoid dying that way—but she did die that way. Angelique's brother Damian was with her when she died just months after her diagnosis. He helplessly held a bowl under her chin as Angelique, still in excruciating pain despite massive doses of morphine and other drugs, died vomiting and choking on her own faeces. It is a death that many of us in this place would seek to avoid if we were able to foresee it. Surely if we could choose to die with a little more dignity we would do so. Angelique knew she could not escape death itself and that it would come soon, she simply sought to go a little sooner before she was gripped with the grotesque and unmanageable pain and suffering that is an inevitable result of the dying stages of such an aggressive colon cancer.

In her effort to die with a little bit of dignity Angelique began searching for the lethal drug Nembutal. During this time she was forced to withdraw from friends, family and medical staff which only added to her stress and suffering. Angelique recorded a number of videos of herself in the last few months of her life and in one of them she stated:

> At a time when I want to spend what good days and precious moments I have left having meaningful time with the people I love I have had to cut myself off writing questions and notes, making inquiries, doing research.

At times she contemplated violent ways to end her life, such as jumping off a building. "If euthanasia was legal", Angelique said, "I could have ended my days as I chose, finding peace before leaving this world, not panic and more pain." None of us here today can help ease Angelique Flowers pain but we can hear her story and let it give us the courage to make the right decision and support the bill knowing that it will help prevent awful suffering like this, or some of it, in the future. This bill is for people like Angelique who are staring death in the face, who are staring down the barrel of an excruciatingly painful and horrific death that could last many weeks or months. Members can hear Angelique's story and they can decide that they are going to have the courage to do the right thing for others like her who are still alive today.

One of Angelique's dying wishes was to see law reform in this area so others do not have to suffer like she did if they do not want to. One of her dying wishes was law reform so that others could choose to die with dignity, a dignity that she was denied—others like Loredana Alessio-Mulhall. I met Loredana two years ago. She has multiple sclerosis, which she has had for 37 years. She is 63. Multiple sclerosis results in the progressive loss of motor and sensory function in a haphazard way over many years, resulting in virtually total loss of movement. People are initially wheelchair-bound, then later bed-bound. They become incontinent, then if their speech and sight are impaired, they lose the ability to communicate. Meanwhile the intellect may remain unimpaired but the person is a prisoner in a body which cannot move or function in any real way.

Loredana still has sensation in her body; she just cannot move. She has told me how she can lie awake for hours at night, her fingers painfully clawing her skin. There is no-one there for Loredana at night so she must wait for the first carer's shift the next morning before her fingers can be pulled away. Loredana continues to tell me she is a positive person and under ordinary circumstances of course she would not want to die but she is very afraid of what is ahead. The multiple sclerosis is now eating away at the nerve endings to her eyes and attacking her voice box. This understandably terrifies her and she knows that her final weeks, months or even years will be spent completely cut off from the world, unable to communicate if she is in pain, unable to speak to her family, unable to do anything at all, at the mercy of everyone and everything. So Loredana was searching for lethal medication in the years before she was totally incapacitated. Her predicament is heartbreaking:

> "I don't want to die" says Loredana "but when life gets too difficult, I should not have to beg for mercy, from the people around me, like I am now, to be allowed to die in peace and with dignity."

Loredana is begging all members today to please support this bill. Loredana wants to die with dignity but she needs assistance to do it. Under our laws as they stand, Angelique was denied and Loredana will be denied a very important choice—the choice to die a peaceful and dignified death, the choice to go a little early, when death from a terminal illness is inevitable and the suffering is unbearable. That is the choice that the Rights of the Terminally Ill Bill would allow, nothing more, nothing less. The bill is the culmination of two years work, countless hours of research, the tireless work of passionate volunteers and advocates, far-reaching consultation and the best elements of longstanding schemes overseas. I am very proud of it and of the compassionate advocates who have worked so closely with me to get us to this point. It is a bill for voluntary assisted dying for the terminally ill.

It will provide that a person who has a terminal illness, with decision-making capacity and who is experiencing unacceptable pain, suffering or distress can choose to request assistance from a medical practitioner to end their life. Subject to extremely stringent safeguards, this assistance would take the form of the provision of a lethal substance that the patient would administer to himself or herself or, in the case of severe physical disability, be assisted to take.

The legislative framework established by the bill will provide protection for persons providing such assistance and set up safeguards to prevent abuse of the right recognised by the bill. To be eligible to receive such assistance the patient would have to meet a number of criteria as laid out in clause 7. The patient would need to be at least 18 years old; be a resident of New South Wales; be suffering from a terminal illness, that is, one which will result in their death and which is causing them severe pain, suffering or distress to an extent unacceptable to the patient; have been fully informed of the diagnosis and prognosis of their disease and all other options, including palliative care; and have decision-making capacity and be making the decision freely, voluntarily and after due consideration.

There must be no medical measure acceptable to the patient that can reasonably be undertaken in the hope of effecting a cure. In addition, any medical treatment reasonably available to the patient must be confined to the relief of pain, suffering and distress, or any one or more of them, with the object of allowing the patient to die a comfortable death. The assessment to determine if these conditions have been met is extremely rigorous. Clause 7 requires that the patient would have to be examined by two independent medical practitioners who would both certify that the patient met the eligibility criteria. In addition, clause 7 requires that an independent psychiatrist, and if necessary an independent social worker, examines the patient to certify that he or she is fully informed of all medical options, able to make an informed decision and is not under any duress from any quarter to make the request for assisted dying.

Clause 6 requires that none of the health professionals involved or their close associates can stand to receive any financial benefit from the patient's death. Clause 6 imposes severe criminal penalties for coercion of the patient by the medical practitioners or of the medical practitioners by another party. Clause 10 imposes severe criminal penalties for the improper certification of eligibility criteria by the medical practitioners or other involved party. Importantly, clause 9 makes it clear that the patients could change their mind at any stage of the process. The passing of this legislation would not result in any health professionals being forced to participate in assisting people to die. No health care provider—whether it be a doctor, nurse, palliative care centre or hospital—is under any duty to participate in the provision of assistance to a patient under the legislation.

Therefore, the bill recognises that some practitioners have conscientious objections to the concept of assisted dying. Their right to hold such a position will be respected. According to the Australian Medical Association's Code of Ethics, when a personal moral judgement or religious belief alone prevents a doctor from providing assistance, patients should be informed that they may seek assistance elsewhere. However, this is not a requirement of the bill.

I will now address how the process would work, from initial request for assistance from the patient, through to the final provision of assistance and the accountability steps afterwards. The process begins when a patient who is suffering from a terminal illness and is experiencing pain or suffering to an extent unacceptable to the patient requests the assistance of a medical practitioner to end the patient's life. This doctor is known as the primary medical practitioner. The primary medical practitioner then assesses the patient according to all the strict eligibility requirements as laid out in clause 7 of the bill.

If the primary medical practitioner does not have experience in palliative care, the information about palliative care options must be provided directly by someone with experience or expertise in the area. A second independent doctor must examine the patient and verify the first doctor's assessment. Then an independent psychiatrist—and, if the primary medical practitioner considers it necessary, a qualified social worker—would have to examine the patient to verify that the patient has decision-making capacity and is not under coercion from any quarter.

For patients to be determined to have decision making capacity they must understand the facts relevant to their illness and condition, understand the medical treatment and other options available, have capacity to assess the consequences of the patient's decisions, understand the impact of those consequences and be able to communicate decisions. If the patient and any of these medical practitioners do not speak the same language then a qualified interpreter is used at all stages of the process. If they are not able to verbally communicate but they can communicate in other ways that is also considered. Following these assessments, if and when all of the eligibility conditions have been met, and only when they have all been met, a written request for assisted dying is signed by the patient and by all the aforementioned medical practitioners and the interpreter, if applicable.

However, an initial cooling-off period of 72 hours would first need to elapse between the original oral request and the signing of the written request. In the event that a patient is unable to sign the request because of physical incapacity, it may be signed on their behalf by another person over 18 years of age. This person forfeits any financial or other benefit they would obtain directly or indirectly as a result of the death of the patient. This must occur in the presence of both medical practitioners and the interpreter, if applicable.

Following the signing of the written request, a subsequent additional cooling-off period of at least 24 hours must elapse before the primary medical practitioner, after being assured again that the patient wishes to proceed, provides assistance by prescribing or preparing a substance for the patient to administer to himself or herself. The doctor must remain with the patient until the point of death. In the event that both the primary and secondary medical practitioners agree that the patient is physically incapable of self-administration and all other conditions have been met, the primary medical practitioner may administer the drug.

Following the administration of the substance and the death of the patient, the primary medical practitioner reports the patient's death to the registrar, citing both the terminal illness and the assisted death. He or she also forwards a copy of the death certificate and relevant medical records to the Voluntary Assisted Deaths Review Panel, which would be established by part 4. This monitoring mechanism would be a specialised body that would oversee the operation of the assisted dying regime. It would be appointed by the Minister and assisted by staff from the department. It would comprise a representative of the Minister and a representative of the NSW Medical Board. Additional members of the panel would include specialists in end-of-life care, a legal expert and an ethicist.

Every assisted death would be reported to the panel and it would review the circumstances of each one to ensure that the procedures laid down under the legislation had been followed. If the panel were concerned that a possible breach of the provisions of the legislation had occurred it would refer the matter to the appropriate authorities. The panel would also have the function of monitoring the ongoing operation of the Act and of fostering research and keeping records about its operation. The panel has the discretion to make a report to Parliament at any time.

> The Rights of the Terminally Ill Bill will do exactly what I have just outlined and nothing more. However, I have no doubt that members in this place will be told otherwise. Over the coming weeks we will all hear from opponents of voluntary assisted dying a barrage of claims about this bill and about existing legislation overseas. These claims often include inaccuracies, misinterpretations and misrepresentations of academic research—piecemeal cherry-picking that presents a distorted and inaccurate picture and claims based on poor-quality data or unreasonable assumptions. These misleading claims are often the basis of the "I support the concept of assisted dying but not this bill" argument.

I am aware of dozens of these misleading claims, but time does not permit me to go through all of them now. I will use my reply to address any such claims if they come up in debate. However, I will inform members of the types of tactics used to discredit voluntary assisted dying schemes in operation overseas. Recently members received an email from Reverend the Hon. Fred Nile regarding this issue. I do not question that Reverend the Hon. Fred Nile believed the material he distributed was academically sound and truthful but, unfortunately, it was not. The material circulated was an article by Peter Saunders headed, "Stunning 4,620 per cent increase in Belgian euthanasia cases in ten years since legislation". The article originally appeared in the web publication *LifeSiteNews*, which is published by the Life Issues Institute, an international organisation based in the United States of America. That organisation is dedicated to right to life issues and campaigns against abortion, euthanasia, gay marriage and similar issues.

Saunders cites statistics about euthanasia and assisted dying in Belgium and The Netherlands. These statistics come from the 2010-11 annual report of the Belgian voluntary euthanasia regulatory agency to the Belgian Parliament. The regulatory body is called the Federal Control and Evaluation Committee. As Saunders says, the number of euthanasia deaths in Belgium has increased from 24 in 2002 to 918 in 2011. However, he has miscalculated the percentage increase. The increase in the 10 years is 918 minus 24, which is 894. So the percentage increase is 3,725 per cent, not 4,620 per cent. In addition, Belgian euthanasia laws were not passed by Parliament until late September 2002, which means the 24 deaths that year were in the last three months. That is why the figure is relatively low.

The following year the number was 235, so arguably that should be the base line number. That is more like a four-fold increase from 2003 to 2011. Of course, this percentage increase still seems large. But presenting the figures in this way is misleading. It stands to reason that in the first few years after the introduction of the legislation the number of euthanasia deaths would be low because the system took some time to be understood by both the medical profession and the public. Once it was more established annual deaths under the scheme began to increase by about 100 a year to the present level of 918. But that figure comprises only 1 per cent of total annual deaths in Belgium, according to Saunders' own source. Another way of expressing the increase in Belgium is to say that between 2002 and 2011 the percentage of deaths from euthanasia increased from 0.026 per cent of total deaths to 1 per cent of total deaths. It is hardly opening the floodgates.

> Saunders' other unsupported assertion is that the Federal Control and Evaluation Committee is now considering "extending the right to citizens who suffer from degenerative mental illnesses like Alzheimer's and also to children". It is true that Belgium and The Netherlands operate a more extensive regime of voluntary euthanasia than operates in, say, Oregon in the United States of America or that has been or is contemplated in any jurisdiction in Australia. Differences include the following: In Belgium a person who is in a permanent vegetative state or in an irreversible coma can access euthanasia via an advanced care directive. No such provision is allowed or is being contemplated in this bill.

In both Belgium and The Netherlands, unlike Oregon, the law permits voluntary euthanasia; that is, the lethal substance is administered by the doctor under strictly controlled conditions. Under my bill, the role of physicians would be to assist patients to administer the dose to themselves—the assistance being by way of prescribing and preparing the substance and remaining with the patient during the process. This bill does not permit euthanasia. The only exception would be if the patient was certified by two doctors as being physically unable to administer it themselves because of some physical disability.

In my bill there is no possibility of the assisted dying regime being used for children. To qualify, a person must be over 18 years of age. In my bill there is no possibility of people with Alzheimer's disease being able to access voluntary assisted dying. To make a valid request for assisted dying a person must have decision-making capacity, as I explained previously, as well as a terminal illness where the only treatment available is confined to pain management. The claims of an automatic slide towards including new categories of eligible persons—such as people with dementia, handicapped people or children—are unfounded. The Rights of the Terminally Ill Bill proposes a highly controlled and regulated system that would be impossible to circumvent. No changes to the regime could be made without parliamentary approval and further legislation. Such changes cannot occur by stealth.

We know how strongly people feel about this issue on both sides of the debate, but feelings and convictions alone are not good bases for important decisions on law reform. I say to those with strong views against assisted dying laws based on their religious beliefs: You do not have to access this law if you find yourself in a similar situation to that of Angelique or Loredana. No, you do not. I say to the church leaders who oppose this and actively campaign against it: You can urge your parishioners to not go down this path, but please do not stand in the way of those who are seeking the right to die with dignity. Please have the humanity and the decency to step out of the way.

It is time for us all as legislators to listen to the people's call on this issue. The people of New South Wales want change, they are demanding change and that call for change will not diminish in numbers or in its urgency. In fact, over the years, public support for voluntary assisted dying for the terminally ill has grown. Now polls consistently show levels of support at between 75 and 85 per cent. The most recent Newspoll in 2011 showed 83 per cent support across New South Wales. The question asked in the poll was, "If a hopelessly ill patient experiencing unbelievable suffering with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to give a lethal dose or not?" That is exactly what my bill does—nothing more, nothing less. In Sydney 80.5 per cent said yes, while elsewhere in New South Wales that figure was 88.4 per cent. There was little variance in the response among different income or education levels or between people with children or with no children.

Those figures have been confirmed during my series of forums, "Dying with Dignity: Your Right to Choose", that I have brought to centres around New South Wales to explain this bill. In partnership with Dying with Dignity NSW, I have held events in Wollongong, Newcastle, Coffs Harbour, Ballina, Katoomba, Orange, Wagga Wagga, Dee Why and Parramatta, with more planned for Balmain, Paddington, Tweed and Mosman. At every forum it has become painfully clear just how far behind public opinion we are. Support for voluntary assisted dying crosses the political divide; in fact, in most of the forums I have conducted at town halls and rooms in clubs—often brimming to capacity—it is hard to spot a Greens voter among the attendees.

Clearly the arguments against law reform are not convincing the public. One of the reasons why the myths do not carry the same weight they used to is because of the successful operation of schemes overseas, such as in Oregon, the United States, with its Death with Dignity Act. Oregon provides a successful, compassionate legal framework for a practice that is actually already happening in Australia behind closed doors and underground.

Several cases were outlined in the booklet I distributed earlier this year. I will speak about one. Triathlon competitor, heli-skier and passionate human being Wayne McCarthy was diagnosed with the brain disease progressive supranuclear palsy, with a prognosis anywhere between three to eight years of progressively not being able to walk, talk, write, eat or see properly. The disease results in a death by choking. After many attempts he managed to obtain lethal medication by stealth. His widow, Ronda, tells the heartbreaking story of their planned goodbye and of Wayne taking the medication alone in a hotel room while she attended church. Ronda said:

> If it had been legal for Wayne to seek assistance from a doctor, he would not have had to do it so early and we would have had him a little longer. Our family and friends would have been able to say goodbye. And it turns out goodbyes are important. I would have been able to be with him in his final moments. It would have been hard, but not as terrible as having to leave him to do it on his own.

This is why having legislation for voluntary assisted dying for the terminally ill is a safer and fairer option. It is far better to regulate what is already happening than to allow it to continue unchecked. And it is going unchecked. Essentially, this bill puts a framework around what is happening anyway. It allows patients and their families and their doctors to talk more openly about end-of-life choices when suffering gets too great. One of the choices available to people who are reaching the end of their lives is to withhold food and water. In other words, the patient slowly starves and dehydrates to death. This can take weeks. Why is this okay, but active, compassionate assistance at the request of the patient is not? Why not?

In all of the jurisdictions where assisted dying schemes are in place palliative care is extremely well-resourced and is respected and valued. In fact, palliative care improves in jurisdictions where voluntary assisted dying is legal. Crucially, it puts the decision about the end of life back into the hands of the patient. Ultimately, this bill is about giving the ultimate choice to dying people, who surely deserve whatever control they can exercise over their suffering when they are nearing the end of their lives. If we in this place today or in the coming weeks do not give people this choice, who will? Are we satisfied to hear that doctors are doing this anyway; that patients are committing suicide anyway; that people are begging their loved ones to kill them anyway? Can members accept that as our law currently stands those who can afford it are spending tens of thousands of dollars travelling to Switzerland to achieve a dignified death? And some of those who cannot afford it are killing themselves anyway.

If this law were passed many terminally ill people would have immense peace of mind. Some would live longer, because they would then not have to resort to finding their own way out of their suffering. The system around end-of-life choices is failing people and it is our job to fix it. The vast majority of people of New South Wales are crying out for a legal framework to be put in place that will enable terminally ill people—people who are dying anyway, people who are facing an unimaginable, excruciatingly painful death—the right to request assistance to die that little bit sooner, with their family around them and at a time of their choosing, instead of dying in ways that we all find too horrible to think about or to talk about. Surely we can grant the people of New South Wales that.

I know some members in this place will decide that it is too much for them to legislate this; that they support the idea in general and they feel sorry for people who are telling them their story, but it is too much for them to do this. I know that when some of the people who helped elect you hear that it was too much for you they will scream in frustration. They will literally scream in frustration, because it is our job. It is why we are here. We are here to make the difficult decisions, to make a difference to people's lives, to improve our society, to advance society, to keep up with the expectations that the people of this great State bestow upon us. This bill is about alleviating suffering. The best palliative care cannot alleviate the suffering of some terminally ill patients. I will read from some of the emails we have all received. One extract reads:

> The palliative care team that visited our home for months and looked after her for the last 7 weeks in Canterbury Hospital were very kind and supportive, but they had no answers and were shocked by her intolerance of the medication. Together we just waited and watched her gradually disintegrate to death.

Another email reads:

> She said she was ready to die before she even left the hospital and wondered why she woke up each day to more pain, nausea and extreme discomfort in spite of palliative medications.

I have a folder of many more such emails. I appeal to all members to make their decision on how they will vote on this important and long-overdue piece of legislation based on sound evidence, well-reasoned arguments and the wishes of the community. Please think about the suffering that people from all parts of the State, from all walks of life, are asking us to help alleviate. I truly hope that in this debate compassion and courage are the victors over fear and self-interest.

I will take a moment to thank the campaigners, advocates for reform and those touched by terminal illness who have dedicated so much to this bill. At Dying with Dignity NSW, I give special thanks to Richard Mills, who is in the gallery today, Sarah Edelman, Jill Weekes, who is also in the gallery, Gabrielle Brown and all the volunteers, staff and board. I have had the pleasure of working with those inspiring people and also Gideon Cordover, Ronda McCarthy, Shayne Higson, James McKay, Loredana Alessio-Mulhall and many others who have shared their deeply personal and moving stories in support of law reform. To all those who have telephoned, emailed and written to me with their stories I say a huge thankyou.

I also thank medical professionals and academics Dr Robert Marr, Dr David Leaf, Dr Chris Ryan, Professor Colleen Cartwright and many others. Particular special thanks must go to our researchers Liz Jacka and Carolyn Williams. Without the significant hours they have invested in this bill and the supporting material I think we simply could not have brought this bill to the Parliament. There are so many others, and I wish I could name them all. Thanks to Margaret Otlowski, Marshall Perron, Nicholas Cowdery, Philip Nietzsche, Ian Wood and John Dowd. I also thank Jamie Parker, Alex Greenwich and Greg Piper for agreeing to carry this bill forward into the lower House should this bill win the support of the majority of members.

Finally, back to Angelique: before she died Angelique gifted her sister, Michelle, 35 handwritten letters for her thirty-fifth birthday. In those letters she did not mention death or dying but the power of words. She wrote:

> Let words be as feathers. I shall gather unto myself these paper wings, and soar to you. Such wings were not made to fly too close to the sun, but nearer the moon.

I commend the bill to the House.