Legislative Council Hansard – 21 September 2017 – Proof

VOLUNTARY ASSISTED DYING BILL 2017

First Reading

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

Second Reading

The Hon. TREVOR KHAN (10:26): I move:

That this bill be now read a second time.

The Voluntary Assisted Dying Bill will provide an option for terminally ill patients whose deaths are imminent the choice to end their severe pain, suffering or incapacity on their own terms. The bill fills a gap in the law of this State, where terminally ill patients do not currently have the ability to exercise such choice and sometimes die in unrelievable pain, suffering and distress. The bill has been developed by the NSW Parliamentary Working Group on Assisted Dying, a cross-party group of members who have come together to develop the bill and strip party politics out of this important issue. The working group consists of the Hon. Lynda Voltz from Labor; Dr Mehreen Faruqi from The Greens; Mr Lee Evans, the member for Heathcote, from the Liberals; and Mr Alex Greenwich, Independent, the member for Sydney.

The bill follows the conservative Oregon model of voluntary assisted dying and not the broader European models of voluntary euthanasia. Under the Oregon framework, only terminally ill patients with less than six months to live are able to request a medical practitioner's assistance for a substance for self-administration, after having been examined by two doctors and assessed as making their decision voluntarily. The Oregon legislation has been in place since 1997, and over the course of 20 years their assisted dying scheme has accounted for less than one half of one percent of deaths in that State. It has not been changed; it has not been amended. It has not led to "unintended consequences" or a "slippery slope" as those opposed to assisted dying would have you believe. It has not expanded the class of persons who are able to access the scheme—20 years later it remains available only for the terminally ill with less than six months to live.

It has not dramatically changed the dynamic between doctors and patients. It has not stopped people going to their doctors out of fear that they will try to encourage them to end their lives. It has not undermined the provision of palliative care in that State. It has not resulted in vulnerable people being coerced into accessing assisted dying—in fact, there has not been a single documented case of coercion in 20 years. What has happened in Oregon is that terminally ill patients who are suffering immensely and whose deaths are imminent have either been able to self-administer a substance to end their suffering or have been able to obtain a prescription but die as a result of their terminal illness.

Indeed, since 1997 a third of patients who have gone through the State's voluntary assisted dying processes have not taken the substance. Rather, for these patients, the sense of control that the patients were afforded and the knowledge that this option was available to them if their condition became simply unbearable was enough.

The voluntary assisted dying scheme in Oregon works. It is a safe and effective framework—so much so that a number other States in the United States have since followed the Oregon model in implementing their own scheme, including Washington, Vermont, California, Colorado and the District of Columbia. Our bill is similar, and also conservative in its approach, but the working group has, in a few key areas of the bill, gone even further than the Oregon model. I will therefore turn to the provisions of the bill. The object of this bill is to provide a legislative framework for the rights of terminally ill persons to request and receive assistance to end their lives voluntarily. Under this framework, certain terminally ill persons may be assisted by their medical practitioners and other qualified health practitioners to administer a substance to themselves.

The bill provides protection for persons providing such assistance and sets up safeguards against possible abuse of the right recognised by the bill. The bill is comprised of 9 parts. Part 1 deals with preliminary matters. Part 2 covers matters of interpretation and key concepts. I will address the pertinent elements of this part concurrently with the eligibility requirements and other matters that follow. Part 3 governs a terminally ill person's request for assistance and the provision of assistance therein. Clause 9 of part 3 provides that an eligible person may request a registered medical practitioner for assistance to end the person's life in accordance with the framework established by the bill.

A person is eligible to make a request if all of the following requirements are met. The person must be at least 25 years of age. The person must be an Australian citizen, or a permanent resident of Australia and be ordinarily resident in New South Wales. The person must be suffering from a terminal illness. "Terminal illness" is defined as an illness that will, in reasonable medical judgement, result in the death of the person suffering from the illness within the next 12 months. Further, the registered medical practitioner to whom the request is made—referred to in this bill as the primary medical practitioner—must have informed the person that, in the practitioner's opinion, the person is suffering from a terminal illness. Finally, as a consequence of the terminal illness, the person must be experiencing severe pain, suffering or physical incapacity to an extent unacceptable to the person. This is a subjective test.

The medical practitioner to whom the request is made must not be a close relative of the person. A person making the request is to be referred to as the patient. A patient may at any time and in any manner rescind the request for assistance. If any health care provider—that is, any nurse, medical practitioner, manager of a health care facility or other person whose duties include, or directly or indirectly relate to, the care or medical treatment of the patient—becomes aware of a request for rescission, the primary medical practitioner must immediately be notified.

Clause 11 provides for conscientious objection without penalty, such that a primary medical practitioner may, for any reason and at any time, refuse to provide assistance to the patient. As an added protection, there is a mandatory 48-hour cooling-off period. Assistance must not be provided to a patient until at least 48 hours have elapsed since the completion of the relevant certificate pursuant to part 4. Clauses 15 and 16 create offences for improper conduct. A person must not engage in conduct that influences the provision of assistance under the bill. A person also must not, by deception or influence, cause a person to make a request for assistance under the bill. The maximum penalty for contravention is four years imprisonment.

Part 4 sets out preconditions to the provision of assistance. A patient who has made a request for assistance must be examined by the primary medical practitioner and a secondary medical practitioner. The secondary medical practitioner must be registered under the Health Practitioner Regulation National Law in a specialty in the medical profession that is relevant to the diagnosis or treatment of the terminal illness from which the patient is suffering. The primary and secondary medical practitioners must not be closely associated. Both the primary and secondary medical practitioners must not be a close relative of the patient.

The primary medical practitioner must not provide assistance unless they are satisfied that the patient is suffering from a terminal illness, and the illness is causing the patient severe pain, suffering or physical incapacity to an extent unacceptable to the patient, and there is no medical measure acceptable to the patient that can reasonably be undertaken in the hope of effecting a cure. The secondary medical practitioner must confirm that opinion. In addition to providing particular information to the patient after having conducted the examination, the primary medical practitioner must offer to refer a patient to a palliative care specialist. The patient is not required to accept the offer of referral.

Once the primary and secondary medical practitioners have examined the patient, the patient must be assessed and examined by a qualified psychiatrist or a qualified clinical psychologist. The primary medical practitioner must not provide assistance unless the psychiatrist or clinical psychologist is satisfied that the patient has decision-making capacity in relation to the request for assistance, and the patient's decision to request the assistance has been made freely, voluntarily and after due consideration. If the primary medical practitioner makes an assessment that the patient is not eligible to make a request for assistance, then relevant documents will have to be provided to any subsequent medical practitioners who undertake assessments as new primary medical practitioners.

Part 5 provides for the review of requests for assistance by the Supreme Court. This part has been included as a result of the view the working group took in respect of judicial review, based on the advice received during the consultation period from key legal organisations in New South Wales. Those key legal organisations were the Law Society of New South Wales and the New South Wales Bar Association. Pursuant to the bill, the Supreme Court has the power, on the application of a close relative, to make an order that the request certificate is not effective so as to ensure no action can be taken as a result of the ineffective request certificate.

The order may be made on any of the following grounds: at the time of making the initial request for assistance the patient was not suffering from a terminal illness; the patient was not at least 25 years of age; the patient was neither an Australian citizen nor a permanent Australian resident; the patient was not ordinarily resident in New South Wales; at the time of making the initial request for assistance, signing the request certificate or undergoing the examination under part 4, the patient did not have decision-making capacity in relation to the request for assistance; or the patient's decision to request the assistance was not made freely, voluntarily made and after due consideration.

A "close relative" of the patient is defined as a parent, guardian or child of the person, or a brother, sister, half-brother, half-sister, stepbrother or stepsister of the person, or an existing spouse or de facto partner of the person. Part 6 addresses the effect of the bill on other rights and obligations. For instance, clause 28 provides that health care facility operators, health care providers and other persons are under no obligation to participate in a request for assistance in any way. They must, however, comply with a patient's request to provided copies of medical records to other health care facility operators or health care providers. Clause 29 provides a protection from civil or criminal liability where compliance with the scheme or a refusal to provide assistance is done so in good faith.

Part 7 sets out the requirements for record-keeping and the reporting of deaths. A primary medical practitioner must keep records in a manner as specified by clause 31 for seven years. The maximum penalty for a breach of this clause is $11,000. An assisted death is taken to be a reportable death for the purposes of the Coroners Act 2009. Clause 33 provides that in respect of the recording of the cause of death, the cause is to be taken to include the terminal illness of the patient, and not include suicide or homicide.

Part 8, which is a new part added to the exposure draft in response to concerns raised in the consultation process about the effect of monitoring and oversight of assisted deaths, establishes the Voluntary Assisted Death Review Board whose functions will be monitoring and reviewing assisted deaths, developing policies and practices for assisted deaths, maintaining a register of assisted deaths, providing advice to the Minister, and reporting to Parliament about the exercise of those functions. The review board's purpose is to monitor the operation of voluntary assisted deaths to ensure the intent of this bill is carried out.

The review board among its functions will provide advice to the Minister for the gazette in the regulations pursuant to the regulation-making power contained within the bill. The board comprises the Chair, the State Coroner or his nominee, representatives from various medical boards and colleges, a representative from Palliative Care NSW and a person who, in the opinion of the Minister, has relevant expertise in law. The primary medical practitioner will be obligated to provide records to the board for the purposes of undertaking the review of the assisted death. The review board has the power to refer matters for investigation to the appropriate authorities in circumstances as considered appropriate by the board.

Part 9 deals with miscellaneous matters. Among these matters is a statutory review of the Act. It shall be undertaken as soon as possible after the period of five years from the commencement of the Act. There are three schedules to the bill. Schedule 1 contains the forms to be completed by the various parties in the assisted death process. Schedule 2 contains the constitution and procedures of the death review board. Schedule 3 contains consequential amendments to other Acts.

For the past two years the working group has worked collaboratively in consulting with parliamentarians, the community and a wide range of stakeholder organisations through an exposure draft process and through community forums to ensure this bill is rigorous in its approach to ensuring strong safeguards and protections. It is imperative that the safeguards in this bill meet the high expectations of our community. I note that, in addition to recent and consistent polling demonstrating more than 70 per cent support for voluntary assisted dying, members have been surveying their constituencies and holding community information sessions. The surveys show overwhelming majority support for the bill. To take a small sample, 67 per cent of those surveyed in the Northern Tablelands, 80 per cent in Ryde, 89 per cent in Myall Lakes and 90 per cent in Manly support a bill such as this. Currently the options can be bleak for a terminally ill person at the final stage of their life.

They are faced with appalling choices. As the Victorian Coroner's evidence to the Victorian Parliament's inquiry into end of life choices demonstrates, between January 2009 and December 2013, 2,879 people committed suicide in Victoria. Of those, 240 people had irreversible physical health conditions, with the highest frequency being for those aged 65 or older. These 240 people died in horrendous circumstances. Seventy-four poisoned themselves, 64 hanged themselves, 34 died as a result of a firearm, 19 died through a threat to their breathing, 13 died from motor vehicle exhaust, eight died from rail—I repeat: eight died by throwing themselves in front of a train—seven died from a jump from height, five died by using a sharp object, and 16 died from other causes. What is absent from these statistics is the profound traumatic effect this has on first responders, such as emergency services personnel, or family members, or friends when they find the bodies—in some cases, sometime well after the fact. It is an appalling situation.

We know also that some doctors currently act on patients' requests to hasten their deaths to end their suffering. This is happening now in our hospitals and medical practices, and it is happening in the dark. Neither patients nor medical practitioners have the protection of a legal framework that protects them. It is only through a bill such as this that we can ensure that both patients and medical practitioners act in a regulated and safe manner. It is only through a bill such as this that we can ensure that patients are properly informed of all their choices. For me and for others in this place as well as for so many in our community, this issue is deeply personal. Too many of us have watched or cared for a loved one with a debilitating illness and have seen them die a horrible and undignified death. I have attended forums at which palliative care specialists painted a picture that was so different from what I saw and so different from what so many people in fact had experienced in life.

My father was a general practitioner in Wollongong, where he practised for more than 50 years. He was a man of profound intellect and wit, and he was respected by the community. He suffered a debilitating stroke whilst awaiting a colonoscopy. He was left incapacitated, incontinent and bedridden in a nursing home and died a slow death over 3½ years. He asked me and my sisters to assist him to die—he asked us to help kill him—but we refused. It was an ignoble and undignified end for a man who had such dignity in life.

Annie Gabrielides is the face of Dying with Dignity NSW's campaign for voluntary assisted dying. She has been petitioning the New South Wales Parliament to pass voluntary assisted dying reform since May this year, and her petition on *change.org* now stands at over 100,000 signatories. Annie is 53, with a loving husband and family—two boys and a girl. One of those boys, or perhaps two of those boys, went through university with my daughter. Annie is a former speech pathologist, but suffers from terminal motor neuron disease. She has lost her ability to speak. She is left gasping for breath, she cannot control her hands, and she is faced with being trapped inside her body with the same intellect, but being unable to communicate, to feed herself, to clean or toilet herself, or to move. However, she is presently able to communicate through electronic technology. Back in May she said:

> I'm asking for NSW politicians to open their hearts and spare those battling crippling terminal illnesses like mine from an undignified, painful and drawn out death. Help me deny this bastard of a disease its last victory.

Let me be clear: The bill is restricted to the terminally ill whose deaths are imminent, who can demonstrate decision-making capacity and voluntariness. The bill will be able to help people such as Annie Gabrielides, but in truth would not have helped my father. He was not terminally ill per the definition in our bill and would not have been assessed to have decision-making capacity. I regret that, but that is the decision our working group properly made.

For some voluntary assisted dying advocates, I note their frustration that this bill does not go far enough. For example, it does not cover all terminal illnesses, it does not cover those with dementia and it does not cover children. But the working group has sought to construct a bill that targets those in our community who are most in need of voluntary assisted dying: that is, terminally ill patients at the final stages of their life, who are experiencing pain, suffering and incapacity. What I say to those advocates and to those attending various forums across the State is this: It is far better to have 70 per cent of something than a mouthful of ashes.

Our bill also seeks to address expected counter arguments upfront. I will spend some time now addressing some of these arguments. I speak for the working group when I say that we agree that palliative care plays a vital role in our society and that palliative care services should be further improved and made more readily available across the State. There is just no argument with that. We agree that palliative care can help to alleviate people's suffering, which is why we have included a mandatory offer of a palliative care referral in our bill. But we do not accept the argument that voluntary assisted dying will undermine the provision of palliative care in this State. This has not been the experience in Oregon, California, Vermont, Washington State, Colorado or Washington DC. In those locations it is demonstrated that voluntary assisted dying can exist in tandem with palliative care.

But what also must be acknowledged is that palliative care cannot help everyone, and it cannot alleviate all pain and suffering in all circumstances. It cannot alleviate the incapacity that my father experienced or that Annie Gabrielides is suffering now. Those who feel uncomfortable about this subject should look into Annie's eyes, hear what her husband has to say and speak to her children. When they do that the platitudes of some of the opponents will be shown to be worthless. For those members who are concerned about elder abuse and the coercion of vulnerable people, this bill contains the most safeguarded process of any voluntary assisted dying scheme presently available in the world. With the safeguards I outlined earlier it is difficult—indeed, impossible—to see how patients can be taken advantage of or coerced to go through the whole process and administer the substance.

The fear campaign being mounted by many opponents of the bill is not just unfounded, it is also misleading. I urge members to take a rational and evidence-based approach in forming their views on this bill. I urge members to read the bill, not emails containing falsehoods. I also urge members to think about the profound positive impact this bill, if passed, will have on our community. Terminally ill people at the final stages of their life, such as Annie Gabrielides, will be able to die on their own terms, at a time and place of their choosing, and with a chance to farewell their loved ones. They will be able to take control of the end of their lives. We hope that we can ease the suffering of terminally ill people.

There are many people who I wish to thank for their involvement in the process of developing this bill. I thank my colleagues on the working group: Lynda Voltz, Mehreen Faruqi, Lee Evans and Alex Greenwich. I give particular thanks to Mr Greenwich for facilitating the drawing of the bill by Parliamentary Counsel. We all know how we have to do these things if you are a Government member. Further, we owe much gratitude to Tammie Nardone in Mr Greenwich's office for her work on the bill. Although it is not included in my speech, because it was prepared by my office, I thank Matt Yeldham and Richard Karaba from my office, who have both put an enormous effort into the drawing of the bill and who have to put up with me, which is like a sentence in itself. I thank the Office of the Parliamentary Counsel for its exacting work throughout the numerous drafts of the bill. It has been an extraordinary effort. The bill that comes before the House is draft No. 30.

I thank Dying with Dignity NSW for its tireless advocacy effort. The working group thanks Annie Gabrielides and her family for their courage and support throughout the campaign. We thank all the stakeholders for making submissions during our consultation process. We received 72 substantive submissions. As I have said in countless interviews, not all of those submissions agreed with the bill, but so many of them made constructive and productive contributions to the drawing of the bill and we have sought to include as many of them as possible in its construction. Finally, I thank my other parliamentary colleagues for their advice and interest in bill, particularly those who have conducted surveys of their constituents or who have held community information sessions. The process that has been engaged in has been an extraordinary democratic process. I urge members of this place to give this matter careful consideration. I commend the bill to the House.

Debate a djourned.