Submission

to the

Senate Legal and Constitutional Affairs Legislation Committee Inquiry into the Medical Services (Dying with Dignity) Bill 2014

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1. Introduction:

On 24 June Senator Richard Di Natale moved in the Senate that his exposure draft of the Medical Services (Dying with Dignity) Bill 2014 (hereinafter referred to as the Bill) be referred to the Senate Legal and Constitutional Affairs Legislation Committee for inquiry and report by 27 October.

The Bill has been so referred and Submissions can be made up to 21 August.

The Commonwealth has shared powers with the states over health but the states have so far not passed any euthanasia bill. Rather than relying on the health power the Bill relies on Section 51(xxiiiA) of the Constitution, which gives the federal parliament the power to legislate regarding “medical services”, and on any other relevant implied legislative powers of the federal parliament under the Constitution.

Senator Di Natale makes these explanatory comments: “This proposed bill uses this power (ie Section 51(xxiiiA) of the Constitution) to define a “dying with dignity medical service” and authorise medical practitioners to prescribe, prepare and/or administer a substance that would assist a terminally ill person to end their life in a humane manner. It provides that the Commonwealth can pay for this service as it would for other medical services. It also indemnifies doctors from prosecution by the states.

The system described in the Bill includes several important safeguards. The patient who wishes to have the option of hastening their death requires the acquiescence of two independent doctors who agree on their prognosis, and a third psychiatrist who can attest that the person is not suffering from treatable clinical depression.”

2. Terms of Reference:

Although there do not seem to be any formal Terms of Reference Senator Di Natale says the inquiry will explore issues such as:

- Should the Commonwealth legislate on assisted suicide/euthanasia?
- Can it survive a challenge if it conflicts with state law?
- Do the safeguards in place strike the right balance? Or is it too onerous to involve three independent medical practitioners?
- Does it contain sufficient protection for medical professionals?
- Should it remain restricted to terminally ill people only?

A further relevant issue that should be addressed as a threshold issue, before any consideration of the provisions of the proposed Bill, is the availability and accessibility of palliative care in Australia.

3. Palliative Care

Clause 12 (1) (h) (ii) of the Bill says that the medical practitioner to whom a request for assisted suicide or euthanasia is made has to have **"informed the patient making the request of "palliative care … that may be available.**

Clause 12 (2) further provides that "the information to be provided …on the availability of palliative care …" must be provided **by a medical practitioner who has special qualifications in the field of palliative care.**

Clause 13 further provides that a medical practitioner must not accede to a request under the Bill if "there ae palliative care options **reasonably** available."

The reality is that not every Australian has reasonable access to palliative care.
The Australian and New Zealand Society of Palliative Medicine says that **1.0 full time equivalent (FTE) palliative medicine specialist per 100,000 people** is the **minimum ratio for a reasonable provision of service**. **Palliative Care Australia** recommends palliative care specialists should be provided to the level of **1.5 FTEs per 100,000 people**. Yet the **Australian Institute of Public Welfare 2013 report on palliative care services in Australia** (see http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545131 Table 7.3) **found that nationally, in 2011, the average ratio of FTE palliative care specialists per 100,000 people was only 0.4**. And it varied from state to state and between the city and regional areas. In **major cities access was at 0.5** while in **outer regional areas it was 0.3** and an **even lower 0.2 in inner regional areas** (see Table 7.4).

So at present in Australia what palliative care services are reasonably available to a patient varies according to where they live and is in any case availability is below that recommended by peak Australian palliative care bodies. To provide that information on the availability of palliative care must be provided before a request for assisted suicide or euthanasia could be granted is devoid of any real meaning while availability of palliative care services is below the standard considered acceptable by expert palliative care organisations and there is inequality of access between Australians living in major cities and in inner and outer regions. And, as the number of palliative care specialists in Australia is well below that recommended per 100,000 people, where would the "medical practitioners "with special qualifications in the field of palliative care" who are required by Clause 12 (2) to provide the information on the availability of palliative care?

Adequate palliative care and equity of access regardless of where the patient lives are issues that should be addressed before debating legalising assisted suicide or euthanasia. This is a serious social justice issue and should not be ignored.

4.1 Invalid use of federal powers in the Constitution:

Clause 6 of the Bill provides that it relies on the Commonwealth's powers under paragraph 51 (xxiiiA) of the Constitution that is the power to make laws with respect to "…medical … services…" It is questionable whether redefining an act that is presently a criminal act under state homicide laws as a "medical service", making it legal and providing that it does not constitute an offence under any state or territory law is a valid exercise of the power of the federal parliament under paragraph 51 (xxiiiA).

It is artificial to define assisting suicide and euthanasia as a "medical service" to find a head of federal power for the proposed bill.

4.2 Inappropriate use of the federal powers in the Constitution:

The Bill also raises the issue whether it would be an inappropriate use of federal power as it would override state laws relating to homicide.

4.3 Death by both assisted suicide and euthanasia are defined as a "medical service":

Clause 5 of the Bill includes both assisting suicide and euthanasia (ie direct killing of a patient) as "dying with dignity medical services."

Clause 5 (1) defines a "dying with dignity medical service" as a medical service provided "**to enable the person to end his or her life** …" Clause 5 (2) provides that includes giving information to the person requesting the service and prescribing, preparing and giving the substance to the person to self-administer to enable the person to end his or her life. This is assisting the person to kill him or herself which is assisting suicide.

Clause 5 (2) provides that a "dying with dignity medical service" would also include "the **administration of a substance to the person** …" requesting the service. This is euthanasia, the direct administration of a substance that will kill (a poison), whether by lethal injection or for by ingestion, to the person.

Describing it as a "dying with dignity" medical service cannot change the fact that to assist a patient to kill him/herself or to directly kill a patient would become part of medical practitioner's care for a patient. Helping a patient to kill him/herself or directly killing a patient has never been part of medical practice and it is directly contrary to the doctor's duty to "do no harm."

Legislating to make assisting a patient to commit suicide or directly killing a patient part of medical practice, or even a 'duty' for medical practitioners to respond to a patient exercise his/her right to request that "service", would seriously change the doctor/patient relationship. It would empower doctors to kill and put them above the law as they would be protected from prosecution or professional discipline (Clauses 24 and 25). The presumption is that patients making requests under the proposed bill have made a free and rational decision to ask the doctor to provide them with or administer them with the lethal dose. But vulnerable patients may be pressured or even just feel a duty to make a request as it is a legal option. The effect is that there would be no legal protection for vulnerable patients. It would be legal to provide them with the lethal dose. This would have to have a deleterious effect on the trust between doctor and patient. In Oregon, under the assisted suicide law, 57% of persons who died in 2012 listed concern about 'being a burden on family, friends and caregivers' as a reason. (see http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf)

Furthermore the doctor could feel pressured, by the patient or relatives of the patient, to provide assisted suicide or euthanasia if it is legalised. In the Netherlands, where euthanasia is legal, a report found that nearly half of GPs have felt pressured by relatives to use euthanasia, …" – (see http://www.dutchnews.nl/news/archives/2011/07/one_third_of_doctors_have_refu.php).

The description of providing assistance to suicide or directly killing a patient as a "medical service" reduces medical practitioners to mere "service" providers.

Describing assisting a patient to commit suicide or to directly kill a patient as a "dying with dignity" medical service falsely implies that any other way of dying would not be dignified and that being given a lethal jab or dose is a dignified way to die. Human beings are not merely animals and deserve more than to be put down like animals. The mark of a humane society is care not killing.

4.4 Does the Bill restrict assisted suicide and euthanasia to the terminally ill?

"Terminal" illness would normally be understood to mean an illness that will in the reasonably foreseeable future result in the death of the patient - that death would be imminent, or at least expected to occur within months. The definition in the Bill is so conditional that it is really not restricted to terminal illness at all.

Clause 4 defines "terminal illness" as "an "illness which, **in reasonable medical judgement will**, **in the normal course**, **without the application of extraordinary measures** or of **treatment unacceptable to the person**, **result in the death of the person.**"

A chronic illness, such as diabetes, will "in the normal course", without treatment, result in the death of the person. With treatment the person would live for years or even decades. The proposed bill would allow that person, if he/she found the treatment "unacceptable", which is a subjective test, to request assisted suicide or euthanasia.

Clause 4 also defines "illness" to include "**injury'** and "**degeneration** of **mental or physical faculties.**"

- So a young person who has a serious injury and needs assistance to stay alive can request assisted suicide or euthanasia under the bill if that assistance is "unacceptable" to him/her.
- So a person just diagnosed with dementia who may live for years before becoming very dependent on the assistance of carers, could request assisted suicide or euthanasia under the bill.

- So a person just diagnosed with a degenerative physical condition which would eventually result in his/her death, such as multiple sclerosis or motor neurone disease, could request assisted suicide or euthanasia under the bill.

The bill is not restricted to those suffering from a terminal illness in the understood meaning of terminal illness.

Furthermore, Clause 10 would allow a request for assisted suicide or euthanasia to be made if the person is “experiencing pain, suffering, **distress** or **indignity** to an **extent unacceptable to the person**.” The proposal is not restricted to pain or suffering but extends to the less measurable “distress” or “indignity.” And that pain, suffering, distress or indignity does not have to be “unbearable”, which has usually been the criteria to seek assisted suicide or euthanasia and which could have some objective assessment, but just “unacceptable to the person.” Theo Boer, a member of a Committee monitoring euthanasia cases under the law in the Netherlands has reviewed at least 4000 euthanasia deaths has warned of increasingly seeing cases where a large part of the suffering consisted of being “aged, lonely or bereaved”, and that some of these people could have lived for decades. They deserved to be offered care and compassion not just be offered death. A provision such as proposed Clause 10 abandons protection for vulnerable, isolated people.

4.5 Safe guards – can they ever be adequate?

This is probably the most important issue in considering legalising assisted suicide or euthanasia. If there can be adequate safe guards then why shouldn’t people have the right to request assisted suicide or euthanasia? However wherever it has been legalised experience has shown the “safe guards” do not work and vulnerable people are therefore at risk. In the Netherlands, Belgium, Luxembourg, Oregon, the record shows that the “safe guards” are often ignored and there is no investigation or any consequences. The main ‘safe guards”, which are contained in the proposed Bill, are:
Voluntary, written request which indicates informed consent – This is proposed in the Bill in Clause12. In the Netherlands despite this “safe guard” more than 500 people are involuntarily euthanized each year (see “End-of-life practices in the Netherlands under the Euthanasia Act.” *van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ,* Hanssen-*de Wolf JE, Janssen AG, Pasman HR, Rietjens JA, Prins CJ, Deerenberg IM, Gevers JK, van der Maas PJ, van der Wal G N Engl J Med. 2007 May 10; 356(19):1957-65.*) Attempts at bringing those cases to trial have failed (see “The medical practice of euthanasia in Belgium and The Netherlands: legal notification, control and evaluation procedures.” *Smets T, Bilsen J, Cohen J, Rurup ML, De Keyser E, Deliens L Health Policy. 2009 May; 90(2-3):181-7.*)

Mandatory reporting of assisted suicide/euthanasia cases – This “safe guard” is not even proposed in the Bill. Clause19 only requires that records be kept by the medical practitioner, not that he/she must report to any relevant authority that assisted suicide or euthanasia has been provided to a person. In any case even where reporting is required that requirement is often ignored. In Belgium, nearly half of all cases of euthanasia are not reported to the

Federal Control and Evaluation Committee (see "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases." *Smets T, Bilsen J, Cohen J, Rurup ML, Mortier F, Deliens L BMJ. 2010 Oct 5; 341():c5174.*) In the Netherlands, at least 20% of cases of euthanasia go unreported (see "End-of-life practices in the Netherlands under the Euthanasia Act." *van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, Buiting HM, van Delden JJ, Hanssen-de Wolf JE, Janssen AG, Pasman HR, Rietjens JA, Prins CJ, Deerenberg IM, Gevers JK, van der Maas PJ, van der Wal G N Engl J Med. 2007 May 10; 356(19):1957-65.*)

Second opinion and consultation - This "safe guard" is meant to ensure that all criteria have been met before proceeding with assisted suicide or euthanasia. The consultant must be independent (not connected with the care of the patient or with the care provider) and must provide an objective assessment. Clause 12 (d), (e), (f), (m) of the Bill contain such provisions. However, there is evidence from Belgium, the Netherlands, and Oregon that this process is not universally applied (see "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey" *Chambaere K, Bilsen J, Cohen J, Onwuteaka-Philipsen BD, Mortier F, Deliens L CMAJ. 2010 Jun 15; 182(9):895-901* and "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases", *Smets T, Bilsen J, Cohen J, Rurup ML, Mortier F, Deliens L BMJ. 2010 Oct 5; 341():c5174.*) In the Netherlands there is evidence of consultation not being sought in 35% of cases of involuntary euthanasia (see "End-of-life practices in the Netherlands under the Euthanasia Act", op cit). In Oregon a patient must be referred to a psychiatrist or psychologist for treatment if the prescribing or consulting physician is concerned that the patient's judgment is impaired by a mental disorder such as depression. In 2007, none of the people who died by lethal ingestion in Oregon had been evaluated by a psychiatrist or a psychologist (Oregon Department of Human Services (DHS) Death with Dignity Act. Portland, OR: dhs; 2007. Available online at:www.oregon.gov/DHS/ph/pas/ors.shtml). Further a 2010 study revealed that among terminally ill patients who received a prescription for a lethal drug under the Oregon assisted suicide/euthanasia law, 1 in 6 had clinical depression and that, of the 18 patients in the study who received a prescription for the lethal drug, 3 had major depression, and all of them went on to die by lethal ingestion, despite having been assessed by a mental health specialist (see "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey." *Ganzini L, Goy ER, Dobscha SK BMJ. 2008 Oct 7; 337():a1682*).

There is evidence that these "safe guards", which are proposed in the Bill, are practically ineffective.

For a detailed examination of whether "safe guards" are effective or adequate see http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3070710/ .

4.6 Other reasons for not legalising assisted suicide or euthanasia:

- For 9 years Theo Boer was a member of a regional euthanasia review committee in the Netherlands set up to oversee the operation of the euthanasia law in that country**.** At first he was in favour of the legislation but now says that, from his experience, legalising assisted suicide is a slippery slope toward widespread killing of the sick. In six years the numbers of deaths doubled. He said**:** "I used to be a supporter of legislation. But now, with 12 years of experience, I take a different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards? Or is it because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort?" (http://www.calgaryherald.com/news/Boer+wrong+euthanasia+slippery+slope/10039178/story.html)
- In the UK House of Lords 62 Peers spoke against the current UK assisted suicide/euthanasia bill - **http://www.theguardian.com/society/2014/jul/18/assisted-dying-legalisation-debate-house-lords.** We in Australia should also think very carefully before we legalise assisted suicide/euthanasia.

5 CONCLUSIONS:

- Not every Australian has access to a palliative care specialist to an acceptable standard and on an equitable basis. This is a significant social justice issue that needs to be addressed before considering legalising assisted suicide or euthanasia.
- Palliative care should not be corrupted by legalising assisted suicide or euthanasia.
- Palliative care services should be extended and accessibility improved rather than assisted suicide or euthanasia be legalised.
- The Bill, if passed, could be legally challenged as being beyond the power of the federal parliament or an inappropriate use of a federal power.
- The Bill if passed would decriminalise assisting suicide or directly killing people which are crimes under state criminal laws. Under the Constitution the criminal law is a state power. (Clause 25 would override state homicide laws)
- The Bill if passed would make directly killing or providing the means of death a "medical service". Killing or providing the patient with the means to kill him or herself is not and should not be part of medical care.
- The Bill does not contain adequate safe guards to protect vulnerable people.
- The Bill is not restricted to people who are dying.

- The Bill would allow people to request assisted suicide for serious chronic depression when they are not dying but need mental health care.
- Legalising assisted suicide would undermine crucially important suicide prevention programs.
- The Bill would expose vulnerable people, those who are old, frail and/or suffering from a chronic illness or disabled, to being made to feel they should request assisted suicide or euthanasia, that they are a burden and it is their duty to use a legal means of removing that burden from their loved ones.
- Legalising assisted suicide and/or euthanasia would send a message to the disabled that death is an option, that they are a burden.

6. RECOMMENDATION:

That the Medical Services (Dying with Dignity) Bill 2014 be rejected.