

**SUBMISSION TO VICTORIAN PARLIAMENT'S LEGAL AND SOCIAL ISSUES
COMMITTEE INQUIRY INTO END OF LIFE CHOICES**

'Voices From The Frontline'

From Andrew Denton

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I am a professional broadcaster, journalist and producer, perhaps best known for the interview show *Enough Rope* (ABC TV) and also for various documentaries about sensitive social issues, including: *The Topic Of Cancer* (ABC TV, about teenagers with cancer), *The International Year Of the Patronising Bastard* (ABC TV, about living with disability in Australia, winner of the UN Media Peace Prize), and *Angels And Demons* (ABC TV, an intimate look at living with mental illness).

For the last five months, along with my producer Bronwen Reid (*Lateline*, *Foreign Correspondent*, *Enough Rope*), I have been researching, what I consider to be, the greatest moral, ethical, legal, and social, challenge facing Australia: The question of whether or not to introduce laws which legalise assisted dying.

Having watched my own father die painfully from what is euphemistically called 'slow euthanasia' (increased morphine over a number of days) I began with these simple questions:

"Why can't we have a law for assisted dying in Australia? And what is stopping it?"

To answer those questions, I have travelled around Australia, to Oregon (twice), The Netherlands and Belgium and recorded in excess of 100 hours of interviews. A partial list of the people I have spoken with is attached to this submission.

The aim of this research was, originally, twofold: First, in preparation for the Wheeler Centre's Di Gribble Argument, which I will be delivering in October.

Second, to be released online as a podcast series, the intention of which is to move beyond the familiar battle lines of this debate and bring to the audience the authentic voices of those who are at its frontline – doctors, nurses, activists, academics, and lawyers, on all sides of the argument.

Above all, I want people to hear the voices of those most affected by the absence of assisted dying laws – the dying and the bereaved.

In doing this, I am hoping to provoke a serious conversation about assisted dying, amongst the Australian public generally, but in particular, within Australia's medical community which, I have been surprised to find, is often poorly informed about an issue on which they, nonetheless, claim to have strong opinions.

I am happy to have discovered a third purpose for this work: To bring to your inquiry the voices of those who seem, often, to be missing from these debates – the people in Belgium, the Netherlands, Oregon, and Australia, who are doing the dying, and the people who would help – or hinder – them.

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1. WHY DON'T THEY JUST KILL THEMSELVES?

I have had that question put to me more than once over the last few months, including by a palliative care physician. 'Anyone is free to kill themselves,' goes the thinking 'what's to stop them? Why do other people have to get involved?'

Lawrie Daniel is 50, married to Rebecca, and father to two almost-teenage children. Lawrie has advanced MS. There is no cure, only palliation. As we talked he described the sensation, that only lets up when he sleeps, of burning and tingling 'like ants crawling through your skin and muscles' and ..

... you want to scream inside because of what's happening in your hands but you've got to carry on a normal conversation and you can't be screaming all day long.

Lawrie has reached that unimaginable point where 'living is more frightening than dying'. I put to him a phrase common to those who object to assisted dying; that people such as him who wish to die ahead of their appointed time do not 'value their own lives'.

Crikey. No, there's not a suicidal bone in my body. I'm married to the girl of my dreams. I got two wonderful children. I'm living in that Heidelberg school painting - a house I designed myself. It's like life - it's the best of times, it's the worst of times, but no, that's all I can say.

Lawrie doesn't want to die. But the relentless, untreatable pain and degradation has got him close to the point where he can no longer live. I asked him what he saw as his options.

LD: *In the absence of voluntary euthanasia, well they're pretty bleak. In order to terminate your life you can't involve anyone else so it's got to be lonely. You've got to go off and do it by itself. And then you need to work out what you have to do to kill yourself. We can't get hold of Nembutal easily. You'd have to go and download eBooks and try and get drugs from overseas, and a lot of people aren't in that position.*

Then you've got to think, well how do you kill yourself? So either there's the sudden trauma or you have to stop the blood flow to the brain in some way or you have to stop the airflow in some way and unfortunately to be absolutely certain that you're going to - I mean people who also take toxic overdoses and these sort of thing - poisons or a therapeutic drug in sufficient quantities that it's a poison. But like I was saying, in order to be certain there are no really easy ways out without the use of someone with medical knowledge. To be certain you have to do it generally speaking a pretty violent way.

The single car accident is out. I was lining up gum trees along the side of the road that I thought I might be able to use but I can't even drive a car any more. It becomes even more difficult.

There's no easy way to kill yourself unless there is medical assistance.

AD: Do you have a sense of helplessness about this?

LD: *Yes, and anger too, that in this day and age this just isn't a regular human right.*

Lawrie's story is confronting enough. But when you realise it is just one tile in a much larger mosaic of mature-age suicide in Australia the picture becomes deeply disturbing.

We sought figures from the National Coronial Information System on the numbers and methods elderly Australians - 65+ - use to take their lives. It provides the most detailed statistical picture publicly available of a dark reality facing too many older Australians. These are only the deaths that have been reported for coronial investigation. There are others, maybe many others, which have escaped coronial attention.

The result underscores the view expressed to me by South Australian coroner, Mark Johns, that the suicide of elderly Australians is an untold story.

Across the period (2001-2012) the NCIS report shows that coroners recorded 3612 deaths by suicide and of those almost one third of people ending their lives were 80 years and older. **On average two octogenarians + a week are killing themselves in Australia.**

The most common method used is hanging.

Lawrie is still only 50 but, with no legal alternative, he is so desperate he is searching for ways to become another NCIS statistic. And it gets harder still. Like everybody I've spoken to in this situation, Lawrie is also deeply concerned about what it would mean for his family if he were able to get hold of some Nembutal and then use that to end his life peacefully.

Well you worry about the repercussions. If for example - you know you can't involve someone. She can't hand you the pills or she can't help you in any way. But you even wonder, if you were to organise the Nembutal and you gather everyone around and you have the ceremony. Would they be in trouble because they didn't call an ambulance while I was dying. You just don't know the legal ramifications.

It's a fear that Rebecca shares.

I'd be worried about the ramifications because knowing his thoughts and his wishes, that side of me would be saying obviously I must step in, but the part that sort of wants to help and do the right thing would be thinking well, I have to call the ambulance, and then you're thinking, 'Well I don't want to then be charged' if he's gone and I'm somehow charged with being an accessory or in any way enabling him, does that mean that I then won't be able to be the mother I have to be to our two children. And then also how do you say to them, 'Yes, oh by the way, yes I knew this was going to happen and I didn't do anything. How's that going to affect them? Are they going to blame me for the rest for their lives?'

The one universal truth I have learned about this subject: There is nothing simple about dying. For good people like Lawrie and Rebecca - and who knows how many others - the lack of an assisted dying law makes the cruel reality of Lawrie's death unimaginably crueler.

2. ALL WE NEED IS BETTER PALLIATIVE CARE

I was fortunate enough to spend a week in St Vincent's Palliative Care, Sydney. Nothing was off-limits as I followed the doctors on their rounds, became a fly-on-the-wall at the weekly team meeting, talked to patients, and shared one of Nurse Fran Damon's perfect home-made muffins as she and two other nurses agreed to be interviewed in the wee small hours one Saturday morning.

I was deeply impressed by what I found. Compassion and professionalism I expected, and they were there at every turn. What I also found was a profound connection – not to death, as you might assume – but to life. The deep way in which the staff at St Vincent's got to know the lives of the people in their care, and the lives of those people's families, will stay with me always.

There is one thing that everybody in this debate agrees on: The service that palliative care offers is invaluable and important. No sensible proposal for assisted dying embraces anything other than a continuation – indeed, an extension – of that care.

But ... there is always a 'but'. And the 'but' of palliative care goes back to the 13th Century and Saint Thomas Aquinas who introduced the idea of 'The Doctrine Of Double Effect'.

It's a bit of an amazing mind game and what it means in medicine is that, if you are tending to someone who is dying, you can give them medication which may have the unintended effect of helping them die more quickly but only if your actual intention is to ease suffering. What you must not do - ever, because only God giveth the hours and only God taketh away – is give them medication with the intention of helping them die. No matter how much they may be begging for it.

Today, that idea is boiled down into the central tenet of all palliative care: 'We will neither hasten nor prolong death'.

What does that mean in practice? Well, because of the universal truth – that there is nothing simple about death – it means different things.

For many people in the expert hands of a palliative care team, medication delivered with the intention of easing suffering, but not to hasten death, is sufficient. Their pain is controlled, nature takes its course, and they die a 'good death'

For some people, with particularly difficult symptoms to manage – agitation, existential distress, a constant sense of drowning, terminal hiccoughs, panicky gasping for breath – the only way their symptoms can be controlled is by terminal sedation; deep sedation that puts you into a coma which, if managed

right, you won't wake up from. You may never have got to say goodbye to those you love but at least the worst of the suffering in your dying hours is controlled.

But for another group of people ...? Ray Godbold, a palliative care nurse who earned the nickname 'Velvet Ray' in the Northern Territory because of his gentle way with patients, explains about the others

RG: *You know, I think everybody - if we all sat down on a Friday night and had a few drinks together and people were honest on what their beliefs were, a lot of them would come out and say, 'Look, that was a shocking death. We should have done something else to help', you know, but you've got the legal - the legal boundaries, the medical professional boundaries are all, you know - yeah, they've got you surrounded and you can't step out or be seen to step out because the next thing you know you could be accused of using excess morphine or - - -*

So there's that religious component to it... I've been there when lots of people have had terrible deaths that - no matter what palliative care people say, the last 24 to 48 hours of somebody's life is - can be completely unexpected, you know, and there's only - the only options you've got is to make that person unconscious and then you've got - the other side of the factor is the family's sitting there looking at this person who's been in terrible suffering, is now unconscious and is going to take hours or days or weeks to die.

You know, ... it's totally unjustifiable, and that's where the doctors and everybody have to turn their back because they are making that decision on the clinical information and that's - palliative care does a really good holistic admission to the service. They do. ..., but at the terminal stage, that's where it all goes wrong.

AD: What did you mean when you said that's where the doctors have to turn their back?

RG: *Thou shalt not hasten death. Well you're looking at a person who's clearly dying and say they've got morphine, 30 and midazolam 5 in their syringe driver, the little green book tells them that they can only increase that by such and such an amount otherwise it becomes out of the - clinical picture - it becomes too much. I'm sure doctors are doing it in their own situation and we're not hearing about it but that's what the letter of the law says.*

Presumably that level of treatment, regardless of the guidelines, varies depending on the individual beliefs of the treating doctor?

Of course. There's still doctors that won't give the after morning pill to different people and they're - the doctors have all got their own beliefs and a lot of them have got religious beliefs and that comes into the clinical area at times. I've seen it.

So when you go into palliative care, you're playing a kind of macabre death lotto. You may get a doctor, or if you're lucky, a nurse, who is prepared to give you more medication in your dying hours even if it might hasten death. Or you may not. Odds made even worse when you realise that **57% of all palliative care**

services in Australia are supplied by the Catholic Church.

No other medical service in this country is so dominated by a group whose core, non-medical, beliefs directly affect the amount of medication they are willing to supply in the course of their duties.

So palliative care, for all its wonders and compassion, cannot – and, on occasions, will not – help everyone.

This is not just an assertion: In 2008 Palliative Care Australia acknowledged that they could not relieve all pain and suffering, even with optimal care.

The latest figures from Wollongong University's Health Services Unit, which collects data from 106 Palliative Care units across Australia, bear this out: They showed that **one fifth of those in the last 24 hour of life died in moderate to severe pain despite the best efforts of palliative care.**

So what's it like to be on the other side of that line?

Spencer Ratcliffe is still deeply traumatised by the death of his partner Deb:

SR: *I'll give you an example of one night which was probably in the last ten days of her life when I was on night duty so to speak with her. The doctors can only administer, as you would know, morphine - certain amount over certain hours otherwise that can put the patient to sleep permanently, and obviously that's not allowed. So as much as the patient may want that, the doctors are understandably - and nurses - scared stiff of overdosing their patients. The pain was getting so intense on this particular night that Deb sort of called out to me and said, 'Spencer I need to walk. I must walk. I've just got to do something'. Well, she could still walk at that point. In the last few days she couldn't; she was in a wheel chair. But we walked around the corridors of this hospital for six hours until she was allowed to have more morphine and during those six hours - I've probably still got the marks - her nails were clawed into my back through sheer hell.*

We just walked past doors wherever they were leading into, you know, utility rooms, and she'd just scratch at the door. She had to do something to alleviate, albeit as a placebo, to alleviate the horrendous pain she was in. I've never seen pain like it. I've been a journalist for 49 years; I've seen people in pain all over the world in wars and whatever else. I have never seen anybody in such pain that she was in that night.

AD: What kind of pain relief did you ask for? Did you speak to the nursing staff and ask for help?

SR: *Constantly, constantly. That little red buzzer that you press, my finger was on it almost all the time, and of course they are busy people, the nurses, especially on night duty, so I was forever walking out to the nurses station looking for nurses, searching for them. They're busy with someone else of course. It was just so intense that you had to become a quasi-paramedic yourself and go looking for doctors. She was told she couldn't have another Endone or whatever. She begged me to give her an Endone.*

AD: Why were they reluctant to provide extra pain relief?

SR: *Because they were scared. I believe - well I know - they were scared that they would overdose her.*

AD: Did they say that directly when you asked them?

SR: *They said we can only - we're not allowed to give any more for another two hours and 14 minutes or whatever. It's all written down on the chart. 'Why not?' I'd say. 'Because that's the amount', the doctor says, 'we're not allowed to give any more than that'. 'Why not?'. 'Because it's the legal limit that we're allowed to give'. She was only allowed a certain amount every hour or two hours or whatever.*

But because the pain just keeps growing and growing and growing, but the amount of morphine grows too but not in accordance with the pain. It's very hard to measure that, but you can tell when someone's screaming in pain and they're just crying. 'Please can she have some more?' No.

I said 'How can you just tell me that? How can you sit and watch her in such pain and tell me she can't have more morphine?'. 'Because the doctor says I can't'. 'Get the doctor on the phone'. I would demand the doctor to come on the phone, the night palliative care - they had special team in the hospital that would come on at night. And probably every night I had them out there, and they would say what they had to say, 'We're not allowed to do any more. When you get her home, we will help you look after her'.

By the time she was allowed to leave the hospital - well, she demanded to leave the hospital in the end because she knew she had a day or two or three left - maybe a week, who knows, but she knew the end was nigh, and she did not want to die in the hospital.

3. WHY SHOULD A COMPETENT ADULT, WHO IS DYING AND WHO ASKS TO DIE QUICKLY, BE TOLD THEY HAVE TO DIE SLOWLY INSTEAD?

It's a tough question to answer. And usually when I asked it of someone at St. Vincent's Palliative Care there would be a long pause before the answer came back: "we don't do that here". "euthanasia is not part of quality care".

The idea that a patient should determine the manner of their own death, and that – worse – the medical staff would be complicit in it, is, to them, unthinkable. Impossible. Immoral and unethical.

Only it isn't. Palliative Care Australia long ago accepted that a patient has the right to choose how they die – and that the medical staff will assist in what ways they can.

There's just one catch: You have to choose a very specific way to die.

Richard Chye, Director of Palliative Care at St. Vincent's, is a formidably bright man, a gifted physician and teacher, and a great person to talk with. On assisted dying he is implacably opposed: It is morally wrong and if it were ever practised where he works he would resign.

But there is one circumstance in which he totally respects the patient's right to choose.

AD: Now according to the [Victorian Palliative Care] submission - this is a legal statement: 'The principle of respect for personal autonomy informs a widely held common law position that a competent adult has the right to refuse medical treatment even if this is considered contrary to their best interests and may result in their death'. Is that your understanding?

RC: *Yes, it is. It is part of the principle of autonomy that patients have the right to refuse treatment even though that treatment may prolong their life.*

AD: I see. Are there people who refuse treatment, all treatment, including food and water, because they wish to die?

RC: *Yes they do. Um...*

AD: How long does that take? If you have gone off food and water, how long does it take a human body to – I mean obviously there is an illness as well that would add to it, but on average, how long does it take a human body to shut itself down?

RC: *That's a very good question, and I have seen patients go in two or three days and I had a patient who went after three weeks, so it varies, and it is according to how much - what I would call - in inverted commas - 'reserve', how much reserve they actually have left in the body that can keep them going, so how much food have they consumed or were given just prior to stopping, so those are the different factors that determine how long a patient would last for, so yes, it varies very, very much, it depends on how much they had just prior to taking that decision.*

AD: My sense is that to refuse food and water is a painful way to go.

RC: *I think not physically but psychologically I think it is a very painful way to go, and I remember a patient who committed suicide who decided to stop eating and drinking and then because she was told, 'If you do that, you will be dead in two or three days'. She committed suicide because it hadn't happened after two weeks.*

AD: Wow, that is a terrible thought. So Palliative Care Australia will accept patient autonomy when it comes to refusing food and water...

RC: *Yes.*

AD: And maybe it can take two or three weeks to die, but they won't accept patient autonomy when it comes to requesting a faster and more merciful death. Why is that?

RC: *I think Palliative Care Australia, and I guess also from my point of view, we are very keen to understand what patients want. So if a patient wants to stop treatment and die as a result of their illness, then that is something we would be very happy to accept, especially when the treatment, mostly when treatments are not going to provide much significant benefit, and especially if the treatment was likely to cause more burden than benefit, then yes, by providing good palliative care, by providing good psychosocial and symptom management, then that is the right thing to do for that patient. I think for a patient to actively say, 'Put me to death, kill me now!' I think that is a fundamentally different thing, because whilst my intent in palliative care is to keep patients comfortable as they die, my intent is not, definitely not, to kill patients.*

AD: Yeah, no, I certainly understand that. From the patient's point of view, though, I would imagine there is zero difference – you know, 'I want to die, I don't have the option of dying quickly because it is not available here, so I will die as quickly as I can' - which unfortunately might be two or three weeks.

RC: *Thankfully that is very rare, that two or three weeks, but yes, I think it is uncomfortable for these patients to think that they are taking longer to die, and it is also uncomfortable for families to say they are taking too long to die.*

AD: And staff too, I would imagine - difficult to watch.

RC: *Yes, for staff too, yes, it is difficult to watch sometimes, when patients are living longer than we would expect and living in a very low state, and yes, we would commonly wish, and it is normal to wish, that patients pass on quickly. Those patients who are waiting a long time to die, those families who are waiting for their loved one to die who are taking a longer time, what it means for us is, 'Yes, I acknowledge, we acknowledge that it is taking longer, but we are still going to provide you with the best care that we can'.*

AD: And I don't doubt that, but to me it still sounds very tough. That patient who is beyond any medical help, who has determined that they wish to die but whose only choice is to have a longer, slower dying - two, three days - two, three weeks - to whose benefit are they being kept alive?

RC: *I think that patients who live do provide some benefit for the rest of the family and for themselves.*

To whose benefit are they being kept alive? The doctor's, whose morality tells him that it is wrong to assist someone to die, no matter that is their clearly expressed wish. Even though they *are* assisting someone to die of course – removing feeding and IV tubes, tending to bedsores, counselling the family, doing what they can – but, of course, their intention is only to relieve suffering, so no ethical problem there.

If you're the patient, though, bad luck. You don't get to choose how you die – unless that choice is starvation and dehydration – because your end-of-life choice is none of your business.

4. WHAT IF PALLIATIVE CARE AND ASSISTED DYING WENT TOGETHER? IS THAT EVEN POSSIBLE? IN BELGIUM IT IS.

Arsene Mullie is the kind of man you'd want to be looking after you when you're dying. Standing in shorts, t-shirt and boots, on his farm outside Bruges, the former President of Flemish Palliative Care, radiates a beatific smile of welcome.

A spiritual man, not unusual in Belgium with its long Catholic history, he was at the helm when the Flemish Palliative Care Federation became the only palliative care organisation in the world to integrate euthanasia in end of life care.

How can you say to a patient who suffers, keeps suffering? he asks. It's stupid to force somebody to live against his inner soul, his inner will.

When you do palliative care you know that you don't know everything. In palliative care there are so many things which are not purely medical. The feeling of medical friendship with your patients are very strong, stronger than in any field of medicine.

Patients are in a locked-in situation where the dying itself, it's so painful, there's a thankfulness that you felt from relieving the pain and hastening death. It's an act from friend to friend. It's a love act.

The biggest value of euthanasia for the doctor is the connectedness to the patient. Because we have the law there is a tendency to talk earlier, to open up talks with the patient about end of life within the last year of life.

In 10% of cases it is not possible for the pain to be controlled. I can say I cannot help you with morphine and sedation alone. I can give you long unconsciousness, the patient has no pain but you wait till death comes...you will be unconscious.

Or I can give you toxic medication which means there is no waiting, you will die immediately. About half chose euthanasia...many say, no I don't want euthanasia, I want my body to do this naturally. It is not a philosophical discussion at this point. It is about him. There is a lot of hard work in dying.

If the patient has no solution anymore and you also feel that there is no other solution and that it's time to die. How can you then not help?

But what of that central tenet, Arsene? The one about 'neither hastening nor prolonging death?

It's a sentence of 20, 30 years ago invented. It was a useful sentence. It was useful thinking, but it's not the issue. It's not the issue of the patient. The patient wants to be helped and It's a form of putting yourself above everything – of over pride.

I mean I am not saying that palliative care in England or France or so on that they are not honest but they are afraid for something which they shouldn't be afraid of and they are too much backing up from their patient.

5. 'YOU THINK WE'RE ALL MURDERERS'

That's what Dr Luc Proot, LEIF (Life Ending Information Forum) physician of Bruges, said when I first met him. For many in Australia that's not far from the truth. And why would it be? Mostly when we discuss Belgium and euthanasia it's in fluent tabloid-speak – 'They're killing children! Blind people! Who next? It's out of control!' – and we completely lose sight of the fact that, wait a minute, maybe these people have ethics and morals too?

But I think also physicians have also the feeling that it is not a slippery slope, not at all. Like some people abroad tell us. There is no slippery slope, because you have to ask it yourself. Nobody can ask it for you. You have to do it voluntarily, and you have to do it in writing. ... the conditions are very strict.

if I am speaking for the physicians here in Belgium, certainly when we are talking about non-terminally ill patients, afterwards they always tell us you do it profoundly, You take your time for each case. You don't follow the procedure because you must. It is much more than an act of euthanasia. You really try to understand the unbearable suffering of the patients, and I think that is important here.

Yves Desmet, the former editor of Belgium's leading paper, *De Morgen*, is aggrieved at how his country is portrayed. After all, the number of euthanasia deaths makes up only 2% of all deaths in Belgium every year - less than 2000 in all. Hardly the mark of a system out of control. Even the conservative Christian Democrat Party - who for years when in Government had opposed euthanasia (the laws were introduced when they were tipped out of power at the turn of the millennium) – made no attempt to repeal or amend them when they got back into office.

It's very confronting for us to see the way, the very harsh way foreigners look at euthanasia practice in Belgium. I think there are historical reasons. I mean the word 'euthanasia' is always associated with brutal selection techniques by Nazis or by eugenicists where people with a mental handicap were sterilised in the Scandinavian countries. That happened long ago. It has that sound about it. whereas as you look at it, the meaning of the word which comes from Greek, eu thanátou, eu - good, thanátou - death - the good death, the death that you choose for yourself, the death that you want to have when the alternative of living is becoming intolerable for you. That's an act of kindness for me, and so you see that people always fear for perversions of that kind act, that it will be performed on people who are too sick to be productive in society, for small children with a small handicap. Nobody's doing that. The slippery slope doesn't exist.

Nobody can force another person into euthanasia so you have to be - the one that demands it, you have to be with the doctor that will do it, who will ask assistance and guidance and advice from two colleagues, who will fill in forms that are reviewed by a board that said, 'Okay all the conditions were met'.

If there was a slippery slope or if there was an abuse of the possibility we would have long heard about it, I think. it's impossible that thousands and thousands and thousands and thousands of cases which we already had in those 10 years would all go unreported if there were cases of abuse. I don't believe that.

6. YES, BUT BELGIUM DOES EUTHANASE KIDS, DOESN'T IT? AND WHAT ABOUT THOSE POOR BLIND TWINS?

It's true, Belgium did extend its euthanasia law to minors last year, although children can only be granted assisted dying if they are close to death and in great pain. As Yves Desmet says, why should a child's suffering be viewed as any less than an adults?

Well it's very simple. If you're suffering from let's say bone cancer and you have two months to live and you live in agony and only doses of morphine can keep the pain under control, what's the difference if you are 15 or you are 18?

But usually, this compassionate medical act is reduced to a horror headline - 'now they're killing kids!' In many ways, this is where opponents of assisted dying want the debate to stay. **The actual figures of those who die in these countries – in over a decade now never more than 4% of total deaths (in Belgium it's 2%, in Oregon, a pitiful 0.4%) and always - always - overwhelmingly dominated by those dread diseases, cancer, heart failure and neurological disorders,** are very hard to attack.

So, instead, we are given FUD. Fear. Uncertainty. Doubt. Sow just one seed of doubt and you can reap a harvest of hesitation.

And as they sow they are gambling on the likelihood that you, the reader, do not have the time or resources to dig deeper, even if your freshly-pricked moral outrage allowed you to.

What could be a greater example of Belgium's slippery slope than the deaf twins who were killed? You may recall the story: Marc and Eddy Verbessern, both deaf, who at the age of 45, and faced with a suite of severe medical problems including the prospect that they would be blind and unable to work and live together, requested and were granted euthanasia.

Not only did they not have a terminal illness – *where does this law stop?* - but did you know it took them *two years* before they could find a doctor who would do the deed?

That's not just a slope. That's a slippery cliff.

Only they didn't spend two years doctor shopping. The family's GP swore as much, in evidence accepted by the Canadian Supreme Court. He had accepted the mens' request as their long-time GP.

When I put this to Paul Russell, the avuncular director of HOPE Australia ('Preventing Euthanasia and Assisted Suicide'), whose submission to the Senate Committee's hearings into Richard Di Natale's Draft Exposure Bill repeated these allegations of doctor shopping, he confessed that he hadn't known that.

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He was also broadly unaware that the twins' parents and siblings ultimately supported Eddie and Marc's decision to seek euthanasia, a remarkable demonstration of compassion and love towards two men making the hardest choice anyone could ever make.

And when I told Paul that we had spoken with the Verbessern family and they had told us how distressing they found it that the death of their sons was being misrepresented as an example of 'law gone wrong' by groups like HOPE, he had the decency to say that it upset him to know that.

Hopefully that story won't appear in HOPE's submission to this inquiry.

But there are far more damaging examples of FUD sown by those who oppose assisted dying: ones that needlessly cause distress and fear to some of the most vulnerable people in our community.

7. BRACKET CREEP: NOW THEY'RE KILLING BABIES.

I watched the Catholic Archbishop of Sydney, Anthony Fisher, debate Peter Singer at Sydney Town Hall recently on the subject '*Should Voluntary Euthanasia Be Legal?*' The two men had very different styles – Singer spoke in graphs, Fisher in pictures – and I thought that, as a performer, Fisher definitely won the night.

Fisher also had a very effective debating tactic: He would run together several emotive, unsupported, allegations about just who was being killed under euthanasia laws in Belgium and the Netherlands to paint a picture of a law that has no bounds or safeguards.

There is bracket creep in euthanasia. It evolves. First we're told its for competent informed consenting adults only. Then its extended to the incompetent the unconscious, babies. First it's for those who judge their own lives to be too burdensome for them. But how quickly societies that go down that path start making the judgment that those lives are too burdensome for others.

Putting granny out of her misery so easily becomes putting granny out of

our misery. The bracket creep is built into the very logic of euthanasia. once we start deciding that death is in the best interests of some people than of course there will be others in the queue. That's exactly what's happened in Holland and in Belgium. In Holland it was supposed to be for people in extreme suffering, consenting adults, but after ten years of that experience it became legal to do it for babies.

Killing babies. What could be worse?

What Fisher was referring to was the sinister-sounding '**Groningen Protocol**', which, he implies, is the Netherlands extending its euthanasia law to allow the killing of newborn babies.

But remember the universal rule? Death is never simple. When you look more closely at the Groningen Protocol, you find what you always find in those countries where euthanasia and assisted dying are legal: the medical profession responding with honesty and compassion to the difficult problems faced by every society, including our own.

Published in 2005, not part of the Euthanasia law but developed by doctors over many years, the Protocol was designed to help doctors provide humane end of life treatment to severely ill babies with a 'hopeless prognosis who experience what parents and medical experts deemed unbearable suffering',

These newborns faced appalling conditions. "Their suffering cannot be relieved and no improvement can be expected". Included in the group were infants with the most serious form of spina bifida. As well, "this group also includes infants who have survived thanks to intensive care but for whom it becomes clear after intensive treatment has been completed that the quality of life will be very poor and for whom there is no hope of improvement."

Doctors were convinced that life-ending measures could be acceptable in those cases '*under very strict conditions*' They were not acting under the Euthanasia law but rather seeking to establish transparent medical practice in the treatment of severely ill newborns who were suffering.

The Protocol meant that the parents must agree fully, on the basis of a thorough explanation of the condition and prognosis; a team of physicians, including at least one who is not directly involved in the care of the patient, must agree; and the condition and prognosis must be very well defined. After the decision has been made and the child has died, an outside legal body should determine whether the decision was justified and all necessary procedures have been followed.

Designed to negate criminal prosecution for doctors ending life in these rare and extreme medical situations, there was nothing secretive or clandestine about it. It wasn't even medically remarkable, as deciding not to initiate or to withdraw life-prolonging treatment in newborns with no chance of survival is considered good practice for physicians in Europe and is acceptable for physicians in the

United States. Most such infants die immediately after treatment has been discontinued.

What's more, **due to developments such as the introduction of prenatal screening, only one case has been reported under the Groningen Protocol since 2007.**

And, of course, what none of this describes is how anguished those decisions, for a parent to end their newborns' life, must be.

Much easier just to say 'they're killing babies!'.

8. THE DISABLED: LIVES NOT WORTH LIVING.

And there are real victims of these carefully planted distortions - the vulnerable, elderly and disabled - the very people who opponents of assisted dying laws believe they are protecting.

I was welcomed as a guest at the HOPE International Anti-Euthanasia Symposium in Adelaide in May. Speakers from around the world spoke lucidly, and with passion, of their fears should euthanasia laws gain a greater foothold than in those few places where it is already law.

I didn't doubt, for a second, the sincerity of their fears. Nor did I think they should be easily dismissed. The questions they raised – How safe are these laws? How do we know they're safe? How are the vulnerable being protected? – are valid and should always be asked.

Some of the things I heard (such as the death of Victorian teacher, Judi Taylor's, 25 year old son, who had used the EXIT International website to source Nembutal and plan his suicide) were genuinely disturbing.

But one thing puzzled me. Why were there people in wheelchairs there and why were they so upset? Nothing I had seen in my research to that point seemed to indicate that disabled people were in any way singled out, or disadvantaged, by these laws. That night at the dinner (guest speaker Kevin Andrews) I got talking to Joan Hume, paralysed after a car accident at 23, whip-smart and funny.

Joan belongs to a disability rights / anti-euthanasia group called **Lives Worth Living**. Their submission to the Di Natale Senate hearings included these words from the Irish convenor of HOPE, Dr Kevin Fitzpatrick OBE:

The false idea that quality of life can be measured leads to the vile idea that 'this life is not worth living' - as a judgment made most often by a third party...once those ideas are accepted as part of any discussion here, the game is over

Lending more weight to the argument for the gullible is the equally dangerous notion of the greatest good (for the greatest number) – Utilitarianism is not just rank bad Philosophy it is a morally bankrupt

philosophy, and yet it is repeatedly used in decision-making (usually as an excuse) for every social and healthcare policy and even for making war. One disabled person Becky was recently told in the UK: You cost the NHS too much money. It would be better off if you were dead.' (This latest example was cited by Baroness Grey-Thompson in the UK House of Lords debate 18 July 2014.)

This attitude to disabled people is so common that we long ago adopted the name 'Not Dead Yet' for our resistance campaign.

What I discovered when I interviewed Joan is that her lived experience as a disabled person in Australia is fertile ground for fears about euthanasia. Its a world in which disabled people - not so long ago described as a 'sub species'- battle, what she sees, as a base line 'hatred'

"I have been spat in the face and told 'why don't you kill yourself?'. Our lives are not as valued."

Joan genuinely fears that, once laws exist that allow people's lives to be legally ended, it is only a matter of time before disabled people – already devalued in the eyes of the medical community and wider society – are coerced into killing themselves, or being killed (never mind that the key part in all suggested legislation is the word 'voluntary').

I asked her what she knew of the lived experience of disabled people in places where these laws exist. She told me that most of her information came from a US online forum called **Not Dead Yet**. Read it and you will see why Joan's fears were in the red zone.

I then told her that, rather than speaking to people who were partisan in the euthanasia debate about this, I had gone instead to speak to people who are partisan about the same issues she is – representatives of peak disability organisations in Belgium, The Netherlands, and Oregon.

I asked them – quite neutrally – did they have any evidence of people with disability feeling more vulnerable under their euthanasia / assisted dying laws? Any evidence that disabled people were being coerced into ending their lives? Were they satisfied that there were enough safeguards in their laws to protect people with disability?

This is what they said:

Pierre Gyselink, president of the Belgian Disability Forum

I have not, and we do not have any knowledge about it because otherwise our members in the annual general assembly would have said to us, 'Please act against something because we have heard that rumour'. But I am sure, in my opinion, and in the opinion of BDF, we have no fear that people with disabilities are more vulnerable since that law was installed.

Bob Joondeph, exec director Disability Rights, Oregon

Since the law has been passed we have not received a complaint from anyone, other than a complaint from a person who was paralysed who was concerned that the law discriminated against them, because the law requires a person to self-administer medication and they were physically incapable of doing that. They were concerned that they were somehow cut out of using the law, but in terms of a person complaining about being exploited under the law that has not happened.

Ilya Soffer, Lederin 'everybody in', representing 250 disability organizations in The Netherlands

Euthanasia as such is no issue for people with disabilities as far as I can see. I think the most important protection in this law is this issue on your own judgment ... The other protective issue is, there must be a case of unbearable suffering ... So there must be really proof for unbearable and not improvable situation, and this must be assessed by two or three doctors and also the family around and the person itself. So I think that procedure which is a very strict procedure, if you look in the Netherlands I think you see more people complain on how strict the procedure is than on how coercive it might be for people who are vulnerable to these kind of practices.

When I read these to Joan she responded in a way I have very rarely seen in an interview. She fell silent. Then she said to me, "You obviously know more than I do. Would it be possible to get those contacts?"

9. 'ELDER ABUSE? ELDER ABUSE IS EXCELLENT'

One of the speakers at the HOPE symposium was former New Hampshire state representative, now organiser of Living With Dignity in that state, Nancy Elliott. Nancy spoke about the kind of tactics that work in arguing the anti-euthanasia case. She strongly recommended a multi-pronged approach:

When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else...Right now the disability argument is really kicking it...It's very powerful. Now will it always be powerful? We don't know. Two, three, four years from now that may have holes kicked in it, just for different reasons, so we have to be flexible. You know, when one of our arguments dies, we need to be ready to pick up another one.

Elder abuse? Elder abuse is excellent. There is nobody in the world that denies that there is elder abuse, and some of the people that are on the left that are most concerned about elder abuse but might be against us can be turned to our side by explaining that this gives another avenue, a very final avenue, to abuse an elder.

Suicide contagion is another very good thing to point out to your, you know, committees, and it has worked very well in the States. The statistics out of Oregon are consistent with a suicide contagion. We all know that when Grandma and Grandpa commit suicide, it makes it that much easier for their children and grandchildren to say, 'Oh this is what you do when life gets hard'.

If you look closely at most anti-euthanasia campaigning, you'll see Nancy's playbook being skilfully deployed. A bit later I'm going to ask you to consider Palliative Care Victoria's submission to this very inquiry as a prime example. Archbishop Fisher knows it well, too:

People whose autonomy is already reduced by pain, fear, depression get the message that they are no longer protected by homicide laws and might be better off dead. Having classed the frail, elderly, disabled and others as expendable, the community is likely to do less for them and leave them feeling worthless. So ironically in the name of autonomy, people's freedom is narrowed and their very lives, the premise of their freedom put at risk.

Their freedom, their very lives put at risk. A community "likely" to do less for them, and make them feel worthless. If this is the truth, then the elderly in Belgium, The Netherlands and Oregon must be leading very precarious lives under these laws, yes?

Again, I went to peak elderly groups in these three places and asked them (again, neutrally) about coercion, vulnerability, and safeguards. Like the disability peak group organisations before them, one by one – sometimes in perplexed tones – they emphatically denied that euthanasia / assisted dying laws had represented any kind of problems for their members:

Mie Meorenhout – Flemish Elders Council

We have no signals that are problems for the elderly since the beginning of the law of euthanasia. There are no signals, there are no claims of that.

Joeri Veen – ABNO, one of 3 big organisations representing senior citizens in The Netherlands

No, no, not really. Not at all even.... the current generation of elderly are much more - they take things in their own hands and they have a very strong opinion about that and they want to move freely in their lives and they want to maintain in control and they do not feel pressurised to do something they wouldn't want to do. What happens in the Netherlands is that people have autonomy over their own lives at all times...Even if someone has a testament [advanced directive] saying this, then still the doctor has to verify whether someone really is not able to command their own will. So even then it is still very difficult to get euthanasia passed. And that's something I want to make clear, because I absolutely deny the - some people who say that it's so easy to end your life here, like you just take a pill. It's not how it works.

Cherrie Broustein – Oregon Elders in Action

It really does not impact either the medically fragile or people with disabilities or older adults, because it really impacts people that are terminally ill.

In fact they went further. Not only had these laws not been a problem for their elderly members, they had been the opposite:

Joeri Veen

No, the opposite is true. People feel stronger now because they can make these big decisions for themselves and they have a lot of control in that. So these laws give them control or give them ways of preventing that [pain]

Cherrie Broustein

No. In fact I would say, as someone that's older and can see death in the future – which you cannot when you are in your 20s and 30s and 40s... I would say in some ways there is a reassurance that you would not – that if you have an illness that is going to cause enormous suffering, that that suffering can be relieved in a way that is humane.

Cherrie went on to explain that she originally voted against Oregon's Death With Dignity laws because she feared that they would make the vulnerable 'more vulnerable'. Seventeen years later, having seen the law in action at close quarters, she would have no hesitation in voting for them were the issue ever raised again.

10. THE TRIVIALIZATION OF DEATH: HOW CAN WE TRUST OUR DOCTORS ANY MORE?

Opponents of assisted dying commonly assert that the introduction of euthanasia and assisted suicide has the potential to erode the trust that patients have in health care professionals. Worse:

Given that euthanasia may be routinized and expedient, there is a distinct possibility that death will be come trivialized.

(Palliative Care Victoria's submission to the Inquiry Into End Of Life Choices p. 23).

One of the most striking things about the doctors I spoke to in Oregon, Belgium and the Netherlands – not all of whom had the same view of the system - was their universal agreement that euthanasia and assisted dying laws had made it possible for them to have far better, and more meaningful, end-of-life discussions with patients.

The very existence of euthanasia, or physician assisted dying, as an option for those who meet the due criteria is, in itself, an invitation to discuss what many still find to be taboo.

The knowledge that your doctor will be there for you right to the end if necessary – that she will not turn away or that, if she has a moral objection to euthanasia, she is obligated to point you towards a doctor who does not – has only increased the level of trust between patients and doctors.

Leigh Dolin, former president of the Oregon Medical Association, put it plainly:

Oregon's law has been a dramatic success. The dire fears that doctors would become less trusted, or worse, just hasn't happened. We have an experiment that works. Anyone that tells you otherwise is giving you a crock of shit.

As for the trivialization of death, on this, the doctors I spoke with could not have been clearer:

Dr Marika Koster, Netherlands, discussing the first time she performed euthanasia.

She (my patient) said 'What I am having now - this disease - which is wasting me, I feel my strength sipping away - sapping. It is so contrary to who I am, who I always have been, how I want to be remembered. Life has nothing in store for me any more. I do not want this last part.'

It was terrible. I felt completely at a loss, and I realised I did not want her to die would she have put the question.

The patient, who had cancer, did put the question and Marika performed the service. Afterwards:

I was standing in the corridor and I was shaking and sobbing,

For doctors it is very difficult to really accept that their patient is going to die.

But I really felt I am doing something that is huge, that is grand. I am going beyond what is normal medical care. I am doing something that is set apart from what is normal care.

You do not do this lightly. It is really something. It is not something doctors like to do; they do not. If you can get around euthanasia as a doctor, you will do it, because it costs you.

Arsene Mullie, Palliative Care Physician, Belgium.

I have a strong memory of my first euthanasia. It never became a habit or routine. I was trembling for about 5-10 minutes. It was not a natural act. Many physicians are so afraid that they will never do euthanasia themselves.

Eric Van Wijlick, Senior Policy Advisor, Royal Dutch Medical Association

Usually it takes a lot of time. It takes time to grow to each other, because doctors first want to alleviate suffering. They want to cure patients, and

when that is not possible, they want to alleviate the suffering. At the end, when there is no realistic option, then killing a patient might be an option. It is very difficult. It is very, very difficult. So the patient really has to have strong argumentation to convince their doctor. Doctors are not willing to perform euthanasia; they will do everything to prevent death.

Rob Jonquierre, President, NVVE Netherlands

And I think that since in all our more than 13 years of experience we see that still doctors do not like to do it - even when I got a request as a family doctor my first reaction [was] 'Let's try and look for something to not to have to do it', instead of 'Oh yes, OK, tomorrow afternoon, I do it'. That is where I am a strong believer that that is one of the safeguards which is not written down in the law but which is part of our practice - where the doctor in the one-to-one relationship with the patient comes to the final decision, 'Yes, I'm going to do it'.

11. THE INTERSTING CONCLUSIONS OF ALEX SHADENBURG – AND WHY THEY MATTER IN AUSTRALIA

The most striking person I met at the HOPE Symposium in Adelaide was Canadian Alex Shadenburg of the Euthanasia Prevention Coalition. Alex travels the world addressing like-minded groups and giving them serious amounts of information with which to fuel their arguments.

To meet Alex is to be bombarded with a multi-pronged attack direct from the Nancy Elliott playbook: elder abuse, disability abuse, invisible crimes, suicide contagion (He actually used the term “suicide contagion” about Oregon. Said it’s “really happening” in that state now they have Death With Dignity laws. You know, once the kids see grandpa do it legally, they’ll think about doing it too. So I checked with Katrina Hedberg, State Epidemiologist for the Oregon Department Of Health. She said that, yes, Oregon does have a higher suicide rate than many other States in America and that they’re not sure why. But that has been the case for the last 40 years and the introduction of Death With Dignity laws in 1997 hasn’t caused those numbers to change one jot. So much for the contagion. Still, it sounds impressive when you say it quickly).

Alex’s big thing is that he’s about facts, not just conjecture. When I made the mistake of suggesting he was asserting something, he said:

See, it's not even my assertion, 'This is what I think '. I'm just extrapolating the data. If this is the research, and it is, that's what they're saying. They published the information connected to it. You can look at the article. I'm not making anything up, which is the crazy thing about it.

In his book **‘Exposing Vulnerable People to Euthanasia And Assisted Suicide’** Alex claims to have gone back to source documents and analysed major studies from the Netherlands and Belgium which prove that no assisted dying legislation can protect citizens from the possibility of abuse.

It's good methodology to go back to source documents rather than do what many others do, which is to work off other people's conclusions.

I was impressed, so I bought a copy of his book and then enlisted the help of Professor Margaret Otowski, Dean Of Law at the University Of Tasmania, to help me determine if Alex's methodology was good, and his conclusions accurate.

As it turns out, neither hold. Because, when you follow Alex's trail, and go back to the same source documents, an interesting thing happens.

Take a 2009 study published in the New England Journal of Medicine called **Medical End-of-Life Practices under the Euthanasia Law in Belgium**. It focuses on *'The unreported cases of euthanasia or those deaths occurring without explicit patient request.'*

Alex's conclusion, after analyzing it, was:

Most people who die by euthanasia without explicit request are from a different demographic group to those who request euthanasia and that this group is more vulnerable.. that is, they're elderly, often incompetent patients with cardiovascular disease or cancer, often dying in hospitals.

On the face of it, very disturbing. This seems to be proof that the elderly are being euthanased without their consent in Belgium - an argument used by critics as evidence of the slippery slope.

But it's what was omitted that is most telling. What Alex left out is the author's own conclusions which directly contradict what he claims they are saying:

"We found that the enactment of the Belgian euthanasia law was followed by an increase in all types of medical end of life practices with the exception of the use of lethal drugs without the patient's explicit request. No shift towards the use of life-ending drugs in vulnerable patient groups was observed. (My underlining)

That conclusion refutes absolutely the point Shadenburg makes. The studies show doctors were not using euthanasia drugs on vulnerable elderly patients..

It happens again with his analysis of the study. **Physician-Assisted Deaths under the Euthanasia Law in Belgium: A Population-Based Survey, appearing in the Canadian Medical Association Journal in 2010**

After careful analysis, Shadenburg concludes that:

'the vulnerable die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime'

Once again, the original author's – peer-reviewed, unlike Shadenburg's – conclusions, which directly contradict his, are omitted:

'As was shown in other research, no evidence was found to support the fear that, once euthanasia is legalised, the lives of elderly patients would be more likely to be ended with assistance of a physician. According to our findings, patients of 80 or older were underrepresented among euthanasia cases compared with all deaths even after controlling for diagnosis and place of death. The number of reported euthanasia cases in this age group did not increase significantly over time. Older patients thus seem not to be at higher or increasing risk of euthanasia after legalisation'

There are other examples. For Professor Otolowski, author of a large body of recognised research in this field, Shadenburg's work is a cause for concern:

I'm really concerned that especially if he is travelling the world with this - on tour to make a strong case against legalist on of euthanasia that these arguments will get traction and that there isn't enough exploring beyond the immediate surface message to understand what is he relying on - is it valid data - and identifying where the gaps are in the account. Because as soon as a close and systematic review of that work of his is undertaken you realise that it's highly problematic.

You could understand that some would, on a superficial read of his work, say 'Well this is just the evidence we've been wanting and needing to demonstrate that it would be dangerous to legalise euthanasia' and they would readily endorse it, but without recognising that there's so much more academic literature beyond his work and that in fact what he has done is to ignore a lot of the conclusions about practice in countries such as the Netherlands and Belgium. So it's not an accurate portrayal of the current situation.

Why does this count in Australia? Because the foreword to Shadenburg's book is written by Kevin Andrews and it contains endorsements from half a dozen other Australian politicians, state and federal, as well. Their weight adds gloss to this counterfeit coin.

How easy, then, for this 'evidence' of a cold, heartless medical profession committing crimes in Belgium and the Netherlands, to slip onto the public record, uncontested? And once there to be repeated – perhaps even at this inquiry – until it is simply accepted as the 'truth' about what's happening under these laws?

12. POISONING THE WELL OF PUBLIC CONVERSATION: PALLIATIVE CARE VICTORIA.

For an example of how unexamined and heavily-coloured arguments designed to make people fearful of the consequences of assisted dying can end up in the public square, look no further than Palliative Care Victoria's submission to this inquiry – **'Living, Dying & Grieving Well'**

Described as an *“in depth consideration of the issue”*, based on *“consultations with our members, discussions with international colleagues, and reference to available evidence”*, it is, on one level, a fully-understandable ‘sell’ for the virtues of palliative care and the need for it to be better-resourced.

But on a deeper level, it is an entirely partisan anti-euthanasia document badged with all the authority of Palliative Care Victoria having given the issue ‘in-depth consideration’.

The first tell is in the footnotes. Look carefully and you’ll see that many of the key sources, while they may look neutral or ‘scientific’, are actually deeply committed anti-euthanasia campaigners from around the world. Alex Shadenburg isn’t there, but many of his arguments and associates are, including:

High-profile anti-euthanasia campaigner and academic Professor Margaret Somerville, who is extensively quoted. Anti-euthanasia campaigner. Emanuel Ezekiel, from the Anscombe Bioethics Centre, Oxford, UK – a Roman Catholic academic institute. The European Institute Of Bioethics – the go-to people in Europe when media need an anti-euthanasia quote. Brian Pollard, a frequent contributor to the anti-euthanasia forum Adelaide Centre For Bioethics And Culture. Professor Theo de Boer, a former Euthanasia Review Committee member in the Netherlands, now a critic. As well as individual, unnamed doctors in Belgium and the Netherlands who oppose the laws.

Of course, there’s nothing wrong with any of these people being cited. But because absolutely no-one is quoted to address their criticisms, the picture that is painted about the systems in Belgium, The Netherlands, and Oregon, is deliberately distorted. For example:

1. Palliative Care Victoria’s submission states that there is an annual increase in euthanasia deaths in the Netherlands of around 15 percent and that this is a cause for alarm. What they don’t do is put that figure in context by explaining that the increased numbers of assisted deaths are consistent with an ageing population - much like ours – presenting with exactly the kinds of diseases one would expect – cancer, heart failure, and neurological disorders, which make up 90% of all euthanasia deaths in that country; that, according to the Royal Dutch Medical Society, two-thirds of euthanasia requests in the Netherlands are not granted; and that the total number of euthanasia deaths makes up a tiny 3.4% of total deaths in the Netherlands.

They also don’t mention that support for euthanasia in the Netherlands sits at 85%, including across all mainstream political parties and every key medical body.

2. The submission states that, in Oregon, “deaths as a result of physician assisted suicide have increased by an average 14% per year over the past 5 years”. Put in context, the picture is very different: The number of people who ended their lives through physician assisted dying sits at a tiny 0.3 percent of all deaths in Oregon; Again, the overwhelming majority of those 105 deaths are

from cancer, neurological disorders and heart failure; and, as with previous years, almost 40% of people who had been written prescriptions for life-ending medication had declined to use it – the knowledge simply that they had it as an option in their dying days effective as palliation in itself.

3. The submission criticises the continued practice of patients lives being ended with out request in Belgium (so-called 'LAWER' cases – Life Ending Acts Without Explicit Request), citing studies in Flanders which show that 1.8% of deaths in the study were due to the use of life-ending drugs without the explicit request of the patient.

The authors of the survey note *“the need to protect patient groups from such practices, which are contrary to the law and go beyond the scope of palliative sedation therapy”*.

The study they are referring to, published last year in the Canadian Medical Association Journal, is **Kenneth Chambaere et al, Physician-Assisted Deaths Under The Euthanasia Law In Belgium, A Population-Based Survey**. It shed light on the clinical decisions of doctors when caring for patients who are within hours or at most a day or so of death. These LAWER cases are interpreted by HOPE and other anti-euthanasia groups as *‘euthanasia cases that are not reported to the authorities’*.

The reality is far less sinister. What these doctors were doing was to increase the doses of drug combinations and opioids (not a euthanasia drug) designed to relieve pain and the deeply distressing symptoms of dying.

In many cases, they did it without the patients' consent. Why? Because the patient was dying, often comatose, and not in a position to communicate. The study showed that medications were given, not because doctors intended to end the patients life, but because they hoped to shorten the agony - something that palliative care teams do worldwide, including in this country as part of their practice, a fact confirmed for me by Professor Richard Chye, Head of Palliative care, St Vincent's, NSW:

AD: If I am looking at this from the outside,,, is it technically correct to say that it is not always possible to get the explicit consent of the patient for terminal sedation?

RC: Yes, very much so. And in New South Wales, where you get the 'consent' - in inverted commas - is then from families, from the wife, from the spouse, from the children. It is a term that we call 'person responsible' in New South Wales. If a patient is unable to give their consent, then we go on to the next person to get consent in a way, or rather to tell them, *“This is what I think is the best treatment, this is the way I think the medication should be used”, and I am bringing the patient and I am bringing the family along with me.*

AD: And this sounds to me like exemplary palliative care practice. Is it your understanding that this is what palliative care does in most advanced countries in the world, that this is standard practice?

RC: *Yes, I think so, and the thing that confuses it that a lot of people think that because we are sedating patients and giving lots of medications, humongous doses of medications, then that must be the same as euthanasia, which it is definitely not.*

By deliberately including only views that suggest something is wrong with what is happening overseas, Palliative Care Victoria have created a reasonably convincing portrait of the 'slippery slope'

But because they have given no space to the views of the bodies charged with overseeing the law in the Netherlands, Belgium and Oregon, this is not a true picture.

In each and every case, those bodies report no systemic abuses of the law. They specifically address the question of the slippery slope - that the law is being extended beyond what was originally intended - and they report to parliaments that there is no evidence of the system being out of control.

It is telling that, in each of these places, despite a small number of cases being referred to prosecutors for examination, none have been recommended for trial since the inception of euthanasia and assisted dying laws.

Critics suggest this is evidence of entire societies that have lost their way. But if you have to choose between a scenario that suggests an entire nation, from top to bottom, it's journalists, police, judges, politicians, lawyers, nurses and doctors, is willfully turning a blind eye to abuse and murder of thousands of its most vulnerable citizens - and a scenario that says the laws are working, largely as they should be, which explains both the large numbers of people that support them and the small number of people who use them - which seems more likely?

The likelihood that this second scenario is correct is supported further by the most legally exhaustive investigation into euthanasia and assisted dying yet conducted, by Justice Lynn Smith of the British Columbia Supreme Court (2012) - a decision subsequently upheld unanimously by the Canadian Supreme Court - which found that there was: **"no evidence from permissive regimes of a slippery slope"**

None of this, however, is a part of Palliative Care Victoria's submission.

When I discussed this obvious bias with Professor Chye, himself a board member of Palliative Care Australia, while he did concede that the report seemed less-than balanced, he argued that they Palliative Care Victoria are prosecuting a case and that they have no need to include their opponent's arguments as they will be well represented in this inquiry anyway.

As a debating point, this is correct. But I argue that Palliative Care Victoria have greater responsibilities. They carry disproportionate weight in this argument. Politicians, who have to decide whether or not to legislate on this most challenging of medical issues, are unlikely to do so in the face of dire warnings from the medical community, no matter how strong the public support.

It is no coincidence that, in the Netherlands and Belgium, the push for euthanasia laws came from within their medical community. Similarly in Oregon, where the Medical Association's decision to take a publicly neutral position - having debated the issue at length and found that they were split down the middle - was, in the words of Dr Leigh Dolin (Oregon Medical Association) a 'powerful message to the public that doctors weren't going to tell them what to do on this issue'.

I believe Palliative Care Victoria have a responsibility - to their members, the public, and their patients - to tackle this crucial public health issue with more openness and more courage.

In this, they could follow the example of Emeritus Professor (Flinders University), eminent palliative care specialist, and the first President of the Australian and New Zealand Society for Palliative Medicine, Ian Maddocks, who states:

If compassionate and loving care towards patients and families is what palliative care is all about then assisted dying is part of that. It is time the profession dealt with it.

13. "THE BURDEN OF PROOF IS ON THOSE WHO WANT THESE LAWS TO DEMONSTRATE THEY ARE SAFE"

Paul Russell, from HOPE, said that to me.

I think, however, that the burden of proof lies on him and those who oppose these laws, to demonstrate - truthfully - that they are not safe.

Because we have been looking intensely at how they operate for more than a decade now. The research on, debate about, and scrutiny of, them is unmatched, as Professor Jan Bernheim (Vrije University) -one of the architect's of Belgium's euthanasia laws - points out:

Belgium and the Netherlands are the only countries, really the only countries so far in the world, where the life end has been so thoroughly and robustly studied.

The only place where apparent abuses are actually on record are the places, are the countries, which have advanced in this field, and which have made a point of it, to study what they are doing.

And I would say that I cannot exclude that there are cases of poor care at the end of life or even really objectionable things happening. They stay under the radar for obvious reasons. We do all sorts of efforts to bring

them to light and to some extent we have some view on them in the Benelux countries – [but] not elsewhere.

But the likelihood of [these] unethical practices going on has been much reduced by the openness of the whole procedure, by the fact that there is control over what is going on, by the fact that there is peer review in hospitals and among colleagues.

And I think that is probably the most effective control, because we have a number of colleagues, probably in the order of 15 or so per cent of doctors in Belgium, something like that - in the Netherlands too - who really do not want to touch euthanasia with a pole. And you know, it is not that they do not want it for respectable, sometimes religious or philosophical reasons. But these guys, we are working with them. They are watching us, right?

Dutch physician, Gerrit Kimsma, also a member of the Regional Euthanasia Review Committees, added:

Every case that has been reported - last year more than 5000 cases - each case is being analysed. There is no country in the world except for Belgium and Luxembourg now where that takes place. I am sure we know from research also that euthanasia and assisted suicide take place everywhere. None of these cases are being reported, none of these cases are being reviewed. We are being transparent and I think we have a good system. We should be proud of it.

When I put to Eric Wiljick, from the Royal Dutch Medical Society countryman Professor Theo De Boer's suggestion that the 15% annual rise in euthanasia numbers in the Netherlands is a sign that the law is becoming too loose, he responded strongly:

*I totally disagree because the risk for society without having a legal system or professional guidelines and safeguards is even more risk for society. So I disagree on that. My explanation for the rise – it is true, the 15 per cent every year. It also depends on the number of people who are dying yearly in society, and that number is rising, and the number of patients who die of cancer is rising. But I totally disagree that it is risky for society, because without a law and professional guidelines and safeguards **you** have the same problems as well. We see it in Canada, we see it in Australia, we see it in Germany, we see it in France, we see it in Belgium, we see it in the United States of America, the South Americas – we see it all over the world.*

14. WHEN DOES A HUMAN RIGHT BECOME A HUMAN WRONG?

Many people believe that euthanasia laws mean Dutch people have come to see death as a 'right'. As Eric Wiljik of the Royal Dutch Medical Society explains, this is a misconception:

Death is a right? Death is a fact at the end of life. No-one can avoid that. People think if you have a law, then you have the right, but it is a misunderstanding.

Dr Mariska Koster:

You are under no obligation whatsoever to do this. That is the essence of the Dutch euthanasia law. It does not give a right to a patient; it protects the doctors. It is something that can be asked. It is something that can be given, but it is not something that can be demanded, and I think that is a good thing. It is an essential part of it.

In Australia, the question of what is a basic right –and what is not – remains vexed. I asked Professor Richard Chye, head of Palliative care at St Vincent's, to explain to me how Palliative Care Australia's pledge to 'protect the most vulnerable' does not extend to those wishing for help to die.

AD: I have spoken with people who are still alive who have been through palliative care in Australia, for whom the pain relief hasn't really touched the sides. I have spoken with families who have seen their family members die in palliative care units in Australia begging for more medication and being told that there wasn't more or there wasn't more scheduled right now. Who could be more vulnerable than these people and why shouldn't they be protected?

RC: *They are vulnerable patients, they are vulnerable people, and yes, if they are not getting the adequate symptom management, then it is a health system issue that we need to try and solve. So some...*

AD: But you know why it is happening - we have discussed it - because there is a limit to how much in some cases pain relief you will give. You said so yourself the other day. And that limit effectively is: 'I want to die, I need to die; I can't stand this anymore'.

RC: *Part of the provision of palliative care is understanding yes, the reasons for wanting to die. If pain is a very difficult symptom and it has led to a patient saying 'I want to die', that they want to die, then it invokes in me the need to do better, to try and improve that pain, and if I cannot improve that pain, then I try and help that patient live with that pain.*

AD: That's very tough if you are that patient, Richard,

RC: *It is a very tough, but I am not going to leave that patient. I am not going to leave the patient in pain...*

AD: But effectively you are. I am not saying you personally but effectively that is what you are doing. For those patients that can't be helped, that is effectively what you are doing.ß

RC: *No, I don't agree with that. I think that I am not leaving that patient in pain. I...*

AD: Who are these people screaming for help that I have spoken to?

RC: *That is a systems issue that I think we need to examine why patients are, as you said, asking for pain relief and being told it is not due yet.*

AD: It is your system though, Richard. And again, I am not saying you, Richard Chye, I am saying it is palliative care, it is end of life care; it is your system.

RC: *We are not perfect.*

AD: Of course not.

RC: *We are not perfect in the palliative care system*

AD: And you can't be. And no-one suggests that you can or should be because there are some things which can't be managed, which are beyond all your efforts and skills.

RC: *But I think we need to look at - I think if someone is saying that I am in pain, we need to be able to look not only at the treatment but look at the system as well. Why is that patient not able to get pain relief? Is it because we have staff, not only in the palliative care arena but also in the hospital, arena, in terms of are they adequately trained? Do they have the resources to manage them? And I am saying at the moment no, I don't think we have all the resources that palliative care in Australia requires to be able to provide the best care that we can at this point in time, and that includes educating the rest of the non-palliative care health system about how to look after our dying.*

AD: And they are all good questions, and they should be asked and asked consistently; however, Palliative Care Australia says that even with optimal care not all pain and suffering can be relieved, and so for those few people, that small number of people that you can't help, you offer nothing. It is not a systemic failure; it is a deliberate decision. Let me ask you this - is it true that there is some suffering that can only be relieved by death?

RC: *In medicine we never say never.*

AD: But in reality?

RC: *I don't know.*

AD: Richard - this is the only time where I thought you were being disingenuous. I think you do know.

RC: *I would feel that there will be times, and I think it is normal me to feel if I haven't controlled your pain or I haven't controlled your depression or your mood, yes, you are probably better off dying earlier than now. But that is not going to stop me from trying. It means that I acknowledge that the problem is difficult. It means I acknowledge to myself, to my team, to my patient that it is difficult, acknowledge that it is not easy to look after a particular symptom, acknowledge that I am going to be trying my best to help that patient, acknowledge that I am going to be with my patient to try look after that patient and try to minimise that suffering as much as I can. Yes, I am not going to be able or may not be able to control that completely, and yes, in my heart I would think that this patient may be better off dying earlier, but that is a normal reaction, normal emotion for me to have, and I think that if I didn't have that emotion, I have to worry about myself, but it doesn't absolve me from abandoning my patient and trying.*

AD: Which is admirable, but with respect, what I hear there is about you but not about the patient.

RC: *No, I also acknowledge with the patient that it is hard, acknowledge that the patient is going through a very difficult period, going through a lot of suffering, yes, acknowledge that. And that is part of that acknowledgement with the patient who understands that they are suffering. Yes, they will say this suffering is very hard for them and they would prefer to die, and I would say to them, 'Yes, I acknowledge that you are feeling that way but I will continue to try and make you feel better so you don't have to feel that way'. So I don't see - it is not for me to say or not my practice or not my ethics or not my morals to say, 'Because I can't look after you, you are better off dead, and I will pursue that end'. No, that is not me, and that is not palliative care.*

AD: And as you know, under these proposed laws, it would never be you saying that; it would be the patient requesting it. I'll finish with Palliative Care Australia's statement that it accepts quality care at the end of life as a basic human right. Does that human right stop with somebody requesting to end their life by their own timing?

(Long pause)

RC: I think quality care is providing the best care that we can, so that the patient is provided with good end of life care. I don't see providing euthanasia as part of the quality care, and I don't think Palliative Care Australia sees euthanasia as quality care.

15. SOME FINAL THOUGHTS

The laws in Belgium, Oregon and The Netherlands were set up, not to create something new and dangerous as critics suggest, but in response to what was already happening – and what is happening in Australia today, whether we like it or not.

And it is this: Because of the universal truth that death is not simple, then there will always be – just as there has always been – situations where even the best efforts of caring doctors and medical science can achieve nothing.

It may be the grandmother dying of cancer. The father of two struck down with MS. Or even the baby born with shocking and untreatable deformities.

And the question before us when faced with these tragedies is not ‘should we do something?’ but ‘what is it that we should do?’

The suggestion that we in Australia should turn our backs because it is simply beyond us to find a way to respond with compassion for the few, and care for the many, is, to my mind, unacceptable.

Because if we continue to hide behind the same discredited arguments and distorted fears, and do nothing, then we do so in the full knowledge that people will continue to suffer, and die badly, because we cannot find within ourselves a more compassionate answer.

We know enough now from overseas. We can see how this works – and that it does.

Not everything that they have chosen to do will be right for us, and we will make our own call on that, but enough of what they do is right for those most in need – the unfortunate few begging for our help.

And so the question falls to us: When it comes to our humanity, where do we draw the line?

PARTIAL LIST OF PEOPLE INTERVIEWED IN RESEARCH FOR SPEECH AND PODCAST

AUSTRALIA

Dr Rodney Syme, Dying With Dignity, Victoria
 Paul Russell, HOPE Australia, Preventing Euthanasia and Assisted Suicide, SA
 Joan Hume, Lives Worth Living, NSW
 Professor Richard Chye, Palliative Care, St Vincents, Sydney
 Professor Phillip Redelman, Palliative Care, St Vincents, Sydney
 Ken Webb, Nursing Unit Manager, Palliative Care, St Vincents, Sydney
 Various nurses and patients, Palliative Care, St Vincents, Sydney
 Professor Ian Maddocks, 'father' of Australian Palliative Care, SA
 Dr Philip Nitschke, EXIT International, NT
 Dr Richard Di Natale, Australian Greens Senator, VIC
 Professor Margaret Otłowski, Dean, Law Faculty, University Of Tasmania
 Marshall Perron, former NT Chief Minister, QLD
 SA Coroner, Mark Johns,
 Former Justice of the Supreme Court of Victoria, John Coldrey QC

NETHERLANDS

Erick Wiljick, Senior Policy Advisor, Royal Dutch Medical Association
 Dr Gerrit Kimsma, Physician, SCEN Doctor, member Regional Review Committee
 Henk Reitsma, Euthanasia Prevention Coalition (Europe)
 Dr Mariska Koster
 Willie Swildens, Brussels Chair, regional Review Committees (Euthanasia)
 Joeri Veen, ABNO, peak organisation representing the elderly in the Netherlands
 Dr Rob Jonquiere Director NVVE, Netherlands Right to Die Society
 Stephen Pleiter Director, Life Ending Clinics
 Illya Soffer, Leder(in), representing 250 disabilities groups in the Netherlands

BELGIUM

Dr Luc Proot, Life Ending Information Forum (LEIF) physician, Bruges
 Tom Mortier, mother euthanased without – at her request, and according to law
 – the family being informed. Critic of system, recently featured in *The New Yorker*
 Dr. Arsene Mullie, President Flemish Palliative Care, 2002-12
 Professor Jan Bernheim, End Of life Research Group, Vrije University
 Dr Lieve Thienpont, Psychiatrist
 Pierre Gyselinck, president, Belgian Disability Forum
 Professor Dirk de Wachter, Psychiatry, University of Leuven
 Jacqueline Herremans, Co-chair Federal Commission of Control and Evaluation
 Dr Marc Desmet, Jesuit priest, Palliative care Doctor, Leuven
 Yves Desmet, former editor, *de Morgen*
 Mie Moerenhout, Flemish Elders Council

OREGON

Eli Stutsman, lawyer, Portland. Helped draft Oregon's Death With Dignity laws
 Peg Sandeen, Death With Dignity Oregon
 Derek Humphry, EXIT International
 Bob Joondeph, executive director Disability Rights Oregon

Katrina Hedberg, State Epidemiologist, Oregon Health Authority
Dr Leigh Dolin, former president Oregon Medical Association
Cheryll Brounstein, Oregon Elders In Action
Alex Schadenberg, Canada, Euthanasia Prevention Coalition.

PEOPLE WHO ARE DYING OR FAMILIES OF THOS WHO HAVE DIED

Ray Godbold, 59 (VIC) and family
Lizzie L , 48 (NSW) and brother.
Albert Leonzini, 71, (VIC) and partner, Sandra Morris
Lawrie Daniel, 50 (NSW) and wife Rebecca
Joan Upton, 89, (NSW) and daughter Annette
Shayne Higson (NSW) on behalf of her mother who died of brain cancer.
Spencer Ratcliff (NSW) on behalf of his partner who died of brain cancer.
Kerry Bromson (NSW) on behalf of her brother who died of stomach cancer.