



Inquiry into end of life choices
Lawrie Daniel

to:

lsic

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To: <lsic@parliament.vic.gov.au>

I have multiple sclerosis. I have just turned 50 and have 17 years before I even reach retirement age. My MS has become rapidly progressive and has gradually stripped me of everything that made up my identity as an autonomous human being; my job, my roles as husband and father, my ability to contribute to others, my driver's licence, my ability to enjoy myself, my dignity. Just when you think things can't get any worse the disease takes something else from you, or gives you something you would never want to have to live with in your worst nightmares.

I divide my time between an electric wheelchair and an electric bed, and pain, fatigue and continence issues make me essentially housebound. Even if I could adapt to those circumstances, you might think that a person could still find things to occupy their time that may make them feel that they have a reasonable quality of life. But pain and fatigue are my constant companions. When I say fatigue, I am not talking about the sort of tiredness I used to get after a hard day's work. I am talking about a bone-crushing weariness, total exhaustion, so that all you can do is lie there, staring at the ceiling for days on end, or just sleeping when you don't want to. When I am talking about pain, I am talking about acute pain, a searing agony that renders you unable to move, and groaning and panting with the terror of it. I am talking about chronic pain that is a dull, endless misery that is there when you go to sleep and there when you wake up, and which disturbs your sleep, and stops you getting to sleep when you want to. I'm talking about pain that we are all familiar with, and I am talking about pain that most of us will hopefully never experience - neuropathic pain. Neuropathic pain is nerve pain that arises in the peripheral or central nervous system. It can be like electric shocks, like a bruise that never goes away, burning, tingling, numbness, sharp stabs, or the feeling of a billion ants crawling through your skin and muscles, AND IT NEVER STOPS, EVEN FOR ONE SECOND. I have uncontrollable spasms, tremor, seizures that wrack my body, render me unable to move until the spasms are over, and cause the agonising sensation of cramp, and afterwards, a bruised and washed out feeling. Any attempt to try and do any exercise is 'punished' by a crash that leaves me bedbound. Even brushing my teeth and eating is exhausting. I avoid showering because I just dread the pain and fatigue of it. I am heat and cold intolerant. I never wake up refreshed. I mostly wake up thinking "oh no, another day".

Let me tell you that there are some things that are worse than death.

If I get worse than this I can expect to lose total control of my bladder and bowels, total control of my ability to move my muscles, the ability to toilet or bathe myself, my ability to eat, and my cognition may go and I may lose the capacity to speak properly. I may lose my eyesight. I may become 'locked in'.

My pain is not controlled. There is little or nothing that can be done for nerve pain and the drugs they offer you for spasms and pain are often worse than the disease, with a long list of horrific side effects. I may live in this hellish way for decades. Would you look forward to ever increasing doses of 'pain relief' for decades, which slowly wreaks havoc on your body and mind? Perhaps at sufficiently high doses there may be a modicum of pain relief, but I imagine that at a dose that actually gives me relief I would be essentially comatose, parked somewhere, drooling. Doctors, even

specialists like neurologists know little about MS. Beyond prescribing largely useless but horrendously expensive so-called disease modifying drugs (again with horrible side effects) which the taxpayer has to fund, they do little, other than to apply what I call band aid medicine. They do not seem capable of investigative or observational, individualised medicine. Our medical model is broken, which is why it is so expensive, and why so many of us are chronically ill. We do not have a single dedicated neurological hospital in the country which specialises wholly and solely on neurological disease. We do not have a holistic model of care. Our MS research projects are obsessed with mice, which are nothing like humans, and which are given a fake disease that is nothing like MS, about which decisions are made regarding the treatment of human beings. The notion of mapping MS distribution, notifying every case of MS and placing each patient on a register, and investigating the health issues of real human beings with MS seems to be a concept which has never occurred to our medical professionals. I am left to rot. There is no residential rehabilitation program for people with MS in NSW. There is one dedicated respite centre for MS patients in NSW but it is almost impossible to get into. We don't have a proper national disability insurance scheme in Australia, and even with the NDIS we won't have one. It will still be about the disabled going cap in hand to a bureaucrat, and that bureaucrat deciding what is reasonable and necessary for someone whose needs they cannot possibly understand. It will not be about the disabled person self-determining what to spend their 'insurance payout' on to make their lives meaningful, because there will not be an insurance payout as such. Just dribs and drabs of funding given out to let the disabled person continue to drag themselves through life with the minimum necessary to appease our 'social conscience'.

There is nothing that can be done for me medically for my 'MS' since I am progressive. I am not being palliated, I am not being made 'comfortable', I am not in suitable accommodation, I am not in a position to find purpose and meaning in my life despite my disability, and I am forced to live (if you can call it living) because I don't have the option to end my life to escape what is being imposed on me by the inhumanity of the system.

I have a chronic disease, and this nightmare could continue for years, decades maybe. There are others like me with a range of intolerable chronic conditions, or the aged who drag on for years despite wanting to go, those with dementia, who would prefer to go early before they lose themselves completely, but are forced to drag on for years or decades in soulless institutions, and the terminally ill, who just want to go on their own terms.

Let me tell you, if I owned a dog like me, I would have compassionately and painlessly ended its suffering years ago.

Why do I want voluntary euthanasia (VE)? I want the same compassion that we extend to a suffering animal, to be extended to me. I want my life to be worth as least as much as a dog. I want to choose when to go, and I want to be able to discuss it with my family, explain why I want to go, and obtain their understanding. I want to give them closure. I would like to spare my loved ones the trauma of having to care for me, and having to see the suffering I am going through. I would like to spare them any suffering that a timely, quick and painless passing for myself would give them. I would like to have a small ceremony, and then go peacefully and painlessly and quickly. Most people fear death because we do not have voluntary euthanasia. I could live my life to the full if I had the option of VE. VE would be an essential part of my palliative care, giving me the reassurance of that option if I chose to avail myself of it.

The majority of Australians want VE. This is not something the politicians should withhold from the people. A politician should not be able to tell me whether I have a right to choose to end my own life or not. Nobody should. If you don't believe that people have the right to VE, then by all means suffer whatever death that your fate imposes on you, but do not impose your views, your beliefs, your values on me.

We have over 2000 suicides in Australia every year. Most of them could be avoided if we have VE, because people would either have got the help they needed to live, or the help they needed to pass on. VE is NOT suicide. Suicide happens in great loneliness, in fear and in very violent and unpleasant ways. It traumatises victims and friends and relatives. It removes all dignity, it degrades and shames, it leaves unhappy memories. VE happens in very controlled circumstances. It happens in pleasant surroundings, perhaps in the home, with friends and loved ones present. It dignifies and uplifts, it provides closure and happy memories. The loved one goes as they want to be remembered, not as the disease will have them remembered. VE does not increase the number of deaths, it just changes the timing and the circumstances of the death for the better.

Australia used to lead the world in framing our society in humane and compassionate ways. Now we are lagging behind other countries in so many ways. VE is already available in the USA and in Europe. It is a basic human right.

I see Australian Government leaders continually complaining about the elderly and the disabled, and the burden we impose on the budget and the taxpayer. We elect governments to provide for the aged and the infirm, and they have

known about the baby boom and its demographic impact for decades, but nothing has been done to provide for that. Well, if we are such a burden, if it is so difficult to fund our pensions, health care, housing, disability services, and so on, if we are begrudged every cent that is spent on us, then please, please give us the option of ending our lives so that at least we don't have to live in poverty, and we won't have to listen to the highest leaders in the land whining on about how they have failed to budget for a demographic inevitability that everyone has known about since at least a decade after the second world war.

Some people may have concerns about how VE will be implemented, and pressures that may be brought to bear on the aged and the disabled to end their lives. People are worried about losing their jobs in industries that are designed to prolong people's suffering for the benefit of others. We are an intelligent nation. Whatever pitfalls there may be in implementing VE can be overcome. Safeguards can be put in place. There can be checks and balances. Come on Victoria. Lead Australia, and lead the world. Implement voluntary euthanasia, and the quicker the better. People are suffering.

I do not wish to attend a public hearing, but I thank you very much for the opportunity to comment.

Best wishes,

Lawrie Daniel.

From: [Inquiry into End of Life Choices POV eSubmission Form](#)
To: [LSIC](#)
Subject: New Submission to Inquiry into End of Life Choices
Date: Monday, 3 August 2015 10:40:31 AM

Inquiry Name: Inquiry into End of Life Choices



SUBMISSION CONTENT:

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On the right of the individual to choose when it's time to go:

Australia, Australia, it's time that we talk
Though the subject may make your face turn white as chalk
So hang tough and promise that you won't turn away
But the fact is we're all going to cark it someday.

It's probably been at the back of your mind
When the time comes, will fate treat you cruelly or kind?
And what if your passing is not quick and clean?
But to quote Eric Bogle it's both slow and obscene?

You may be quite lucky and grow really old
With your skin dry and wrinkly and your feet always cold
Then one day you know that you've run out of puff
That you've just had a gutful, and enough is enough

Or you may find that whilst you are young and you're fit
That dementia starts taking your mind bit by bit
And you realise with horror as your world fades to grey
That your partner can't cope and must send you away

Or something might get you that cannot be cured
But the treatments are vile and they must be endured
And you grow weak and wasted and you suffer too long
Leaving traumatised family behind when you're gone

Or you get something tragic that won't kill you at all
But a fate worse than death can occur after all
And decades of suffering are about to ensue
And there's nothing your doctors or loved ones can do

Now remember you promised that you'd not turn away
But this harrowing stuff goes on day after day
You would not believe what some people go through
And how might you feel if this happened to you?

When it's time, and it's kinder to go than to stay
Could you graciously let someone just slip away?
Could you still your disquiet and just heed their voice
Honour their selfhood and honour their choice?

What would you want for your dad or your mum?
Your sister, your brother, your daughter, your son?
Now fellow Aussie, to thine own self be true
What would you want for your lover, or you?

For myself and for others, well this is my dream
That our deaths will be gentle, and painless, and clean
In our homes, with our loved ones gathered round by our side
To be present with kindness as we cross the divide

So let's have the talk now, let's take a deep breath
Let's define new and kinder approaches to death
Let's end needless suffering and answer the call
For 'dying with dignity' choices for all...

Bitzer Doggerel 01/06/15

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File1:

File2:

File3: