

Looking back at the years of campaigning to achieve Legal Voluntary Assisted Dying in NSW

*A talk to Dying with Dignity NSW Central Coast Group on 17 August 2018
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What I am going to look at today:

The 2013 campaign: what DWDnsw did and what we learned;

The 2017 campaign: some major points; and

The institutional influence of the Churches, the doctors and the politicians, and what we can do.

The 2013 Campaign

In September 2010, a Greens Member of the Legislative Council, Cate Faehrmann, moved to introduce a Private Member's Bill called "The Rights of the Terminally Ill Bill". It remained at the bottom of the list until May 2013, when, surprisingly, the Government allowed the Bill to be debated.

Here was a real test for DWDnsw.

A number of things were encouraging.

DWDnsw already had close relations with Cate. She had facilitated our annual Parliamentary Forum, and we had been active in advising her on all aspects of her Bill.

The latest opinion poll reaffirmed what we already knew. Over 80 per cent of Australians supported voluntary euthanasia for terminally ill patients.

The independent think-tank Australia21 had just released a thorough report calling on Australia's parliaments to embrace assisted dying.

There was pressure for law reform in other States, especially South Australia and Tasmania.

Overseas, the Canadian province Quebec had announced it would introduce a law to recognise aid in dying as a legal and protected medical practice.

A number of legislatures in the United States had assisted dying Bills up for debate, and in Massachusetts, a citizens' initiative had just failed by the barest of margins - 51% to 49% - to approve an assisted dying law.

So what did DWDnsw do to support Cate?

We wanted to meet directly with representatives from each of the major parties, so we hired a Parliamentary lobbyist to get us into the offices of thirty MPs. We saw a number of ALP members, including the leader and his deputy. However, not a single Liberal or National Party member would agree to meet.

We encouraged our DWDnsw members and other supporters to write to politicians, and many did. We persuaded "GetUp" to urge its members to write to their MPs in support of the Bill.

We ran or attended a number of public forums that generated lots of good publicity, especially in regional NSW. We created a short video of three compelling personal stories, and sent this to the media. We also sent it, together with comprehensive briefing, to all Members of the Upper House.

We sent opinion pieces and letters to newspaper editors, and responded to wilful misinformation that our opponents put out. Nevertheless, we continued to hear that the vulnerable would be abused, that people would be killed against their will and that palliative care was all we needed.

We tried to galvanise our DWD ambassadors, but apart from some notable exceptions like Tracey Spicer, without a great deal of success. Andrew Denton would have been a huge help had he been involved then.

And the result? The "conscience" vote was 13 in favour to 23 against. The Bill was supported by eight of the 13 ALP members and the five Greens members, but not one of the Liberals or Nationals. The two Christian Democrats opposed it, as did the two Shooters and Fishers.

So what hard lessons did we learn then?

We realised that massive public support and abundant factual evidence that overseas laws worked well was not enough. They were necessary, but not sufficient. It was not true that more publicity about horrendous deaths was all we needed.

A continuing difficulty for us was that opponents continued to advance arguments that were simply false or wilfully misleading. How many times did we have to repeat the findings by numerous independent analysts that there was no slippery slope, that the vulnerable had not been abused and that palliative care was fine but was not enough?

We recognised that there was no fact checker or independent arbiter that we could turn to who would be accepted by all. I thought the best we could hope for was a media informed enough to expose bald assertions from opponents that they knew to be untrue, misleading or at least arguable.

If the MPs had voted as representatives of their electors, then at least 70% of them should have voted "yes". So if popular opinion was not the driver, and factual argument was not persuasive, what other agendas were they pursuing?

We concluded that religious values and especially **organised** religion (I stress "organised") were probably at the bottom of all this. A Catholic Cardinal said once, in an unguarded but honest moment, that "you cannot have a choice". In other words, God has told me what's right and there is no room for differences of opinion on this question.

We saw that Party politics was more important than personal opinion and rational argument.

Research shows that Party membership is the most important influence on conscience votes and that MPs generally vote with their party colleagues. While that seemed to apply to the Coalition members, because they all voted the same way, it did not apply to the ALP.

The Shooters and Fishers voted "no" because they had a general deal to act in concert with Christian Democrat Fred Nile to hold the balance of power in the Legislative Council.

Four MPs - two Liberals and two Nationals - abstained. One of the Liberals who personally supported the idea of law reform abstained simply because the Bill was proposed by a Green. One of the Nationals abstainees was Trevor Khan - now a leading supporter.

We also experienced again how difficult it was to get politicians to even talk about voluntary assisted dying, let alone saying whether they supported it or not. Why was this?

We thought that probably MPS were reluctant to get into a public argument with powerful vested interests like the Churches and the Australian Medical Association over an issue that did not seem to be a vote-changer.

They were either unaware of, or discounted, the public surveys that said that almost a quarter of electors would change their vote if their preferred parliamentary candidate opposed assisted dying.

We saw that we needed champions in all the Parties, people who were prepared to act in a joint way and lobby their colleagues. It would be especially important to have the support of the leaders of the major Parties.

Lastly, the process was inadequate. This was not Cate's fault, but it was criticised for being too short and not being consultative enough. We concluded that we needed a thorough cross-party Parliamentary inquiry that took evidence from individuals and organisations, took into account the latest research from overseas and, presumably, produced a joint-party report supporting the need for law reform.

So we lost. And we lost Cate, who resigned to contest a Federal Senate seat.

The 2017 Campaign

It was some time before Nationals MP Trevor Khan emerged as our next champion, and some time before he set up a joint Parliamentary Working Group to prepare for the next campaign.

In the meantime, there were some encouraging signs of slow progress.

In **2014** in Tasmania, a Government-supported Bill lost by one vote in the Lower House. Again, as in NSW, not one Coalition member voted in favour.

In **2015**, there was an election in NSW and the Voluntary Euthanasia Party ran candidates for the Legislative Council. While there was no Bill at issue and the prospects of electoral success were dim, the hope was that voters would give their first preference to the VEP and thereby send a clear message to the major parties.

The party polled 40,971 primary votes, which represents about one percent of the vote and a fifth of a quota to get one seat.

Overseas, the Canadian Supreme Court unanimously overturned a twenty-year-old ban on doctor-assisted dying and gave the Canadian Government a year to change the law.

A really significant development was the changed attitude of the Canadian Medical Association. It now "recognize(d) that there are rare occasions where patients have such a degree of suffering, even with access to palliative and end of life care, that they request medical aid in dying ...(and)... We believe in those cases... that medical aid in dying may be appropriate."

In **2017**, as you all know, another assisted dying Bill was introduced into the Upper House of the NSW Parliament. It was the product of the joint-Party group led by Trevor Khan.

And, as you all know, we fell agonisingly short of success by one vote. Nineteen for, twenty against.

Six of the twelve ALP members, two of the eleven Liberals, five of the six Nationals, the five Greens and the Animal Justice Party representative voted in favour. The two Christian Democrats and the two Shooters and Fishers voted against - again.

I'd like to offer you some reflections on the campaign and the vote that seem to me especially significant.

One is that the outcome was in real doubt right up to the last minute, although I believe Trevor Khan thought he had the numbers. (Perhaps just as on Wednesday Senator Leyonhjelm thought - wrongly - that he had the numbers in the Federal Parliament to pass his "Restoring Territory Rights (Assisted Suicide Legislation) Bill").

My local member, the admirable Trish Doyle MLA, took it upon herself to contact directly two members of her own Labor Party whose position was uncertain and whose support would almost certainly ensure success.

In the event, those two, Daniel Mookhey and Ernest Wong, voted "no".

It's worth spending some time looking at Mr Mookhey's reasons for voting "no". Briefly, he presented ethical and empirical reasons.

First, he referred to Paul Keating and his opposition to assisted dying. To endorse assisted dying, Mr Mookhey said "Parliament must irrevocably traverse the ethical threshold that maintains that all human life deserves protection and it must take leave of the golden principle that says the State's responsibility is to honour all human life. I struggle with crossing that threshold".

Second, he was worried about "the active involvement of the state in a citizen's death. I worry because when the state had that power the state's fallibility led to injustice and I am not satisfied health care will differ.... Historically our answer to evidence of our fallibility is to show caution. The precautionary principle which reigns in so many of our laws sprang first from the wellspring of medical regulation. We prohibit practices if there is a plausible risk that harm will result. The error reports attest to plausible risk".

And third, he wanted support from doctors. He said "The only mitigation which would have alleviated my anxiety about a physician assisted dying bill is the fulsome support of physicians. Physicians are not supporting this bill. The Australian Medical Association's opinion is clear. I am invited to consider the view of other physicians in support of the bill and I am sure they exist in great numbers, but if we are to bestow this power on physicians, my preference is for near unanimity of support from physicians upon whom that power is bestowed".

Is it possible to change his mind? The ethical concern alone seems unalterable and is very similar to the Catholic Church's position that all life is sacred and only God should take it away. It ignores the fact that every day doctors do help suffering people to die.

The empirical concern that there will always be some risk is valid, and that is why the safeguards are in the legislation. Of course there are risks in the judicial system that innocent people will be convicted and that guilty people will escape punishment. But that does not mean you abandon the system. And I suspect that no amount of overseas experience showing that the safeguards work would satisfy him.

And the preference for unanimity of doctors is unreal. Mr Mookhey thinks that doctors in favour of assisted dying "exist in great numbers", but prefers the institutional view of the AMA.

He may not be aware that as long ago as 2001 an academic survey of Australian doctors asked "Do you believe that there are **any** circumstances in which it is morally acceptable to give a terminally ill patient sedatives or analgesics ...in doses greater than those required to relieve symptoms, with the **intention** of hastening the patient's death?" Fifty-four per cent of those surveyed said "yes".

The same survey also asked "Have you ever, for the purposes of relieving a patient's suffering, given drugs ...in doses **greater** than those required to relieve symptoms, with the **intention** of hastening the patient's death?" Thirty-six per cent said "yes".

Another interesting aspect of the 2017 campaign was that a lot of focus was placed on Legislative Assembly members, in the hope or expectation that it would pass the Upper House. This invariably raised the question of representative democracy.

Should MPs simply vote the way their electors wanted, regardless of their personal opinion, or should they exercise their own judgement (another word for conscience)?

I would argue that on **this** issue their personal opinion is irrelevant. This is because the question is simply: “do you agree that a dying person should have the legal choice of a medically assisted death?”, not “is assisted dying a good thing?”.

Very few politicians seem to agree with me.

An admirable exception is the Nationals member for Tamworth, Kevin Anderson, who asked his electorate if they were in support of the Bill. Surprise, surprise - 80% said they were.

Significantly, Mr Anderson said that “The Lower House would have been given a free vote, so I could have voted however the electorate wanted me to vote; I was preparing for that to happen, but the bill was defeated.”

Another interesting example of democracy in action was that of Phil Donato, the Shooters, Fishers and Farmers member for Orange. He had won the seat from the Nationals because the Government did not listen to the electors’ opposition to their policies on greyhound racing and council amalgamations.

Initially, Mr Donato said he would have “trouble supporting” the legislation. “I don’t know enough about it, but my feeling is that I don’t support it.” However, some residents, including a prominent doctor, urged him to reconsider his views. He then said he was more than willing to do so. His capacity for sound political judgement had clearly increased.

He will face something of a dilemma next year. On the one hand, he, more than most, recognises the power of local feeling and I imagine he wants to be re-elected. On the other hand, his Party opposed the Bill in 2013 and I imagine will do so again, for the same Party political reasons.

If I may add a personal note on this theme: last year I wrote to the Premier offering to pay for a scientific survey of her electorate’s wishes if she would agree to abide by their decision. It will not surprise you to learn that she did not respond.

The influence of institutions and what we can do about it

Let me turn to the institutional influence of the Churches, the doctors and the politicians.

If you were a modern policy adviser, you would probably start out your analysis of the problem by asking “who are the stakeholders?” They are the people who are affected by the issue, the opinion makers and the decision makers.

Of course, **we as individuals** are the majority stakeholders. There are more than 80% of Australian voters who think as we do.

Sadly, we are not the opinion makers or the decision makers.

And those who are, are opposed, or at best non-committal.

A good question in thinking about this is: what might make them change their minds?

These big institutions, like the Churches, the Army and the universities are, I believe, essentially conservative, and place great pressure on their members to conform to existing doctrine. It takes a lot of effort and ability on the part of a senior individual, as well as external pressure, to introduce significant change. It takes even more to persuade others in senior management that policy positions they have held publicly for a long time are wrong.

However, I make the point that these institutions are neither monolithic nor in possession of the sole truth, even though they very much want to appear to be.

We know that Christians generally are very supportive of voluntary assisted dying law reform, but that the Church hierarchy are not. Worse, the hierarchy will not acknowledge that views other than their own are valid.

A recent example of the Anglican Church's response to dissent - this time over same-sex marriage - was to prevent a Sydney priest from preaching. This turbulent priest had originally vowed "to drive away all false and strange doctrines that are contrary to God's word" - as "received" by the Anglican Church - but now found that the Bible was "an ancient text, pregnant with ancient assumptions and beliefs, many of which we no longer reasonably hold". So the Archbishop took away his licence.

Every now and again, however, a senior member breaks ranks. In 2014, the former Archbishop of Canterbury, Lord Carey, said he would support assisted dying for the terminally ill. The former Archbishop Desmond Tutu agreed.

One might ask why these worthy gentlemen did not do this while they were actually in a position of power.

What can DWD do about all this? Not much.

We can hope that brave priests will speak out before they retire.

We can hope that the Churches' influence will continue to decline, especially in the light of recent scandals about child sex abuse. But that does not mean that their attitudes will change.

We also have to recognise that some people with views opposite to ours will work actively to influence the political process. They are driven, and are prepared to do the work. They join the committees, seek executive positions and eventually come to dominate.

By way of example, in Victoria recently, at least 10 of the 78 people elected to the Liberals' administrative bodies are Mormons. The *Age* concluded that "combined with conservative Catholics, (and) evangelical Christians..., the religious right-wing now has unprecedented sway in Liberal Party politics".

We can hope that their willingness to become involved will be countered by equally committed people with more progressive views.

Doctors and their organisations present a similar challenge. While a substantial proportion of doctors are in favour of assisted dying, the Australian Medical Association is not.

There are encouraging signs that opposition from doctors' organisations is decreasing, but the changes are slow.

I mentioned the change in the Canadian Medical Association - pushed, I believe, by political and legal pressure. And ten state chapters of the American Medical Association have now switched from "opposed" to "neutral".

In Australia, we saw a former president of the AMA, Dr Brian Owler, become an advocate of assisted dying and a major influence on the Victorian Government's introduction of a Bill, which as we all know, passed last year after a mammoth Parliamentary sitting.

He recently backed Senator Leyonhjelm's "Restoring Territory Rights (Assisted Suicide Legislation) Bill".

We can hope that doctors' attitudes, particularly of younger doctors, will continue to change, and that courageous doctors like Dr Rodney Syme in Victoria and Dr Alida Lancee in Western Australia will speak out.

But again, there is not much that DWD can do about that.

Let me turn to the politicians and the main game.

Ideally, the political parties should pre-select the right people. But the party selection process is dominated by the wrong people.

Only the Greens support assisted dying as part of their official party policy, and there is no indication that either the Coalition or the ALP will adopt it any time soon. Nevertheless, attempts should be made to persuade Party State and Federal conferences to do just that.

Last year, I talked to my local ALP Branch and asked them to pass a motion supporting assisted dying and urging that the State Conference do likewise. They did, but it was not picked up.

My successor as President of DWDnsw, Dr Sarah Edelman, wrote after the vote in 2017 that "We will focus on Lower House MPs again in the months before the March 2019 NSW election, to let candidates know that their stance on VAD must reflect the view of their constituents, and will affect the way we vote. This will be particularly important for MPs representing marginal seats."

A concerted campaign to offer to pay for a scientific survey in marginal seats if the candidates agreed to abide by the decision would certainly attract media attention.

I think we should ask every MLA if they intend to abide by the wishes of their electorate, and if not, demand to know why not.

Ask them to assume they are stopped in the street by a national pollster and asked: as a matter of principle, are you in favour of a dying person having the legal right to choose a medically assisted death?

I would like to think that would work, but sad experience tells me otherwise.

Politicians go to great lengths to avoid taking a position.

When the Queensland Premier was asked recently about assisted dying, she said: "So we will look very carefully at what is happening in Victoria, I think it is something Queenslanders do want to have a conversation about, but in the meantime can I emphasise that our priority in this term is abortion law reform". What she is really saying is "I'm not going to do anything about this, and I'm not going to tell you why".

Here are some of the other excuses MPs have offered in the past:

"I cannot make a judgement because there is no bill before the Parliament."

"I would seek advice from both sides if it comes to Parliament."

"I need to see the draft Bill."

“I will listen to the debate before making a decision.”

“A Government should take the issue to an election to obtain a mandate.”

“I want the Commonwealth to legislate at a national level, not the states.”

“We need a national referendum.”

In the absence of Party policy, we need Party champions and preferably the Party leaders to support us.

The Victorian bill last year had the very distinct advantage of being a government bill, driven by Health Minister Jill Hennessy and Premier Daniel Andrews. But remember that that happened largely because the Premier had a change of heart after his father suffered a dreadful death.

We are not supported in NSW by either the Premier or the leader of the ALP, but we are by the leader of the Nationals, and the first reaction of an undecided MP, especially one who hopes for advancement, is probably to ask what the Party leader might want.

Our Premier’s public reasoning is of interest.

In May last year, she declined to reveal her position on assisted dying.

By September, she came out, as it were, saying “Traditionally I’m someone who’s quite progressive on social issues, but that’s a difficult one for me. I don’t think I can support it.”

She went on to say that “for me personally there is no wrong or right answer”, but “what makes me feel that I can’t support it is the notion that even if one person feels they’ve got no option but to do this because of pressure from family or because of pressure for being a burden or for whatever other reason”.

In November, after Victoria became the first state to legalise assisted dying, she said that she was open to a national approach on euthanasia. That is of course not the same as saying that she supports the idea.

She has emphasised that she is not trying to influence others in her Party and that she is just one of the 93 MLAs.

It would seem pointless to repeat yet again that every assisted dying law is founded on the word “voluntary”, and that the extensive safeguards in the legislation are there to prevent coercion. It would seem equally pointless to repeat that years of regular monitoring and reporting, especially in Oregon, the Netherlands and Belgium, have shown no evidence of anyone being coerced. Perhaps the Premier’s words “even if one person” are carefully chosen to allow her to say “well, maybe there has been no instance so far but you never know”.

Luke Foley, the leader of the ALP in NSW, said last year: “I worry about the message it sends ... where some old and frail people feel that they are too much of a burden on their loved ones that they have to end it all.”

His middle name is Aloysius. I say no more.

John (Giovanni) Barilaro, our Deputy Premier and leader of the Nationals, is a supporter. Good.

Former MPs can be champions. Amanda Vanstone is one; Paul Keating is not. Neither is Howard, Rudd or Gillard. Hawke is a supporter but, I think, does not want to become actively involved. The ALP’s Geoff Gallop and John Faulkner would be ideal.

We should of course continue our campaign stressing the factual evidence overseas.

to counter fear, uncertainty and doubt by

And we should continue to try to find out what are the basic values behind individual positions and to frame our messages to resonate with them. Care, compassion, choice, fairness, and liberty are examples. But recognise that loyalty, authority and sanctity can be equally powerful.

We have lost many times and won only once. Winning in one state does not mean automatic victory in others. Should we not change a losing game? If so, what is it that we might do differently? What do you think?

In my view, our aim should be to get to individual MPs and threaten their re-election. Grab them by the self-interest and their hearts and minds will follow.