

KEYNOTE ADDRESS - ASIA PACIFIC CORONERS SOCIETY
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VOLUNTARY EUTHANASIA AND THE CORONIAL PROCESS

(A message from the dead)

I was very pleased when I received the invitation to address you today from Mark Johns. This conference gives me the opportunity to press further - points I made to coroners in a letter 3 years ago - and is not to be missed.

In brief, I advocated that coroners should identify a cohort of self-inflicted death by the elderly and the terminally and hopelessly ill that is premature, lonely and usually violent. I wanted coroners to report that such deaths would likely be delayed, and trauma reduced, if the person could legally access assistance to die at a later point in time.

This is one audience that knows better than any other the awful facts about how desperate people die, and the effect on those close to them. (actually, I wonder if anybody who has not had the experience really knows effect... on those intimately close to an unexpected suicide.)

To another gathering I would get attention by referring to a man who killed himself with shots to his head and chest with a nail gun that Victorian coroner John Ollie spoke about recently.

You are familiar with such occurrences. All in a day's work I guess. (I presume not without an effect)

Mark Johns responded to my advocacy by agreeing that the current situation was a sad reflection on society, but that what I asked would not only require resources way beyond those available to coroners, but also that... Quote "*as members of the judiciary, coroners should not involve themselves in a political debate as hotly contested as that one.*"

He said politicians, who I claimed were blissfully ignorant of the extent of the problem, were quite capable of ascertaining the facts if they cared to inquire. That is surely true, however our MP's seem so preoccupied with bagging each other that the plight of constituents who may not be alive at the next election, is not of great interest.

I emphasize here that my following remarks refer to people who are terminally ill, not any other group of troubled citizens who might consider ending their life.

Today I want to argue that there is a fundamental flaw in the charter coroners operate under. That is, the presumption that all unnatural death should be prevented.

It is wrong to believe that every instance of suicide is a tragic event that governments should do everything in their power to stop.

The progression of lifespan in the advanced world, with death now the result of degenerative disease, often preceded by a long period of debilitation, is changing the way we view our inevitable demise. (a reduction in religious belief and the desire for autonomy and control no doubt contributing factors.)

The over-whelming majority of Australians want the option of a peaceful death for themselves if their end of life circumstances warrant.

They realise the adage 'growing old is better than the alternative' - is only true up to a point.

When I announced I would introduce a Bill to legalize voluntary euthanasia 25years ago in the Northern Territory, the reaction was completely unexpected. I and my colleagues were overwhelmed with mail and calls from all over Australia, from people with a terrible story about the death of someone close to them.

It was like I had scratched society and it started to bleed.

People desperately wanted to tell someone of a dramatic experience they had kept bottled up (inside) for years. At last they felt there was someone who might understand what they had been through.

I spoke to people who had killed their parent in response to desperate pleas to end the suffering. Ordinary people with no experience or knowledge of how to extinguish life, pushed to the very edge of emotional endurance. Acting in sheer desperation. The experience seared into their memory forever.

I received moving letters that put a lump in my throat and were hard to finish.

The outpouring convinced me to pursue the agenda. The objective of relieving futile suffering was a just one.

I regularly hear the view that legalizing voluntary euthanasia is a very complex, hard thing to do.

I just do not see it that way, never have.

Everyone knows how to kill themselves, people are doing it all the time.

You know that better than anyone – the problem is how the group I'm talking about do it. Violently - and alone.

We simply need to define the group we believe have good reason to want to hasten their death, and allow them the option of doing so serenely. Competent terminally ill adults fill the first criteria, and pentobarbital the second.

Slide 1. "My bill was based on this principle.. *"If there are terminally ill patients who wish to end their suffering by accelerating inevitable death, and there are sympathetic doctors who are willing to help them die with dignity, then the law should not forbid."*

I describe it as getting the keys to the medicine cabinet...

It would be a law that did not require anybody to do anything. Anyone who disagreed could live their life as if the option did not exist.

A couple of years ago I attended the big funeral of a 92-year-old man I admired greatly. Those attending heard stories of a long life of hard work, tears, love, laughter and giving within a large family and his community.

What the congregation was not told was that Henry died miserably and alone. A classic case of rational suicide to end unbearable suffering from the ravages of multiple operations, and a decaying body.

To protect his family Henry devised a plan and assembled the equipment needed without help from anyone, and died when the family were out of the house.

Questioned by police, the family denies knowledge or involvement and goes into lockdown to try and prevent the truth becoming known. (it's hard to hide from the neighbours with police cars out front for a few hours.)

It's a pretty standard story - Similar and worse happens every day across the country.

Who cares how Henry died? I do.

I'm incensed that the only knowledge of Henry's plight the community will ever see, is the usual platitudes in the death notices saying, 'died peacefully', and a figure published by the ABS in about 2 years.

Instead of 'Death by suicide' being 3112 it will be 3113.

In reality, the world is oblivious to the way Henry died.

If there was a political reaction – it would be to throw some more money at suicide prevention programs, an action completely contrary to what is needed to help people like Henry. We don't need money, we need legislative change.

I believe it is a tragedy that Henry, like so many others, was denied the opportunity to die peacefully in the arms of his wife of 70 years and generations of his descendants.

While we deplore any waste of healthy life, I find people in their 80 & 90's, even 100 years old, hanging them-selves to be particularly horrifying. Not because of the life foregone - but because a society that patronizes the elderly leaves some of them no choice but to die violently and alone.

I guess Coroners are too busy to keep up with goings-on in other states, so I want to talk about the Dying with Dignity movement's new pin up celebrity.

Victorian Coroner John Ollie. His evidence before the inquiry into end of life choices by the Parliamentary Standing Committee on Legal and Social Issues - October 2015, had a considerable impact on the committee.

Close observers believe it was the turning point in the committee making the ground-breaking recommendation that the government sponsor a Bill to legalize assisted dying. (which they have done)

I suspect Coroner Ollie was unusually personal when giving evidence by saying. Quote *"My motivation initially some time ago to refer several cases that I was investigating to our coroners prevention unit, was really - would I want a member of my family to die in the circumstances of loneliness, fear and the horror of some of these cases we are privy to — would I want that? The answer was a resounding no. People who have invariably lived a long, loving life surrounded by family, die in circumstances of fear and isolation."* End quote

This is the classic 'me' test we should all take when deciding if assisted dying should be legalized.

Mr Ollie described 5 shocking cases to the committee. I will not go into detail as most in this room would be familiar with the horrific ways 'intentional self-harm' occur(s).

He defined the cohort as 'Irreversible decline' - terminal disease; death was foreseeable; incurable chronic disease but death not imminent; permanent physical incapacity and pain. The cohort did not include mental ill health.

He said they were people who unlikely would meet the criteria of palliation....and that it is information Coroners alone are privy to.

I quote further from his evidence..."When I first referred this cluster of cases, they are obviously — and for anyone would be — so distressing. There was no panel; there was no inquiry afoot, or even mooted, and that was my great concern — that there has not been information that we have, that the community do not have, and should have - to be aware, and to address this important issue."

...There is a cry for help. It may be muted, it may be veiled, but it is there nonetheless, and they all know it — including doctors. They know that this person is screaming for help, but no-one is going to answer this call; not in this society. So they have got to die alone.

...to my knowledge the people we are talking about in this small cohort have made an absolute clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life" end Quote.

Politicians may not listen to us lay citizens who have bleated about such suicides for decades but they certainly listened to coroner Ollie.....

If 'reassuring the public' is a role of the coroner, Mr Ollie's evidence did just the opposite. His powerful evidence alarmed the committee and hopefully will sway MP's when they vote on the Bill. I applaud him for what he did.

He may have broken a legislative logjam where 30 Bills in the last 20 years have piled up in the face of ignorance, misinformation and innuendo.

The West Australian parliament has recently established an inquiry into end of life options with the same terms of reference as Victoria. I hope and expect the WA Coroner's Office will give evidence of similar deaths contained in their files.

The Victorian experience demonstrates that coroners have an important contribution to make as our society grapples with the legislative changes

required to authorize voluntary assisted death - the new term to sit along-side one you are very familiar with - *Intentional Self Harm*.

Progressing this concept requires revisiting the doctrine 'That death is to be prevented in all circumstances.'

We have reached a stage in our biological and social evolution where an individual can reasonably conclude that, for them, the stage has been reached where living longer is undesirable - even unacceptable.

When thinking about suicide - I'm always drawn to the awful example of people leaping to their death from the burning World Trade Centre. In some respects their plight was similar to the terminally ill. Both know they are going to die and are seeking the least painful way for it to happen. From that point on their situation differs significantly. One has only minutes or seconds to make a decision between two options.

The terminally ill however have the advantage of a much longer period to consider what to do, the ability to discuss the subject with others and multiple choices regarding method.

What they do not have however is access to the most effective way to die quickly, or to assistance from others. In both cases the action has to be taken while the individual retains the physical and mental capacity.

In my research to talk to you today I came upon this description of the coroner's role. ^{Quote}"The coroner speaks for the dead to protect the living." End quote.

(This drove home to me that the dead really can communicate - I was a skeptic when once asked to join a seance.)

That may be an appropriate description for most of your important work however there is another message from the dead that we have not been hearing. - Until Coroner Ollie shocked his audience.

The cohort of Intentional Self Harm, terminally or incurably ill, or the new description 'irreversible decline' send the message....

Slide 2 "*Death is not the worst thing that can happen to you – relentless unbearable suffering is.*"

We have ignored the message from the extraordinary lengths competent people are prepared to go to end their suffering - to escape the life they live, or face, as their health deteriorates and the capacity for experiencing anything even remotely enjoyable slips away.

How determined would one have to be to die from injuries to the head and chest from a nail gun.

Adding to the agony of ending one's life secretly is the knowledge of what it will do to loved ones who are often taken by surprise. And the certainty they will face investigation by the police and possibly the coroner.

We accept that life-saving medical treatment can be refused to allow nature to take its course – but we will not condone anyone deliberately shortening their own life.

While it may not be unlawful to take your own life, we do what we can to make it hard. Rope, knives, trains and tall buildings are available as is starvation but to get hold of the means to a quick tranquil death requires becoming a criminal.

And, of course, don't ask anyone for assistance.

Elderly people fret about their arthritic hands failing them while opening the valve on the gas bottle, or travelling to Mexico when they are very ill and dealing with dodgy characters in the street to buy Nembutal, and hoping like hell it is the real thing. Then having to become a criminal by smuggling it home without appearing nervous in the customs hall. Reports of the Australian Federal Police searching homes to confiscate your treasured bottle of insurance is a worry. Many fear suddenly losing control by being hospitalised or sent to a nursing home or even palliative care - places they associate with agonising prolonged deaths.

This group, who we are often told are the vulnerable in society are certainly vulnerable to being denied their wishes if they express a wish to die.

Our attitude – stop them! Remove the means, tell them we love them, pump them full of drugs so they can bear the pain... and if that doesn't work - sedation and death by dehydration will.

One very successful example of removing the means occurred when (in 2011) a NZ coroner reported on two helium deaths and recommended that the gas be contaminated with oxygen to prevent people dying this way.

This action was brilliantly successful... one gas company announced they would... and now word thru-out the DWD community is helium is out. Whether the company did or did not add oxygen is irrelevant. No-one is prepared to take the risk.

I doubt it has reduced VE deaths. It has probably just meant a swing to nitrogen....

The driving force behind the voluntary euthanasia movement is, in fact, not the gruesome suicides that come across a coroner's desk. The ones like my friend Henry, who the public know little about because it is deemed they should not be told.

What Coroners see is the tip of the iceberg,- below the surface, mingled among the non-reportable deaths are the 'hard' ones. Those who, in the opinion of witnesses, die dreadfully. And I don't just mean die dreadfully in the opinion of family members who might be considered biased, but nurses and doctors and palliative care practitioners as well.

The number of hard deaths is unknown and depends on the definition used but some studies put the figure between 8 and 23% of all deaths in Australia. That's 12 to 36 thousand. I believe knowledge of such dying experiences is what is convincing the public there should be a more acceptable way to die.

The majority of hard deaths are not reported or required to be under the law - so I acknowledge I cannot ask coroners to speak for the dead you are not obliged to consult.

... and the living can speak for themselves.!

However there is an elephant in the room with bad deaths and there may be a case for Coroners, perhaps thru the NCIS to recommend a study of the incidence and administration of terminal sedation in Australia. Currently the extent of the practice is unknown, no guidelines exist to regulate it - there is no scrutiny. Palliative care practitioners are reluctant to talk about it.

Death is unnatural but certainly expected.

However one looks at it, terminal sedation is *slow euthanasia*, the sole purpose of withholding food and fluid from a sedated patient is so they will die. Otherwise they could be fed intravenously until death was caused by the underlying illness.

The charade that has been played out for decades is the pretence that hastening death to end intractable pain and suffering is not intended. The difference between the act being murder or one protected by the doctrine of double effect rests solely in the mind of the administrator. Where it remains opaque, near impossible to prove - making investigation futile.

Who would know if the doctrine of double effect is shielding abuse or cover up? It is likely doctors sign dozens of certificates every day where death was the result of sedation and withholding hydration.

Confirming what we already know, Dr Brendan Nelson, when president of the Australian Medical Association in 1995 supported doctor assisted death. He said, quote "*Technically it would be illegal but somebody would have to report it and register a complaint. "Now if you do your job properly there's no way the family's going to complain."* He said the police would not lay charges if the doctor could prove he had the family's backing and had sought the proper expert advice.*

When Prime Minister, Tony Abbott, agreed with his radio interviewer that pain relief was often given with the intention of speeding death. He said, quote "*Quite possibly you're right, Neil, and when was the last time any doctor or anyone was prosecuted for something like that? I think the situation that we've got at the moment is a perfectly acceptable one.*" **

There we have it, no lesser authority than the Prime Minister and the head of the AMA saying doctors intentionally kill terminally ill patients now, that it is breaking the law and that is perfectly acceptable.

The 'rule of law' is being trashed every day and no one seems to be concerned. (we once sent a former Federal court judge to jail over lying about a parking fine yet we let doctors get away with murder)

If part of a coroner's role is to consider *the administration of justice*, there seems to be some attention needed here.

It is perverse to us advocates that one's death can be deliberately hastened with the administration of drugs over several days - yet a request for drugs to die within minutes is prohibited.

The position of Coroner I see began in England over 700 years ago. (1281 - impressive) I read quote; "*A person who found a body from a death thought*

sudden or unnatural was required to raise the 'Hue and Cry' and notify the Coroner." End quote

So – on behalf of Henry and a thousand others – and in the interest of a compassionate society - I HEREBY RAISE A HUE AND CRY.

There is unnecessary misery, grief and trauma out there in the suburbs caused by outdated laws that compel rational adults to die violently and alone.

You may respond by saying Coroners do examine such deaths as resources permit and report their findings accordingly, that it is not your role to set public policy or change the law, and I agree.

That is a job for politicians. Therein lies a problem.

The political agenda is jam packed. Our legislators face severe pressure juggling their party, electoral, government and private lives in this age of almost frighteningly rapid change and a 24 hour news cycle.

One old cliché, “The squeaky wheel gets the oil” is still true.

I find it perplexing that our federal government can be shocked into conducting a royal commission into youth detention within 12 hours of seeing a picture of a boy in a spit hood, when the fact that 600 elderly Australians died with plastic bags over their heads in the last 20 years hardly rates a mention.

We voluntary euthanasia advocates simply have not made enough fuss to be heard by politicians. The ‘Hue & Cry’ has to be louder. Much louder.

While our legislators do have access to your work, (if they ask) all the grim findings, recommendations and statistics, they are either unaware, unmoved or afraid to tackle the issues involved in devising a legal assisted dying regime.

Notwithstanding public support of between 75 to 85%, none of the 30 private members bills introduced in state parliaments over the past 20 years have been successful.

I’m here to push the gravity of the case for change. That’s where you come in.

We advocates have for two decades now, badgered MPs with individual experiences of bad deaths both personal and as relayed to us by others. We express our determination to do whatever it takes to avoid our own inevitable death being a repeat of what we have witnessed.

We claim law reform would extend lives and reduce trauma but our message has not been heeded by legislators. Mostly - letters are ignored, newsletters are binned and appointments fobbed off to a staffer. Nothing we have done has elevated the issue to priority status. We are yet to see if the message will get through in Victoria.

Even the extraordinary level of public support for law reform is discounted on the basis that come the next election, the deciding major issues will be those established beforehand by the major parties.

The bad deaths, the resulting trauma, some of it lasting for years, are out of sight and out of mind.

Sometimes I wonder if some of our elected representatives do not want to hear the truth of what is contained in the files of coroners.

I'm reminded of the scene in the film 'A Few Good Men' when Jack Nicholson playing the tough General answers the prosecuting lawyer Tom Cruise with "The truth! You can't handle the truth." He was referring to what special force soldiers do out there in the dark to protect the community.

Meanwhile the search for the holy grail, the 'peaceful pill' that governments cannot control continues.

While our politicians scramble to catch up with technological change, from driverless cars to personal data collection to artificial intelligence, we are on the verge of the first head transplant and genetically designed babies. I predict an app will become available to end life painlessly. When it does, the angst about law reform to permit voluntary assisted dying will likely disappear. We won't need anyone's permission. (the app might cost a bit though - no repeat customers)

Back in 1998, American professor of Philosophy Margaret Battin wrote of a societal change in attitude toward death - she predicted it could lead to

Slide 3. *'Dying becoming not something that happens to you, but something you do.'*

This change she said followed the formal recognition of a right to refuse treatment, the removal of life support, the ability to appoint surrogate decision makers and advance care directives.

It seems, if as the polls show, most Australians want the option of an assisted death if things get bad – that we are inching toward dying being, for some of us, *‘something you do’*.

Part of our cultural evolution perhaps.

A couple of thousand years ago, Epicurus is said to have coined the phrase.....

Slide 4 *‘The circumstances of my death are too important an event to be left to chance.’* (Considering life back then was short and brutal I think Epicurus would feel even stronger today if he thought he might die in a nappy, having been spoon fed for 2 years.) I confess this sentiment appeals to me.

Mark Johns told me that it is not for Coroners to enter a debate as hotly contested as this one... Ok, I won't ask you to...however - I am asking you to build on the action of Coroner Ollie when he exposed the dark and tragic drama playing out (every day) across the country...conveniently masked in media reports by the term *‘no suspicious circumstances.’*

Every MP in every government needs to have the information you alone are privy to. Even if the Bill in Victoria does pass, there is a long way to go before all our citizens have the option of a peaceful death.

I acknowledge that Coroners can only comment on cases before them however your authority to make a recommendation to a minister, a statutory authority or another entity on issues relating to public health and safety and the administration of justice is virtually unfettered.

While a coroner's report on the death of a single individual can lead to legislative action, the chances of it occurring are naturally multiplied if similar cases in other jurisdictions are added. Therein lies the value of the NCIS.

The NCIS has an important role producing fact sheets in relation to issues of community and public importance. I am advised the topics for NCIS factsheets are decided are based on a number of factors, including data quality, feasibility, and the extent to which the fact sheet would provide a novel contribution to public debate.

It is hard to imagine a subject of more interest to the public you serve than that which concerns 85% of the adult population of this country i.e. access to the means to die a tranquil death in the face of a dreadful one.

I repeat, the cases in your files are just the tip of the iceberg. There are many more in the same desperate situation who want but are denied a peaceful quick death as they are trapped in the confines of a hospital, palliative care unit or nursing home where the timing of their demise is out of their control.

The current wave of baby boomers are an educated, assertive lot, less in awe of doctors than ever before with a diminishing belief in spirituality. Having witnessed the deaths of their parents and grandparents and knowing that even the best palliative care cannot relieve all suffering.... many consider their own death too significant an event to be left to chance. They want an option to avoid the cruel lottery that natural death can be and the human cost of the unexpected discovery of a mutilated body by family.

It does not have to be that way. A compassionate society would permit the option of a gentle, peaceful death at a time of choice in the company of loved ones.

John Ollie has opened the subject by describing a cohort of self-inflicted deaths that are understandable, reasonable and without coercion.

They are however brutal in every way. Acceptable alternatives are available but they are currently illegal.

I conclude by posing the question Mr Ollie asked himself - to you. "Would you want a member of your family to die in circumstances of loneliness, fear and horror?"

If the answer is no – then please, in the public interest, find an opportunity to say so - and reveal the information only you are privy to.

END

* Sunday Territorian May 21 1995

** Neil Mitchell talk-back 3AW Sept 2013