SUBMISSION TO THE STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES
(Legislation and References)
58th Parliament Inquiry into End of Life Choices

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T: [redacted]
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END OF LIFE CHOICES

or

HOBSON'S CHOICE?

Noun-Hob·son's choice - "a situation in which you are supposed to make a choice but do not have a real choice because there is only one thing you can have or do"

"an apparently free choice when there is no real alternative"

SUBMISSION CONTENTS

1. The Title of the Inquiry –

What does it mean?

At first glance the word “choices” gives the impression that this inquiry may offer every Victorians something positive. I believe this title is misleading.

Of course, we all like to be able to select and indeed to have **more** choice. This extends from food selections, to travel options to technology and now to death.

By linking the words “end of life “and “choices” suggests that any changes being proposed will be for everyone. The catch is that **only the competent** will really be able to choose for themselves.

I think that the title of the inquiry should have been “End of Life Care” not end of life choices.

A person with dementia is not able to make a submission to this inquiry. This means if you are not able to make the choice others wanting to change laws **could and will make the choice for you. i.e Hobson’s choice.**

Many individual submissions to the inquiry are from relatives advocating for the choice of euthanasing their relative. If the inquiry and outcomes are for all Victorians, how would a person with dementia in a nursing home who wants to live, but has relatives wanting to end his/her life be able to “select” the other choice i. e a choice to live?

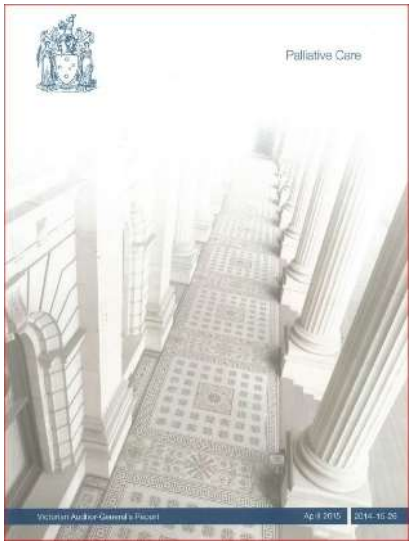
Many will say that being able to select to die should be an individual’s right. Indeed, when you are in the middle of a life threatening illness, it is hard to think positively about daily treatment, let alone your future. There is fear to be faced.

Yet the other aspect is that this situation also offers us a “gift”. It is a chance to work through issues that may have not been resolved, it is a chance to reconnect with our spiritual side, it is a time for going slowly and appreciating the little things in life.

Having experienced a period of life-threatening ill health I feel confident in making a contribution to the inquiry as my thoughts come from a personal viewpoint against the proposition that life should be able to be ended.

2. What is happening in Victoria now?

(a) Victorian Auditor General's Report- Palliative care (April 2015)



An excellent report was produced by the Victorian Auditor General in April 2015, less than 4 months ago.

At virtually the same time a motion was put to the Victorian Parliament to refer Voluntary Euthanasia to the Law Reform Commission, the Victorian government released the Victorian Auditor General's Report on Palliative Care (2015).

This Inquiry should focus on End of Life Care not End of Life Choices

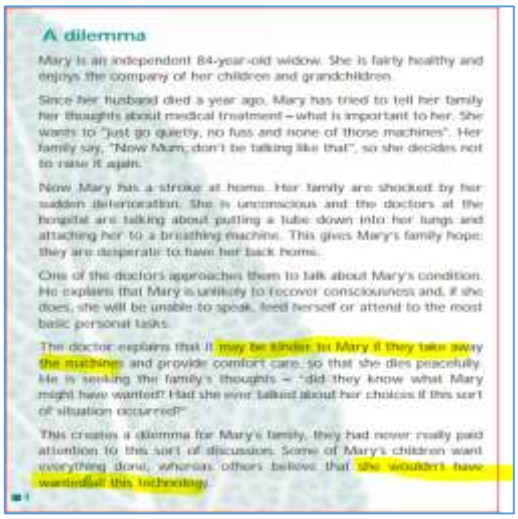
My view is that the continued implementation of services with improved funding for structure and provision of palliative care services should replace the money being spent on this inquiry.

The report assessed whether Victorians with a terminal illness have access to high-quality palliative care that is timely, coordinated and responsive to their needs and wishes.

> *The Auditor-General Mr John Doyle, said "Demand for home-based care is increasing and some metropolitan community palliative care services have struggled to meet this demand, resulting in waiting lists to access services"*
>
> *"There is more that could be done for carers and families. While there have been improvements in areas such as after-hours support, further work is needed to ensure carers and families can access support at critical times. In particular, respite provision and access to psychosocial support remain major priorities"*

If the recommendations in this report were funded and implemented, patients and carers would feel confident in the provisions of care for terminally ill Victorians. The emotive words "lingering" "undignified" "dependency on others" and "intractable pain" are used to scare people into thinking that there are no other options.

2 (b) The danger of advanced "care"



A dilemma

Mary is an independent 84-year-old widow. She is fairly healthy and enjoys the company of her children and grandchildren.

Since her husband died a year ago, Mary has tried to tell her family her thoughts about medical treatment – what is important to her. She wants to "just go quietly, no fuss and none of those machines". Her family say, "Now Mum, don't be talking like that", so she decides not to raise it again.

Now Mary has a stroke at home. Her family are shocked by her sudden deterioration. She is unconscious and the doctors at the hospital are talking about putting a tube down into her lungs and attaching her to a breathing machine. This gives Mary's family hope; they are desperate to have her back home.

One of the doctors approaches them to talk about Mary's condition. He explains that Mary is unlikely to recover consciousness and, if she does, she will be unable to speak, feed herself or attend to the most basic personal tasks.

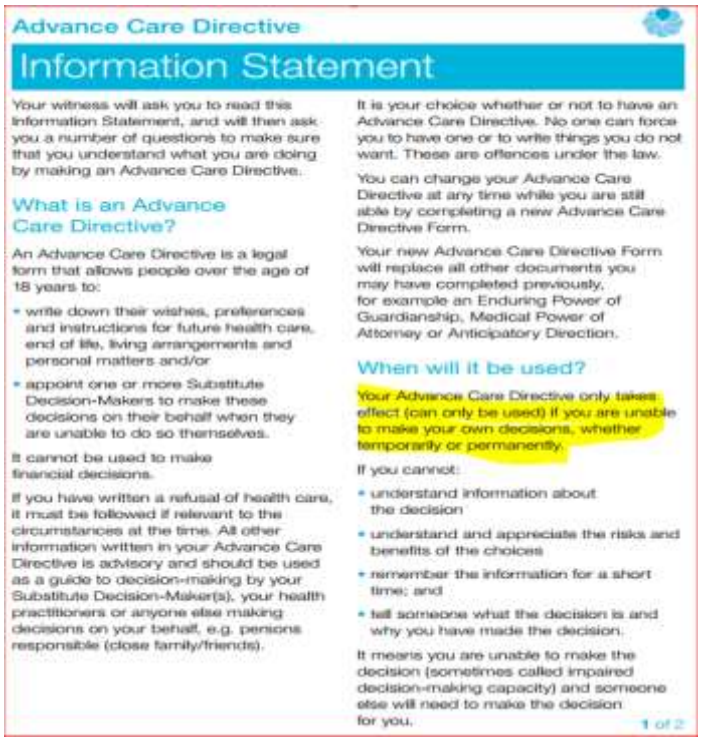
The doctor explains that it may be kinder to Mary if they take away the machines and provide comfort care, so that she dies peacefully. He is seeking the family's thoughts – "did they know what Mary might have wanted? Had she ever talked about her choices if this sort of situation occurred?"

This creates a dilemma for Mary's family, they had never really paid attention to this sort of discussion. Some of Mary's children want everything done, whereas others believe that she wouldn't have wanted all this technology.

End of life "choices" are already operating in many states in Australia including Victoria. Advanced "care" Plans (ACP) lock the person into a legal document making decisions well in advance of decline in health.

Reading one of the information sheets that Austin Health uses - participants are asked to "list situations they would like avoid or which would be unacceptable if they were dying". Look at the emotive wording – "it may be kinder to Mary to take away the machines…." Of course who would not select the kinder choice?

The South Australian "Advanced Care Directive DIY kit" -wording (left) shows a directive can be activated when someone is unable to make decisions, **whether temporarily or permanently.**



Advance Care Directive

Information Statement

Your witness will ask you to read this Information Statement, and will then ask you a number of questions to make sure that you understand what you are doing by making an Advance Care Directive.

What is an Advance Care Directive?

An Advance Care Directive is a legal form that allows people over the age of 18 years to:

- write down their wishes, preferences and instructions for future health care, end of life, living arrangements and personal matters and/or
- appoint one or more Substitute Decision-Makers to make these decisions on their behalf when they are unable to do so themselves.

It cannot be used to make financial decisions.

If you have written a refusal of health care, it must be followed if relevant to the circumstances at the time. All other information written in your Advance Care Directive is advisory and should be used as a guide to decision-making by your Substitute Decision-Maker(s), your health practitioners or anyone else making decisions on your behalf, e.g. persons responsible (close family/friends).

It is your choice whether or not to have an Advance Care Directive. No one can force you to have one or to write things you do not want. These are offences under the law.

You can change your Advance Care Directive at any time while you are still able by completing a new Advance Care Directive Form.

Your new Advance Care Directive Form will replace all other documents you may have completed previously, for example an Enduring Power of Guardianship, Medical Power of Attorney or Anticipatory Direction.

When will it be used?

Your Advance Care Directive only takes effect (can only be used) if you are unable to make your own decisions, whether temporarily or permanently.

If you cannot:

- understand information about the decision
- understand and appreciate the risks and benefits of the choices
- remember the information for a short time; and
- tell someone what the decision is and why you have made the decision.

It means you are unable to make the decision (sometimes called impaired decision-making capacity) and someone else will need to make the decision for you.

1 of 2

Temporarily is an arbitrary word, - many different medical circumstances could apply.

Temporarily could include a stroke, in which the patient improves after a few months. IN this case, you may have actually signed your life away. If you have advanced care directive!

Other suggested statements are:

"If I am unable to recognise family and friends (for example, having dementia) and unable to communicate, I do not want any health care which prolongs my life.

Of course most people would feel guilty wasting hospital resources and would not wish to select a treatment that may deprive another patient of that treatment or would stretch the resources of the hospital!

Life has now become a tick the box system. Dying should be a natural part of life, and now it is a menu selection!

3. (a) Overseas trends

Several countries, and/or states have legalised "end of life choices". Organisations such as Dying with Dignity and EXIT International market themselves as advocates for individuals to **select a safe and peaceful death -** the reality is far from that. Data from the Netherlands, Belgium and Switzerland definitely shows that "choice" soon extends to "no choice". In Holland the use of drugs for compulsory terminal sedation have increased by 300% since 2004. (see dot point 4 below).

- A 2010 study published in the Canadian Medical Association Journal found 32% of all euthanasia deaths in the Flanders region of Belgium were without request or consent.
- 2009 Statistics from Switzerland show almost a 700% increase in assisted suicide deaths of Swiss residents (Does not even included foreigner assisted suicides).

Henk Reima (below), an academic and statistician from Holland studies Dutch death statistics and is alarmed at the increase in the use of "continuous deep sedation". He states that the use of midazolam for termination sedation has increased 300% since 2004 and statistics mask the true **situation** in Holland concerning medical acts with the deliberate intention to kill.

- I attended the 4th HOPE International Symposium on Euthanasia and Assisted Suicide in Adelaide in May 2015. Guest speakers told how THEIR relatives who were coached by pro "choices" organisations to end their lives. www.noeuthanasia.org.au

Dr Tom Mortimer PhD - an academic from Belgium Son-challenges-Belgian-law-after-mothers-mercy-killing described how his mother - Godelieva De Troyer, age 64 was euthanased by lethal injection in a Brussels hospital in April 2012. Tom was only notified to liaise with the funeral director to donate her body to science.

Godelieva De Troyer

Judi Taylor of Mornington Peninsula, Melbourne, spoke of her 26 year old son Lucas committed suicide with "death coaching" from Philip Nitschke's EXIT organisation. Lucas paid $600 to Join EXIT and was involved in their on-line forums for two years prior to his death.

The Daily Mail Australia published an article in June 2015 which refers to the situation in Belgium. Belgium's Euthanasia Act restricts the practice of mercy killing to adults and 'emancipated children' who are suffering unbearably and who are able to consent. It remains officially illegal for doctors to kill patients who have not given their consent to death. The study

found, however, that many GPs are killing their patients without consent and that lack of consent may be more common than officially-approved deaths. In the article in the Journal of Medical Ethics, Professor Raphael Cohen-Almagor of Hull University said

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Belgian GPs 'killing patients who have not asked to die': Report says thousands have been killed despite not asking their doctor

- Thousands killed under GP care despite not asking to die, report says
- One in 60 deaths involves someone 'who has not requested euthanasia'
- Half of patients killed without giving their consent were over the age of 80

By STEVE DOUGHTY, SOCIAL AFFAIRS CORRESPONDENT FOR THE DAILY MAIL

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NO END of LIFE CHOICE IN THE MATTER!

In Holland on 19 June 2015 the Times Live published an article showing that the Dutch Paediatricians' Association think that the under 12's now have the right to die!

Times LIVE

Watch NYPD beat black man as he lies on store floor

Watch parents rescue baby after daycare centre locks him in after closing

Sunday Times

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Under 12s have right to die: Dutch paediatricians

AFP | 19 June, 2015 14:32

File photo
Image by: Wikimedia Commons

Terminally ill children in unbearable suffering should be given the right to die, the Dutch Paediatricians Association said on Friday, urging the suppression of the current 12-year age limit.

3 (b) A hassle free death is not guaranteed!

Prof Peter Singer in a debate with Sydney Archbishop Fisher on 13 August 2015 said that choosing euthanasia would be a painless, simple death.

However a program on Australian TV in November 2014 shows this is not the case.

The ABC TV "Four Corners" programme was aired in November 2014. Peter Smedley travelled to Switzerland to end his life in an apartment owned by pro "choices" organisation Dignitas (Switzerland).

The website states:

"Welcome to DIGNITAS, the Swiss self-determination, autonomy and dignity advocacy group"

While Mr Smedley's wife and Dignatus representatives surrounded him seated on couches in the lounge room, Mr Smedley started drinking a champagne glass of a poisonous fluid in front of them, and the TV viewers.

He started choking and asked for water. The staff would not give him water. After this slumped in the chair and died, next to his wife.

His death was <u>not</u> dignified.

It was disturbing viewing. My friend and I both watched this programme independently. Interestingly we viewed the program again later and the segment showing Mr Smedley coughing and choking, then asking for water was no longer there.

The video has since then, been blocked from You Tube viewing.

3 (c) A "choice" is not necessarily a good choice!

Philip Nitschke's demonstration (SEE You tube video link) of how to end your life using nitrogen from a cylinder is still viewable on the You Tube site today- one and a half years after it was first uploaded

Nurse Betty, who looks fit, active and jolly shows how a "peaceful, reliable and totally undetectable death" can be achieved. 12,192 viewers have seen this video so far!

Another 400 viewers have viewed the video since I downloaded the picture in early August. T

The irony is—if we are horrified at this on line video why should we be? – isn't it just another example of "choice"!

I find it very odd that on the one hand when there is a program on TV in relation to suicide which is disturbing to some viewers, we want to prevent suicide and rightly state the telephone number of Lifeline and Beyond Blue at the end of the programme, to assist people who may need counselling. Yet, we are happy to promote the views of the pro euthanasia lobby.

4. Nursing home standards - no reason for end of life "choices":

Many people mistakenly think poor nursing home or hospital standards are a reason to 'release their relative out of misery'.

Former teacher Julie Landvogt in her article (The Age 30/3/15) lamented the life being led by her mother in a Melbourne nursing home. She described a scene where her mother sitting in front of daytime television with a tea towel for a bib, hair awry, no jewellery or make up and bits of breakfast still in crumbs on her chair. Dr Landvogt's view is we "should be able to be assisted to depart"

ASSISTED TO DEPART? Just another euphemism.

Shouldn't the nursing home be held to account for her mother's standard of care?

In Australia accreditation of all nursing homes is mandatory and quality standards are monitored by the Australian Aged Care Quality Agency. In terms of accreditation standards – health and personal care and care recipient lifestyle are two of the four areas legally covered. Not only are standards set out in detail, but they are bound by quality reviews. "Unannounced visits" and audits have resulted in Melbourne nursing homes being closed down. There is a legal requirement for a process to enable relatives to express their concerns. Many facilities have a regular "relatives meeting" where feedback can be given in a supportive environment.

The same difficulties in service provision occur in hospitals. In terms of meal services, many hospitals have divided services into different departments. Effectively this means that there is not one reporting chain for the whole meal service and patient's food intake. Now, one department delivers the meals and collects the trays, another department takes the meal orders, Feeding of patients is now a non nursing duty in many acute hospitals. Many patients do not have relatives, and volunteers are not authorised to feed patients.

Another stumbling block is that many meal items are sent in individual portion control items, which cannot be opened easily. This includes milk portion, juice and lids on containers. I recall having a drip in my arm and not being able to reach the tray which was put on a table out of reach, let alone cut up the food.

This can result in patients losing weight and not meeting nutritional requirements. Again, this leads to poor health.

Relatives may not see these signals, and like Ms Landyogt see that their mother's situation is unacceptable – for the wrong reasons.

Ms Landvogt said instead she "can't deny that I would relish being freed from the duty".

Is this a reason to euthanize her mother?

DECISIONS FOR THE COMMITTEE

YES:

- Make a formal commitment to the dignity of every human being, at all stages of life.
- Continue with the recommendations for the full implementation of the Victorian Government Palliative Care system.
- Expand support services particularly psychological help to relatives or patients with terminal illness.
- Give a message of hope and not despair to our youth who have one of the highest rates of youth suicide in the world.
- Maintain our world class hospices staffed by qualified doctors and nurses, providing quality palliative care with pain control & real not counterfeit, death with dignity.

NO:

- Our Parliament of Victoria must not accept the euphemism of “end of life choices”.
- Every person has innate dignity not dignity conferred by our interpretation of the value of their life.
- There is no legislative change required.
- Killing patients with life ending drugs is not “dignified”.
- Euthanasia strips a person of all dignity.

Mary Collier, BHSc (Otago) and Grad Dip Nut & Dietetics, Grad Dip Mgmt (RMIT). Mary is a trained dietitian and has practiced in Australia and NZ. She has worked as a Quality Manager in a Melbourne tertiary hospital, and was involved with accreditation standards for Acute Hospital and Aged Care (Food Services) She has also lectured in Nutrition at Monash University (Melbourne) in Nutrition and Food Services Management.