eSubmissions

Inquiry into End of Life Choices

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Title

First Name (required)
ROBYN

Last Name (required)
ANASTASIOU

Phone Number (required)

Email (required)

Address 1 (required)

Address 2

Suburb (required)

Postcode (required)

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Submission 594

Organisation Name

Your Position/Title

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Signature (required)

Sign and Submit

Robyn Anastasiosv

Last Updated on Wednesday, 27 May 2015
Submission: Inquiry into End of Life Choices

INTRODUCTION

My interest in the Inquiry into End of Life Choices originates from a professional background in nursing and social work; and from personal experiences.

Through my work in both professions I have cared for people at the end stage of life. From a personal perspective I have cared for my daughter and my mother through their respective non curable illnesses.

In this submission my aim is to identify some of the gaps that exist in current practices to manage end of life care; and to put forward some recommendations about how to better assist people to manage end of life care.

Secondly, advocate for change to the current legal framework to include the choice to voluntary assisted death.

SUBMISSION

I have a particular interest in the care of people with a diagnosis of dementia, with a focus on planning for care pre diagnosis and in the early stages of the disease. Existing documents should be expanded to include options on how a person chooses to be cared for at end of life. There is a need for a universal, recognised document that clearly states how a person with dementia chooses to be cared for at end of life.

Dying With Dignity Victoria have developed two separate documents; one is an Advanced Health Care Directive General, the second, Advanced Health Care Directive- Alzheimer's Disease(and other dementias), (refer to attached documents). The documents are accessible by attending a workshop, led by an experienced doctor. Detailed written, clear information is provided with the documents. To the best of my knowledge, this dementia specific document is the only one of its kind. A dementia specific document could be made accessible to those people who have a verified diagnosis of dementia from appropriately qualified professional people such as the treating physician (Neurologist, Geriatrician, GP), who are involved in a treatment care plan. Qualified counsellors from Alzheimer's Associations could also provide additional information to clients on how to access a dementia specific document that directs how their end of life care is managed. Of equal Importance is the inclusion of an Enduring Power of Attorney (Medical Treatment). Hospital files
should have a tick box on individual patient files to indicate whether the patient has an EMPA.

It is critical this information is available before dementia progresses to an advanced stage and while the person is mentally competent. There is no option to sign a legal document when the impact of dementia has damaged or compromised cognitive functioning.

Clearly, public access to such documents requires a responsible and knowledgeable approach from appropriately qualified people.

Sadly, I have examples of people with dementia who wished to not prolong their lives but did not leave a written record of their wishes for end of life care. Thus, medical interventions were put in place that prolonged life, while the quality of life was often obviously compromised. For example, peg feeding, administration of psychiatric medications/chemical restraint, antibiotics, and preventive medications to treat cholesterol, hypertension, and more.

Provision of basic nursing care can be neglected as a result of difficult behaviours/noncompliance, or resident ‘declined’ assistance explanations. In 2006, my mother, in an advanced stage of dementia was an example of the latter. According to nursing/care staff her aggressive behaviours precluded her from basic nursing care. Psychiatric medication (zyprexia) was prescribed which made some difference in that it subdued her, but it did not prevent the development of a horrible, open sore on her coccyx. It was very painful; even though I reported her pain to staff, it was not acknowledged or treated for several days. On one occasion, I observed agitated behaviour, when my mother was constantly touching the painful sore. I verbally expressed my concerns to the registered agency nurse, in charge, who assessed my mother was not in pain. My mother’s dementia was advanced to the stage where she could not verbally communicate her pain. She could not verbally communicate to any of her children or grandchildren. She was totally dependent on others to care for her.

To cut a long story short, in the next day or so, I requested palliative care, quoted a section of the Medical Treatment Act 1988, Preamble (f) to her GP, who, at last seemed to recognise she was entitled to some much needed attention. An improved standard of nursing care followed. Morphine was ordered and she died two or three days later. In my opinion, my mother suffered intolerably. I could not observe any quality of life for her, only indignity and pain.

My mother, in some of her more lucid moments, had verbally made her wishes known to me that she did not want to lose control over her life.
Had she, pre diagnosis or when still competent, a choice to provide a legal document that clearly stated her end of life care wishes, she hopefully could of avoided some of the indignity and pain by dying sooner rather than later.

Yet, if a similar situation was to occur in the current health system, there is no guarantee that if such a document was sighted by treating staff that patient wishes would be implemented. My sense is that it is hit and miss, dependent on a number of variables: The type of facility, staff awareness and education, beliefs and values held by staff; and more significant, the ability of the patient’s Medical Power Of Attorney and/or family to advocate/negotiate within an often complex system that can seem intimidating.

A letter to The Age, 8/7/15, from Associate Professor Neil Orford, director of Intensive Care at University Hospital Geelong and director of Critical care services at St John of God Hospital Geelong, draws attention to similar issues he confronted when his frail, elderly father was admitted to hospital. 'I have learnt it can be hard to be heard', he writes, going on to share how his experience of trying to advocate in his father’s best interests was hard to do when medical staff sought to intervene with what he viewed as unnecessary interventions.

Though reluctant, he identified his professional role, determined to fight for an appropriate end of life care for his father. Neil Orford points out, for staff to make decisions related to the best interests of patient care they need to hear from the family’s perspective, to gain insight into how to include the family in a plan of care that reflects the background that led to the patient’s admission to hospital. Only those closest to the situation can provide the bigger picture, (refer to letter attached).

One of the ways to provide better end of life care, is to focus on the development, and improvement of current and future curriculums for medical students, nursing students and social science students. The curriculum should include a course unit that informs on end of life issues. Guest speakers from a range of disciplines could contribute from their specific knowledge base. For example, staff from intensive care units, hospitals, palliative care, aged care, social work, legal services and ethicists could present on how end of life care is managed, and how to better practices. It is important to involve front line staff in the planning of curriculum development. An emphasis on the rights of patients and their families to be heard is paramount. People like Neil Orford would have much to contribute to student learning.

I acknowledge that some moves towards improvement of patient choices occur in some sectors of the health system. I understand The Alfred and Epworth Hospitals have a document that relates to end of life choices. The Government, under the
direction of Tanya Plibersek, the former Labour Minister for Health, in 2013 thereabouts, invested $10 million to enable advance care directives to be stored on the Personally Controlled Electronic Health Record. The Respecting Patient Choices program model was also funded. To the best of my knowledge RPC training is now being introduced to management in Aged Care Facilities in the ACT. A national program should be implemented into all Aged Care Facilities.

Associate Professor Dr Bill Silvester, from the Austin Hospital supports RPC, and has spoken out in relation to unnecessary interventions to terminally ill/frail patients. The Government may be taking steps to address legislation that ensures doctors recognise Advanced Health Care Directives and follow through with Medical Power of Attorney/patient wishes.

To conclude, it seems a review of who is doing what, where and how is required so a unified approach to an accredited RPC program is implemented across the health care system, and that all medical, nursing and allied health personnel are informed of their responsibility to recognise end of life care choices; in particular, staff in management of care positions.

From a personal perspective, I support reform of the Medical Treatment Act to include the right to voluntary medical assisted death when suffering intolerable and unrelievable pain brought about by an incurable illness or other condition, such as extreme long term unrelievable pain from arthritis.

The overwhelming majority of Australians support the right to choose when to die when suffering from an incurable illness that can cause intolerable physical, psychological, emotional and existential suffering.

Within the Australian population there are many and varied views of euthanasia (voluntary medical assisted death). Whilst I respect most of the views I have heard and read about, I do not necessarily agree with all of them. Those who oppose euthanasia/voluntary assisted death, based on religious beliefs are entitled to disagree, but I do not want others’ beliefs imposed on the majority who want the right to choose when to die with dignity (in circumstances previously stated)

For those who oppose on the basis of ‘the safe guard’ debate, I believe that much work has been done, to date, to achieve safe guards to protect both patient and practitioner from unlawful interventions.
Doctor Richard Di Natalie tabled a detailed Exposure Draft Medical Services (Dying with Dignity) Exposure Draft Bill 2014 in the Federal Parliament. I found it educational to further understanding of proposed legislative reform. The parliamentary inquiry, I’m sure also finds it a valuable reference.

The Medical Treatment (Physician Assisted Dying) Bill 2008, while defeated in the Victorian Legislative Council, is a document that could be further developed to satisfy the concerns expressed by members about more stringent safeguards, but who favoured the bill in principal.

Despite all the arguments put forward that palliative care is able to alleviate all types of pain, the reality is that pain is experienced on an individual level. Sure, there are various methods used to gage the intensity of pain, but with respect, no doctor has the ability to know how another’s pain is felt. I believe that palliative care would be better if maximum relief from pain and suffering included the choice to voluntary medical assisted death. If I am correct, of the current methods to relieve unbearable pain, terminal sedation is one option. Not an option that is wanted by everyone who is in unbearable pain. I for one would prefer a swifter, more dignified death, one of my choosing while I am conscious and competent, with my closest loved ones by my side. My beloved, terminally ill, dog had a peaceful, vet assisted death at home. I want the same choice to a legal voluntary medical assisted death if I am in intolerable and unrelievable pain. In my opinion, it would be far more dignified than many of the human deaths I know of.
Advance Healthcare Directive — General

TO MY FAMILY, MY PHYSICIAN AND ALL OTHER PERSONS CONCERNED,
THIS DIRECTIVE is made after careful consideration by me:

(Name) ............................................................... Date of Birth: ....../...../20...

Of ..................................................................................

.................................................................................. (Address)

at a time when I am rational and of sound mind.

STIPULATION/S:
This Advance Healthcare Directive applies only if the following stipulation/s are met:
☑ If at any time I have become unable to participate effectively in decisions about my
medical care.
☐ If two independent doctors (at least one a specialist) are of the opinion that I am unlikely
to recover from a severe illness to a state of independence and competence, or that such
recovery could only be to a state of profound physical or psychological suffering. Such
an illness could include severe and lasting brain injury or dementia.
(If you want the second stipulation above to apply, tick and initial it. If you don’t want it to
apply, strike through its entire paragraph and initial at the end of the paragraph.)

IF THE STIPULATION/S ARE MET, THEN IN THOSE CIRCUMSTANCES I DECLARE
that I am not to be subjected to any medical intervention or treatment aimed at prolonging
or sustaining my life, AND QUITE SPECIFICALLY:

(For each treatment, Initial the column choice that reflects your wishes):

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I DON'T want</th>
<th>I want</th>
</tr>
</thead>
<tbody>
<tr>
<td>Artificial feeding (nutrition and/or hydration)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Antibiotics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Artificial respiration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any surgical procedures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Circulatory support including CPR</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I DON'T want</th>
<th>I want</th>
</tr>
</thead>
<tbody>
<tr>
<td>Corrections of abnormal levels of any toxic substance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blood transfusion</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug treatment of hi/lo blood sugar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug treatment of hi/lo blood pressure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renal dialysis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Once you have initialled one of the choices for each treatment, draw a simple diagonal
stroke, / through each of the unsigned choice boxes so that none is left unmarked.)
AND, again where the stipulation/s apply, **any persistent Distressing Symptoms are to be maximally palliated** by appropriate analgesic, sedative or other palliative treatment, even though that palliative treatment may also have the additional consequence of shortening my life, **AND QUITE SPECIFICALLY:**

<table>
<thead>
<tr>
<th>Distressing Symptom</th>
<th>Maximum Palliation</th>
<th>Not Maximum Palliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathlessness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extreme weakness or paralysis leading to total dependence</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(For each Distressing Symptom, _Initial_ the column choice _that reflects your wishes_)

<table>
<thead>
<tr>
<th>Distressing Symptom</th>
<th>Maximum Palliation</th>
<th>Not Maximum Palliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those caused by lack of food &amp; fluid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological suffering such as fear, panic, terror, extreme anxiety or delirium.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of appetite, nausea, vomiting, diarrhoea or incontinence.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Once you have initialled one of the choices for each distressing symptom, draw a simple diagonal stroke, _I_ through _each of the unsigned choice boxes_ so that none is left unmarked.)

AND, again where the stipulation/s apply, if it should be legal to do so at that time, I request that my death be hastened by a doctor providing or administering a fatal dose to allow me to die with dignity.

I wish it to be understood that I dread degeneration, prolonged dependence, inability to communicate and indignity far more than I fear death. I ask my medical attendants to bear this statement in mind when considering what my intentions would be in any uncertain situation. I hereby absolve my medical attendants from any civil liability arising from compliance with this Advance Healthcare Directive.

I RESERVE the right to revoke this Advance Healthcare Directive at any time, but unless I do so it should be taken to represent my continuing directions.

**SIGNED BY ME: _________________________________ (Signature)**

this __________________________ day of ___________ 20__

in the presence of ______________________________ (Signature of Witness)

(Name & address) __________________________________________

_of witness) __________________________________________

Page 2 of 3
**Attachment A: Your Health Status at Time of Signing**

At the time of signing this document,

(Tick and initial the one that applies.)

<table>
<thead>
<tr>
<th>I am in good health</th>
<th>Initials</th>
</tr>
</thead>
</table>

☐ I have been advised that I am suffering from:

........................................................................................................

........................................................................................................

......................................................................................................... (Write in the diagnosis.)

<table>
<thead>
<tr>
<th>Initials</th>
</tr>
</thead>
</table>

**Attachment B: Your Medical Practitioner to Sign Here**

I, ................................................................. (Medical Practitioner’s name),

of ................................................................. (address of Medical Practitioner)

attest that ....................................................... (patient’s name), is of sound mind.

Medical Practitioner’s Signature: .................................................. Date: ......................

**Attachment C: Your Chosen Appointed Agent**

(Tick and initial the one that applies.)

<table>
<thead>
<tr>
<th>I have completed an Enduring Power of Attorney (Medical Treatment) form and appointed the following person as my agent:</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ ...........................................................................................(name of agent)</td>
<td></td>
</tr>
<tr>
<td>of .........................................................................................................................</td>
<td></td>
</tr>
<tr>
<td>.................................................................................................................................</td>
<td></td>
</tr>
<tr>
<td>.................................................................................................................................</td>
<td></td>
</tr>
</tbody>
</table>

☐ I have not completed an Enduring Power of Attorney (Medical Treatment) form and have not appointed anyone as my agent.

**Attachment D: Organ Donation**

In the event of my death,

(Tick and initial the one that applies.)

<table>
<thead>
<tr>
<th>I want to donate my organs for transplantation</th>
<th>Initials</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I do not want to donate my organs for transplantation</td>
<td></td>
</tr>
</tbody>
</table>

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05a Advance Healthcare Directive - General 11-04-12 doc
Give death its due in a system focused on life

Neil Orford
Published: July 8, 2015 - 12:00AM

Recently I sat by my father's bedside as he died. He was unconscious, in a fog of sedation and painkillers, and I had the privilege of a long goodbye. In the end he had a peaceful death, but my family had to fight for it. Fight the passive resistance to providing care focused on a comfortable death, rather than care focused on cure. Fight the lack of recognition that we could simultaneously love this man, while advocating for care that allowed him to die without agitation and suffering. Fight the insidious guilt this conflict let creep into our last week with him.

In itself this is not a remarkable story, our difficulties navigating the end-of-life landscape have been shared by countless other families. What is remarkable is that our experience was so difficult despite my role as a senior intensive care specialist in the Australian healthcare system, a clinician who regularly deals with grief and dying. I had imagined I would be able to smooth the bumps for my father and family. I was wrong, and there are lessons I have learnt.

I have learnt it can be hard to be heard. My father had fallen in his courtyard, toppling backwards and striking his head on a rock wall. Hard enough to cause a large scalp laceration, a lot of blood on the ground, a small amount of bleeding into his brain, and needing urgent hospital care.

We asked to talk about treatment limitations because this was much more than a fall and a head injury. It was his second fall in a few months, occurring on a backdrop of progressive dementia and physical deterioration that had slowly but relentlessly taken him from us. A shadow that transformed a man with intellect, humour and compassion, to a frail figure grappling for a mental handhold on the world around him, struggling to remember our names and faces. Cruelly, it left him with enough presence to feel alone in hospital, wishing he were home with the woman he had loved for more than half a century.

We wanted to talk about our fear this injury would lead to a more rapid decline in his quality of life, that he would not be able to return home, and that this would be unbearable for him. We wanted to say we didn't want him to receive care that would prolong his life, only to see him die away from home soon after. It is not easy to say these things about someone you love, and when we did we were told he would get full resuscitation, that the doctors involved in his care were not
available to talk to us about treatment limitations until the next day, or the day after that. We were not heard.

I have learnt it is easy not to get good end-of-life care. Although there is growing recognition at all levels of the health system that it is better to provide end-of-life care that focuses on people rather than just disease, it is still easy not to die well. It is easy not to know you are in the last part of your life. It is easy not to be asked what you value in life, or to be offered care that puts this first.

At his most vulnerable my father suffered, and we were treated clumsily. Over 10 days in hospital he became progressively more distressed and frightened, and lost strength and dignity. When he developed urinary retention and could not empty his bladder, it took more than 24 hours for a catheter to be inserted, despite his extreme distress. When we asked if he could have night-time sedation for his delirium and agitation, we were told he couldn't because of his brain injury. Yet at night we were called and asked to reassure and comfort him while urgent sedation was organised. When we expressed concerns that he could not eat or swallow, we were told daily a speech pathologist would see him. Almost comically they came for the first time the day his palliative care regime began, ensuring a carton of thickened fluid was delivered to his bedside three times a day while he was unconscious. When we asked, daily, for a referral to a palliative care team, it took more than a week for it to happen.

I have learnt that good end-of-life care is worth fighting for. After a week of anxiety, we flashed briefly into anger and frustration, and then in desperation we pushed back. I did what I had tried to avoid, and identified myself in my professional role. By the end of the day the doctors involved in his care had spoken to me, understood our concerns, and agreed to our requests for care that concentrated on comfort. When the palliative care team arrived they listened to us, and delivered clear, effective comfort care, lifting a burden of anxiety off our shoulders.

It did come at a cost. A cost to my father, who suffered when he could have been peaceful. A cost to my family, left to feel guilty for demanding comfort over cure. A cost to me, because the days spent advocating as a doctor could have been spent grieving and saying goodbye as a son.

I have learnt that our healthcare system is full of vulnerable families and caring health professionals. In the final days, weeks, months of life, when a new event tips the scales further against us, there is lot at stake, and patients and families become vulnerable. Even though we had expected a frailty event like Dad's fall for some time, we were shocked by the sudden lurch into the last weeks of life. We struggled with the immediate threat to his life, then the dilemma of curative or comfort care. There are families like us throughout our hospitals, their loved ones deteriorating with diseases that are progressing, frailty that can't be stopped, and like us they become distressed, become the "difficult family". Unless we identify them, and approach them, we can't help them.

Our health professionals care. As a family we spent hours with nurses who gently cared for my father, and engaged with us as the mood demanded. In a hospital environment that is alien, controlled, full of strange smells, noises, and the lurking threat of suffering, they care, laugh, listen, explain and bring humanity back into the room. They make a difference patient-by-patient, family-by-family.

I have learnt we need to do better. Our story is played out continuously, 24 hours a day, in acute hospitals across our country. The script may differ in details, shades and nuances, but always describes the same journey. In a health system that does a remarkable job curing or controlling diseases, returning us to lives we value, the default is set at intervene. To provide better end-of-life care to patients and families, we need to identify them, offer support, listen, and give advice and treatment tailored to their needs. If we don't, only those lucky enough to know the system, know someone, or stumble across a hospital that is really good at this, will be given the choices we all deserve.

Grief is awful, and dying is a process that takes all our attention. We don't need distractions.