“Good noW!”® **B”H**

07 August, 2015 / 22 M Av. 5775.

Dear Members of the **Standing Committee on Legal and Social issues Inquiry into end of life choices in Victoria, Victorian Parliamentary inquiry 2015**.

Submission.

General Index: End of Life Decisions.

- **A. Overview.**
- **B. Specifics**
- **C. Recommendations**
- **D. References and sources.**
- **E. Appendix (AA)**
- **F. Specific Index (and Summary)**

A. Overview; Perspective and Definitions.

(1) General interpretation of End of Life Decisions.
Definition: Any decision that results in end of life.

(2) Standing Committee context: Decisions made at the end of one's life.

(3) General interpretation of Advance directive.
Definition: Any directive or statement made in advance that indicates what can be done or not done in a condition or were an event to arise that prevents expression of such preference by the person concerned.

I have previously proposed (2008) that an advance directive, which is signed by two witnesses and the principal person involved be called as such, and be recognised, but not as a document on which a medical action can be taken, unless one of the witnesses is a doctor, and in such case the document be referred to as an advance**d** directive, i.e. has a D added to advance, rather than one made in advance, to one that is to be advanced were the occasion of the anticipated event to arise..

In either case it needs to be appreciated that the advance(d) directive applies only were an event to arise.

The conclusion in 2008 and now, is that a person whom one trusts to advocate for you, is in a better position than any intended advanced plan, even Advanced directive, in the vent that you are unable

to make the decision for yourself, as conditions change, both those of the person's health and with time. New applications may make some situations reparable which were previously regarded as insurmountable, all of which has to be taken into account, including options related to financial support and carer availability, to fulfil a person's wishes, and therefore "best interest".

In the Legislative framework, an advance(d) directive needs to be seen for what it is. It is not an end of life decision. Rather, it is an "in anticipation of" or "following event of life" decision, and may or may not have relevance to end of life.

The reasons A/Professor Silvester said people gain from making an Advance directive is five-fold.

"**Associate Professor William Silvester works in an intensive care unit setting. Here events unfold and one is at the cliff-face in terms of decision making to ensure patient's choices. Advanced directives in this setting he said achieve the following:**

(i) Not prolonging dying
(ii) relieving symptoms
(iii) maintaining control
(iv) relieving family burden
(v) strengthening family ties

A patient stated, "Now I can concentrate on what I want as I now that I am going to get what I want, through advanced care planning and palliative care delivery". (The benefit) offsets the anxiety in family members by involving them in the discussion.

Improve life care and improve level of satisfaction. Important to know their wishes are respected and inclusion of whom will make those decisions. Talk about it, involve those who wish to be involved.

Diagnose dying or change of dying and discuss this at this time.

Hope for the best and plan for the worst, if you have home insurance why not also appoint someone near to you who can make decisions for you if you need it, gives hope, does not destroy it."

(4) Where does or is an advance(d) directive more likely to have relevance to end of life decisions?

In situations where the condition or event is pre-terminal and/or provides cause for the person to be admitted into an intensive care unit setting or where interventions may be employed, that may or may not help the situation may be chosen as preferred options, which are not the expressed wishes of the person involved, so an advance(d) directive can be referred to, to avoid doing something that the person would not have chosen.

(5) **The progressive nature of decision making**.
As mentioned by A/Prof Silvester advanced directives may be changed. He quoted international research that has shown these changes become more limited or conditional. Such refining occurs not by chance. Rather this trend indicates that as the condition becomes more predictable choices are narrowed to better suit the occasion that any prior advanced directive, which it replaces, was able to do. This applies to all situations of decision making, that as more information is known, decisions are narrowed which reflects this.

(6) **Communication. An outcome of expression of wish or "best interest"**. Whether as a result of discharge plan pre-admission to a hospital or any care facility, or as a result of a discussion in relation to an event, a decision or statement is made in regard to goals, values and preference, or an advanced Directive or Advanced Care Plan is prepared or an advocate appointed, the benefit is the expression of personal wishes and desires, for all to take note of. Note that one of the main advantages or outcomes of the advanced directive is the fact that wishes are spoken about, communication between family members takes place and actions are requested or not that relate to the person's wishes and values. This may include organ donation.

(7) **Mental function in end of life decisions. The role of a trusted person as Medical Advocate**.
Because conditions change as do responses, and as they become more serious or life threatening, a person's ability to express what they do want may be affected, even were they able to express their desire, a trusted person, previously appointed as a Medial Power of Attorney, who can be appraised of the situation as well as communicate with the person, is preferable to any Advance directive and perhaps even Advance(d) Directive, if the doctor who witnessed the document was not the patient's trusted doctor, but a third party or appointed person.

(8) **Who can make a decision or be appointed to do so** depends on **Trust.**
In any situation, the person advocating for one or other choice needs to be someone whom the person trusts and who can communicate or was able to communicate with the person.

(9) **Definition** of **"best interest".**

"Best interest" is the situation which fulfils a person's wishes and brings them (true) happiness. It is a personal viewpoint. It has been described in terms of social and psychological wellbeing (Elder Abuse prevention. Office of Senior Victorians. 6 October 2005).

"Best interest" is not a negotiable outcome. It is an outcome that reflects the person's personal viewpoint and wish.

"Best interest" cannot be imposed.

Expression of wish equates with expression of Capacity and/or "best interest"

Legislative viewpoint. Neither the Guardianship & Administration Act 1986 or it's revised version, unconditional respect "best wishes". Rather it states, "will be taken into account". Such tokenism makes no sense and is a denial of Rights, and of Right to choose what one wants for oneself, and which an Advance(d) directive is intended to ensure and address.

As intimately described in the following publication, the only Act that ensures a person's wish is respected in respect of end of life decisions is the Medical Treatment Act 1988. The advantage of this Act is that it recognises context and the role of the person's treating doctor, though supposes this is the person's appointed and trusted doctor, and as stated in the preamble, which is all important in regard to all these points, exonerates the doctor from civil, Board and criminal proceedings, that may be brought against him/her while performing his or her duty to his/her patient.

(10) Legislative viewpoint. **The doctor's role in the doctor patient relationship. T**he Hippocratic Oath determines the doctor patient relationship. Primum non nocare – first do no harm. Based on this, it needs to be understood and written in law, that the doctor's duty is to his or her patient. Third party views, unless agreed to by the patient, have no place for various reasons, privacy, confidentiality and trust, in order for the doctor to be able to do what is in his patient's "best interest".

(11) Legislative viewpoint. Informed consent.

Two components plus the element of trust, determine the principle of "informed consent".
Trust must underpin each of the components.

(a) The doctor provides the expertise and presents up to date options, in terms of efficacy and risk, to the patient

(b) the patient decides the treatment.

Informed consent relates to treatment. It does not relate to role, as engaging in a role is by its very nature one of consent, whereas informed consent relates to a provision of some service or receipt of it above any formal or informal engagement. Thus agreeing to an Advance(d) directive needs no consent, if there are no conditions or treatment requests entered or stipulated.

Notes are given of a case in point, below.
Please see **Appendix A**.

(12) Legislative viewpoint. **Role of a third party**.
A third party, even a referral to another doctor, requires the patient's consent.
Whomever, can only ever be involved in discussions regarding treatment or no treatment if they have been invited and been given permission to do so by the patient.
In end of life decision making where the patient is no longer able to decide it may come down to a third party government appointed officer of the Office of the Public Advocate being chosen to make a decision, only to avoid legal ramifications, not because this is the best option.
In relation to making the decision Legislation needs to specify that the role of the appointed third party, is to give consent to what is medically the most relevant option.

(13) Legislative viewpoint.
Third party and Officers of the Office of the Public Advocate.

What is medically relevant is a medical decision not a third party role by someone who in any event is not a doctor.
This important distinction would help to disentangle the legal angle from the medical one and would make appointed officer's role relevant to all concerned, instead of as an imposter given an honours award of a medical certificate to someone who has no such credentials.

The Officer's job needs to be defined as "to give legal authority to doctors to make the medical decision". Ideally this must be a trusted doctor informed of the circumstances, not necessarily the treating doctor who may not know the patient.

The Officer's job needs to be defined as "to give legal authority to family to access and administrative matters, which do not only not conflict with the patient's wishes but which ensure them".

In all legislation Officers of Office of the Public Advocate must be regarded as facilitators to Medical decision making to avoid legal repercussions, which could arise upon later legal challenge, to indicate their appointment is not to make medical decisions or even lifestyle ones, such as regards family contact or other lifestyle decisions, as they are in no position to do anything as they do not know the patient. They usually become involved where there is dispute among family, but even where there is no such dispute they take over, first of the administration of and decisions related to finances and then medical and then lifestyle progressing to full Guardianship to exclude the family and have control of the finances as well as inheritance, ridding the patient or person of their "end of life decisions" or Will and intentions regarding inheritance, or interfering in the administration and choices regarding it and family, including access by family to their loved ones and visa versa of patient to their loved ones.

(14) Legislative viewpoint. What an Advance(d) directive can contain.

What patient's want for themselves, which **decide their right to "happiness"**, **in their own terms** as to:

i. timing of and
ii. choice of place of residence, and
iii. treatment choices in end of life decisions,
iv. appointment of a Medical Power of Attorney
v. appointment of a Guardian in terms of lifestyle decisions
vi. appointment of an Enduring Power of Attorney in relation to financial decisions and or administration of finances.
vii. That any appointee does not make autonomous decisions but that while the person can and is able to instruct or express, his/her expression be regarded as an instruction, which to be respectfully acted upon, not any other – and for this condition to be agreed to by anyone who accepts such undertaking as an appointed person.
viii. view in regard to any imposed third party decisions,
ix. whether by well or ill-intentioned family or members of the Office of the Public Advocate or other third party.
x. Communication of wishes and values
xi. Informed consent, and therefore therapeutic reassurance.
xii. Family concordance.
xiii. Highlights the importance of the "family meeting", which a rebatable Medicare item, at which an Advanced directive can be made, or be done in private and discussed or announced at the family meeting by the doctor and patient, to all to know and be informed of, and/or to seek their

views if the patient so wishes, and **only if the patient so wishes**.

xiv. To formulate goals if these had not been done ideally prior to admission, which is possible in rehabilitation settings, or when able in emergency settings.

xv. Other particulars.

Case report (1). Highlights Emotional factors i.e. “happiness” in addition to cognitive factors in: assessing outcomes, and serves as the goal standard related to patient's wish in regard to treatment mode, discharge planning and goal achievements, and standard of care in all health situations including, end of life, in:

(i) end of life events and decisions;

(ii) pathogenesis of disease;

(iii) patient management and respect of patient's wishes.

(iv) respect for family and family wishes.

(v) involvement of other health professionals, social workers.

(vi) Duty of care or duty to care, by hospital.

(vii) Goals and outcomes, patient's personal viewpoint and wishes

(viii) Happiness as an end point, to live for not to die for.

(ix) Role of Legislation. Relevant Law.

(x) The decision makers. Can they go on without accountability, onus and “duty of care”.

(xi) A System of “Evaluation of Decisions”. Objective and prospective evaluation of outcomes arising from decisions.

(xii) Legislative viewpoint: The need to incorporate patient “Happiness” in standards of care, outcomes and goals achieved and award compensation and to remove decision maker's immunity therefrom, when relevant Law, Medical Treatment Act 1988, is ignored in relation to their decision-making, such as to invoke “error” and invite “wrong”, and “injustice were the decision to stand though wrong”, as their Honours Buchanan J. and Nettle J. were wise to and addressed in recognising that “there are tenable grounds open to the applicant”, as was unanimously determined by them. [VSCA 2005/7516-04-11].

(xiii) Note: in the case in discussion, the daughter in law did not attend the family meeting at which discharge planning was discussed, bearing in mind the patient's wishes and assessment as to reaching that goal, the outcome being that the patient was able to go home with supports, where she was cared for to her satisfaction, as required for personal activities of daily living and cooking and house cleaning, shopping, for 14 months, by carers she interviewed and employed, before she needed to be admitted again to hospital for different reasons.

The case also highlights the point in the Health Department's presentation, Public Hearings, 23 July 2015,

Deputy director health service performance and programs.

Ms Frances Diver

51% who want to die at home do
92% who want to die in a hospital do
87% who want to die in a residential facility do.

i.e. that *49% of people of want to die at home do not, whereas in hospitals 92% who want to do and 87% people in Residential facilities who want to, do.

Additional Case report.

On Monday after i and submitted this to the Parliamentary Committee, prior to the deadline extension, someone whose mother is living at home because i advised him to not comply with the social worker's intention to have a neuropsychological assessment done on his somewhat eccentric mother, and which is done to support an application for a Guardianship appointment, as in any such assessment may find an area of underperformance, for various reasons, upon which a Disability is found, which gives the Tribunal an excuse to impose a Guardianship and/or Administration Order on the person - true - if this interferes with function, but that is seldom adhered to.

His question though, was not in relation to his mother, but in relation to a man admitted to hospital from a nursing home, who wanted to go home. This request, which could have occurred, was not only brushed off, but as usually occurs in such situations is kiboshed and opposed by Social workers and occupational therapists as well as nurse professionals on the basis of duty of care. Of course nursing homes do not want to lose a client, and neither do the health professionals want that person's bed to be lost or given away to another. Still, a person has 28 days leave a year he/she can take from any such facility, and not lose the "bed" or placement. He said the person knows what he wants. I said if he has capacity, then according to law, the Tribunal has no place and is not entitled to make a ruling to abort his wish. His decision is final. He can go home. The arrangements have to be made for him to do so. The he told me, "it's too late. He's gone to heaven."

Well what are the Committee member's thoughts on that?

Is priority given to social workers hows job it is not only to apply for Guardianship but one would have hoped to arrange support required and or requested to support this man's wish to go home. Of course they do not know how to diagnose, so where were the doctors, or more to the point, where were the advocating doctors who understood this man's wish, could have assessed his longevity or chances and positively led the health professional to do what this man wanted, in essence to be at home, that's it and die there if that is the notion, or more positively put, to live out his life there.

The truth is in public hospital, where these Geriatricians usually work, they too are "institutionalised" by having to work according to whomever holds an Administrative role over them and do not have the moral courage to do what is in the patients' interest, but take the path of least resistance, not to upset other health professionals, who all want to have a say, yet whose functions do not include "to overrule patients", and to fall into line with social worker bullies, who have no regard for patient rights and wishes and "best interest", and some Occupational Therapists and or bureaucracy, or according to their self driven agendas, including to appease the Medical Board, if called as expert witnesses for the Medical Board in cases against the best and only caring doctors, which is my experience (see below).

Ideally, or theoretically, in either Case report (1) and the additional Case Report, was the best option to sign oneself out, with assurances those who will are there as needed to care for one?

Mrs A (Case 1)**could have signed herself out**, and should have done, as she was already deemed palliative, when on Anzac Day, 26 April 2000, she sat outside her ward, like a happy soldier, with her frame and waited for me to arrive to take her. Of course i didn't have a power of Attorney and couldn't do so until she was formally discharged, as she was not under my bed card, which is something i adhere to. Even so four weeks later, i still adhered to this, but the social worker's intervention confounded the issues, and i was found to have "discharged" the patient, which i thought her hospital doctor and agreed to. Justice Kaye, gave reasons, indicating that he didn't understand the difference between "discharge the patient" and "arrange the discharge", that in his view was a semantic difference, and made a finding against me. In any event nothing happened following my direction to arrange the discharge, as having just spoken to the bed card doctor on the phone i thought that was what he agreed to tell the nurses, but he did not or could not or did not wish to remember that, when questioned, as he said "*he acted with expediency to cover his own backside - at the expense of the patient's happiness* - *while* "*Dr Myers' intentions*", he said, "*are pure*".
It would take a Tribunal hearing to order the discharge and another three weeks of "withdrawal, refusal to eat, development of a leg ulcer" before she was sent/discharged home, with the supports that ending up "killing" her, the next day, as palliative care nurses were deployed, while i was no longer there to care for her, and Registrar Nelms, the Tribunal registrar at the time, refused to permit Morris, who was then President of VCAT and who presided at that hearing to testify about this, which led their Honours Buchanan J and Nettle J. to decide to grant leave to Appeal Kaye's J. and the VCAT decisions and their reasons for decision.
See Myers JB. (2105) in Discussion under Happiness and advocacy, in manuscript entitled, "Erratum to .. ", op cit.

(15) The defining *Challenge of this Legislative Council Inquiry.
(Please refer to cases above and below)

I believe that this* is the most important statistic presented and one which the Inquiry must address, as more people are affected by variance in terms of their wishes than die or are put onto treatments they

do not want, as much as that is an important focus of the Inquiry, in respect of Advanced decision, quality of life for those who live is even more salient and pressing.

I believe if they were able to, it would take another five years for the Health Department to unravel this story, for the reasons given, that have been painstakingly obtained through experience, that relate to Elder Abuse and the other reasons given below, and in relation to which I have stood in three consecutive Victorian Parliamentary State elections to bring these very matters to the attention of the Parliament and the Public. Their graph (histogram) shows the number of people who wanted to die in their home and did, has increased to reach this 51%. They were much less likely to previously. The case reports discussed are indicative as to why, as enumerated in the Case report in Discussion and in the Article by Myers JB, errata to Alzheimer's Disease and Happiness. Op cit.

i And the answer to this question, which I believe would take the Health Department five years to uncover, if ever, relates to the cases presented herein and published, the underlying issue being denial of Rights due to:
ii Imposition
iii Bureaucratic and biased decision making, collusion, conspiracy and alleged misfeasance,
iv legal ramifications, (see in Discussion and Reference 21).
v Legislative loopholes (AHPRA Act 2010) oversight or failure and failure to Evaluate and Quality Review, and failure to ensure People Rights in the Legislative framework, and
vi by Judicial choice to ignore the relevant Law, the Medical Treatment Act, which recognises the patient's wish and exonerates doctors who uphold their patient's wishes in these, difficult, circumstance, in order to make a finding according to the Professions Act which does not recognise the patient's wishes and does not exonerate doctors who abide by the relevant Law that ensures this.
vii Elder Abuse.
viii Awarding costs in non costs jurisdiction, where rules of evidence do not even apply; where intent, indicating prejudice and motif, regarding judicial decision-making was stated.
ix See two attachments re costs Appendix AA iiia, iiib.

The Health Department’s histogram shows the number of people who wanted to die in their home and did has increased to reach this 51%. These are favourable outcomes and were much less likely to occur previously, as the data presented shows.

The case reports discussed show why, as enumerated below and as discussed in the Case report in Discussion in the Article by Myers JB, errata to Alzheimer's Disease and Happiness. Op cit.

(i) The need for an advocate.
(ii) The need for a doctor to act as advocate
(iii) The need for a doctor whom the patient trusts, and can depend on to not waiver, but to persist to get the patient's wishes fulfilled, without compromise yet not to anyone's disadvantage.
(iv) Family views, vexatious (daughter in law) or helpful (husband)
(v) Availability of carers
(vi) Financial considerations
(vii) "Duty of Care" or "Duty to care"
(viii) Role of social worker and other paramedical health professionals
(ix) Role of Directors of Nursing in hospitals and even in nursing homes or residential facilities.
(x) Role of Public Advocate
(xi) Role of contemporaneous Tribunal hearings
(xii) Role of Medical Board, Tribunals and courts in decision making regarding notifications.
(xiii) Relevant Legislation which protects the Rights and wishes of patients and which exonerates doctors who advocate for their patient's wish (within the Law), and which recognises the doctor is acting in difficult circumstances Medical Treatment Act 1988.
(xiv) **Legislation which is deemed relevant, but which does not even recognise the wishes of the patients nor context as stated in (xiii) above. Such Legislation is the AHPRA Act 2010.**
(xv) **The Mental Health Act 1988 stipulates the least effective option to control the symptoms must be used, yet despite Mental health Tribunal Hearings, the imposition of an Involuntary Treatment Order, or Community Treatment Order that can determine the fate of a person are imposed "Advance Directives" that:**
(xv) **- cause harm,**
- **are given despite being contrary to Lawful provision, and**
- **the effects and outcomes of which are unaudited.**
- **Effects include effects not only on the person but also Based on Case Report Appendix AA i, ii.**
- **the effects such treatment results in,**
- **including adverse reporting of the advocate needed in these situations by do gooders from Legal Aid, who do not understand the patient's condition or effects of treatment,**
- **making an adverse report to the Medical Board to avoid rightful payment for advocacy and medico-legal services rendered and agreed to by both parties, albeit verbally, given the distraught state of the patient, in the case below, as the daughter in law refused to pay for the patients' medical services and to submit even though Medicare said, that in that case in which medical services per se were rendered to the patients and which following a full investigation, that they would pay for.**
- **Abrogation of payment by lodging a complaint or notification to the Medical Board also occurred in the Medico-legal case situation, ITO, CTO**
- **non payment for services rendered,**

- effects of misplaced agenda driven legal action taken by Medical Board
- and conspiring nature of Administrative Tribunals in Medical Board matters, and
- inevitable conspiracy, procedural unfairness and conflict of interest by virtue of the constitution of panels – the prosecution is also the judge, collusion between these agencies (decision makers in these agencies and between staff of same) of government and jurisdictions protective not of the public, but of one another and of one another's self serving agenda – which is why the Health Department will never uncover the reasons people who wish to die at home, do not, as this would mean having to expose the corruption and duplicity, that needs to be uncovered and routed for your attention and action, post haste, in the public's interest, and in fact in Australians' and Victorians' best interest, and that of the world, which this opportunity provides for the members of the Legislative Council inquiry in to End of Life Decisions to report on, to recommend to Parliament. vic.gov.au. to act on and decide in the interests of the public and the public's protection.
- Vindictive judgements and decisions, vexatious determinations, are exemplified when costs are awarded to the Medical Board for cases that have been decided on bias, and in the case in discussion, where the Chief Justice as one of a panel of three, drew up the decision, only a draft of which was admittedly read by another (Chernov J.), who became Victoria's Governor, which is like signing off on something one has not read, which undermines the validity a) of the decision and b) as to the legitimacy of this being a three judge unanimous decision. This must rank with the false signing of a Statutory Declaration for a speeding fine, that resulted in that judge being stripped of his Bar Association membership, Australian Honours and having a (jail) sentence imposed. His action was dishonest intentionally, but is this not also, and added to this is the fact that great penalty was and has been and is being caused by any finding and penalty that is based on it?
- The Chief Justice chose to ignore the relevant Legislation, namely the Medical Treatment Act 1988, which exonerates the doctor who advocates for the patient's wishes, though in this case the doctor was not the treating doctor but the person's advocate.
- and no compensation, let alone Legislative response to improve the situation.
- Results in ongoing abuse of/unaudited of ITO, CTO.
- Ongoing unaudited review of Health Tribunal decision with respect to outcomes
- Morbidity data and mortality data, or improvements
- Death at home, according to patient's wish, but death was not expected, occurred seven months after continuous fortnightly antipsychotic treatment by injections, that was not the least restrictive option. See Appendix A.
- and her death or complications of treatment was foreseen and forewarned by the advocate, a medical doctor,
- whose advocacy resulted in being targeted by the Medical Board, instead of praise and
- instead of ensuring payment was effected, they served a reason to not pay for treatment, which was one reason to complaint, to get out of payment, yet legal was paid, not for helping the patient, their client through her predicament, but to complain about her unwillingness stemming from her confused state

resulting from the ill advised and imposed treatment she was receiving, that made no difference to her “paranoia about finances”, except to make her cognitive function worse

- and unwillingness to pay as she was still on the CTO.
- instead of attending to the need to right the situation of the treating doctors.
- They again used the advocate as a scapegoat for the maltreatment given, by saying he was one of the treating doctors, although they did that so they could have a go at him, because although her complaint was erroneous, it was only about the invoice that the person complained, not about the advocacy and the invoice and charges were considered in the normal ball park, and reasonable, so that allegation was dismissed.
- The allegation that I was the treating doctor is not something any reasonable Tribunal, knowing the way hospitals work, would find. To be her treating doctor was impossible under the circumstances as she was in a psychiatric unit on an Involuntary treatment Order, under a team of psychiatrists with their own physician support and the Tribunal members, Hicks J, at least, agreed, that the advocate, though a doctor, gave no treatment, which interestingly is what he advocated for i.e. no treatment. Yet she stayed on it and the CTO. The advocate wanted the treatment team to determine whether or not the person's alleged behaviour required an intervention or treatment, on an objective prospective basis. There were also Tribunal Hearings, which Hicks J did not refer to which indicated the advocate had no medical records as the person was not his patient.
- The Committee of Inquiry has to ask, “Which was the end of life decision that determined the death of this patient” –
- was it ?:
- her unwillingness to pay – so that the advocate withdrew and there was no-one to objectively oversee her physical condition as well as her response to antipsychotic treatment and fortnightly compulsory visits by the psychiatric team, that in each instance upset her, such that they increased the dose of the “toxic and ineffective “medication
- The imposition of the ITO and then the CTO
- The first Mental Health Tribunal's decision and instruction that the Hospital arrangement to send her home
- The advocate's push that they investigate her left leg swelling and follow up ultrasounds which showed she had a changing superficial thrombosis
- the advocate's push that the venous thrombosis be monitored and treated by the treating team, who did call in their support team of physicians who advised on oral anti-platelet (Aspirin) treatment.
- Was this treatment enough?
- The second Mental Health Tribunal's decision after discharge to continue the CTO?
- The second Mental Health Tribunal's decision after discharge to continue the CTO and to get a second opinion, other than the advocates to discontinue the CTO.
- Failure of Legal Aid, to obtain a second opinion to review the need for treatment and continuing the CTO.
- The ongoing treatment by the psychiatrist of a condition that was delusional, but not compromising the patient,
- their diagnosis that the patient had schizophrenia with masked symptoms?

- **Finding the patient had been lying on the floor in her flat for forty hours unable to get up, off it, which is a side effect of the CTO related treatment.**
- **Diagnosis of renal crush syndrome and admission to hospital, perhaps without a clear history – that this patient had leg swelling and was on Aspirin for the diagnosis of superficial venous thrombosis.**
- **Being allowed to go out from hospital where the injectable antipsychotic treatment was replaced by the psychiatrists with oral medication that they now entrusted her to take, whereas previously they did not hence the CTO.**
- **Being allowed to go out from hospital to attend the first Medical Board meeting, that would have been stressful for her.**
- **Being allowed to go out from hospital to her home, alone, where she died two days later?**
- **She had previously stated she intended to live a long life, and was robust enough to do so. She knew how to take her asthma medication given to her by her local doctor.**
- **Does this death add to the statistics of wanting to die at home and doing so?**
- **There is no doubt that her "paranoia" about her finances and not wanting to pay for the advocacy and medico-legal reports and Tribunal attendances she agreed to, as the advocate accompanied her to both Mental Tribunal hearings, resulted in her advocate, an experienced physician withdrawing his services, even before he learned of the Medical Board's involvement.**
- **She died because she was too confused to pay for the advocates services rendered to her, though not medical services.**
- **The advocate doctor was the only one who helped her in her predicament, and took meaningful steps to help her to deal with this.**
- **How does one make an advanced directive with such a person, when the only person who could have helped her was in effect not paid and thus withdrew an and all efforts to stop adverse CTO treatments, to which the person strongly objected, was not supported by the relevant Mental Health Service and Mental Health Tribunal.**
- **See Appendix A – supporting contemporaneous documentation.**
  AA1.i excerpt from letter to Director of Health Services.
  AA1.ii Letter to the Hon Lisa Neville, MP, Minister for Mental Health.

See: The following Re: Case report in: Discussion regarding goals and "happiness", 3. Happiness and Advocacy, and need for a System of Evaluated Decisions. Myers, J.B. (2015) Is Alzheimer's Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention. *World Journal of Neuroscience*, 5, 180-187. http://dx.doi.org/10.4236/wjns.2015.53020

and **Errata thereto, which in Discussion contains constructive and objective critique of case material in relation to judicial decision making and relevant Law in end of Life decisions**. The case discussion addresses insights as to decision making by the Medical Board that were not addressed in the The Legislative Council Inquiry into AHPRA March 2014, which nevertheless recognised (I) the failure of AHPRA and the Medical Board to adequately handle notifications (II) as did the Ombudsman as quoted therein. (III) The Inquiry noted the actual conundrum of the complex relationship between AHPRA and the Medical Board; the lack of confidence in the notification system by the public, which does not ensure health services nor protect the public, and (IV) failure to include financials in AHPRA's 2012-2013 Annual Report.

Erratum to “Is Alzheimer’s Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention” [World Journal ofNeuroscience 5 (2015) 180-188]

(15) (i) Decision making that the Legislative framework needs to address.

(1) decision making which is adverse, being the precipitating factor of end of life events and outcomes, and

(2) decision making which is relevant and appropriate, and which addresses what to do or not do in end of life situations once an event has occurred.

B. Specifics

see **F**. for **Specific Index**

1. Valuing Life. The Last Gasp. ”Morphia” = “More fear”.

At a Palliative Care conference I explained that those who advocate Morphia at end of life do so out of fear, rather than objective assessment.

1.i. When not to give sedation and analgesia.

On that occasions that I presented to the Palliative Care Society of Australia, I explained “life” to them as follows: Life, I said, can be likened to having a milk shake of one's choice through a straw, and making a noise at the end, which even the Queen would tolerate. And I described the last gasp as exactly that, enjoying the whole of it in one last gasp.

People who do not know how to assess pain, or how to move a patient – by first telling them what they plan to do, and rolling the person rather than pulling or pushing the person, or not observing the person to see what they do and that moving them does not change that when it is done properly, will, because of mis-assessment, administer pain relief when there is no need to do so. In such circumstances Morphine ends life.

1.ii Misdirected administration of sedation and analgesia to a patient.

Sedation needs to be given to anyone who requires it. But, sometimes this is the carer, not the patient or person they are anxious about.
The observer who is stressed and anxious can be any age. Giving sedation, whether as sedation or counselling, or education, that may be needed, needs to be directed at the person exhibiting that behaviour, as such behaviour has been shown to be counterproductive instead of giving it to the person they are anxious about, which if given, is misdirected.

1.iii When to give analgesia.

If there is pain.

The following steps need to be taken first.

Analgesia is to be given for pain. A person who grimaces spontaneously on and off may well need the creases taken out of the sheets on which they are sleeping if they cannot move themselves. In other words the signs of pain have to be assessed or the behaviour demonstrated needs:

(i) to identify the behaviour is an indication of pain,
(ii) identify the cause.
(iii) deal with the cause appropriately before giving analgesics,
(iv) as in the above situation analgesics is only going to make the situation worse not improve it. Therefore do (i)-(iii) as above, first.

In the case mentioned in the article above, when the patient finally did go home from hospital, as per a VCAT Order that she do so, analgesia was given by Palliative care nurses.

While in hospital the Consultant Physician, a specialist, looking after her said she had no pain and in the eight weeks while she was kept there she did not need, nor was she given any analgesia. And at home she had no pain and did not complain of it. Yet within 15h of being at home, with no change in her condition Palliative care nurses administered a dose of Morphine, as a routine, at 0600h a.m. And the patient was dead within a half an hour.

1.2 Legislative Provision. Seeking permission, advice and and consent.

1. Had the palliative care nurses asked her, she would have refused.

2. Was there an indication that she had pain? No.

3. Why was the drug prescribed? It was prescribed as A PRN , which means as required, in case, it was needed.

4. Who asked for this to be written up? The palliative care nurses who attended did. They had never seen this patient before and did not know her situation, and they did not take into account the fact that months before, the patient was given an antipsychotic by the GP at the request of the daughter in law, as she complained that the patient did not trust her and alleged her mother in law was paranoid. Well she was not. She just knew whom she was dealing with. Still the local doctor, to whom the daughter in law complained, consented to this. He was also the daughter in law's doctor. He also prescribed the analgesic requirement that the Palliative care nurses asked for. As a result of the anti-psychotic dose administration previously, the patient complained that she could not stand without feeling dizzy and she asked me to stop it. I took her standing Blood pressure and while she lay in bed and then in an upright position and found that she became hypotensive on standing as a result of the medication. Stopping the dose relieved the situation.

5. Had they been open to it and asked me I would have forewarned them. Obtaining the history is all important in any management of a patient,

especially as regards their susceptibility and allergy profiles, if they are to be given novel agents, in novel situations by novel agents.

6. Thus it was claimed I wanted to discharge her and had not adequately assessed the situation was unfounded, as there was no test that what I would have organised was not adequate, yet in the hospital eagerness to put in palliative care nurses and more than was required, they in fact caused an inappropriate situation to develop into one that “killed “ the patient.

7. As has been reported in the Press recently, “he stopped the medication”. This was the ONLY thing to do in support of the patient. What they did not report is that the medication rendered the patient hypotensive, i.e. caused intolerable side effects, which my patient identified as the cause and asked me to stop it, which I did, because she could not function. She could not be showered, as she could not even get out of bed without feeling faint, at which time her blood pressure dropped sharply. The GP did not object because he and I discussed her needs and requirements. Antipsychotic medication was not one of them, but he had listened tot he daughter in law, who was also his patient, which is a conflict of interests, and she was forceful. In fact on questioning before VCAT, in a review of the Medical Board's findings, he said that the daughter in law had suggested that he prescribe that treatment.

Well if that needed to be stopped, and given that was months previously, and that her condition had deteriorated because she was kept in hospital against her will, and would not eat as she wanted to go home, it was a no-brainer that she would have side effects from Morphine. Clearly, that provoked her death or killed her. And the Medical Board did nothing about that. President S Davis, VCAT on hearing this evidence stopped proceedings and did nothing about it, either as the proceedings were to find me guilty of something rather than to commend my actions, to do what this patient asked for and needed to be done, within the Law, let alone best practice.

As A/Professor Silvester advised the Members of the Inquiry, “one needs to reduce medication”,

let alone those that are detrimental to the condition and state of the patient.

1.3 Context.

See. Ref 21. Myers JB. Medical Ethics: Context is the key word. IJCM **5**, 1030-1045. doi: **10.4236/ijcm.2014.516134.**]

So too, taking matters out of context, in referring to the matter in which their Honour's Buchanan and Nettle J. gave leave to Appeal the findings below, the Press stated I stopped her treatment, as if that was a bad thing to do. **Of course it was the only thing to do and the patient had the sense to identify the cause and asked me to do stop it.** <u>No wonder she and her husband trusted only me</u>, as

I not only listened to her, as she was competent to make her own decisions, and did not trust her GP, whom she said had an ear for the daughter in law, whom neither she nor her husband trusted, knowing that she was the one who opposed their wish to stay home and wanted them institutionalised, to which they both objected.

I also did as she asked and was responsible for arranging carers, whom she interviewed and employed to care for her at home, and to assist with domestic chores and cooking for her and her husband, as well as her son, who attended daily. Thus the family were kept together, and as the patient wanted, and she and her husband, both patients' wanted, to be in their own home, which ensured they would be able to interact with their family as they wanted.

In addition I involved the Office of the Public Advocate (OPA) (Paula Irani), to ensure the specialist spoke to the husband, who was concerned about his wife's condition and whom the daughter had told the hospital to not talk to him, so he could not get the information he wanted. The specialist was intimidated by the daughter in law, and as he said, “he acted with expediency to cover his own back side at the expense of the patient's happiness” and “that because the husband was emotional about his wife's condition, and the carer was told to not take him to his appointment to see the specialist, so the specialist said he would discuss the matters with the daughter in law, who could tell the family, unaware of the ploy to miss the appointment and the family breakdown.

The OPA was of some assistance but when needed she did not testify in the matter of the Medical Board vs Myers, and neither did the registrar of VCA, Nelms, permit the Deputy president to testify regarding his Orders, and said it was vexatious to request that he do so, yet flaunted natural justice as resorting to the fact that VCAT is a jurisdiction in which rules of evidence do not apply, does not mean one need not testify.

The husband was well aware of his needs, and wishes and showed no signs of a dementing illness over the time I looked after him. Even today there is no treatment other than activities for mild cognitive impairment, and I took him to activities which according to the carers, “he enjoyed”. He could clean his pool and was independent in all his personal activities of daily living and personal care. Apart from being hard of hearing he was fully aware.

Thus contrary to Medical Board as well as Tribunal findings, and decisions and negative Press coverage, especially at election time (see Submission (2015). Re: State election 2014, to expose the corruption of the Medical Board and unjust Tribunal and Court decisions, then and since, **as the care I gave and management which they asked for allowed them to have more quality,** as well as, QUANTITY TIME WITH THEIR FAMILY, IN THEIR OWN HOME, FOR WHICH THEY WERE UNCONDITIONALLY APPRECIATIVE. **HOW**

IN THE WORLD WOULD OR COULD THE MEDICAL BOARD AND THE CHIEF JUSTICE FIND FAULT WITH THIS? UNLESS THEY HAD ANOTHER AGENDA, IN COLLABORATION OR IN SUPPORT OF ONE ANOTHER, IN OTHER words **of making biased and prejudicial findings, which abet Elder Abuse.**

(see current State Election 2014, and previous submissions by Myers JB. SUBMISSIONS 1-5, in particular (1) as below.

Myers John B. Invited Submission per The Chairperson, the Hon. Louise Asher MP. to Vic. Parliament (2015) Inquiry into State Election 2014.

Previous submissions include.

2. Myers JB. Submission to the Law Reform Commission, Consultation paper on Victoria's Guardianship & Administration Laws, submitted June 2011, tabled August 2012. www.vic.gov.au

3. Myers JB. Submission to the Law Reform Commission, Review of Victoria's Guardianship and Administration Laws, May 14 2010 quoted in "Inquiry into Powers of Attorney", Law Reform Commission, August 2010. www.vic.gov.au

4. Myers JB. Submission on Elder Abuse prevention. Office of Senior Victorians. 6 October 2005.

5. Myers JB. Submission to the House of Representatives Standing Committee on Legal and Constitutional Affairs Inquiry into Older people and the Law. LACA Reps. September 2007, Parliament of the Commonwealth of Australia. ISBN 978-0-642-79013-2 (printed version), ISBN 978-0-642-79014-9 (HTML version).

1.4 Role of Family.

Family can be a help or a hindrance, as any third party can be. Their status as next of in also varies in Legislation.

The validity of any help must be ratified by the patient, who must consent to whomever wishes to advocate in the patient's best interest, or take control.

They are a hindrance the further away they live, if the target or principal person wishes to live at home and seek further assurance, but they prefer does not, and do not take into account the effect this has on the principal person, whose decision it really is.

The above published case discussion indicates that family involvement may result in patient isolation and exclusion of their spouse from decision making and preference re choices which relates to values, and therefore something they are able to express even if deemed, though do not necessarily have, mild cognitive impairment, which does not impact on the expression of their values and choices related to personal needs and wish. Thus capacity is maintained even where cognitive testing, which tests intellect and abstract reasoning, shows a deficit – see Myers, Alzheimer's Disease article, also other publications appended.

Family may actually be vexatious and directly opposed to what the principal person wants.

1.4.i. The Family meeting.

The patient must not feel intimidated by anyone attending the meeting, (or not attending).

This, then affords an opportunity to discuss the issues, circumstances, options and goals, in a patient centred environment, and patient action environment, with support of family and medical health professionals, led by the doctor. It may serve as a fact finding opportunity as well as directive opportunity.

It can be held as required and as possible and may be followed up by further such meetings.

Whomever the patient wishes to attend needs to be invited to attend. Permission may be obtained for any other person to attend if agreed to by the patient.

1.5 Palliative care.

As shown in the example, above, palliative care can be a burden rather than a relief depending on who is directing the “palliation”, what assessments has been made and whether instructions given uphold the Right of the patient, the Rights of the patient to decide their own treatment, by being able to refuse it, and to be understood correctly when they ask for it.

Dose and timing must relieve pain when pain is present. The argument is if relief of pain requires higher doses that will or could lead to cessation of respiration there needs to be informed consent, explanation and opportunity for family to engage with the patient beforehand. The pain must be investigated first as indicated above.

1.6.i. Supportive family, palliative services with different cultural ties, and last few hours or days able to communicate, at home.

The patent's long serving and trusted GP asked me to see the patient at home. He was obtunded, because of the Morphine being given by them, according to the Palliative Care nurse's instructions, and he was unable to communicate with the the family. All knew he was dying of cancer, but they wanted to talk to him and he could not respond. I told them to stop giving the injections to let him wake up, which he did. He did not need any further injections and did not complain of pain. They were so grateful that they could communicate with him for two more days. True they were Greek and they may have a different approach to life and end of life decisions, than the palliative nurse has. It ought to not come down to what the health professional thinks the person needs, but rather what they do want, and which gives opportunity to all for meaningful time together, forever to be remembered.

1.6.ii. Supportive family, palliative services and ongoing time at home.

The family matriarch had her own home but was now living with & between her two daughters' homes, as they cared for her, though she wanted to be in her own home, and sometimes was. She suffered from severe Obstructive Lung Disease. The Palliative Care nurse suggested Morphine in small doses, to settle her, as she was very short of breath. This worked well and gave her many more months at home, in relative comfort.

1.7 Interceding illness. (The event)

Interceding illness, such as a bout of Diarrhoea, or pneumonia, may render a person helpless. Palliative care includes treatment of the condition and supportive therapy such as intravenous fluids if nil orally is indicated. This needs to be given unless the patient refuses treatment.

In cases where a person does not have capacity to make decisions, someone who is trusted by the patient to make the appropriate choices for them, and where advocacy has been obtained to do so, by having obtained a Medical Power of Attorney document, suffices if treatment is not to be given, or a Guardian appointment will have to be made.

There is no problem if there is agreement.

There is a problem if there is disagreement. If the patient was well and able to make a choice before the interceding illness, one has to treat as the patient will recover. It is only when there is no recovery despite treatment or where capacity was assessed – not neuropsychological tested, but is vouched for by someone the patient trusts and could communicate with, that view must be adopted, even if a guardian has been appointed from the Office of the Public Advocate, as there is less likelihood that a stranger whom the patient or person does know will be able to relate any better.

In fact in the case discussed above, the patient refused to talk to the social worker who approached her on four occasions in six weeks, and she refused to cooperate with the Aged Care Assessment Team, but she was wholly conversant with the treating physician who knew she wanted to go home, but who wilted under the pressure of the daughter in law, to actually discharged the patient, despite there being carers to do so – he interviewed only two, and one was reticent, until she changed her mind to do what was right for the patient and not what the daughter in law told her to do, and of course the patient was absolutely clear and cooperative when she spoke with the trusted Dr Myers, her husband and the carers who also came in to see her and who brought in homemade soup as they were directed to do by Dr Myers, and did so, which the patient enjoyed. The patient was actually ready and waiting to go home, but the bed card doctor had not discharged her, though he agreed to when he spoke with Dr Myers on the phone, who was ready to take over the treatment once the order was given by the bed card doctor to discharge her. The social worker then intervened and advised the daughter in law to apply for Guardianship to strengthen her hand, and was surprised when the Deputy president ordered that the patient go home, albeit awarding Guardianship & Administration over the patient, but not her husband, to the daughter in law and the granddaughter, and in response to the carers;' evidence that the elder couple could choose to see Dr Myers, as was their wish, if they wished to do so. It was their home, and not the daughter in law's. That she complained and that the matter was taken up by the Medical Board requires redress and compensation to Dr Myers as it is clearly against the Law, the Medical Treatment Act 1988, to have decided as did the Medical Board, the Tribunal and the Chief Justice as indicated clearly, above, and abrogation of the duty of the High Court to act independently of the lower courts and Tribunals, and by doing so abetted Elder Abuse instead of ensuring the welfare of the elderly and end of life choices for patients.

1.8 Role of Nursing Directors (DONs).

In my experience DONs have interfered in patient welfare and family involvement causing untold misery to family and patient and resorting to VCAT and Guardianship. In one case the DON was put down by VCAT and in the other a shocking Guardianship appointment intervened such that the daughter who had been caring for her mother over ten years since her mother's stroke, and while in alternate accommodation did not attend her mother for six months, after which the guardianship order was cancelled.

The adoption of the Australian health Care Standards for hospitals needs to be extended to include nursing homes to avoid and control DONs who do not relate to the personal needs of the patients in those places.

An industry standard has to be set and be held to, and accountability measures applied to ensure they do comply with the required standards. Some are very helpful.

1.9 Wanting to eat.

One of the matters that set the condition which led to DON interference was the DON wanting most if not all the residents to have vitamised food to avoid aspiration – and to cut down on costs. The patient would not eat it, and wanted to have soft foods. Dietitians were involved, one from the Nursing Home and an independent one in private practice who was called in to assess the situation. Each gave a different recommendation. However, it is the patient's wish to eat that is important, and she could not afford to lose weight if she did not eat. I settled the matter by attending the nursing home, assessing the problem myself a, which ensured the patient's welfare and food as she liked it served to her. The guardian's role did not help during the six months that the daughter chose to not see her mother as the conditions were so unpleasant when she visited her mother. The patient was moved to a nearby facility that was prepared to do as the patient requested and wanted and where the daughter could visit without incident. The Guardianship Order was revoked, that was a relief fort eh daughter, who could attend to her mother as they wished, until her mother died. Six months of abuse, neglect and isolation is a long time to have to suffer in the last year or so of one's life. Also Paula Irani who was involved in the case mentioned above, was the appointed Guardian in this case.

1.10 Wanting to window shop and say hello to store owners one knows.

Quoted in Hansard, the case of a resident who was living in in a unit and whose daughter moved her mother into the hostel. She walked across a double lane highway to go to the shops and sat on the median strip. When she returned they asked her whether she would go out again without notice and she said if she wanted to she would, so they interned her in the dementia unit of the hostel. I alerted the OPA who said that is where she must stay and that I could not take her out. She was eventually moved to a nursing home and died there after an internment of about a year or more in that lock up with mentally confused patients, though she was totally with-it and independent. She was an expert at baking scones. The OPA's input did not help. Her daughter wanted to go overseas to live and not have to worry about showing care to her mother. All those were end of life decisions for this person. She would have liked to go at age 80y and euthanasia was for her a certain option. But so was treating her as a person with dignity and care and consideration, organising that she did have outings and could shop and walk to see those whom she knew at the shopping centre she was used to going to by herself.

I wrote to Hon. Minister for Aged Care about it and the matter was recorded in Hansard, and I wrote to the Mayor of the Council to put a bench or two on the strip and call it after her, as a Park. I received no reply from him and nothing was done about it. The hostel is still separated from the shopping centre and village with no avenue to help people get across.

1.11 The remaining spouse

When he died she was devastated. People wanted her to move into a home. I advised her to continue with her interests, gardening and sewing, though over 80y herself, which she did and she is still doing that. In fact, in her street a lady felt sorry for her, she said, and then her own husband died at age 68y of a massive stroke. At the time she thought how would she be able to care for him. But he died within two days. She sought company from her neighbour and told her "i felt sorry for you, but I did not know what it was like". "I hug his pillow at night and wear his shirts to help me get over it".

1.12 Recommendation to help the remaining spouse.

There is certainly a place for a widow/widowers portal on the internet to function as a support group, instead of having assessments, lifestyle changes, and family giving advice, "when according to the person, "they have their partners and they don't understand".

1.13 Assessment of capacity v cognition.

These are not the same. Cognitive tools do not test nor do they evaluate capacity. Capacity reflects a person's values and personal preferences and choice. Cognitive assessment is abstract and tests deficit, whereas capacity determines what is retained in terms of assessment, beliefs, values and awareness. See ref. Myers Alzheimer's Disease. Op cit., and Functional Mental State Measure (FMSM), a Functional tool for measurement of capacity that utilises the patient's own assessment of matters relevant and personal. See ref. Myers Alzheimer's Disease. Op cit.

Definition of Capacity: Capacity is defined in terms of “best interest” and “happiness”.
Definition of Capacity: Capacity is related to “best interest” which is defined as consistent expression of one’s wishes relating to one’s personal situation or place of residence and happiness expressed or shown in relation to same, not only at the time of the request or expression of wish but also at the time of its realisation and fulfilment, and consistent views as to the opposite or another alternative to one’s wish and unhappiness expressed or shown in relation to same, not only at the time of the request or expression of wish but also at the time of its realisation and fulfilment. I.e. Capacity relates to what a person does and/or does not want for themselves, and which can be achieved and be achieved within the Law or is supported by the Law.

Capacity in terms of “happiness”. It goes without saying that happiness and unhappiness are life measures.

Definition of Advocacy: Advocacy is defined as unconditional support and respect to carry out a person’s wish, which defines “best interest”, within the Law.

Definition of Cognition: Cognition may be defined as intellectual performance. It relates to intellectual function, which does not include expression of values or beliefs and does not relate to values or assessment of values and personal wishes or belief.

Test of Capacity:
The Functional Mental State Measure **(FMSM)**, a Functional tool for measurement of capacity that utilises the patient's own assessment of matters relevant and personal. This test was first proposed and described in 2002 (See Ref. 30) and is described, amongst other places, in: Myers John B. Erratum to “Is Alzheimer’s Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention” [World Journal of Neuroscience 5 (2015) 180-188]. DOI: 10.4236/wjns.2015.54027 Pub. Date: July 31, 2015.

The importance of context: Capacity assessment, to be valid, takes personal context into account, wheres even valid cognitive testing does not.

See Ref. Myers, J. (2014) Medical Ethics: Context Is the Key Word. *International Journal of Clinical Medicine*, **5**, 1030-1045. doi: 10.4236/ijcm.2014.516134.

1.14 When “end of life” is imposed, without knowing it.

See Appendix AA i, ii..

1.15 Why people who want to die at home or live there don't?

1.15.i. The risk of having an ACAS assessment.

One is already “at risk” (of “being taken from one’s home) when one is assessed. This is compounded by an attitude of “duty of care” rather than “duty to care” (see ref. 6.), albeit well-meaning, at the expense of the patient’s Rights and happiness and wishes or “best interest”.

(a) **What motivates people determines their fate.**

A motivated person will triumph, in my experience. Thus any decision made which overrides that person's wish, which is what motivates them, demotivates the patient unless their will overrides.

Mrs SD was in her 90's and wanted to die on her birthday. It was her 94th birthday. I came in to see her. She used to always cll out my name. Sheila, I said, you are not yet in heaven, She woke up, but on her birthday the following year she didn't.

(b) **why I have written this submission to the Victorian Parliamentary Inquiry**.
No-one would know what is going on unless someone is prepared to stand up for what is both “Good and Just or fair” [Deuteronomy 6:18], and ensure we have Courts of Justice and decision makers who value other’s values and protect them in the interests of a functional and honest society.
The end of life for me would be to not do this.
Medical Board and Tribunal corruption, all aimed to stop me practising because they do not act in the public interest as they say they do, and because they are agenda driven and self-serving, they have responded with unconditional force, to stop me practice=ing medicine, and earn in as the are concerned. They know that they are wrong and fear being sued, but I am motivated to continue to do good and develop an ethical and just society – see Myers, JB, Submission to Vic. Gov. Parliamentary Inquiry into State Election 2014, that ensures that the Rights of others are not taken away, are respected and kept, and that Laws are reviewed for their cogency and relevance, and use or abuse. The Legislature sets the parameters of judicial power but has neglected to review, monitor and control the privilege to ensure natural justice and procedural fairness, as well as respect for the Legislative basis of Law.

In Vic. State election 2006 I stood to have the Guardianship & Administration Act 1986 reviewed because mental and physical conditions could be a factor that determined a person's competence, which many Disabled people would not have been happy about. In the revamp following a Law Reform Commission review, on Advocacy Tabled March 2010, and Guardianship August 2012, the clause that says a person's wish will be taken into account, is again stated and will be done by an Officer from the Office of the Public Advocate. This is tokenism. People Rights are absolute, and as I stated in a poster presentation to the Australian Society of Gerontology in 2012, and to the World Stroke Conference in 2014, as well as in an e-poster in Berlin in 2014, **requires further amendment by Parliament if we honestly respect the Rights of another**.

1.17 Standing in elections, in relation to Rights, Evaluation of decisions, and Judicial decision making and procedural reform.

1.17.1. Role of context. See Ref. 21. Myers, J. (2014) Medical Ethics: Context Is the Key Word. International Journal of Clinical Medicine, 5, 1030-1045. doi: 10.4236/ijcm.2014.516134.

I have also stood to bring to the public's attention the fact that case law is anecdote, and no more, that is used in an attempt not only to glorify past decision makers and present holders of such positions, but which transposes events being discussed and are current with decisions relating to a different time and place and in relation to anything else, which is a mockery of context itself.

Context is a determining factor of whether what is being done is ethical or not. Once context is removed, so is integrity and honesty and objective truth, all of which determine whether an act or event has an ethical basis or not. It is in relation to context that Parliament can have a say in Judicial decision making without bias, by introducing and ensuring that context is taken fully into account, or, consider every decision as the last, because injustice "kills" and wounds, and leads some people to take their own life. Allowing this to occur by taking a stance of neutrality and non-interference in the judiciary by parliament, which it is not, is not in the public interest, whereas ensuring context is taken into account, and is included in every legal report and every news report, is in the public interest and freedom of association and respect of peoples' Rights.

The effect of standing for a System of Evaluation decisions as an Independent candidate in 2010 in Bentleigh District changed government.

The effect of highlighting alternatives to Medical Board, Tribunal and Court bias, procedural unfairness and denial of natural justice, as well as conflict of interest, all of which invalidate any decision made, and need for context in any legal report, and including all Press and media coverage, or fines would apply, resulted in defamatory remarks, devastating personal attacks and derision, which only highlights the need for these matters to be attended to as a Legislated priority, See Myers JB. (Invited) Submission Parliamentary Inquiry, State Election 2014.

1.18 When life is ended by decisions taken out of one's hands.

1.18.i. **Quality and Safety v Rights and Responsibility. See Ref 13**.

Quality and Safety is used by third parties, para health professionals and Medico's in Institutionalised settings under the brow beaten whip of DON's, and legal challenge or exposure to override an elderly person's preference to go home.

Case Report, as discussed. see Discussion in:

Myers, J.B. (2015) Is Alzheimer's Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention. *World Journal of Neuroscience*, **5**, 180-187. http://dx.doi.org/10.4236/wjns.2015.53020 and August publication: **Errata thereto, August 2015, for a more detailed critique, in discussion.**

In the case report discussed in WJNS, above. 1. the patient rolled over when the Geriatrician approached her to do his assessment, and said to him, "i want to sleep". He gave her a nursing home level of assessment as he had no option but to do so, or wait until she gave her approval to be assessed, as she did not request it. She may well have known the social worker and daughter could have done so, as the daughter in law had arranged for other assessments which concluded by the elder couple instructing them that they did not wish to move from home and were not going into an institution, and were happy to be in their own home.

An ACAS assessment is necessary before one can place one's name on a waiting list for nursing home care. That doctor had nothing to do other than certify the patient was nursing home level of care, but that did not and does not mean that the person has to take up the position – it is simply a certificate of level of care. In 1984-85 I was among the geriatricians who went to assess appropriate placements of patients already in nursing homes, which is when the ACAS arrangements came into being. One patient in particular improved, his cardiac failure came under control that he assisted the staff, and was independent now, to the extent that he did not have to be there.

As a physician in private practice and Geriatrician not connected with an Institution or government position I became the champion of people who wished to be independent and live life as they saw fit and enjoyed. One patient and her husband moved from Sale to Melbourne so that I could continue to look after her when she was discharged from hospital, which proved effective for the following 18 years, and she was able to continue to live at home for seven of those years, with supports, and her daughters' involvement, fro a further seven years, though she was deemed nursing home level of care to begin with.

As stated in Ref 13,

Quality and Safety applies to products, toys and cars and can be applied to services.

Rights and Responsibility refer to human beings.

The two are represent an imposed view v a ;personal viewpoint, and the personal viewpoint must override the former, for obvious reasons, or put every one in cotton wool, or in jail, which is the equivalent of institutionalised living to some.

(see also Social dentistry, in Ref. 26. Myers JB. Periodontal Disease – A Physician's viewpoint. Chapter 29, 663-671. 2015. In: "Emerging Trends in Oral Health Sciences and

Dentistry", book edited by Mandeep Singh Virdi, ISBN 978-953-51-2024-7, Published: March 11, 2015 under CC BY 3.0 license. © The Author(s). Intech publishers. http://www.intechopen.com/books/emerging-trends-in-oral-health-sciences-and-dentistry/periodontal-disease-a-physician-s-viewpoint. http://dx.doi.org/10.5772/59264)

1.19 Aged Care Assessment Teams. ACAS Assessments.

An Aged Care Assessment is an indication of "at risk" of being taken from one's home against one's Will.

Aged Care Assessments, made by any member of the team, at any point in time pose the biggest and most significant threat to an Elderly person's Rights to continue to live at home. In some cases support is provided as may be required, such as inserting rails, but often the ACAS Assessment is done because of an event or report that may result in a Guardianship application by the social worker if the Elderly person fails to comply with whomever, including case manager's appointment or member of the office of the Public Advocate, even where family member could be appointed instead.

Legislative viewpoint. Definition. Case manager. A case manager is not a case manager, but a **person who manages the services and provision of those services to a person. They have no legal entitlement to make decisions for the person or on the person's behalf.**

This alludes to the cases discussed above, including ACAS assessments, whether in hospital or home. Safety over Responsibility and Rights, to live, which involves taking acceptable risks. That is not to say that one does not or won't fall if one is in a residential facility or nursing home. That happens, The difference is a personal one, and concerns goals and happiness, which is personal, compared to a third party's concerns re a duty of care, rather than a duty to care, which in effect creates unhappiness, and is the irresponsible decision which leads to the withdrawal and to the death of the patient.

1.20 A home trial is a valuable tool. It permits a patient to leave hospital under guidance and with support, as if they had been admitted for a fracture and are now improving, that will continue to improve and with full support permit adjustment to occur.

Legislative viewpoint. A home trial needs to be a legal option provided in Law/Legislation which would ensure an improvement in the Figure of 51% of patients who wish to die at home do, and 49% do not, bearing in mind that such a provision is not to focus on where people wish to die, but rather where they wish to live.

Following a reasonable period that a good doctor who knows the and can asses the patient's physical state correctly, that no other health professional is trained to do do, nor can, granted the time and support the patient can get back to a reasonable level of independence. Such was the case of a patient I treated who would not go into a specific hospital but needed attention for seven vertebral fractures. She was a Veteran and so was able to be kept in a private hospital where she was given hydrotherapy after six weeks and after discharge to home, where she lived with her husband when he died she continued to live with supports and ongoing care. For over 15-18years., with her two daughters able to pop in to help her., and carer support as required on a regular basis. All the patient has to be able to do is transfer on and off her bed, and on and off the toilet to be able to stay in their own home and for someone to eat meals if the patient is unable to do so, but who can take drinks through a straw left within reach of him or her

If the trial does not work out, it has at least given the person the opportunity to test the situation so that ongoing care elsewhere will be more easily accepted, which reduces complainants and potentates acceptance as well as better accord with family members who don't need to suffer the guilt of not having granted that opportunity tot heir loved one.

And it affords the person time to be in their own home again and gather their thoughts an things, previous to them, as the incident or event that required their hospitalisations may have been sudden and not given an opportunity to prepare for a departure.

It goes without saying that to sell someones home before they have recovered sufficiently to at least consider a trial of home is to inflict irreparable harm as may be perceived by the patient and be the decision that can be linked not to their frailty per se, but to their demoralisation, feeling of loss and to their demise.

She regarded me as her guardian angel. Had she been interned, which she would not have stood for anyway, it would have been another of those “end of life decisions”

1.21 **Happiness has to be the goal of medical treatment** (includes surgical and all forms of support and care). And must be taken into account as the goal standard of medical care and outcomes assessment.

1.22 Why “euthanasia” is not an end of life decision.

<u>Euthanasia is not about how to die, it is about how not to live.</u>

Does euthanasia indicate a wish to end life or to end the pain associated with life. Is it necessarily a call to die or for relief? It is clearly a call for relief. Death as a cure for life is a non-starter and no-brainer. If that was the case we would not be born, apoptosis (cell death) would override growth and development.

Legislative overview. Life is a challenge and living is to accept that challenge with joy.

Helplessness is not a call for death, but a call for life, for assistance and attention, which can be ernest or selfish.

The latter, egocentric position typifies the psychiatric person's mentality and many who are not deemed psychiatric but are, as their world is based on egocentricity not context.

Psychiatric patient live to be the victim (See Ref 21), even though they cause untold misery to others and will never be satisfied until they do.

Ask yourself, would you employ ISIS as a euthanasia service? This point arose in a Q&A (ABC) program.

What would become of compassion, if that were the case. What would become of research and hope and cures, if dejected we accepted the will of abandoning life, as if life has no purpose?

1.23 The reason for pain and suffering is to drive compassion.

This has been known since Biblical times. King David could not fathom,

"Why G-d made madness and why has He created spiders".

Yet it was only through feigning madness before the Philistine King, while running from King Saul, that David appreciated the act of madness was life saving, because it introduces compassion into the world.

The same with spiders, a strange and frightening creation to many, to make us understand that even stranger creations are here to drive compassion, as in another escape he hid in cave. A giant spider spun its web over the opening, so when King Saul's men came and saw the intact web, they realised there could be no-one inside or the web would have been broken. Thus it was the spider which saved King David's life.

Legislative framework. To save a life is to show compassion, and to imbue life not only one's own but of another with a sense of and opportunity for "happiness" is the purpose of our existence

1.24 Advance(d) Directives.

I have written previously, see references, that an advance directive tells one what the person is thinking at the time it is written and signed. But is does not tell the person who signed it what the circumstances are when the event in ind, happens, or happens in a way that is not the same as the signatory intended. It is better to have an advocate, whom the person trusts, on standby at the time that any decision is needed. The decision also needs to stand up before the law. If the matter signed was not explained by a doctor, as no-one else is trained to do so, at a later date, any doctor cannot act on some instruction that does not align with standards of informed consent. I therefore suggested that the word advance(d) directive be employed if the discussion and one of the witnesses to the document is an informed doctor who was treating the patient at the time, (and one whom the patient trusted), and who has informed the patient who is giving consent.

In the Legislative framework, an advance(d) directive needs to be seen for what it is. It is not and end of life decision. Rather, it is a following event of life decision.

Sometime events are known will occur and are (i) foreseen e.g., in the case of degenerative disease, while others occur within a more rapid time frame are, in terms of timing, vs probability or "risk" (ii) usually unforeseen, where sufferers reach the Intensive care to receive treatment, prior to which they were living independent lives.

It is the latter to which advanced directives apply, but any event may provoke the need to make one.

For instance buying a packet of cigarette and lighting up, one needs to make one, which could be arranged at the point of sale. But then an advanced directive may also be ordered when one is about to cross a road.

Putting a seat belt on is making one, i.e. by taking precautions as a voluntary act or in having to respond to an unforeseen event.

So when I was first hit by a car that went through a red light, and was taken to the Alfred Hospital and they said they had no beds, and that I could go home, on condition, " I refused" as my condition had not yet stabilised, so they found a bed for me in the surgical ward. By saying so I was making an advanced directive. By the way in both collision, which were side on, I do not believe the seat belt had any saving effect, and I saw as much as I was able to that the woman who drove through the red light at 70km/hr had a bruise on her neck form it, as she hit my car front, front on.

If a wearing a seat belt can be legislated, as a proactive advance directive before driving and while driving, can donning a condom before and wearing a condom while one engaged in non-marital sex, be legislated?

It is easier to educate than to Legislate, and probably more worthwhile.
How can we get people to act responsibly and to make wise choices?

Advanced directives (Benefits of and relevance to events & timing)(see above)

1.25 The role of a trusted person, be that friends, family or doctor.

People relate differently to different people. To one whom one trust answers will be given, that may not be give to others, as shown and the first case above, and covered in the article entitled "Happiness ", as above.

1.26 Spirituality and physicality. Why do the righteous suffer?

So why do the righteous suffer? This is to test their resolve and belief in G-d.
It is not the event that tests us, but the response to it which vindicates us.

The Legislative challenge is no different.

1.27 Role of decision makers. Ethical implications.

There are basically two types of people,

1. those who are self oriented, and
2. those whose priority is to contribute to the care of others.

What they decide depends on which of two types they belong to.

Essentially negative view of self and life	Positive self esteem and esteem of world and intentions of others.
Bureaucratic, controlling.	Administrative, entrepreneur, creative, inspiring
Unethical, biased, dishonest. Unforgiving	Ethical, sensitive and responsive to context, honest. Forgiving.
Feeling of having been misunderstood - subconscious psyche.	Confident. Calm sub-conscience.
Challenge is taken as personal and an unwanted burden and / or cause for complaint.	Challenge is considered as an opportunity to focus on task accomplishment, not on self.
Nihilistic “spoilt” child syndrome.	Loves generously, loves life
Self centred. Never able to be satisfied. Wanting to portray themselves as “victims”	Makes others feel satisfied
Agenda driven.	Concern is helping others, not with self
Takes out feelings on those who do good, and do so under the guise of doing good e.g. uses the guise of “to protect the public” and “ensure health services”, but really are not doing good for anyone, except their view of themselves, for themselves.	Every choice moment is an opportunity to do Good noW!”®, which includes giving another the benefit of doubt in favour of intention to and doing good.
Denies context and therefore foregoes ethics. This is the effect of self serving bias and agenda	Recognises context and thus morality and ethics.
No Sense of Humour - a sense of humour is a heightened awareness of sense of self, not of non-self.	Sense of humour i.e. ability to be able to laugh at oneself or situation.

1.28 Time line of events and elucidated need for responses.

Birth,
growth,
education,
maturation,
marriage,
job,
parent,
any event along the way,
celebrations and
end of life events.

An end of life event can occur at any time. Certainty is death, timing is not.

C. Recommendations. Legislative approach to end of life decisions.

A. Overriding contingency: A person's Rights, to express their wish and for that wish to be respected, advocated for and achieved – to override all other Legislation conditions and tokenism in that regard.

1. Pre-admission assessment (usually performed by Rehabilitation Hospitals assessment person in deciding whether to transfer a patient from an acute hospital bed), provides for these Hospital admissions to have a section on Goals, which facilitates aims, therapeutic targets, length of stay, and discharge Planning.

2. Hospital admission which precludes pre-hospital assessment, i.e. from home or the public arena to have an Advanced care plan, which facilitates aims, therapeutic targets, length of stay, and discharge Planning, needs to be done on admission, or in the ambulance.

3. Hospital admissions requiring intensive care unit admission, or where the prognosis is in doubt and use of invasive treatments optional to include an Advanced care Directive, to facilitate life saving measures being used or not – bearing in mind this is a time when the principle, the patient is ill and asking him or her, while in a state of shock or unstable condition, what they prefer, before treatment has had a time to act to treat the person, and give motivation a chance, one needs to err on the side of wait to decide.

4. Emergency meeting. When one's had is force as may occur due to the deterioration in the patient's condition a family meeting needs to be called, use of videoconferencing not forgotten, to indicate severity, options and opportunity to respect the person's wishes, unconditionally.

5. Where disagreement abounds, while the patient in a state of limbo, an objective third party with legal power needs to be called in. In the past this has been a member of the Office of the Public Advocate. However, this appointed person is usually one who has no medical qualifications. In such a case their decision will fall short of doing what is in the patient's best interest, for at least two reasons - (i) they do not know the patient (ii) they are not medically trained, so they must act according to what the medical doctor treating the patient advises, which does not occur in most cases, (iii) They may not be the sort of person the principle (patient) would confide in or trust.

6. Trust. The most appropriate person to make a decision is one with whom the patient has a relationship based on trust, e.g. the person's self appointed doctor whom the person usually sees, or someone who understands the patient's wishes and advocates without conditions and or any other agenda.

7. An Ombudsman. Given that not every case will settle before a treatment decision has to be made, the appointment of a Medical doctor who understands critical care medicine, is a superb assessor of physiological reserve and factors that can recover, and who acts unconditionally in the patient's interest, while taking all opinions into account, and who has an understanding or the relevant Legislation, is the primary choice for such a decision making position, surpassing all Officers of the Office of the Public Advocate because of active experience and expertise, in situations where it is impossible to make an Advanced Directive

8. Bearing in mind the **Legislative Council's Findings re Inquiry into AHPRA, March 2014,** and the lack of the public's confidence in the notification system, that results from AHPRA's internal funding arrangements based on case complexity and length of investigations, which clearly raises issues of interference, purposeful delay, umbrage, dissatisfaction by the public, health professions and Ombudsman's office, the appointment of an ombudsman to review all notifications first, as adopted by Queensland, commencing July 2015, Victorians deserve the same, unless investigation into AHPRA's and the Medical Board' complaints and notifications handling is shown by detailed investigation of their methodology by third parties who have suffered as a result of their glaring misfeasance.

9. An Inquiry into the collusion between Medical Board and Tribunals/conflict of interest, or audit of Medical Board decisions and Tribunal and Court decisions is needed. To be done, and to include whether preferential judicial appointment on such cases favours one Judge more than any other.

10. A wider brief of such an Inquiry, i.e. than in 9 above, is required to investigate the issue of case law as anecdote, and as unaudited opinion without fair recourse and opportunity of achieving justice, simply because one can only appeal on the basis of error of Law, and because all appeals are costly, so an alternative option, such as arbitration needs to be trialled, instead of trumped charges and confrontation.

11. At leave to Appeal. To recognise that the only point of justice, but where decisions are not made, is in seeking leave to Appeal, as reference to transcript and to the Decision can be made, whereas at each successive level, it is to the decision that the Appeal has to be made, without recourse to transcript reference.

12. A System of Evaluated decisions, which prospectively and objectively evaluates the effects of decisions made, needs to be adopted or trialled, run by an independent committee, not of the Court or Board collegiate, but constituting of people who have been through the system which in their view has been found to be wanting. Certainly the matter of context needs to be determined in any audit of decision-making, in order to determine intention of the act. The points of view of the Judge, applicant and respondent after each decision on a matter would form the grounds for evaluation of outcomes.

13. How long can we tolerate a Tribunal System that determines end of life decisions; that is legally able to make decisions that could end a life, by suicide because of their prejudice able to be effected through a system and jurisdiction which is not evidence based, and on which an appeal can only be made on errors of Law, though no basis of evidence is given or guaranteed, represents a basic abuse of Freedoms and denial of natural justice, which Judge Curthoys (in SAT WA) said, there is no such thing. May G-d help us. We, who have suffered, directly and indirectly from such abuse, appeal to the Legislative Council Standing Committee on End of Life Decisions to do something about this appalling state of affairs.

14. In deciding at end of life decisions, outcomes remain the focus of decisions.

I add here a case reference of a man in late sixties who developed a Parkinsonian Syndrome as a side effect from the antipsychotic medication he was given, that resulted in him being unable to walk or talk and he developed pneumonia. There is no doubt his situation was morbidly untenable and appalling, in hospital. I was asked to see him by his wife. His local doctor, whom they trusted was treating the pneumonia, but was also administering Morphine, which did not stop his breathing, but made him more settled and obtunded i.e. not conscious. I may have changed the antibiotic and I stopped the Morphine. He recovered from the pneumonia, and when the Morphine wore off, he was not suffering as much from the Parkinsonism. He does not walk nor talk. He is awake and his wife sits with him everyday in the nursing home. He appears comfortable, has a pleasant appearance, and appears to have some reaction when spoken to. He has not had high tech scans to determine the activity in his brain. His family all gather on a weekend to be together, This has gone on for more than five or six years. As far as they are concerned dad is still here, and he is still the centre of his family, able to be seen and touched by his grandchildren in a growing Italian family. Loved by his daughters, son and his wife and their family. There is no doubt his wife lives in his presence. You could say he is the ideal father and husband. I do not know what his wife would do without him.

1.29 ii Proactive approach. Educational Measures and lifestyle and values motivators.

1. Promotion of a wellbeing strategy (as opposed to an “end” strategy)

2. This is the time of your life Diary©. What about Me?©

Everyone wants to have the time of his/her life. Well this is the time of your life diary, makes one realise that. This could be targeted to children in schools and all ages above, as a national project, aimed at three dimensions of life.

What about **Me?** **- personal**
What **about** Me? **- environment**
What, about Me**? - social dimension**

3. AHA Australian Health Ambassador Schools Charity program

Give ten cents a week to a Charity of the class or schools choice.
Children are empowered to change the world so that by the time they leave school they have a meaningful and integral connection to the world they wish to live in. Everyone becomes an **A**ustralian **H**ealth **A**mbassador,
This could be exported as **AHA** can also become A for America, Africa, Asia, And the Middle East and And European Health Ambassador.

4. 3 R's, Rally, Responsibility and Respect.

This is a proactive opportunity to generate morale, a sense of community, through responsible action which precedes yet generates respect.
As with the other opportunities this is also able to be implemented within Australia, and exported to our neighbours and friends world-wide.

5. Improve communication and certainty

- through Family meetings,
- Advance(d) directives,
- Home trial with support options,
- uphold personal choices and wishes unconditionally in Legislation,
- respect values and personal considerations.
- Advance advocacy and dependability based on mutual trust.
- Institute a System of Evaluated Decisions in Tribunals and Courts, Medical Board
- Review case Law in terms of context and applicability, as currently just anecdote and undermines context.
- Ask yourself, if in a Tribunal there is no rule of evidence, can a quantifier of standard be applied, e.g. Briginshaw standard.
- Regard “end of life decisions” as any decision made that results
- (a) in end of life, as well as
- (b) decisions made in later life and
- (c) decisions that follow or made because of an event or circumstance that affects quality of “life” or “life itself.
- In terms of (a) regard these as negative, as having a negative impact on society and “hope” and “achievement, “joy” and “Happiness”.
  (b) regard these with respect and “duty to care”

(c) Ensure discussion, family meeting – patient permitting, Advanced directive, to be able to care for and act according to the patient's wishes – or choice, and informed consent.

6. **Recommended Title of Act. Act in the Patient/person's best interest.**

Aim. To permit a treatment or withhold a treatment.

Legislation that allows withholding of treatment according to patient choice is available in Medical Treatment Act 1988.

7. **Notes from the Public Hearing 23 July 2015**.

Advance(d) care planning needs to be part of routine medical care in end of events.

Ensure Quality of care at the end of life that patients want. Indeed this must be applied throughout life and even with regard to thriving babes in utero.

Even if found, the Advanced Care Directive made, that precedes the current event, needs to be confirmed, by the treating doctor, or more appropriately by a doctor whom the patient trusts in the presence of the treating doctor who is aware of all the facts of the case, so that their combined knowledge of the patient, in terms of wishes and function (physiology) can be combined to obtain informed consent or other directive.

See Myers, Goals (2006), Role of happiness, and incorporate this in discharge planning, let alone planning about treatment,

Goals need to be decided even before hospital admission (in Rehabilitation outcome and admission assessments, not possible in acute situations usually, other than as an outcome), to define aims and be included in the discharge plan, **whereas advanced directive** is not about values **but** about treatment options, though lifestyle can be included in this document – as not all patients die, some actually survive, and motivation is a major factor that determines who will thrive and who may not. Medical attention that foster belief in the doctor who can can and does objectively assess improvement likelihood and duration of stay to obtain this, even using temporary placement options, helps patient recovery and goals achievement, unless a family member steps in. Family members who are nervous about a family member being on their own at home, are those who usually live further way and therefore want some form of reassurance, often obtained by compromise at the principle's expense, i.e. by moving into a home, not their own, or who are furthest away in terms of relationships i.e. they have an agenda of their own, which is not in the patient's best interest.

Patients can recover, NB, but discussion is NB and is and must be done to uphold people's Rights which is their wish, and that equates with what is "in their best interest".

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E. Appendix (AA).

AA.1.i Excerpt from letter dated

5th February 2007 \ 5767 FAX PAGES = 6, including cover page.

To: Attention. Dr. Ruth Vine, Director Mental Health

(xix) I believe the decision of the Mental Health Review panel is not supported in law, because even if they decided to maintain the diagnosis of "delusional disorder", none of the other four categories support the option of a community treatment order, and as far as informed consent is concerned clearly she is able to give this and has elected to have her own medical practitioner monitor her to allay the fears or possibility of mental disorder that APAT think she has.

Unfortunately, case managers' opinions dominated the agenda swaying Mental Health Review Boards to formulate their decisions on subjectivity not on objectivity, and limited assessment by Dr. Keogh in relation to this and contradiction within the team, Professor Ames finding no evidence on his examination, and the lack of awareness of expertise and/or fair-mindedness and which are more, not least, restrictive.

(xx) Clearly, objective intervention is needed not only in this case, but to clean up the Mental Health system and its procedures and the lack of quality of APAT training or continuing education and assessment as it is clear that they extend the bounds of their "training or expertise" into clinical decision making which to render their actions as incompetent. A further psychiatric opinion has been suggested to add leverage to either the APAT view or my own prior to a third round of appeal, and is to be obtained, despite the "incestuous nature of psychiatric decision making", but it would have been least restrictive to suspend the community treatment order until this occurred, in my view, particularly as it is agreed there is no risk in taking this approach.

(xxi) Thus, in the interim, we seek the rescinding of the order, which is invasive and in administering medication, which is potentially toxic exposes the patient to even further harm than has already been the case to which she has been exposed as a result of the APAT intervention. The treatment option was adopted despite the expectation that if any or only minimal benefit will occur only in the longer term, although according to recent published studies may do no

\5..

good and is more likely to cause harm (NEJM 2006;355:1525, Schneider et al. effectiveness of Atypical Antipsychotic Drugs in patients with Alzheimer's disease), which they (Dr Anne-Marie Keogh/others) also claim she may have, despite limited follow-up and minimal observation, raising questions of medical impropriety or competence.

I once again thank you for your attention and to an immediate investigation and action to resolve the plight of an elderly citizen and indeed the plight of the Mental Health Service for whoever may randomly and unjustly become exposed to it are put at risk of emotional trauma, desecration of their rights to privacy and respect and to ongoing abuse under the cover of the Mental Health Act by employees in the health services and Mental health Review Boards of Government.

Yours sincerely,

Dr. John Myers

Appendix A

AA 1.ii

21st January 2007 \ 5767 FAX PAGES = 6, including cover page.

To: Attention. Lisa Neville, MP FAX NUMBER 613 9

Dear The Hon Lisa Neville, MP,

Re: Mrs "OP"; Community Treatment Order.

Next (second) injection 22 January, Review 5 February 2007.

Your immediate intervention is sought to halt the Risperidone intramuscular injections that are being given to Mrs "OP" against the PBS guidelines.

She does not have Psychosis.
This treatment has had no effect other than alter her cognitive function.
It only abets the feeling of power over her by the psyche community nurse and abuse, by M West.

As a review is due on February 5th, 2007 it would be in the panel's interest to see her as she is, not drugged as she was in hospital, as an involuntary patient, and made to comply, which she did only to gain her freedom and for no other reason, as any "delusions" were unsubstantiated, and in any event which have no effect to cause her to be a danger to herself or any other person.

Counselling and education may be of use but medication is not. It is forced, causes harm through its effects and has side effects causing impairment. There is no medical indication and it is "ineffective".

Please read the accompanying documentation of events and call for enquiry into the Mental health service in relation to this case and harassment that occurs in psychiatric hospitals, by psychiatrists and psychiatric community nurse practices.

Please would you personally contact Mrs "OP" directly at her home, with her permission, on [redacted].

Yours sincerely,

Dr. John Myers

AA iii a, iii b. Award of costs in non cost jurisdiction - a driver for adverse decisions.

Costs awarded to Medical Board / AHPRA is of significance and concern to all Victorians, health professionals, and all Australians and health professionals in Australia, perhaps with some safeguards for Queenslanders as Queensland has appointed an Ombudsman to handle notifications and complaints. These invoices are available to the Legislative Council Standing Committee, should you wish to review these.

F. Specific Index (and Summary)

A. Overview; Perspective and Definitions.

(1) **General interpretation of End of Life Decisions.**
Definition: Any decision that results in end of life.

(2) **Standing Committee context: Decisions made at the end of one's life.**

(3) **General interpretation of Advance directive.**
Definition: Any directive or statement made in advance that indicates what can be done or not done in a condition or were an event to arise that prevents expression of such preference by the person concerned.
In the Legislative framework, an advance(d) directive needs to be seen for what it is. <u>It is not and end of life decision</u>. Rather, <u>it is an “in anticipation of” or “following event of life” decision</u>, and may or may not have relevance to end of life.

(4) **Where does or is and Advance(d) Directive more likely to have relevance** to end of life decisions?

(5) **The progressive nature of decision making**.

(6) **Communication. An outcome of expression of wish or “best interest”.**

(7) **Mental function in end of life decisions. The role of a trusted person as Medical Advocate**

(8) **Who can make a decision or be appointed to do so** depends on **Trust.**
In any situation, the person advocating for one or other choice needs to be someone whom the person trusts and who can communicate or was able to communicate with the person.

(9) **Definition** of **“best interest”.**
“Best interest” is the situation which fulfils a person's wishes and brings them (true) happiness. <u>It is a personal viewpoin</u>t. It has been described in terms of social and psychological wellbeing (Elder Abuse prevention. Office of Senior Victorians. 6 October 2005).

“Best interest” is not a negotiable outcome. It is an outcome that reflects the person's personal viewpoint and wish.

“Best interest” cannot be imposed.

Expression of wish equates with expression of Capacity and/or “best interest”

Legislative viewpoint. Neither the Guardianship & Administration Act 1986 or it's revised version, unconditional respect “best wishes”. Rather it states, “will be taken into account”. Such tokenism makes no sense and is a denial of Rights, and of Right to choose what one wants for oneself, and which an Advance(d) directive is intended to ensure and address.

(10) **Legislative viewpoint**. **The doctor's role in the doctor patient relationship.**

(11) **Legislative viewpoint. Informed consent**. Please see Refs. 6, 21.
Notes are given of a case in point, below.
Please see **Appendix A**.

(12) **Legislative viewpoint**. **Role of a third party**.

(13) **Legislative viewpoint.**
Third party and Officers of the Office of the Public Advocate.

The Officer's job needs to be defined as “to give legal authority to doctors to make the medical decision”. Ideally this must be a trusted doctor informed of the circumstances, not necessarily the treating doctor who may not know the patient.

The Officer's job needs to be defined as “to give legal authority to family to access and administrative matters, which do not only not conflict with the patient's wishes but which ensure them”.

(14) **Legislative viewpoint. What an Advance(d) directive can contain.**

The case in discussion also highlights the reasons that explain the glaring difference between people who wish to die at home and do not and those in other places of residence.

Health Department's presentation, Public Hearings, 23 July 2015,
Deputy director health service performance and programs.
Ms Frances Diver

51% who want to die at home do
92% who want to die in a hospital do
87% who want to die in a residential facility do.

i.e. *that 49% of people of want to die at home do not, whereas in hospitals 92% who want to do and 87% people in Residential facilities who want to, do.

Additional Case report.

I said if he has capacity, then according to law, the Tribunal has no place and is not entitled to make a ruling to abort his wish. His decision is final. He can go home. The arrangements have to be made for him to do so. Then he told me, "it's too late. He's gone to heaven."
Ideally, or theoretically, is the patient's best option to sign him/herself out? Depends on who is there to help care for them as needed.

Well what are the Committee member's thoughts on that?

(15) The defining Challenge* of this Legislative Council Inquiry.
I believe that this* is the most important statistic presented and one which the Inquiry must address, as more people are affected by variance in terms of their wishes than die or are put onto treatments they do not want, as much as that is an important focus of the Inquiry, in respect of Advanced decision, quality of life for those who live is even more salient and pressing.

I believe if they were able to, it would take another five years for the Health Department to unravel this story, for the reasons given, that relate to Elder Abuse, as below. Their graph shows the number of people who wanted to die in their home and did has increased to reach this 51%. They were much less likely to previously. The case reports discussed show why, as enumerated in the Case report in Discussion and in the Article by Myers JB, errata to Alzheimer's Disease and Happiness. Op cit.

See Appendix A – supporting contemporaneous documentation.
AA1.i excerpt from letter to Director of Health Services.
AA1.ii Letter to the Hon Lisa Neville, MP, Minister for Mental Health.
Appendix AA iiia, iiib. Costs in non cost jurisdiction.
See: The following Re: Case report in: Discussion regarding goals and "happiness", 3. Happiness and Advocacy, and need for a System of Evaluated Decisions.
Myers, J.B. (2015) Is Alzheimer's Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention. *World Journal of Neuroscience*, 5, 180-187. http://dx.doi.org/10.4236/wjns.2015.53020
and **Errata# thereto, which in Discussion contains constructive and objective critique of case material in relation to judicial decision making and relevant Law in end of Life decisions**. The case discussion addresses insights as to decision making by the Medical Board that were not addressed in the The Legislative Council Inquiry into AHPRA March 2014, which nevertheless recognised (I) the failure of AHPRA and the Medical Board to adequately handle notifications (II) as did the Ombudsman as quoted therein. (III) The Inquiry noted the actual conundrum of the complex relationship between AHPRA and the Medical Board; the lack of confidence in the notification system by the public, which does

not ensure health services nor protect the public, and (IV) failure to include financials in AHPRA's 2012-2013 Annual Report.

Erratum to “Is Alzheimer’s Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention” [World Journal ofNeuroscience 5 (2015) 180-188]

(15) (i) Decision making that the Legislative framework needs to address.

(1) decision making which is adverse, being the precipitating factor of end of life events and outcomes, and

(2) decision making which is relevant and appropriate, and which addresses what to do or not do in end of life situations once an event has occurred.

B. Specifics. Contents Index.

1. Valuing Life. The Last Gasp. ”Morphia” = “More fear”.
1.i When not to give sedation and analgesia.
1.ii Misdirected administration of sedation and analgesia to a patient.
1.iii When to give analgesia.
If there is pain.
The following steps need to be taken first.
1.2 Legislative Provision. Seeking permission, advice and and consent.
1.3 Context.
See. Ref 21. Myers JB. Medical Ethics: Context is the key word. IJCM **5**, 1030-1045. doi: **10.4236/ijcm.2014.516134.**]
(see current State Election 2014, and previous submissions by Myers JB. SUBMISSIONS 1-5, in particular (1) as below.
Myers John B. Invited Submission per The Chairperson, the Hon. Louise Asher MP. to Vic. Parliament (2015) Inquiry into State Election 2014.
1.4 Role of Family.
1.4.i. The Family meeting.
1.5 Palliative care.
1.6.i. Supportive family, palliative services with different cultural ties, and last few hours or days able to communicate, at home.
1.6.ii. Supportive family, palliative services and ongoing time at home.
1.7 Interceding illness.(The event)
There is no problem if there is agreement.
There is a problem if there is disagreement.
1.8 Role of Nursing Directors (DONs). An industry standard has to be set and be held to.
1.9 Wanting to eat.
1.10 Wanting to window shop and say hello to store owners one knows.
1.11 The remaining spouse
1.12 Recommendation to help the remaining spouse
1.13 Assessment of capacity v cognition.

Definition of Capacity: Capacity is defined in terms of "best interest" and "happiness".

Capacity in terms of "happiness". It goes without saying that happiness and unhappiness are life measures.

Definition of Advocacy: Advocacy is defined as unconditional support and respect to carry out a person's wish, which defines "best interest", within the Law.

Definition of Cognition: Relates to intellectual function, which does not include expression of values or beliefs

The Functional Mental State Measure **(FMSM)**, a Functional tool for measurement of capacity that utilises the patient's own assessment of matters relevant and personal.

See Ref. Myers John B. Erratum to "Is Alzheimer's Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention" [World Journal of Neuroscience 5 (2015) 180-188]. DOI: 10.4236/wjns.2015.54027 Pub. Date: July 31, 2015.

The importance of context: Capacity assessment, to be valid, takes personal context into account, wheres even valid cognitive testing does not.

See Ref. Myers, J. (2014) Medical Ethics: Context Is the Key Word. *International Journal of Clinical Medicine*, **5**, 1030-1045. doi: 10.4236/ijcm.2014.516134.

1.14 When "end of life" is imposed, without knowing it.

See Appendix A.

1.15 Why people who want to die at home or live there don't?

1.15.i. The risk of having an ACAS assessment.

(a) What motivates people determines their fate.

(b) **why I have written this submission to the Victorian Parliamentary Inquiry**.

1.17 Standing in elections, in relation to Rights, Evaluation of decisions, and Judicial decision making and procedural reform.

Role of context. **See Ref. 21**. Myers, J. (2014) Medical Ethics: Context Is the Key Word. International Journal of Clinical Medicine, 5, 1030-1045. doi:10.4236/ijcm.2014.516134.

The effect of standing for a System of Evaluated Decisions as an Independent candidate in 2010 in Bentleigh District changed government.

The effect of highlighting alternatives to Medical Board, Tribunal and Court bias as biased Press and media coverage highlights the need for these matters to be attended to as a Legislated priority, See Myers JB. (Invited) Submission Parliamentary Inquiry, State Election 2014.

1.18 When life is ended by decisions taken out of one's hands.

1.18.**i. Quality and Safety v Rights and Responsibility. See Ref 13**.

and discussion in:

Myers, J.B. (2015) Is Alzheimer's Disease an Adaptability Disorder? What Role Does Happiness Have in Treatment, Management and Prevention. *World Journal of Neuroscience*, **5**, 180-187. http://dx.doi.org/10.4236/wjns.2015.53020 and August publication: **Errata thereto, for a more detailed critique, August 2015.**

1.19 Aged Care Assessment Teams. ACAS Assessments.

An Aged Care Assessment is an indication of "at risk" of being taken from one's home against one's Will.

Legislative viewpoint. Definition. Case manager. A case manager is not a Case manager or person who can make a decision over someone, but is a manager of Services provision, meant to support someone needing assistance to continue to live in their own home or wherever they choose to do so..

1.20 A home trial is a valuable tool.

Legislative viewpoint. A home trial needs to be a legal option provided in Law/ Legislation

1.21 Happiness has to be the goal of medical treatment

1.22 Why "euthanasia" is not an end of life decision.

<u>Euthanasia is not about how to die, it is about how not to live.</u>

Legislative overview. Life is a challenge and living is to accept that challenge with joy.

1.23 The reason for pain and suffering is to drive compassion.

1.24 Advance(d) Directives.

It is easier to educate than to Legislate, and probably more worthwhile.

How can we get people to act responsibly and to make wise choices?

Advanced directives (Benefits of and relevance to events & timing)(see above)

1.25 The role of a trusted person, be that friends, family or doctor.

1.26 Spirituality and physicality. Why do the righteous suffer?

It is not the event that tests us, but the response to it which vindicates us.

The Legislative challenge is no different.

1.27 Role of decision makers

What they decide depends on which of two types they belong to. Ethical implications. See Ref. 21.

1.28 Time line of events and elucidated need for responses.

An end of life event can occur at any time. Certainty is death, timing is not.

C. Recommendations. Legislative approach to end of life decisions.

A. Overriding contingency: A person's Rights, to express their wish and for that wish to be respected, advocated for and achieved – to override all other Legislation conditions and tokenism in that regard.

1. Pre-admission assessment
2. Hospital admission which precludes pre-hospital assessment
3. Hospital admissions requiring intensive care unit admission, or where the prognosis is in doubt
4. Emergency meeting.
5. Where disagreement abounds, while the patient in a state of limbo..
6. Trust.
7. An Ombudsman.

8. Bearing in mind the **Legislative Council's Findings re Inquiry into AHPRA, March 2014**
9. **An Inquiry into the collusion between Medical Board and Tribunals / conflict of interest.**
10. **A wider brief of such an Inquiry**
11. **At leave to Appeal**.
12. **A System of Evaluated decisions**
13. **How long can we tolerate a Tribunal System**
14. **In deciding at end of life decisions**, outcomes remain the focus of decisions.

1.29 ii Proactive approach. Educational Measures, "lifestyle and values" motivators.

1. **Promotion of a wellbeing strategy (as opposed to an "end" strategy)**
2. **This is the time of your life Dairy©. What about Me?©**
3. **AHA Australian Health Ambassador Schools Charity program**
4. **3 R's, Rally, Responsibility and Respect.**
5. **Improve communication and certainty**
6. **Recommended Title of Act. Act in the Patient/person's best interest.**
   Aim. To permit a treatment or withhold a treatment.
   Legislation that allows withholding of treatment according to patient choice is available in Medical Treatment Act 1988.

7. **Notes from the Public Hearing 23 July 2015**.

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D. References and sources. Including Legislative Council Inquiry (2014) into AHPRA.

E. Appendix (AA).

AA.1.i Letter to Director, Mental Health Department. (2007).
AA. 1.ii Letter to the Hon. Minister Lisa Neville, MP. (2007).
AA iii a, iii b. **Award of costs in non cost jurisdiction - a driver for adverse decisions**.

Costs awarded to Medical Board / AHPRA is of significance and concern to all Victorians, health professionals, and all Australians and health professionals in Australia, perhaps with some safeguards for Queenslanders as Queensland has appointed an Ombudsman to handle notifications and complaints. These invoices are available to the Legislative Council Standing Committee, should you wish to review these.