

28 October 2015

Victorian Parliamentary Inquiry into End-of-Life Choices

Victorian Parliament

Spring Street

Melbourne VIC 3000

Cc Victorian Health Minister

Dear Sir/Madam,

Enclosed is my submission for consideration by the above inquiry.

It commences with a few page review of the health care my late father received over the past couple of years, but then becomes a list of 41 suggestions based on my experience supporting him throughout the Victorian system.

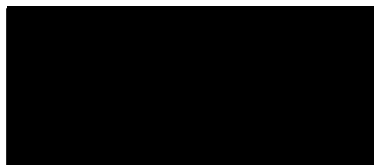
I can provide published evidence, photographs, documents and other witnesses if required, or speak to the document and respond to questions if they require additional explanation.

As background, I have many years experience as a public health administrator/business manager/accountant across several organisations, and have also been on Boards. My wife, who lost her mother last month, is a nurse with many years experience in Emergency and Aged Care. We have a substantial network of friends throughout the system, however these are my personal thoughts.

Thanks you for your time in considering them.



David Dillon



**My reflections on the health care provided to Bill Dillon
and suggestions for improvements.**

(For Victorian Parliamentary Inquiry into End-Of-Life Choices)

At the time the Parliamentary Inquiry was hearing submissions in Geelong on 29 July 2015, my 90 year old father's body was returning from the State Coroner and I was preparing his funeral arrangements for that Friday.

My father William 'Bill' Dillon was an active man who typically enjoyed good health up until around two years ago. Many years earlier he had a hip replaced and his spleen removed. Throughout his ensuing two years of illnesses, medical staff regularly made comments like, "Well he's had a good innings." or "At his age these things are bound to catch up." or "It's just his time." His treatment seemed to be driven by a pre-judgement based on his number in years compared to the national average, with little regard for his actual health outlook. In fact his father died at age 94 and his youngest uncle only died in the past 12 months at age 99.

In reality, Bill would typically spend even the better parts of a Winter's day driving half an hour to my farm and helping prune the 20,000 vines. It was only three years ago he and his wife of 61 years Margaret bought their first ever brand new passenger vehicle, so they could enjoy getting out and about to more distant tourist attractions.

I mention the car because it was a vehicle related issue that started the rot approximately two years ago. Dad thought he nudged a parked car in the shopping centre car-park. There was however, no sign of damage on his car. He waited for over an hour for the owner to arrive without success. He was racked with guilt. It became the start of a psychotic episode whereby he mistakenly thought the car owner would track him down and sue, and he and Mum would lose everything. Apparently this is quite a common misconception for senior in their advancing years to think their finances might be challenged.

His GP amended his combination of medications, however the enduring effect was to numb him to the point where he communicated very little and walked awkwardly without lifting his feet properly. One day the phone rang, he stepped out of his lounge chair and commenced to walk towards the phone, but as he said, his feet were asleep. He collapsed to the floor with a fractured foot. He was prescribed pain killers and fitted for a 'moon boot' for 6-12 weeks. The lack of mobility and independence dampened his spirit further and the psychosis got worse.

Things escalated into him thinking erroneously that his retirement funds were insufficient to last his lifetime, and that all the children would lose all their assets as well because of his actions, as debtors chased him. He started to talk about ways to kill himself. Mum was also stressing out from this change, and we found her crying on the nature strip.

After great effort and delay an Aged Community Mental Team member from Barwon Health (BH) attended and Dad agreed to an admission to the BH Swanston Centre at the BH Geelong Hospital.

Bill did not like it there. He always had a great appetite and said one particular large male night nurse ate parts of Dad's meals especially the juice, sandwiches and ice cream. And someone came into the room at night and took his possessions including his dentures and the selection of family photos we displayed to encourage him to come home. Because of his mental health status, no one seemed to take much notice of his comments, and besides, we had to leave him there vulnerable each night, so we didn't want to make a fuss about the staff.

The 'moon boot' started to smell and Dad had a welt the size of piece of soap on his foot going bad. The nursing staff said they only provide Psych care, but would refer our concerns across to the Acute Hospital. Showering in the boot, then wearing the wet boot, did not help. No one attended to this for days. Dad was on a walking frame. For days the staff did not know how to retract the 'L' shaped winder for height adjustment at the foot of the bed. I let staff know Dad had mentioned he could use it to hang himself from.

The winder protruded into the clearance between the bed and the wall and meant Dad had to negotiate his walker frame carefully between the two, but fell. I also witnessed the Cleaning staff connect the vacuum cleaner on one side of the passageway, then cross over to the opposite and into a patient room out of sight, but leaving a birds-nest of cabling 40cm-50cm high in middle of the walkway for another female patient to stumble on. There were many health care related items mentioned to staff across this admission that seemed to go unaddressed. They were busy, locked away in their glass cubical.

Although I was Dad's Medical Power of Attorney, staff would not let me have access to his Medical Record, saying things like they belonged to the Doctors or some other staff member needed to record something in them. This sort of issue with viewing Medical Records was a constant challenge throughout ensuing admissions.

Fortunately a young Psych Registrar on his last few day's rotation, got involved with Dad's total care plan. Dad responded well to the medications and is transferred to a respite facility with Mum for a fortnight. They only serve up small meals and restrict family members bringing in food or birthday cake on 'food safety' grounds. There is some 'catchment' issue regarding who and which health services can do what while both parents are on-site at respite. The stress of everything meant Mum was also receiving BH Aged Mental Health Team support through counselling, and her care and abuse as an orphan surfaced for the first time, due to this added stress.

Although the negative thoughts were largely hidden away, a haze still hung over Dad. Some of the spark had gone from his eyes and personality. He was a little difficult to engage in conversation. He stopped doing Cross Word or reading. His gate was restricted and he often did not fully lift his feet when he walked although he had not had a stroke. He was assessed for dementia and was fine. It seemed he was overmedicated and numb.

There was a level of uncertainty as to who would control his Psych medications for the immediate term. BH staff or the GP.

It became apparent across the two year period that there is a lot of uncertainty still in the choice, selection, lag time between variations and volume of aged care medications for depression and delusion, while avoiding excessively negative side effects.

Once Dad returned home, at least the five children could assist with either hands on care or coordination, we could see a care plan and participate in it. But the medication selection meant he never quite returned the same.

We thought a monthly visit by a qualified mental health practitioner who could establish a rapport with Dad and have the professional status to document a base line description/understanding of his typically normal mental health would be a better determinant of the effectiveness of his medications. However BH could not suggest any private providers and said he was discharged from their care.

The consequences of the medications were a burden on his physical and mental health, and that of his family and friends. There was also a personal financial burden on him directly and family members taking time off work to take him to medical appointments. And this financial burden extends to the private, public and insurance health sectors, with Dad's multiple ambulance call outs and hospital admissions. The medication concerns were raised in many and varied ways with his GP and slight tweaks were made.

I believe the medication mix was responsible for all of Dad's subsequent admissions, specialist and GP visits. He had admissions for blocked bowels due to the medications making him constipated and neither he or his aged wife being able to administer a suppository. There seemed to be no home visiting service for this in a timely manner, so 60YO children did it to relieve the pain. Dad had admissions for falls related injuries when he got out of bed at night to go to the toilet, but collapsed to the floor and his thin blood meant he would bleed easily. It created a black swelling on his buttock the size of a grapefruit that was at risk of rupturing or infecting.

He had falls walking between the kitchen table and the sink, resulting in a shoulder reconstruction with rod and plate and pins. He lost 50% of mobility from his left arm. As a 'lefty' that was big. He now couldn't even wipe his back side effectively. His quality of life was slipping away further and he lost 25% of his weight. The BH Hospital's on site Geriatric Emergency Medicine (GEM) ward where he was transferred to post surgery recovery, considered him a wandering/falls risk when he tried to get himself to the toilet at night or did his own rehab walking the ward. They degraded him further by making him wear pull up nappies after they medicated him to sleep throughout the night.

When he was discharged following that broken shoulder admission, he came home without a 'Discharge Plan' for any supports from the likes of BH Post Acute Care, BH Hospital In The Home or Vet Affairs (DVA White Card for Psych admission only). Apparently very little was passed onto his GP either. It appeared a one way information flow.

The family driven coordinated care plan was to get whatever support services we could for Dad, public or privately funded. Lots of general health services said he would need a formal referral from a medical professional, with a clear diagnosis before any eligibility or assessment could be undertaken. The Victorian health system is an unnavigable labyrinth.

Gatekeepers are more highly focused on keeping people out and secretly finding subtle floors in people's description of need or eligibility, to exclude them, than ushering them in and helping them recover. And when they are looking like being eligible, they have lavers of delaying assessments without actual service provision.

Organisations offer lip service to terms such as equity (eg some people are better informed than others on how to qualify or the medico language and acronyms used in confusing even for people well versed in English) and access (eg not all services are available across geographic areas or not all publically funded services choose to offer the same mix) and patient charters (eg patients can request to see their current records, but may not actually see them or there are clinical codes/abbreviation that cannot be understood).

In recent months dad's GP recognised the frustrations and Bill's further gradual decline, and provided a referral to the BH Palliative Care Service. For weeks before that dad had been complaining of increasing pain in his groin region and no-one had been able to provide a definitive cause or offer remedies. Pain management and timing of doses became problematic. Enough to ease the pain but not so much as to knock him out.

The GP refused to conduct a home visit, insisting on dad coming to the clinic. This wasn't going to happen. He couldn't even step into a car without pain. The clinic has just been in a half page colour spread saying it "...recognises the importance of accessible services for the community." And also having a musculoskeletal GP. We asked if any other GP linked to the clinic would be allowed to conduct the home visit and relay the finding to his regular GP. Not unless the specific GP allows it under certain circumstances. We then faced another ambulance trip to the BH Emergency Department to try to identify the pain and problem.

BH Palliative Care send a casual staff member to undertake an assessment. My stoic mother with a touch of forgetfulness or early dementia recoiled at the thought of a Palliative Care assessment (implying he was dying) for her husband just numbed on medications. She answered that they didn't need any support services, not realising the consequences of her replies. It just happened I dropped by as the assessment was concluded and asked to be shown the forms.

I re-asked a couple the questions and reminded Mum of things like, "No, he can't shower himself and remember two days ago when he fainted in the shower and you couldn't hold him up and you call the ambulance?" and "No, he can't manage his bowels, remember how he hadn't pooped for six days and you couldn't get a suppository in, he got unwell and you called the ambulance when no other service would come around?" and "Remember no one in the household drives anymore and we are all at work miles away if it is an emergency?"

And so began the long line of assessments. Dad needs help. For many weeks he had severe pain in his hips and groin. None of the X-rays prescribed identified what the problem was. He had no diagnosis of his specific illness at the time. This becomes a problem, not just because of pain management and movement issues, but because of the blinkers of service providers.

BH Palliative Care needed to know he was likely to die in the next few months before they formally put him in their full program. They would coordinate limited services for six weeks, when they would reassess the situation – so no specialist pain management doctors yet.

Two days later a nurse from BH Community Nursing arrived. Not to commence care, but to do her own assessment. Yes someone from their service based just two streets away, might come in a couple of days depending on their schedule. The suggestion was for assistance with personal hygiene M/W/F each week for continuity, but no two nurses were the same.

And then they stop after one week because they expected the care to transfer to the City of Greater Geelong (COGG), but no one came. Another assessment needed by COGG.

A BH Occupational Therapist came and did an assessment of the home and in particular the ensuite for safety of Bill and staff. They recommended we hire/buy a shower wheel chair but gave no indication as to which one might suit the BH nursing staff better. We got the brochures and waited to ask the nurses, but none of them were prepared to commit to a choice saying they were there just for one visit and perhaps it was best to ask a staff member when a regular roster was established. Again, we could not move ahead.

There was a recommendation that we install a wheelchair friendly ramp at the front door. Possibly concrete for ease of construction and rigidity. To be removed when no longer required. If it were to Code with a 1:17 gradient, it would almost reach to the footpath. Bill didn't want anything that might signal there were weak people inside the house, let alone this oversized solution. We drew up plans for one out the back door.

Dad's insurer GMHBA had been informed and their contracted allied health provider Remedy Health (RH) phones. It was a promotional feature of dad's private health insurance to get free allied health care after acute admissions. RH said they might provide some limited services, but only once a formal diagnosis is confirmed to their liking and only for a few weeks. If it is to assist recovery from an illness OK, but if it is general ageing NO. They will wait six weeks and recontact us to see if there is a diagnosis by then. For some reason there is a procrastinated discussion about Sustigen samples to Dad's GP to help maintain weight and limit a further decline. When I return a call to the RH voicemail, my contact turns out to unsurprisingly be a Dietician conducting the services wide assessment.

Just a couple of weeks into this melee of assessments endlessly asking the same questions, but not delivering very much, Bill has another fall in the dining room at home and broke the front window as he went down. It takes two ambulance crews to pick him up. He is admitted to BH Geelong Hospital on the Thursday night with a suspected broken hip. As medical power of attorney, the BH Registrar, surgeons and anaesthetist all run through the risks in great detail before his Saturday evening surgery and have confidence of success. To do nothing would mean a high likelihood of a painful few weeks and death. We give the go ahead and he has his second hip repaired with rod, plate and screws. They phone afterwards and confirm everything went well.

His BH Cancer Specialist tells us there is nothing in his results to suggest a cancer is causing the pains in his groin region. X-rays also apparently identify nothing in the hip region. BH hospital staff are having some difficulty identifying what medication dad has been on and ask for us to bring in the drug list off his pharmacy blister packs. We bring the whole pack in since he has missed a couple of days since being in there, but they say BH is only allowed to administer the drugs if their own pharmacy supplies them. So dad has to wait another couple of days to get back to his usual schedule.

Why is something thing like the current drug listing or significant past/current treatments not immediately accessible by ambulance, GP's and BH, and why is there such a wait for a formal 'Discharge Plan' that is only relevant for 'well' people?

Dad has come through another surgery. He is in pain, but untypically he is off his food.

They think the antibiotics from his procedure have killed the cells in his palette and in a few days it should be back to normal. I see he is on a 'nil solid' diet. The food looks disgusting. Imagine a dinner plate of hot 'food' that smells bad, is swirls of red, pink and white, with porridge consistency that looks more like something the bloke in the adjoining room had left on the floor of the toilet.

He tries a few things but refuses them all. We all see and smell before we taste. Food should look appealing especially if we want frail people to eat it. Why couldn't there be a step down level of 'nil solid' that allowed for soft foods that look like food. Perhaps steamed fish, mashed potato etc not just whatever is on the normal menu vitamised.

BH have a Speech Pathologist seeing him. She recommends Polident to better secure his dentures. Then he should be able to eat. It seems they are treating symptoms not the root cause. I tell her he is complaining of poor taste in his mouth and the oral thrush he had post his previous procedure that also made his tongue swell. No response. Just bring in the Polident.

I spy a look at his medical record with coded/unclear entries. For some reason he is still not being given his anti-depressants and anti-psychotic medications. This might unbalance him. I raise this with the attending nurse. No explanation is given. She suggests I speak to the attending doctor but has no idea when they will be available. She suggests I just stay by his bedside all morning and see if they walk in.

I do catch his BH Dietician. She says Dad is refusing foods and medications. I explain what Dad has said about all food, even water, tasting terrible, and mention the past oral thrush issue. She mentions his taste should come back to normal post-surgery soon. I talk to the nurse about suggestions he is refusing his medications. She says she manages to get most pills down, and because he really struggles with the larger ones, she has been instructed to break them in half.

The following day I wait all morning and see the young visiting BH doctor. She is thinking of transferring Dad into the BH GEM ward for rehab. I talk about the past difficulties and our preference for the McKellar Centre with a more structured rehab program. She says Bill will get whatever bed next becomes available. I ask about his poor taste for food. Is it possible that once the large pills are broken in half the protective coating that masks the vile flavour is gone, and this is contributing to the lasting poor taste.

I said I understood the main problem pill could be substituted for a liquid. She says BH Pharmacy have specified the large pill format and would not provide a liquid. I have been told by someone that it was a cost saving choice not a clinical one. I ask if Mr XYZ is still the pharmacist. The Doctor agrees to switch the offending pill to liquid, and cop any flak from the pharmacist herself.

We talk about the recent newspaper by the BH/SJOG physician regarding his own father's death and the helplessness of trying to get support and compassion from health services at this trying time. She mentions her own mother is dealing with like issues with her aged grandmother.

The BH doctor reinstates the two missing anti-depressant and anti-psychotic medications, and lists Bill's preference for rehab at the McKellar Centre.

Several times while he is in TGH, my wife and I shower and shave Dad and change his bed sheets if he has been left until after lunchtime. Although he is in a brand new wing, staff say they don't always have time if there are new admissions.

Although he is having trouble with his food intake, if staff see you bedside, they do not assist in feeding him. On his last day there, an eyedropper with medicine to be added as a couple of drops per meal to address the oral thrush is on his bedside table, but we do not see anyone add it to his food or record it in his health records.

Apart from food intake, his vital signs seem to be on-the-improve and the BH doctor arranges a transfer to the BH McKellar centre for rehabilitation.

As a Private patient, Dad is in shared room at McKellar, but now he gets a newspaper daily for the added fee of an insurance claim. The patient in the next bed is crook. Most days there is blood over front of the toilet chair etc. until the cleaners come in the afternoon. On a couple of days I shower, shave and change dad when the staff say they have a lot of new patients on the ward and he hasn't been seen to by shift change in early afternoon. He feels more alive and talkative sitting up out of bed. But he is doing a lot of sleeping and no real eating, still complaining about bad taste in his mouth. The pain in his groin and across his hips, is now moving half way up his back. He is uncomfortably curled over and refusing to roll over in bed.

On one occasion while I am visiting, a woman with no apparent identification showing or stethoscope around her neck, or clipboard etc, urgently breezes in. It turns out to be a BH doctor. She doesn't seem to acknowledge I am in the room and presses on with a brief discussion with someone in attendance with her. I introduce myself as Bill's son. She asks me some questions about his past medical history and takes my replies into consideration when instructing her assistant what to include in dad's future care. "Has he had cataract surgery?" (one eye slightly larger than the other). I am surprised that she could have been talking to anyone visiting dad and gotten different answers, and besides, BH holds all of dad's medical records, so a review of his file would have given the authoritative answer.

This happened at other BH sites also. "Why has he been on low dose anti-biotics?" (Spleen out years earlier – weakened natural resistance). "He is off the blood thinners." (No, he needs them because of a narrowing above his heart). "He is not lifting his left arm, he may have had a stroke." (No, he had a broken left shoulder and never recovered complete movement.) "Do you know all the medications he is on?" (Yes we have the pharmacist blister pack at home, but isn't it on your records also.) "He is complaining of no bowel movement in several days?" (Your choice of pain management has blocked him.) "He can't keep his dentures in." (His tongue is swollen with thrush and his gums sore.) "His hands are very shaky when he tries to feed himself." (You have taken him off some of his medication.) "He seems to have a certain smell." (The 'moon boot' stays wet from the daily shower and it is rotting his skin.)

Just like in the hospital, they have dad wearing some type of disposable underpants with a disposable pull through insert. Apparently this is seen as more cost effective than the usual pull ups. If he moves about too much, the pull through dislodges. Even more humiliating.

He is still off his food due to the taste. On occasions nursing staff come and collect the ice cream "...for another patient". Mum brings home-made soup, but he refuses it also. We regularly tell nursing staff he is complaining of pain, especially in his groin region and back. They consult charts and say they are administering what they can. It would be up to a doctor to review. Who is responsible for prompting and following this through?

BH Social Worker comes in and commences yet another BH referral for the services she might offer. Dad sees this all as past a joke, being asked the same first 20 questions over and over again across the last few weeks. He doesn't want to engage. The services may be worthwhile, but the entry process is implausible.

Why be writing it all down again on a 'service specific' referral when BH already holds this and should just printout a sticker with the common fields on it, to include on the 'service specific' forms.

If they are actually trying to build a rapport with a client, show you have read the client file and make comments like "I see you have been married for 61 years, Bill, that's a record these days" or "So you grew up in Carnegie. I had cousins there. Did you know the Jacksons?" Show some personal interest. And why don't each of these potential service providers state from the outset, what they might be able to provide. Instead it is a one way conversation flow, where the client does not know why the questions are being asked, or more importantly the consequences of their answers to an otherwise stranger.

The head BH Geriatric doctor, support doctor and lead nurse have a meeting with my mother and I, and to our surprise say dad is in decline. He has only been off his food a few days post-surgery. There doesn't seem to have been any special attention paid to him. They are ordering further X-rays for the pain in his middle back, but will be transferring him to a bed outside the nurse's station for closer observation. They feel that in his condition, he shouldn't have been transferred from TGH even though he was walking about back there. No beds are available in the BH Palliative Care ward at McKellar, but staff would do what they can in these surroundings. Palliative Care.

It has hit us. This is the first serious flag that he might not recover. Is he in any condition now to review his BH Advanced Care Plan, or will it be passed across to his shocked family.

After dad's X-rays, he complains it really hurt being pushed about to get the images. He lays crumpled over, eyes closed but not asleep. Speaks about two sentences every 20 minutes. He cries out in pain, especially if moved. When prompted, nursing staff say the x-rays are inconclusive showing no change in his lung function from the past results. We are confused. We thought these were to be of his back, not lungs.

Just a day later I get a call to say dad had a bad night. They suggest I get mum for another meeting. I ask to be able to get all the siblings in. They agree to a lunchtime meeting. As a family, we can't think of anything that might actually be going to kill him. He is having a little water and only some small amounts of food, but people can live for weeks without any food, or they could be fed by peg line until they recover. There has been no mention of rising temperature suggesting infection etc.

And the biggest questions are – what is causing this downturn, how do they manage the pain and what can be done to get him better.

The medical team say he has had two bad nights. Hallucinating, crawling on all fours in pain. We discuss dad's BH Advanced Care Plan he prepared years earlier, that nominated his preference not to have unnecessary treatments or life support, if the likelihood was he wasn't going to recover. It has not been reviewed or amended by him in years as he aged. What would he think of it now, if he knew the cause of his current illness.

We agree to a plan to keep the antibiotics and additional treatment going for another 48 hours to see if things stabilise. They will prepare Bill for a drip line for better pain management just in case. Dad told me that same morning, he thinks he is going to die tonight. A nurse manages to get in touch with dad's former priest doing the rounds who Bill recognises when he visits at 6PM. At approx. 9.30PM I get a call from BH to say my father had died.

I am told that the McKellar centre does not have the facilities to hold a body and that I should contact our undertaker. I am called again, to say that since dad has died within 14 days of surgery it is now a Coroners matter and if any member of the family needed to see him one last time they needed to meet in dad's room before midnight. I get the family together, including rousing my mother from her sleep in the dark of night. I get to the room first and have to ask for dad's upper and lower dentures to be placed back in to make him more dignified and recognisable. It takes five minutes for them to find a staff member available to do this. When we gather at his bedside there is the strange sense of foreboding with two Police officers at the doorway outside the nurse's station. They are to collect the medical records. I need to sign some records.

As the others leave, I am asked when I will be back to collect dad's clothing and personal effects. It is after midnight and I don't have a suitcase. I live 30km away. I say I will be back before 9AM. They suggest a little earlier might be better before other residents get up and about. Or was it to reallocate the bed for a full day?

My Medical Power of Attorney ends with my father's death and the Coroner's Office (CO) call my mother as next of kin to ask if she has any specific concerns. She approves of the CO talking to me as her proxy. If things look straight forward enough, the body will be released in a few days. If there is a need for a full autopsy it may take several more days depending on workloads and what is found. We don't like the thought of people cutting up dad, especially if they have no certainty in finding his actual definitive cause of death. We would rather have him home for his grieving family and a funeral. We are also told by another party that a full autopsy might delay services by weeks, and the issuing of a Death Certificate by months. The latter meaning that if the surviving spouse had shared bank accounts, the Will and accounts would be frozen and not be released until the Death Certificate was issued, potentially leaving some widows in necessitous circumstances.

Dad's Death Certificate was dated 28 August 2015 and the cause of death shown as "Complications of surgical repair of a pathological fracture of the Femur in the setting of lymphoma." This was the same cause of death verbally presented to me four weeks earlier when I was told his body was being released, but the paperwork took four weeks to follow. I think this cause of death unfairly suggests the surgeons were responsible for this, when there were other symptoms presenting that ward staff did not address adequately in the 10 days following. A failure to save.

I feel the true cause of this death was the treatment he received for his mental health issues that kept causing the falls. My dad did not get to make an End-Of-Life Choice. The government funded highly skilled and remunerated medical professional did and excluded him from meaningful input.

Suggestions

These suggestions may be attempting to 'draw a long bow' to be included in any recommendation regarding to end-of-life choices, but they may help people manage their treatments as their end-of-life approaches, regardless of their age, to have improved quality of life, health outcomes and informed choices. Population forecasts indicate many parts of Australia will complete an almost doubling of over 65's in the next 10 years and these people are expected to live longer even exceeding 100 years, increasing the burden on health services. New global life expectancy figures released in The Lancet medical journal forecast the final 12.3 years will be spent with the onset of major illness and disability. So if this is not the right vehicle to have my concern addressed, please let me know what is.

1 Health care should be governed by the individual's need, not by their actual age in years compared to the national average, otherwise this is another form of age discrimination. Comments such as "Well he's had a good innings." or "At his age these things are bound to catch up." or "It's just his time." or "This disease is typically aggressive." show a systemic pre-judgement to expect someone to die soon and not extend too much health care. In-service training should stress this point.

In my dad's case, his father died at age 94 and his youngest uncle only died in the past 12 months at age 99. We had reasonable expectations he would have loved a fruitful life for many more years. His age and mental health were descriptors not diagnoses. It should have been the start of a new journey, not an abrupt end. End-of-life choices should not be driven by age, but a more holistic assessment of the persons complete health outlook, both physical and mental.

2 Key critical patient data needs to be almost instantly accessible. If not on a patient carried smart chip card, or on a QR code, which are cheap technologies to implement, then in a computer system the patient can authorise access to on any site from first responders, to Emergency Dept, to GP's, to Pharmacy.

The data should include Blood type, Next of Kin, Medical Power of Attorney, GP and details of other regular health professional seen like Cancer specialist. There should be a full list of current medications and why these are required, the Medicare number, Ambulance membership number, DVA number, Private Health insurance number, allergies and alerts, Religion and flag a Mental health record, plus in situ medical aids like hips and pacemakers.

Other prompts are needed since not all medical staff seem equally skilled in immediately recognising signs. Spleen out – less immune system – needs low dose antibiotics. Cataract off eye – one eye slightly larger than the other – not a sign of stroke. Aortic stenosis above heart – restricted blood flow – needs blood thinners and prone to bleeding and fainting if bent over. Past admissions for compacted bowel – some pain medication cause constipation – choose wisely – treat regularly/gently – not late/harshly. Gets up to toilet overnight – avoid fluids after 7pm – keep floor area clear. Non Hoskins Lymphoma – reduced white cell count – weaker bones – not likely to kill. Recent blood transfusion – elevated red and oxygen blood levels – not typical readings.

And whatever else key medical decision makers need instantly, not just 'available' if they have the time to trawl through 100's of screens of old records with each contact. Much of the current health care model is about quickly addressing the symptoms of what someone is currently presenting with or maintaining care according to a pre-templated care plan, with some practitioners seemingly loathing deviating from the norm or incapable of more detailed analysis due to time constraints or lack of skills.

Having a better instant understanding of a presenting patients complete health record, makes supporting end-of-life choices more accurate and defensible, no matter which nomination was chosen.

3 Likewise, key non-critical patient data should be easily transferable from record system to records systems. On Acute admission there is a sticker for the wrist band and the initial medical file with fields such as UR #, name, address, DOB, age in years and months, contact number, GP, Medicare number, with a scannable barcode and which can be printed off as stickers that can be put in a header space on any medical form. However there are also a huge number of common fields repeatedly sought by multiple staff from the same organisation for the likes of referrals and so called specialist service assessments.

The common fields should be asked only once. The Quality Department staff should be able to quickly access and process map all these documents to prove the frequency of unnecessary duplication. There also seems to be a lot of duplicate patient data entry in unrelated systems for minimal benefit even after whole of enterprise systems have been introduced.

Either some departments want to retain legacy systems, or funders require different data or new enterprise wide systems do not adequately address specific department clinical needs. One example was the requirement for the continence staff to adhere to a new Continence Care Management Plans that required many seemingly irrelevant questions to be answered taking 12% longer than the old system and pushing out waiting lists.

Healthcare workers and patients have better things to be doing in their all too brief contacts, than to be unnecessarily duplicating data, and a greater number of patients could be seen.

4 Advance Care Plans developed for health networks try to capture an individual's early wishes to among other things, identify what aspects of their life they value most (ie good health) and at what point they expect medically assisted living to not be offered or cease (ie if it was unlikely they would return to independent living at home). It is not well publicised that these are a Legal document (to protect the actions/inactions of medical staff).

People not yet at the end-of-life stage might answer differently to those staring down the barrel of such nominations. Family members and medical power of attorney might want to guide health care, based on the patient's wishes, but the nomination may be old, or the client may now be saying something counter to the documented nomination once the reality of it draws closer. The Advanced Care Plan should record the names of formal Medical Powers of Attorney.

The words used in some nominations are open to completely different interpretations. I would like to suggest the Advance Care Plan is reviewed annually, either as a GP consult or Social Worker visitation, and the changes tracked over time to ensure the patient has provided informed consent, is compass mentis and expectations are consistent for the people that need to be guided by them.

A person in great pain or suffering inadequately managed depression might not make an appropriate nomination, due to the moment they are in. Likewise there are statistics that show people will on average spend their whole life's savings on unsuccessfully trying to sustain their life in the final few years.

Perhaps the best measure of the effectiveness of current Advanced Care Plans could be gauged by formally surveying the families of deceased as to whether they felt the individual's nomination and the medical treatment received, matched. It might be an early indicator of whether pre-documented end-of-life choices would be likely to be acceptable to loved ones.

5 Organ donor records should be included on the individual's Advanced Care Plan with a space to record the family's approval, well in advance of actually needed this. At the point of facing end-of-life, the family is emotionally overwhelmed and not wanting to face major decisions suggesting the person might be dying, with current figures showing up to 50% of families not allowing a donation to proceed.

Also then, the person making the Advance Care Plan has the time and passion to convey their nomination to their family to have the document countersigned, to prevent donor delay. Up to 150 Australian a year are missing out on life-saving organ donations, with 1,600 currently on the waiting list. In Victoria, we have a world class post transport accident survival rate, yet one person dies each week on the waiting list.

People on these lists have made an end-of-life choice to fight for their life, not end it, but public health administration has not done enough to help facilitate it.

6 Mental health drugs. Australia has a voluntary reporting system, in which doctors are responsible for noting adverse reactions to drugs in their patients. This takes time and GP's are rewarded more on throughput by the government than on thoroughness, and I guess if they see enough repeated minor reactions, they become normalised.

Bob Whitaker in *Anatomy of an Epidemic* showed in the US the number of people "disabled" by mental disorder had risen from 1.25million in 1987 to 5.04 million in 2013. International data shows the same upward trend across the developed world including Australia. The percentage of our population affected over their lifetime of depression is 16%, of an anxiety disorder 25%, of substance use disorder 25%.

Almost 7 Australians a day suicide. Clearly not enough is being done by government to address this. Mental health issues can impact on anyone, and access to assisted end-of-life choices must ensure it is not being driven by inadequately managed short or long term, mental health matters.

7 In Victoria we have 81,000 people recorded as having dementia. By 2050, this is forecast to increase to 246,000. Australia wide there will be 400,000 diagnosed in the next 5 years, and that will double again in the following 25 years. Who will care for them and step out of the workforce, or will they progress to the NDIS, Social Security, Carer's Pensions. Caring for them can impact the mental health of carers.

Dementia specific Wirrunia Lodge at Winchelsea is an award winning benchmark model in facility design by benefactor Lyons Construction, but at a higher cost. However many aspects of designs like it, should be integrated into all future facilities partly funded by government.

The whole public community landscape needs to be audited for physical changes since people with dementia find simple things like public transport and signage in public toilets confusing.

Likewise there is a growing need for dementia related aids such as clocks that show not just time, but day/date/month at a reasonable price while visually pleasing. My mother-in-laws only non-digital clock option was 50cm x 50cm and cost \$170 from China! Without these supports for living independently at home in surroundings they prefer, dementia sufferers end up in residential aged care facilities. Or worse, often unknowingly, suffer gradual personal degradation from failing to take medications, missing the shower on the usual days, forgetting to wash cloths regularly, not eating foods before they spoil, being harassed for not paying bills on time etc and generally not maintaining their usual personal health and wellbeing.

She had been enjoying attending an Adult Day Activity Group at the Bannockburn Golf Course, however the shire relocated them to a boring room at the shire offices to help validate the need for the building. Client need should have been given a greater priority.

For a person with dementia, they may be beyond making an informed end-of-life choice, but if they could see the way they were living, might wish they had. And how would you assess its relevance.

8 Greater use of relevant BigData analysis should be undertaken, just as they have in gathering evidence that if a child is born with an adequate birth weight into a household where at least one person has paid employment, they will most likely complete all their schooling, find work and not require social security.

The latest national Population Health Survey found around 50% of Australians over 45 suffer from two or more chronic diseases (co-morbidity) restricting their quality of life. Many of these stem from lifestyle choices such as poor diet, overeating, under exercising, smoking, alcohol and drug issues etc, leading to diabetes, heart disease, etc. Others such as asthma, dementia, lower back pain, mental health are less linked to lifestyle choices.

Better analysis needs to be undertaken to understand when each of these categories of people are likely to reach the end-of-life phase and what resources they requires.

If there have been lifestyle choices, patients may have been well informed for years of the likelihood of resultant premature death or painful consequences of past choices (like from smoking ads), and may opt early to choose to end their own life, once the tipping point has been reached.

Presenting more evidence based predictions from the likes of Actuarial records showing the life reductions of the lifestyle choices and handed out by health educators on first Admission/diagnosis might help influence the future behaviour of the patient and their loved ones. It is these loved ones that are capable of successfully turning around the lifestyle choices in households such as children returning home from school armed with information about the ill effects of smoking and pressuring their parents to stop. Mine the data, present the real facts and arm the loved ones to target the individuals in need.

With over half of all Australian born today being forecast to live beyond 100 years, we need to study what will give them their best chance of living a health life longer without medical interventions. An ongoing American study into the life choices of a community of people who successfully lived from 80yo into 100yo's found factors such as a cumulative 15 minutes moderate exercise daily, not being over or under weight, fresh foods, brain activity like cards and current affairs, only moderate red wine consumption but not abstinence etc were all that were required.

What evidence are we building in Victoria from data-mining. How do we promote positive messages (doing x is good) to overcome the constant negative messages (don't do y). How do we help people make informed lifestyle choices, which if ignored will in all likelihood lead to them dying early and in unnecessary pain. Documents like Advanced Care Plans and end-of-life nominations, formally presented to people making poor lifestyle choices on early contact with health organisations, might make their behaviour 'top of mind' and generate positive actions, while they still have a chance.

9 Data sets should be reviewed. Much of the data captured in the provision of public health is of little research value due to its coarseness, the title of its field or irrelevance, but could be improved if the needs of research bodies were considered.

As an example, people suffering traumatic injury as a result of motor vehicle accidents are supported by TAC in Victoria. TAC knows which clients live in which suburbs and allocates a case worker to support a package of care. Often what they don't know is how effective that care is until it is too late and something goes wrong.

For many, GP's are the main service provider. However you cannot interrogate their data system to identify categories of patients such as paraplegics or quadriplegics who have had Urinary Tract Infections (UTI's). It is only when they have had an hospital admission for an advanced infection that more detailed data appears, but this does not include the pre-cursors.

If research at the GP system level were possible due to better code categories then something could have been done to look at the size of the problem, why the UTI's occur, is it client/carer technique, lifestyle, education, product related. Were self-lubricated, pre-lubricated or silver tipped catheters used and to what effect. What antibiotic were prescribed and to what effect.

TAC's expends around \$1B a year on supporting its clients. Just this continence related sector alone cost millions but effective analysis is difficult until it becomes an acute admission. Primary Health Networks may in the box seat to coordinate this question of data set relevance beyond just GP requirements. If clients have better supports throughout their life, the need for end-of-life choices is deferred.

10 A patient's records should be accessible by the patient, their next of kin or Medical Power of Attorney at all times. To satisfy hospital concerns, there should be a space for them to sign the viewing if necessary. Medications and results of observations etc should be explained, and notes in the records should be in a common understandable and non-confusing format, with a legend for acronyms, medical jargon or abbreviations if they still need to be used.

When the actual hour in which pain management medication is administered is not recorded, just AM/PM, how can the next shift staff know when it is too early or overdue to offer more? Sometimes extra pain management needs to be timed ahead of showering or rehab exercises. When anti thrush drop are left on the meal table and there is no record in the medical chart, how do you confirm it has been added. When bowel movement charts show "~~" what does that mean to the next nurse?

When family asks to see the treating doctor, there should be some record of this noted on the system so the relevant expert can phone the family or arrange a mutually agreeable time, rather than just expect the family to wait and wait in the hope the right clinician comes in.

There are regular complaints in my local newspaper that staff appear to spend all their time in the staff area and they do not know who to speak with if they have a concern. When staff do pass by, the staff cannot discuss the records, with some citing Privacy issues and don't seem to record your queries anywhere.

Family members have been especially critical of the treatment they have received from receptionists and staff at mental health facilities, when carers cannot gain access until someone behind a glass screen meters away deems they are prepared to leave their safe workstation and escort a visitor into the geriatric low level ward.

When a person is very ill, they cannot advocate for themselves well or necessarily understand the significance of what is being said to them, so we should encourage and facilitate the input from family members/carers etc. At every point during their care, the patient should know what is happening and why, which medications are being administered and what they should resolve. If you asked someone what they heard in the next five minutes after being informed by their doctor they have cancer, it would be next to nothing.

Patients need to make end-of-life choices based on actually understanding evolving information from multiple inputs and the most trusting of these is a loved one who can engage in a meaningful discussion.

11 Access and equity should be formally reviewed. These are key elements of public health, but often only given lip service, leading to some people receiving inappropriate support and inadequate health outcomes

I have seen GP's advertise their recognition of the need for accessible services, only to find they do not conduct home visits for a long standing 90 YO patient they have been fully informed cannot make it into their clinic two streets away. I have worked for GP's who have received tens of thousands of dollars from government grants for being accessible after hours. Their real performance statistic showed they were not actually staying open longer hours to see patients, but were claiming this on the basis of maybe one patient a fortnight not completing their consult by the usual closing time.

I have been on a health service board where the entity would not provide additional or varied services to the fastest growing township in its catchment because of a clash of opinions with that town's local LGA, who they believe want to run missing services themselves. To ensure the status quo, they have refused to interview highly skilled medical and child services board candidates from that township, instead seeking to attract more people from their original base township 40km away to strengthen their historic focus. I have witnessed them vote to extend loss making services and enter new ventures with no hard evidence of enduring need and potential risk, while deferring formal strategic planning.

I have experienced no waiting lists for some allied health services in some hospital catchments and huge waiting lists for the same services in adjoining catchments, and others again who stop including names on lists if they get too long and thereby understating them. I have experienced these same catchments offering access to these services as home visiting versus in clinic only versus no service at all. Yet the government funding for all these services is allocated on a population basis which should give people comparable access.

I have seen 'contacts' counted as one person or overstated as all family members in the room. I have seen services 'offered' counted as 'hours of service delivered' even though no one attended. I have seen contacts delivered from Commonwealth funded grants also counted as services for State funded grants.

I believe there should be a formal access and equity survey maintained of which services are funded per LGA and by which health service provider, with annual data on what was actually delivered in each township/suburb to ensure its relevance to the community. Not just in the format of Health Service Agreements which seldom map to the reality. As an example, a grid matrix could show that in town X or suburb Y there is an ambulance within x minutes, x GPs hours/eft per 1,000 people M-F 9-5 and 2 hrs per day after 5pm, x hours of family day care per 1,000 people, x low level, high level and dementia beds per 1,000 people, x hours delivered of district nursing, physio, podiatry, OT, mental health services by y entity etc.

These could be matched to the Population Health Survey for the area to confirm trends of over/under-servicing and provide the evidence to guide future government funding decision making.

A further information output should be a website clearly stating the criteria and gate keeping requirements of these services such as only for over 65YO's, or for people with a Health Care Card, or requires a GP referral, or is only available of six weeks, or has a \$6 fee, etc with hyperlinks to the relevant authoritative websites.

And it is not just fully government funded service providers that need to show what they provide more clearly. Recently a local charity listed the 40 entities it was donating funds to assist the health and well-being of the local community. Many of these names I did not recognise and their name provided no incite as to just what they offered. How do members of the general community navigate this in a time of need.

It does not require consolidation of entities and loss of volunteering etc, but technology should be adopted to de-mystify and disseminate, thereby showing overlaps and gaps. The format should be capable of Google type searches on key works like mental health services/15yo/Corio/free..

Government policy is encouraging ageing in place and consumer directed care in service models such as MyAgedCare and National Disability Australia, with the growth in aged care beds in decline and CAPS packages reducing as a percentage of the ageing population. Aged care at home is growing at 13% a year, far more quickly than residential aged care.

Chronic disease accounted for 90 per cent of all deaths in Australia in 2011. Around half of all Victorians have a chronic disease and one in five have at least two. These require more supports as people age. People need to be able to make informed decisions about how to keep themselves healthy, with whom to spend their consumer directed care funds and how to recover. It should be easier to navigate and access. The well documented teething problems at introducing the MyAgedCare site since July 2015 are an example of what not to do. Again, Primary Health Networks could play a key role in compiling and maintaining this.

12 Clarity of referrals. I have a daughter who has been picked on at school because of a growth on her upper lip. We went the GP, he referred us to a Plastic Surgeon, who referred us to a Laser specialist, who has referred us to another specialist, and we finished up with another Laser specialist. Each contact is getting paid hundreds of dollars for an opinion that "...someone else would be better at undertaking the procedure" ie doing nothing themselves, and we cannot self-refer to avoid this dilemma. We miss time at work and our daughter from school, waiting days between appointments.

No wonder so many people just arrive at the Emergency Department of hospitals to get some attention conveniently after hours and without charge. Would an older ailing person reliant on public transport keep trying to navigate the health system in an attempt to make a full recovery, or would they start to emotionally give up, and bring about more complicated and expensive health conditions.

13 Complements and complaints should be prompted from patients and families, catalogued and analysed, just as successful businesses do.

All should be presented to Boards and Accreditation Agencies (or Peer review) each month in full to avoid the likes of the maternity department incidents at the Bacchus Marsh & Melton hospital.

In some cases there needs to be a format to give better credence to anonymous complaints due to patients or family members wanting an issue to be addressed for the benefit of others to come, weighed up against not wanting any negative treatment of their loved one on next admission. It seems regularly that complaints from mental health patients are readily discounted unless independently validated by an unrelated party.

Whilst I was on a Health Service Board, I heard the CEO explain the reason why complaints had increased significantly was because a new system had been introduced to make it easier to report them. He did not feel the need to explain the actual nature of the new complaints, or whether they were coming from patients, families or staff. He felt celebrating praise had a greater benefit than addressing potential issues, and that also formal Policies should not prescribe certain potential breaches should be referred to the Police or health authorities 'too early'. The majority of the long standing Board agreed.

An effective complements and complaints mechanism for the public, staff and anonymous submissions to be addressed in a consistent and positive manner can prevent adverse outcomes.

14 Patients Charters should be reviewed. Does what the Charter present actually occur from the patient's perspective. Is the Australian Charter of Healthcare Rights actually in place, or is too much left to inconsistent interpretation impacting on patient care.

15 There is a need for clinically skilled Patient Advocates not connected with the actual service provider, to aid patients and their families navigate the system and the procedures being administered. If even people with a level of medical awareness have difficulty dealing with the system, what do less informed people face.

These Patient Advocates could be aligned with an hospital Accreditation Agency to be in the best position to link patient care into a formal review system. Recent funding has been supplied to mental health advocates, but mainly for people subject to compulsory treatment orders. Many other levels of mental and physical health patients need assistance also.

Would you wade into a complex legal matter without your own legal advocate, even one funded by Legal Aid. When a patient is stressed, unwell and confused, how do they make informed decisions. How do they assess whether they have received substandard surgical or post-operative care, or whether the urgent procedure offered in the Emergency Dept is the best option.

I bumped into the community Aged Mental Health nurse who assessed my father almost two years ago and who encouraged him to self-admit at a time when dad was considering self-harm. He asked how my father was, and then went on to say "I feel I should apologise to you. The young fellow your father got was inexperienced and he should have received better." He wouldn't elaborate and I couldn't work out which 'young fellow' had done what!

Harvard-trained surgeon, Rhodes scholar and World Health Organisation program leader Atul Gawande talks about the need to take on calculated risks in undertaking surgery, and more importantly preventing failures from becoming a catastrophe. Scientists call this a failure to rescue. He feels the real story of human and societal improvement is around doctors not failing less, but in rescuing more.

As my father's surgery showed, it was a success, but clinical staff in the following week did not identify the problems post-surgery in their care plan and inadequately addressed them, leading to his premature death from just what, we still do not know.

We recently saw an advertisement by Monash Health calling for volunteers into a study of "C.diff" Clostridium Difficile Vaccine Trial for people over 50 having hospitalisation or having received antibiotics over a long period, and wonder if it was a factor.

There is so much about health treatment that the average patient just does not know and if they are to consider end-of-life choices, they may need an expert on their side to assist.

16 Medical terminology should do the same as Lawyers have been pushed to do, and present information in plain layman's language. It needs to be adequate and understandable. As our ethnic diversity extends (currently 25% of people born overseas and from over 300 different Territories), the use of online translation technology and apps should be widely encouraged over booking interpreters to attend delayed bedside visits.

Apps such as Google Translate offer over 90 of the main languages in voice, handwriting, camera or key-board, and Google has recognised the prevalence of online searches for medical information and teamed up with an authoritative medical institution to improve the accuracy of searches for medical related topics.

The wording in health related documents, diagnosis, in brochures, in Receptions, on walls and overhead in hospitals should be re-written in many instances. First you have the department names and sub programs like nuclear medicine, oncology, pathology, palliative care, respite care, acute care, ambulatory care, post acute care, hospital in the home.

Then you get the terminology. What does benign v malignant mean to the common man. Cardiac infarction, aortic stenosis, pulmonary embolism, anaphylaxis, anti-natal, peri-operative, something myopathy, something in Latin or Greek. Then comes the acronyms. HARP, HITH, BPAC, SWAH.

Apart from people coming from non-English speaking countries, I suspect that for many of the patients suffering from lifestyle choices such as poor diet, overeating, under exercising, smoking, alcohol and drug issues etc, leading to diabetes, heart disease, etc, and others with the likes of asthma, dementia, lower back pain, mental health, and more, the language used excluded them further and they fail to engage. Kids from poor socio economic backgrounds are four times more likely to drop out of school. Not because they can't learn, but because the way the information is presented to them.

It is too bigger gap for them to bridge. The powerful government and the rich and elite clinicians showing them they are superior and should be grateful for the benevolence they receive. Medical information should be supplied to all in a format of choice so they are better informed for making life choices.

17 With one in four Australians born overseas and 60% of those not speaking English at home, the health system needs to be able to cope with language and social diversity rapidly. There is evidence that as people age, they revert to the language of their birthplace, especially if dementia is an issue. As mentioned above, apps like Google Translate may be of assistance if widely distributed on electronic devices.

Understanding of ethnic, religious and social protocols are other considerations. Why do some nationalities only want male children, or seek female circumcision, or feel female abuse is OK (one in four females in Australia have experienced abuse from an intimate partner), or that ageing parents should live with the oldest daughter.

Health services have regular in-service training on new systems and procedures, and even annual revisions on fire safety etc, but what do they do to inform staff on ethnic, cultural, religious and social diversity. Some service industries such as Law hold annual residential training programs to keep their staff current and informed, because they recognise the potential impact on their business. Health should consider something similar for all staff.

How would you feel if someone came into a room speaking a different language and handed you a form in that foreign language and prompted you to sign something if you wanted a medical issue addressed. How would you feel if it went on for an hour. Where is the choice in that.

18 Just as Food Safety Standards do not apply for family functions or school fetes etc Food Safety Standards should not prevent family members bringing in home-made meals for their loved ones, provided they are not supplied to other patients, and the contents are recorded on the dietary chart (in case there is an allergy or medication issue).

As our migration nation increases the multicultural base (25% currently born overseas and from over 300 Territories), greater levels of admissions will be from people who might find the standard hospital food menu very unfamiliar and unattractive, thereby rejecting food intake and restricting recovery. If unwell patients refuse/reduce sustenance they stay in hospital longer or develop complications and may even bring on an early end-of-life scenario.

As an example, recent research undertaken by Beyond Blue showed people from China with a Mandarin backgrounds are more than twice as likely to suffer dementia and revert to traditional ways. How will they respond on standard hospital foods.

Many nursing homes, including respite facilities, likewise totally prevent privately prepared food entering their grounds, saying all must be prepared in their kitchen by staff.

19 Record on hospital meal sheets what the unwell patient (not those functioning ok) did and did not eat, so dieticians and others have a record of intake, rejections, preferences, food trends and deter theft. If one staff member takes the untouched ice cream to give it to another patients, it should be recorded, so it is know by others the original patient did not eat anything rather than assuming they are on the mend because the ice cream was eaten.

Special attention should be made immediately where food is being almost totally rejected, especially when the patient is stating why, to gather the evidence to look at the cause and not just the effect. For many, untypical rejection of food is a major flag something is wrong, either medically or the patients will to live is shutting down.

20 With the advent of the internet and Dr Google, potentially many patients and their families will have a greater need for information about the diagnosis and treatment options, and compare this with their own 'research'. Currently 1 in 20 of all Google searches are for health related topics.

This should not be seen as either a negative or positive things. All levels of clinicians and caregivers need assistance in being open to input and contributions that are potentially positive. Likewise they should also be equipped to handle less constructive suggestions that are neither evidence based nor clinically proven.

There may also be times where questions are being asked by a family member who is a well-informed clinician, where undocumented protocol suggests they do not wish to intervene, but feel there are some shortcomings in the care being provided at this critical time of end-of-life. How can this be exchanged in a positive and constructive way.

The father of my sister-in-law is also currently dying from kidney failure. Her son is a young doctor doing additional studies in radiography at the same hospital his grandfather had his last stent surgery. When as part of his role he reviewed the x-rays across the weekend shift, he identified his grandfather's soon to retire surgeon had placed the stent into the wrong kidney. It was a Sunday and early intervention might be called for. He phoned the surgeon at home on a Sunday and was given a significant spray for his troubles. As soon as the surgeon retired a case review occurred and the error corrected and all is well again.

Obviously the elite hierarchy in health still needs to be addressed. How can the bona fide concerns of a junior for the life threatening actions of a senior, be raised in a forum where the person flagging the concern is not going to be punished, in either obvious or hidden ways. Greater recognition of end-of-life choices might mean certain clinicians make different interpretations of medical situations to their colleagues and there may need to be a robust mechanism for appropriate constructive peer review.

21 Health service boards should be reviewed to confirm at least 50% of its members have a relevant professional skill, and if the balance are essentially community representatives, they actually reside in the spread of regions across the catchment of the entity and are representative of those communities ie young/old, male/female, etc.

Board members should be rotated throughout the sub-committees and no Chair should endure beyond 6 years in the role. CEO's of health entities, especially smaller ones should have contracts not exceeding 3 years x 3 for a total of 9 years duration to encourage excellence and currency. I have experienced too many 'comfortable' relationships where questionable activity, and inactivity, have been ignored.

Each board should have an accountant as the Treasurer, not simply a well-meaning elderly citizen. Entity auditors should not be the same organisation undertaking the day to day financial transactions due to actual or perceived conflicts of interest. Entities with Government funding in excess of \$2m should employ an accountant even on a part time basis to gain the professional skills, rather than have CEO oversight and contracted accounting/audit firm, again for better risk management.

I spent a year trying to assist the potential care provider my mother-in-law with dementia might one day reside with. Part of that, trying to demonstrate they needed to secure their income sources by claiming their appropriate entitlements and minimise unnecessary financial waste. All of which would have no impact on service delivery, but improve viability.

One example was to loan them a 40' shipping container to eliminate the storage fee they had paid for years while wondering about building a shed onsite. After 2 years free usage I asked did they want to return it or buy one for \$3,000 (and later re-sell it). After a further 6 months deliberation their solution was to return my container and hire 3 x 20' shipping containers at a cost of \$38.50 a week each (= \$6,006 a year).

A proper financial performance audit of health entities, moving up from the smallest and to the larger ones and learning along the way, would give them all the same chance to improve performance and reduce excesses, as do clinical reviews. The cost of the exercise would be self-funded many times over by the cumulative savings. Funding for health is in short supply and the tax base is reducing further.

Reducing non-labour costs can be achieved without impact on service delivery, especially while learning and refining strategies as you progress from small entities to the larger ones. Imagine the value of savings just 1% of non-labour expenditure across the health network and delivering additional health services with it.

Entity Policies and Procedure should be in a board schedule for revision in a 24 month cycle, with each meeting addressing 1/24 of them. These are easily timed to relate to like topics ie finance around budget and FBT time, HR around Christmas, clinical around accreditation etc.

Unresolved meeting items should remain on the upcoming meeting agenda. Meetings should be convened across all major regions of their catchment, not just one token meeting once a year away from the usual base.

CEO's performance and remuneration should be reviewed by the whole board, not just a cosy sub-committee. Key performance data should be presented in formats that actually show what is going on and is actionable.

I have seen boards discredit State circulated performance data claiming it is irrelevant, and pay a CEO's performance bonus for delivering a \$500k surplus as projected in the start of year budget, when in fact the entity significantly overspent and under-delivered throughout the year. It presented the appearance of a surplus by simplistically taking up a fully four years government grant in June for a new service, meaning the shortfalls would be delayed.

I also question why it is board positions need to be applied for through the CEO (who might vet them) rather than directly to the Board. Why is it that membership to boards of health services (which are not remunerated), that rely on government funding to operate the entity and are not posted directly by the Minister; when boards of the likes of Water authorities or chairs of Cemetery Trusts (which are remunerated), that derive the bulk of their income directly from consumers fees and are directly appointed by the Minister as a political process.

All of the above would deliver better quality health services.

22 When residents in government funded high or low level aged care beds stay for an extended period of time at the one facility, the level of remuneration paid by the Government reduces. They could be patients with high care needs and the reduction in funding needs to be avoided. The effect of this has been that some entities exchange frail aged patients between facilities or entities.

These are often, but not always, people with few regular visitors, so who will complain. The impact on the patient however can be significant, with an unacceptable percentage becoming so emotionally agitated that they die. This happened to my mother's aunt Mavis, after being exchanged from Camperdown with all her friends in the nursing home, to Colac some 50 minutes away.

The Coroner is apparently alerted in cases where the 'new admission' dies within 24 hours, but Mavis lasted just beyond the timeline. When I took up the matter with the Colac Area Health CEO, the reply simply said she was frail and aged, and "...it was her time". They determined 'her time'.

I would like to see the Coroner maintain statistics on all aged care deaths within 30 days of an admission from another facility, to get an evidence based assessment on the impact of this practise beyond the initial 24 hours. Other forms of agitation include constant turning of the frail aged in beds day and night when they are not at risk of bed sores. There may also be the risk that patients with few visitors, receive poorer treatment.

23 There have been leading international studies that show how well residents of high level aged care facilities respond to human contact, especially one-on-one conversation and skin contact like a hand rub. These studies have also recorded the average actual one-on-one communication in Australian facilities to be as low as just 6 minutes per day, with most of that during drug administration. To achieve better clinical outcomes, there should be training in this area and a section included on health care plans to record the actual times of daily contact.

24 Farmers in rural areas of Australia apparently, on average, fail to live a further one year when placed in a residential aged facility.

Is it that they were significantly more ill when admitted or that the life offered in such facilities does not offer them much appeal. What is also apparently prevalent is their slide into uncharacteristic depression, eventually willing themselves to death.

Again, we need to do more to manage appropriate mental health issues, rather than accept we are pushing some categories of senior Australians into making an end-of-life choice to die early rather than exist in a depressing environment. If rural people do fall into depression, due to the work and life experiences, they are highly efficient at taking their own life.

They know that if they visit a GP while losing their skills/health, there is a chance the GP will recommend their drivers licence be taken away, so they don't visit. They know that their gun licence renewal requires them to nominate whether they have a mental health issue or seen a GP regarding one, so they don't visit. And with one gun for every eight Victorians, they need to be able to protect themselves as they age.

They know that their health insurance policy will be suspended for a year or more and premiums increased if they are diagnosed with even a skin 'cancer', so they don't visit. They know their life insurance will be at risk if their death in the first 12 month and one day is not an accident, so they don't tell anyone what they are thinking, in case they need to go through with it.

Men over 85 are the highest rate of suicide of any group NSW Mental Health Commissioner recently said, at a rate of 37.6 per 100,000 and for 80-85yo's 28.1 per 100,000. Yet Medicare spending on mental health services for over-85's is almost non-existent. We need provide access to mental health care to this sector that is effective, appropriate and expecting success. I believe my father's premature death was caused by poor management of his mental health and associated medications.

25 Hospital Pharmacy product choice should be driven by what is best for the patient, not just cheapest or most convenient for the Pharmacy. It was very difficult to get my father's pills supplied in a different form when he was having difficulty swallowing, and simply breaking the larger ones into smaller pieces exposed the bad taste.

The delay in hospital Pharmacy issuing products needs to be documented as a performance metric. If dad attended hospital with his own long list of medications in a pre-packed blister pack for one week, why wouldn't the hospital let him administer his own while they wait for days for the hospital Pharmacy to get its act together.

As someone averse to paying too much for identical products, why is it so often the case that some widely used products sold by pharmacies have huge differences in prices depending on which outlet you buy from. Pre-packaged Moxiclav Duo Forte \$18.65 versus \$9.85, and the higher priced pharmacy refused to reply to a letter asking them why they charged so much.

If so many people are dependent on doctor prescribed medications to maintain their quality of life, why do some pharmacies systematically delay or profiteer from it.

26 Continence issues. Surveys of paraplegics have shown whilst they are generally accepting of their injuries, they have a major concern with their self-esteem, independent living and social life, with regards the adequate management of bowel and bladder function. Likewise people having an acute or aged care admission feel demoralised and humiliated if they are required to wear what is in effect a nappy.

Hospitals have access to trained Continence Nurses, but do not see them as being funded under the acute stream. They do not require acute doctors and nurses to undertake periodic in-service training in this area. The end result of this is, medications are administered that cause some patients to become incontinent or blocked.

If blocked for days, health risks increase, but there is no early intervention by hospital staff with soft options to keep things moving. Rather a harsh suppository or enema is called for days later.

For what seem economic reasons, hospitals and linked residential aged care facilities insist on using disposable type underpants with a pull through absorbable pad. These dislodge easily and are uncomfortable, and feel like you have a 'full nappy' if you try to walk around with them on. There are plenty of fitted pull up options on the market to cater for all sizes and mishaps.

The health sector should consult with its Continence staff to guide usage of products in this area. Suppositories and nappies etc are demoralising and depressing, and could contribute to tipping someone into make an end-of-life choice.

27 Establish a Government backed 'essential items' loan plan to help genuinely necessitous aged, disabled and those on welfare to purchase necessary household goods such as washing machine or fridge, or home safety modifications (anything a Sherriff would not reclaim in a Warrant) at the prevailing Federal Reserve Cash rate ie 2%.

It is apparently commonplace for the aged to fear having insufficient income to live and opting for self-harm as the only way out. There are a raft of cut throat entities who market products like 'consumer leases' and charge an effective interest rate of 884.34% (The Age 12/09/15) even though they are guaranteed repayments direct from Centrelink and Pension payments. Radio Rentals was also recently cited as receiving many \$Millions via social and family service payments. Others are 'payday lenders'.

Government entities like the TAC in many cases pay for clients to have their soiled linen picked up by courier, taken to a commercial cleaner, and couriered back at a huge cost. The depreciation cost of providing a \$1,000 washing machine and dryer over five years plus electricity and detergent for six washes per week amounts to around \$2 per wash, which is approximately only 10% of what the commercial laundry/courier arrangement is.

A Centrelink recipient ended up paying more than \$3,000 for a \$345 clothes dryer. Multiplied by how many washes, by how many people...The savings to Government could be many \$millions and administered through contracted not-for-profits already offering seed funding to the desperate trying to avoid the excessive profiteering.

The program could be extended further into the likes of prepaid funeral, where instead of undertakers gouging \$200 plus on sign-up and 12.5% on deposits only to find that if the balance is insufficient to cover actual costs the estate has to foot the difference. In these cases you could create a deposit account product with tax exemption, capped to the value of a funeral quote. Even part of social security payments could be directed to these, for piece of mind.

The Australian Household Expenditure Survey into people's spending habits showed people with the lowest gross income spent roughly the same percentage of that income as the highest gross income earners on education, medical and health expenses, and domestic fuel and power. Yet they needed a far higher percentage of their gross income to pay for housing costs. It is these housing related expenditures at 22.5% that become the greatest burden and drive poorly resources people with few options to waste money on extortionist financing costs that the government unwittingly pay for, leaving less for essentials like food and health.

28 Just as Food Safety Standards do not apply for family functions or school fetes etc Codes for wheel chair ramps requiring a 1:17 gradient at private homes should be exempt, since it is for a private benefit and the risk is low. Currently if you contact a Contractor to create a ramp at home it must be to code regardless of how practical that is.

Some elderly also feel the long ugly ramps make them vulnerable by telegraphing to thugs that a fail easy target resides at the house. As a consequence, many seniors defer their installation until it is too late and they fall down their steps and find themselves facing an end-of-life admission.

Alternatively they attempt their own non-code installation, which is riskier for themselves, visitors and attending emergency medical staff. As noted in another suggestion, many elderly suffer because of a mental condition whereby they believe they have insufficient funds. Please see my suggestion regarding low cost loans for 'essential items' etc which could be extended to include home modifications undertaken by otherwise unemployed/underemployed over 50's Grey Army type skilled tradespersons.

29 Older people and those with disabilities may need assistance with technologies that keep them feeling safe and connected within their communities. Even 2/3rds of residents in the 2300 retirement villages are female and feel most vulnerable. Products like First Alert Personal Alarms are a great safety product for the aged and comfort for their family, although apparently some only send a voice message to 000, which 000 are not obliged do not respond to. Others fail to function once you leave the house.

Another enabling technology that could be rolled out is a basic PC's linked to the home phone line to access SKYPE to keep residents connected with loved ones. Done cheaply using old PC's or basic tablets, it would also give them access to GP's for consults when they are unable to attend clinics.

The uptake of computer technologies by the over 65's has been limited, since for many, it was never a feature of their working life. Governments need to recognise that relying too heavily on computer accessed systems is problematic as the MyAgedCare has shown since July 2015. If you don't get it

right, they won't support it. If they have has experience with Centrelink automated phone services which have showed 29% of callers waited over 30 minutes to be answered, then government automation is loathed. More beta testing by people unfamiliar with these technologies and applications should be undertaken before their role-out, if you seriously want people to utilise it in maintaining their health care.

30 Establish a state, then national, on-line register of all suicides, and attempts, drug overdose misadventures and the likes of single occupant vehicle accidents fatalities and near misses. Most people are not aware of the size of the issue and trends need to be better identified, analysed and responded to.

End-of-life choices should be a focus for people suffering from incurable physical ailments, not the likes of unresolved, inadequately treated mental health conditions. The public needs to know these things because the loved ones are the people in the front line of responding to situations as they evolve.

Past analysis of Avoidable Death statistics seems to be unnecessarily delayed, and does not delve deep enough into the potentially contributing factors such as education, employment, social connectedness, family, etc that contributed to these health outcomes.

31 Early recognition of pending demise in the final days gives a greater chance of having a Christian or other religious leader, administer last religious rites to the dying person. Ministers such as priests are becoming scarcer on the ground and supporting larger areas of parishes. Without sufficient notice, they might arrive too late, or if too early might frighten the patient unnecessarily.

Likewise, the earlier patient and family members can be alerted to the fact the scales are tipping against a recovery, the more time they have to prepare themselves, fly in for visits and get their affairs in order.

32 In the case of a fatality, the Police system should not flag the deceased had any record of mental illness, to prevent the risk of the Officer completing the initial on-site investigation being prejudiced in what they review and record. My sister's partner died in a motor vehicle where his car collided with a truck. In reading the Police report, the first Officer on site identified the deceased had issues and believing it was straight forward, passed the investigation onto a junior Officer directing traffic 3km away to write up his first accident finding a clear case of car driver error, possibly suicide.

The family believes the deceased was stable and happy at the time, and the condition of the faulty road edge at the intersection may have contributed. It was never commented on by the Officer completing the report. When I visited the site just hours after the body was removed, the poor condition of the road verge was obvious and an hour later a repair crew appeared to grade in gravel along the road edge to repair the fallen away section. The driver of the truck was not blood tested, or his Log Book recorded.

Pre-judgement of persons with a past or current mental health issue remains a problem.

33 Drug and Alcohol. In Victoria 1 in 17 people tested positive for drugs, and 1 in 424 people tested positive for alcohol. Currently there is political and media appeal in campaigns against Speed and Ice, but the problem is a sign of broader social issues such as unemployment and is requiring huge volumes of resources. More than half of all road fatalities are now recording drugs in the system, not alcohol. Almost 25% of the population will suffer a substance use disorder in their lifetime.

The recently signed Trans Pacific Partnership agreement provides state and federal governments with the opportunity to tackle tobacco companies without the risk of litigation from restricting the trade in cigarettes. Many of the drugs of choice like ice and cocaine are absorbed by smoking. The uptake of smoking by today's youth may be dropping, but for someone seeing smoking as rebellious and cool thing to do, it makes it an easy step across to instantly addictive drugs.

There is a huge amount of data held by each Health Department and related NGO's that shows the personal, social and budgetary cost of tobacco smoking and medical procedures. Frankly the government's first world response is pathetic and hypocritical allowing tobacco, but crack down on other smoke ingested drugs.

What I propose is a state and federal coordinated program to lift the legal age of sale of tobacco by one year each year from 2018. This would mean that in 2018, if your proof of age showed a birth date from 2000 onwards you could not access tobacco. In 2019, the same mandatory 2000 rule would apply, meaning then only 19yo's could purchase. In 2020, 20yo's etc. Eventually smoking would die out, as would the pre-cursor to smoke other drugs.

Tobacco companies would have little fallback, given they still have the aged market they had pre the change and it is only their product that is killing of their customers. Any under aged person smoking at all would be in breach of some tobacco or drug related law.

34 All health care facilities receiving government funding should be subject to publishing their performance monthly on the Net to help transparency and guide choice. The CEO of GMHBA said recently "There is no correlation between the cost of the service and the quality of the service". "What we end up with is a very disempowered consumer of healthcare. They don't know much about the quality of the provider, the outcomes, the average length of stay, the infection rates, the out of pockets – in fact they know nothing."

In the case of residential aged care providers, it would assist residents and potential residents. Residents, families and staff reviews could be like TripAdvisor. Staff and qualification ratios to patients, age of facilities, menus from the past four weeks, record the actual number of people attending outing, not just that 5 outings per week were offered (but only one occurred and it had only five people on it). Ratio of volunteers, average Bond rates, daily living fees, extra fee items, length of stay, and frequency of GP visits, etc. Names of owners, post discharge reviews by families after their loved one left.

Nurse-to-patient ratios have been in place around for 15 years, but do not apply to private and not-for-profit aged care facilities, so ratios should be published. Key performance figures should demonstrate how entities are addressing the greatest emerging needs – health services for the aged and those targeting the prevention and management of chronic disease in a scalable and sustainable way.

35 There is currently a TV advertisement promoting more places for youth specific residential aged care facilities. These need not be a whole dedicated facility, but perhaps 15 beds of 120 bed facilities throughout key areas of the state. This would be scalable, flexible and sustainable. Facilities need to be close enough to the client's family and friends, that they continue to visit and support, hence no need for a single mega multi bed facility that people would age out of anyway. NDIS models whereby huge levels of costly supports are rotated into a single person's house seem excessive and isolating by comparison.

36 Recently it was announced Southern Cross Care would be building a 90 bed facility at North Williamstown on a parcel of land acquired by the Aged Care Land Bank. Since 2006 the land bank had secured strategic inner suburban sites for aged care where land cost/availability was preventing not-for-profit aged care facilities close to the city. Available land is an issue not only for communities close to the city.

Victorian Planning laws should factor in sufficient land and changing land use needs in Local Government Planning. There are plenty of suburbs where a lack of foresight lead to the sale of government school sites as populations aged, that turned into housing and now there is a shortage of community and aged care facilities. LGA's should pre-plan aged care sites, near day care, schools, parks, open space, sportsgrounds, shops, transport routes. This is just like planning for ring roads, economic development, Council offices and should be part of the standard fabric.

Expending money on community infrastructure should mandate broad community access not just for a single tenant. Sports clubs should be able to use shared meeting rooms, food preparation zones and public toilets. And why can't the bird fanciers, motor sports, artists, wood workers etc have a lockable bookcase for their members on the same site. It is as excessive as church's having a building used one hour per week, and wanting public funding to contribute.

Public money could go further and more people benefit from the social interaction and connectedness to the community to maintain their health and wellbeing.

37 For new housing development, models should consider at some point in time that the communities will age and want to move to smaller homes still within their communities. For security and commonality, often surrounded by others of a similar age. Homes need to consider ageing in place, few steps and risks of falls, close enough to residential aged care facilities to transition. Ideally located within walking distance of basic shops or public transport.

Relying on the private sector to retro-fit this into ageing suburbs is expensive and problematic. Many also have unfair entry contributions, plus monthly service fees taking a huge slice of their pension, plus deferred management fees and you must sell through their agency at set fees on exit. Some structure the entry contribution to be below \$150,000 to avoid the home being in an asset test and gain rental assistance for what is essentially just a right to occupy.

Sufficient land held for strata title one/two bedroom self contained units would be more financially viable. Even people on Newstart in suburbs like Ringwood are paying \$250 a week rent for a one bedroom unit, which represents 90% of their income. Established suburbs are awash with ageing single and dual occupancy residents in three bedroom houses, not wanting to leave their familiar surroundings, and not having options.

38 Greater consideration should be given to the loved ones of the deceased when they nominate a desire to view their dearly departed as early as possible after being phoned and informed of the passing. I arrived with my mother at 11pm (1 ½ hrs after being called) to see Dad for the last time and found him almost unrecognisable with both sets of dentures missing and his collapsed jaw gaping wide open. I remember years earlier taking my Mother-In-Law to see her late husband and sensing he was soiled.

Another assault on the senses was the presence of two Police apparently at the doorway to the room to collect the medical record for the Coroner since Dad had died within two weeks of surgery. Dad's body then had to be whisked away to Melbourne.

I was not able or prepared to collect Dad's personal effects from his room, and had to return the following morning before dropping the kids off to school, in a distressed state to collect them while the ward was a hive of activity. Yet assumedly early enough as to allow the support staff to prepare the room for another patient that morning, and the facility to claim an additional 'bed day's' funding.

39 Last year I was asked to be the Executor for a friend of mine who passed away a few days later and who only prepared his Will nominating me a short time before his passing. Fortunately I was able to establish the existence of an earlier Will with no inconsistencies and therefore less risk of challenge, with both passing all net assets to his surviving spouse.

As end-of-life approaches some people want to make revised nominations. I have also seen a prevalence of significant bequests to the last few not-for-profit or public organisations that provided care at this vulnerable time such as District Nursing, Palliative Care, Cancer Clinics. Potentially some are affected by their illness and medications. The choice of end-of-life medications may also influence this.

There needs to be a simpler and more predictable legal mechanism to determine under what circumstances challenges to Wills and bequests made in the last 12 months of life, can be made and would be likely to be successful, to deter greed.

40 I would like to see the establishment of a state wide set of specialist volunteers from retired CPA's and Lawyers etc to help recently bereaved navigate funerals, wills, Executors, Coroners, personal alarm monitors, single person concessions for Rates, Drivers Licence, Phones, Postage stamp concessions, electricity etc and stop telemarketers/door knockers switching utility service providers. Or perhaps set up a checklist with weblinks on www.myagedcare.gov.au .

My mother-in-law (with dementia) was even fined for a late payment when she sent the wrong cheques with the right remittance advice when paying multiple invoices. The biller didn't bother returning the cheque to alert her, just the fine! Many recently bereaved are capable of handling their own affairs over time, but others stress significantly which could lead to hospital admission and a downturn in their own health.

41 Why was this Parliamentary Inquiry not advertised more widely for public submissions, rather than seeking mainly presentations from clinical bodies, or as in the case of the Geelong hearing just 19 professionals. And why was it listed under the Victorian Parliament Inquiry subset of Legal not Health. Is its focus mainly on the legal protection of State and clinicians supporting assisted deaths, and overshadowing aiding people's health? This is something that will impact all of the general population and requires bi-partisan input, and the broadest possible input.