SUBMISSION TO: Parliament of Victoria, Legal and Social Issues Committee Inquiry into End of Life Choices

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This submission is a report of the circumstances surrounding the illness and death of my father, Alan Stewart, how he wished to die, and how – and why – those wishes could not be realised.

ALAN'S LIFE

Alan Stewart was born in England in April, 1931. The eldest of five boys, he survived peritonitis secondary to a burst appendix in childhood, no mean feat in the pre-antibiotic age. He enlisted in the RAF as a young man, where he served in the Middle East, then worked as a forester and a teleprinter operator. We migrated to Australia in 1969, as £10 poms. Alan worked as a postie in Australia. Always moderate in habits – never a heavy smoker, he quit in his early 40s and he was careful to keep his weight under control – he enjoyed robust good health, with his only medication being for non-allergic asthma. He enjoyed an active and fulfilling retirement, with a wide circle of friends, hobbies and interests, and on a weekly basis volunteered his time and skills to several community organisations.

ALAN'S ILLNESS

Then at Easter 2012, around the time of his 81st birthday, Alan was diagnosed with melanoma. He had the presenting lesion surgically excised from his neck, after which he was followed up with what he described as a "full body scan" and was given the all-clear. I was living and working in Adelaide at the time; as was typical of Alan, he did not inform me of his diagnosis until he'd been through the process of surgery and follow-up investigations (he didn't want to trouble me or interrupt my work, he said). While we were both alarmed and anxious he nevertheless felt that he'd dodged a bullet in being given the all-clear. He had follow-up scans every three months, again with the all-clear being reinforced after the scans did not show any evidence of metastases. So we continued with our lives, me in Adelaide, dad in Brisbane, speaking at least fortnightly by phone (as we had done since I left Brisbane for Adelaide in early 2012).

Then I rang on the morning of December 25th, to extend season's greetings to my dad. He then broke the news to me that he had suffered some kind of neurological event a few days prior. He was in the garden, found himself unable to stand. A neighbour came to his assistance, and he was transported to his local General Practice, after which he had urgent brain radiography. That scan revealed several lesions in the occipital region of his brain. He was informed that the lesions were likely to be metastatic melanomas, and that his prognosis was poor. He was given an appointment to see a specialist (who, as I was later informed, no longer sees melanoma patients, so on his return from leave in mid-February would have simply referred Alan on to another consultant).

So that's how I found my dad on Christmas Day, languishing at home, awaiting a specialist consultancy in February. His illness had chosen a most inopportune time to manifest itself, just before the country heads off to the beach for Xmas through January. Unhappy with this situation, I made some phone calls, got through to the on-call oncology registrar at the private hospital where Alan had gall bladder surgery some years previously. This registrar arranged for Alan to be admitted that day so he could be assessed; my nephew drove him to the hospital. I then made arrangements to fly to Brisbane so I could spend time with my dad.

During his stay at this Brisbane private hospital, Alan saw a locum oncologist, who Alan said was kindly, sympathetic but nevertheless straightforward in explaining that his condition was very grave, and without treatment he was likely to live for only two months. The oncologist held out the option of having a course of palliative radiotherapy, which might extend his time by a few more months. Dad was willing to undergo such a treatment, after both he and I were assured that the likelihood of side effects such as nausea and vomiting would be minimal, and with Alan's full understanding that this intervention would be palliative, not curative. But before that treatment could commence, Alan needed to have a diagnostic scan in order to exclude the presence of a different kind of cancer that may have explained the presence of the cerebral lesions (it being inappropriate for Alan to undergo a brain biopsy in order to confirm the diagnosis of metastatic melanoma, a decision with which we all concurred). And thus began our travails in attempting to interact with an Australian health system during its January go-slow.

This diagnostic image (a PET scan, from memory) required a trained technologist to operate the scanning machine, and none was available in the last week of December or early January. So we waited at Alan's home, and proceeded with other aspects of his life and dying: arranging his financial and legal affairs, receiving visitors and well-wishers from Alan's circle of friends and fellow volunteers, an outing to a favourite restaurant. And much reminiscing, sometimes until the small hours. I am particularly grateful to have had these weeks to spend talking with my dying father – to learn and relearn about our family, about our many shared impressions about how the world works, and our few diverging opinions of same. But while waiting to get the call that a scanner technologist was available, Alan's condition continued to deteriorate. His declining visual acuity in particular made it increasingly difficult for him to use his computer and follow a TV screen. And his mobility became increasingly – and quite rapidly – impaired during the first weeks of January. Frequent phone calls only resulted in continuing disappointment insofar as a technologist could not be found to run the PET scan. So this combination of his rapidly declining health and the holiday-related inertia that stymied our attempts to proceed with a medical plan came together in Alan's mind, such that he asked me to explore, in his words "…the euthanasia option."

THE EUTHANASIA OPTION

Alan had long been an admirer of Dr Phillip Nitschke and his work with Exit International and Dr Rodney Syme (V-P of Dying with Dignity Victoria), as have I. But like many individuals, including elderly folk like Alan, while in good health the focus is quite understandably on living. So while Alan supported Nitschke's and Syme's work and philosophy on death and dying, neither he nor I had taken any practical steps to consolidate that support at a personal level and to prepare for the possibility of actually needing to implement any of the steps that are presented and detailed in Exit International's publication "*The Peaceful Pill Handbook*".

That evening, when Alan first expressed to me his wish to explore "the euthanasia option", I asked him to confirm that he would like me to contact Exit International. Which he did. So I made a call to EI; as it happened Dr Nitschke answered the phone, and after briefly outlining Alan's condition, Dr Nitschke advised us to read PPH and to discuss the various options therein. Dr Nitschke was also careful to emphasise (possibly after discerning my naivety here) that assisted suicide is illegal in Australia, and that the available penalties for transgression are severe and daunting, with lengthy custodial sentences a distinct possibility.

So I took out a subscription to *The Peaceful Pill Handbook* on my father's behalf, and I sat down to read and discuss the contents with him. It was clear that Alan would not be able to avail himself of the opportunity to procure and use Nembutal, not least because of the uncertainties surrounding delivery times, possible interception of the consignment by Australian Customs, and confirmation of pharmacological integrity, but also because his vision was impaired to the extent that he could not place an online order for the drug. Likewise Alan would not be able to procure and assemble the equipment required for a hypoxic gas inhalation method. He would not permit me to risk prosecution and imprisonment in order to help him with his end-of-life choices, so after much deliberation we elected to pursue the option of palliative care, but understanding the inherent loss of control that decision entailed (where decision-making on end-of-life options must essentially be surrendered to medical practitioners, who are legally constrained to only treat and manage signs and symptoms as they present; also the degree of sympathy or antipathy towards voluntary euthanasia by individual physicians and other workers at the selected palliative care centre – or perhaps the only available centre – cannot be predetermined).

"NO MORE TREATMENT"

Alan's condition continued to deteriorate, such that it became increasingly difficult for him to mobilise. We rented a walking frame from a local pharmacy, which helped, but he needed assistance to get in and out of bed, to the toilet and shower. I was happy to provide that help. Meanwhile, still no scanner technician. One day early in January, Alan resolved to abandon the option of palliative radiotherapy. He was shocked by the rapid progress of his illness; in his words: "Well, if the treatment holds the cancer at bay for a while, I'm going to have to go through this all over again." What he meant by "this" was his diminishing independence, loss of mobility, failing vision and, by this stage, the beginnings of cognitive impairment, manifesting primarily in an occasional but evident alteration in his verbal sentence structure, with looping and repetition. His quality of life was declining so quickly that he declared that he wanted no more treatment and did not wish to keep his appointment with an oncologist. He clearly and emphatically stated that he wanted no more intervention – including pharmacotherapy – that might prolong his life.

One important feature of Alan's illness in January 2013 was that he did not report any pain. Aware that he had space-occupying lesions in his brain, my several-times daily interrogation of my dad in this regard: "Dad, have you got any pain?" "Dad, have you got a headache?" was always met with a negative response. He frequently referred, when asked about pain, to a "thick" sensation in his head, about which he seemed unwilling or unable to elucidate, but he always denied that it was painful. We discussed this in some detail; I wanted to be sure that my dying father was not attempting to suffer in silence. But Alan did not have any particular history here; throughout his life, he did not have (in my opinion) a low pain threshold; neither did he present airs of false bravado. He seemed to deal with pain (for example, after surgery on the melanoma in his neck) appropriately, understanding that its diminishing intensity over time was a sign of normal wound healing. But Alan knew he was dying, and that the growing lesions in his brain would soon exert their grip on him. So when he denied suffering headaches, I believed him.

But back now to Alan's stated wish in early January of 2013 for his death to occur as soon as possible. Again, because my dad and I had ascertained that he was not able to procure Nembutal or the gear needed for a hypoxic inhalation without assistance – and any such assistance being illegal, with severe penalties – we decided to take our chances with palliative care. We hoped that he might then be prescribed a cocktail of opiates and benzodiazepines that could facilitate the transition from his life of diminishing independence and cognitive impairment through to his death. But here's the rub. Because the spectrum of his suffering did not encompass headache or any other physical pain, and knowing that palliative care physicians are legally obliged to treat presenting signs and symptoms, I told my dad to tell the palliative care team that he was suffering headaches. But with so many other things happening around this time, we didn't get to work out a code so that I could discriminate between a "headache" that was for the benefit of the palliative care team, or the very real prospect that at any time my dad's growing cerebral melanomas might cause him genuine pain. So it was that one Saturday morning, when I asked him whether he had any pain or headache, he answered – for the first time throughout the course of his illness – in the affirmative. "Yes, a headache" was his somewhat hesitant response to my regular, by now routine interrogation of my dad's pain status. So I got him into the car, and we drove to the emergency department of the aforementioned private hospital. Thus began another sub-chapter in his less-than-satisfactory encounters with the medical system.

THE WRONG ANALGESIA?

On Saturday January 5th 2013, Alan was seen by an A&E registrar. We explained to her that Alan did not wish to have any further treatment interventions, including palliative radiotherapy. I had brought to the consultation Alan's brain CT scan from late December that had informed the diagnosis of metastatic melanoma, as well as his Advance Care Directive. But this registrar, who seemed distracted, possibly disinterested throughout the consultation, refused to consider prescribing any analgesics until another CT scan had been completed. I started to argue the case with her, but Alan intervened and said that he was OK to have the scan. Thus informed by the updated CT scan, which predictably revealed further progression of his cerebral metastases, the registrar duly prescribed Panadeine Forte, this being a compound pharmaceutical containing paracetamol and codeine phosphate. I'm not sure whether this over-servicing (an unnecessary CT scan) was an example of defensive medicine or whether it was simply a routine income-generating tradition involving the corporate radiology provider. But we then drove home, stopping on the way at a pharmacy to have the prescription dispensed.

Coincidentally, while waiting in the car for the prescription to be filled, Alan complained of a burning sensation in his upper chest. Prior to this event, as we had only discussed the possibility of headaches – whether real or fictitious, as discussed above – I had no doubt that this symptom of a distressing burning sensation was genuine. I strongly suspected that this was a side-effect of the dexamethasone therapy that Alan was taking at the time (corticosteroids steroids have strong anti-inflammatory properties, and were presumably prescribed here to reduce the impact of cerebral oedema. However, steroid therapy can be accompanied by a diverse range of unpleasant side-effects, including pain resembling acid reflux). I took the decision there and then to get my dad off dexamethasone, reducing his dosage by half, and further tapering it over the ensuing three days (I was aware that abruptly terminating steroid therapy can have unintended, adverse outcomes).

So after explaining my proposals to Alan (to taper off and then cease his dexamethasone therapy, because of the likelihood that the steroids were causing the burning pain in his oesophagus, and starting him on regular doses of analgesics) with his consent that's what happened. But in retrospect, the analgesic therapy was a mistake. He quickly became constipated, a condition that continued despite aggressive soluble fibre therapy until his death some two weeks later. Codeine in high doses is notoriously constipation-inducing; I was, to my continuing regret, aware at the time of the propensity of codeine therapy to cause constipation.

ALAN CHOOSES TO DIE IN HOSPITAL

The week commencing Monday 7th January 2013 was a period of increasing activity, with arrangements made for Alan to arrange his legal and financial affairs, and with medical and nursing services beginning to trickle back to functional capacity. After a rather circuitous and challenging series of telephone calls the week prior, I managed to have a palliative care team visit Alan at his home. Arrangements were then made for a visiting nurse to assist with a daily shower. We had detailed discussions about end-of-life care, with a hospital-style bed being brought into the house, and visiting nurses to help me with his care and management. That was my preference, and I explained to my dad that I was very willing and capable of looking after him at his home. But later that week, at the palliative care team's second visit, an offer was made of a bed at a Brisbane terminal care hospital. Alan emphatically accepted that offer, despite my reservations. And so it was that on Friday 11th January, Alan left his home for the last time.

My principal recollections of Alan's first days in this hospital are of his distress at being constipated. I assisted him to the toilet adjacent to his room; I think that when I did this – with difficulty, as his lower limb function was by now very limited; he could not support his own weight – it was the first time he'd managed to sit on the toilet there. The nursing staff presumably were not permitted to risk an occupational injury by performing the task that I took upon myself to do (which I have no particular complaint about; back injury amongst nurses is a very real issue, and relevant OH&S principles and practices are there for good reason). Anyway, to no avail; his constipation was by now severe and unremitting.

My dad then began refusing to eat. He was by now confined to bed; it was too difficult for me or anyone else to help him out of bed. One recurring image I have of these few days before the medications rendered him insensible was of my father fixing me with a haunted stare, holding his index and middle fingers against his temple, thumb cocked in an easily recognisable mime, and asserting in clear, firm voice the single word: "BANG!" He did this three times that I can recall over these few days. He packed a lot into that small pantomime act, as we both understood it to be a rhetorical gesture; neither Alan nor I had much regard for guns or gun culture. It certainly wasn't a humorous gesture. Grim irony at the hopelessness of his situation, I guess.

Alan slipped into unconsciousness as he was prescribed opiates and benzodiazepines, along with high doses of dexamethasone, by subcutaneous infusion (from memory). I'm not sure when or for what reason these drugs were prescribed; the medical staff in this terminal care hospital never took me aside to discuss a treatment or care plan (although it is possible that they may have done so with my sister). I saw his assigned consultant only briefly during ward rounds. Over this last week or so of his life he became unresponsive to verbal stimuli, did not move his limbs, developed a Cheyne-Stokes breathing pattern, and died in the early hours of 22nd January 2013.

AFTERWORDS

Now some reading this account may feel obliged to observe that Alan's decline and death was, in the scheme of these things, a relatively easy transition insofar as he only had a month from when his cerebral metastases fully manifested in the form of a mini-stroke just before Christmas of 2012. Maybe so; and I don't doubt that many experience a more prolonged period of pain, incapacity and suffering. But that's not really the point of this story. And besides, none of us – Alan included – knew at the time just how little time he had left, in particular how long he would need to live after having organised his affairs and said his goodbyes. Death is rarely a calm, orderly process, and certainly my dad's dying was suffused with sadness and unpreparedness. Again, he was fit, active and fully engaged with the world and with living through to the end of his 81st year. I had every expectation that he could continue that way for another decade and more, and I certainly encouraged him to take that view. But we also both knew that death can arrive unforeseen. Alan met the rapid decline in his health and independence with dignity and courage, albeit tempered with disappointment and a sense of foreboding. But at home, in the days before he took up the palliative care hospital bed, he expressed the sentiment that "All this…" (by which he meant all the arrangements we were making at the time for his end-of-life care) "… is so unnecessary. It would be so much better if we could have a family gathering, share a meal and some good wine. And then I could drink the potion and fall asleep for the last time."

What vexed Alan most about dying was his loss of independence and concomitant loss of control over decision-making. As I have tried to outline above, I was never fully satisfied that he suffered headaches as a result of his fulminant illness, so the principal self-justification for palliative care (that good palliative care can adequately manage pain) didn't really apply in his case (though it remains entirely possible that he did spend his dying days suffering the discomforts of constipation and gastric acid reflux-like symptoms, these likely being side-effects of codeine and steroid therapies respectively).

So in the absence of legally-sanctioned availability of a drug such as Nembutal, we were forced to submit Alan to the uncertainties and indignities of interactions with the medical system. These interactions were disparate and variable, from the young nurse at the hospital who cared for my father with remarkable compassion and calm authority (she spoke to him constantly with a gentle naturalness and complete absence of contrivance, even when he was deeply unconscious towards the end. She hailed from either Malaysia or Thailand – I did ask her once, I've forgotten which. But I'm forever grateful) to the rather odd nurse who seemed to become strangely animated and energised on the few occasions when feelings spilled over into raw emotion. One medical doctor (who was otherwise a kind, empathetic and openly informative individual) remarked, after taking a history (with the pertinent details here being diagnosis of melanoma in April 2012, followed by the all-clear from follow-up body scans until late December when his metastatic disease became manifest) "Oh, well, you got to have a whole nine months of living…" But that comment, for some reason, stayed with me. It wasn't until later that it became apparent to me that this observation was a kind of medical condescension. Sure, he did have nine months ostensibly free of the diagnosis of metastatic disease. But I often wonder how different his dying and death might have been had his GP providers arranged brain radiography. Yes, he would presumably then have been made aware that his prognosis was indeed grim, but then he – and we as a family – would have had more time to prepare, perhaps even consider palliative radiotherapy options well before the mass egress of staff for the Xmas holidays. Perhaps also my dad and I might have had time to have the conversation about Exit International and he may have been able to place an order for Nembutal while his vision and mobility were still intact. Alan was certainly disappointed by the knowledge that the lesions in his brain might have been discovered earlier. Looking back over this period, I think that both my dad and I were affected by an unease, an apprehensiveness about what might be coming for him and when. But neither of us could act on that unease without a clear diagnosis. Again, I was in Adelaide at the time of Alan's initial diagnosis; I took up a work contract there in January 2012. While I was alarmed to hear of his melanoma diagnosis a few months later, both he and I were reassured enough at the time by his GP's "all-clear" pronouncement. So I didn't travel home to Brisbane then, and even though we communicated regularly by phone and email, we didn't get to have our face-to-face conversation about end-of-life decisions until, with hindsight, it was much too late.

MY REGRETS, ADVICE ARISING

I have some other regrets about decisions I made during my father's decline, which I will outline here in the hope that others reading this may be able to avoid making the same mistakes. My deepest regret is that we mentioned to medical practitioners the fact that we had sought information about end-of-life choices from Exit International. Looking back, this was a mistake. And, to be clear, the mistake was not that we elicited information from EI – again, both Alan and I had long admired the work of Drs Nitschke, Syme and others – but that we told attending medical practitioners that we had made contact with EI. Sure, there were some doctors that were untroubled by that news, but others seemed to adopt a defensive approach, which was not helpful to our family in terms of exchanging information and participating in Alan's treatment plan. My advice here to others who may be forced to rely on the diminished-choice option of handing over end-of-life decisions to the medical profession is to keep quiet about any interactions with or advice from EI or similar organisations, unless and until you are confident that you have the ear of a sympathetic medical practitioner.

My impression of the standard of medical care for the dying, though that standard was very likely influenced by the aforementioned holiday mode we encountered in December and January as well as the compressed time-frame that my father's fulminant disease imposed on the speed of decision-making, was of a poorly joined-up system. When I first spoke to my dad on December 25th, he had been told that there was a serious problem revealed by his skull radiography, but was languishing at home with an appointment to see a consultant in mid-February (who, as it transpired, wouldn't have seen him anyway and would have only referred him on. I had to make the phone call to the private hospital on Xmas day to have him seen and assessed). Then came the saga of waiting for a PET-scan technician to return to work. And after Alan decided that he didn't want any more intervention that would prolong his life, I then took on the somewhat challenging job of making contact with a palliative care team, a task that seemed to involve a degree of luck insofar as I stumbled across a discharge planning nurse who gave me the contact phone number for that team. When we visited dad's GP practice to have an assessment of his capacity to make a will, after he'd decided not to proceed with palliative radiotherapy, he was berated for failing to keep an appointment with an oncologist (an appointment made not by the GP, but booked during the late-December hospital admission that I had arranged). The information flow between GP, hospital, consultants and ancillary services seemed to me to be poor and piecemeal. I did pose the question around this time as to whether my father might have been better served by a more integrated approach in the public hospital system, but I was quickly shot down by assurances that the public hospital system wouldn't have been any better. My experience in negotiating the assessment and treatment maze was daunting enough, and I've worked in clinical healthcare for most of my working life, so presumably families without some knowledge of how the system works (and fails) could be even more at sea.

FAMILY DYNAMICS

Other difficulties I experienced pertained to differences in approach within our family. Alan's step-daughter – my sister – was, I think, somewhat overwhelmed by the rapid sequence of events in January 2013. She is guided by religious imperatives with which neither Alan nor I were encumbered, so I think the discussions we had about end-of-life options and Exit International were rather difficult for her, though she did not overtly express opposition to Alan's wishes. While her love and concern for dad was in no way under question, she did seem more willing than I was to hand over decision-making and responsibility for his care to the palliative care team. So it was that during the last days of Alan's awareness, in hospital, after refusing food but before opiates and benzos rendered him insensible, he quizzed me about the dexamethasone treatment (terminated by me after his complaints of burning, reflux-like pain but subsequently reinstated by his medical carers). "Are these [tablets] delaying the end?" he asked me. But being aware of my sister's tendency to respond with reflexive and rather noisy defensiveness when her decisions or motives are questioned, and seeking to avoid a confrontation at his bedside, I – to my continuing regret – murmured something about the tablets were to keep the swelling down on his brain. So I didn't answer his question there; if not for those potentially destabilising intra-family dynamics, I would most certainly have questioned, possibly challenged, the need for his high-dose steroid treatment.

Religion reared its head once more within our family. After Alan's passing, I informed his surviving brothers (Graham and Richard) in the UK of the event. Graham reminded me that Alan had discussed with him some time ago, before his illness, that he would be pleased to donate his body for biomedical research. Dad hadn't gotten around to completing the necessary documentation for this to happen, and we were too preoccupied with the rapid progress of his disease to raise the topic. But I was pleased to make those arrangements after his passing; I made contact with a group at a Brisbane university that has a cadaver donation program to support their research into (from memory) road trauma and orthopaedic injury. We came close to finalising these arrangements, but my sister vetoed them when she became aware that his remains would not be present at the funeral service. Something about his spirit needing to be in the room; so we had a conventional funeral service followed by cremation.

I mention these matters here only to emphasise that discord and disharmony within a family can – and likely will – exacerbate tensions relating to end-of-life decision-making. While my sister and I didn't always manage to keep our disagreements under wraps during that January, I suspect that our family's travails were somewhat minor and understated compared to what some families endure. We didn't have major slanging matches, tantrums or other such unseemly behaviour over a dying relative's bedside. Indeed, the occasional dispute my sister and I could not avoid was viewed by our dad with – to me – surprising equanimity and barely concealed amusement. He'd presumably seen all this before; looking back on these events it reminds me that we go on living until we die. And I should also note that my sister and I seem to get along much better now than we have for a very long time. This was a surprise to me; in an unexpected way, our dad's passing has brought us closer together. But I'm not so guileless as to imagine that for some families, profound and long-standing ruptures will be either temporarily abated – for the sake of the dying relative – or reparable in the long term. My advice here – and this is likely to be gratuitous advice from someone who has lived and experienced only a very small number of the multifarious and complex ways by which families don't get along – is to try and sort out family dynamics so that the needs and wishes of the dying can be the paramount consideration. Maybe the dying individual might consider sole Power of Attorney by their most trusted family member as a way of shoring up their best interests, but again, I'm not so naïve as to imagine that such action will resolve all complications within fractured families.

CONCLUDING REMARKS: DYING WITH DIGNITY

Now to sum up. There is something fundamentally wrong about the way my father, a decent, unassuming, hard-working, law-abiding man, had to submit to the various indignities of loss of independence, fear of cognitive impairment, self-imposed starvation and the likely experience of medication side-effects in order to depart his life. He had a terminal illness, he was well aware of that fact, and he clearly and unambiguously expressed a wish to be able to leave with dignity. One day, such wishes will be routinely available to the terminally ill, when we as a community can manage to elect and hold to account parliaments that will honestly and actively represent majority opinion. Until such time, however, my advice to those dealing with end-of-life issues who do agree with the right to die a dignified death would be to inform yourselves, and if necessary avail yourselves of the means to achieve the desired outcome, in good time while you or your family member is still in control of your/their faculties. We left it too late to have this discussion. Join Exit International, and read the Peaceful Pill handbook. While it is of course a difficult topic to approach, especially for those who are fully engaged with the business of living, the book is a fundamentally humane work, full of helpful advice on how to retain as much decision-making as possible about end-of-life choices. Although the need for DIY manuals like PPH is something of an indictment on our current state of politics; again, in my opinion, access to voluntary euthanasia by those with a terminal illness should be routine. That my father, an honest and decent man, should have to consider lying to doctors about having pain and headaches in order to access treatment that might ease his suffering is a thoroughly disheartening memory.

And a particularly poignant recollection, when we were considering his end-of-life options, is of my dad apologising to me for having the discussion about assisted suicide "…after what happened to your mother…" Alan's first wife, Jean, took her own life in 1965 at the age of 32; I was nine. This was understandably a significant tragedy for all concerned, but my extended family rallied to the cause, particularly dad's wonderful brothers and their families and my paternal grandparents. I always had kindly and generous folk keeping an eye out for me at the time. Of course dad did not need to apologise for seeking to die with dignity. Any similarity to my mother's distress was not present in my mind; it is the illegality and attendant guilt and shame surrounding voluntary euthanasia and assisted suicide that led him to even consider apologising that I find offensive. We as a society should be able to do much, much better than this.

CONCLUDING REMARKS: PROPERTY INHERITANCE

Finally, some thoughts about inheritance laws. It has been put to me that one of the principal reasons why religious organisations, including the Catholic Church, are so very active in seeking to subvert dying with dignity measures is that of a slippery slope argument; that grasping family members seeking to get their claws on their inheritance might not act in the best interests of their relative. This is a conflict of interest issue, and I for one would be more impressed with the churches if they were to focus their attention on the other side of this equation, i.e. instead of denying a dignified death to individuals because of the actual or potential behaviour of would-be beneficiaries, how about we fix the problem by setting our sights on a society where such a conflict of interest couldn't occur? Imagine a world where postal workers, mining magnates and media barons alike understood that their children's ability to succeed in life would, by definition, be independent of any and all wealth and property accumulated at the end of said postie's, magnate's or baron's life. Their kids simply wouldn't be in the game.

When Alan and his wife Pauline – my step-mother – first informed me back in the mid-1990s that they were preparing wills in the event of their deaths, I suggested that they should make bequests to their favourite charities. Which they did. I've long been uncomfortable about property inheritance, which is of course a form of middle-class welfare. From my perspective, my father's advice and example for financial planning were the better gifts: "Don't borrow more than you need to, and pay down your mortgage as soon as you comfortably can." Seems rather quaint nowadays, but that approach worked just fine for him, as it does for me. I admit to being somewhat alarmed to hear young people state quite bluntly, as one co-worker recently explained to me about her friends in Sydney, that their property ownership plans are entirely based on inheriting the family home. Which to me says a lot about the housing affordability crisis in that city.

By raising this topic in the context of end-of-life choices, I must make it clear here that I am a beneficiary of my father's estate; if this makes me a hypocrite, then so be it. Yes, Alan's earlier will did leave a modest cash payment to both my sister and I, with the rest to be distributed amongst several charities. Which again, I was fine with. But the advent of his terminal illness brought about a strong desire in Alan to divide his estate equally between the two of us. He expressed a wish that, if we could manage it, he would be pleased if his house could remain within the family. And we've done that; I sold my house and then bought out my sister's share – with her complete cooperation and agreement – so I now have the privilege of living in my father's house. But my unease about conflicts of interest and potential conflicts of interest is still apparent to me. While my dad was in no doubt that I would act in his best interests during the time of his illness and dying, I was not entirely sure that everyone we encountered in the medical and nursing profession during this period thought the same way. This may have been more of a problem inside my own head, but the question still troubles me. After all, why should the medical and nursing staff we met for the first time when Alan was sick (and who therefore didn't know me) not harbour some small but lingering suspicion that this bloke's wish to see his father depart as soon as possible might not be directed by the noblest of motives? Mitigated somewhat, I guess, in our case by the very brief illness and decline that Alan suffered. But for those families whose loved one experiences a more prolonged decline, if we are ever to completely eliminate actual and potential conflicts of interest – and the perception of same – that serve to muddy the waters around end-of-life decision-making, we need to get to a place and a time where it is simply a fact of life that descendants do not benefit financially from their parents' estate. I freely admit that I don't know how or when we could get there. But setting sights on where we need to get to is at least making a start. And I will be able to take religious institutions more seriously if and when I see them advocating against middle-class welfare and in favour of death with dignity, instead of the other way around.

See our YouTube clip of Alan presenting some of his work on beneficial insects for home gardeners. Recorded about 12 months before his illness, but edited and posted posthumously. Search "AJS beneficial insects"

I thank the Parliament of Victoria for considering the topic of end-of-life choices, and for granting me the opportunity to make this submission.

[redacted]

Ian Stewart