272. H MacGillivray

Name: H MacGillivray

Proposal 2–1

Proposal 2–2

Proposal 3–1

Proposal 3–2

Proposal 3–3

Proposal 3–4

Proposal 3–5

Proposal 5–1

Proposal 5–2

Proposal 5–3

Question 5–1

Question 5–2

Proposal 5–4

Proposal 5–5

Proposal 5–6

Proposal 5–7

Proposal 5–8

Proposal 5–9

Proposal 5–10

Proposal 5–11

Proposal 5–12

Proposal 5–13

Proposal 6–1

Question 6–1

This submission is an attempt to provide a helpful answer to Question 6-1 (a) and (d)  and, simultaneously, Question 6-3.  It consists of one overarching answer - or solution - that applies to each of the issues raised in these questions. That solution would likely also be helpful accross other issues being considered in this discussion paper too. But I'm only addressing Question 6 issues specifically because they were the ones that detrimentally affected my late mother and myself the most. That is to say, it was the power of attorney and power of guardianship related problems that most impacted us, in a horrible and ultimately tragic way.

To be more specific, Mum's power to make the decisions she wanted to make and my power to implement them as I had done for a long time in the mother-child relationship we knew and were comfrotable with were unjustly denied to us, by those in a position of authority, whose decisions were at best over-zealous and heartless. At worst they were illegal and criminally cruel.

Those people in authority positions were able to  'perpetrate' these wrongful decisions and actions against Mum (and me) because of an habitualized acceptance of a double standard in society, when it comes to different levels of respect that are accepted as normal, when applied to the old-aged and the non-old aged. And those who wanted to make worngful decisions were also helped by the ease with which 'those who seek to grab empowerment away from where it should truly be' (whatever their individual motives might be) can, in effect, collude with each other, to make their task easier.)

**So, first of all,** I want to submit what I believe 'the overarching answer' to all this, at it's core, is, viz., PREVENTION of the problems associated with assigned powers! We need an essentially very simple pro-active, preventative scheme. Reactive, punitive, accusatory, blame-filled measures just aren't as helpful when complex human relationships are involved.

**Then secondly,** (after I have I described as best I can what I envision that scheme would be) I would like to share some of the experiences of my mother and myself that have prompted me to crystalise my thoughts into an idea for such a scheme. And I'd like to allude to better outcomes that might have happened for us had such a scheme already been in place.

[Sadly there will be no benefit for my late mother now even if such a scheme ever becomes a reality. So all I can do is to make this submission in honour of my mother's unique character, personality and life experience, in the hope that it may help the uniqueness of others in the future, in their old age.]

This scheme I want to propose really just subtracts a harmful component which currently prevails in aged care thinking and practice.That component is the way in which those who have 'some degree of authority over others' too often seek, first and foremost, the comfort, for themselves, that is provided by their applying black and white solutions to intractably grey problems, because they perceive this as being easier (for them) than understanding and working with 'the grey areas' ... ie with the real complexities of real life. The scheme I am proposing (as follows) deals with the complexities of life as something that should be seen as 'normal and manageable and non-threateningly ongoing and gentle' and to be dealt with  BEFORE 'crisis management' becomes the only remaining option!

**IT IS A PRO-ACTIVE, PREVENTATIVE SCHEME (here with the working title of EMPOWERCARE.)**

This is envisioned as A COMBINED MEDICARE & LEGAL-AID LIKE SCHEME - for convenience here called "EMPOWERCARE" whose servics would have to be run from within the physical environment of any medical centre, because most people - especially old people - aren't intimidated by visiting a medical centre.This is very important because for EMPOWERMENT to exist right through into old age it needs to become highly normalised; seen as a part of normal care for each one's legal and and emotional and physical wellbeing!) EmpowerCare would be staffed by specially trained legal consultants (who would have easy access, eg via Skype, to specialist lawyers for difficult cases) working alongside specially trained nurse practitioners (with easy access to doctors including specialist doctors - for example, geriatric-specialist psychiatrists, for difficult cases.)

**What Would EmpowerCare's Exact Purpose Be?**

It would exist to would be to provide a bulk billed style service in **education/training** and **consulting/advice/conversation** **about the parameters** of 'powers' and to **legally execute the documents associated with power of attorney and power of guardianship assignations**, **family agreements.** It would also provide or organise non-threatening (eg by being in a medical centre environment) **mediation services** and **any other related service** that may be deemed by appropriate experts and/or via suggestions from the public  to be suitable to be conducted by such an EmpowerCare scheme service. For example, there could be connections established, via EmpowerCare, between school groups and elders who might like to interact with each other, ... so as **to normalise aged and non-aged interactions and mutual respect**. EmpowerCare could also make **T.V. campaigns promoting Elder empowerment** before a crisis state is arrived at in old age, not unlike campaigns that already exist promoting vaccinations or regular health checks. EmpowerCares services would be **avaialble to and welcome the particpation of all parties involved.** **It would be all about prevention of problems only!** (If litigation or punishment or court resolutions etc were needed then that would be a situation that had already progressed beyond Empowercare's field of expertise and would have to be referred on appropriately)

**How Would The Integrity EmpowerCare's Purpose Be Kept On Track?**

\*There would be an ombudsman for EmpowerCare Services just as there are obbudsmen for services like utilities or insurance or transportation etc.

\*Conventions and social mores would become more exacting (just as they did in the past regarding the issue of sexual harrassment in society. When that problem was left unchecked social mores reflected that, but when legal protections and societal infrastructures became more visibly established then social mores changed and became powerful 'integrity checkers' in their own right.) So too with this issue, where wrongdoing is currently still very common, social mores would evolve to help change that too as a result of the establishment of an EmpowerCare scheme.

One problem that needs to be controlled by a visible societal sign,' like EmpowerCare, of social mores changing is the problem of 'empowerment thieves' effectively colluding with each other - consciously or not, including family members who don't really care at all what the Elder relative wants AND who are aided in that non-caring by other 'players' in the system! eg the Nursing Home Industry wants more 'units of currency' in the form of old people who can be recycled into currency! Such industry 'players' really do 'silently collude' with adult children who are prepared to 'make the exchange' in order to be relieved of their care responsibility, either willingly or probably more often through work and other (eg family) pressures that push the Elder way down the list of priorities!

Another form of collusion that needs tracking and controlling is that which occurs when the same person who is in charge of a hospital's discharge policies and practices for the elderly also has fingers in other Aged Care related pies ... such as the DVA and the Aged Care Assement Team and the Nursing Home Industry - be those collusions be in the form of personal friendships or professional affinities. That is, if an EmpowerCare scheme were ever created then conflict-of-interest type safeguards would need to be built into the scheme, or program, to ensure that EmpowerCare's staff would be committed to fairness for the elderly, and for all genuinely involved in, or concerned that is to say, first and foremost for the Elder's empowerment. Access to Empower care could start at a young age, as things should not be left till they get to crisis stage. In other words, the acknowledged nature of (and accompanying documentation of ) 'empowerment issue' relationships of any sort should start earlier rather than later. People should be brought up to speak freely about and present their concerns to interested and highly trained staff well before 'perplexing issues' become 'big problems.' EmpowerCare should be a hub of well thought out and anticipated, preventative resolutions ... **not a crisis managment centre** nor a place where 'punitive simplicity' is used to try to resolve, or worse still manipulate, 'complex relationships.'

\*There should be culturally sensitive specialists for groups needing that too.

**How would EmpowerCare services be paid for?**

A small levy not unlike the Medicare levy. For example, I recently read that the Medicare levy on all income earners is 2 percent of income. Imagine then if an extra 1/16th of a percent of every earner's income was also levied to pay for EmpowerCare. (If 12 million people out of the entire  population are earning an income averaged-out at $80,000 each. If each paid 1/16th of a percent of that average income per year (or $50 per year each) that would work out to $600 million per year available from that levy, to run such a service. That should be at very least be a good starting amount. But, no matter how much is actually needed, it would be ineviteably less than the much more complicated Medicare levy, so it should work. (Empowercare would be definately NOT ABOUT LITIGATION, so no costs for court battles would be needed. The idea of an EmpowerCare scheme is education and support and changing norms and then supporting the new norms ... for greater inclusivieness in empowerment in society. Prevention of anything always costs less than trying to find a cure, after the fact!)

There might be other revenue raiser possibilities too. eg Events can raise money - maybe art exhibitions or musical performances by older Australians or there could be any number of creative ideas that might encourage donations. For example, an Elders' Talent Biennale?

**Would The Personal &/Or Social Value &/Or Econmic Value To Society Be Worth The Cost?**

\*Yes, because it would create employment.

\*Yes, because it would raise the profile of Elder contributions - to society and to inter-generational communications, which can only broaden the perspective and (eg historical) perceptions (and therefore soulfulness and compassion) of young people as they themselves grow up. (This would make it a hub of the type of activities that increase mental and emotional health benefits all round. It should help to lift societal and individual morale as norms, eg workplace norms, subtly adjust to new social mores.

\*Rigorous studies might be designed to test cost vs benefit, for certain.

**Now I'd like to speak about the Experience of Mum and I - under the inadequate system which still exists it seems (and which made Mum's full empowerment entitlement very difficult and exhausting to try to achieve, in the light of the reality of family complexities alongside other societal and/or marketplace and/or workplace complexities.**

If an EmpowerCare-like scheme had aleady been in place then it might have gently ironed out many of the grey areas  of complexities that existed in Mum's whole of life experiences, and our family circumstances in conjunction with societal complexities ... so as to allow for respect of Mum's wishes to also exist.

But as it was, what was in place, and still is no doubt, is a system that encourages (or at least does not prevent) some people from using their authority and/or influence to re-render those complexities of life as harsh, sharply black and white perceptions of older people's life. Such fauulty and/or inadequate perceptions were freely allowed to tear my mother's life to shreds in her last months. No adequate Elder  Empowerment iInstitutions existed or were easily accessible to (or even knowable  by) us.

So to explain this, first I need to call out **the black and white thinking** **style** that the current system unabashedly allows to run riot throughout Aged Care 'sevices,' and which, in consequence, destroys with impunity people's emotional life and physical health, under the guise of delivering of 'aged care.'

So first we need to consider why would anyone in authority want to engage in black and white, or over-simplified, thinking if it is potentially destructive of some people's rights?

It is because, as I mentioned earlier, it **makes life easier for those in authority**. If they have egos that like to be in control, then black and white thinking make that feling of control easier to come by. If they have mindsets that like problems to be crossed off the 'to do' list then that is also easier to achieve if everything is seen in simplistic black and white, easily compartmentalised, terms. For those who want to keep those in authority, over themselves, happy - so as to be ensured of keeping their own job - then it's less tiring and scary to keep it all overly simple. (And in a convoluted system that does not allow the real complexities of real life to be present then 'simple' really does equate to a 'black and white', highly compartmentalised, way of perception.)

**More specifically, the things that happened to Mum, would have, in any other situation, ie in a situation not involving a a vulnerable aged persW,  been regarded as, 1.) kidnap, 2.) false imprisonment and 3.) cruel and unusual punishment.**

(What happened at this stage of the event happened without any protection of Mum's wishes that I would have been able to secure had I had enduring powers of attorney and guardianship. I did not have such prottective powers over Mum's wishes due to an interaction between family complexity and societal or Marketplace complexity - that effectively colluded. This involved my sister not wanting me to 'control Mum' which was her peception of the situation and it involved Mum's perpetual habit of trying to appease my sister, whilst simultaneously wanting, and expecting, me to 'just make everything right.' But I'll explain that later in the section re the details of family complxity that interacted with the black and white authoritative thinking we encountered.)

**To try to keep a very long story as short as possible,** Mum had by mid 2013 been living in a specially designed and built semi independent living unit attached to the back of my house - all under the one roof (not a detached granny flat) since January 2005.

Mum paid for the unit and I designed it and we made our own written Agreement which was witnessed and then kept at a solicitors along with Mum's Will - in which she stated that she would leave her modest assets to me alone as I was looking after her and my financial situation was so much worse than my very well off sister, whose marital situation meant there was a lot of wealth in her life. (Unfortunately that solicitor was near retirment age and it happened that when she retired she apparently disposed of our informally written, but witnessed and accepted by her, Agreement which she had agreed to keep safe. I think I still must have somewhere a copy only of that agreement between Mum and I in which I promised her a home and care for life, though I am not sure where it is as we just assumed the original was all we needed and had no idea the solicitor would 'ditch' it!) Mum's Will however remained with the solitiors who took over, even though the Agreement was mising, (We didn't actually find out it was missing till 2013 when we needed it.)

From 2005 till mid 2013, Mum and I were both very happy and Mum at the then age of 95 years enjoyed going to an art class at a day care centre a couple of times a week. We loved car outings and picnics with our lovely kelpie. Mum enjoyed the comforts of her living accomodation arrangement and the garden etc. She had a vibrant personality and was a creative person. And I enjoyed her company. Mum had certain mood and mental health issues but when she was happy they did not surface. And even when they did I had never been unable to cope with them, even as a child.

In mid 2013 I was diagnosed with a treatable, but initially troublesome, heart condition (Atrial Fibrillation) immediately after I had a (succesful but large) operation for uterine cancer. Respite care was necessary then for Mum but it was planned to be for as short a time as possible. But Mum became very depressed in respite. No one there noticed she was not eating. The new tin of Sustagen I had left there with requests to watch her food intake and supplement her meals with Sustagen was ignored and the tin was unopened during the approximately ten days I was initially out of action for.

Mum begged me to bring her home. I did that because she wanted me to but also because it was also actually easier for me to care for Mum at home. I was already having to go into the respite care facility to shower her as they didn't do it often enough and the bathroom was set up in such a way she couldn't work the taps on her own safely. This was despite my having had a major operation only ten days earlier.

But she had become so dehydrated and malnourished in the respite respite care facility becuse no one cared that when Mum is depressed she wouldn't eat or even drink much unless coaxed and encouraged. Mum had a heart condition too and it played up - I think due to the dehydration. So the day after she had come home she had to be admitted to hospital. My own heart condition was not yet fully stable and so Mum went to another respite facility, which she also hated.

When medications finally stabilized my heart condition (Atrial Fibrillation) Mum came home again. This time she was near catatonic in her depression. Her doctor at the time prescribed anti depressants against Mum's will (and my will.) I knew Mum well enough that I felt she was emotionally exhausted and so needed mostly just lots of rest alternating with, as she grew stronger, activity - hydrotherapy specifically as she loved the water. But the doctor said "no, anti depressants first." Mum had a very bad reaction to the anti depressants and within a few weeks could not walk - and never walked again.

Mum was then, as a result, rehospitalized. She was there a long time - about two months, from memory. I was able to organize through a DVA representative a hoist and full hospital style bed and large pushable recliner chair to have at home (Mum had a Gold Card.) We  had no idea that there was still to be more obstacles put in our way. I had always been super resilient. I knew I could look after Mum. Mum wanted to come home and I wanted her to come home too. Apart from no longer being able to walk, since the anti depressant, Mum was doing fine. She was enjoying reading and talking and looking forward to rehabilitating as much as she possibly could, including hydrotherapy when she was up to that again. She had always loved the water.

Mum was **not** demented. On the contrary, her brain was always lively for her age and her memory way beyond excellent. The Patient Discharge Officer at the hospital and the Head Social Worker there both confirmed quite willingly to me that Mum showed no signs of dementia and had expressed to them that she wanted to come home.

But then some Marketplace/Workplace/Societal Space complexities began to 'collude' with a family complexity, as far as I could tell.The Head Social Worker without ever telling me why inserted herself into our 'case' - possibly influenced by my sister who livd in another state but who had done highly deceptive things before that seemed aimed at disempowering me and how I related to my parents. (In 1989 my father had cancer and I was caring for him and my sister intervened terribly to disrupt that care, by influencing a doctor friend of hers, but that is too long and sad a story in its own right to tell here.) But I did know from that and other incidents that my sister is a 'behind the scenes' player.  So I wondered if she had somehow colluded with the Head Social Worker at the hospital where Mum was. It would have to have been  by phone as my sister was thousands of miles away in another state.

All I knew though was that the Head Social Worker at the hospital was utterly determined to not let Mum come home again. She wanted to send Mum to a place, for 3 whole months, that she called "slow stream rehab." It was located in the grounds of a much smaller rural setting hospital about 30 minutes drive from home. I went to visit that place. What I saw there could not be described with any degree of honesty as "slow stream rehab!" Rather it looked to me more like a "stagnant water holding bay" for the elderly who were waiting to be sent to where they are finally processed into 'units of currency' for the benefit of the nursing home industry, in return for 'taking elderly parents off the hands of busy adult children' who don't know what else to do, or don't want to know.

I could see from the state of the place and its (lack of) care facilities that I would have to visit at least twice a day to care for Mum there. That would be two round trips of an hour each or else I could just stay there most of the day and evening. But I knew i couldn't rest at all if I stayed there all day and I hadn't had any real recovery time myself! There was no staff actually on permanent duty. I was told that by the person who showed me around who said he was in charge of that ward. When I wondered why no lights were on over the 'nurses station desk and when I asked could I speak to the staff. he said no one was on duty there full time, but rather that "staff come down from the hospital." Old people were just sitting staring at blank walls on their own. And expected to be there for 3 whole months! I asked him how many people had been rehabilitated back to their homes. He looked stunned that anyone would ask such a thing and said "Well, there was one lady once who ..."

 I went back to the social worker at the hospital in Ballarat where Mum was and said "Mum can't go there" to the so called "slow stream rehab" I knew it would kill her! She couldn't ever take such abandonment ... not all the time I had known her, which was, in 2013 for around 63 years! She was far more fragile an emotional soul than most people ever realised. (I was once told by a psychologist, some years earlier who hadn't actually seen Mum that what I dscribed to him of her behaviour sounded very much like she had undiagnosed Borderline Personality Disorder with manic Features. She had an absolute fear of abandonment - despite her seemingly magnetic personality. And that is typical of Borderline Personality Sufferers; an nbearable fear of abandonment that can make them seem crazy, thye react so strongly to it. Mum could only ''dance" in life if she had 'a rock' to dance on. Dad had been her rock. And in her old age I had that role to occupy mostly on my own. (I had been 'the rock' too in a sense when I was a very young child, though.)

That Head Social Worker told me then - and she seemed to know by then that I didn't have power of attorney or guardianship - that she would offer a compromise, such that if I didn't accept it she had the authority, she said, to send Mum "to any nursing home anywhere in the state!"

The compromise was that she would send Mum for one month to a local nursing home. She told me that I would come to appreciate that Mum would be better off there full time. I said that that is not what Mum wants. She said "we don't always get what we want!" She seemed very angry at me for not making this 'easier for her.'

I discussed it with Mum and told her that I was afraid of this woman's power as she had let me know that she was also associated with the DVA and with Aged Care Assessment and I had heard stories of people being banned from even visitng their relative in nursing homes for having the 'audacity' to speak up or complain. Mum said she would be guided by whatever I thought was the safest way to proceed because she couldn't stand it if she would be taken away from me forever, if this Head Social Worker started throwing her weight around. That Head Social Worker had told me that her motivation was that I might sue the hospital if I was unwell enough to look after Mum at home and she had a fall and they had let her come home. (Duty of Care, she claimed.)

BUT, Mum was not demented! They admitted that ... and I was confident I could look after Mum. It sure would be easier than looking after her - as I could tell I would have to do anyway - with all the added burdens and obstacles to proper care that nursing home environments bring. I knew that if I signed Mum away for that one month that they would have to let her come home after that month, but if I refused and fought it she might be taken away forever, especially as whenever Mum became depressed she tended to not express herself to others, though she would speak to me. Others cold well interpret her silence as dementia, rather than as her depression and mood disorder generally. So we took that option: of the one month 'in captivity' close to home! I still don't know if it was the right thing to do ... as that last nursing home undermined Mum's spirit just so very much and was so so so stressful and robbed us of a whole month at that precious advanced age when how much time is left to live is even more uncertain than ever. It was said to be 'the best nursing home in Ballart.' I'd hate to see the worst. (In fact I don't think there is much difference from 'best' to 'worst,' in nursing home anywhere ... apart from the presence or not of chandeliers and the like. The basic care and business models are the same everywhere: save as much on wages as possible so cut corners on care at every opportunity!

**Because of the duress, ie, because we were under threat of Mum being sent to any nursing home anywhere in the State if I didn't agree to the one month in "the best nursing home in Ballarat, " I believe that what happened amounted to KIDNAP and FALSE IMPRISONMENT of a person of sound mind who clearly had expressed her view to the powers that be that she didn't not want to go anywhere other than home!**

**Unfortunately we did not know that the torment was not yet over.**

The Director of Nursing of the nursing home where Mum had to reside for that month appeared to me to 'know things' about me pertaining to my attitude towards Mum's 'care' that could only have come from the head Social Worker at the Hospital. She was very hostile towards me. I wondered if she was trying to provoke me and so I made a deliberate decision to not 'take the bait' as I thought it would take very little for her to start proceedings to have mum permanently admitted to nursing home care,

Mum was not given a shower for the whole month there. (I was told in no uncertain terms I was not to intervene in m mother's hygeine care and it would have been impossible for me to gain access to the hoists without their consent.) They said it was not possible for two nurses to safely shower her. Mum had gone from 65 kg to 46kg during the whole respite fiasco (she was last weighed before discharge from the hospital to this nursing home) so it wasn't that she was too heavy for them! And when she did come home after that enforced month I was able to easiliy use the hoist for daily showers for Mum for about 18 months, right up until near the very end of her life.

So she only had bed washes in "the best nursing home in Ballarat"... and not great ones at that from what I saw. One evening staff came by with a hgeine care trolley and didn't, for once, send me out of the room before they 'washed' Mum before settling her for sleep. They had a roll of kitchen paper towel. With it they scooped roughly to remove a lump of faeces, put it in their bin on the trolley and went to move on. I said "Aren't you going to wash her bottom properly?" They said "The night staff do that." I had to find disposable gloves in the bathroom and do it myself. There were many issues of poor care. This is not to say that there weren't individual staff who were caring and conscientious, but that was not the overall work culture of the nursing home at all.

There was one 'small gang' of staff members who brazenly ate off the residents' plates on the trolleys. One was clearly a favourite of the Director of Nursing and she took a dislike of me. I had brought in ice cream cones (Cornetto style) of the type Mum liked and had them in the freezer there. One day the ring leader of that 'gang' took an icecream out of the freezer - it may or may not have been Mum's - then pulled up a chair directly accross from me and turned it around so she was sitting facing the back of the chair, legs straddled accross the seat and started eating that ice cream in a very exaggerated way in front of me. I just didn't look at her as I wondered if she was 'working for' the Director of Nursing who seemed to want me to 'loose it' if she could get me to.

At one point Mum was breathless and I had to nag to get a doctor to see her. I knew that with her heart condition a urinary tract infection make her breathless. Finally after about three days I overheard a staff member talking to someone on the phone saying "Oh there's nothing wrong with Mrs MacGillivray. It's the daughter!" But when the urine tests came back she did have a urinary tract infection! Several other incidents of that nature also occurred. And I had to balance what to speak up about and what to keep quiet about for fear of retaliation of some sort.

The very worse - and this was I believe unarguabley **cruel and unusual punishment** (punishment just for being old!) was when I decided that I would take three days off going in to see Mum (as I had been doing at least once a day and often more) as I still had had no real recovery time for myself. The one thing that was excellent was the food, thanks to the chef, Peter. he was one of the few beautiful souls there. He would come out after each meal and ask the residents if they had they enjoyed their meal and speak to each for a little while. Mum loved him and his cooking. He spoke to Mum and the others as if they truly were 'real people' .. which seemed not to have occurred to many of the staff there, although there were exceptions ... and there were certain easy-care residents (eg people who walked around and around all day and demanded nothing much) who were treated better than those who needed or wanted more.

Mum was eating again and enjoying her meals. There was only a week or so to go before she came home and so I said to Mum I would have a few days off. About a day and a half into that 'time off' I got a phone call saying that "we've had to put your Mum on a pureed diet." I went straight back in and the first (heartbreaking) thing Mum said to me was "I'm so thirsty. They don't put the water where I can reach it." I was roused at, by the Director of Nursing who told me in a very aggressive tone "Your mother has deteriorated!" as if to say that I should 'just accept it' and stop being a great nuisance to them. So I allowed myself the only opportunity to snap back at that Director of Nursing a little bit by replying "I'll say she has!" (One nurse had the courage to say to me quietly "Your mother can swallow her tablets perfectly well.") So I then had to sneak in when the Director of Nursing had gone home with whatever Mum wanted - fish and chips, MacDonald's cappacino, ham sandwhich ... and she'd be sitting up in bed at night chompng that down! In the day the pureed muck would be there in front of her and I would pretend to have brought in lunch for myself and while no one was looking I would sneak it to Mum to eat After a few days of that, the Director of Nursing suddenly said in an exasperated manner to one of the staff, one lunch time, "Oh put her back on a normal diet!" (I had offered to sign the 'food book' to take full responsibility for any food I brought in for Mum, but I was forbidden to go near it for some reason.)

I believe that the reason why Mum was unnecessarily and cruelly and illegally put on a pured diet (though I was told "a speech therapist has ordered it - which would make it 'legal' - but never found out who such speech therapist might be!) was that, in my opinion, 1.) nursing homes can claim more money for residents needing that 'extra care' whilst at the same time, 2.) saving on wages because they can get one staff member to sit between two residents on pureed diets feeding one with one spoon and the other with another - ambidextrous feeding for speed! Mum however just would not eat it, as she was strong willed ... even in depression she would not do what she did not want to do. She would just go silent!

Finally that horrendous month was up and Mum came home. No-one at the nursing home saw her off. I had to go and find somone on duty to say we are going now and ask did I need to sign anything else to say we were going and was told "no it's all been done." The ambulence men came and off we went home!

It was then around the end of January 2014. The DVA people had delivered the hoist and hospital bed and the special moveable recliner chair so Mum could sit out in the sun  if she wanted on the back patio or sit in the cool shade etc. We fell into a nice routine, and with the help of the wheelchair access maxi taxis (as Mum could no longer get in the car) we could go on outings, but sadly could no longer take our beautiful dog with us to go on leisurely picnics, for example, as the maxi taxis are just for transport to and from a set place at a set time. (We did eventually get a disability van nearly 18 months later, but sadly Mum soon passed away after that.)

**So now we come to the final part - where the family complexities really kicked in!**

So as soon as possible after Mum came home from the last nursing home we went to a local solicitor recommended by Legacy. Mum wanted me to have enduring power of guardianship and for me and my sister to have enduring power of attorney. I knew that this was going to end in grief ... but Mum was determined that she wanted my sister to take some responsibility.

In other words, Mum was using the assignment of power of attorney in a way that did not really reflect it's true role. I think Mum was using it as an instrument that might force my sister to participate in 'family unity.' My sister agreed by phone to particpate. It was to be a 'severally' held power rather than .one held 'jointly' as I had told Mum that I was really worried about not being able to contact my sister in an emergency nor to get any agreement with her on 'what Mum would want.'

At the solictors Mum signed, and so did I, the relevant documents, fully witnessed by the solicitor and a legal assistant. All that was required then was for my sister to recieve them by post, sign and return them.

As we waited for that Mum was getting better. The physiotherapist gave us hope that she may even walk again. And we waited and waited for my sister to sign the papers. The soliciotr contacted her, a couple of times, I believe. Then several months later he phoned and said he had received a single sentence letter from my sister saying **she would not be signing** and was returning the documents to him. Mum became depressed again at that and began going down hill again.. The solicitor said we would have to get a doctors letter now to say that Mum was still of sound mind. He would not even let me have the power of guardianship as it was he said somehow on the same documentaition as the enduring power of attorney, ie the one my sister would not sign. He seemed to be worried that there must be a good reason for my sister to do what she had done. But what he didn't know was that my sister did not need, never had needed 'good reasons' to disrupt any thing that was to do with my relationship with either of  our parents, nor before that, with our grandparents. It was par for the course, within the family complexity that it sprang from. But strangers to a family tend to want black and white, and some sort of sense-making, reasons for family members using legal instruments as wieldable weaponry!

Mum's reaction to my sister's latest 'contribution' (of deciding she did not want to participate) was to return to a near-silent state. She would speak in a faint childish voice. (Mum had had a magnificent mezzo soprano singing voice - but stopped singing after Dad died. She regained her wonderful capacity for song, in terms of being pitch perfect and having a lovely tone in her last months with a music therapist who came to our home and was amazed at Mum's . voice. Mum didn't ever regain the full vigour of her voice, but all the same sang "How Great Thou Art" as one of the last songs she ever sang and the music therapist praised how well she sang, saying it was a very difficult hymn to sing well but that Mum had sung it exactly right, despite the weakness in her voice ... she pitched the notes and their timing exactly as they should be.

Mum had also always had a beautifully timbered speaking voice as well as a singing voice and people responded to it very positively. I said to her "Mum, please I can't do all this trying to convince people on my own that you aren't demented. If you speak in that babyish voice of course they are going to respond differently. They'll put you back in a nursing home!" She just belly-bellowed "NO!" in a full and loud voice and then said she couldn't cope with going back there and then said "Well I'll try and use my old voice again then."

Another thing that made it difficult to get a doctor's note saying that Mum was of sound mind was that she had changed doctors several times in the (at that time) 8 years she had lived with me. In fact all her life she had been afraid of anyone suspcting she might have depression or other mental health issues and was a terrific actress and could come acrross as anything she wanted to come across as. Finally we found a doctor - my doctor - who Mum liked, but of course that doctor wanted to wait a while to get to know Mum ... and towards the end Mum did start to speak to her normally. But before there was a chance for Mum to show that doctor definitatively that she was more than capable of deciding what she wanted (and Mum refused any cognitive tests as she knew that in her depression she couldn't be bothered to do them and so we couldn't rely on anything other than her talking sensibly and sensitivley and with a sense of humour etc to the doctor) she began to become physically weaker and it turned out it was liver cancer, so we never got the final word from the doctor of Mum having a sound mind and so I never did get enduring power of attorney or guardianship!

Two days before Mum died we visited the doctor and bloods were taken from Mum, but  the results did not come back till after Mum had passed away, showing the results were consistent with liver cancer. I believe that all the stress she endured created that cancer!

That final time we went to the doctor Mum wanted to go out for coffee afterwards. I said "you look so tired we can go another day if you like?" But she insisted and we went in the maxi taxi to her favourite garden nursery cafe. In retrospect she may have known what I didn't: that it would be her last social outing ... and she insited upon it. She was strong minded till the end, but that determination had, in the end, only my (severely disempowered, mostly by people in positions of authority) ability to speak up for what I knew Mum wanted, for what I knew about how she wanted to live.

All my life Mum had provided a roller coaster ride. But it didn't bother me. People in authority who couldn't keep up with her creative spirit bothered me and scared me a lot more. Mum used to say of me and her "We understand each other." and "you are very patient with your crazy old mother!" She said to me occassionally over the years, of my sister, "I've never known what's going on behind those big blue eyes and I don't suppose I ever will." But she was a mother who wanted both her daughters to be involved in her life. In the end my sister had a couple of Skype sessions playing the guitar while Mum sang. I said to Mum, that that's what she (my sister) could do -when she wanted to - and that Mum should accept that. And I think in the end she did accept that my sister could give only what she wanted to give at any given time. My sister always  wanted to be seen as responsible, and could convince people that she was ...she just didn't want to do the work of actually engging in responsibility towards our parents in accordance with the expressed wishes of them! On that last Skype session, Mum just couldn't take her eyes off my sister and smiled, enjoying their shared musicality. It was as if Mum had finally accepted the reality of that family complexity!

That very long story is in fact a shortened version of all the complexities of my mother's life.

**How would an EmpowerCare scheme (such as the one have suggested, had it existed) have helped Mum?**

It would have helped, I think, for everyone involved to have had the parameters and dimensions of instruments of empowerment (of Mum's wishes) more clearly in mind. eg An assigned power of attorney document is not where family complexities and dramas are meant to be worked out!

If there was an easily accesible place to learn this, to take it in well in advance of when its really needed, a place where complex human emotions are acknowledged and accepted and redirected to appropriate places, that would have helped!

It would have helped too, in this age where The Marketplace/Workplace is too often revered and respected above Home and Family if there was a strong infrastructure that 'taught the example' of ongoing respect all round. If there was a place where doctors and other health related staff and lawyers and other para legals and people who are subject to 'power orders' and people who are assigned 'powers over' an elderly resident could all interact in a more naturally complex way!

If  strong guidelines and 'good' help and advice were available it would go a long way to discouraging all the 'reductions to black and white perceptions' that end up causing tragedy to a real and complex life, in old age.

Proposal 6–2

Question 6–2

Question 6–3

Please see my answer to Question 6-1 (a) and (d) above as it addresses Question 6-3 at the same time ... by proposing an inclusive-of-all-parties scheme that is proactive and preventative, rather than reactive and curative. Thanks.

Proposal 7–1

Proposal 7–2

Question 7–1

Question 7–2

Proposal 8–1

Question 8–1

Proposal 9–1

Proposal 9–2

Proposal 9–3

Proposal 10–1

Proposal 10–2

Proposal 10–3

Proposal 10–4

Proposal 11–1

Proposal 11–2

Proposal 11–3

Proposal 11–4

Proposal 11–5

Question 11–1

Question 11–2

Question 11–3

Proposal 11–6

Proposal 11–7

Proposal 11–8

Proposal 11–9

Proposal 11–10

Proposal 11–11

File