

This is the story about how I stumbled into aged care advocacy, the type of advocacy that interests me, and why I recently transitioned from advocacy to activism.

It includes my personal story of how the financial and emotional abuse of my mother broke my heart.

The story begins when my mother and father moved to an aged care home in 2010.

By way of introduction, this is a photo of my parents before their wedding, and another on their 60<sup>th</sup> wedding anniversary.

Although 2 of my older siblings are doctors, and I once worked as a critical care nurse, we wanted our parents to choose their own aged care home.

They chose Victoria By The Park primarily because they could sleep together in the same bedroom. It's important to stress that "they" chose the aged care home themselves. Unlike many families who are forced to make the decision quickly after an older person has a health crisis (e.g. fall, heart attack), my parents moved into the aged care home when they were both in reasonably good health.

Dad continued to enjoy playing crochet, and mum enjoyed a day out fishing in our family's boat, Joey. Mum had been fishing in Port Phillip Bay for over 80 years – and still knew where to find the best spots.

Mum and dad were very happy living at Victoria By The Park. Most staff treated them with kindness, respect and love. Mum had her favourites – Charlotte, Alex, Argus, Vicky, Kunal and Jenny... Far too many to name here.

I noted with interest during the Royal Commission that Merle Mitchell, who had once been the president of the Australian Council of Social Service (ACOSS) and now lives in an aged care home, did not describe her aged care home as "a home". In contrast, mum called Victoria By The Park her home. This suggests there are huge variations in aged care homes – ranging from the dangerously bad (like Epping Gardens) to the very good. My parents were lucky to choose a good aged care home. However choosing a good aged care home should not rely on luck.

Here is a photo of mum and dad at my 50<sup>th</sup> birthday party, a year or so after they had moved into the aged care home. Dad died 6 months after this photo was taken. He had a very happy Xmas with his family, and then went downhill very quickly

The end of Dad's life was managed extremely well, primarily because I arranged a family meeting at the aged care home – to ensure my brothers and staff at the aged care home were on the same page as me. I had also ensured the GP had written an 'as required' (prn) order for morphine when it was clear that dad was dying. So, after most of his grandchildren – in fact all but one – had said goodbye, and after dad's middle son returned from Italy, it was easy for me to insist the nurses at the aged care home begin to administer 4 hourly morphine.

When mum was dying years later, I also asked the GP for an 'as required' order of morphine several weeks before it was first administered. Again, this made it easy to insist the nurses at the aged care home begin administering the morphine when the time came without having to wait for the GP, or a locum GP, to visit.

When Dad was dying, the manager encouraged one of his five children to be at his bedside 24 hours a day. She allowed us to bring a stretcher bed into his room, so one of us could sleep with him overnight. The kitchen staff arranged a constant supply of sandwiches for us. Several years later, when mum was dying, there was a new manager. She asked me to leave mum's bedside when mum was dying – but I am jumping ahead.

On one of my day shifts with dad, I noticed how many staff were sad that he was dying. I asked the Manager whether staff would like to visit dad to say goodbye. The woman who worked in the laundry (who was a sports fan like dad) and the cleaner (who was exceptionally kind) both came to say goodbye, as did many other staff. Unfortunately, the staff were not given this opportunity when mum was dying because the manager did not agree this was a good idea.

I also invited some residents to his bedroom to say good-bye. I have very fond memories of Trudi having a whiskey at dad's bedside and Sam giving dad a Jewish blessing.

On the night dad died, one of my brothers told the nurse not to administer the morphine. He wanted dad to die of "natural causes". I explained to my brother that dying of metastatic prostate cancer is painful, and the morphine is helping dad to die without pain. He refused to listen to me, something I was accustomed to as the youngest child and only female in a family with 4 older brothers. I left the room to find the nurse. I asked her to return to dad's room with the morphine and explain to my brother that 'cheyne stokes' breathing (also known as end of life breathing) can be painful. My brother listened to the nurse and the morphine was administered. Dad died a few hours later.

After Dad died, I arranged a BBQ at Victoria By The Park to celebrate his life. It was a festive occasion – with bubbles and speeches to thank the staff.

I also MCed a celebration of dad's life at my brother's house. I was thrilled and surprised when I looked into the crowd to see staff from Victoria By The Park. They had only known dad for 18 months, but some staff genuinely loved him.

At dad's celebration, a brother asked me if I thought mum was legally capable. I replied: "Mum is depressed. She has just lost her husband, a man to whom she had been married for 60 years. That does not make her legally incapable!"

A few days after this conversation, mum's GP did the paperwork to have mum declared legally incapable. He did not assess her nor did he administer any cognitive tests. In my submission to the Victorian Royal Commission into Family Violence, I claim a proper neurological assessment should be undertaken before an older person is declared legally incapable.

A few months later, when I took mum to a psychogeriatrician, he undertook a thorough neurological assessment. He assessed mum as legally capable. However, I had learnt to choose my battles with my brothers. I did not think the battle to reverse the assessment of mum's legal capacity was a battle worth fighting.

Once mum had been declared legally incapable, her youngest son became her financial power of attorney and I became her medical power of attorney. I was now legally able to make medical decisions on behalf of mum. However, I felt it was important for mum to remain in control. We wrote her advance care directive together.

In contrast, mum lost control of her own money. Several "family meetings" were convened to discuss mum's finances. My sister-in-law explained: "Your brothers are worried about their inheritance. What's wrong with that?" Gob-smacking stuff.

Then came the zinger: an email in which it was suggested, and I quote: "the family consider Mum gifting some of (her) money to her children in the near future". A second email explained and I quote: "(If this money is given) to the ultimate beneficiaries to Mum's will (us), depending on the beneficiaries personal circumstances, this money could reduce loans and thus after tax payments of interest on loans. In the long Mum is no worse off, and the children are better off."

I replied that it is morally unjustifiable for middle-aged men, who all have professional jobs with decent salaries, to rely on inherited money to help them manage their current finances. I could not fathom why my brothers expected mum to help them out with loans and mortgages that they had chosen to take out to support their lifestyle.

I then asked a simple question: "Would you have treated our father like this?" I was told that my email was "hurtful" and "offensive". Three out of four brothers then simply chose to ignore me, as powerful men often do. How do you resolve an issue when there is no communication?

I will return to the story of financial and emotional abuse later. For now I want to focus on mum.

After dad's death, I began visiting Mum most days for about 3 years until her death in September 2015.

She established 'her spot' in the communal lounge room from where she observed everything with a nurse's eye.

Mum trained as a registered nurse at the Royal Melbourne Hospital. Although she loved nursing, she had to stop working when she got married in 1948. She happily dedicated the next 25 years to being a housewife and mother. She called this period of her life "a labour of love". She considered being able to stay home and raise a family as a privilege. In 1973, mum returned to the Royal Melbourne

Hospital as an evening nursing administrator after her youngest child, me, started high school.

Mum appreciated staff at Victoria by the Park who treated her respectfully though not all did. She gently rebuked, using a tone I imagine she used as a nursing administrator: "Please don't talk to me as if I am a child" or "My name is Joan, not sweetie".

Many staff took a moment to stop and have a short chat with mum when they walked past. This suggests there were enough staff on duty so they weren't all rushed off their feet like I hear they are in other aged care homes.

With my encouragement, mum began to make friends with other residents. Greg was one of her favourites – though soon after this photo was taken Greg fell in love with another resident, Heather. The staff treated their relationship respectfully.

Mum made lifelong friends with several residents at Victoria By The Park– though many of her new friends did not live for long. Her good friend, Trudi, died in 2014. Soon after, so too did Sam, Val and Alma. Greg and Heather also died.

Mum celebrated her 90<sup>th</sup> birthday with a lovely party with family and friends at my house. After the party, residents and staff celebrated Mum's 90<sup>th</sup> birthday with leftover champagne and a lovely cheese platter.

I felt sad when a 94 year old announced that her GP had told her not to eat her favourite soft cheeses. She was told that eating soft cheeses would raise her cholesterol. My mum also loved soft cheeses – and I encouraged her to eat as much blue castello as her heart desired. In my view, she had reached an age when she could eat whatever she wanted, irrespective of her cholesterol levels. Mum loved me taking her to McDonalds for a cheeseburger, fries and chocolate shake. Mum also loved eating fish and chips at the beach.

On her 91st birthday, staff gave Mum flowers and a birthday card and the kitchen staff made her a large birthday cake that was shared with the other 60 residents after they had all sung "happy birthday". Mum invited her family to eat lunch with her in the residents' communal dining room. We ate what the residents ate – and we all said it was delicious.

I began a routine of arriving each day around lunchtime. I would sit at the table with Mum's friends. Mum did not have a large appetite – but she was always given a full portion at lunchtime so that I could eat her leftovers. The food was excellent.

Every Tuesday afternoon, Mum, Etta, Marion and I played bridge. Etta was once a State Champion. She was a formidable opponent. Other afternoons, Mum, Lorraine Kay and I did the Age Crossword.

Sometimes several residents would sit and knit together in the afternoon. The residents helped knit this blanket for Mum's newest great grandchild, Alfie.

After lunch, I took mum out to the park next door. Sometimes other residents came with us. This photo is of mum in her wheelchair, Frank Breadmore in his electric scooter and Esther Friedman with her walker. The total age of these gadabouts is 287 years.

There was a large playground in the park – and mum loved watching children having fun. When Mum's great grand children visited they transformed the lounge room into romper room which Mum and the other residents really enjoyed. We had our own 'Old People's Home for 4 Year Olds'.

After I had been visiting Victoria By The Park for about 6 months, Jane Morison approached my brother and me to express her concerns that standards of care had declined at Victoria By The Park since the manager who we all loved had retired. Jane told me she was forming a relatives' group. My brother said he didn't want to get involved. But I did.

I attended a first meeting with 25 relatives and listened with amazement to their grievances – many of which sounded very serious. Most of the complaints were about standards of care. There were also allegations of theft, abuse and negligence.

Sharing complaints with each other was extremely important. Rather than everyone think their complaint was a "one-off", it highlighted the fact that there was a systemic problem in the aged care home.

So what did we do? Some wanted to go straight to the media but I did not see how this would resolve our problem. I suggested, in the first instance, families documented their grievances. I then spoke with staff – particularly the ones who I felt provided wonderful care to Mum. They met with me off-site and shared stories of bullying and intimidation by the manager. I also talked with several residents about their concerns.

Some family members provided evidence with photographs of badly maintained bathrooms and disposal of waste.

I collected all the grievances from families, staff and residents and wrote a 60-page report.

The grievances mostly related to management, staff morale and standards of care. I believe there is a correlation between staff morale and standards of care. If staff are happy in the workplace they are more likely to provide good quality care to the residents.

I then met with the owner. I gave him the documented list of the grievances. The first thing he did was to apologise. I could tell that it was a genuine apology. Then to his credit, he responded quickly.

The manager 'retired' and several carers were not seen again. My concern is the carers went to work in another aged care home. I am glad one of the recommendations of the Royal Commissioners is to introduce a system of

registration for PCAs similar to other health care workers. I see no reason why this recommendation cannot be introduced immediately.

With a new manager, staff morale improved and standards of care were restored.

This is where my advocacy began.

With my background as a public health researcher and a registered nurse who had worked in intensive care units, I began to observe life in the aged care home through a critical lens. I began analysing issues in the aged care system and writing regular letters to the *The Age*.

I soon developed a reputation in Melbourne as an aged care advocate.

At the same time as writing Letters to The Editor, I was also sharing Mum's experience of financial and emotional abuse in articles in *The Age*. Given my brothers had chosen not to engage with me, I started a public conversation.

To protect mum, I published the initial articles under colleagues' names. After mum's death, I began to write these opinion pieces using my own name. My intention was to raise these issues in a public forum, not to embarrass my brothers.

I also sought advice from Senior Rights Victoria. They encouraged me to make a submission first to the Victorian Royal Commission into Family Violence and then later to the NSW Inquiry into Elder Abuse and the Australian Law Reform Commission's Inquiry into Elder Abuse. Like most things in aged care, there have been numerous inquiries on the topic of elder abuse – but not much action.

In all these submissions, I claimed the abuse against mum was underpinned by ageism, misogyny and entitlement. I am credited with coining the phrase "Early Inheritance Syndrome". However this term was first used by Adele Horin. I had asked Adele for permission to use her term "Early Inheritance Syndrome" in my opinion pieces.

I was pleased, though I am sure my brothers were displeased, that the Final Report of the Victorian Royal Commission into Family Violence quoted me several times. This is a section from the report:

*The Commission was told that elder abuse can involve stereotypical assumptions that women, particularly older women, are less capable than men. As one person explained, and that one person was me: '[s]ome children assume that an older woman, particularly a woman who has not been the family's breadwinner, is unable to manage her own finances after her husband dies'.<sup>23</sup> She concluded that '[m]y brothers' perspectives of power, entitlement and gender roles led them to financially abuse their mother'.*

I believe in conversation not escalation. So I tried again to encourage my brothers to attend formal mediation. I received an email agreeing to

“independent medication”, a typo that I found funny given my two eldest brothers are doctors. I replied that we should all take “kindness pills”.

Soon after agreeing to mediation, 2 brothers cancelled due to their health and one cancelled due to disinterest. 5 years after my mother died – I tried again. I was told: “I am not interested in covering old ground again. I see no value in mediation and would not attend.” In contrast, I believe honest conversation is the only way relationships heal.

So instead of conversation, we had escalation. One brother sought legal advice about my public submissions on elder abuse despite the fact that I had quoted their emails and text messages verbatim.

And just when I thought it could get no worse, I was told mum could not visit her own beach house at Christmas because a granddaughter had booked it. I was told that mum had no respect for the “google booking”.

My brother told that: “mum would not want to cause any inconvenience”. In his mind, mum should cancel her plans for her Christmas holiday because older women don’t make a fuss. This blatant display of misogyny and ageism was breathtaking.

While I batted back a flurry of angry emails and text messages, my heart was breaking. Surely my brothers understood that mum was entitled to use her own beach house whenever she wanted.

I ignored their efforts to prevent mum visiting her beach house at Christmas. I then began taking mum to Mt Martha with a carer for a few days every month. Mum looked forward to these trips, away from the routines of the aged-care home.

Mt Martha was mum’s special place. When she was 11, her parents had bought a block of land and built a beach house there. For the next 80 years, mum was happiest when her beach house was overflowing with family and friends.

Towards the end of her life, mum came alive sitting on the deck with family and friends or in front of the fire surrounded by people and dogs, chatting and reminiscing. She even enjoyed her daily exercise walking around her beloved tennis court.

After mum died, I discovered Mum’s will had been changed with a codicil. The date on the codicil was soon after mum had experienced a stroke. My head literally exploded. I sought legal advice.

Unbeknown to me, the legal firm I chose had once been called “Read and Read”, a firm that my great great grandfather, Albert Read, had begun in 1860s. Albert Read had developed a reputation for acting on behalf of the ‘under dog’. In a battle against these men, I knew that I was the under dog.

The first thing I discovered was mum’s solicitor had destroyed all the files pertaining to her will. So there was no way of knowing who had instructed the

solicitor to prepare the codicil. Given mum's difficulty with speech after her stroke, I was sure mum had not instructed the lawyer.

I made what I considered to be a fair proposal to my brothers. In response, my brothers hired the "best QC in Australia", just as you'd expect. Fortunately, she advised my brothers to accept my offer so we avoided court.

I have chosen to tell this family story about power, entitlement and gender because this experience taught me the skills I needed to deal with men in the aged care industry who respond aggressively to my Opinion Pieces, some even threatening legal action. Every time I receive an angry email, I respond politely and invite the provider to publicly contest my claims. I never hear from them again.

So – back to Mum living in an aged care home. After a year or so of visiting Mum, I became concerned that the media only reported horror stories about aged care. Surely Mum was not living in the *only* good aged care home in Australia.

I designed an open-ended questionnaire for family and friends who visit an aged care home. The questions included:

What do you like about the aged care home that you visit? What don't you like? If you could change ONE thing to improve quality of life of residents, what would you change?

I also asked specific questions about personal care, services, activities and physical environment. The questionnaire concluded with: "What things reassure you that residents are safe in the aged care home?"

I recruited using a community engagement method. Every time I had a letter published in *The Age*, people completed the questionnaire. The findings focused more on negative experiences than positive.

After completing this research, my plan was to write a personal story about mum's experience living in an aged care home. This would have been a positive story. However, things changed dramatically during the last month of Mum's life.

The details of Mum's fall are not important except to say that the instructions on Mum's walker were not followed. The manager apologised for the error. Given a brother's predilection for threatening litigation, this apology was probably important.

Like many older people who have a serious fall, the fall hastened Mum's death. In fact, the story of Mum's preventable death made headlines in the *Sydney Morning Herald*.

When Mum was dying, I sat at her bedside to protect her from inflexible routines and policies. I ensured she slept as long as she needed, and ate when (and if) she wanted. I had once worked as a critical care nurse – so I knew how to care for a dying woman. It was a surprisingly happy time for us both. Some days Mum wanted to have breakfast in bed; other days she wanted breakfast at the table.

One day a family doctor visited Mum when she was sleeping. While he was at her bedside, he spoke over her to a nurse who was standing on the other side of the bed. The doctor wanted Mum to have stronger analgesia. Later that morning Mum asked me if the doctor wanted her euthanised. I tried to give the doctor some feedback – to remind him not to talk over his patients – but he walked away saying: “I am not going to listen to this”. This illustrates how some people consider constructive feedback as criticism that must be silenced.

I was Mum’s medical power of attorney and often disagreed with this family doctor about his changes to Mum’s medication. I had put an alert with the pharmacy so a pharmacist would phone me whenever Mum’s medication chart was changed. This became the basis of yet another letter to The Age. It was titled ‘Too quick to prescribe’:

I am the medical power of attorney of my 91-year-old mother, who lives in an aged-care home. She was recently reviewed by a psychogeriatrician, who prescribed a new drug to slow down the progression of Mum’s dementia, despite the fact her dementia is progressing slowly without this drug. Instead, I prescribed lifestyle intervention, such as outings and conversation, to improve Mum’s quality of life. Another doctor was concerned my mother was taking a diuretic without a potassium supplement. I explained that she ate several bananas a week, because they are her favourite fruit. Surely, this is preferable to taking a drug. Last Saturday, my mother had a fall. The doctor was sure she had not fractured her ribs, but still ordered an X-ray. The only treatment for a fractured rib is rest and analgesia. I cancelled the X-ray and instead prescribed trips to the park in a wheelchair and The Age crossword. With burgeoning healthcare costs, I call on all medical doctors to ask: is that drug or medical test really necessary?”

As the days went by at Mum’s bedside, I was shocked that only the experienced staff had the skills required to care for Mum when she was dying. Some PCAs, many of whom were caring people who I liked, provided thoughtless task-oriented care. On one occasion, I arrived to find Mum almost on the floor. Later that morning, a PCA came to her room around 8am to change Mum’s night incontinence pad. Mum was sound asleep. I asked the PCA to let Mum sleep and to change the incontinence pad when she woke up. She replied: “*It is policy. She must have a day incontinence pad because it is day time.*” I questioned this so-called policy, and the PCA replied: “*I just work here. I do what I am told.*”

Soon after this incident, I received an email from the Manager. She asked me to leave Mum’s bedside: “*I need you to let my staff do their jobs... Interfering with Mum’s care is not helping her.* I was gobsmacked.

I replied: *I hope you will re-consider your comments in your email and perhaps educate your less experienced staff about working in partnership with family members. Some relatives want to be involved in ‘hands-on’ care, others don’t. I believe this should be our decision, not yours.*

I did not have confidence that staff could do their jobs and refused to budge from Mum’s bedside.

The day after Mum's death, the aged care home's GP phoned me to confirm the time of death. Staff had told him she had died at 6.30pm. I told him it was in fact 5.35pm. He also asked me what he should write on her death certificate. After visiting Mum monthly for several years, I expected him to at least know her medical history.

I doubt I would have continued my aged care advocacy after Mum died if I had not received the manager's request to leave my Mum's bedside or felt so bewildered by the GP's incompetence.

I published Mum's obituary in *The Age*. Most obituaries are about men whose work has been important. Although Mum did not split the atom – women of her generation were the social glue that held everything together. She was also a champion Mum and I wanted to acknowledge this publicly.

Soon after the obituary was published, the opinion editor at *The Age* phoned to discuss the letters I had written. She asked if I would consider writing an Opinion Piece. I agreed. The article was given the title: "*The Aged Care Gravy Train*". This Opinion Piece catapulted me into serious aged care advocacy.

Soon after this opinion piece was published, several long-time aged care advocates phoned me. They talked at me at length about the systemic problems. Another who had been an advocate since late 1990s also phoned regularly. However, when I saw her Tweets, it became clear that our advocacy styles were different.

While many aged care advocates use ad hominem attacks on social media, my aim is to focus on solutions, not problems. I do this by engaging with 'key stakeholders'. Although my focus is on older people, their families and staff, I also collaborate with providers, health bureaucrats and politicians. I believe it's only by working collaboratively that we will find sustainable solutions.

My qualitative research business is called Research Matters so I decided to do my advocacy under the umbrella of Aged Care Matters. (I also have a fishing boat called Nothing Matters and a sailing boat called Everything Matters).

Aged Care Matters began as a small group of 60 people who were concerned about residents' quality of life in aged care homes. Over the past 5 years, the group grew to have over 3,300 members in my Facebook Group 'Aged Care Advocacy Group'. It became a go-to page for older people, families and staff wanting to share their experience with aged care services or to seek advice from other members on how to tackle problems.

My first research report: *Living well in an aged care home* provided evidence about standards of care in homes around Australia. Some providers found the feedback very useful. One contacted me to say: "I am keen to explore how providers get this feedback and use it successfully". I think it is essential that senior people working in the aged industry use this type of critical feedback constructively – rather than respond to it defensively. Critical feedback provides an opportunity for quality improvement.

When an advisor to Aged Care Minister, Ken Wyatt, read *Living well in an aged care home*, she asked if I could do something similar for home care. She wanted an independent researcher to interview recipients of home care packages. This led to an interesting experience with the federal Department of Health. The report *Living well with in-home care* identified systemic problems. I also began to recognise that many of the systemic issues in the aged care sector originate in the Department of Health. That is why I was pleased Pagone recommend Australian Aged Care Commission in the Royal Commission's Final Report – removing aged care from Department of Health.

During the Royal Commission, I became concerned about the impact the 'heart-breaking stories' were having on staff who work in aged care homes. As a researcher, I am aware that the Royal Commission heard experiences from a biased sample. Older people and families who had a good experience in aged care homes or with home care were less likely to make a submission than those who had bad experiences.

I decided to ask staff what they liked about working in an aged care home, what they didn't like and for their suggestions for how to improve residents' quality of life. Unfortunately, I could not find an organisation to fund the analysis of the data. I decided to go ahead unpaid and analyse the data on what staff liked about their job. I released the report *Working well in an aged care home* on Aged Care Employee Day in 2019. It is disappointing that the data on what staff don't like about their jobs and their suggestions for improvements remain unanalysed.

Last year, several aged care advocates who disagree with my collaborative approach to aged care advocacy began abusing me on social media. The abuse began by comparing my meetings with aged care providers to "*having lunch with George Pell*". It later escalated to vulgar, bullying and harassing posts.

I wrote an article about the bullying and abuse for HelloCare. This article caused the abuse to escalate with numerous abusive comments on my Facebook page from those using IDs such as: Marilyn Munro, Kirri Billi and Tess Tickle.

I later named in a comment on HelloCare those who had made uninvited comments on my Facebook page. I referred to them as "trolls", unaware that one of those who had posted on my page was a real person. This person subsequently sued me for \$100,000. I did not drag my case through the courts and instead settled the case with "go away money".

To claim this money on my Indemnity Insurance, I needed the owner of HelloCare to share an email she had received from the plaintiff. She, however, claimed this email was private. She clearly felt no obligation to help me despite the fact that I had written numerous articles for HelloCare – and had made a submission to the Royal Commission on her behalf.

After this horrible experience, my intention was to walk away from aged care advocacy. However, my local MP and friend, Ged Kearney, told me that my advocacy was important. She encouraged me to join Twitter.

Every time I read my Twitter feed, I am reminded that we need conversation not escalation.

So I am still here –willing to work with whoever shares my vision on how to improve the quality of life of older people who use aged care services.

Recently, two retired women, both very knowledgeable about aged care system based on their first hand experiences, contacted me and asked for my help to start a “People Power Movement” to reform the aged care system. We initially called this movement Aged Care Reform Matters, but given the urgency to fix aged care, I later changed it to Aged Care Reform Now.

These two women encouraged me to shift my focus from advocacy to activism. We started meeting around a kitchen table. Two months later Anna Willis from issue.watch contacted me. She wanted to improve the aged care complaints system. She told me that a mature industry deals with complaints as an opportunity for quality improvements. I invited Anna to join us at the kitchen table.

Later, I put a call out in the FB group for volunteers to help us to design a website. Erietta Sapounakis volunteered. Later Michelle Cameron also volunteered to help.

Erietta and Michelle have brought their professionalism, enthusiasm and extraordinary IT skills to our movement. Working together around the virtual kitchen table – that is, via zoom, I began to see a light at the end of the tunnel.

I am excited that two older people started this movement. Their determination to see reform was powerful. I began to see a future in which older people carried signs that said: “Nothing about us without us”

Although membership of our team has changed over the past 6 months– and will continue to change - our team is united with a shared vision for the future of aged care. Our core values are kindness, empathy and compassion. We are all committed to a new aged care system that is focussed on the human rights of older people, not the profits of providers.

I continue to believe it is only by working together – with older people, families, staff, providers, unions, academics, bureaucrats and politicians – that older people in Australia will receive the care and support they need. I do not believe reform will come via Twitter.

While many have their hopes on the Royal Commission into Aged Care Quality and Safety, I am aware that governments – both Liberal and Labor - have ignored key recommendations from so many inquiries, reviews, thinktanks, consultations and taskforces over the past 20 years.

We must work together to make aged care an election issue at the next federal election.

A journalist asked me recently why I continue to advocate for aged care reform given both my parents are dead. His question implied that all activism is based on self-interest. I continue to speak out because Aged Care is a social justice and human rights issue.

Older people deserve access to high quality aged care services – both at home and in residential care. The current system is broken. We must fix it. If not now, then when?

Thank you.