Submission
No 287

INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Name:	Name suppressed
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NSW Parliament Legislative Council Rural Health Inquiry.

I refer to the following terms of reference:

a) health outcomes for people living in rural, regional and remote NSW;

(b) a comparison of outcomes for patients living in rural, regional and remote NSW compared to other local health districts across metropolitan NSW;

(g) an examination of the staffing challenges and allocations that exist in rural, regional and remote NSW hospitals and the current strategies and initiatives that NSW Health is undertaking to address them.

I wish to raise awareness about SYSTEMIC AGEISM within NSW Health and Hospital services, which my Father first experienced in a rural health setting.

AGEISM and a general acceptance within the entire medical sector that younger patients should be prioritised for treatment is not only ending the lives of otherwise healthy and productive patients, it is also forcing people into Aged Care facilities that would otherwise be able to maintain their independence and remain in their own homes.

In 2012, the AGEIST and dismissive attitude of a rural GP resulted in a misdiagnosis that left my father close to death.

While his life was ultimately saved by staff in a Sydney hospital, by the time they treated him, because of the ongoing neglect and malpractice of the rural GP, his health had deteriorated to such a degree that the quality and enjoyment of the remainder of his life was compromised.

While he lived his life to his full capacity, his life was forever changed.

MY FATHER’s EXPERIENCE.

My Dad, was born in Sydney in 1936.

His working life as a teacher, statistician and epidemiologist, mostly in rural NSW, was dedicated to education and research, and until his death he maintained contact with one of the students from the first class he ever taught in 1958 in north-western NSW.

He loved sport and exercise and was physically active all of his life.

He ate well and after retiring aged 60, was dedicated to maintaining his health and fitness, attending the gym several times a week, swimming, cycling, lifting weights, doing yoga and tai chi.

- In 2007, aged 70, Dad was living in Bathurst NSW, when he was diagnosed with Prostate Cancer.

After researching his health options locally, he undertook Brackytherapy at St Vincent's Hospital in Sydney and made a full recovery.

- In 2011, after Dad had undergone Hip Replacement surgery in Bathurst, I accompanied him to a post-operative appointment with his Bathurst GP, Dr who I found dismissive to Dad's questions.

At the time Dad was aged 74 and Dr responded to Dad as if he didn't consider what Dad was asking or saying to be important.

I asked Dad afterwards if he was always so dismissive and I remarked to Dad that **I considered his manner to be "ageist".**

This was my first encounter with such behaviour.

- In 2012, my father consulted the same GP because he was having chest pain each night as he tried to sleep.

After several months Dad asked the Dr if he should be referring him to see his cardiologist who was located in Sydney.

The Dr dismissed the request and without performing any tests or referring Dad for any tests, he diagnosed "heartburn and asthma" suggesting he use Gaviscon.

It turned out that **for 6 months my father was in fact having small nightly heart attacks.**

This misdiagnosis almost claimed his life and ultimately reduced the quality of his remaining years.

- In September that year, while staying with my brother in Sydney, Dad became ill.

My brother's GP diagnosed heart failure and immediately referred Dad to Royal Prince Alfred Hospital.

As a result, Dad was fortunate to be at RPA when several hours later he had a massive heart attack.

When the surgeon operated, he found **Dad's heart was black from prolonged blood deprivation and he declared it was the worst case he had seen.**

Post-surgery my Dad's liver and kidneys started to fail.

The RPA doctors considered my father's history of fitness and healthy lifestyle and knew his life was worth saving and proceeded with a successful second surgery.

- Dad spent a month in RPA, mostly in ICU, including 12 days in a coma, then another month in rehab hospitals.

- He was fitted with an implantable defibrillator and gradually recovered and returned to his healthy diet and a modified fitness regime.
- Despite the damage to Dad's heart in 2012 being assessed as likely being irreversible, during a 2018 appointment with his cardiologist, Dad was told that because of his healthy lifestyle and dedication to fitness his heart was in excellent shape.

The staff of RPA gave my father due consideration based on his LIFESTYLE rather than his age, giving him CHOICE and a second chance at life, and he lived his subsequent years as actively as possible.

- **Dad's near death survival following the negligence of the Bathurst GP forced Dad to make the difficult decision to leave his life and friends in Bathurst in order to have ready access to his Sydney medical specialists.**
- **It's unacceptable that substandard rural healthcare forced my father to completely uproot his life.**
- Post 2012, Dad permanently relocated to Sydney and continued to see the GP who had diagnosed his heart failure and referred him to RPA.
- He continued to provide respectful, professional care for Dad.
- From 2014 - 2018, to address a number of age-related conditions, Dad required various surgeries which were performed either at North Shore Private Hospital or the Mater Hospital at North Sydney.

These were completed with no complications and Dad received excellent care.

Unfortunately in 2019, despite having private health cover, Dad was forced to seek treatment in the public hospital system in Sydney, where he again encountered AGEISM and discrimination.

Among a range of unacceptable experiences; requests for diagnostic services were rejected, my father was dumped in the ER for 26 hours, we faced coercion to sign a Do Not Resuscitate Order and repeated requests to return Dad to his Oncology team in the hospital of his choice were denied.

The denial of diagnostic services delayed the diagnosis of Non-Hodgkin's Lymphoma.

Despite this, after months of preventable pain and suffering, when Dad was eventually diagnosed and received treatment, the cancer responded and it was predicted Dad would be in remission within two months.

However, again systemic AGEISM saw him denied the treatment he deserved which led to his death within the following two weeks.

- On the three occasions Dad was admitted to RNSH in 2019**, staff, (many of them young, inexperienced and with little apparent supervision), failed in their duty of care.**

- **Much of the treatment Dad received was substandard and mismanaged, with necessary standard drugs not provided as required.**
- In May 2019, **Dr in the RNSH Aged Care Ward told my father he needed to have a colonoscopy.**
- **He then denied Dad's REQUEST to facilitate the recommended colonoscopy.**
- **When** I asked for the procedure to be done while Dad was already in hospital, said quote: **"it isn't urgent"** and quote: **"WE HAVE TO BE CAREFUL NOT TO OVER DIAGNOSE THESE THINGS".**
- **Had that colonoscopy been performed it would have immediately diagnosed Dad's Lymphoma and allowed life-saving treatment to start three months earlier than it eventually did.**
- **As a result of the delay, from May to August 2019, Dad suffered significant weight loss, pain, sleep deprivation and his mobility drastically declined because of pressure from a tumour on his spine.**

For the first time in his life Dad was forced to use a walking stick and then a walker, a severe blow to the morale of someone previously so fit, active and physically strong.

This along with the constant fatigue from lack of sleep saw a drastic decline in Dad's mood.

- **My father's age meant that he was pre-judged and written-off by staff in the RNSH ER, who wanted him/me to agree to a DNR order, BEFORE he'd even been examined or diagnosed.**
- **Staff never once asked if Dad had an Advanced Care Directive.**
- **When they wanted me to sign a DNR order, I told them that Dad's ACD would show them that was not his wish.**
- **The ER Dr named who wanted me to sign DNR papers said "I wouldn't put my father through it" (resuscitation), which to me amounted to emotional blackmail.**
- **I wondered if this is standard hospital practice or if I'd simply encountered a rogue doctor.**
- **Sadly I have since learned that our experience is common.**
- **When Dad had arrived in the ER, two nurses also spoke with him about signing paperwork rejecting antibiotics if he needed them. He did not sign.**
- **Dad's conclusion was that they didn't consider his life worth saving.**
- **In the following weeks, t**hree days before he died, my father was left in the RNSH ER for **26 HOURS** leading him to again declare "they don't think my life is worth saving".
- Countless younger patients in the ER came and went during that time.
- **After finally being moved in the evening to a single bed room, in the middle of the night without explanation Dad, (who had private health insurance) was moved to a noisy four bed ward, with his bed going to a younger patient.**
- **Dad said he felt he had been "dumped" there.**
- **My father was repeatedly denied a standard, basic drug required by all chemotherapy patients before each meal.**
- In my/Dad's experience, **the RNSH discriminates against older patients and largely wants them shipped out ASAP, potentially to high level aged care facilities.**

- **RNSH staff repeatedly denied my father his freedom of CHOICE, despite him having private health insurance.**
- **Because of his age, my father's rights to CHOICE and CONSULTATION under the Australian Charter of Healthcare Rights were repeatedly breached, with decisions presumed and made for him without consultation.**
- **Dad’s repeated requests to return to his Oncology Team at North Shore Private Hospital, (where he received the correct medication & the best of treatment and care, as well as respect with no sign of age discrimination) were repeatedly denied.**
- Dad's Oncologist at NSPH was professional, encouraging and positive about Dad's prognosis, saying the treatment had an 80 per cent success rate and she had successfully treated someone in their 90s with the same condition.

In the NSPH Oncology Ward Dad felt relaxed and happy and said he had "peace of mind" and believing he would make a full recovery, was making plans for the future.

Having seen Dad's determination and resolve to recover from previous health challenges, our family shared his optimism and believed completely that he would make a full recovery.

A scan on October 2nd 2019, showed that the chemo Dad received at North Shore Private Hospital was working; Dad's body was responding to the treatment and it was predicted he would be in remission by December.

Between chemo treatments at North Shore Private, Dad contracted a flu virus requiring him to be taken to RNSH and that spelled the beginning of what would ultimately be the end of Dad’s life.

- **Calls to Dad’s haematologist who was based at RNSH were never returned.**
- When I saw him, I repeatedly asked him when Dad could go back to NSPH, but he kept saying Dad “wasn't well enough”. But **the treatment at RNSH wasn’t conducive to wellness.**
- **I got the impression that it was for the convenience of the haematologist that Dad was not being transferred.**
- **A blood transfusion Dad was supposed to receive never eventuated, again leaving us to believe he was not considered a priority or worthy of optimal treatment.**
- **I am also left to wonder if the antibiotics he was supposed to be receiving in the final four days of his life, were also being deliberately withheld.**

  Just as in the wider community, AGEISM is rife within parts of our health system and it is KILLING loved and cherished seniors, who if properly treated would resume their productive, happy lives.

  When an older person presents to hospital with Delirium as a result of dehydration or malnutrition, it’s common for them to be written off as having Dementia, prompting hospitals to want them off their hands ASAP, without bothering to investigate what’s led to the dehydration or malnutrition.

> **At the height of Melbourne's covid wave,** the assertion by the Australasian College for Emergency Medicine that "**aged care residents are taking up valuable resources in Melbourne hospitals", was** abhorrent!!!

But it perfectly illustrates how out of touch that cohort is with community expectations.

And it vindicates my conclusion that hospital staff who see seniors as a burden on the system or a waste of time and resources, should be either RE-EDUCATED or RE-DEPLOYED to ensure they have no future access to older patients who are at their MOST VULNERABLE and EXPLOITABLE, especially when in a public hospital EMERGENCY ROOM.

Ideally these people should change their vocations, with their names recorded and registered to ensure they cannot simply move to another hospital or medical facility to put other seniors at risk.

It is unacceptable that vulnerable senior patients and their families are powerless to control their treatment in a hospital setting and FEARFUL of potential negative consequences or repercussions if they speak up.

It is heartbreaking that my father, a dedicated teacher who changed many lives for the better, was led to believe that HIS life wasn't considered "worthy of saving"!

My father was a unique and beautiful man, who rather than being treated with consideration, care and compassion, was pre-judged by negligent medical staff because of his age, and written off as a mere statistic, not a "person" but a "thing" they wanted out of their way as quickly as possible.

My father ultimately died from Septic Shock, after his ailing body succumbed to two weeks of malpractice, neglect, discrimination and disrespect at RNSH.

I will be forever haunted and traumatised by the suffering my father endured in the final months, days and hours of his life, primarily because he was denied the right to make informed CHOICES about his own treatment, with decisions taken out of his hands by ageist RNSH staff.

It was my father's CHOICE to bravely face his illness, receive hospital treatment, heal, recover and <u>*LIVE*</u>! A CHOICE that he was completely denied by RNSH.

CONCLUSION

IT IS MY CONCLUSION THAT AGE DISCRIMINATION AT ROYAL NORTH SHORE HOSPITAL AND THE RESULTING BREACHES OF A PATIENT'S RIGHT TO **CHOOSE,** ARE PREMATURELY COSTING LIVES.

- In our experience, older people are treated as if they're not capable of making informed decisions about their own treatment, therefore **CHOICES are denied them and made for them, with no consultation or explanation.**

As I have learned from senior friends of my father, this **often results in transfer to an aged-care facility, not of the patient's CHOOSING,** where, as the findings of the Aged Care Royal Commission have already revealed, they are often vulnerable to exploitation and receive substandard care.

Having their right to freedom of CHOICE taken away from them, they are left to feel powerless, prompting them to give up hope, resulting in premature death, which would seem to be what the "system" wants for them, so they are no longer a "burden" on resources.

- This sort of behaviour was compounded by other **negligence which led to my father becoming demoralised and believing his life was not valued or considered worth saving**.

Aged Care Mental Health experts acknowledge that **the morale and mental wellbeing of older patients are significantly compromised, when they're pressured or coerced into signing DNA orders or denied hospital beds in favour of younger patients.**

They say it leads them to believe their lives are considered by medical staff to be of little value and therefore not worth saving and can prompt them to "give up".

It's heartbreaking my Father was led to believe that his life wasn't considered worthy of saving.

It's also heartbreaking that many elderly residents in rural areas have resigned themselves to the fact their health is also not treated as a priority!!

MY OBJECTIVE

I am speaking up because my father can no longer speak for himself.

- **My father was a proud, dignified and private man and out of respect for that I am willing to provide more detail and speak publicly about his experience, on the condition my identity (and thus by extension his identity), are protected.**

My Dad, like every hospital patient, deserved to receive the best medical care available.

I tried to be my father's voice during his time in the medical system, but despite my best efforts I have been left traumatised by his suffering and overwhelmed by the feeling that I failed him when he needed me most.

- Even with an advocate by his side, Dad did not get the respect he deserved and was **denied the ability to die in the pain-free, peaceful way he would have CHOSEN and deserved.**
- My father had top private health insurance and **paid his way in the public system so as not to be a burden on the public purse,** making the substandard care he received even more unacceptable.

- **What is the point of having an Advanced Care Directive** if it is going to be completely ignored?

A friend who has had a similar traumatic experience in hospital with her aged father was told by a doctor working in a public hospital**, “older patients are not a priority but are down the pecking order”.**

How can this be acceptable on any level anywhere in Australia?

THANK YOU

My thanks to all of you in the NSW Parliament who are working to raise awareness about the lack of resources and unacceptable and systemic AGEISM and malpractice that’s rife in the RURAL Health system.

But sadly, as I have illustrated, in my/our experience, malpractice and discrimination is also common in better-resourced city health settings.

It is therefore obvious that “throwing money” at the system is only part of the solution.

Health is a sector involving people, human beings, which is in desperate in need of an injection of “humanity”.

It is therefore obvious that only a combination of adequate infrastructure, human resources and a change in attitude of those directing those human resources, can achieve any real change.