Submission No 142

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

Name: Name suppressed

Date Received: 8 December 2020

Tuesday, 8th December, 2020

SUBMISSION REGARDING JOAN CARE AT WYONG HOSPITAL

I am writing my submission to inform the Inquiry about the thoughtless, dangerous, careless and heartless treatment my Mum, Joan received at Wyong Hospital between September 6th – September 10th, 2019. I have a range of complaints about the care Joan received, the most serious of which is that I believe the totally unsatisfactory treatment Joan received contributed to, hastened or caused her death, which occurred on September 10th while she was in hospital.

Please find included in my submission:

- **Background about Joan**
- **Summary of the Issues we experienced**
- **A Summary of Joan's Care at Wyong Hospital**
- **My Recommendations**
- **A copy of Joan's Resuscitation Plan (sent separately)**

I am happy to be contacted if anyone wants to speak to me. If it is more helpful to the Inquiry process to share my name publicly I am willing to share my name but would want to be consulted about that.

BACKGROUND
BEFORE JOAN'S DEATH

At the time of her hospitalisation, Joan was a 93 year old lady living in the community. She had a range of health conditions which meant she could not live independently so she lived with my family (5 days a week) and with a live-in carer in Joan's home (2 days a week). Her various health conditions included moderate dementia, high blood pressure, high cholesterol, chronic kidney disease and an aortic dissection (September 2106), which were being carefully and well managed with medication and other measures.

Joan did not experience any serious illness or even any minor illness or require hospitalisation for any health needs during the 3 years she lived with us after her hospitalisation for the aortic dissection in 2016. Joan had not been hospitalised at any time during the decade prior to her aortic dissection.

Joan was mobile with a walker and able to look after her personal care needs with minimal or no assistance. She was able to look after various other simple needs such as making her breakfast and lunch. She was able to enjoy activities such as knitting, reading and watching television. Joan was able to enjoy a generally normal diet and loved to go on outings with family or friends in the community, which she accessed by walker or wheelchair. She loved her family and friends and was still living a happy life.

Joan was well and active in the time immediately before the events described in the following pages.

I am stating these things about Joan to show that she was still functioning well for her age and enjoying life in the time immediately preceding her hospitalisation. I am also stating these things so she is seen as a person not simply as a 93 year old deceased patient with multiple health conditions. Joan's life mattered as much as anyone's and did not matter less because of her age and health.

I was Joan's Enduring Power of Attorney, Enduring Guardian and Person Responsible. I was at the hospital or easily contactable at all times during Joan's hospitalisation.

SUMMARY OF ISSUES

Please see the following pages for more detail about the problems we experienced

During Joan's hospitalisation the following problems occurred:

- **Poor, inconsistent and contradictory communication about Joan's condition and her diagnoses**

- **Poor assessment of Joan's risk for aspiration and Aspiration Pneumonia including no communication with me about Joan's swallowing history**
- **Poor management of Joan's risk for aspiration and Aspiration Pneumonia including the misuse of Olanzapine**

- **Unforgivable misuse of Olanzapine:**
  - **Olanzapine was prescribed and used without any consultation with Joan or her Person Responsible (me)**
  - **Olanzapine was prescribed and used without even informing Joan or I**
  - **According to some drug information sources, the use of Olanzapine was contraindicated for Joan due to her health conditions so it should never have been given to her**
  - **Joan did not meet the criteria of being 'distressed' to justify the use of Olanzapine**
  - **Joan's Health Records show one nurse justified the use of Olanzapine due to staffing issues**
  - **Medical staff did not even manage to follow the hospital guidelines and over-prescribed Olanzapine to Joan**
  - **Joan had never taken an antipsychotic medication before**
  - **There is no evidence that Joan was monitored for side effects after she had taken the Olanzapine**
  - **Joan was given an excessive dose of Olanzapine, which I believe led to her being sedated and to experience a swallowing issue**
  - **Joan experienced a serious swallowing issue, which I witnessed**
  - **This issue occurred approximately 4 hours after Joan was given a second 5mg dose of Olanzapine within 8 hours (at 1.11 am and 8.39 am)**
  - **Joan was given an excessive dose of 10mg, in total, within 8 hours and against hospital guidelines**

- **Joan experienced serious mismanagement of her risk for Aspiration/Aspiration Pneumonia**
- **Joan experienced serious misuse of Olanzapine**
- **I believe this combination of factors and events potentially contributed to, hastened or caused Joan's death**

- **Failure to *consult* with Joan or I about the Resuscitation Plan (please see copy of the Resuscitation Plan)**
- **Life-changing decisions were made which changed the response to Joan's condition and Joan's access to treatment and *we were not consulted***
- **Joan and her Person Responsible had every right to be consulted about decisions about her care and this was denied us**

- **Failure to *inform* Joan or I about the Resuscitation Plan**
- **Life-changing decisions were made which changed the response to Joan's condition and Joan's access to treatment and we were *not even informed***
- **Joan and her Person Responsible had every right to be informed about decisions about her care and this was denied us**

- **Failure to complete the Resuscitation Plan according to NSW Health guidelines with the authorisation and signature of an AMO making the Resuscitation Plan medically and legally INVALID**

- **Joan became unresponsive very suddenly, with a nurse close by, but the invalid Resuscitation Plan directed there was to be no Rapid Response Call**
- **The prompt action of a Rapid Response Call and other measures could have resulted in a completely different outcome and potentially saved Joan's life**

After Joan's hospitalisation and sudden and unexpected death we experienced the following issues:

- **Poor, inconsistent and contradictory communication about Joan's diagnoses and her cause of death**
- **Failure to discuss the possibility of a post-mortem/other given the cause of death was actually unknown**
- **The Death Certificate stated 2 causes of death/illnesses, Aspiration Pneumonia and Acute Kidney Injury, that were never diagnosed by tests or examinations and were not communicated to us as confirmed diagnoses**

- **Failure to release all of Joan's Health Records as requested through the application that was made to Medico Legal**

- **Poor investigation into concerns about Joan's care by the Consumer Feedback department**

- **Poor investigation into concerns about Joan's care by the HCCC**

Please see the following pages for a detailed SUMMARY of JOAN CARE AT WYONG HOSPITAL…

SUMMARY of JOAN CARE AT WYONG HOSPITAL

FALL

Monday, 26/8/2019

- **Joan experienced a fall getting out of bed at home that caused injuries to her face, arm and leg**
- **She was taken to hospital by ambulance, checked etc and released the same day back into my family's care**
- **She was on antibiotics Alphaclav Duo – 500/125 (500 mg Amoxycillin, 125 mg Clavulanic acid) for 10 days up until the morning of 5/9/2020**
- **She was still active and going about most of her normal activities and routine**

CELLULITIS and DELIRIUM

Thursday, 5/9/2019

- **Joan was diagnosed with cellulitis by a GP and put on antibiotics Ibilex 500 (500 mg Cephalexin)**

Friday, 6/9/2019

- **Joan developed delirium and was taken to Wyong Hospital by ambulance from her home (where she was with a carer)**
- **(The paramedics *walked an unwell 93 year old lady with mobility issues and multiple health conditions, including cellulitis in both legs, down* her long, steep, slippery driveway to get her to the ambulance!**
- **This was completely unacceptable and I followed this up and received an apology from NSW Ambulance)**

HOSPITALISATION

Saturday, 6-7/9/2019

- **X-rays showed Joan's lungs were clear**
- **The diagnosis of cellulitis was re-confirmed**
- **We were not officially given any other diagnoses during Joan's hospital stay**

- **Joan was prescribed Olanzapine without any consultation with us**
- **Joan was given Olanzapine at 8.02 am without our knowledge**
- **Joan was admitted to a busy general surgical (?) ward into a very busy 4 bed ward/room**
- **Joan remained delirious that day**
- **Joan's diet was not modified to a soft diet despite what we now know were numerous risk factors for complications, particularly Aspiration and Aspiration Pneumonia**

Sunday, 8/9/2019

- **Joan was given Olanzapine at 1.11 am without our consent or knowledge**
- **Joan was given Olanzapine at 8.39 am without our consent or knowledge**
- **Joan appeared to remain delirious that day**
- **Joan experienced a swallowing/breathing issue after eating her lunch**
- **Although she was making an awful noise she showed no awareness**
- **I believe I was witnessing effects of the Olanzapine (sedation and swallowing difficulties), which caused her to experience a serious swallowing difficulty**
- **She was examined by Dr who said her lungs were clear**
- **At my request, Joan's diet was modified to a soft diet**
- **I believe I saw the Olanzapine wear off later that afternoon and Joan became more aware and talkative though still delirious**
- **Joan's Health Record shows that later that evening Joan became crackly and gurgly**

Monday, 9/9/2019: 5 – 7.30am

- **Joan was examined again by Dr**
- **An x-ray was done which showed her lungs were clear**

- **Around 7am, Dr rang me to say Joan had had another issue but did not clearly describe what had happened and did not say she had developed Aspiration Pneumonia**
- **He went on to say *"We won't be taking her to ICU"*, that she had *"a lot of health conditions"* and that *"she's had a lot of birthdays."***
- **He said she sounded gurgly and crackly and they would start (more) antibiotics to treat her**
- **Joan was made nil by mouth**
- **Joan's antibiotics were changed to cover her for the *possibility* of aspiration pneumonia**
- **The phone call with Dr was very one-sided and felt rushed. I was not given any opportunity to express my thoughts or opinion**
- **Dr *did not ask for my agreement* about Joan not being taken to ICU and *I did not give my agreement to this***
- **We were asked to come into the hospital expecting to discuss things further, including we assumed her ongoing care, but this conversation was not followed up on…**

- **We later found out that a Resuscitation Plan was completed at about 7am without consultation with Joan or with me and without even informing us**

The Resuscitation Plan directions were:

- **NO Non-invasive ventilation**
- **NO Bag and mask ventilation**
- **NO Intubation**
- **NO Referral to ICU**
- **NO Rapid Response Call**
- **NO CPR**

- **We were never informed about the Resuscitation Plan during Joan's hospitalisation**
- **I only found out about it in January, 2020 when I specifically asked the hospital how the decision was made not to resuscitate Joan**

- **The diagnosis written on the plan was Sepsis. Sepsis was never mentioned to us and is not mentioned in her Medical Notes**

- **A Nursing Progress Note in Joan's Health Records at 5.19am says *'doco Not for ICU or RR'***
- **The Resuscitation Plan including ACC were being acted on before any attempt was made to even contact me**

- **The Resuscitation Plan only had one signature on it**
- **This one signature was a JMO's signature**
- **There was no signature or authorisation by an AMO**
- **This lack of authorisation with a signature made the Resuscitation Plan medically and legally INVALID**

Monday, 9/9/2019: 9 am – 1 pm

- My husband and I went into the hospital after the call from Dr
- We had no idea the Resuscitation Plan had been 'activated'

- I wanted to know what ongoing care Joan herself wanted. I spoke to Joan and asked her if she wanted to get better. She thought about it and said *'Yes.'* I asked her the question a second time and she again said *'Yes.'*

- Dr and 3 junior doctors arrived to check Joan
- Dr said the cellulitis was improving
- He hoped the delirium would resolve in the next few days
- He listened to her chest and said her lungs were clear and he did not say she had Aspiration Pneumonia
- He spoke to the junior doctors about when the last chest x-ray was done. The last x-ray that appears in Joan's records was taken early Monday morning. This has been confirmed as the last x-ray (via email to Medico Legal 14/5/2020)

- (From our interpretation that xray report showed Joan's lungs were clear ie *no confluent consolidation*
- A letter from Wyong Hospital dated 7/11/2019 stated *'A chest x-ray was ordered which was carried out on 9 September 2019 and showed no changes from her previous x-ray* (in Emergency 7/9/2019)'
- The letter also stated *'the possibility of aspiration pneumonia… was never confirmed')*

- Dr assessment of Joan's condition and illnesses was completely different to Dr assessment only 2 hours previously
- I expressed my relief regarding Joan's condition and said *"I thought we were going to have 'the talk'"* (ie re our opinion about treatment, comfort care etc) and I expressed that I was glad we weren't having it
- The doctors looked at me without comment and left the room

- Nothing was said about the Resuscitation Plan
- Again, nothing was said about Aspiration Pneumonia or that Joan's condition was potentially declining or life-threatening
- Joan's breathing was noisy and the dr had said he thought this was from her not swallowing or coughing to clear the secretions (*text to my cousin at 10.15 am*)
- Later the nurse indicated this should be temporary (*text to cousin at 10.15 am*)
- I think Joan was suctioned around this time
- I was not made aware of her being suctioned again
- Joan spoke to her son on the phone and had to end the call because she was having a 'coughing fit'

- Joan had not slept properly, due to the delirium, since a short nap on Friday afternoon and around 1pm Joan finally went into a sound sleep

Monday, 9/9/2019: 1 pm – 9 pm

- My husband, and I were in and out of the hospital the rest of the day visiting Joan
- We were with Joan most of Monday from about 9 am to 9 pm
- Her breathing sounded normal to us during this period
- Joan slept soundly from 1 pm-ish which we assumed was the sleep she needed after being awake with delirium for nearly 3 days
- *Text to cousin at 1.36 pm* to say Joan was finally having a good sleep
- I did not mention Joan's breathing and my recall is that her breathing was fine
- Joan was put on oxygen though nasal prongs in the morning and a fluid drip to keep her hydrated in the afternoon
- These measures were explained by a nurse as being to help her while she was recovering and nil by mouth
- At no point, during this period, were we told Joan had developed Aspiration Pneumonia or Acute Kidney Injury or that she was declining, deteriorating or dying

Monday, 9/9/2019: 9 pm – Tuesday, 10/9/2019 6.30 am

- At no point, during this period, were we told Joan had developed Aspiration Pneumonia or Acute Kidney injury or that she was declining, deteriorating or dying. The hospital has since confirmed that Joan was not considered to be declining, deteriorating or dying.

Tuesday, 10/9/2019: 6.30 am

- Call to say Joan had died

Talked to the nurse, about how Joan had passed away

- She had slept soundly and comfortably through the night
- The notes indicate she had been alert and oriented
- The nurse did not report that Joan had experienced any breathing difficulties, decline, deterioration etc through the night
- No mention was made of suctioning
- He reported that Joan had been responsive and communicative minutes before she died. She had answered his questions (*Are you ok?...Yes. Do you have any pain?...No)* and followed his instructions to help adjust herself in bed. Joan bent her knees and pushed herself up in the bed. He went away for a brief time and came back and she was found unresponsive

- **No Rapid Response Call or action was taken to resuscitate Joan because of the directions in the Resuscitation Plan, which we had not agreed to, not been consulted about and not even been informed of**
- **The nurse expressed his shock that Joan had passed away so suddenly and that it was unexpected**
- **No attempt to resuscitate her was mentioned and I did wonder why this was not done**

Tuesday, 10/9/2019: 10 am – after 12pm

- **My husband and I went to the hospital to spend time with Joan**
- **We asked to see a doctor because we wanted to understand the suddenness of her death**
- **We waited approx. 2 hrs until someone came. We had to ask a number of times for someone to come**
- **I asked about the cause of Joan's death and the doctor explained to us it was probably a HEART ATTACK**
- **He spoke to us in some detail and for some time about how a heart attack would have occurred**
- **He did not once mention Aspiration Pneumonia or Acute Kidney Injury when explaining the cause of her death**
- **He said that the medical staff were all surprised by the suddenness of her death. The nursing staff also expressed the same surprise**
- **I came to my own conclusion a heart attack was not proven but I expected the doctor was basing his belief it was a heart attack on some form of clinical evidence**

- **(We later found out that Joan's Medical Notes said that Joan had experienced a *'Terminal event overnight and was likely a very sudden event, most likely an MI or PE.'***
- **We were later told during the Consumer Feedback 'Investigation' process (First response from Hospital 7/11/2109) that Joan's *'passing was an unexpected event and* (it was) *impossible to be exactly certain as to what happened.'* The letter also said, *'At no point was Ms considered to be dying and as previously mentioned her death was unexpected.'*)**

30/9/ 2019: Arrival of Death Certificate

- **When we received Joan's Death Certificate I was shocked to see the first illness in the *Cause of Death and Duration of last illness* was listed as *Aspiration Pneumonia*, and the duration as *days*, when this was diagnosis was not**

communicated to us before her death or mentioned by the doctor who spoke to us after her death

- **I was equally shocked to see *Acute Kidney Injury* listed second, and the duration as *days*, when this was never diagnosed and communicated to us before her death or mentioned by the doctor who spoke to us after her death**

Consumer Feedback process

8/10/2019 – 15/4/2020:

- **Wrote First Letter to Wyong Hospital because of questions about the Death Certificate**
- **I asked for a thorough investigation into communication about Joan's care but the hospital was not forthcoming**
- **The hospital avoided providing me with crucial information about Joan's care, the most serious of which was failing to inform me about the Resuscitation Plan until I specifically asked how the decision was made not to resuscitate Joan. I was given a minimal and very dismissive response to that question along with a very hollow apology**

- **I wrote two more letters before the process was shut down in April and I was told to go to the HCCC for 'resolution'**

- **My experience with the HCCC has been frustrating and prolonged**
- **The HCCC provided a response that failed to satisfactorily address a number of my complaints including some of the most serious ones:**
  - **The legal and medical validity of the Resuscitation Plan**
  - **The impact of the directions in the Resuscitation Plan on the response to Joan's condition and the outcome for Joan**
  - **The unnecessary use of Olanzapine**
- **I am currently involved in the Review process and awaiting the response**

Medico Legal assistance

9/10/2019 – 9/11/2020:

- **Applied for Joan's Health Records asking for ALL information relating to her care**
- **I was initially only given the records for her time in Emergency**
- **It took 3-4 more requests before I received all of Joan's Health Records**
- **I only received Joan's Resuscitation Plan after making a specific request for it in January, 2020**
- **I was asked if I wanted the information for litigation purposes**

- **When I read the Resuscitation Plan, I was shocked and deeply insulted that such life-changing decisions about Joan's care were not discussed with us and we were not even informed about the changes to her care**
- **The last Health Record information I received was sent to me in November this year/2020 after I made a further application for Joan's Health Records**
- **I believe the Medico Legal department was deliberately uncooperative and obstructive**

MY RECOMMENDATIONS

My dear Mum, Joan, died in highly questionable circumstances and I am still waiting for answers about her care and treatment nearly 15 months later. I have experienced a huge amount of unnecessary confusion, distress and delay in getting resolution. I am doubtful I will receive resolution through the processes available.

After watching the recent 60 Minutes story and hearing that an Inquiry had been announced I was hopeful that things might change but reading the stories of other people, who spoke after the story was aired, made me lose hope.

I very sadly and shockingly learnt that my Mum's experience was not an isolated incident. I sadly and shockingly learnt that poor experiences and outcomes in NSW hospitals are all too common, all too easily accepted and tolerated and all too easily forgiven and forgotten. Mistakes get swept under the carpet. I dislike this saying but it is so true that often 'doctors get to bury their mistakes.'

Changes to policies, processes and procedures need to be made urgently to avoid these mistakes being repeated and to avoid more lives being put in unnecessary danger or prematurely lost. It is unbelievable and completely unacceptable that some current practices allow medical staff to completely ignore the patient's right to be consulted and informed about *their own care*.

I recommend the following SHOULD BE DONE URGENTLY:

1. **The process for preparing Resuscitation Plans needs to be reviewed and CHANGED, so that it is not possible for a doctor to complete and activate a Resuscitation Plan, without the patient and their Person Responsible/guardian or loved ones knowing. Patient consent is essential.**

2. **The process for preparing Resuscitation Plans needs to be reviewed and CHANGED, so that it is not possible for a JMO to complete and activate a Resuscitation Plan, without consultation with and authorisation from an AMO.**

3. **The process for prescribing antipsychotic medication to the elderly needs to be reviewed and CHANGED, so that it is not possible for a doctor to prescribe antipsychotics, and for staff to then administer antipsychotics at their discretion, without the patient and their Person Responsible/guardian or loved ones knowing. Patient consent is essential.**

4. **Medical staff must be educated/re-educated so that they respect the patient's right to be consulted and informed about their condition and treatment. Medical staff must be educated/re-educated to consult, inform and keep their patients up-to-date about their diagnoses, their condition, changes to medication, treatment decisions etc**

I appreciate the chance to submit our experience and concerns. It is sadly not possible to change the outcome for our dearly loved Mum and Granny but I have some hope that this Inquiry will result in change and improve outcomes for future patients in NSW hospitals.

Wishing all the best to everyone involved in this very important Inquiry.