Submission
No 416

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

Name: Mrs Barbara Seis

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Partially Confidential

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Re. Inquiry: Health Outcomes and Access to Health and Hospital Services in Rural, Regional, and Remote New South Wales

To the Committee Members,

I am writing a submission to the above inquiry with regards to the treatment received by my late husband, Barry Seis.

Barry was diagnosed with melanoma on his lung cavity in mid-December 2019. In early January 2020 he received a further diagnosis that the melanoma was in his brain. Barry commenced treatment for the melanoma in mid-January 2020.

On the 24th of January, Barry was taken to the Gulgong Multipurpose Service (MPS) as he was very confused and his vision seemed affected, which he had not experienced until that point. We arrived at the MPS at about 5pm. Barry's diagnosis of melanoma on the brain was made known to the attending nurses. The visiting GP was informed that Barry was at the MPS. The GP was also aware of Barry's diagnosis. The GP did not arrive to treat Barry until 9pm. My son and I were advised by the GP that his initial diagnosis was that Barry might have bleeding on the brain and he would be sent to Dubbo Base Hospital for further tests. My son and I were also told that if it turned out he did have bleeding on the brain he would most likely not be receiving treatment and he would be sent back to Gulgong MPS.

With Barry's condition and diagnosis, it was not acceptable that he waited 4 hours to be seen. When Barry was sent to Dubbo Base Hospital on the 25th of January, he was seen by a neurosurgeon. It was confirmed that Barry did have the brain bleed, however they were going to do everything they could to stop the bleeds and relieve the pressure. This was in compete contrast to what was said to my son and I the night before by the visiting GP.

Barry continued to receive treatment for the melanoma. On the 19th of March 2020, after being admitted to Gulgong MPS Barry suffered a seizure and was taken by ambulance to Dubbo Base Hospital early in the morning. On the way he suffered another seizure. He received a diagnosis from his treating oncologist that his cancer was terminal and he only had 2 weeks to live. My family and I were advised that an ambulance would be arranged to transport him back to Gulgong MPS that afternoon however there was no transport available and my daughter and I waited with Barry in the Emergency Room with Barry until a bed was found for him. Barry was transferred to a General ward at around 5.00pm in a room with 4 other patients. By this time, Barry was immobile and needed assistance with feeding, toileting, moving, and showering. A general ward is not an appropriate place for a man that has been diagnosed with a terminal illness, has low immunity from chemotherapy and needs additional care. This was also at a time when there was a heighted risk from COVID-19.

When my daughter and I left Dubbo Base Hospital that night, we were advised that Barry would be transported to Gulgong MPS the next morning. I rang Gulgong MPS on the morning of the 20th of March and was informed that they had not been advised by Dubbo Base Hospital that Barry was being admitted back to Gulgong MPS. After contacting Dubbo Base Hospital, I was advised that there had been a delay. I was told in a later conversation that Barry had left Dubbo Base Hospital at 2.50pm. My daughter rang the Gulgong MPS at 5.00pm and she was told that the MPS had not heard from Dubbo Base Hospital since that morning when Dubbo Base Hospital informed the MPS that Barry's transport was delayed. Barry did not arrive at Gulgong MPS until around 6.00pm that night. For the length of his stay in Dubbo Base Hospital, Barry remained in the General ward. I am not aware as to why it took so long to transport Barry back to Gulgong MPS.

Barry was admitted to Gulgong MPS in one of the 4 sub-acute beds, each bed with its own room and the ability to be closed off. My son, daughter and I went to visit him the day he was admitted. We were informed that under the directive from the Western NSW Local Health District (WNSWLHD) only one person could see him at a time due to COVID-19. For the duration of Barry's admission, there never appeared to be 100% utilisation of the sub-acute beds. There are also closed-off residential aged care beds at the other end of the facility. Despite the MPS being able to isolate people within the building, we were told that there could be no flexibility to be able to accommodate our request to go in to see him together. This was a very difficult situation for me already, and I really needed the support of having my family with me.

Before Barry's brain bleed on the 24th of January, he was still a very active man at 78 years of age, being heavily involved in the physical job of running the family farm. 2 months later he is completely incapacitated physically, but his mind is still working very well. As the restrictions became even more rigid with COVID-19, we were told that we could not even take Barry outside in a wheelchair. This is one thing that he kept on saying he wanted to do while he was at the MPS. As Barry's bed was near the side staff entrance and would not have gone into any of the other rooms or the residential care, we believe that the approach of not allowing more than 1 person at a time or accommodating a dying man's request demonstrates inflexibility, and a lack of compassion, caring, understanding, and common sense by the WNSWLHD.

On the 25th of March, my daughter received a phone call from Gulgong MPS. One of the things that she was asked about was whether Barry would be able to spend his last few days at home. My daughter expressed concerns to the staff member about the ability to care for him at home given what his needs were, and to even contemplate it our family would need a great deal of medical and care assistance. This discussion went no further. At no time did we say that we would be able to look after him.

On the 31st of March, my daughter and I went to see Barry. My daughter was inside with Barry and I was sitting outside. Barry mentioned that someone had said to him that he could go home, however Barry did not identify who that was and did not say any other details. During our visit, the had a discussion with myself, my daughter, and Barry, that Barry would be fine to go home if we would be able to care for him, and he

asked questions about how we would be able to do that. This discussion occurred without any prior knowledge or discussion with me as to how we would be able to look after him. As noted above, my daughter had already expressed concerns about his care at home. I understand that Barry was asked in his previous discussion what could be done to help him and that is why the Acting Nurse Unit Manager was speaking to us, however subsequent discussions should have been held with myself only as the primary caregiver. That these discussions occurred the way they did was wrong and cruel as it gave Barry a hope that was never there.

On Sunday the 5th of April, I received a phone call early in the morning that Barry's family needed to come in and see him today as he was getting close to the end of his life. When I arrived at the hospital with my daughter to see him, we were informed by an MPS staff member that the COVID-19 directive still stood and that only 1 person at a time could see him. I had to go and sit with my dying husband with no support close by from my family, who had to stay outside.

The continued lack of compassion, empathy and understanding from this directive made an already difficult situation unbearable. It was not until that afternoon at 4.45pm we were informed that after some phone calls were made to a higher authority, we could all go in together if we wore masks, did not leave the room, kept the door shut to Barry's room, and exited by the side door. My family and I were happy to comply with this. It is very disappointing that it took so long for this to occur. For a facility set out like Gulgong MPS, this action should have happened much earlier. It is also worth noting that the phone calls were only made after another member of staff told the nurses that the treatment of my family lacked compassion.

When my daughter and I went to see him on Monday morning, we were informed by Reception that we could not go in together. This caused much distress given that we were allowed in as a group the night before. The confusion was cleared up and we could go in together. Nonetheless it was very upsetting that it was thought necessary for the directive to be in place, and again showed a complete disregard and understanding of the circumstances given how close Barry was to the end of his life.

Barry had not been complaining about pain for most of the time that he was in hospital. On Saturday, the 4th of April his pain became less bearable, and his pain medication increased. On Sunday, the 5th of April he was given an injection of morphine at 11am. He complained of worsening pain repeatedly. I pressed the buzzer several times for assistance. After a while, I was informed by a member of the nursing staff that they had 3 cases in emergency and there were only 2 nurses, so there was not sufficient staff to be in both places and they could not attend to Barry at that time. He received an injection for pain relief at 2.30pm, some 3 and a half hours after his previous injection. Gulgong MPS did not have an automatic device on hand to administer his pain medication. One had to be brought in from Mudgee Hospital 30 minutes away which did not arrive until later in the afternoon. During this time, the care Barry received was far from adequate given the amount of pain that he was in. To the best of our knowledge, he did not receive any consultations from a doctor. It is very concerning that there was such a lack of resources that the staff were not to be able to deal

with an emergency and existing patients, especially when there are only 4 patient beds at the MPS. I also do not understand why the automatic device was not brought out from Mudgee sooner when it was obvious it would be needed soon. It should have been set up ready to be used. This showed complete lack of planning and foresight.

I would also like to highlight that during the course of his admission to the MPS, Barry received a combination of visits from the local visiting GP and consultations by virtual doctors. Given the nature of his condition, he needed a doctor to see him face to face at least on a daily basis. A doctor that can only see him though a monitor is not in the best position to make an informed decision as to how to best care for him in the final stages of his life. Asking Barry "how he is" through a monitor and Barry responding is not proper patient care. He also received no palliative care. There are Palliative Care Nurses based in Mudgee.

Barry died at 1.55pm on Monday the 6th of April. There was some confusion around what needed to be done next, and my family and I were advised that we could ask a virtual doctor, and that the virtual doctor would pronounce Barry dead as the local visiting GP was not available at that time. We spoke to the doctor on a monitor and he pronounced Barry dead. It was very impersonal and lacked the sensitivity needed when my husband had just died.

On the 20th of May, I wrote a formal letter of complaint to the WNSWLHD regarding Barry's treatment at the Gulgong MPS including much of the above, and wanting answers to the following:

- why the possibility of Barry's leaving hospital to be cared for at home was never discussed with myself prior to involving Barry in the discussion
- why there are not adequate on-call resources for weekend shifts to cover emergencies and care for the remaining patients;
- as a result of the above, is it acceptable for a dying man in severe pain to wait for 3 and a half hours to receive pain relief; and
- why the automatic pain medication device was not at the MPS sooner when it was known that Barry was close to the end of his life

I also stated that I was disgusted by the policies instigated by the WNSWLHD to manage the COVID-19 pandemic. I believe that they lacked empathy, compassion, and were so inflexible that the same rules apply to the large hospitals as the smaller country hospitals who would not have the same needs. It appeared that the staff were not able to show discretion in being able to make our situation more bearable.

I received a response back from WNSWLHD, dated 17th of June 2020. The response said that the COVID-19 restrictions were at the directive of the Australian Government. This is not quite correct. Each state was independent in how it enforced the overall directive. Health is ultimately the responsibility of each state, and the responsibility for NSW is with NSW Health. NSW Health could have been more flexible but chose to adopt a strict "one size fits all" policy with very limited flexibility at local hospital level and it failed to recognise the different needs of different hospitals. For the other points raised in the complaint: I received

apologies; was advised that “staff have been reminded” that there is a plan to source additional staff and of the importance of forward planning in the final days of someone’s life; and that sharing Barry’s experience “provided us with an opportunity to make improvements in the care we deliver for our patients”.

These seemed like hollow words at the time, and considering what happened to Dawn Trevitt at Gulgong MPS a few months later, the concerns around lack of resources have not been addressed. There have been no noticeable changes to resourcing levels and for a time they were reduced as there was not even a visiting GP. It seems that the “opportunity to make improvements” was not acted on, and I can understand why people do not raise concerns about treatment received. The concerns are met with false promises and nothing actually changes. There did not seem to be any point in progressing my concerns about Barry’s treatment for that reason.

Barry was admitted as a private health patient. Gulgong MPS (and prior to that Dubbo Base Hospital) were the recipients of funds because of his stays in hospital. He was not treated as a private patient, and I would be interested to know how the funds received from his stays were used given that the private health coverage did nothing to improve his standard of care.

During Barry’s treatment, I saw many examples of medical staff who do an incredible job despite being so clearly overwhelmed with the number of patients and the limited resources. They are a credit to their profession despite the circumstances they are placed in by NSW Health.

I understand the NSW Health believes that there is nothing wrong with the provision of rural health services. If that is indeed the case, then NSW Health is very out of touch with the staff and community that they are meant to be supporting. We are not numbers or costs that need to be cut. We are people. Where a person chooses to live should not determine the quality of medical care they receive. I suggest that maybe some politicians and those making the decisions at NSW Health spend quality time (not just fly in and out) at some rural and remote hospitals to see what is actually happening. If it is not happening to you directly, it is easy to ignore it. If what happened to my husband happened to some of their family members, I imagine change would happen very quickly.

It is not good enough that NSW continues to allow its rural citizens to receive health care below an acceptable standard.

Yours faithfully,

Barbara Seis