Submission No 579

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

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Inquiry into Health outcomes and access to health and hospital services in rural, regional and remote New South Wales

Submission by Malcolm Knight

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The death of Brian Knight in Macksville Hospital 16 September 2013.

This submission has relevance to Terms of Reference (a) to (e), (g) & (h), and (j).

Background

My father, Brian Knight, was 78 years old, living independently in the community at Nambucca Heads. He walked without aids, drove a car, and swam every single morning at Shelly Beach, but he needed a hip replacement. Before that could be offered, he was told he required a heart valve replacement.

The first issue is that the cardiac surgery was either not available or not offered on the Mid North Coast, and he had to travel to Sydney for the heart surgery at Prince of Wales Hospital in January 2013. This meant that his support-person had to travel to Sydney (also from the Mid North Coast) and pay for accommodation (albeit at a reduced rate). It also meant that other relatives had no opportunity to visit or provide support.

Despite having an hypoxic seizure from a surgical pneumothorax a few days later, the surgery would probably be regarded as successful, however nine months later he was dead from other complications. He never received the hip replacement.

The Patient Experience

After being transferred by Air Ambulance to Coffs Harbour Hospital for rehabilitation, his progress was slow. He also received a prostate resection at Baringa Private Hospital, which didn't resolve his urinary retention, but he went home and lived independently for a short period – even driving his car once – until he had a stroke, and was taken to Macksville Hospital. The time and distance to a facility with acute stroke services meant he was never considered for thrombolysis or clot retrieval.

From Macksville, he was sent back to Coffs Harbour for more rehab - about four weeks - and then to Pacifica Nursing Home as he couldn't be managed at home. We were assured physiotherapy would be available three times a week, but funding was withdrawn before he got there. Physiotherapy was only provided once a week, and if he was unwell on that day then he missed out.

Dad was eventually admitted to Port Macquarie Hospital (21-6-13 to 23-7-13) where it was finally realized that he had infective endocarditis and that the embolic stroke was just one of a cascade of issues secondary to sepsis from the infection.

At Port Macquarie Hospital (PMH), Dad's multiple conditions were managed aggressively by a cohesive multi-disciplinary team, and we felt optimistic about his prognosis. His care included repeat courses of strong antibiotics, surgical debridement of a recurrent heel ulcer, and other therapies, but it seems that the underlying intracardiac infection was never cured.

Dad was eventually returned to Pacifica Nursing Home, however he was still being actively managed with follow-up care by his GP, physiotherapist and the Specialist at PMH. Despite his physical condition, Dad was often alert and had meaningful interactions with relatives on a daily basis. Unfortunately, the fact that he was in a nursing home seems to have impacted on his subsequent treatment at Macksville Hosp.

On Friday 13 September 2013, Dad was unwell again, but he had an appointment with his Specialist at PMH for which an ambulance transfer was already booked. The nursing home made several calls to NSW Ambulance but, due to other cases being given higher priority, it was unable to provide the transfer and Dad missed his appointment. It is safe to assume that his Specialist would have recognized Dad's condition and had him admitted immediately, and he may not have died at the time or in the manner that he did.

The fact that this transfer did not happen is a major factor in my father's death. While it sounds understandable that emergency calls should take priority for an ambulance service, the reality is that at least some of those "emergency" patients are likely to have been much less unwell than my dad was. The importance of "routine" patient transport is possibly underestimated, however it is relevant to this inquiry that routine transport is not performed by NSW Ambulance in metropolitan areas where a completely separate Non-Emergency Patient Transport Service is provided.

The nursing home, to its credit, immediately rebooked the Specialist and transport for the first available appointment, which was to be on the following Monday.

Within hours, however, Dad became very unwell and an emergency Ambulance call was made. Dad was taken to the closest Emergency Department, which was Macksville Hospital, staffed at the time by a single locum doctor who we believe had flown in from Melbourne to cover the shift.

The doctor initially provided standard supportive treatment in the form of oxygen and IV fluids, however he appears to have made a biased interpretation of Dad's condition based on the fact that he was "almost 80 and from a nursing home" (which were his first words to me, on the phone later). Despite Dad's immediate improvement, the doctor drafted a document and asked my sister (who was present) to sign to indicate *her* request for palliative care. My sister was not comfortable signing such a thing as Dad had never been considered palliative. Instead, the doctor drafted a new document and convinced my sister to sign indicating her *agreement* for Dad to be given palliative measures only.

The doctor appears to have assumed Dad was having a major cardiac event, due to some chest pain and ECG changes, despite the fact that his main symptoms were respiratory and that he must have been febrile at the time. I think the assumption was that he had pulmonary oedema and was in cardiogenic shock. The doctor appropriately contacted the referral hospital (Coffs Harbour) however that hospital had only known Dad as a *cardiac* and *stroke* patient, months earlier, which only lent further support to the doctor's impression. Had the doctor contacted Port Macquarie Hospital, where Dad was treated for *sepsis*, the advice may have been different.

Whatever notes the Macksville doctor wrote were so convincing that the regular doctor, who was on duty when I arrived the next morning, also felt that Dad should not be treated actively. He gave Dad's chances as "50/50", even though Dad was now talking, comfortable and stable. We - as a family in consultation with the regular doctor – then made the wrong decision to allow Dad to be palliated. He was expected to die within 24 hours.

Dad's IV fluids were removed and a syringe driver was inserted. He was given only morphine and oxygen therapy from then on, and still did not die until 16 September, three days later! It does not take much research to know that it does not take three days to die from untreated cardiogenic shock. My belated suspicions were confirmed when I asked a nurse about the colour Dad's respiratory secretions, and was told they were "green". (Green is not the colour of pulmonary oedema. It is the colour of rampant infection.)

Following our later complaint, a reviewing doctor (from the Health Area) described the initial doctor's impression as a "cognitive error". While anyone can make a mistake, one of the issues for this inquiry is that the doctor did not have any other doctors around him that could have taken even a quick look at his patient for a second opinion.

Another issue is that we became aware, later, that some nursing staff were not comfortable with Dad's treatment, but they were working with a doctor who had never been in the hospital before (and possibly never since). Having rosters sufficiently resourced with local, familiar staff, could have increased the nurses' confidence to raise any concern with the treating medical officer.

My main experience with NSW Health is with hospitals in Sydney, where more than one doctor is on shift at any time, referral hospitals are close, and patient transfer is relatively quick and easy. I am sure that one of the factors in the doctors' decisions to palliate Dad was that transfer to a higher-acuity hospital would involve a drive-time of an hour.

Although I was fatigued from driving through the night to Macksville from Sydney, I have always regretted that I did not even consider that the situation would be different in a rural hospital, and that I placed too much faith in the workings of the rural health system.

Palliative Care

As mentioned, Dad's palliative care consisted of morphine and oxygen. Nursing staff were caring when attending his regular turns and hygiene, however he was soon unconscious

from the morphine and he stayed that way, under constant sedation, until he dehydrated to death.

My experience of palliative care was working in a specialist palliative facility, some years ago, where opiates were only given to manage actual pain, patients were sedated only as necessary, and they were allowed to eat, drink and converse as desired until the natural end. Had Dad received proper palliative care, he would not have remained sedated nor dehydrated, and it would have become apparent that he was not suffering a terminal event.

It seems to me that access to specialist palliative care services needs to be improved in regional areas, if not everywhere.

Complaints

With a desire to prevent future similar situations, we made complaints to Macksville Hospital, and to the Healthcare Complaints Commission regarding the failure of NSW Ambulance to deliver a timely routine transport.

We received a lovely apology from the nursing Unit Manager at Macksville Hospital, and two relatives were even allowed to participate in a subsequent case review, however they left feeling as though little had changed that would prevent a similar situation arising.

My complaint to the HCCC was referred to the CEO of NSW Ambulance, who was similarly apologetic however I could tell he had no power to change the way routine patient transport services are provided on the Mid North Coast.

I can see from my correspondence with the HCCC that I allowed it to focus on just one of the 'holes in the Swiss cheese' that lined up to ensure Dad's untimely death. I was never completely comfortable that the complaint was deemed "suitable for local resolution", as his case really did involve multiple failures and missed opportunities across different Health Areas and departments. For brevity and relevance to this inquiry, I have focused only on the aspects that relate to rural and regional health.

Summary of Issues

- The availability of cardiac surgery on Mid North Coast
- Access to timely routine patient transport in regional areas
- Communication between hospitals
- Rural hospitals relying on a single doctor unfamiliar with staff and the community
- Access to (and understanding of) proper palliative care
- The ability of the HCCC to flag a complaint as significant and worthy of formal investigation.

Malcolm Knight (signed electronically)