

I would like to offer both my professional and personal experience and insight for consideration during the 'Inquiry into End of Life Choices'.

I have 24 years' experience in healthcare. I have a Bachelor of Nursing Practice, post graduate qualifications as a registered mental health nurse in addition to studying and completing most components of a Bachelor Social Work. Furthermore I am currently employed as a 'Quality Improvement Consultant at a major Public Hospital and am a member of their Safety & Quality Unit. In brief, the core business of this unit revolves around assessing and elevating clinical standards in both public inpatient and community healthcare facilities. The above mentioned clinical experience and qualifications offer some demonstration that I am qualified to have an informed opinion with respect to the aforementioned inquiry. In the first instance I shall speak in my professional capacity.

I have worked in most areas of nursing including, mental health, high dependency, theatre, coronary care, palliative care, surgical units, neurology and neurosurgical wards to mention just a few. I will just add that I have also worked within both public and private hospital systems.

The subsequent statements describe and document my observation during the past 24 years with respect to the relevant issues.

Policies, Protocols, Procedures and Standards

We do have policies, protocols, procedures and standards but they are not unfailing, consistent or implemented uniformly by relevant organisations. In many cases these policies, protocols, procedures and standards fail to translate effectively across the numerous services or organisations. This includes the non-governmental organisations (NGOs) such as those in the business of; Disability Services, Age Care, Community Care, Public and Private health systems in addition to the varying levels of clinical provisions dictated and limited by private health insurers and dwindling crisis support resources usually provided by charity organisations. Furthermore we can add the convoluted 'Centrelink processes and demands to even more complicated legal matters which may or may not involve a Guardianship Board decision/s and potentially imposed Public Trustee involvement or ongoing disputes surrounding access to life insurance or superannuation funds. To say that those people experiencing chronic suffering and/or dying is complicated for the patients, their families and significant others is to say the least. We will now **add** another dimension to a unreliable and inconsistent system

As a nurse I have on numerous occasions commenced my shifts which included the care of patients with chronic / extreme pain or who were there for palliative care. Upon reading their notes and checking their drug charts I would frequently see that analgesia which was ordered by medical staff had not been maintained as a regular dose as per orders. Despite ongoing education and reporting, under-medicating was common practice. When I was a student nurse the nurse educators at Flinders University in South Australia promoted critical thinking as a necessary tool for nurses. The issue of under-medicating and issues surrounding palliative care, right to life, confidentiality etc. were also discussed in topics including Ethics for Nurses. Despite the education many nurses fell and continue to fall through the net because of their inability to remain objective and put their personal value systems or fears aside. This was not, and still isn't unusual. Currently '*Professional objectivity*' appears to be an *ideal* to strive for, not necessarily attainable by '*all*' practitioners due to ongoing personal conflict with their cultural, political or religious beliefs or a combination thereof.

In my experience this is not solely a matter to be redressed with better staff education, nursing has been around for a while now and attempts to address these issues with education or attempts to enforce organisational policies, standards (and so on) alone has not worked effectively to date. It is a far more complex an issue. For instance, hospitals utilize agency nursing staff to backfill their staff shortages. If we look at the current transaction model between agency and hospital we can see cost benefits as leading sources of motivation. The agency provides a service and upon doing so they are generously remunerated for that service. The turn the hospital requires and is temporarily given the services of a nurse. One could look at this superficially and say, 'great, its win-win'. However, in reality a nursing agency may offer mainly core competency education for nurses including: CPR, drug calculations, manual handling diabetes monitoring to name a few. Another contributing issue is the varying levels of experience as nurse clinicians, levels of self-confidence as nurse practitioners, junior nurses submitting to peer pressure that suggests a patient is *'drug seeking' and for that reason they withhold narcotic or other analgesic medication*. On more than a few occasions, I have worked with nursing staff who used the patient's need for pain relief as a tool to get them to comply in some way. For instance, "...when you've eaten your lunch I'll go and get you some pain relief..." or on another occasion, "...When you've had your shower I'll go and get you some Endone". These attitudes, behaviours are a significant part of a patient's experience when they are at their most vulnerable. I'm not suggesting that it is all nurses or even most nurses. I am suggesting that the reality is that one may not count on being allocated a nurse who has the experience to accurately assess who is 'drug seeking' and who has genuine pain. Who has the confidence to provide high doses of narcotics (such as may be required for patients with chronic pain or admitted for end stage palliative care). Palliative care patients may need to be admitted to a facility that does not have a palliative care bed available. In that case the patient is admitted to a bed on a different ward. Nurses may err on the side of caution (*from their perspective*) and administer the lowest dose within the range of medication prescribed and that is readily available for administration. Mostly this is because those are the usual doses on that ward.

When I was a junior nurse I became suspicious when a patient I had cared for during the previous three days, suddenly became, "attention seeking" according to their nurse. The protocol for administration of Narcotics S8 drugs included two nurses checking off the medication against the patient's wrist band information. I advocated on behalf of the patient with their primary nurse to provide immediate pain relief. Their primary nurse and I went to the treatment room and organised a morphine injection. After checking off the vial of morphine, the nurse asked me to get the patient's insulin from the treatment room fridge which I did. During this moment the nurse drew 1ml normal saline into the syringe and kept the unopened vial of morphine. I offered to manage that patient as I had an established rapport with them. The nurse agreed. I performed a full assessment of their vital signs including pulse and blood pressure. I can no longer tell you exactly what the figures were, what I can tell you is that the blood pressure was extremely elevated as were their pulse, I checked them again thirty minutes later when the patient reported they had no relief from that injection and the vital signs had not lowered closer to normal as would be expected following an injection of morphine. I reported this to the Team Leader for follow up. As I was *'only'* an agency nurse at that time, my concerns appeared to be dismissed. I was later informed that the Team Leader was friends with that particular nurse outside of the work environment.

These examples were not localized to the same clinical setting. Many nurses have been educated one way at a tertiary level but their practice is formed by their peers and senior nursing staff.

The not so secret truth is that nursing is highly political and often, this is to the detriment of their patients. Nurses who speak out are perceived as '*not being a team player*'. The junior nurses observe these behaviours and soon learn that if you want to fit in ...this is not dissimilar to the domestic violence model. In short, organisations are comprised of many individuals (*and all that entails*) and professionals of one description or another. This is not only it's strength but also and ironically, it's weakness. Having appropriate protocols and policies **does not guarantee** that a patient's pain will be managed in a timely or appropriate fashion. When we drill down through the obstacles and issues surrounding appropriate pain management we still say, we are striving towards improvement and better management of pain. My question is, whilst we are 'striving' where does that leave a person suffering and / or dying? How many people need to suffer unimaginable pain and indignity or die in agony whilst we get our house in order?

I mentioned that I would also speak from personal experience and so I shall.

During 2001 my brother was misdiagnosed with depression. Following a conscious collapse (*one of many prior to that*) whilst driving a truck (into a tree) scans of my brother 's head were finally taken and revealed a Grade 4 (terminal) Glioblastoma Multiform. He was forty-two. Three months later, I was diagnosed with Breast Cancer. So on occasion we were in hospital at the same time or having radiotherapy and chemo... We lost our hair together, we shared our deepest fears with each other, things we denied to everyone else. I was the healthier of the two of us. My brother visited me home fell into my arms sobbing. The pain was unbearable. He tried to mask it from his family as long as he could but it became too much. The doctor's plan involved him being admitted to a palliative care unit which my brother refused. He later told me that he knew if he was admitted there he would never see home again. My brother trembled as he pleaded with me to take care of him at home. I couldn't deny him. My brother and I met with his Pall care team and GP and a pain management plan was developed. Hospital furniture was delivered to his home including an electric bed. As I was a Registered Nurse the team were happy for me to follow their medication regime, chart and administer pain relief subcutaneously and intramuscularly. He was also on oral medication and in short, on high doses of 'everything'. There were no good days during that last three months. He asked the doctor if there was something he could take so he could just go to sleep. The obvious agonising pain was unbearable. The only consolation he said was that he had family and friends twenty-four hours a day in his home with him. One friend confided that my brother had begged him to acquire a handgun. He knew I couldn't help him without prosecution so he was trying to find an alternative. Mercifully in the days before his death he was in a coma and did not regain consciousness. He could have been spared so much pain...I nursed him at home for three months.

I need you to know how this impacted on me. If you could imagine caring for someone in that situation, wondering if what they were currently enduring, would you too have to endure next week, next month, when? When was it going to be my turn? There were no more registered nurses in my family, no twenty-four hours a day care at home for me. I still struggle to talk about the indignities my brother endured. He cried when I applied a Uridome catheter to his penis so he was no longer incontinent in bed. He wouldn't let the other visiting nurses do it but knew that as a large man changing the bed was difficult. When he experienced faecal incontinence he was so ashamed that he didn't tell me for hours. When it became obvious and I eventually persuaded him to let me change

the bed he once again articulated his desire to have a dignified death. He had an 18 year old son (with all that entails) who walked into the room whilst we were changing the bed and cleaning his bottom. His son burst into tears and so did my brother and that was too much for me. I couldn't hold the tears in any longer. The flood gates opened and I just couldn't stop crying. We were all inconsolable. I lost 20kg in weight over that period, I didn't sleep and I struggled with my own physical recovery from bilateral partial mastectomy. Again, I struggled with the questions such as, how will I cope with days like today?

I was terrified at the thought not only for myself but for my family. The law needs to be amended to reflect an understanding of one's intrinsic right to maintain one's dignity and right to say, 'no more'.

I am still cancer free today but I can say with authority that this journey should and could be taken as a family (whatever that means to you) and not alone if that is your wish. Your family should not at a time like this have to consider the reality of potential prosecution for holding your hand as you die.

I have held many hands as their owners died. Many of those many could have had better, more dignified and less lonely a death. Please take the first step in making this happen. My apologies for any typos its 0224am..off to bed now...