Submission No. 100 AUTHORISED:

29th August 2005.



To whom it may concern,

The following notation relates to the death of my son at Gold Coast Hospital, Southport on the 1st July 2002. My issues relating to the lack of duty of care, informed consent, pain management, restriction of visiting hours and the transfer from Intensive Care Unit to a general ward, to mention some major issues, will be discussed and evidenced at length.

Jay Michael Finadri had a motor vehicle accident on the 23rd of June 2002. He died on the 1st of July 2002. He was admitted to the Gold Coast Hospital via ambulance (QAS) following the accident. The writer of this letter of complaint is Jay's mother. I am a Registered Nurse in Queensland. This complaint discusses many issues. However, for reasons of time many details have been excluded.

This letter of complaint has taken me almost three years to complete. I have found it extremely difficult to write about events that remain so close to my heart. I am writing this for my son and also myself, but even more so that no other person should ever experience what we did. The health care system has a lot to answer for and I wish that my concern be investigated further.

On the advice of particular medical staff of the Gold Coast Hospital, who shall remain anonymous for reasons of confidentiality, I was advised to contact the Patient Liaison Officer at the Gold Coast Hospital to make known my complaints.

On The 26th August 2003 the Patient Liaison Officer of the Gold Coast Hospital arranged a meeting. (After several previous arrangements had been made and cancelled by several different members of liaison staff) I attended this meeting accompanied by a friend who is also a registered nurse. The Intensive Care Unit Manager, and a doctor, the head of ICU were present. The Patient Liaison Officer to my understanding was supposed to attend also, but was not present for reasons unknown. The meeting was an emotional one. In addition, this meeting did not resolve many questions that have been left unanswered. I received a phone call the following day, from a person who was present at the meeting and, the person advised me to take this matter further. There was no further contact with the Patient Liaison Officer.

Restriction of visiting hours; I find it extremely difficult to deal with this issue as we were told we were only allowed to stay with our son at certain hours. Under no circumstances can I believe that anyone can restrict a mother and father from staying with a dying son. The hospital's Unit Manager of ICU at the time of Jay's confinement pulled me aside and told me of her decision. I sat there, cried, and told her that this was my baby and there is no way I could leave him. The decision remained; she would not change her mind. The hospital nursing staffs were informed of this decision, and therefore we were only allowed in at certain times.

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Their reasoning for this was that he was not going to die and we should go home and get some rest. I find this restriction as taking away your parental rights. I feel that this did not help a terrible situation and only added to the stress and shock that we were already struggling to cope with. Yet, after investigation, it was disclosed that on another floor within the same hospital when people were critically ill, the nurses would make up beds beside the patient for relatives to stay.

There was some nursing staff in ICU, who were as shocked at this decision as I was, and felt that it should not have happened. Some of these members of staff would have to sneak me in the ward in order for me to be with my son overnight and then make sure I was gone before other members of staff came on the next day.

During Jay's confinement in ICU, I met another mother whose daughter was also in ICU. One night I went out to the waiting room to have a coffee. This mother was lying on the dirty waiting room floor. There was nowhere else for her to go. She had just been told her daughter would not make it though the night. She wanted to remain close by, as any mother would. I felt so sorry for her I went and got her a pillow and blanket. (No-one else had offered her anything). She was crying and very distressed. About an hour later, a staff member came out and told her she could not stay there. This is disgusting, unacceptable treatment. I would argue that any person with a member of their family dying would find it acceptable to be told they cannot stay close by, or for that matter, be with their relative at this sad and very emotional time.

The situation continued after his transfer from ICU to a general ward. On the day Jay was transferred, a friend who was a doctor was present at the time of his transfer. On

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entering the ward, I introduced myself to the nurses at the nurse's station. We received no response, no introduction, or any form of orientation to the ward. We went into Jay's room and looked at each other in amazement. The doctor (friend) left about an hour later and was going to do everything he could to have him transferred out of there. He felt the outcome was ominous. However, felt Jay required critical care. The staffs both in ICU and on the ward were quite persistent in stating that Jay was not going to die. The staff insisted Jay was stable and did not require treatment in ICU. In fact, one of the staff gave me a contact number for head injury rehabilitation. Despite the staff's positive outcome for Jay, I knew by the evidence of his physiological signs he was still critical. Regardless of my need to be with my son, again I was asked to leave him, and the nurse stated, " we will tell you when it is appropriate for you to stay." I very reluctantly left that night. I knew that Jay was critically ill and maybe it was just a mother's instinct but I knew he was going to die. He died that night only a few hours after I left.

The hospital staff following the meeting agreed and admitted negligence in this matter and said it should never have happened. However, this is not good enough and continues to cause me so much grief. I do not believe that anyone should die alone. In addition, the guilt and depression this continually causes me is beyond words. I should have been there when my son died, he was my baby, and he should not have died alone.

Private/ Public Patient: Jay had private health cover, which was handed over to the hospital staff on several occasions. Yet at no time was the option of Jay being

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transferred to a more appropriate facility ever discussed. I wish to point out that I am aware of hospitals in Brisbane that specialise in brain trauma.

At the time that we were told that he was to be transferred to a general ward, I requested that he be transferred out of the hospital and the response was that this was not possible. On investigation of this further, Jay's medical records do not state that he had private health insurance. (This information was obtained at the meeting at the Gold Coast Hospital on the 26th of August 2003). While I believe that unbiased health care should be provided to every person, regardless of health insurance status, in Jay's circumstances, I question the benefit of Private Health Insurance. I also wish to acknowledge that I am aware that those with private health insurance receive higher health services, than a public patient (Although at times this is questionable). Pain management: Interventions that are meaningful to the family are reassurance that the patient is receiving adequate pain medication. There is a belief that that patient without higher cortical functioning has no perception of pain. Conversely, the inability to interpret the nociceptive transmission does not negate the transmission (Urden, L., Stacey, K.M., Lough,M.E. Critical Care Nursing. 2002). Therefore, it is the nurse's task to evaluate the pain in alternate ways such as vital signs.

Jay was denied pain medication in the last 3 days of his life I find this inconceivable and very unacceptable. His Vital signs if nothing else indicated to me that he had pain. Following the meeting with the hospital, one person present also admitted his medication was not appropriate. While the doctor present denied that he required any medication, in fact, he pointed out that one day Jay was given 1g paracetamol. Jay had injuries to the extent that paracetamol would not be sufficient medication.

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While I question the medication in all areas of Jay's treatment the pain management is one of the more distressing areas of concern. Assuring Jay was Pain-free should have been a major part of his care.

The following signs were present to indicate that Jay was in pain and unstable. Systolic blood pressure increased by more than 20mmg /hg. Heart rate increased by 20-beats/min. Respiratory rates greater than 30 breaths/min Diaphoresis was present. His temperature was 40 he had diabetes insipidus. Use of accessory muscles of ventilation. His respirations were unstable. Blood Haemoglobin: Hb 6 g/dl = normal 14-18g/dl (Urden.,L. Stacey.,K.M., Lough. M.E. Critical Care Nursing, 2002).

During the meeting, I questioned the doctor regarding his low blood haemoglobin, the doctor informed me that it was normal in ICU to let a persons Hb drop this low. Research evidence suggests that a person requires every oxygen carrying capacity to maintain oxygenation to tissues and cells of the body. Jay was ventilated so he required all the oxygen carrying capacity he could get. I have discovered no research that suggests or explains the theory of the doctor's response.

Critical Care is provided in specialised units or departments, and importance is placed on the continuum of care, with an efficient transition of care from one setting to another. There should also be provided a care consistence, which includes interaction with families.

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The treatment Jay received was inconsistent. In fact, with every change of shift of doctors, his treatment would change according to the doctor's preference. There was no consideration as to the previous effectiveness of previous treatment. Eg: One particular doctor preferred the use of paracetamol for a patient that was febrile (* high temperature) another preferred a cooling blanket. They both had different opinions and yet failed to look at the most effective treatment for Jay.

All health care workers in this area should provide a safe passage for patients and families who are in the most vulnerable circumstances and the most threatening environments. An important aspect in the care delivery to and recovery of critically ill patients is the personal support of family members and significant others. The value of both patient and family centred care should not be underestimated. It is important for families to be included in care decisions and to be encouraged to participate in the care of the patient needs. Patients and families must have all of the information about a particular situation before they can make a decision that is most appropriate for them. They should not only be given all the pertinent information and facts but also have a clear understanding of what was presented. (Urden, L., Stacey, K.M., Lough, M. E. Critical Care Nursing, 2002).

Transfer from ICU to ward; I question how a 17-year-old boy can be transferred to a general ward that openly admitted they were short staffed due to a strike. A boy who has a temperature of forty degrees is unconscious, has just come off a ventilator, and bilateral chest tubes removed only hours before. He was critically ill. How does anyone explain that an 80 year old can be in ICU for months to keep him or her alive

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but a 17 year old does not get the same opportunity? I feel that generally, we were inadequately informed and consent was definitely denied to us.

In the case of Rogers v Whittaker (1992) 175CLR 479 at 485 it was established that informed consent involves providing an accurate description of the medical procedure, disclosing risks that respects a patients autonomy in deciding the importance of those risks for themselves (Forrester & Whittaker, 2001). Skene (2001) explains that in any democratic society, the Individual's right of self-determination and autonomy is recognised in both common law and statute.

The only doctor who I ever considered to have properly informed us of what treatment Jay was and would receive, told us that Jay would be in ICU for at least another 3-4 weeks, this was told to us only the day before we were informed of his transfer. The same doctor informed us that there were no decisions to make regarding the withdrawal of life support or treatment. He said that as a 17 year old that was in previously good health, was legally and ethically entitled to every life savings measure for a minimum of twelve months. The majority of the staff insisted that Jay was going to live and that everything was stable.

I question the treatment Jay received in all areas. I believe that the standard line of treatment was not followed and have been given no explanation as to why. I have requested his hospital notes through the appropriate channels and these have been denied. I was originally advised to do so by the Queensland Health Rights Commission. Following the first request for his notes through the Gold Coast Hospital, I received a phone call to say that Jay had to request the records himself.

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The request that I wrote included details of his admission and date of death. I can only say this is another inexcusable example of gross negligence.

Code? The staffs, which were on duty the night Jay died, told me there was a code called. There is no way this took place. Emergency contact numbers were not used. He was already deceased when I arrived at the hospital, which would have been a matter of minutes from the call from the hospital saying he had deteriorated. (I was staying at a motel directly opposite the hospital). I believe there was a failure to monitor Jay. And a failure to maintain accurate, timely, and complete medical records. There were no nursing notes written the night Jay died. This is illegal.

On arrival to the hospital, it was clear that despite what the staff had said there had been no code called. Jay was deceased. He was laying in a bed that was wet from diaphoresis and covered in vomitus. I was in shock and could not speak. I felt that my son had been just left there to die. I told the nurse that I was going to wash him. She replied that it was handover soon and there was not much time. I insisted and said that I was going to do it and did not want any assistance anyway. I began to wash him and some of the staff came in two nurses and a wardsman. Once again, the staff intimidated me. I wanted to do this on my own. I did not want to be rushed. Nevertheless, once again I was denied the right to care for my son.

What time of death? Telephone call when? Why not emergency contact number? My emergency contact number was my mobile. At no time did I give them the motel number and yet the staff rang the motel. Treatment consent to cease? Treatment was obviously ceased ... why ??? Who made this decision?

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I begged that the hospital not perform an autopsy stating that Jay had been in hospital for 8 days and the tests, x-rays etc had been performed. Of course, the autopsy was carried out and yet did not disclose the actual cause of death. The coroner's report stated the cause of death was MVA. This was not the cause of death. I question how an autopsy can state the cause of death being a MVA; this cause cannot be accepted as conclusive, when on transfer to a general ward Jay was in an apparently stable condition 8 days post accident.

The standard decision process which is to be followed for the withdrawal of life support when an adult patient is not able to participate in the decision making and continued life support.

1. The consideration should include; good clinical practice and evidence based medicine. Respect for human life.

2. Patients and their families should be treated with dignity and compassion by all disciplines of the health care staff. The decision of withdrawing life support must involve consideration of all possible outcomes.

3. It is the responsibility of the medical practitioner to ensure that;

An order for the withdrawal of life support is written in the patient's medical history and the order is dated and signed.

4. All other treating health care professionals are informed of the order and understand it.

5. The relatives and support persons are kept informed at all stages.

Any role the patient or relatives had in making the decision is documented in the patient's history, signed, and dated.

6. Directives for the staging of withdrawal and any necessary medications for that process must be documented in writing prior to commencement of withdrawal of life support.

7. It is the responsibility of the nursing staff to ensure that; all health care professionals involved in the patient's management fully understand the order.

8. The patient is kept as comfortable and pain-free as possible at all times.

9. Each step is taken in withdrawing life support are clearly documented in the patient's medical record, with a description of events and time of occurrence. Each entry must be signed.

10. Changes in the patient's clinical status are communicated immediately by the attending nurse to the treating medical practitioner and nearest available relative and carers.

11. The existence of the "withdrawal of life support" order must be noted at every nursing handover.

12. Relatives and carers are fully supported during and after the time of withdrawing life support;

Explanations of all events are provided.

Opportunities are given for expressions of grief.

Religious arrangements are made if required.

13. A decision to withdraw life support does not mean that the standard of general medical and nursing care is to be reduced in any way. Treatment and care to keep the patient comfortable and pain-free must always be provided.

14. Disputation from any of the parties involved in the decision making process must be immediately referred to director of nursing who may refer the matter to legal counsel (**References 1-10**).

The duty of care can be rather extensive in the work of health care professionals. This view is supported by Forrester and Griffiths (2001,p.93) who states "[a] duty is owed not only to the patients but also third parties. The third parties could include the relatives of the patients or persons whom may suffer injury while under the care of the health professional."

In the case of Donoghue v Stevenson (1932) AC 562 the duty of care was recognised by the 'neighbour principle', which was enunciated by Lord Atkin. The 'neighbour principle' states that one must take reasonable care to avoid acts or omissions, which you can reasonably foresee, would be likely to injure your neighbour. The neighbour may be described as those people who are so closely or directly affected by your acts or omissions that it would be reasonable to have them in contemplation (Forrester & Griffiths, 2001; Trindade & Cane, 1986). In this context and in relation to this matter, the "neighbour principle" could be recognised to apply to the nurse, the doctor, the hospital, the patient, and the family. Moreover, in this circumstance is it not foreseeable that the mother of a dying child would be deeply affected by the acts or omissions of the health care providers.

The salient features which are evident to the writer, acknowledge that the nurse, doctor and hospital should have the level of knowledge and information to appreciate the existence of a foreseeable risk, the health professionals have a duty of care to the patient and families, ethical and legal considerations such as patients rights and informed consent. In this case, the significant risk should be disclosed and confirmation of the relatives understanding of the risks should be satisfied. Informed consent was not satisfied. The nursing notes are required to be sequential and

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written contemporaneously. The treatment and care of the patient should be timely documented, clear, concise, and accurate. The information documented should only be entered if it has been performed or witnessed by the nurse or health professional writing the notes. In the context of this case, the importance of recording detailed medical records and notes are invaluable. Once again, there are no nursing notes available for the night of Jay's death. The accuracy and detailed documentation may provide evidence and proof of the reasonableness, and prove a consistent standard, of the conduct of the nurse and the health professional, therefore strengthening the duty of care provided.

This complaint is not about the fact my son died. It is about the treatment that every human should be entitled. Health care is attending basic human needs, and should be focussed on holistic care not only the medical model of care. I have to live with the fact my son died and I did not do the best I could. I have suffered major depression not just because of grief but the failure to do the best for my child. I should have never been denied the human right to be with a dying child.

The health care system is responsible for delivering health care. The World Health Organization states; "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (Peplau, 1997, p.225-226). Freedom of choice, while promoted by health promotion policy seems rather insignificant when health care is an issue not effectively resolved.

I have no doubt that there are very good caring staff, but there is also a big downfall in the system that needs to be recognised. The Gold Coast Hospital is a major, and the

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only hospital for the Gold Coast when addressing emergency trauma care, regardless of health insurance status. From personal experience, I would not wish anyone be subject to care within this system. The care that Jay received is questionable. In addition, from experience, the care we received was based on the staff we received, not on a standard of care. This is not good enough for anyone, and for my child Jay, is unacceptable, as it would be for anyone that has a family member or friend dying. For myself in practice as a nurse I always remember that every person belongs to someone or that someone else may be affected by their outcome. Moreover, at some point in time, every person who takes on the duty of care for another is accountable for holistic care should remember this regardless of personal bias. I hope this matter is taken seriously and is addressed with the respect it deserves.

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Yours faithfully,

Susan Dale

Cc.

Federal Health Minister. Tony Abbott Parliament House Canberra. ACT. 2600.

Queensland Government Minister of Health; Stephen Robertson G.P.O. Box 48 Brisbane. Qld. 4001.

Morris Hospital Inquiry G.P.O. Box 13147. George Street, Brisbane, Qld. 4003.

Premier Peter Beattie. Executive Building. 100 George Street, Brisbane. Qld.4000.

Queensland Ombudsman Office of Health 25th Floor, 288 Edward Street. Brisbane. 4000.

Local Member; Margaret May. Samuel Plaza, 1045 Gold Coast Highway, Palm Beach, Qld. 4221.

Local Member; Jan Stuckey Suite 1 Samuel Plaza. 1045 Gold Coast Highway. Palm Beach. 4221

Gold Coast Bulletin. 385 Nerang Southport Road, Molendinar, QLD.

Channel Seven Gold Coast News 207 Gurrumburra Road. Ashmore. QLD. 4214.

Channel Nine Gold Coast News. Level 17/50 Cavill Avenue. Surfers Paradise. QLD. 4217.

Channel Ten News. Brisbane News Service. Corporate Centre Level 15. Cnr Slayer Street and Burnett Road. Bundail. Qld. 4217.

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