

# Ethical decision making and end of life decisions



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Nursing practice is often encountered by the ethical dilemma of who can make end-of-life decisions for a patient. The problem arising in this particular situation was when a patient was admitted into hospital with his carer due to deterioration in his medical condition. They both requested to stay within the local community to discuss options for future care. The dilemma occurred when the patient's daughter felt that neither her father nor mother were mentally capable of making this decision and felt that the patient should be transferred to a metropolitan hospital for intensive treatment and care. This caused family member conflict. Conflicting opinions may arise among family members when making health care decisions for loved ones whether they are adult or children.

A patient has the right to withhold consent to treatment as well as consent to treatment. It is a fundamental common-law right of all patients of legal capacity (Staunton & Chiarella 2008: 139). Even though this is true many Australian States and Territories have strengthened this by enacting legislation to guide decision making. In South Australia this is the Consent to Medical Treatment and Palliative Care Act 1995.

Nurses also are bound by the Australian Nursing and Midwifery Council (2008) Code of Ethics for Nurses, which in Value Statement 4 discusses the importance of patients having a legal and moral right to participate in informed decision making.

The role of the nurse is to talk about end-of-life decisions with the patient and their carer and then communicate this to medical officers and other family members. Nurses need to advocate and support the informed decision

of the patient and the right for the patient to make that decision (de Veer, Francke, Poortvliet, 2008; Australian Nursing and Midwifery Council 2008). Good communication at the end-of-life is vital to good healthcare (Centre of Bioethics 2005) and nurses play a vital role in facilitating discussion between patients, their family and medical staff. Specific issues relating to this patients end-of-life were discussed. They included:

Who did the patient want to make decisions for him if he was not able to make his own, both on financial matters and health care decisions?

What medical treatments and care are acceptable? Did he wish to be resuscitated if he stopped breathing and/or heart stopped?

Did he want to stay within his local area for health care, and therefore what medical care and treatment could be offered? Did he want to be hospitalised or stay at home as his condition deteriorated?

Following this discussion a decision was made by the patient and his wife to stop all active treatment and undergo good palliative care.

My duty of care for the patient included ensuring that he got appropriate information about his treatment, prognosis and quality of life to be able to make an informed decision regarding his future, even if this meant stopping all interventions. It is also to act as an advocate for him with medical, nursing staff and family members.

It was necessary to get his daughter to come to the hospital and be involved with her parents and see and feel what they have been experiencing since the patients first diagnosis. It was necessary to get counselling for his

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daughter so that she could accept the decision of the patient and his wife. We were able to allow this gentleman the opportunity to make their decision to stop all treatment and allowed him to die with dignity.

One of the most important tasks of the nurse is to empower patients and families to participate in the final act of living. Through ongoing assessment, communication, and skilled physical care, they can communicate reassurance, confidence and support for the vulnerable patient and family (Kuebler & Heinrich 2001: 456). The decision to support this patient to stop active treatment, I believe was the correct one for him and his wife. The nursing and medical staff looking after this family needed to respect their informed decisions and support them anyway they could.

## **Portfolio Activity 2 – Patients’ Rights**

Patients’ rights to receive and refuse medical treatment in South Australia are found in both legislation and in the common law. The requirements for consent to treatment are contained in the Consent to Medical Treatment and Palliative Care Act 1995. This Act outlines the patient’s rights, one of which is the right to decide whether or not to undergo medical treatment, after receiving a reasonable explanation of what the treatment involves and the risks associated with the treatment.

In South Australia, there are three legal documents that apply to health related decisions. These include two advance directives that appoint a proxy decision maker and an instructional advance directive. An adult can appoint a Medical Agent or an Enduring Guardian as their proxy for future health care decisions. They can include written instructions for the proxy. Patients can

also complete an Anticipatory Direction and not appoint a proxy. An Anticipatory Direction only covers the situation when a patient is in the final stages of a terminal illness, or a persistent vegetative state (post coma unresponsiveness), whereas a Medical Power of Attorney or an Enduring Power of Guardianship operates at any time that the patient is unable to make their own decisions about treatment (Austin Health 2007; Staunton & Chiarella 2008). .

Legal cases that have arisen where patients have refused medical treatment and the health care professionals have felt that this was not the correct choice. Two recent cases in Australia, *Hunter & New England Area Health v A [2009] NSWSC 76*; *Brightwater Care Group 9inc) v Rossiter [2009] WASC 229*, upheld the right of patients with intact decision-making capacity, to refuse medical interventions even when those interventions are life-sustaining. The patient who has the decision-making capacity or the patient without capacity but who had earlier expressed treatment preferences for end-of-life care either verbally or in a written advance directive document generally have these wishes upheld.

In cases where patients have lost their capacity but had indicated in an advance directive that they did not want life-prolonging procedures, courts have ruled that their advance wishes should be followed. The Consent to Medical Treatment and Palliative Care Act 1995 provides for medical powers of attorney under which those who desire to do so may appoint agents to make decisions about their medical treatment when they are unable to make such decisions for themselves (Staunton & Chiarella 2008 p142). These instructions legally bind agents, families and health professionals. Advanced  
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Care Plans (Austin Health 2007) may also be in place. These are Non-legislated informal documents that record end-of-life wishes; they are recognised under common law but are not legally binding.

In cases where patients have expressed their wishes prior to losing capacity, the proxy decision makers should follow those wishes rather than make their own judgment about what to do. This is referred to as “substituted judgment” because the proxies substitute the patients’ prior judgment about treatment matters for their own. This is not only an important legal concept, but also one that has practical application in counseling proxy decision makers at the bedside, as they can feel uncomfortable in deciding to forgo life-prolonging interventions because they see themselves as deciding between life and death for another person (Samata & Samata 2006).

Situations where there is no written advance directive, the patient has never communicated thoughts about end-of-life care or the patient lacks decision-making capacity, courts have articulated standards for proxy decision making (Samata & Samata 2006). This means that an individual other than the patient assists in decision making for the patient. The courts have reasoned that the loss of capacity to exercise the right to refuse treatment does not entail the loss of the right itself. If a person does not appoint a Medical Agent or an Enduring Guardian and becomes unable to make or communicate decisions, certain medical decisions can be made by family members (Erer, Atici, & Erdemir 2008). The Guardianship and Administration Act 1993 allows informal arrangements whereby families are authorised to make medical and lifestyle decisions on an incompetent person’s behalf where there are no formal arrangements in place. However family members

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can only consent to treatment. They cannot refuse treatment or consent to the withdrawal of life-sustaining treatment.

A patient's right to refuse treatment, whether exercised directly or by proxy, is not an absolute right (Government of South Australia 2004; Government of South Australia 2010). Social interest that must be balanced against a person's right to refuse medical treatment. The preservation of life, the prevention of suicide, the protection of third parties, and the preservation of the ethical integrity of the medical profession are all aspects that may be taken into account. In most treatment refusal cases, these interests are not found to outweigh a competent adult's right to refuse unwanted medical intervention. However, in some cases, the right to refuse treatment is overridden.