

MEDICAL CARE DECISION MAKING FOR GUARDIANS AND FAMILIES

Dr Jerome Mellor GP, March 2009

This information sheet shows how families can be helped to make medical decisions for close relatives who are in nursing homes with dementia or vegetative-like states, sometimes known as "Substitute Decision Making".

Families of elderly relatives are often called on to make decisions about medical treatment for them if they suffer from dementia, severe strokes or vegetative states. This can often be very difficult, so this article discusses how families can improve and make sense of this process. Usually the decision is made by the "person responsible". There is section at the end that deals with this issue. The family may make a joint decision but legally *the person responsible has the final say*. If you think they are still capable of making decisions you should help then fill out an Advance Care Directive.

Let's say, your mother is in a Nursing Home with dementia. If she then has a stroke, to what extent do you want treatment to prolong her life and to what extent do you want treatment that is strictly palliative? By palliative treatment we are really only talking about strong pain killers and sedation for comfort. These issues crop up frequently as many demented patients can live for several years in Nursing homes.

Patients with dementia commonly die from heart attacks, strokes, pneumonia, influenza, cancer and sometimes when they can no longer swallow solids or fluids. If you don't wish to needlessly prolong the life and sometimes suffering of your relative you will need to consider whether you would want to prevent or treat any of these conditions. It is not uncommon that families will want Active Treatment for the first year or two in Nursing Homes and then start considering Palliative Care as they become more mentally and physically disabled.

You should have some understanding that *life prolonging treatments* include

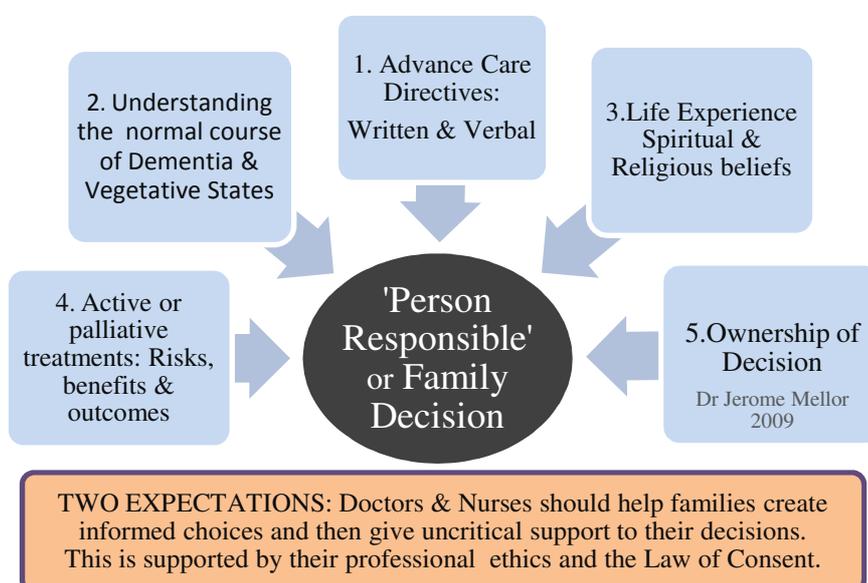
- Operations for cancer and other illnesses/fractured hips.
- Hospital admission for more intensive treatment.
- Medications such as aspirin, cholesterol and blood pressure tablets (for strokes and heart attacks).
- Immunisations for flu' and pneumonia.
- Nutritional supplements in end stage dementia (for example Sustagen).

Many people feel that by refusing treatment or prevention, you are letting nature take its' course. This view is not shared by everybody and this issue can cause some conflict in families. The debate for some is about *quality versus quantity* and for others *life itself is all important*. Remember, stopping treatments such as aspirin or cholesterol tablets *may actually make no immediate or long-term difference to how long a patient lives*. A decision whether to operate or have only palliative care following a fractured hip should be discussed with both the orthopaedic surgeon *and your GP*, as the outlook in terms of disability and life expectancy can be poor in patients with *severe* dementia. There is no need to make a hurried decision.

In Figure 1 there is a 'Decision Tree'. The trees' branches should inform your medical care decisions. Its' roots are grounded in the Law of Consent and the expectation of professional support from doctors and nurses.

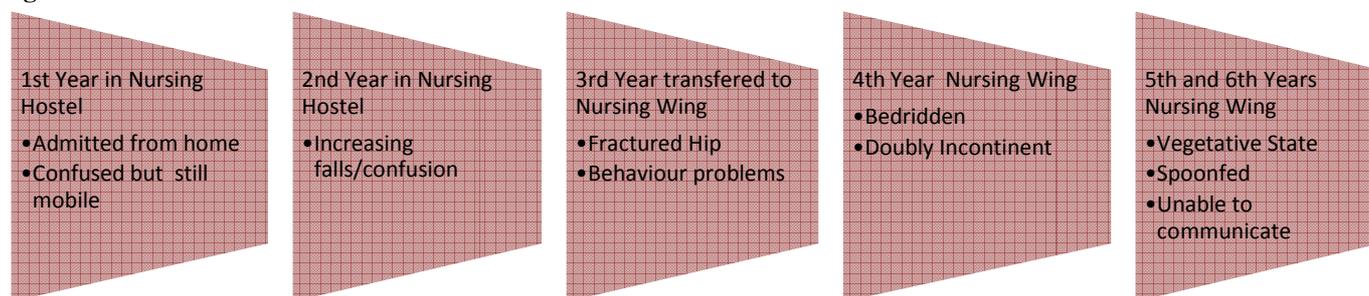
The first branch of the decision tree you should consider is what you thought your relative might have wanted for him/herself. If they have a written Advance Care Directive, you should follow its' directions. They may have discussed these issues with you before they fell too ill to decide for themselves. This may be a general direction such as "if I'm ever *like that* I don't want *any* treatment to prolong my life". Discuss the spirit of any principles they have passed on to you with their Doctor or Nurses and try and include them in your decision.

Figure 1: A Decision Jacaranda: Issues to consider when making decisions



The second branch is to understand the normal course of dementia. Sadly, dementia is characterised by three things. Firstly, that patients admitted to Nursing Homes can live for several years. Secondly, that it is a progressive illness with marked mental deterioration, physical weakness and falls culminating in a vegetative-like state (becoming bedridden, incontinent, unable to communicate and spoon-fed). Thirdly, can frequently be complicated by other illnesses. Figure 2 gives a timeline of an example of a patient living for several years in a Home. So, you should consider the stage of dementia that your family member is at and how well or badly they are faring when deciding between active and palliative care.

Figure 2: Normal Course of Dementia



The third branch is to draw on the life experiences, religious and spiritual beliefs of the patient. You may have had valuable previous experience of sick relatives or friends who have lost the capacity to decide and have had to have decisions made for them. They may also have specific religious and spiritual beliefs on the meaning of life which will influence your decision.

The fourth branch is to consider the current problem; perhaps a stroke, pneumonia or fractured hip. Consider the risks, benefits and possible outcomes of *active treatment* for any of these problems. Then consider whether, at this point in time, the option of *palliative treatment* is preferable. Many nursing home patients die peacefully in their sleep, but some take hours and days, needing morphine and sedatives. This can be distressful for families and can happen whatever option you choose. You may wish to discuss these options in detail with your doctor.

The fifth branch is to make sure that *you own the decision*. You should feel that you have made the decision and not your doctor or nurse. For example; if you had told them to do “whatever you think is best” and your relative dies because treatment was withdrawn or not given, you may feel angry and robbed if this was not *your* intention. Doctors sometimes suggest radical treatment or surgery with the words “otherwise she’ll die a horrible death”. With modern palliative care this outcome is unlikely and should be good reason for you to seek the opinions of others.

The decision tree is grounded by its roots: firstly in your right as the “person responsible” to consent or refuse treatment through the Law of Consent. Secondly in reasonable expectation that Doctors and Nurses as professionals should give you free and informed choice *and* should support whatever decision you make.

When confronted with any illness in your family member, discuss the various issues in the decision tree with close family, nurses and doctors. You may come to the decision that you want them to have palliative care and no other treatment. If so, inform the Nursing Home verbally *and in writing* and make sure that you specify that you are refusing consent for all the *life prolonging treatments* listed above and any hospital admission unless the admission is to improve palliative care.

Reviewing with the patients’ GP: It is in everyone’s best interests that you see your family members GP at least once a year or whenever their health circumstances change substantially (hospital admissions, fractures, pneumonia, stroke etc). You can make an appointment to see the GP at his rooms or when he makes a routine visit to the Nursing Home to review with them the priorities for their ongoing treatment. If you see them in their rooms, take a copy of their medication chart from the nursing home with you.

Definition of the “Person Responsible”:

The role of the person responsible is to make ‘substitute medical decisions’ that consent to or refuse consent to treatment. The person responsible should have regard to the views of the patient but is not bound to follow them unless they were in the form of a written Advance Care Directive. The ‘person responsible’ is defined in the NSW Guardianship Act 1987 in the following order:

1. The Enduring Guardian, if there is one. If there is no one in this category then:
2. The de facto spouse who has a close and continuing relationship with the person. If there is no one in this category then:
3. The carer or person who arranges care on a regular basis and is unpaid (the carer pension does not count as payment). If there is no one in this category then:
4. The carer before they went into residential care. If there is no one in this category then:
5. A close friend or relative.

This article and several Advance Care Directives and links, can be found and printed from the internet site: www.nrgpn.org.au