

### **Three case studies reflecting the consideration or use of Advance Care Directives in the Italian Australian community.**

*The following are case studies gathered from a conversation held between Aged Care Service Improvement Coordinator and Team Leader, Home Care Packages in February 2015*

1. Man – non verbal, catatonic, trouble swallowing, dementia. At home receiving Level 4 Home care Package- at that time EACH package.  
Family initially investigated placement in RACF then stopped looking.  
Mother/ wife and two adult 50 odd year females living at home, neither having ever been married.  
Both daughters work full time, one who does more of the caring and comes home from work at lunch time every day to assist with toileting.

Family thinks that it is taking good care of father whilst service provider was concerned that harm was perpetrated by things like: force feeding, feeding with foods not approved - using the not approved thickeners etc., introducing fluids in an inappropriate way. Family would rather food be more natural not augmented with thickeners.

Geriatrician believes the family is providing the best care that they can.

Service provider thinks that current practices are putting their father at risk and want to implement strategies to better assist their father.

Service provider is guided by duty of care and needs to enforce this whilst providing care.

Family provides their care out of the sight of the service provider.

Service provider seeks a written report by geriatrician to say that in his opinion the family is providing the best care that they can.

Family believes the service provider is being controlling and intrusive and are preventing the family to deliver care that they think is best.

In this family's case the guardianship by default goes to the wife. As a family (wife, and two daughter make the decisions of care).

Service provider needs to be sure that the father's best interests are observed given that he is non verbal and cannot communicate.

One daughter does most of the caring/ hands on and the other daughter does less so of the hands on and also does more of the telephone and meeting communication with service provider.

#### **Issues:**

Family distrustful of service intervention and of the rules imposed.

Family questions nurse assessment.

Family gets emotional when they hear assessments of father's condition and regarding the measures that are suggested to be followed . They do not like what they need to hear from the service provider and the nurse. They do not believe the father's condition is as deteriorated as it is. Can't confront the reality. Believe in hope of stability at all costs.

The actual service usage and needs of this man are quite heavy – there may be a cutting back of purchasing of services because of point made above and this is masked by the emotions of the guilt exercised by the caring offspring.

Family is able to exercise dignity of risk – family was trained on use of transfer equipment etc..

For services there is the duty of care and its compromises.

Dynamics between the carers is particular – there is always one who performs most of the caring duties and there is a more assertive one that makes decisions and carries out the results of the decision making process and usually holds the majority of the legal control and power.

Service providers, health professionals need to understand that there might be more than one power holder/ gate keeper to the communication dynamics.

Service provider needs to state that they have a duty of care towards both the client and the carer.

In this case the conversation that was needed to allow an advance care plan to be written, did not ever go ahead prior to the father becoming catatonic. Service provider proceeds according to duty of care and family reacts to this. They are not proactive towards a strategy of care taking into consideration the reality of father's deteriorating condition ( are reactive ) or only pro active in the areas that they feel that they can provide best care – total care, being present.

In this family's case it might appear that introducing the subject of Advance Care Directives would have been difficult given their disposition.

Given that all the family communicate well with each other regarding the father's care, an Advance Care Directive might even seem extraneous.

A service provider might have a difficult time even introducing the subject even whilst the father was well enough to communicate his wishes.

2. Man – 72 years old living with advanced dementia, non verbal, but is aware of his surroundings, has a deep complicated pressure sore that has to be packed and dressed many times regularly. This dressing is overseen by the GP. This pressure sore has become infected. The pressure sore has remained stable in light of infection.  
2 sons – one who provides most of the daily care and the other who has been granted both the power of attorney and guardianship. The full time carer is the more passive one who waits for his brother to agree to major changes before agreeing or signing off on them. Both carers agree that the family believed in Eastern medicines/ holistic approaches to health and medication at the time before the father lost the capacity to make his own medical decisions.

The sons' research best methods to care for the father utilizing natural medicines which are seen to work and also seen to on the other had sometimes work slowly. Both agree that they don't want the father to be given antibiotics as the side effects cause him significant suffering. It is agreed that all the family hold the same values and beliefs in how to provide the best care to their father and that these values were held by all even before the father became sick and lost his capacity to give informed consent.

Service provider needed to have the family demonstrate to them that their father's beliefs on how to provide care for him was established before he got sick. The guardian should have proof of this.

This family uses the family dynamic to designate roles in the care of the father and it seems to work for them. They assume and exercise the right to refuse western model care and medication.

The father passed away peacefully in his sleep recently. Palliative care was offered and family accepted but the use of morphine was refused.

In this family's case, one might assume that there could have been a possibility of introducing a formal Advance Care Directive but again , it might seem that such a directive might be extraneous, given that both the sons and the father all agree that everyone knows the wishes of the father, all hold the same values regarding using western medicine, and all

are informed of best practices in the field of wholistic medicinal practices and all are disposed to keeping abreast of such practices.

3. Woman, 97 years, has advanced dementia. All family has agreed to uphold mother's wishes outlined in the Advance Care Directive. The bottom line of the advance care directive in this case is that the mother is not to be resuscitated in an acute medical event, not to call the ambulance but instead to call the family members. This is a legal document written by the woman's GP.

The service provider's duty of care overrides the family's directive so that the ambulance must be called in the event of the woman's acute medical crisis. When the ambulance arrives, the officers will be given a copy of the woman's advance directive. The responsibility becomes that of the ambulance officers.

This Italian family is an unusual example of one who has been proactive in the response to a parent's wishes for self determination and autonomy . This family has had conversations and has determined a strategy for care. They have an Advance Care Directive.