NSW HEALTH | Clinical Services Redesign Program

Advance Care Planning

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Executive Summary

Over the last few decades improvements in medical knowledge and technical successes have made it possible to substantially extend the lives of some patients. At the same time there has been a growing concern about the focus on technology rather than the patient. This is combined with a growing community presumption that individual wishes for future health care will be respected. This presumption is particularly strong where an individual may lose cognitive ability that impairs their decision-making capacity (NSW Health, 2004).

Prior discussions and/or documentation of a person's wishes, values and beliefs for medical treatment and end of life preferences can help an individual to maintain control of their wellbeing. It also removes the burden of responsibility and conflict that may arise when families, carers and health professionals must make these decisions without knowledge or understanding of an individual's preferences. At these times, patient autonomy and respect for individual preference regarding life-sustaining treatments may become lost.

There are many indicators and life events that signal when discussions about Advance Care Planning should begin. These indicators occur across a range of settings including residential aged care facilities, in general practice, the community and in hospitals. Implementing Advance Care Planning can be challenging due to space, staffing and time issues but it can achieve significant results particularly within the residential aged care facility setting. It can also be a major tool to assist with appropriate management of residents both within these facilities and when residents present to hospital. It can be a time consuming process, however the benefits to both patients and health professionals are considerable.

The Need for Change

Winnie's Story

Winnie's Story Prior to ACP

Winnie was 88 years old and had lived at a high level care Residential Aged Care Facility for three years. Her daughter lived near the residential facility and visited her mother regularly. Winnie suffered from heart failure for several years. Last year her heart specialist told her that nothing further could be done for her heart failure.

Winnie's story shows how patients and families can have poor end of life experiences without advance care planning.

This is a real story, only the names have been changed.

One night Winnie became increasingly breathless and the night staff called an ambulance to transport her to hospital. Winnie was unconscious when she arrived at the hospital at 3:00 am. The registrar rang Winnie's son who lived 200 km away to discuss his mother's treatment. Winnie's son was emphatic that the registrar should 'do everything you can'.

Winnie's family arrived at the hospital the next morning and found her on life support in the intensive care unit. Winnie was sedated and unconscious, with lines and tubes maintaining all her functions. The family was told that Winnie's organ systems were failing, and that nothing could be done to prolong her life.

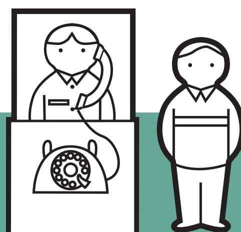
Winnie's daughter was very angry with her brother for requesting further treatment. Winnie had made it clear to her that she did not want to be kept on life support. Her daughter was angry and upset that Winnie was going to die among strangers in hospital rather than surrounded with her friends and carers at the residential facility.

Winnie died the following day without regaining consciousness but her children remained angry and upset with each and refused to speak to each other at Winnie's funeral.

What's wrong with this story?

- Winnie was not able to die comfortably and surrounded by her friends and carers in her home as she wanted.
- Winnie's son was asked to make a decision about her end of life treatment without knowledge of what her preferences were.
- Winne's daughter was not contacted for her views.
- Lack of knowledge about Winnie's preferences led to conflict within the family.

Winnie, who has incurable heart failure, is taken to hospital.



Staff phone her son who requests further treatment.

Winnie's daughter is angry that her mother is being treated in hospital and not able to die at home as she wanted.

The family remain angry with each other after Winnie's death

Background to the Model

Improvements in medical knowledge have made it possible to substantially extend the lives of some patients. In parallel there is a growing presumption that individual wishes for future health care should be respected if an individual loses cognitive ability that impairs their decision making capacity. Many older people also express fears that life sustaining procedures when they are seriously ill, will prolong their suffering and compromise their dignity and quality of life (Taylor & Cameron., 2002).

In 1999, less than 1% of acute care inpatients in NSW had any record of conversation about their treatment preferences and less than 0.2% of residents residing in high-level residential aged care facilities have any documented treatment wishes.

(Nair et. al., 2000)

As Winnie's story illustrates, a lack of prior discussion and/or documentation about a person's wishes, values or beliefs about medical treatment and their end-of-life preferences, means family members and health professionals are left to make important treatment decisions without knowing the person's wishes. This may lead to conflicts over decisions and in some instances over-zealous treatment regimes. It is at these times that respect for individual preferences about life sustaining treatments may become lost.

Planning health care decisions in advance of any problems gives families and carers the opportunity to respect choices in the full knowledge of an individual's beliefs and value systems. While no one expects to lose capacity to manage their own affairs, many people are comforted knowing that a trusted relative or friend can make decisions on their behalf if necessary. This is particularly so for older people who are entering the later stages of a chronic illness.

There are many indicators and life events that signal that Advance Care Planning discussions can and should begin. These indicators occur in many settings including the community, general practice, in hospitals and within residential aged care facilities. Most importantly it is vital that timely conversations about the end-of-life choices begin and decisions made before cognitive decline renders a person incapable of participation (NSW Health, 2004).

Initially programs that helped patients to exercise control and autonomy over their end of life care focussed on achieving written directives and providing information about legal rights and processes. More recent and successful approaches emphasise discussion and communication about preferences with loved ones as more important factors in the patient's mind (Evans, 2003). The success of Advance Care Planning depends on motivating patients to plan, the quality of the planning process and the system of practices, policies and staff education that allow plans to be known, retrieved, updated and finally respected at the proper time (Hammes & Briggs., 2004). Ideally discussions are held with staff trained in Advance Care Planning and can be one-on-one or with a range of family members and health professionals. Few individuals want to specify specific medical treatment although most want to express more general preferences such as values and goals for care and to allow their person responsible some leeway in decision making (Hawkins et.al. 2005). Advance Care Planning can also stall when there is conflict between what patients, carers, persons responsible and clinicians want and when there is an unnecessary focus on writing directives.

Discussions about Advance Care Planning can be particularly effective in improving quality of life within residential aged care facilities. This is because older people in residential aged care facilities are the frailest and sickest people in the community, and

are more commonly affected by a loss of decision-making capacity because of dementia and other cognitive disorders. Advance Care Planning discussions combined with collaboration between hospitals and residential aged care facilities means that many patients can be cared for in the comfort of their residence and improve their outcomes. Implementing programs to increase the uptake of Advance Care Planning requires a comprehensive staff and community education program to overcome some of the major barriers. It can be a time consuming process but there are considerable benefits for patients, relatives and health professionals.

Reasons why there is a low uptake of Advance Care Planning

- The complexity involved in decision making.
- Anxiety related to death.
- Denial.
- Lack of time dedicated to understanding principles.
- Inability of patients, health care providers and other professionals to identify a substitute decision maker or a 'person responsible'.
- Lack of trust in the process and general confusion about the term advance care planning.
- Care teams having a poor level of knowledge and skills.
- Reluctance of health care professionals to discuss or initiate conversations about Advance Care Planning or to discuss end of life issues.
- Difficulty of interpreting plans in the 'real world'.
- Patients fear that they may not be able to change their mind.

(Taylor and Cameron 2002 and Department of Health and Ageing 2004)

Advance Care Planning (ACP)

Maria's Story

Maria's Story Under ACP

Maria was an active, strong and independent woman who had spent her working life as the cook at a special school for young boys.

> This is the story of Maria.
>
> Advance Care Planning has helped Maria to be clear about her wishes for her future healthcare.
>
> Her adopted family, GP, and other care staff have certainty around caring for Maria in line with her wishes.

The Boyd family 'adopted' Maria when she was a young woman. Ruth Boyd became like a sister to her and she is godmother and aunty to Ruth's son George. Maria is now 79 years of age and she continues to have a close and loving relationship with the extended Boyd family. George is particularly close to Maria and over the years has actively supported and advocated for her in her decision making. Five years ago, Maria nominated George as her 'substitute decision maker' in case the situation ever arose where she lost capacity to make her own decisions.

Three years ago Maria's health had deteriorated to such an extent that she decided to move to a high level residential aged care facility. Maria settled in well to her new home and the Boyd family continued their frequent, regular visits. Over the last few months the family had started to notice a decline in Maria's functioning as she became weak, withdrawn from activities she previously enjoyed, reluctant to walk and always feeling cold. One evening when he was out to dinner, George received a call advising that Maria had taken ill and was being transported to hospital. George immediately rang Maria's GP who advised George that Maria needed to go to hospital because of a dangerously low red blood cell count.

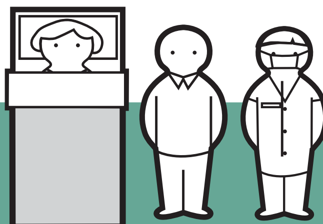
The next morning George visited Maria in the Intensive Care Unit. Maria was tired, disorientated and fearful but clearly pleased to see George. The intensive care nursing staff explained that Maria needed three blood transfusions and would probably need exploratory surgery to find the source of her internal bleeding.

> **Choices**
>
> *It is important that people are aware they have choices.*
>
> *I was distressed when the nurse told me Maria needed an operation.*
>
> *We wouldn't have known we had a choice if the Intensive Care Nurse hadn't told us.*
>
> *You need to know that you do have a choice.*
>
> Maria's "adopted" son George

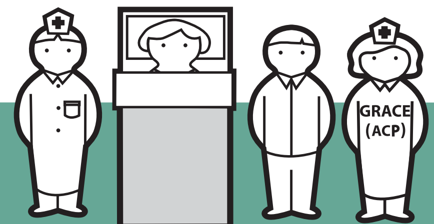
George is very concerned about this as the previous year, Maria needed a 30 day hospital stay for minor skin cancer surgery. It was during this hospital stay that the Boyd's first noticed a significant decline in Maria's happiness and willingness to participate in family

Maria's Story

Maria's functioning is gradually declining and she has been admitted to hospital.



Maria and her advocate George, are worried about the proposed surgery.



Staff specially trained in ACP and the medical team work with Maria and George to explain all Maria's choices.

What is good about this story?

- Maria is given the opportunity to clearly articulate her wishes and involve George to support her decision making.
- Both Maria and George are informed about and realise that there are choices.
- George, Maria and her GP understand that George will be Maria's 'person responsbile' to make medical decisions if Maria loses capacity.
- Key people including those trained in facilitating end of life discussions were are involved.
- There was a focus on understanding medical conditions and treatment options as well as values and beliefs.
- Systems are in place so that all Maria's carers and health professionals know her wishes and work collaboratively to respect her wishes.
- There is flexibility and an opportunity for further review and change.

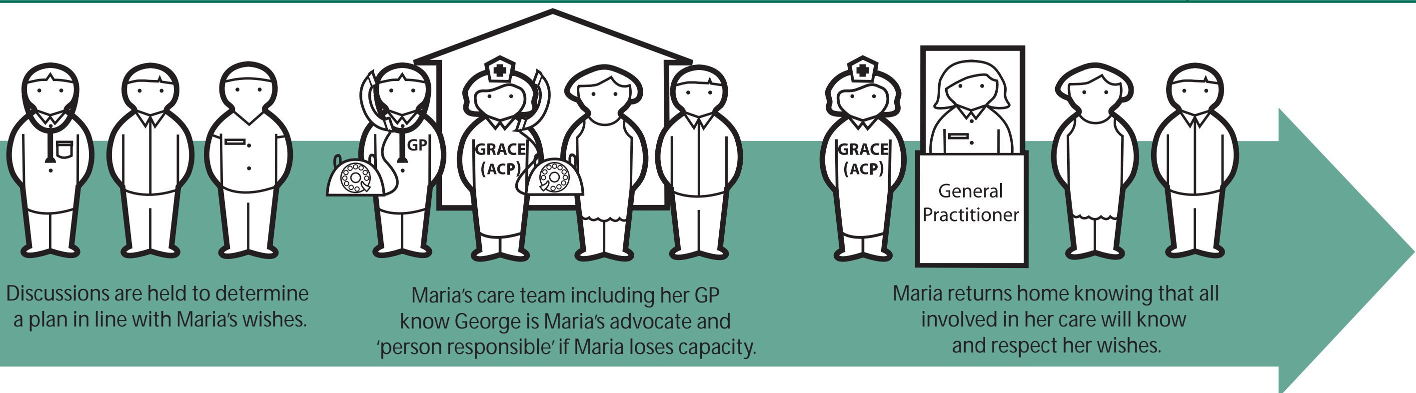
activities. On this occasion Maria was only discharged because of George's persistent lobbying. Once Maria returned to her residential facility home she became much happier and more her "old self'.

George expressed these concerns to the nursing staff, and they referred him to Annie, a specially designated Clinical Nurse Consultant. Annie's main role is to help facilitate a smooth return home for older patients. George spoke to Annie, all of Maria's doctors and a social worker. He understood the reasons for the transfusions and surgery but at the same time he thought that Maria probably had other choices.

George discussed these choices with Maria who was clear that she didn't want an operation and wanted to return home as quickly as possible. George asked Maria's doctor to discuss what she wanted to do. The doctor ensured that Maria was orientated to person, time and place. He asked her some direct and simple questions and then said that he was satisfied Maria realised the consequences of refusing an operation.

A meeting was then held with Maria, her carers and George and together they agreed on Maria's care plan. It was agreed that Maria would have the blood transfusions and then return home. Annie explained all the medical terminology to George and Maria. George thought he was becoming well informed and this in turn relieved his anxiety about being able to respect Maria's wishes. Annie also contacted Maria's GP and requested that George be contacted before transferring Maria to hospital in the future. Annie also explained that George was Maria's 'person responsible' if she ever became incapable of making her own treatment decisions. The hospital rang George when Maria was discharged home and the residential facility also rang him when she arrived.

Now back at home, Maria's appetite has returned and she seems to have gained a new lease of life. If Maria requires additional transfusions at some later date George will be contacted first to discuss her care plan. George is comfortable and clear that his role is be Maria's advocate and support her decision making while she is competent. He understands that if Maria loses capacity he will be her person responsible and must take her wishes into account when deciding what treatment she needs.



What Is Advance Care Planning?

Advance Care Planning refers to the process of planning in advance based on a person's wishes before treatment decisions are made. This process involves exploration and identification of values and concerns relating to a person's health care and health related decision making and management at the end of life. (Singer et. al., 1996).

Key Characteristics

- People know they have choices.
- Discussions that result in agreement of a person's values, goals and preferences for end-of-life care.
- Clarifies who is responsible in the event of incapacity.
- Promotes appointment of an enduring guardian.
- A multi-disciplinary approach across more than one setting.
- Staff have relevant skills and knowledge.
- Systems and process are in place to ensure everyone is aware and follows the individual's wishes.

Advance Care Planning draws on a broad range of resources that includes and coordinates services in both health and social systems and assists an individual to:

- Reflect on their goals and values and clearly state their wishes about end-of-life care.
- Have a conversation about what is important to them as they approach death, and specifically the role of life-sustaining treatment.
- Engage others in the decision-making process about their wishes.
- Understand their medical condition and consider the benefits and burdens of current and future treatments.
- Have flexibility in how treatment decisions are made.

Identifying a Person Responsible

Planning may also include discussions and identification of a 'person responsible' to help ensure that a person's individual choices are respected for future medical treatment (NSW Health, 2004). The role of this person is to decide whether to consent to or refuse medical treatment. The aim of Advance Care Planning is to reach a clear and agreed understanding between an individual, their person responsible and their treating medical practitioner about the individual's future treatment preferences in the event of incapacity.

Appointing an Enduring Guardian

Alternatively some may choose to appoint someone else, such as an enduring guardian, to make decisions for them in the future when they no longer have capacity. The enduring guardian can have a broader role than the person responsible because they can make decisions about non-medical matters as well.

Advance Care Planning is always optional as some individuals prefer not to make decisions for the future, but prefer to make them as the need arises (NSW Health, 2004). It is not only applicable to older people but is applicable to any individual who wants to plan their end of life care.

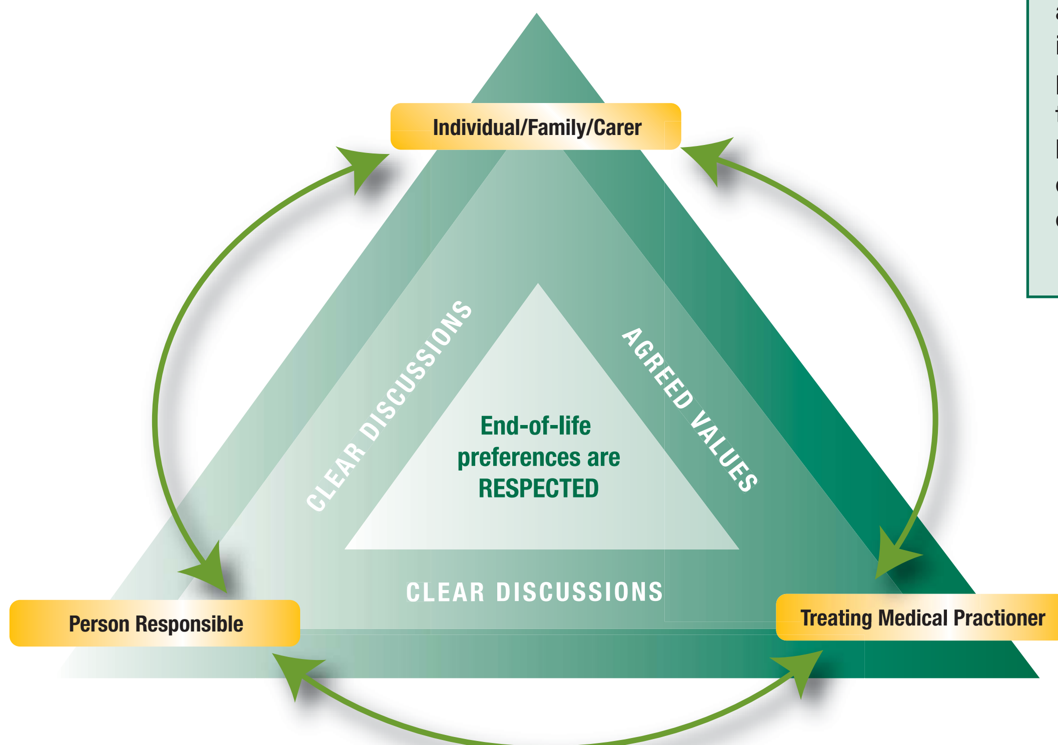
Elements for Success

- See Advance Care Planning as a process, not an event.
- Focuses on the discussions and not on developing a document.
- Trained third parties initiate and facilitate discussions.
- Personal relationships are valued.
- The identified 'person responsible' including an enduring guardian, is recognised as the most powerful influence on enacted end of life decisions.
- A systematic approach so that plans are known, respected and followed sensitively.
- Incorporated into routine patient management and decision-making events.
- A systematic and comprehensive education program is in place combined with systemic documentation management and common policies.

(Hammes, 1998; Molloy, 2000; Reilly, 1995; as cited in Evans, 2003)

Key success factors

The aim of Advance Care Planning is to reach a clear and agreed understanding between the individual, their "person responsible" and their treating medical Practitioner.

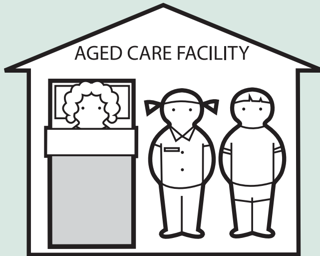


Lessons Learned

Successful programs usually emphasise that communication about preferences with loved ones as being the more important factor in the patient's mind, knowing that loved ones would not have to make hard decisions about their health care (Evans, 2003).

How Advance Care Planning Works

1. Residential Aged Care Facility (RACF)



Possible indicators to begin Advance Care Planning discussions

- Making a will.
- When additional services/support are provided.
- Initial assessment before entering a residential aged care facility.
- Family conference after residential facility admission.
- Diagnosis or progression of a chronic disease or terminal illness.

Key people to involve in discussions

- Resident and family
- General Practitioner
- Residential aged care facility Director of Nursing and nursing staff
- The 'person responsible'
- Any enduring guardian

Bett's Story

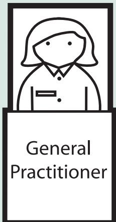
Bett was 83 years old, had four children, twelve grandchildren and six great-grandchildren. She was very interested in all her family. The family kept a close eye on Bett and helped her to manage at home. As Bett became increasingly frail it became obvious to all that despite the help they gave she was having difficulty managing. Bett talked to all her family and they agreed that she would be safer living in hostel accommodation with her family continuing to visit and taking her on outings. During the discussions, Bett decided she would like her children, especially her middle daughter Emily, to make medical decisions when she could no longer do so. Before she moved to the hostel, Bett made arrangements to appoint Emily as her Enduring Guardian.

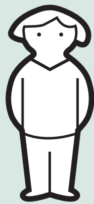
Initially the move went well and Bett settled in comfortably at the hostel. Unfortunately her arthritis started to take its toll and her general health continued to deteriorate. Not long after moving to the hostel it became obvious to Bett and her family that she could no longer go out except in a wheelchair. Not long after her 84th birthday as she became frailer and less mobile, Bett agreed in consultation with her family to move into the high care residential facility.

Bett assured all the family when they visited her at Easter that she was happy in the residential facility but she was also clear that *'..if anything happens to me, I don't want to go to hospital. I'd sooner be looked after here.'* Emily, Bett and Bett's GP talked together to discuss her wishes and the GP agreed that it was a reasonable plan to try and keep Bett at home rather than transport her to hospital. At a subsequent visit to the nursing home the GP sat with Bett, Emily and the nursing home staff to write a plan in Bett's record, that if she got seriously ill with pneumonia, had a stroke or a heart attack, the GP and Emily would be notified before an ambulance was called.

As winter came on, Bett became less mobile, in more pain and her health generally deteriorated. One night, Emily got the call she was dreading. Bett was unconscious after having a stroke and could not be roused. Emily checked that Bett's GP had been called and then phoned her siblings before going to the nursing home. The GP was already with Bett when Emily and the rest of Bett's family arrived. In consultation with the GP, Emily and the nursing home staff, Bett's family sat with her and even though she couldn't speak it seemed as if Bett knew they were there. Just after dawn Bett passed away with all her family around her. A few days later at Bett's funeral, her son gave the eulogy saying "Bett died as she lived - surrounded by her loved ones, and in charge, as always".

2. General Practice Setting





Possible indicators to begin discussions

- Diagnosis or progression of a chronic disease or terminal illness.
- Age of patient.
- Provision of additional services/support.

Key people to involve in discussions

- Patient and family
- General Practitioner
- Divisions of General Practitioners
- Community services
- The person responsible
- Any enduring guardian

Gavin's story

Gavin is 80 years old and lives at home. His wife and son died several years ago but his two grandchildren visit regularly. Although Gavin has mild dementia, he is still able to make decisions for himself.

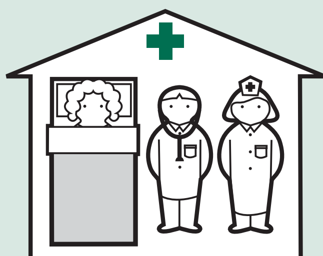
One of Gavin's grandchildren accompanied him on his last visit to his GP. During a discussion about Gavin's need for daily assistance and support the general practitioner mentioned the idea of Advance Care Planning and gave Gavin some information to take home.

Over the next few weeks, Gavin talked frequently to his grandchildren about what he wanted if he got sick or needed more help with his daily care. He was adamant he did not want to be 'kept going' if he got really sick. He talked a lot about what he felt he wanted to do and experience to give his life pleasure and meaning. After several weeks Gavin and his grandchildren visited the GP again. Following the GP's advice, Gavin sat down and wrote a letter to his grandchildren about his medical goals and the treatment he should receive if he became life threateningly ill. He discussed the letter with his GP and gave him a copy. The GP told Gavin that it could be used to help his 'person responsible' make decisions if Gavin became too unwell to make his own medical decisions.

Two months later, Gavin had to move to a low level residential aged care facility. Gavin's family asked for a copy of his letter to be kept with his medical records and that it be brought to the attention of any doctor who visited or treated Gavin.

Several months later Gavin suffered a stroke and his family and GP felt confident about making care decisions based on Gavin's stated choices. He didn't want to go to hospital or want any "hero" tactics to keep him alive. Gavin's wish was to be with his wife and son.

3. Acute Hospital Setting



Possible indicators to begin Advance Care Planning

- Diagnosis or progression of a chronic disease or terminal illness.
- Life threatening illness or trauma
- Post acute life threatening event that requires intensive medical treatment and intervention e.g. transfer to an acute care unit, or Medical Emergency Team calls.
- Patient transfer to another acute facility to receive interventional care e.g. cardiac, respiratory or renal disease.
- Increasing frailty with multiple admissions to acute care.
- Patient is not expected to die this admission but is near the end of life.

Key people to involve in discussions

- Patient and family
- Treating medical officers
- Emergency Department staff particularly GRACE and the Aged Care Services in Emergency Team (ASET)
- General Practitioner
- Other hospital staff trained to facilitate Advance Care Planning Discussions.
- Community services who may continue discussions after the acute episode.
- The 'person responsible'
- Any enduring guardian

Jim's story

Jim is in his mid sixties but has been chronically ill and very unwell for some time. Jim has an oxygen tank at home and has had to sleep sitting up in a chair for the last year. Jim's breathlessness makes it difficult for him to eat and he has lost a lot of weight.

Recently Jim had an acute episode and was admitted to hospital. The next day, Anna his wife was visiting Jim when his specialist came to see him. Jim just came out and asked the specialist about what was going to happen "when I can't breathe?" The specialist was clearly reluctant to discuss Jim's prognosis although after some discussion informed Jim that the 'only treatment option is to put you on a breathing machine, but you wouldn't get off it again'.

Jim was too upset and breathless to respond and eventually the specialist, clearly anxious to end this uncomfortable conversation said "…but of course you don't have to, if you don't want. We have some people who could talk to you about your choices. The choices might be about how we manage your symptoms, and make you as well as we can for as long as we can."

Jim nodded, and glanced across at Anna and said "I reckon you'd better come, too."

4. Community Setting	**Possible indicators to begin discussions**	**Key people to involve in discussions**
	• Significant birthday • Trauma • Diagnosis or progression of a chronic disease or terminal illness • Provision of additional services/support • Making a will	• Patient and family • Community acute/post acute care service staff • Community nursing staff • Lawyers • Aged care facility staff • The 'person responsible' • Any enduring guardian

Jean's story

Jean is 48 years old, lives alone and is an active member of her local community. Jean has no close family or "person responsible" and recently suffered a stroke. She is receiving rehabilitation at home and is now able to get around quite well and her speech is good.

Jean thinks very clearly and is able to articulate her goals and values about her future health care. As part of her rehabilitative care, the Community Acute/Post Acute Care CNC visited Jean at home and Jean raised the issue of her future medical care and the need for an Advance Care Plan.

Not long after this discussion Jean talked to her friend Patricia about Advance Care Planning options and asked if she would agree to be her Enduring Guardian. Patricia agreed but wanted to be clear about Jean's future medical care needs. So Jean and Patricia had further discussions with the Post Acute CNC. Patricia was able to ask questions and gain a better understanding of Jean's needs.

Jean ordered an 'Appointment of Enduring Guardian' form from a charitable organisation. Jean filled in the form clearly stating her wishes and directions to Patricia as her Enduring Guardian about how she was to make decisions in certain areas. Jean and Patricia signed the form in front of the Registrar of the Local Court. Jean gave copies to Patricia, her GP and her priest. She also requested that a copy of the Enduring Guardianship appointment be placed in her medical records at the local hospital. Jean keeps the original with her other important documentation and is well aware that she can change it as often as she likes or revoke it at any time. Just in case she wants to make changes, Jean records exactly who has a copy of the appointment. Jean sees the appointment of an enduring guardian as a mechanism to ensure that if a crisis arises and she is incapable of making decisions for herself, then someone she trusts will make decisions for her. Jean is reassured that Patricia will make decisions in her best interests and is fully aware of Jean's health care preferences, values and beliefs.

Advance Care Planning Process

Ben has just been diagnosed with a debilitating disease. He is worried about losing his ability to make decisions.

Ben has many options.

- Tell someone
- Identify a 'person responsible'
- Write wishes down
- Do nothing

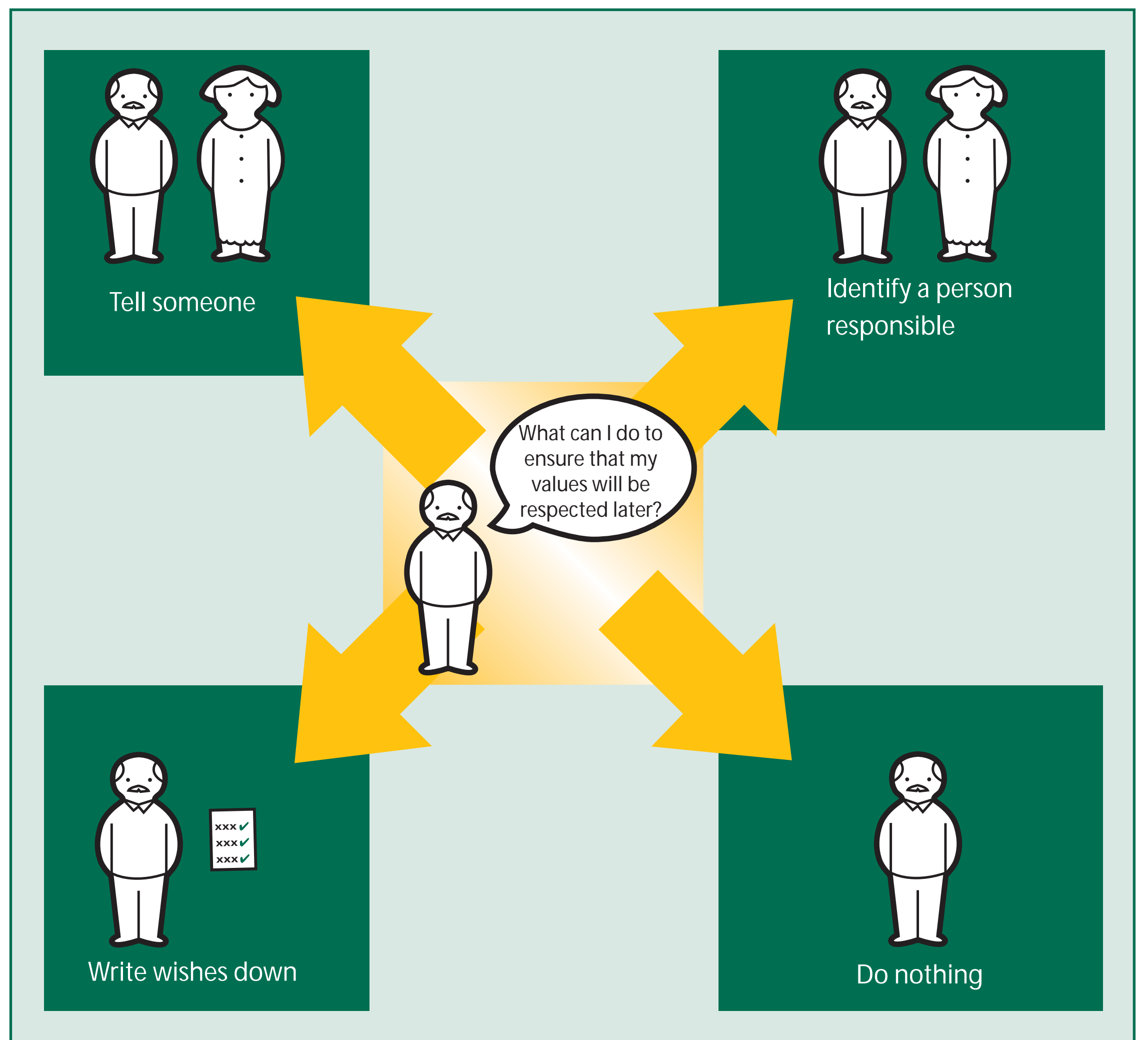
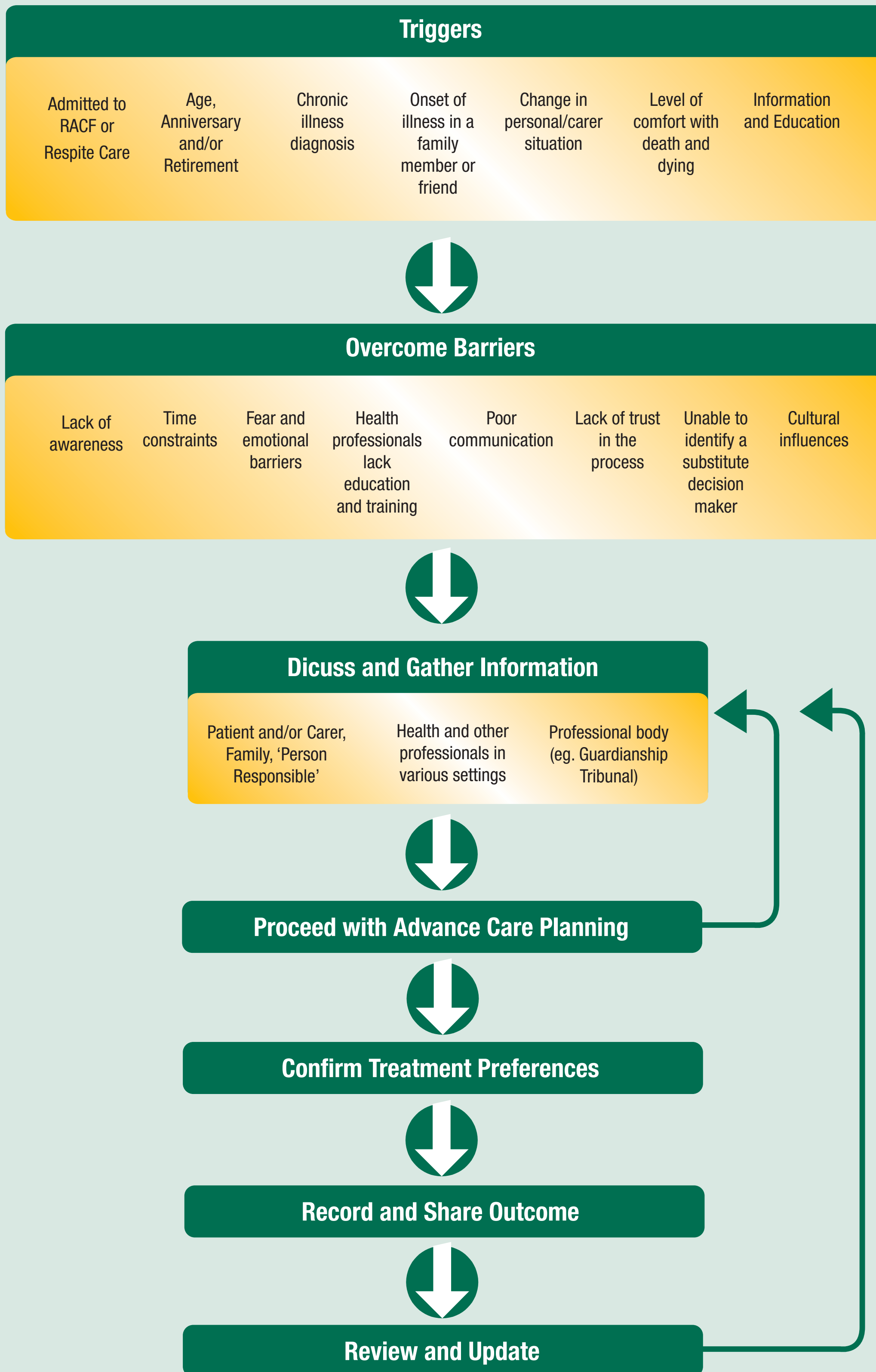


Figure 1: Advance Care Planning Process



How Does Advance Care Planning Work?

Successful Advance Care Planning occurs when a person's wishes and choices are communicated via an Advance Care Plan or person responsible and these are respected and fully informs medical treatment.

Post acute care program manager

Offer information/discussion

Discussion is vital because there are differences between what patients, carers and health professionals value.

Begin a conversation about an illness and its prognosis with significant people. Conversations will centre on medical preferences but will include values, spiritual beliefs, goals and preferences.

Advance Care Planning may be a private affair or involve extended family, friends and professionals. Potential people involved include the individual, family members, enduring guardian, GP, nurses, cancer or palliative care team members, social workers and unpaid carers.

More than one meeting will be needed.

Part of routine practice

Ideally Advance Care Planning is incorporated into routine patient management and decision-making processes. For example, residential aged care facilities may routinely initiate discussions when assessing new residents.

Document patient wishes

The plan can be as simple as a hand written letter, a verbal agreement or an entry in patient notes.

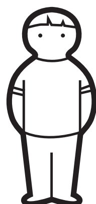
An Advance Care Directive or 'living will' documents preferences in anticipation of a time when one is unable to express those preferences due to illness or injury (NSW Department of Health, 2004).

Involvement of others, particularly the 'person responsible' is crucial to ensuring that an Advance Care Directive is easily available when needed.

Note: There is substantial evidence that stand alone written advance care directives have little or no impact on end of life care. This means it is important to focus on the discussions not the document.

More info: See toolkit for Using Advance Care Directives NSW Health 2004

Appoint a 'person responsible'

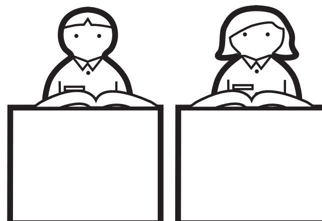


A key task is to identify who would be the substitute decision-maker for the patient if they lost capacity.

In NSW the 'person responsible' is the substitute decision maker for medical decisions.

The role of the 'person responsible' is to make substitute decisions that consent to, or refuse consent to medical treatment (NSW Department of Health, 2004).

Ongoing education campaign



All staff and health professionals need to have a broad understanding of Advance Care Planning and access to additional resources to help facilitate discussions.

Individuals who are trained to initiate discussions should be identified.

Ensure there are resources available for patients and family members.

It is also important to raise broader community awareness.

It takes time

Allow plenty of time after discussions so that patients and families can reflect, and have the opportunity to change and amend information and choices.

Prepare to take up to 18 months to formulate an advance care plan (Jezewski & Meeker, 2005).

Patients want to:

- Communicate verbally.
- To talk about values and goals.
- To have their 'person's responsible' confident in their decision making ability.
- Exercise choices about what their substitute decision maker can do.

(Hawkins et.al. 2005.)

Staff Skills

Staff skills required

- Interpersonal and communication skills.
- Knowledge of conditions, treatment, medical knowledge to explain common terms.
- Knowledge of consent, legal and ethical issues.
- Cultural and religious competence and awareness.
- Comfortable talking about end of life choices.

One way to ensure that Advance Care Planning is implemented effectively is to equip health professionals with the skills and knowledge they need to do the job.

All health professionals involved in the process should have the skills to initiate conversations about Advance Care Planning with adults. These conversations need to include discussion about the person's views on future medical care as well as have the competence to facilitate the planning process with each individual.

Residential aged care facilities and palliative care staff, in particular, should have specific training to help communication with seriously and terminally ill patients and their families. Staff need to be comfortable discussing end-of-life decisions and have sufficient knowledge about medical conditions, treatment and terminology.

Reviewing current staff training and development opportunities to include the specific training needs surrounding discussions on end-of-life decision-making can help to up-skill staff. Junior staff, or those who do not often find themselves in a position where discussion is needed, may also benefit from specialised training and participation in such discussions with more senior staff.

An understanding of current systems and processes relating to the transfer of information between residential aged care facilities, acute hospitals, GPs and the community settings are essential in the absence of electronic health records, to ensure an individual's wishes are followed.

By ensuring staff have adequate training to facilitate the Advance Care Planning process, staff can minimise the conflict relating to the circumstances of a loved one's death and help to reduce the anger that is often associated with grief.

Definitions

Advance care planning (ACP) - refers to the process of planning in advance based on a person's wishes before treatment decisions must be made. This process will involve exploration and identification of values and concerns relating to a person's health care and health related decision making and management at the end of life.

Advance care directive (ACD) - sometimes called a 'living will', is a document that describes one's future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury. Completion of an ACD ideally should be one component of the broader advance care planning process.

Carers - usually family members and sometimes friends. Their work is based on a pre-existing relationship and is unpaid and often unrecognised. The primary carer is the person who has provided the most informal assistance to the resident in relation to self-care, mobility and communication. When the word 'family' is used, it also includes carers.

End-of-life (terminal) care - a form of palliative care that is appropriate when the individual is in the final days or weeks of life and care decisions may need to be reviewed more frequently. Goals are more sharply focused on the individual's physical, emotional and spiritual comfort needs, and support for the family.

Enduring guardian - is a substitute decision maker that an individual appoints under the Guardianship Act 1987 (NSW) to make lifestyle and/or health care decisions should the individual lose capacity to make their own decisions at some time in the future.

The terms of all enduring guardianship appointments must be carefully checked to ensure that the enduring guardian has the authority (called 'functions') to make the particular decision at hand.

Family - can be considered as any person who is part of the central core in the support network of an individual, including carers. A definition of family is "those closest to the patient in knowledge care and affection". This includes the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (not related biologically, by marriage/contract). Based on this definition, family could include carers, friends, neighbours, and extends the boundaries beyond biological and legal relationships.

Informed Consent - the voluntary and informed agreement by an individual required before the commencement of a medical procedure, test, or medication.

Power of Attorney - is a legal document which appoints a person (the attorney) to make decisions about a person's financial affairs, such as accessing bank accounts or selling land. An **enduring power of attorney** is a power of attorney that continues to be effective even if the person loses mental capacity. A power of attorney can only be used to make financial decisions, it cannot be used to make medical or lifestyle decisions.

Person Responsible - the role of the ‘person responsible’ is to make substitute decisions that consent to, or refuse consent to medical treatment for someone who lacks capacity to consent/refuse. This person is required to have regard to the views of the patient but they are not bound to follow them. The ‘person responsible’ replaces the old term ‘next of kin’ as the person from whom consent for active treatment in the incompetent patient must be sought. The ‘person responsible’ is determined according to the hierarchy within the Guardianship Act 1987 (NSW) and in the following order:

- A guardian whether appointed by the Guardianship Tribunal or an enduring guardian appointed by an individual with the function of consenting to medical and dental treatment.
- A spouse or de facto spouse who has a close and continuing relationship with the person.
- The carer or person is someone who provides care on a regular basis and is unpaid (the carer pension does not count as payment).
- The carer of the person before they went into residential care.
- A close friend or relative.

Health professionals are obliged to seek consent from the ‘person responsible’ and can give them the same information they would have given the patient if they had been able to consent themselves.

Residential Aged Care Facility (RACF) - residential aged care is for older* people who can no longer live at home. Reasons include illness, disability, bereavement, an emergency, the needs of the carer, family or friends, or because it is no longer possible to leave at home without help. RACFs can provide either permanent or short-term care. Short-term is referred to as ‘respite care’. There are two broad types of aged care - low level and high level care:

- Low-level care homes (formally know as hostels) generally provide accommodation and personal care, such as help with dressing and showering, together with occasional nursing care.
- High-level care homes (previously know as nursing homes) care for people with a greater degree of frailty, who often need continuous nursing care.

**There are instances where younger people with disabilities receive care in aged care homes*

Implementing Advance Care Planning

Process Map

Visit the online version of this process map on the ARCHI website at www.archi.net.au/elibrary/build/moc

Here you will be able to access more information on each of the steps in implementing the model. You will have access to tools and templates as well as hints and lessons learned by others who have implemented the model.

	Planning **Where are you now?**
Governance	• Identify leaders • Establish a Steering Committee
Patient Journey How do patients flow through the model	• Map the patient journey (include family and/or carer perspective)
Policies and Protocols	• Understand current systems and processes • Identify policies, protocols and guidelines
People Understand who the staff are, how they function and what role they play in the patient journey	• Stakeholder analysis • Stakeholder engagement • Form key partnerships
Resources	• Survey current resources
Communication	Develop a communication plan for both internal and external target groups.

• Develop a Governance Plan • Recruit project officer • Establish governance structures • Develop Key Performance Indicators (KPIs)	Monitor and evaluate against the KPIs.
• Describe the ideal patient journey	• Regularly monitor and remap the patient experiences
• Develop policies, protocols and guidelines that clearly articulate how Advance Care Planning is initiated and discusses.	• Go live and refine the process • Develop a policy review process • Monitor compliance with policies and protocols
• Develop position descriptions for staff who have a key role in Advance Care Planning. • Establish a mentoring process • Provide training and education to all staff	• Develop competency standards and a review process • Mentor staff to sustain implementation and achieve best practice • Regularly update staff skills in Advance Care Planning
• Deliver required resources	• Monitor use of resources
• Implement the communication plan • Develop information tools and education materials for staff and patients • Identify how results will flow back to staff and patients.	• Review and revise the communication plan as goals are achieved. • Celebrate successes

Resources

Literature

Australian Government Department of Health and Ageing, 2004. *Guidelines for a Palliative Approach in Residential Aged Care*, Rural Health and Palliative Care Branch, Department of Health and Ageing, Canberra.

Benevolent Society of NSW and the Centre for Education and Research on Ageing (1999) *Taking Charge: Making Decisions for Later Life, Report for the NSW Committee on Ageing,* Benevolent Society, Sydney.

Benevolent Society (2005) *Your Future Starts Now: A guide for the over 50's*, The Benevolent Society, Sydney. Reprinted March 2008.

Caplan GA, Meller A, Squires B, Chan S & Willett W (2006) Advance care planning and hospital in the nursing home, *Age & Ageing*, 35 (6):581-585.

Clayton, JM, Hancock, KM. Butow, PN. Tattersall, MHN. and Currow, DC. Clinical Practice Guidelines for communicating prognosis and end of life issues with adults in the advance stages of a life limiting illness, and their caregivers. *Medical Journal of Australia Supplement* 2007, 186:12.

Curtis JR and Engelberg RA (2006) Measuring success of interventions to improve the quality of end-of-life care in the intensive care unit, *Journal of Critical Care Medicine,* 34(11): 341-347.

Department of Ageing, Disability and Home Care (2005) *Planning Ahead Kit: Resources for managing financial, health and lifestyle decisions into the future,* NSW Department of Ageing, Disability and Home Care, Sydney.

Department of Ageing, Disability and Home Care (2004) *Guidelines for a Palliative Approach in Residential Aged Care*: Chapter 3:33 - 40, Edith Cowan University, Western Australia.

Department of Health, April 2006, *NSW Chronic Care Collaborative Resources*, Department of Health, NSW, viewed 16 November 2007 <http://www.health.nsw.gov.au/health_pr/chronic_care/ccc/resources_acd.html>

Department of Health, 2004. *Using Advance Care Directives*, Department of Health, NSW, 2004.

Dunn H (2001) *Hard Choices for Loving People: CPR, artificial feeding, comfort care and the patient with a life threatening illness,* A&A Publishers, Virginia.

Evans, J., 2003. *Advance Care Planning: A Review of the Literature*, Eastern Health, Department of Human Services, Victoria.

Hammes B. J., Rooney B .L., 1998. Death and End of Life Planning in One Midwestern Community, *Archives of Internal Medicine,* 158:383-390.

Hampshire, A, Squires, B, Wall, S, Thompson, R, 1999 *Taking Charge. Making Decisions for Later Life*, Report for the NSW Committee on Ageing, December 1999, Benevolent Society of NSW and the Centre for Education and Research on Ageing, NSW, viewed 16 November 2007 <http://www.maca.nsw.gov.au/pdf/taking_charge.pdf

Harvey, P, Storer, M, Jackson, B, Lim, W, Advanced Care Planning In Residential Aged Care Facilities, *Int. Med. Journal*, June 2004;34(6):A49.

Hawkins N A , Ditto P H, Danks J H, Smucker W D, 2005. Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making. *Gerontologist [NLM - MEDLINE]*, 45 (1):107.

Jordens C, Little M, Kerridge I & McPhee J (2005) From advance directives to advance care planning: current legal status, ethical rationales and a new research agenda, *Internal Medicine Journal*, 35: 563-566.

Jezewski M A. & Meeker M A, 2005, Constituting Advance Directives from the Perspective of People With Chronic Illnesses, *Journal of Hospice & Palliative Nursing,* 2005;7(6):319-327.

Molloy D, Russo R, Stiller A, O'Donnell M, How to Implement the "Let Me Decide" Advance Care and Personal Care Directive Program, *JCOM*, 2000;7(9):41-47.

Molloy, D W, Guyatt, G H, Russo, R, Goeree, R, O'Brien, B J, Bedard, M, et al., 2000, Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial, *Journal of the American Medical Association*, 2000;283(11):1437-1444.

Mularski RA, Curtis JR, Billings JA, Burt R, Byock I, Fuhrman C, Mosenthal AC, Medina J, Ray DE, Rubenfeld GD, Schneiderman LJ, Treece PD, Truog RD & Levvy MM (2006) Proposed quality measures for palliative care in the critical ill: A consensus from the Robert Wood Johnson Foundation Critical Care Workgroup, *Journal of Critical Care Medicine*, 34(11): s404-s411.

Nair, B, Kerridge, I, Dobson, A., McPhee, J, Saul, P, 2 Advance Care Planning in Residential Care, *Australia New Zealand Journal of Medicine* 2000;30(3):339-43.

Nelson JE (2006) Identifying and overcoming the barriers to high-quality palliative care in the intensive care unit, *Journal of Critical Care Medicine*, 34(11): 324-331.

Reilly B, Wagner M, Magnussen C, Roos J, Papa L., Ash J, 1995, Promoting Inpatient Directives about Life-Sustaining Treatments in a Community Hospital, *Arch Intern Med*., 155:2317-2323.

Shanley C (2007) *Planning for and Managing the End of Life - Symposium Final Report*, Department of Aged Care and Rehabilitation, Sydney.

Singer P A, Robertson, G, Roy, D L, Advance Care Planning, Bioethics for Clinicians Series 6. *CMAJ*, 1996;155(12):1689-92.

Stapleton RD, Engelberg RA, Wenrich MD, Goss CH & Curtis JR (2006) Clinician statements and family satisfaction with family conference in the intensive care unit, *Journal of Critical Care Medicine*, 34(6): 1679-1685.

Taylor, D McD, & Cameron, PA, 2002. Advance Care Planning in Australia: Overdue for Improvement, *Internal Medicine Journal*, V.32(9-10): 475-480

Treece PD, Engelberg RA, Shannon SE, Nielsen EL, Braungardt T, Rubenfeld GD, Steinberg KP & Curtis JR (2006) Integrating palliative and critical care: Description of an intervention, *Journal of Critical Care Medicine*, 34(11): 380-387.

White DB, Engelberg RA, Wenrich MD & Lo B (2007) Prognostication during physician-family discussions about limiting life support in intensive care units, *Journal of Critical Care Medicine*, 35(2): 442-448.

Tools

Aging with Dignity (1999) *Five Wishes*, Commission on Aging with Dignity, Florida.

Aged Services Learning and Research Collaboration (2007) *NSW Advance Health Care Directive*, Southern Cross University, Coffs Harbour.

Department of Ageing, Disability and Home Care. *Planning Ahead Kit Resources for managing financial health and lifestyle decisions into the future.* NSW Department of Ageing Disability and Home Care. 2006.

Department of Health and Ageing, 2006, *About Residential Aged Care*, Department of Health and Ageing, Canberra, viewed 8 November 2007, <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/5D86020729E69196CA256F1900106532/$File/02about.pdf>

Hammes, B and Briggs L. *Respecting Choices Advance Care Planning Program Quality Improvement Toolkit.* Gundersen Lutheran Medical Foundation 2004.

Mellor J (2007) *My Treatment Choices: An Advance Care Directive*, Dr Jerome Mellor, Ballina.

University of Hawaii Centre of Aging (2007) *The Complete Life: Care of the Dying - Advance Directive Values Clarification Worksheet*, University of Hawaii, Honolulu.

Molloy DW (2004) *Advance Directive for capable adults*, Vancouver Health Authority, Vancouver.