

Advance Care Planning Information Guide for GPs

Revised by The Respecting Patient Choices Program, Townsville Hospital, 2005.

This information kit forms part of the process of informing GPs about the project and their role in the Respecting Patient Choices Program.

The Information kit contains:

- ◆ Advance care planning information guide for GPs.
- ◆ Advance Health Directive.
- ◆ GP laminated quick reference card: *Steps to advance care planning & assessing competence*
- ◆ Office of the Adult Guardian Fact Sheets
 - ◆ Advance Health Directive
 - ◆ Statutory Health Attorney
 - ◆ Enduring Power of Attorney

Respecting Choices® was conceived as an advance care planning program in Wisconsin USA, at the Gundersen Lutheran Medical Foundation. Austin Hospital in Victoria was then granted a licence for the Program as *Respecting Patient Choices* in Australia, and now pilot sites in each state have been approved with Townsville the lead site for Queensland.

The Respecting Patient Choices Program aims to

- promote an individual's understanding about their health and the treatment options available to them
- assist them to document their wishes and preferences about future medical treatment, particularly end-of-life treatment, in an Advance Care Plan.

This Program facilitates conversations between the patient, their attorney and their family and important others about their values, beliefs and goals in life, and, in light of their current health status, what medical treatments they would and would not want in the future.

Key success factors at Wisconsin were

- Moving the focus on end-of-life decision-making away from completing documents and towards facilitating discussions about the patient's values and preferences
- Educating medical and other key staff about the program and its relevance to daily clinical practice
- Developing a system to highlight the patient's advance directive at the front of their medical record. This ensured the patient's advance directive went with the patient and had maximal impact on end of life care when needed [1]. In Queensland this is the "blue divider" system, with the patient's Advance Health Directive and Discussion Record placed behind it.

Initial results from the USA program were favourable in that in 98% of deaths, treatment was consistent with the advance directive. Out of 540 people studied in the community after the program was initiated, 85% had advance directives and 81% were in the medical records [2].

Respecting Patient Choices Program

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Purpose

The purpose of this information kit is to:

- inform GPs about the Respecting Patient Choices Program and their role in the Program
- promote a health outcome that is positive for the patient
- provide support for GP to consult patients on wishes for care
- assist GPs to participate in the advance care planning process
- assist GPs to complete advance care planning documentation

Advance care planning and end of life care in Queensland

Conflicts frequently arise in medical decision-making, and there can be a discrepancy between a patient's end of life care and their wishes for care. To address this problem, attempts in several countries have been made to introduce an advance care plan, also called an advance directive or living will.

In Queensland advance care planning is based on powers enabled by the Powers of Attorney Act 1998 and encourages patients to appoint an attorney for personal/health matters. The Respecting Patient Choices Program helps to encourage the writing of an Advance Health Directive and appoint an attorney for personal/health matters.

What is advance care planning?

Advance care planning is a process enabling a patient to make decisions about his or her future health care in consultation with their health care providers, family members and other important people in their lives. Based on the ethical principle of patient autonomy and the legal doctrine of patient consent, advance care planning helps to ensure that the concept of consent is respected if the patient becomes incapable of participating in treatment decisions.

Medical practitioners can play an important role by informing patients about advance care planning, supporting them with appropriate resources, discussing their values and goals with them as they engage in advance care planning and helping them to tailor their Advance Care Plan to their own health condition

The GP's role in advance care planning

The GP may be the key person to facilitate the process with some patients, their relatives and the health care team in some health services. For other patients, the GP may be asked to support the process by signing the documentation.

The specific role of the GP in supporting advance care planning includes:

- Introducing the topic of Advance Health Directives
- providing the patient with information regarding their current health status, prognosis and future treatment options although hospital specialists may be more involved in this capacity
- Signing the nominated doctor statement.

The Respecting Patient Choices advance care planning process is a team approach involving patients, family and important others, the GP and other relevant care providers. Respecting Patient Choices facilitators are trained to facilitate the conversations involving as many of these people as possible. If the patient requires further information regarding their current health status, prognosis and future treatment options, it is recommended that the patient consult their GP or treating Consultant who can then discuss future plans in the context of wishes expressed in the Advanced Health Directive.

It is also recommended that the patient's GP signs the nominated doctor form in the Advanced Health Directive. This ensures the GP has an opportunity to

- be involved in the advance care planning process
- assess the capacity of the individual to make informed choices and sign the document voluntarily.
- inform the patient appropriately about their treatment choices
- take an advisory role in the advance care planning process

Advance Care Planning across health care services

The intention of the Respecting Patient Choices Program is to create a system where patient treatment choices are communicated well within the organisation, to the patient's GP and on transfer to the hospital or other facilities. The system of communication is to be consistent. This ensures the plan will be consulted and will have maximal impact on end of life care when needed, especially after hours, or on transfer to hospital or other services.

Where is the Advance Care Plan kept?

In the organisations that have implemented the Respecting Patient Choices Program, the Advance Care Plan is stored behind the blue divider.

It is essential that advance care planning documentation is prominent in the patient's medical record. There is also a fluorescent red alert 'Advance Care Plan Enclosed' sticker on the alerts page or cover of the history. Behind the blue divider is:

- the Advance Care Plan Discussion Record, where the results of any discussions about advance care planning are documented
- the Advance Health Directive, if completed
- Contact sheet

Who will know how to find it and how to use it?

All health care service staff involved in medical care should know where the Advance Care Plan is, when to use it and the implications it may have for future medical treatment and end-of-life care.

How will the information be communicated?

After the Advance Care Plan has been completed, the original remains with the patient and copies are given or sent to:

- the attorney for personal/health matters.
- the GP
- medical records at the hospital
- other hospitals/clinics the patient normally attends (with a covering explanatory letter)
- extra copies to share with others (eg. next of kin, minister or solicitor).
- A copy to keep in the car.

When the patient is transferred to another institution, a copy of the Advance Care Plan is sent with them with a covering explanatory letter.

If the plan is changed, the old plan should be destroyed and the new plan placed in the records.

What is the role of the RPC facilitator?

RPC facilitators have been trained to initiate and facilitate advance care planning discussions with patients, their families and friends and those providing their health care. Facilitators prepare the documentation in the patient's medical record, document the discussions on the Advance Care Plan Discussion Record and assist with completing Advance Care Plans. They ensure that the organisation's advance care planning systems are followed and that the documentation is kept up-to-date.

GP Involvement in Respecting Patient Choices

Patients have the right to make decisions about their health care, now and for the future. Medical treatment should only be given with fully informed consent and patients have the right to consent to or refuse treatment. If, in the future, a patient becomes unable to express his or her choices for treatment, those providing medical and personal care and the patient's family and important others may not know the patient's wishes. Advance care planning provides the opportunity to discuss and record a patient's care and treatment choices in advance.

GP steps to advance care planning

Step 1. Incorporate advance care planning as part of routine care

When advance care planning discussions are held with the patient, the attorney and family and the health care professional, treatment choices are more likely to be understood and enacted when needed. If initiated early, while patients are still capable, these conversations can provide the necessary information and the time and resources to assist patients in understanding and interpreting the information in the context of their values and goals. If these types of discussions occur late in a person's illness, s/he is more likely not to be capable of participating in decision-making, and decisions may be more difficult for staff, families and doctors to make.

The advance care planning process usually involves several discussions plus documentation of a patient's wishes over weeks to months.

If initiating

- offer/initiate advance care planning when doing a comprehensive medical assessment or medical care plan
- reassure the patient that advance care planning is part of routine care
- explain the rationale and steps for advance care planning
- suggest that the family be involved in future consultations about the patient's wishes
- Offer written patient information, fact sheets and documentation.

Step 2. Assess capacity of patients

- To complete an Advance Health Directive.

The GP may be requested to assess patient's legal capacity.

Patients need to understand their options for life-sustaining treatment and the value to them of this treatment. To assist in assessing a patient's capacity the GP may ask the individual questions to ensure they understand the following:

- Advance care planning includes future choices
- The Advance Care Plan is only used when they are incapable of making decisions for themselves
- Advance care planning may include selection of an Attorney for personal/ health matters
- Their choices can be changed at any time.

When assessing an individual's capacity to make an Advance Health Directive, the GP should also consider if the individual understands the following:

- They understand the general nature, consequences, broad benefits and burdens of what is being discussed
- They are able to take responsibility for making a choice
- They are able to make decisions in the context of their current medical condition.

It is advisable that the GP review the patient's capacity throughout the advance care planning process, taking the opportunity provided by the patient reflecting on their decisions over a number of visits. The GP may also need to judge whether a formal assessment of capacity is required, eg by a neuropsychologist.

Step 3. Support discussion and writing of Advance Health Directive.

- Discuss patient wishes with patient and family if desired.
- Provide information on medical conditions, benefits and burdens of treatment

Individuals can make general assessments about future medical care, in terms of goals that might be possible, without knowing a great deal about the specific pathophysiology of the disease process or the specific technologies that might be used. When thinking about the goals of treatment, a person might think about how it might help and might harm, for a particular circumstance.

- Patients may be in a position of weighing benefits against burdens and deciding how treatment affects intended goals. Preferences and goals may change as an illness progresses. Certain goals may assume higher priorities over time or short-term goals may be balanced against long-term goals. At times, individuals may have the goal of deferring as much decision-making as possible to others, eg the GP, palliative care team or family

Step 4 Selection of an attorney for personal/health matters.

A patient may only select an attorney who is:

- over 18 years of age
- has the capacity to make decisions on the patient's behalf.

Once nominated, the attorney has the power to:

- agree to medical treatment on the patient's behalf
- refuse medical treatment on the patient's behalf if the treatment would cause the patient unreasonable distress or if the attorney believes on reasonable grounds that the patient would not wish the treatment to continue.

The attorney does not have the power to decide on donation of body tissue, sterilisation, termination of pregnancy, research or experimental care, certain psychiatric or other specified health matters.

When selecting someone to be an attorney, it is important to choose someone who is:

- trustworthy and knows the patient well
- willing to respect the patient's views and values
- able to make decisions under circumstances that may be difficult or stressful.

Often a family member is a good choice as an attorney, but not always. The attorney should be someone who will closely follow the patient's choices and advocate on the patient's behalf.

Before completing an Advance Health Directive it is important that the patient discusses his or her values and beliefs and the content of the Advance Care Plan with the person whom he or she wishes to appoint as Attorney for personal/health matters so that they understand and respect the patient's choices.

NB Statutory Attorney in Queensland refers to the person automatically responsible for decisions regarding medical care if no attorney for personal/ health matters has been appointed. This is (in order) spouse, primary unpaid carer, family member or close friend or the Adult Guardian as a last resort.

Step 5. Using an Advanced Care Plan

- Incorporate Advance Care Plan into medical records (hospital and GP)
- Consult Advance Care Plan and attorney when patient no longer able to participate in decision-making and major clinical decisions need to be made
- Review plan 2 yearly or after significant change in patient's condition

The GP should advocate for the patient if a situation arises where another health service seeks to override the patient's choices.

Step 6. Review the Advance Care Plan

- Review 2 yearly or when health status changes significantly
- Can be changed or revoked at any time

There are a number of reasons why a patient might want to change or revoke an Advance Health Directive. For instance, the relationship with the attorney may change, or the person appointed may no longer be appropriate for the role, or the patient's medical and other circumstances or wishes may change.

Advance Health Directive documents can be changed verbally or in writing. The patient may destroy the documents or request that they be destroyed. Completing a new document (eg, appointing a new attorney or recording new choices) can also revoke documents as the most recent dated document overrides the older document. It is important to inform the attorney and family members of the changes and provide them with copies of the new directive.

NB. The Advance Care Plan only comes into use when the person is no longer able to communicate his/her wishes.