ST VINCENT'S CARE SERVICES

A SERVICE OF ST VINCENT'S HEALTH AUSTRALIA

Advance Care Planning Workshop Modules 8 to 13

St Vincent's Care Services 2013

What is this course about?

eLearning Modules

Section one
Relationship with Catholic Health Australia

Section two
Introduction : What is ACP

Section three
Role of the Health Professional and ACP Facilitator

Section four
The surrogate decision maker

Section five
The legal documents and the Qld position

Section six
Alternative documents

Section seven
Decision making and capacity

Face to Face Modules

Section eight
Future health care issues including capacity

Section nine
Supporting wishes

Section ten
How we do it in St Vincent's Care Services – the documents of ACP

Section eleven
Having the conversation

Section twelve
Recording people's wishes

Section thirteen
Reviewing recorded and expressed wishes

What we are doing today

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In the online session you have covered the first seven modules. The next six modules are covered in this face to face session today.

You need to have completed the full course before you are able to do Advance Care Planning in St Vincent's Care Services. We call staff who have completed the full course, Advance Care Planning Facilitators.

Important note!

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This course discusses complex issues that are of an emotional nature.

Participants are advised the standards of confidentiality apply to any Advance Care Planning forum where personal information may be shared.

Parking Lot

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Time for questions you have from the elearning modules

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Section 8

FUTURE HEALTH CARE ISSUES INCLUDING CAPACITY

Session 8 objectives

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- Discuss capacity and related issues
- Discuss CHA view and documents related to ACP
- Examine the common forms of life preserving treatment that are elements of decision making around end of life
- Investigate the meaning and implications of benefit verses burden to people who are thinking about their end of life
- Relate how discussing benefit verses burden with a person and their representative impacts upon decision making

Review of capacity

Generally, someone can be regarded as having decision-making capacity if they are able to:

- understand the basic medical situation
- understand the nature of the decision, including:
  - the implications - benefits, risks and what the medical treatment entails
  - alternatives to the medical treatment proposed, including the implication of making no decision
- weigh up the information e.g. by asking questions.
- retain the information (short-term memory).
- freely and voluntarily communicate a decision in some way (for example, by talking, using sign language or any other means).

Settling disputes about capacity

If there is a dispute about someone's capacity to consent or make decisions about their health care treatment, then an application can be made to the Queensland Civil and Administrative Tribunal (QCAT).

QCAT is the only legal entity that can make decisions regarding capacity; decide if the person requires a guardian and if so, make an appointment.

Capacity assessment in SVCS around ACP

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- Any questions surrounding a person's capacity to make informed decisions is to be referred to their GP or Specialist.
- The RN should ensure all relevant nursing assessment is current and completed in full to assist with the assessment process
- The assessment tool used to support a decision on capacity is the Psychogeriatric Assessment Scale (PAS) – must be current

Capacity of the representative

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- The representative should have capacity to make informed decisions
- If there is any concern the representative is not making decisions that are in the best interest of the individual, then a case conference should be initiated inclusive of the key stakeholders involved in the individuals care to discuss concerns

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Section 8

PART B – FUTURE HEALTH CARE ISSUES

View of the Catholic Church

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A Guide for people considering their future health care

- This document is offered to individuals on admission

Briefing Note on the Obligation to provide Nutrition and Hydration

End of Life Issues

- Provides additional information – offered as required

A Guide for health care professionals implementing a future health care plan

- All four (4) documents must be read by ACP Facilitators and Health Professionals facilitating ACP discussions to gain an understanding of the Churches view and ethos

View of the Catholic Church

- Withdrawal of treatment occurs only when it becomes **therapeutically futile** (makes no significant contribution to cure or improvement) or **overly burdensome** (the benefits hoped for do not justify the foreseeable burdens of treatment)
- It is *not ethical* to provide a futile treatment
- It is *never permissible* to end a person's life – euthanasia is any action or omission which of itself and by intention causes death with the purpose of eliminating all suffering*

*Catholic Health Australia, 2001, Code of Ethical Standards for Catholic health and Aged Care Services in Australia, Part II Decision Making in Health Care, Euthanasia 5.20, p 46

Common End of Life Choices

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- Choice to initiate or withhold life sustaining treatment
- Choices to withdraw life sustaining treatment once commenced
- Choices related to comfort care

Common forms of life sustaining treatment

The types of life sustaining treatments that might warrant discussion include:

- Cardiopulmonary resuscitation (CPR)
- Artificial ventilation
- Artificial nutrition and hydration
- Antibiotics
- Dialysis
- Hospitalisation

Respecting Patient Choices, Advance Care Planning information for professionals , Choices related to life prolonging treatments, www.rpcprogram.org

Facilitating discussions on life sustaining treatment

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Individuals will need assistance with:

- Understanding life sustaining options
- Deciding whether or not the treatments are appropriate for them
- Considering their circumstances
  - ✓ The goals of each treatment
  - ✓ The benefits and burdens of each treatment
  - ✓ Whether they would regard the treatment as overly burdensome in their special circumstances

Respecting Patient Choices, Facilitating Advance Care Planning Decision, www.rpcprogram.org

Benefits verses Burdens

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Potential benefits:

- Sustaining life
- Restoring function
- Relieving suffering
- Promoting an individual's goals or values
- Slowing down progress of the disease

Potential burdens

- Prolonged pain or suffering
- Increased symptoms
- Damage to body function
- Psychological distress
- Financial distress
- Excessive demands on family

Making decisions…

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Substituted judgment standard

- Considered to be subjective in interpretation
- Implies intimate knowledge of the other uninhibited by emotions surrounding the present events.

  Example:

  When the person making the decision says: 'I think that X would want this done in the circumstance.'

Best interests standard

- More objective interpretation
- All members of the health care team can evaluate the situation and come to some agreement about the facts of the case.
- Involves using a more formulated approach to the burdens and benefits of a treatment.

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Section 9

SUPPORTING WISHES

Section 9 objectives

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- Relate potential responses to conversations regarding future health care
- Discuss scenarios where ACP becomes relevant to invoke
- Relate issues that could occur at times of health deterioration and decision making

Change and decision making

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Making a choice in the current light of day is not always the same choice you would make in a different light, on a different day.

Decision making process

When it is time to interpret the ACP, all involved need to consider:

a) Do the present circumstances correspond to the situation that the individual imagined when he or she recorded their values and wishes

b) Do the treatment and care options available correspond to those of the individual's future health care plan?

c) Do the effects of implementing the individual's values and wishes correspond to the effects that the individual understood would be their consequence?

d) Are there new or changed factors in the present circumstances that the individual may not have taken into account but might have wanted to be considered in the present circumstances

Catholic Health Australia, A Guide for health care professionals implementing a future health care plan (undated)

What is reasonable?

As health care professionals we also need to establish:

- That acting on the values and wishes is ethical and lawful, given both the individual and their own moral responsibilities

Questions to assist in deciding what is reasonable:

- Is the request in keeping with responsible medical practice, individual professional conscience and the values of the institution?
- Has collaborative discussion with the person or their representative, GP and other key stakeholders occurred

Activity

Mrs Smith is in the active stages of dying. Her son from Melbourne arrives and immediately insists his mother is sent to hospital so they can “do everything possible to save her”.

Is this a reasonable request?

What might be difficult in supporting a person's wishes

- More than one family member is the Enduring power of attorney and one lives in Sydney
- There are 3 family members and all 3 do not agree about what their mother wanted
- The resident requests that they do not wish to go to hospital if they deteriorate but they are found choking on a cherry at Christmas time
- There is no living relative or the relative declines all contact with the person
- The client flatly refuses to answer questions about ACP and asks if you are trying to kill them
- During an ACP discussion the resident reveals that they have fallen out with their brother and have not spoken in 43 years. They feel that they cannot got to their grave until they speak with the brother.
- The client has dementia at a moderate stage with only short periods of lucidity and no existing ACP information
- The family member who visits most frequently is not the EPOA
- The family member, when asked if they wish to discuss ACP declines vehemently but the client states they wish to talk about it.

Section 10

ST VINCENT'S CARE SERVICES – HOW WE DO ACP

Section 10 objectives

- Discuss policy – purpose, principles and overview
- Discuss how ACP is undertaken on admission and during the individuals journey
- Discuss risk minimisation

Documents

- Advance Care Planning Policy
- Advance Care Planning Procedure
- Statement of Wishes for Future Health Care
- Information Sheet on Statement of Wishes for Future Health Care
- CHA documents (discussed previously)

Policy - Purpose

Advance Care Planning (ACP) provides a framework for health professionals and other staff to improve the journey of individuals receiving services from St Vincent's Care Services. ACP is a discussion that occurs between the individual, their representative, family members, significant others (if appropriate) and health professionals involved in care. It takes into consideration the individual's wishes, values and beliefs about future health care in order to prepare for end-of-life care.

Policy - Principles

- Advance Care Planning is a right of all people if they so choose
- Advance Care Planning reflects the individuals own values and views and respects their autonomy to make decisions about what they want
- Advance Care Planning should be commenced early to allow the individual time and assistance to reflect on the meaning of end-of-life care, to face and resolve personal differences within their families, and to minimise potential future conflict between family members
- Some individuals may trust their families and health care professionals to know and do what is best for them; others prefer to provide specific guidance for their treatment in the form of a written advance care plan or other document e.g. Statement of wishes for future health care
- The health care environment and an individual's health care status are dynamic. Earlier expressions of advance care planning provide evidence of the individual's past wishes; however health care professionals must still make responsible decisions in the present circumstances, with the guidance of the individual's appointed representative.

Policy - Overview

- Ethos and guidance of CHA
- Provide opportunities to an individual to participate in ACP
- Inform GP/Specialist the individual wishes to participate in ACP
- Assessment of capacity is completed by the GP with RN support
- Completed internal or external training relevant to ACP
- All documents recording ACP will be recognised and shared with consent
- Staff will accurately record ACP wishes if asked to do so
- ACP records must identify a representative (as a minimum)
- All attempts will be made to follow the ACP in consultation with the individuals GP, and representative
- ACP must be accessible for clinical staff to refer to

Procedure - Admission

Establish if the individual has an existing Advance Health Directive (AHD) or Advance Care Plan

- If yes
  - Request a copy of the document and file in the ACP section of the individual's chart (a spare copy can be kept in the administration file)
- If no
  - The individual and their family will be informed an ACP process is available
  - The CHA 'A guide for people considering their future health care' is offered
  - Allowed at least a month or longer to come to terms with their needs and if they want to continue
  - ACP Facilitator is made available to provide information and support

Procedure - Ongoing

Initiating ACP may also be prompted at other times in an individual's journey with SVCS and hence may start at any time.

Examples:

- When their condition/s changes
- If their family circumstances change
- After a discussion with their family or another individual
- When a new treatment is offered to them

Procedure - Risk Management

Spiritual distress:

- Encourage the individual to seek appropriate professional support (social worker, pastoral worker, clergy or similar)
- Assist in referral process (as required)

Legal issues:

- Witnessing of internal SVCS ACP documents can only be done by an ACP Facilitator, Health Professional, Program Coordinator or Manager
- Staff must not witness or complete external ACP documents e.g. AHD

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Section 11

HAVING THE CONVERSATION

Session 11 objectives

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- Identify key elements which must be discussed in ACP conversations
- Discuss important elements of communication which influence the conversation
- Relate timeframes and timing that are important to factor into ACP conversations

The conversation and the process

- People often need time and assistance to reflect on the meaning of death in their lives – to face and resolve personal differences within families, and to minimise future conflict between family members.

- Give it time, give it space, start a conversation, seek clarification – their views

Communication principles

- Communicate hope
  - Hope for the best , prepare for the worst
- Eye contact / Body language
- Engender trust
  - Encourage to talk
  - Acknowledge past experience
- Demonstrate respect
- Explore and paraphrase for clarity
- Active listening
- Focus on positive – sense of control
- Impartiality / non bias
- Attend to person's emotions
  - Identify loss
  - Legitimise feelings
  - Offer support

Preparing for scheduled conversations

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- Does the individual have capacity?
- Is there an EPOA or representative already appointed?
- Does the EPOA have authority to make decisions on behalf of the person – health and personal matters?
- Does the individual wish to have family members present?
- Check the level of knowledge and understanding the EPOA/representative has about the individual's health status and future health wishes

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http://www.youtube.com/watch?v=8Yic-AOHbMs

Having the conversation

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- Introduce self and explain the purpose of the conversation
- Provide introductory materials on ACP
- Establish an understanding of what they know about their health status
- Give time and encouragement to establish important elements of their values, wishes, needs and beliefs
- Do not push the need for a written document - be prepared for more than one discussion
- Do not force or push for information
- Discuss benefit vs burden of life-sustaining treatments and likely scenarios (refer to GP or health profession if outside scope of practice)

Having the conversation

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- What is important to you to live well?
- What things are important for you about your life?
- What are the things you most value?
- Do you have beliefs that are important to you?
- What is important to you about maintaining your body/health ?
- If you become really unwell what sort of treatments would you find appropriate, expect?
- How much aggressive intervention would you wish for to sustain your life? (scenarios)
- If your heart stopped would you expect doctors to try to restart it?

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Section 12

RECORDING AN INDIVIDUAL'S WISHES

Session 12 objectives

- Identify methods of documenting people's wishes
- Discuss the health care professionals responsibility in recording ACP conversations
- Practice the process of recording that will facilitate meaningful and sensitive records

Principles of documentation

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FACTUAL

- Focussed – about the client
- Accurate - to what is said
- Complete – covers all of the information from the event/ time /process
- Timely – Contemporaneous -record as close as possible to the time it happens
- Understandable – can people understand what is written – spelling, grammar, sentence structure, meaningful content
- Always objective - not opinions or biases
- Legible – can be read

Statement of wishes for future health care

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Can only be completed by:

- The individual themselves
- The appointed representative/s
- An ACP Facilitator
- Health Professional

A record must be made in the progress notes and the ACP information filed in the ACP section of the individual's chart

Other ACP

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- Informal documents are accepted as an ACP
- Health professional may document ACP discussions in the progress notes
- May be completed by external health professionals – request a copy for our record
- Should be signed and dated appropriately
- All ACP records including 'declining to participate' must be filed in the ACP section of the individual's chart

When a person wants to complete an ACP alone

Completing an ACP without the involvement of a representative/s, family or GP does not meet the principles and ethos of ACP. However, it is recognised this situation may occur. If intervention to gain involvement is not successful, the staff should seek consent from the individual to release information and provide copies of the ACP to the individual's representative, family, GP and other relevant key stakeholders

Communicating ACP to the care team

It is recommended that once an individual has completed an ACP process or has entered the facility with an ACP, a notation is place permanently on the handover sheet to identify those individuals

Transfer of ACP information

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- Do not send original documents
- Staff should make every effort to inform the receiving facility and treating doctor the individual has an ACP
- If the individual is a risk of being sent to any one of a number of different hospitals the ACP should be copied and sent each time
- If the individual is sent to the same hospital e.g. private the representative should be encouraged to provide the hospital with a copy of the ACP for their records or alternatively a copy is sent each time

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Section 13

REVIEW OF WISHES

Session 13 objectives

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- Discuss timeframe for review of ACP
- Identify issues around lack of review
- Evaluate rationales for review of ACP with people and/or their representative

Review of ACP

- Three monthly with the care plan review
- If the person experiences a change in their health status or cognition
- When the person or their representative requests a review
- If there is a change in the representative's situation
- Before an individual is transferred to another facility (if time allows)

NOTE:

Review of Advance Health Directive – recommended it be reviewed at least 2 yearly – annually is preferred

Case Study

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Read the case study about Mrs Brown. Discuss and answer the question

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Advance Care Planning is not about saying “no”

Its about saying “yes” to who you are and what you value