ST VINCENT'S CARE SERVICES

A SERVICE OF ST VINCENT'S HEALTH AUSTRALIA

Advance Care Planning

St Vincent's Care Services 2013

This course has two (2) parts

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In this online session you will cover the first seven modules of the advance care planning course.

There are an additional six modules that are covered in a face to face session with a facilitator. You need to have completed the full course to become an Advance Care Planning Facilitator with St Vincent's Care Services.

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

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.

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Section One

RELATIONSHIP WITH CATHOLIC HEALTH AUSTRALIA

Relationship to Catholic Health Australia (CHA)

- St Vincent's Care Services (SVCS) is one part of a wider group of health care providers
- We are part of St Vincent's Health & Aged Care
- Further to this, St Vincent's Health & Aged Care is affiliated with Catholic Health Australia (CHA)

Catholic tradition and approach

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CATHOLIC HEALTH Australia



"The Catholic tradition sees the overriding goal of health, aged and community care as being to assist people to sustain the life and health which are fundamental to their total well-being. When someone is close to dying the goal is to keep them free of pain and other suffering as much as possible so that they may die comfortably and with dignity."#

#Catholic Health Australia 2010, "A submission in response to the NHMRC *Ethical Issues Involved in the Transitions to Palliation and End of Life Care for People with Chronic Conditions, Discussion Paper: October 2009*, January 2010

Catholic tradition and approach

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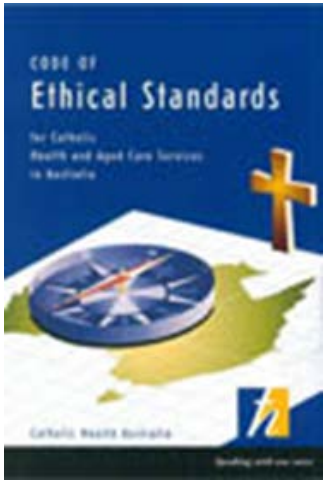
- Firstly… recognises that we are obliged to take reasonable steps to preserve our own life as stewards of our life

  An adapted excerpt from a presentation by the Reverend Kevin McGovern, Director Caroline Chisholm Centre for Health Ethics, East Melbourne...

- This comes from the central tenet of 'sanctity of life'



Catholic tradition and approach

Secondly, this approach recognises that while there are many things that we could do to preserve our life, we are not obliged to do all of them. For example, we are not obliged to try something if it's futile – that is, if it almost certainly won't work. Or again, we're also not obliged to try something if it's too burdensome, or too hard to do. Something could be too hard in any number of ways. It could be physically too painful, or psychologically too distressing, or socially too isolating, or financially too expensive, or either morally or spiritually repugnant, and so on.

Catholic Health Australia 2010, "A submission in response to the NHMRC *Ethical Issues Involved in the Transitions to Palliation and End of Life Care for People with Chronic Conditions, Discussion Paper: October 2009,* January 2010

What we do at St Vincent's Care Services?

Nowhere does the values and ethos of SVCS become more apparent than when we work with people who wish to discuss their future health care and perhaps their end of life.

We do this by working within the values, philosophies and ethos of CHA and the Australian Catholic Church. We use the CHA model to support our terminology, processes and work practices when we discuss future health care planning with our residents/clients and families.

Current societal approach

The Church's point of view differs in some ways from the current societal approach to Advance Care Planning (ACP) which is based on the modern principle of autonomy. The principle of autonomy recognises the rights of individuals to self-determination. This is rooted in society's respect for individuals' ability to make informed decisions about personal matters.

Fundamentally what is important is that: "Care for the whole person is critical, not just the clinical component. This is particularly so as the person is nearing the end of their life."

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Section Two

INTRODUCTION TO ADVANCE CARE PLANNING (ACP)

PLEASE READ THE RESOURCE ATTACHED TO THIS COURSE: “PATIENTS' AND FAMILIES' EXPERIENCE” TO REVIEW THE EVIDENCE BASE FOR ACP

Advance Care Planning

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"Though illness can be unpredictable, we may choose to offer those entrusted with our care some guidance about our wishes for our future health care"

Catholic Health Australia, "A guide for people considering their future health care"; Booklet. (undated)

What is Advance Care Planning?

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Advance Care Planning (ACP) refers to "the process by which individuals, together with their families and health practitioners, consider their values and goals and articulate their preferences for future care".*

*Respecting Patient Choices, Frequently asked medico-legal questions, http://www.respectingpatientchoices.org.au

What is hard about ACP

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- Perceived as onerous – takes too long
- People don't know what it is and how it might apply to them
- Discomfort talking about death on the part of the individual, family or health professional
- Fear about not being able to change one's mind
- Confusion over who should or does control decision making
- Health professionals concerns over acting or not acting on what is documented
- People don't know enough to make informed decisions
- Timing of decisions may be crisis driven – too little time to absorb information and decide
- Grief, loss and emotional pain make it too hard

How can ACP be done?

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- They may simply consider their values and wishes about their own life and death and the care they want
- They may talk to a health professional about the dying process and future scenarios in their health
- They may talk to family and friends about these matters
- They may determine a substitute decision maker (representative) and/or make this a legally formalised arrangement
- They may consider organ donation, will and/or funerals
- They may record any of these elements in written form either formally or informally

How is ACP different from other types of planning?

Advance Care Planning differs from general forms of planning in that it is completed in the context of an anticipated deterioration in the individual's condition in the future, which is associated with a loss of capacity to make and/or communicate decisions. (Killock et al 2010)

ACP in St Vincent's Care Services

The doctrine of informed decision making is a central commitment in ACP for St Vincent's Care Services

- Respect for the dignity and decision-making of the person

- "*Sane adults ought to have some autonomy about what is done for them, how they would like to be treated, and what their life's commitments mean in terms of what they see as reasonable.*" *

*Catholic Health Australia, "End of Life issues"; brochure.(undated)

SVCS - Principles of ACP

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- Is a right of all people if they so choose
- Reflects the individuals own values and views and respects their autonomy to make decisions about what they want
- 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

SVCS - Principles of ACP

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- 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
- The health care environment and an individual's health care status are dynamic (things change).
- 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

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Section three

HEALTH PROFESSIONALS RESPONSIBILITIES IN ACP

Who is a Health Professional

- "…has the appropriate accreditation, authority and/or experience to assist a person in the process of informed decision making and can include medical, dental and nursing practitioners…"*
- Health professionals facilitating ACP discussions and making records of those discussions should have completed the internal SVCS ACP education or a similar external ACP course

*Queensland Health, (2011), Guide to Informed Decision Making in Healthcare, p.viii, Patient Safety and Quality Improvement Centre

Who is an ACP Facilitator

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Within SVCS an ACP Facilitator is someone who:

- May not be a health professional e.g. Pastoral Carer, Non-clinical Manager, Program Coordinator
- Has an interest in supporting people to make decisions about their future health care
- Has completed SVCS 7 on-line learning and 6 face to face training modules or a similar recognised external course in ACP
- Is able to support the learning and development of other staff with ACP practice

Role of the Health Professional

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- Have knowledge of the Ethos of CHA and SVCS Policy and Procedures surrounding ACP
- To provide education and information to the individual and their representative on ACP
- Educate and support other staff in regards to ACP
- Communicate ACP needs and outcomes to the care team including the GP and other key stakeholders e.g. spiritual advisor
- Refer an individual to their doctor for enhanced understanding of their health status
- Support the individual to appoint a representative if not already done

Role of the Health Professional

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- To be familiar with the person's values and earlier wishes
- To review his or her wishes with the person's representative in light of any changes in the current situation
- To resolve differences, where possible, according to his or her individual professional conscience and professional and institutional codes of ethics
- Support the representative with information when decision making
- To ensure that the decisions made when they are necessary are as soundly based as possible

Role of the ACP Facilitator

Non health professional

ST VINCENT'S CARE SERVICES

- Have knowledge of Ethos of CHA and the SVCS Policy and Procedures surrounding ACP
- To provide education and information to the individual and their representative on ACP
- Educate and support other staff in regards to ACP
- Support the individual to appoint a representative if not already done
- Refer matters related to ACP outside their scope of practice to the appropriate person when identified e.g. RN, GP, Facility Manager

Role of the ACP Facilitator

Non health professional

- To be familiar with the person's values and earlier wishes
- To review his or her wishes with the person's representative in light of any changes in the current situation
- To resolve differences, where possible, according to his or her individual professional conscience and professional and institutional codes of ethics
- Support the representative with information when decision making
- To ensure that the decisions made when they are necessary are as soundly based as possible

Getting help

We may encounter issues in the ACP process that need to be taken into account to achieve the desired outcome for the individual; such as relationship conflict , lack of information, inappropriate or unethical wishes.

Health professionals can seek assistance from:

- An ACP Facilitator
- Their line manager, another health professional or Facility Manager

The Facility Manager can escalate the issue to the Mission Executive, St Vincent's Care Services for additional support and consultation.

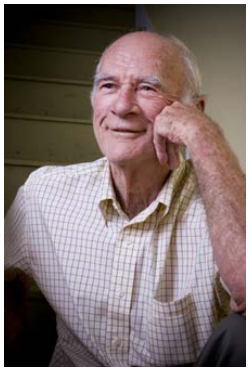
What we can't do

Our roles are bound in law, ethics, organisational policy and professional standards. There are some elements of ACP and End of Life that we cannot do:

- Decide who should be the person's representative
- Ignore the wishes of the person or their representatives
- Block or not inform doctors or representatives of either wishes or changes in status
- Change any informal documents unless requested by the person or their representative
- Change an Advance Heath Directive under any circumstances
- Witness an Advance Health Directive and/or EPOA document
- Force our personal views upon others
- Ignore people's expression of wishes when we don't agree with them

And Most Importantly

"No one … should be compelled to issue instructions about future care, nor should any guidance we leave be too prescriptive."



Catholic Health Australia, "A guide for people considering their future health care"; Booklet. (undated)

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Section 4

THE REPRESENTATIVE (SUBSTITUTE DECISION MAKER

Substitute Decisions

"A substitute decision is one made on behalf of a person who lacks capacity to make his or her own decision. A substitute decision maker seeks to replicate the decision it is thought the person would have made." *

In SVCS the person who makes substitute decisions for another person in advance care planning is called the representative.

* The Clinical, Technical and Ethical Principal Committee of the Australia Health Minister's Advisory Council, *A National Framework for Advance Care Directives*, Sept 2011

Who can be a representative?

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A representative is a person/s who:

by appointment by an individual on an advance care plan, (appointed representative)

or

by the nature of the authority of their relationship to the individual (Statutory Health Attorney),

or

by legal appointment by the individual or a statutory authority (Enduring Power of Attorney, Guardian),

can make decisions on behalf of the individual in the event the person cannot speak for themselves.

1. Catholic Health Australia, (2009), *Provision of Palliative Care in Catholic Health and Aged Care Services*, p.54

Lets take a closer look at

- Statutory health attorney
- Enduring power of attorney

Please read the attached resources from the QLD Justice Department

- What is enduring power of attorney
- What is a statutory health attorney

Statutory Health Attorney

In the event a person does not have either a legally appointed guardian or a legally appointed attorney, the *Powers of Attorney Act 1998* authorises the Statutory Health Attorney to make a decision about a health matter. A statutory health attorney can be:

a) a spouse of the adult if the relationship between the adult and spouse is close and continuing; or

b) a person who is 18 years or more and who has the care of the adult and is not a paid carer for the adult; or

c) a person who is 18 years or more and who is a close friend or relation to the adult and is not a paid carer.

Enduring Power of Attorney

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- Person or persons appointed under a **legal** process
- Documented and witnessed on a **legally recognised form**
- May be the appointed attorney for:
  - ✓ Financial matters
  - ✓ Health and personal matters or
  - ✓ Both financial, health and personal matters
- Decisions can be made:
  - ✓ A sole attorney is one person appointed as attorney.
  - ✓ Joint attorneys are two people appointed as attorney, who must act together and agree on all decisions that are made.
  - ✓ Joint and several attorneys are two people appointed as attorney, who can make decisions independently or together

Enduring Power of Attorney

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To make decisions about an individual's health, the enduring power of attorney must have been appointed for:

- Health and personal matters

or

- Both financial, and personal and health matters

The individual must have lost capacity before an attorney appointed for health and personal matters can make decisions for that individual.

How decisions are made…

An individual's representative makes health decisions for the person, based on:

- the individual's previous written or verbal advise
- the individual's values and beliefs,
- input from health care professionals
- their own good judgement*

*Catholic Health Australia," A guide for health care professionals implementing a future health care plan". (undated)

Guidance re: representatives

A representative must:

- Be over 18
- Have capacity themselves
- Not be a paid carer

Should:

- Know the person, their values and wishes
- Listen carefully to the person's wishes for future health care
- Be able to make decisions that may need to be made under difficult circumstances.
- Be available to be the representative
- Make decisions in the person's best interests and not restrict their rights in any way

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Section 5

THE LEGAL DOCUMENTS AND THE QLD POSITION

PLEASE READ :
ADVANCE HEALTH DIRECTIVE FACTSHEET
FORM 4 ADVANCE HEALTH DIRECTIVE

Concerns with written documents

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Catholic Health Australia expresses some concerns about the use of documented Advance Health Directives (AHD) or Advance Care Plans (ACP).

These concerns are:

- Inflexibility for changing circumstances
- Some Australian states or territories have forms which are binding
- Some forms can refuse valuable care or insist on what is inappropriate at the time
- Lack of guidance by the person's values and what is important to them

Types of Advance Care Plans

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Advance Care Planning discussions will often result in a written Advance Care Plan being made.

There are two types of Advance Care Plans:

- Informal
- Formal

Informal ACP

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An informal ACP:

- Is not a legally binding document
- Is a statement of future health preferences
- Can take many different forms and names e.g. Statement of Wishes, Living Will, End of Life Discussion, Future Health Care Plan
- Appoints a representative to make decisions on behalf of the person if they loose capacity (not a legal appointment)
- Can be completed by another person e.g. representative, staff on request of the individual
- Does not require a GP to complete
- Should be witnessed and dated

The informal ACP we use at SVCS is called "**Statement of Wishes for Future Health Care**"

Formal ACP

A formal ACP is one which is enshrined in legislation. In Qld this document is called “Form 4, Advance Health Directive”. This Advance Health Directive:

- Can only be completed by the person themselves
- Person must be legally competent to complete
- Is a legal document
- Has sections that must be completed by a GP
- Must be witnessed by a JP, commissioner for declarations, a lawyer, or a notary public
- Appoints an Enduring Power of Attorney to make decisions when the person looses capacity


Form 4
Queensland
Powers of Attorney Act 1998
(Section 44(2))

ADVANCE HEALTH DIRECTIVE

This form deals with your future health care.

The time may come when you cannot speak for yourself. By completing this form, you can give directions about your medical treatment at such a time.

This document can be used by non English speakers if a qualified interpreter/translator reads it to the person in the person's own language and a signed Statement of Interpreter/Translator is attached. Blank statements are available from GoPrint offices, WC Penfold Stationers and most newsagents throughout Queensland.

Queensland Government

*Form 4, Queensland, Powers of Attorney Act 1998, (Section 44(2))

The QLD position…

In Qld, doctors must make decisions about a person's medical care based on "good medical practice" . This expectation is supported by law and as such allows the doctor to:

- Follow the choices and wishes as documented on the Advance Health Directive or Advance Care Plan as stated by the person

Or

- Provide treatment based on "good medical practice" which is contrary to the stated wishes on the Advance Health Directive or Advance Care Plan

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Section 6

ALTERNATIVE DOCUMENTS

The written word

In keeping with our values, we view any document that expresses the future healthcare wishes of the person as a part of an ACP. This can include:

- Letters,
- Statutory declarations
- Progress notes
- Records of interview …

But think about the following:

- What would make you feel more secure about the document as a relevant piece of information about the person's wishes?
- To what degree would you feel these would be useful in a discussion with a doctor?
- Would you feel they were enough on their own if you never speak to the family and or EPOA?

At the very least – read it!

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Section 7

DECISION MAKING AND CAPACITY

Assessment of decision making capacity

- Decision making capacity is assessable, and its assessment depends on the type and complexity of the decision to be made
- Loss of decision making capacity may be partial or temporary and may fluctuate
- Decision making capacity should be assessed at the time a significant decision is required in order to establish the person's level of cognitive ability to make the decision
- Capacity does assess whether the decision is considered 'good' or 'bad'
- A formal assessment of capacity by a qualified professional may be indicated if decision making is uncertain at the time when a decision is required.

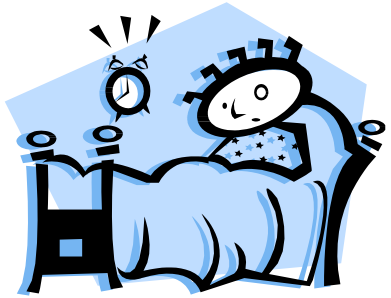
Capacity is…

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 no decision
- Weigh up the information e.g. by asking questions
- Retain the information (have short term memory)
- Freely and voluntarily communicate a decision in some way e.g. sign language, words, or other means

Person centred care and decision making

Just because a person lacks legal capacity to make informed medical decisions, does not mean they cannot contribute significantly to decision making surrounding advance care planning and their end of life care.



Where to next?

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- Now it is time to do a short assessment about the concepts of Advance Care Planning
- Following on from your assessment will be a workshop in which you will look at SVCS documents and how to approach the conversations about people's future health care wishes
- On completion of the full course you will have become an ACP Facilitator