Advance Care Planning or Care Planning… What's the Difference? Is There a Difference?

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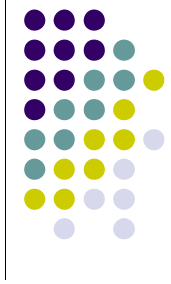

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Learning Objectives

- Understand the fundamentals of health care consent and the need to get consent or refusal of consent
- Understand issues involved in planning care
- Understand the connection between health care consent and advance care planning

Scenario 1

"You have been caring for a terminally ill client whose wish is for no resuscitation. The family has been involved in the discussions about resuscitation and has supported the client's choice. You are at the bedside with the family as the client's death is imminent. When the client stops breathing, the family members shout, 'Do something!'"

Practice Standard on Resuscitation, College of Nurses of Ontario, 1999

Questions

- What would you do?
- What would you feel in this situation? Confident? Comfortable? What?
- What does the law require of you?
- What do your Standards of Practice and/or Professional Policies state?
- Do you have a consent to not treat? Is one necessary?

Scenario 2

Mr. J is a 69 year old man with fairly advanced dementia (type not diagnosed). Up till recently, he underwent extensive investigation to determine the cause of his neurological signs and symptoms. He still recognizes people, but his cognition is poor. He is pleasant, but profoundly depressed. He has expressed a wish to die several times and attempted suicide once. He has frequent falls from severe postural instability and is incontinent of urine and feces. His wife of 40+ years is his primary caregiver. They have two adult children, one close by, the other in Florida.

Scenario 2 cont'd

A third child died after extended drug and alcohol abuse. Mr. J has been having recurrent bladder infections. Whenever Mr. J shows signs of infection, his care providers respond quickly by sending him to emerg, where it is often decided to admit him. His wife has been slowly coming to terms with the reality that her husband is going to die, but she is not yet prepared to let him go. She wants desperately to care for Mr. J at home, but struggles to cope. She was told that her husband will one day require admission to long term care.

Questions

- What are the issues?
- Who should be making decisions?
- How do you know?

Scenario 3

Mrs Smith is a new resident in a long term care home. Mrs Smith and her daughter Vera were given a number of documents and were asked to sign them. One of these is a Level of care form.

LEVEL ONE: Comfort care; no treatment of non-reversible and reversible conditions; no CPR

LEVEL TWO: Comfort care; treatment of reversible conditions; no treatment of non-reversible conditions; no CPR

LEVEL THREE: Comfort care; treatment of non-reversible and reversible conditions; no CPR

LEVEL FOUR: Comfort care; treatment of non-reversible and reversible conditions; Full CPR; Transfer to Hospital

Questions

- What does such a process accomplish?
- What does it not accomplish?
- Is this a Consent?
- Is it an Advance Care Plan?
- Who can sign it? Should it be signed?
- How would it/ should it be used in practice?

General Challenges to Patient-Physician Communication

- Time constraints
- Language differences
- Mismatch of agendas
- Lack of teamwork
- Discomfort with strong emotions
- Quality of physician training
- Resistance to change habits

Buckman (1984), Ford et al (1994), Buss (1998)

Questions

- What planning needs to be done?
- What is advance care planning?
- What is an advance care plan?
- In advance of what?
- Circumstances in which a person might advance care plan?
- Who, how, why, when it is that they might do this?
- What is consent? When do you need consent? Who can provide it?
- How, if at all, do Health consent and advance care planning intersect?

Web Posting

"As many end-of-life decisions are critical and most would consider they require dialogue with both patients and/or their next of kin, do any [organizations] follow a protocol for these consents to be fully documented for audit purposes? And are these consents ever reviewed by a third party or, better still, full committee (containing lawyers and lay personnel) to establish that such decisions were appropriate to the intended wishes of the signatories. In this international world where relatives may be far from patients and others may 'assume' the status of next of kin what safeguards do we [utilize] to prevent ourselves being misinformed or in making assumptions that therapeutic decisions are legally defensible. And where there are no relatives but only well meaning friends what do we collectively [do] to prevent breaches of a [patient's] individual human rights... Where this deviates from [what is stated,] does anyone document why the objectives may have changed and who [authorized] subsequent interventions..."

Philip Harrison, GP, Upper Hutt New Zealand (UK Trained),
April 27, 2008 www.palliativedrugs.com

Legal Context of Decision-making (1)

- Before providing treatment, Health Care Providers must get **an informed consent or refusal of consent** to a treatment from the patient if capable.
- If the patient is not capable then the consent is from the patient's SDM. The consent ALWAYS comes from a person not a piece of paper!!!

Legal Context of Decision-making (1 Cont'd)

- In an emergency, Health Care providers do not need consent in order to treat
- In an **EMERGENCY**, Health care providers must follow any known wishes of the patient in respect to treatment

Legal Context of Decision-making (2)

- A Patient, if mentally capable for treatment decision-making, is the decision-maker
- A Patient can also expresses **WISHES** about future health treatment (Advance Care Plan)
- An Advance Care Plan is **NOT** a consent – Wishes are **NOT** decisions. Even if an advance care plan exists, the consent/ refusal of consent must come from a person

Legal Context of Decision Making (3)

- If the Patient is not mentally capable,then his or her Substitute Decision Maker (SDM), is the decision- maker
- SDMs can only Consent or refuse Consent to treatments and **cannot Advance Care Plan**
- SDMs must follow the wishes (advance care plans) of a patient when making treatment decisions for the patient if known. If no wishes are known then the SDM makes decisions in the “best interests” of the patient

Treatment taking place in the future is NOT necessarily an advance care plan

- A Person can give an informed consent to a treatment that takes place or is withheld in the future if the decision for that treatment is relevant considering the persons **PRESENT HEALTH CONDITION**
- This is not Advance Care Planning but is Consent

What is Valid Consent?

- Health Care Consent Act (HCCA) s. 11

1. must relate to **the** treatment
2. must be **informed**
3. must be given **voluntarily**
4 must not have been obtained through **misrepresentation or fraud**

What is Informed Consent?

- Patient must receive information on the
- Nature of the treatment
- Expected Benefits of the Treatment
- Material Risks of the Treatment
- Material side effects
- Alternative Course of action
- Likely consequences of not having the treatment

Who gives or refuses the Consent?

- In Ontario ------Consents and refusals of consent come from PEOPLE not pieces of paper, not advance directives
- So who gives of refuses the consent – the Patient or the SDM?
- Depends on whether the patient is **mentally capable** for treatment –
- What does **Capacity** mean in this context?

Capacity- Legal Definition

- Mental Capacity is a socio-legal construct and its meaning varies over time and across jurisdictions
- Assessment/Evaluation refers to a **legal assessment** that the health practitioner does - not a clinical assessment
- Clinical assessments underlie diagnosis, treatment recommendations and identify or mobilize social supports
- Legal assessments remove from the person the right to make decisions in specified areas

Definition of Capacity in respect to Treatment, Admission to Care Facilities, and Personal Assistance Services

- **Health Care Consent Act** (HCCA) s.4
  Able to understand the information that is relevant to making a decision about the treatment, admission, or personal assistance service as the case may be and able to appreciate the reasonable foreseeable consequences of a decision or lack of decision.

Mental Capacity for Treatment

- Not the score on the MMSE or any other test
- Not a Diagnosis
- It is an analysis/ determination you make based on your own conversations with persons/ observations
- Just because a person is old, does NOT mean that they lack decisional capacity
- Just because a person is a resident in a long term care home does NOT mean that he or she is incapable to make treatment decisions

Who Assesses Capacity in Respect to Treatment?

- The health practitioner who proposes a treatment is required to form the opinion about the capacity of the patient to consent to treatment
- If a plan of treatment is proposed, one health practitioner on behalf of all the health practitioners involved in the plan may determine the patient's capacity for treatment

Decisions (Consents) vs. Wishes

- Health practitioners must get CONSENTS which are DECISIONS that are obtained from patients after the patients have the necessary information on their PRESENT health condition on which to make an informed decision
- Wishes are NOT Decisions – Wishes are speculative/ made without all the information . Wishes are speculative – made up based on "if" scenarios – "If I have a terminal condition.. If I am in pain.. If I have dementia…" – not on facts

Consent to One treatment or to a Plan of Treatment

- Consent can be to one specific treatment OR
- Consent can be to a PLAN OF TREATMENT

Plan Of Treatment – HCCA s.2(1)

- developed by one or more Health practitioners
- deals with one or more of health problems that a person has and may, in addition, deal with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and
- provides for the administration to the person of various treatments or courses of treatment and may, in addition, provides for **withholding or withdrawal** of treatment in light of person's **current health condition**.

Decisions can be for present care and for care taking place in the future

- Plan of treatment ….(may) deal with one or more of the health problems that the person is likely to have in the **future** given the person's **current health condition, and**
- ……may, in addition, provide for **withholding or withdrawal** of treatment in light of person's **current health condition**.

Advance Care Planning

- “Key informants from all sectors agreed by a margin of more than 3:1 that confusing terminology can create barriers to effective advance care planning. There is general agreement that the concepts are simple and easily understood, but that the terminology can be confusing for both consumers and professionals. One key informant stated that, "If professionals don't understand the terminology, how can we expect the public to?“”

http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/2006-proj-glos-1-eng.php#Toc144091364

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What is Advance Care Planning?

- Almost unanimously understood as a *process of communication* that may take place over a long or short period of time and may be initiated while a person is healthy or when they are facing a serious illness
- Most respondents understand advance care planning to involve the patient, family, physician and possibly other members of the health care team.
- Several informants stressed that this is not necessarily a process involving the creation of a document prepared by a lawyer or notary.

http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/2006-proj-glos-1-eng.php#Toc144091364

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What is Advance Care Planning?

- "Advance care planning has been defined as the "process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions."[2] … When patients become ill and as illness progresses, physicians should ensure that the patients' advance care instructions and wishes are reassessed with the patients or substitute decision-makers, and family if there is consent, on an ongoing basis."

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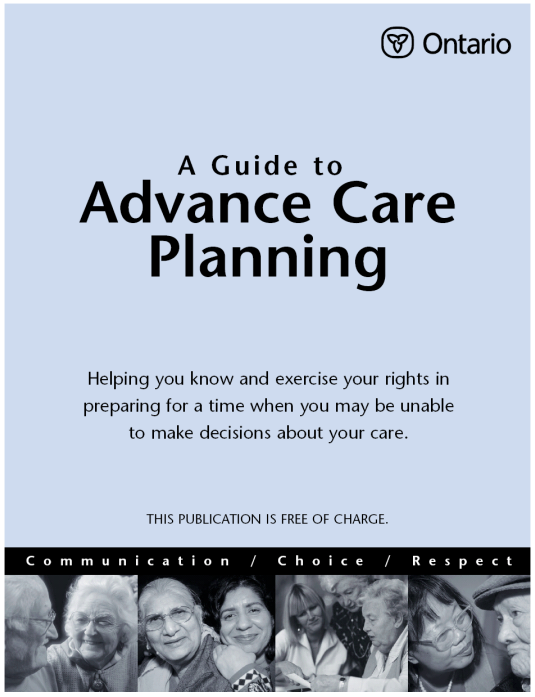
http://www.cpso.on.ca/policies/policies/default.aspx?ID=1582

What is Advance Care Planning?

- "Advance care planning is about making choices now, while you are capable, about how you wish to be cared for in the future if you become incapable of making decisions."
- "It is also about giving someone you trust the information and authority to act on those wishes for you. This person is called your substitute decision-maker."

A Guide to Advance Care Planning, Ontario Ministry of Health and Long Term Care



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What is advance care planning?

"If you become unable to make decisions, your doctor or other health care providers must contact your substitute decision-maker to seek their consent before your doctor or other health care provider can give you treatment. An exception would be an emergency situation where a health care provider may not know your wishes and may have to act quickly…"

A Guide to Advance Care Planning, Ontario Ministry of Health and Long Term Care

Problems in Health Consent and ACP (Advance Care Planning)

- Facilities/ organizations/ health providers are not always getting informed consent before treatment
- Organizations are misusing ACP, using it as a replacement to an informed consent – ACP documents and advance wishes are NOT consents
- Organizations are misusing ACP documents and are not getting consent from patients when capable or the SDMs when the patient is not capable for treatment
- Organizations are using patient's "wishes" inappropriately instead of making application to the CCB when the health practitioners disagree with SDMs
- A number of organizations use "levels of care forms" inappropriately as consents or as ACP documents
- Some organizations try to get "preconsent" – this is not legal

Advance Care Planning

- Describes care and treatment that a person wants in the future when he or she is no longer mentally capable for decision making about treatment
- May focus on end-of-life care or also include wishes about care and treatment over course of life
- May provide information on patients values and beliefs **to guide the SDM's decision-making** when the patient is mentally incapable

Guide to Advance Care Planning

- Should have been titled Guide to Health Care Consent and Advance Care Planning
- Need to get consent or refusal of consent before treatment
- Advance care planning may be part of the process for patients as it allows them to consider whether they want the SDM highest in the SDM Hierarchy in the HCCA to make treatment decisions for them for them if they are not mentally capable for treatment in the future

- Advance care planning allows patients to select a particular person or persons to act as SDM for them if they are not mentally capable to make decisions about treatment
- Advance care planning allows patients to express wishes about future treatment and care, about their values and beliefs, about what they believe to be quality of life etc.

Rules for ACP

- Only capable people can ACP.
- Capable patients can express “wishes,” which may or may not be “informed.”
- When a person has an advance care plan about a potential future health condition:
  - consent has not been acquired.
  - if the patient is incapable, consent must still be acquired from a substitute decision-maker(s) (SDM(s)) (except in emergencies)

Options for Advance Care Planning

- Wishes can be expressed ORALLY
- Wishes may be expressed in WRITING
  - in a Power of attorney for Personal Care , a document used to that appoint an attorney (SDM) and in which a person may also express wishes
  - In an “Advance Directive” or “Living Will”
  - In any other written format
- or communicated by OTHER MEANS (ie communication boards etc)

Advance Care Planning

- Does not need to be in writing
- Wishes may be expressed at any time that a patient is mentally capable in respect to decisions about the subject of the wish
- Later wishes, however communicated, expressed while capable prevail over earlier wishes
- This is true **even if the previous wishes were in writing and the later wishes are oral**

Written Wishes

- Advance Directive/Living Will - only mentioned in the legislation as “Wishes”
- Not a specific format- Usually just a statement of wishes about health care and no appointment of SDM
- **Only POAPC gives authority to name SDM**

Substitute Decision-Makers (SDMs)

1. Guardian of Person
2. Attorney in POAPC
3. Representative appointed by Consent and Capacity Board
4. Spouse or Partner
5. Child or Parent or CAS (Person with Right of Custody)
6. Parent with right of access
7. Brother or Sister
8. Any other relative
9. Public Guardian or Trustee

Definition of Spouse

HCCA s. 20(7) – Opposite or Same Sex

(a) married to each other; or
(b) living in a conjugal relationship outside marriage and,
  i) have cohabited for at least one year, or
  ii) are together the parents of a child, or
  iii) have together entered into a cohabitation agreement under s. 53 of the *Family Law Act*.

Not spouses if living separate and apart as a result of a breakdown of their relationship.

Definitions- Partner and Relative

- **PARTNER**
  HCCA s. 20(9) - have lived for at least one year and have a close personal relationship that is of primary importance in both person's lives
- **RELATIVE**
  HCCA s. 20(10) - are relatives if related by blood, marriage or adoption

SDMs

- List is Hierarchical
- All persons on same level have equal right to be SDM (ie all brothers and sisters equally rank)
- Person ALWAYS has SDM if incapable as OPGT is SDM if person has no one higher on hierarchy or if conflict between equal ranking SDMs

Requirements for Person to be an SDM

Person highest in hierarchy may give or refuse consent only if he or she:

a) is capable in respect to the treatment
b) is at least 16 years old unless the parent of the incapable person
c) is not prohibited by a court order or separation agreement from acting as SDM
d) is available
e) is willing to act as SDM

How SDMs Make Substitute Decisions

It is the responsibility of the SDM to make treatment decisions for an incapable person by:

a) following any wishes of the patient expressed when capable that are relevant to the decision; and
b) if no wishes are known or are relevant to the particular decision, to act in the best interests of the patient

Best Interests Definition

1. SDM to consider:
   a) values and beliefs
   b) other wishes (i.e. expressed while incapable)
   c) whether treatment likely to:
      I. improve condition
      II. prevent condition from deteriorating
      III. reduce the extent or rate of deterioration
   d) whether condition likely to improve or remain the same or deteriorate without the treatment
   e) if benefit outweighs risks
   f) whether less restrictive or less intrusive treatment as beneficial as treatment proposed

SDM's Role - CONSENT not ACP

- SDMs **cannot** advance care plan however, if the patient's present plan of treatment **"deals with one or more of the health problems that the person is likely to have in the future given the person's current health condition, and provides for the administration to the person of various treatments or courses of treatment and may, in addition, provide for the withholding or withdrawal of treatment in light of the person's current health condition"** then the SDM can CONSENT or REFUSE consent to these "future" treatments

- **This is NOT advance care planning.**

Scenario 1

"You have been caring for a terminally ill client whose wish is for no resuscitation. The family has been involved in the discussions about resuscitation and has supported the client's choice. You are at the bedside with the family as the client's death is imminent. When the client stops breathing, the family members shout, 'Do something!'"

Practice Standard on Resuscitation, College of Nurses of Ontario, 1999

Questions

- What would you do?
- What would you feel in this situation?
- What does the law require of you?
- What do your Standards of Practice and/or Professional Policies state?
- Do you have a consent to not treat?

What Happened?

- Doesn't the nurse have to acquire consent from the SDM?
- If so, why?
- If not, why not?

Discussion

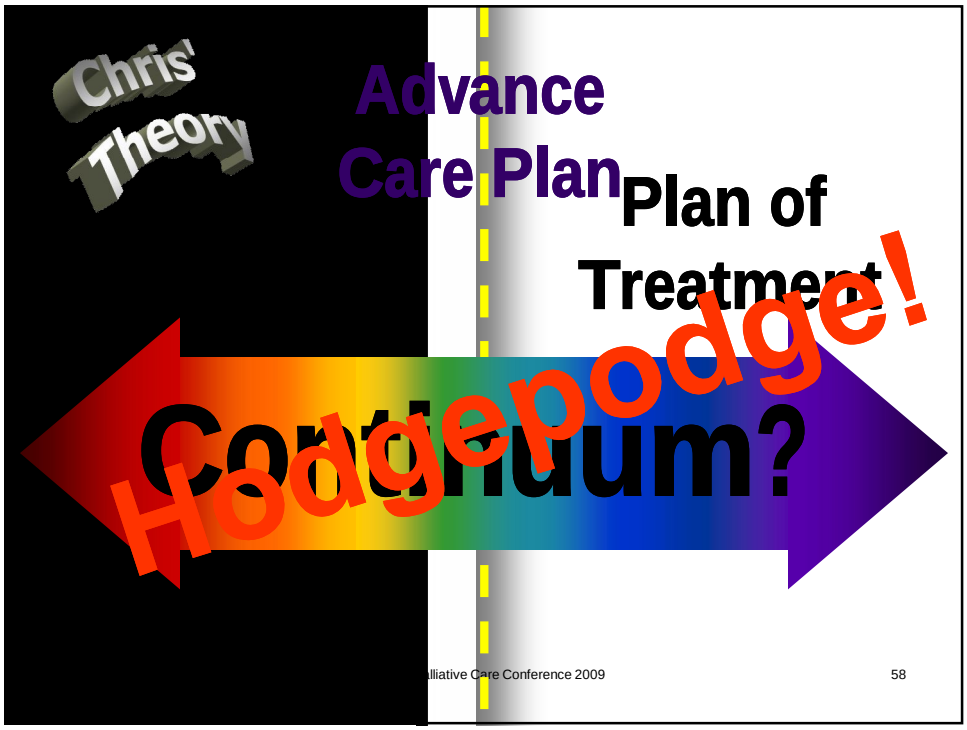
"This situation is challenging and stressful for the nurse. However, the client's wishes take precedence. The nurse's role is to provide comfort and support to the family members. It may be helpful to remind them that this was their loved one's wish, and that CPR would likely be ineffective and could lead to intubation and other invasive procedures. Sometimes in these types of situations, the nurse absorbs the family's anger. A comprehensive process of planning for the death and preparing the family may help to prevent this type of scenario. If there were any questions about the nurse's actions in such a scenario, this standard would be utilized as a key measure of the nurse's care.[7]"

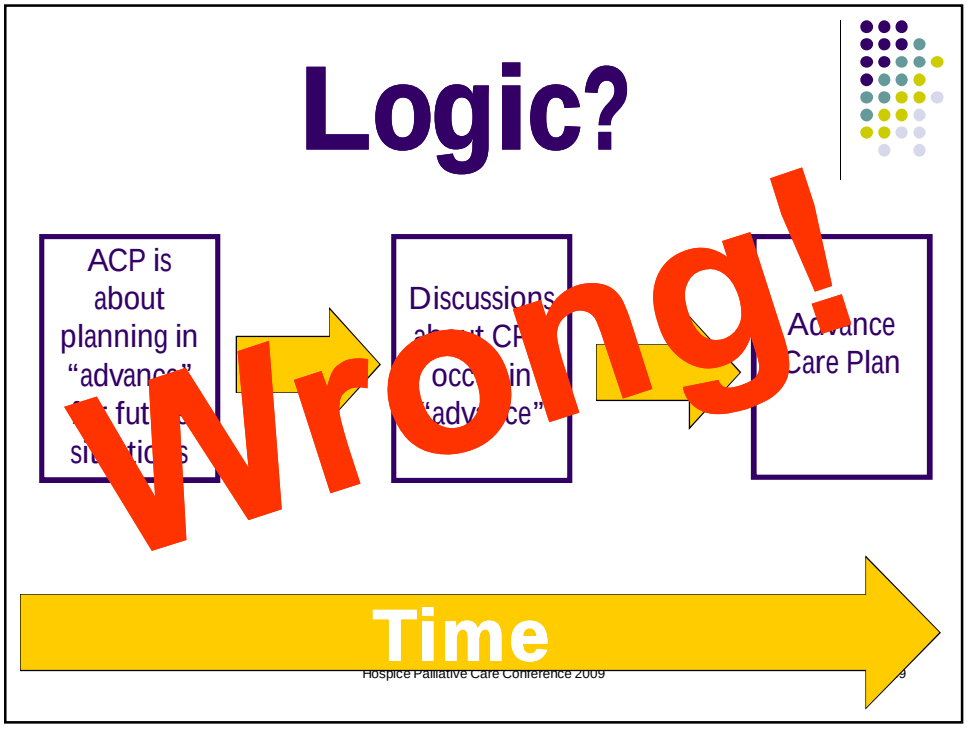
Practice Standard on Resuscitation, College of Nurses of Ontario, 1999

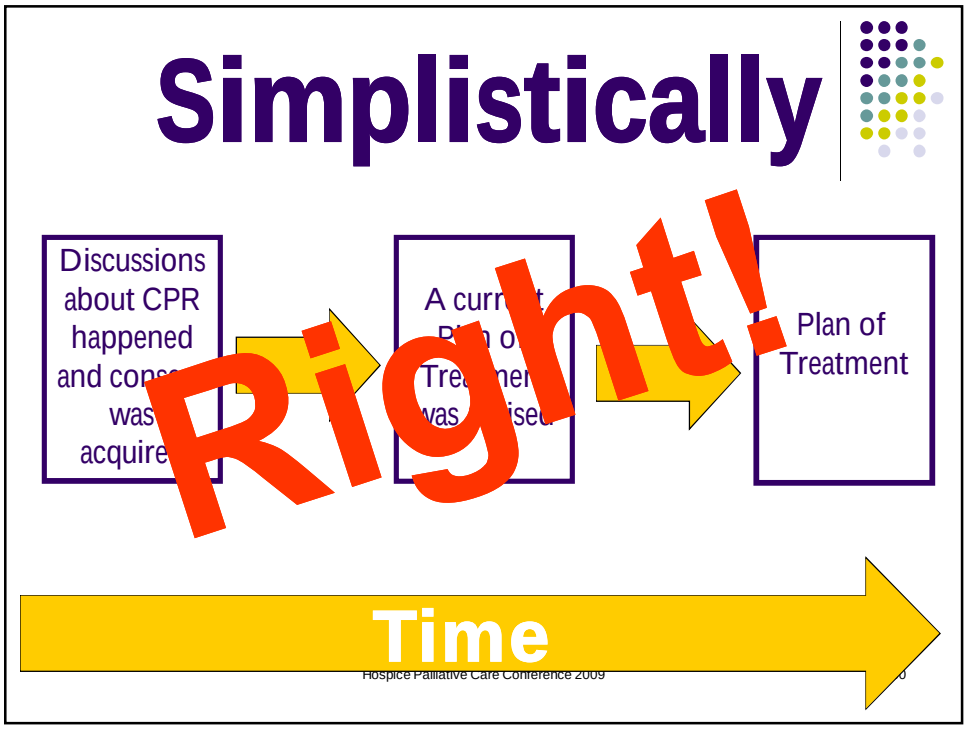
Footnote

"In a legal review for this document, it was noted that Subsection 29(5) of the Health Care Consent Act makes it clear that a nurse "who in good faith, refrains from administering" a treatment such as CPR, if the nurse has reasonable grounds to believe that the client "expressed a wish applicable to the circumstances to refuse consent to the treatment," will not be liable for failing to administer the treatment."

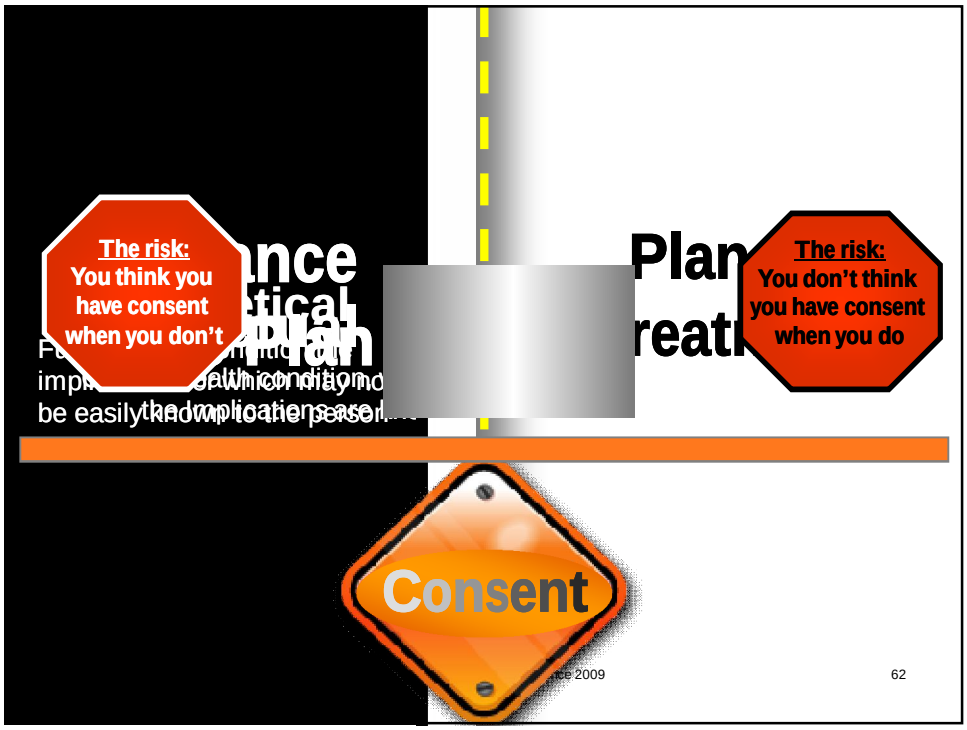
Practice Standard on Resuscitation, College of Nurses of Ontario, 1999

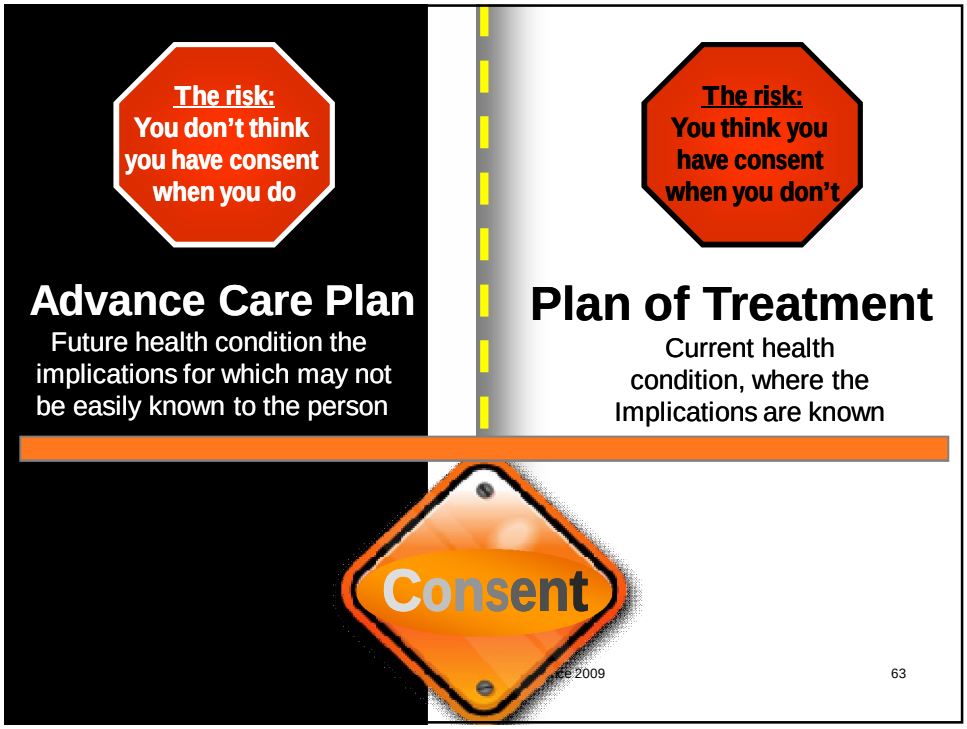



Logic?
ACP is about planning in "advance" for future situations
Discussions about CPR occur in "advance"
Advance Care Plan
Wrong!
Time
Hospice Palliative Care Conference 2009


Simplistically
Discussions about CPR happened and consent was acquired
A current Plan of Treatment was devised
Plan of Treatment
Right!
Time
Hospice Palliative Care Conference 2009

It's about the Plan, and whether consent has been acquired, not so much about the timing of when the treatment is performed!!





Example 1

- A capable person with ALS diagnosed x 1 year states, "When my heart and breathing stop, I don't want CPR." A discussion ensues with health care providers about the benefits and risks of CPR, alternative courses of action and the consequences of not treating

1. This is a current health condition.
2. The requirements of informed consent have been met
3. Therefore, consent does not need to be acquired again.
4. This has been documented in the person's health record
5. The person has a current plan of treatment that does not include CPR.

The risk:
You don't think you have consent when you do

Example 2

- A capable person, while healthy, discusses his wishes re: future health care with the person who would be his SDM when he becomes incapable.

  He states, “If I ever become incapacitated and dependent, I don’t any heroics, no CPR etc.”

1. This is a future health condition.
2. Therefore, it is not possible for the patient to understand and appreciate what it would be like to live in a state that has not yet occurred
3. Therefore, he/she can not provide consent
4. And therefore consent still needs to be acquired.

Consent to Plan of Treatment

- Note that if the patient’s condition has changed and the original plan of treatment that the patient consented to is no longer valid because of that change, and the patient is now mentally incapable to give or refuse consent to treatment, or a new plan of treatment, then a new informed consent must be obtained from the patient’s SDM

Health Practitioner and Conflict with SDMs

- It is NOT appropriate to just refuse to take consent/ refusal of consent from the lawful SDM – the legislation provides the process to seek an answer
- It is not appropriate to just look at what the advance care plan, if any, states – Consent comes from a person not a piece of paper

Health Practitioner and Conflict with SDMs

- If a Health Practitioner (HP) doubts that SDM is fulfilling his/her role:
  - Check if SDM understands the patients condition
  - Check if SDM appreciates implications of the illness, treatments, risks, benefits for the patient
- HP get a second opinion about own interpretation of illness and treatment options for the patient
- Make Application to Consent and Capacity Board to direct SDM to follow advance wish of patient or act in best interests or otherwise be removed

Applications to Consent and Capacity Board re Consent and ACP issues

1. Application by SDM or Health Practitioner for directions if patient had expressed wish and wish not clear etc.
2. Application by SDM or Health Practitioner to depart from wishes
3. Application by Health Practitioner to determine if SDM in compliance with HCCA s. 21 (wishes/best interests)
4. Application by Patient to challenge finding of Incapacity to Make Treatment Decisions

Scenario 2

Mr. J is a 69 year old man with fairly advanced dementia (type not diagnosed). Up till recently, he underwent extensive investigation to determine the cause of his neurological signs and symptoms. He still recognizes people, but his cognition is poor. He is pleasant, but profoundly depressed. He has expressed a wish to die several times and attempted suicide once. He has frequent falls from severe postural instability and is incontinent of urine and feces. His wife of 40+ years is his primary caregiver. They have two adult children, one close by, the other in Florida.

Scenario 2 cont'd

A third child died after extended drug and alcohol abuse. Mr. J has been having recurrent bladder infections. Whenever Mr. J shows signs of infection, his care providers respond quickly by sending him to emerg, where it is often decided to admit him. His wife has been slowly coming to terms with the reality that her husband is going to die, but she is not yet prepared to let him go. She wants desperately to care for Mr. J at home, but struggles to cope. She was told that her husband will one day require admission to long term care.

Questions

- What are the issues?
- Who should be making decisions?
- How do you know?

Scenario 3

Mrs Smith is a new resident in a long term care home. Mrs Smith and her daughter Vera were given a number of documents and were asked to sign them. One of these is a Level of care form.

LEVEL ONE: Comfort care; no treatment of non-reversible and reversible conditions; no CPR

LEVEL TWO: Comfort care; treatment of reversible conditions; no treatment of non-reversible conditions; no CPR

LEVEL THREE: Comfort care; treatment of non-reversible and reversible conditions; no CPR

LEVEL FOUR: Comfort care; treatment of non-reversible and reversible conditions; Full CPR; Transfer to Hospital

Questions

- What does such a process accomplish?
- What does it not accomplish?
- Is this a Consent?
- Is it an Advance Care Plan?
- Who can sign it? Should it be signed?
- How would it/ should it be used in practice?

If Mrs Smith Capable in Respect to treatment

- Capable patient
- No info on present health condition
- No info on specific treatments, on risks, benefits, etc
- Not a consent
- Not really much of an advance care plan as is so generalized
- Will be misleading to staff at home
- High potential for misuse as will likely be treated as if it's a consent to guide care for Mrs Smith

If Mrs Smith is not Capable to make treatment decisions

- Is the daughter her SDM or just the person in the family that is available to assist Mrs Smith on admission?
- If Vera is the proper SDM, not a consent because Vera would need info on mothers present health condition, specific treatments proposed, risks, benefits etc
- Not a plan of treatment as too generalized, not specific treatments listed, not specific to Mrs. Smith's health condition
- Vera cannot ACP as only Mother when still capable could have expressed wishes for herself
- If completed by Vera will be misleading to staff at home
- High potential for misuse as will likely be treated as if it's a consent to guide care for Mrs Smith

If Mrs Smith not capable for Treatment

- If Vera is the proper SDM , she can give consent to a plan of treatment that includes reference to no CPR if:
  - Patient – Mrs Smith- present health condition is such that discussion of CPR/ No CPR is appropriate
  - If Vera has been given all info about Mrs Smith present health condition
  - If Vera has been given all the information about this treatment of CPR and its risks, benefits etc for Mrs Smith

In these circumstances Vera is NOT advance care planning but giving or refusing consent to a plan of treatment

Questions

- What planning needs to be done?
- What is advance care planning?
- What is an advance care plan?
- In advance of what?
- Circumstances in which a person might advance care plan?
- Who, how, why, when it is that they might do this?
- What is consent? When do you need consent? Who can provide it?
- How, if at all, do Health consent and advance care planning intersect?

Questions

- For a patient in your care, do you have a current plan of treatment or an advance care plan?
- How do you know?
- What documentation is there?
- If the patient has an ACP, do you need to develop a current plan of treatment.
- If so, do you have consent where necessary?
- How do you know? From whom does consent need to be acquired? i.e. who is capable and has the requisite authority?
- What has been done to ensure that all team members (current and potential) are aware of the plan of treatment

QUESTIONS?