# The Chinese University of Hong Kong
# The Nethersole School of Nursing
# CADENZA Training Programme

## CTP003 – Chronic Disease Management and End-of-life Care

## Ch 10 - End-of-life care: advance care planning, ethical and legal issues



香港賽馬會慈善信託基金
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# Lecture Outline

- Patient rights in terminal illness
- Advance care planning
- Ethical and legal issues in end of life care
  - ethical principles
  - ethical and legal issues

# Patient Rights in Terminal Illness

# Patient rights in terminal illness

- Many decisions have to be made when a person is approaching the end of life.

- The decisions should respect the person's values and wishes while maintaining comfort and dignity.

# Patient rights in terminal illness

- There are two concerns in making decisions: what kind of medical care and the level of care that would be received.

- There is no question that the patients have the following rights:
  - the moral, ethical, and legal right to receive full information about their conditions and treatment choice.

(Smith, 2000; Pace, 2000)

# Patient Rights in Terminal Illness

- RIGHT to know the truth
  - about the condition, prognosis and options
- RIGHT to consent to or refuse treatment
  - and input into plan of care
- RIGHT to expert care
  - to alleviate emotional and physical symptoms
- RIGHT to confidentiality and privacy
  - and respect for personal values
- RIGHT to control environment and setting
  - for the final days of life
- RIGHT to determine care
  - and disposition of the body upon death

**(Smith, 2000)**

# Patient Rights in Terminal Illness

Role of the medical team:

- To make sure that the patient is adequately informed of the risks and benefits about the decisions.
- To properly assess the patient's mental capacity for decisions;
  - capacity is not simply dependent on a person's abilities, but on the match or mismatch between his/her abilities and the decision making demands of the situation.

(Scully, 2000)

- The Hospital Authority requires the team to provide further explanations in a sympathetic manner when the patient's refusal of treatment (Tx) is against his/her benefits.

(Hospital Authority, 2002)

# Advance Care Planning (ACP)

# Advance Care Planning

- Planning and discussing the patient's wishes and choosing ahead with family members because the patient may be incapable to make decisions himself – for instance, in a coma.

# Advance Care Planning

- ACP is a collaborative process between
  - patient
  - family members
  - health care professionals
- Patient clarifies his or her
  - goals
  - values
  - preferences for future medical treatment

(Moore, 2007; EPEC Project, 1999)

# Advance Care Planning

ACP

- is not a ‘one-off’ discussion and documentation. It takes place regularly in the process of care.
- should be reviewed and updated
- medical team should make sure that a patient's wishes will be respected even when the patient is incapable of making his or her own decisions.

# Advance Care Planning

- Formally, ACP can be thought of as a stepwise approach:
  1. Introduce the topic
  2. Engage in structured discussions
  3. Document patient preferences
  4. Review, update
  5. Apply the plan when need arises

- Less formally, the process fosters personal resolution for the patient, preparedness for the proxy, and effective teamwork for the professionals.

# Importance of Advance Care Planning

Let others know what type and the extent of care the patient would prefer.

Increases communication about end-of-life needs and concerns.

Helps the family in making decisions about the patient's care.

Lessen the stress and anxiety of the patient, the family and the proxy.

Builds trust and a sense of teamwork between the patient, the proxy, and health care professionals.

Avoids future confusion and conflict.



(Heart Failure Society of America, 2005; EPEC project,1999)

# Advance Care Planning

- An advance care plan may consists of:
  - an advance care directive
  - a do-not-resuscitate order
  - a living will
  - a power of attorney

# ACP --- Advance Directives (AD)

In The Law Reform Commission of Hong Kong report, the concept of advance directives has been explained by Chiu and Li as follows:

> *"An advance directive for health care is a statement, usually in writing, in which a person indicates when mentally competent the form of health care he/she would like to have in a future time when he/she is no longer competent. The development of advance directives is largely derived from the principle of informed consent and the belief in a person's autonomy in health care decisions."* (The Law Reform Commission of Hong Kong *p.12)*
>
> (Chui & Li, 2000)

# ACP --- Advance Directives (AD)

- It is a form of "anticipatory decision"
- This is effective even when the patient loses the ability to make decisions at some future time.

( The Law Reform Commission of Hong Kong, 2006)

# ACP --- Advance Directives (AD)

## In Hong Kong

***Substitute decision-making and advance directives in relation to medical treatment***

- consultation paper, 2004
- report, 2006
- For the details of the report, please click:
- http://www.hkreform.gov.hk/en/docs/rdecision-e.pdf

***Introduction of the Concept of Advance Directives in Hong Kong***

- consultation paper, 2010

# ACP --- Advance Directives (AD)

*Substitute decision-making and advance directives in relation to medical treatment* report recommendations:

- "The concept of AD should be promoted initially by non-legislative means."
- "The government should review the position in due course once the community has become more widely familiar with the concept and should consider the appropriateness of legislation at that stage."

( The Law Reform Commission of Hong Kong, 2006, p.188)

# ACP --- Advance Directives (AD)

Report recommendations:

- "Encourage individuals to consider and complete AD in advance of any life-threatening illness." ( The Law Reform Commission of Hong Kong, 2006 p.188)
- "The model form of AD requires that it be witnessed by two witnesses, one of whom must be a medical practitioner, neither witness having an interest in the estate of the person making the AD." ( The Law Reform Commission of Hong Kong, 2006,p.189)

# ACP --- Advance Directives (AD)

Report recommendations:

- "If revoked in writing, it should be witnessed by an independent witness who should not have an interest in the estate of the person making the revocation." ( The Law Reform Commission of Hong Kong, 2006, p.190)
- "If revoked orally, the revocation should be made before a doctor, lawyer or other independent person who should not have an interest in the estate of the person making the revocation, and where practicable that witness should make a written record of the oral revocation. "( The Law Reform Commission of Hong Kong, 2006, p.190)

# ACP --- Advance Directives (AD)

- “If medical staff learn that an individual has revoked his advance directive, the information should be properly documented in the individual's medical records.” ( The Law Reform Commission of Hong Kong, 2006, p.190)

# ACP --- Advance Directives (AD)

Proposed model form of advance directive can be browsed from the following link:

http://www.hkreform.gov.hk/en/docs/rdecision-e.pdf

P.193-197 of the report

( The Law Reform Commission of Hong Kong, 2006, p.193-197)

# ACP --- DNR order

- A do-not-resuscitate (DNR) order is a type of advance care directive that tells the health care professionals what they should or should not do when the patient suffers respiratory or cardiac arrest.

(Heart Failure Society of America, 2005)

# ACP --- DNR order

A DNR order can include instructions on whether to use different methods to revive the patient, including:

- cardiopulmonary resuscitation
- defibrillation
- breathing tube and machine
- medications

- The importance of writing the do-not-resuscitate(DNR) is to avoid unnecessary and unwarranted cardiopulmonary resuscitation.
- It is also important to assure the patient and the caregivers that comfort will continue at the end of life.

(Cavalieri, 2001)

# ACP --- Living Will

- A living will is a legal document that lets the patient express his/her wish about life sustaining treatment when he/she is unable to participate in decisions about their medical care.
- A living will guides health care providers and allows the patient to set limits on what will be done to him/her.

(Heart Failure Society of America, 2005)

# ACP --- Power of Attorney

- The function of a power of attorney is to let the surrogate make decisions for the patient legally.
- A health care power of attorney lets the surrogate make all health care decisions for the patient including the decision to refuse life-sustaining Tx.
- If the patient has made a living will, the surrogate has the authority to interpret the living will in making the decision for the patient.

(Heart Failure Society of America, 2005)

# Advanced care planning

The WHO Regional Office for Europe's publication *Better palliative Care for Older People* suggests:

- Despite hopes that ACP might reduce the number of unwanted interventions, there is no evidence that such plans are always followed.

More comprehensive methods need to be explored in order to ensure ACP is well followed.

(Davies& Higginson, 2004)

# Ethical and legal issues in end of life care

# Case 1

- Mr. Leung M / 70 diagnosed with hepatocellular carcinoma (HCC)
- complaint of dyspnoea
- chronic smoker
- found to have hepatomegaly and ascites
- treated with dexamethasone
- abdominal paracentesis done
- anaemic; transfused Hb 11.2 g/dL
- cachexic

# Progress

- Chest X-ray: raised right hemi-diaphragm, lung fields clear, cardiac shadow normal
- Treated with bronchodilators with little improvement
- Hypoxic, given oxygen supplement
- Treated with oral morphine

# Progress

- Still dyspnoeic
- Mr. Leung requests euthanasia

# What would you do?

- Kill Mr. Leung
- Refuse to provide euthanasia
- Refer Mr. Leung to someone else, e.g., clinical psychologist
- Discuss other options with Mr. Leung
- Explore the inner suffering of Mr. Leung

# How do you make your decision?

# Ethical and legal issues in end of life care

## Ethical principles

# Ethical Principles

- There are several principles to guide the life and death decision-making process:
  - beneficence
  - non-maleficence
  - principle of double effect
  - respect for autonomy
  - respect for life
  - justice
  - veracity
  - confidentiality

# Ethical Principles

- The principles will not automatically lead to decisions or conclusions about the particular end-of-life situations.

- Offer guidance on acting benefit to the patient, respecting his or her choices, and treating him or her fairly.

**(Kleespies, 2004)**

# Ethical Principles

- According to the Hospital Authority:
- “Ethical principles are fundamental values which provide the basis for reasoned analysis of, and justification for, making a decision or taking an action” (Hospital Authority, 2002,p.8 )
- “It is important to consider the clinical situation fully and to evaluate risks and benefits”

(Hospital Authority, 2002,p.8 )

- For details, please click the following link:
- http://www.ha.org.hk/haho/ho/cc/clinicalethicreport_eng_graphic.pdf

# Beneficence & non-maleficence

- Beneficence:
  - Seek the best interests of the patient.
- Non-maleficence:
  - "Do no harm" to the patient. The avoidance of harm or injury to the patient.

# Beneficence & non-maleficence

- The primary goal of medicine is to benefit the patient's health with minimal harm.
- Beneficence & non-maleficence almost always need to be considered together.

(Smith, 2000; Kleespies, 2004)

# Principle of double effect

- Effects that would be morally wrong if caused intentionally could be permissible if foreseen but unintended.

# Principle of double effect

Four key conditions:

1. Nature of the act must be good.
2. The good effect and not the bad effect must be intended.
3. The bad effect must not be a means to the good effect.
4. The good effect must outweigh the bad effect.

(Becker & Becker, 2001)

# Respect for Autonomy

- Respecting the rights of the patient to refuse or accept treatment options and the scope of care.
- When a patient is competent, this balancing between benefit and burden must ultimately be made by the patient.

(Smith, 2000)

# Respect for life --- **Hippocratic Oath**

- The **Hippocratic Oath** is an oath pertaining to the ethical practice of medicine traditionally taken by physicians.

- "…I will not give a lethal drug to anyone if I am asked, nor will I advise such a plan…"

(NOVA Online, 2001)

# Justice

- Equality of access to and distribution of health care resources.
- Fairly treating all patients

(Smith, 2000)

# Veracity (the truth)

- Openness and honesty in providing the information that is necessary for the patient to give informed consent, or in providing further information upon request by the patient.

(Smith, 2000)

# Ethics of truth telling

- There are also principles adapted in a ***"statement of assumptions and principles concerning psychological care of dying persons and their families"***

1. "Right to choose whether or not to be told the truth of dying"
   - "Individuals may request that they not be told of news that they may not be able to face"
   - good communication skills is recommended

(Connor,1996. p.131)

2. “Right to be told you are dying”
   - If patient asks for the truth then it should be told. However, sometimes disclosure of prognosis should be avoided because it will harm the patient .

3. “Right to acknowledge or not acknowledge the truth of dying”
   - “After a patient is told that he/she is dying it is their business to do with that information whatever they must”

(Connor,1996,p.132)

- In conclusion, there are cultural differences that we must consider.
- Chinese vs Western culture

# Confidentiality

- Respect for the privacy of the patient, with personal or medical information shared only among team members for the purpose of appropriate care planning.

(Smith, 2000)

# Back to Case 1

- Whose autonomy should we respect?
- Is performing euthanasia a way of paying respect to the patient's autonomy?
- Besides autonomy, what other factors should be considered?
- What are the underlying needs of the patient?

# Ethical and legal issues in end of life care

## Common issues

# Common Ethical and Legal Issues in End-of-life Care

- Euthanasia
- Withholding / withdrawing life-sustaining treatment

# Ethical and legal issues in end of life care

## Euthanasia

# Euthanasia

Definition:

- The deliberate action to terminate life by someone other than, and at the request of, the patient concerned.

# Euthanasia

- Voluntary euthanasia:
  - is euthanasia provided to a competent person on his/her informed request.
- Non-voluntary euthanasia:
  - is the provision of euthanasia to an incompetent person according to a surrogate's decision.
- Involuntary euthanasia:
  - is euthanasia performed without a competent person's consent.

(Euthanasia.com, 2008)

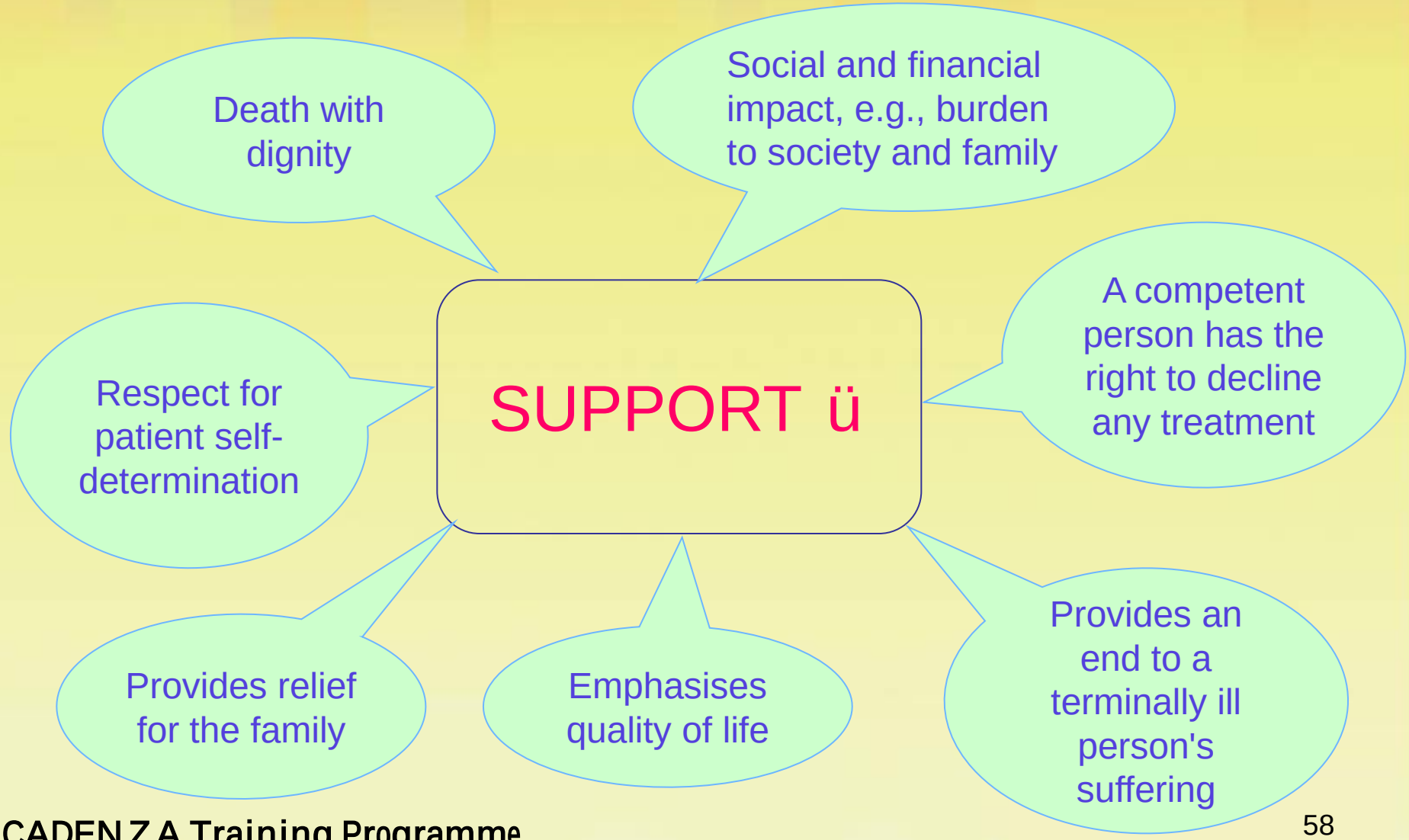
# Euthanasia

- Active euthanasia:
  - involves a deliberate act (or commission) which results in the patient's death

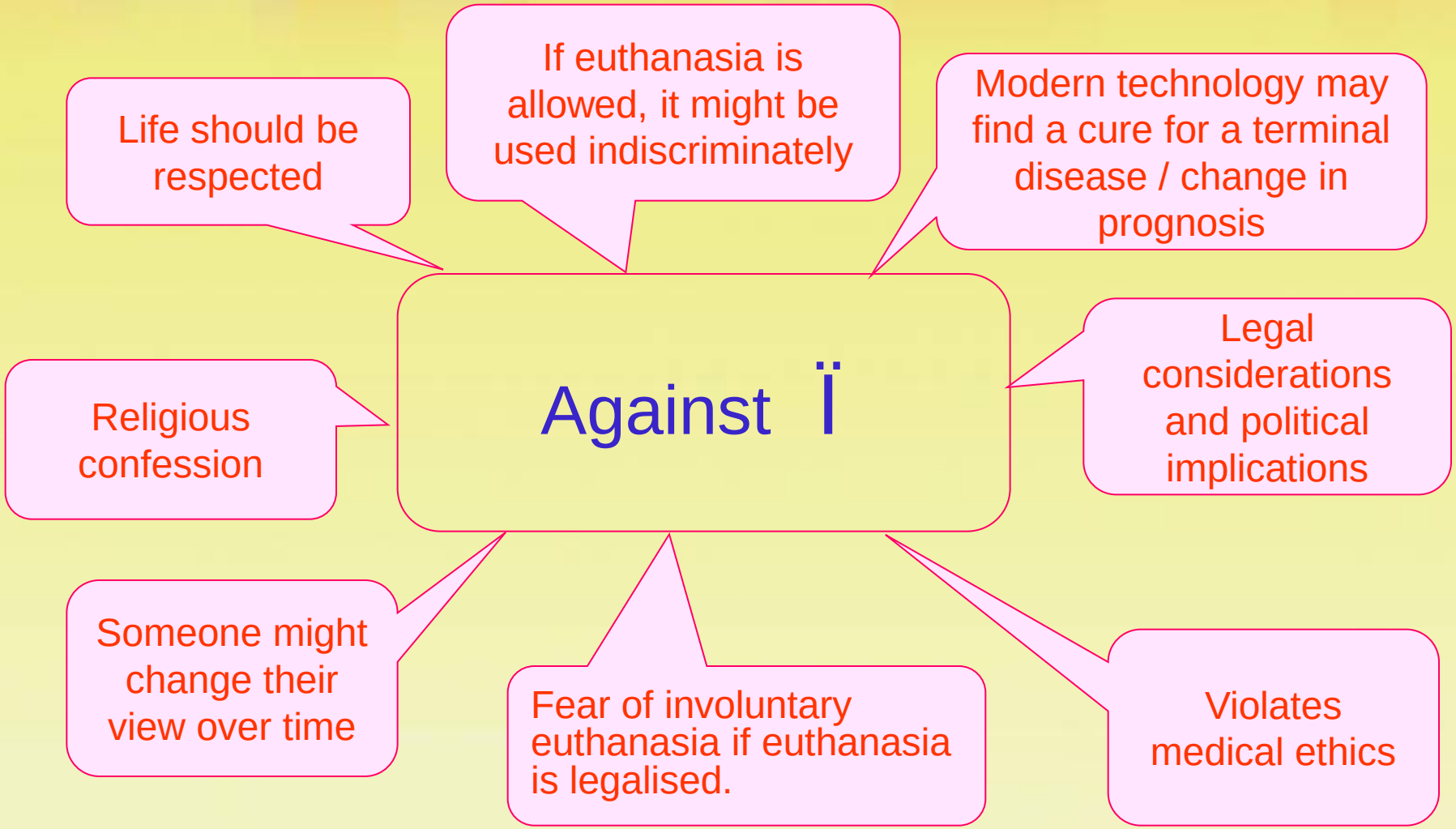
- Passive euthanasia:
  - involves a deliberate omission or the withholding of certain life-supporting cares and treatments

(Euthanasia.com, 2008)

# Arguments for Euthanasia: Support



# Arguments for Euthanasia: Against






(Johnstone,1994)

# Euthanasia: a view from the EAPC Ethics Task Force

European Association for Palliative Care (EAPC) redefines the definition of euthanasia and physician-assisted suicide.

# Euthanasia: a view from the EAPC Ethics Task Force

The following should not be seen as euthanasia:

- withholding futile treatment
- withdrawing futile treatment
- ‘terminal sedation’ / palliative sedation (the use of sedative medication to relieve intolerable suffering in the last days of life)

# Euthanasia: a view from the EAPC Ethics Task Force

- Medicalised killing of a person without the person's consent, no matter nonvoluntary or involuntary, is a kind of murder rather than euthanasia.
- Euthanasia is active by definition, therefore the expression ‘passive euthanasia’ is contrary to the definition.

# Euthanasia: a view from the EAPC Ethics Task Force

Adoption of the following definitions is recommended.

*Euthanasia* is killing on request and is defined as:

- "A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request." (Materstvedt et al., 2003,p.98)

*Physician-assisted suicide* is defined as:

- "A doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request."

(Materstvedt et al., 2003, p.98)

# Euthanasia: a view from the EAPC Ethics Task Force

The Ethics Task Force takes the following position:

- If euthanasia is legalised, then the following concerns will exist:
  1. pressure on vulnerable parties
  2. the development of palliative care will be hindered
  3. value conflict of physicians and other healthcare professionals
  4. widening of the clinical criteria to include other groups in society
  5. increase in the number of medicalised killings;
  6. killing to become admissable within society.

# Euthanasia: a view from the EAPC Ethics Task Force

The Ethics Task Force takes the following position:

- Within the modern medical system patients may fear that life will be prolonged unnecessarily or end in unbearable distress. As a result, they will request for euthanasia or physician-assisted suicide.
- ‘Living wills' and advance directives can be an alternative through mutual communication between patients and professionals.

# Euthanasia: a view from the EAPC Ethics Task Force

The Ethics Task Force takes the following position:

- EAPC should respect individual choices for euthanasia and physician-assisted suicide, but it is important to refocus attention onto the responsibility of all societies to provide care for their elderly, dying and vulnerable citizens.

(Materstvedt et al., 2003)

# Euthanasia: a view from Hong Kong Hospital Authority

- The Hospital Authority reaffirms its stand against euthanasia and physical assisted suicide.

- Medical Council Code defines euthanasia as "Direct intentional killing of a person as part of the medical care being offered."

- The practice of euthanasia is unethical and illegal.

(Hospital Authority, 2002, p.3)

http://www.ha.org.hk/haho/ho/cc/clinicalethicreport_eng_graphic.pdf

# Euthanasia: a view from Hong Kong Hospital Authority

- Patients facing uncontrolled bio-psychosocial-spiritual problems will sometimes request euthanasia.
- It is often a call for help, therefore health care professional should address these problems instead of acceding to the request for euthanasia.


http://www.ha.org.hk/haho/ho/cc/clinicalethicreport_eng_graphic.pdf

(Hospital Authority, 2002)

# The Role of Palliative Care

- The development of palliative care is a way to relieve the total pain and distress symptoms of a patient, and improve their quality of life through:
  - symptom control
  - pain management
  - psychological, social and spiritual support to address the underlying distress of the patient
  - using a team approach to address the needs of the family, including bereavement counselling

# The Difference between Euthanasia and Palliative Care

| Palliative Care | Euthanasia |
|---|---|
| Live in dignity | Die in dignity |
| Will enhance quality of life until death | To avoid poor quality of life through intentionally killing a person |
| Team approach to support patient and family | Doctor's action |
| Emphasises and affirms life | Emphasis on death |
| Provides relief from pain and other distressing symptoms | Uses drugs to terminate life |
| Emphasis on relationship | Emphasis on personal wishes |

(cite in Society for the promotion of hospice care, 2005)

# Ethical and legal issues in end of life care

## Withholding / withdrawing life-sustaining treatment

# Withholding/Withdrawing life-sustaining treatment

Definition of life-sustaining treatments:

- All treatments which have the potential to postpone the patient's death without reversing the underlying medical condition.
- They include:
  - cardiopulmonary resuscitation
  - artificial ventilation
  - blood products
  - pacemakers
  - vasopressors
  - specialised treatments for particular conditions such as chemotherapy or dialysis
  - antibiotics when given for a potentially life-threatening infection
  - artificial nutrition and hydration

 (British Medical Association, 1999, section 3.2) 

# Withholding/Withdrawing life-sustaining treatment

- The Hospital Authority agrees that it is ethically and legally acceptable to withhold or withdraw life-sustaining treatment when:
  - "a mentally competent and properly informed patient refuses the life-sustaining treatment
  - and/or the treatment is futile"

(Hospital Authority, 2002, section 4.2)

# Withholding/Withdrawing life-sustaining treatment

Determination of futility:

- Futility can be viewed in the strict sense of physiologic futility when clinical reasoning or experience suggests that a life-sustaining treatment is highly unlikely to achieve its purpose.
- For example:
  - performing CPR in a patient in refractory septic shock despite maximal vasopressor support.

(Schneiderman, Jecker & Jonsen,1990)

# Case 2

- Ms. Chen, F/84, brain tumor
- Comatose, on nasogastric tube feeding
- Her daughter demands removal of nasogastric tube so that she no longer has to suffer

# What should you do?

# Case 2

- Whose decision is it?
- Patient, family or healthcare provider?

# Withholding/Withdrawing life-sustaining treatment

When futility is considered, the decision involves:

- burdens vs. benefits
- best interests of the patient in choosing life sustaining treatment

- It is not an appropriate goal of medicine to sustain life at all cost with no regard to its quality or burdens of the treatment on the patient.

(British Medical Association, 1999)

# Withholding/Withdrawing life-sustaining treatment

- The decision-making process should be a consensus-building process between the three parties:
  - health care team, the patient and the family.
- The health care team provide a realistic assessment of the patient's prognosis through communication with the patient and the family
- Assessment considers the effectiveness of the treatment, the likelihood of pain and suffering, and the invasiveness of the treatment, etc.

(Nasraway, 2001)

# Withholding/Withdrawing life-sustaining treatment

The HA guidelines on life-sustaining treatment in the terminally ill (2002) claim that:

- The decision-making should be taken in a consensus-building process between the health care team, the patient and the family.
- The decision of Tx by a mentally competent and properly informed patient must be respected.

# Withholding/Withdrawing life-sustaining treatment

(cont'd):

- For a mentally incapacitated patient, valid advance directives refusing life-sustaining Tx should be respected.
- A guardian of a mentally incapacitated patient is legally entitled to give consent for Tx if it is considered to be in the best interests of the patient, or withhold futile Tx to the patient.

# Withholding/Withdrawing life-sustaining treatment

(cont'd):

- For a mentally incapacitated patient without any advance directives or a guardian, the final medical decision should made based on the best option for the patient.
- The health care team have no obligation to provide physiologically futile Tx if requested by the patient or the family.
- Doctor is allowed to withdraw life-sustaining treatment when the treatment is futile.

http://www.ha.org.hk/haho/ho/cc/clinicalethicreport_eng_graphic.pdf

# Back to Case 2

- Patient's preference is unknown
- Patient is comatose and does not appear to be suffering
- Feeding could prolong life and does not place additional burden on patient
- Feeding continued
- Use of empathy to comfort daughter

# Other Ethical and Legal Issues in End-of-life Care

- Palliative sedative
- Pain control
- Hydration, etc.
- The ultimate autonomy of life

# Conclusion

# Conclusion

- Euthanasia is illegal and unethical the world over (except some countries, such as the Netherlands, Belgium and Luxembourg).
- There are many decision-making and ethical and legal issues about end-of-life care. Thus, it is very important to encourage the patient to express or write down his/her wishes about the type of care and the extent of care that he/she would like to receive.

- These instructions could help the family, the surrogate and the health care professionals to honour the patient's values and wishes while maintaining comfort and dignity.
- Life must be respected.

- Many ethical dilemmas can be avoided through good dialogue between patient, physician and caregivers.
- The role of the physician as a moral agent must be included.

(Cavalieri, 2001)

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# The End of Chapter 10