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

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

Module II Enhancing Quality at End of Life
Ch 1 – Coping with Dying

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Lecture Outline

- What is a ‘good death’?
- Coping with dying
  - Dignity-conserving care: a new model for palliative care
  - 2Ls + 3Ws framework of promoting positive preparation for death

To die —

that is the human condition;

to live decently and to die well —

that is man's privilege.

- Herman Feifel, 1971 –

(The pioneer of death study)

‘Good death’

- Everyone’s life ends with death. In view of this inevitable fact, people still hope for a ‘good death’.
- Different cultures may have different constructs of ‘good death’.

(Chan, Tse & Chan, 2006)

What is good death? — Western

- **12 principles of good death** by Smith (2000)

  The dying person able to

  – know when death is coming, and to know what can be expected.
  – retain control over what happens.
  – be offered with dignity and privacy.
  – have control over pain relief and other symptom control.
  – have choice and control over where death occurs.
  – have access to information and expertise when necessary.
  – have access to any spiritual or emotional support.

What is good death? — Western

- **12 principles of good death** (cont'd)

  The dying person able to

  – have access to hospice care.
  – have control over who is present at the end of life.
  – to issue advance directives which ensure wishes are respected.
  – have sufficient time to say goodbye, and control over other aspects of timing.
  – to leave when it is time to go, and not to have life prolonged unnecessarily.

(Smith, 2000)

What is good death? — Chinese

From the terminally ill patients' point of view

- Mak (2001) interviewed 33 (17 men & 16 women), aged 34-86, Chinese hospice patients with terminal cancer. 7 important elements for good death were found.
  1) Being aware of dying ***(death awareness)***
  2) Maintaining hope ***(hope)***
  3) Being free from pain and suffering ***(comfort)***
  4) Experiencing personal control ***(control)***
  5) Maintaining social relationships ***(connectedness)***
  6) Preparing to depart ***(preparation)***
  7) Accepting the timing of one's death ***(completion)***

What's good death? — Chinese

From the terminally ill patients' point of view

- Chao (1993) interviewed 20 patients with advanced cancer in Taiwan and concluded that there are three important elements in constituting "good dying"
  - ***Peace of body***
  - ***Peace of mind***
  - ***Peace of thought***

What's good death? ––– Chinese

From bereaved's point of view

- Hsu, Hahn and Hsu (2002) interviewed 35 Taiwanese widows and concluded the following are important elements of 'good death'
  - accomplishment of familial responsibility
  - without suffering
  - old death

What is good death? ––– Chinese

From bereaved's point of view

- Chan (2004) interviewed 15 bereaved Chinese older people, who are between 66 to 86 years old. Five themes were found:
  - ***Little suffering before death***
  - ***Presence of family members at the moment of death***
  - ***Good family***
  - ***Natural death***
  - ***Not being a burden to others***

What is good death? ––– Chinese

From general public's point of view

- The Society for the Promotion of Hospice Care in Hong Kong conducted a large scale survey of 'good death' in 2004 which involved 719 Chinese adults.
- An expert panel with a bereavement counsellor and a medical social worker was formed.
- A questionnaire was developed
  - based on a literature review and frontline experience
  - to explore to what extent the public agreed to statements related to the concept of 'good death', from 0 (totally disagree) to 10 (totally agree)

What is good death? ––– Chinese

From general public's point of view

- By factor analysis, four theme of 'good death' were found
  - ***Physical aspects of the dying persons***
  - ***Psychosocial aspects of the bereaved***
  - ***Psychosocial aspects of the dying persons***
  - ***Post-mortem aspects***
- The most concern is the "no physical suffering and torture"
- The least concern is the "post-mortem items"

Implication of ‘good death’

- Charlton (2006) stated that
  - if a patient having adequate **palliative care** until they die, that a good death has been promoted and achieved.
  - **Euthanasia is not a provision of good death**, but an indication of inadequate palliative care and a call for help.

- The meaning of “good death” may serve as guidance for care of the persons who are **coping with dying**.

(Chan, Tse & Chan, 2006)

Coping with dying

- Coping with dying
- Care for the dying
  - ☺ Dignity-conserving care
  - ☺ 2Ls + 3Ws

Coping with dying

- What is coping?
  - The term coping has been defined as

"constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141)

(Lazarus & Folkman, 1984)

What is coping?

- Coping is
  - the response one makes to manage any situation that is perceived as stressful
- However,
  - the effort might be successful or unsuccessful
  - it is not necessary to master the stressful demands.
  - it is most important for a person to accept, endure, minimise, or avoid stressful demands.

(Charles, Corr, & Nabe, 2009)

Coping with dying

Who is coping with dying when a person is dying?

The dying patient only?

Or those who involved in the situation?

Coping with dying

- Dying involves more than a single individual.
- This is not confined to the dying person.
- It includes
  - family members
  - friends of the patients
  - professionals
  - volunteer caregivers

(Charles et al, 2009)

Coping with dying is

multifaceted

Involves more than one person

Therefore,

it involves more than one set of perceptions of what is going on, and more than one way of coping.

Empathetic listening is required to understand what coping means for each individual involved in the situation.

(Charles et al, 2009)

Dying Trajectories and Awareness Context

- Glaser and Strauss (1965, 2005) claimed that there are two key variables in coping with dying.
  - **Dying trajectories**
    - The nature of the dying trajectories
  - **Awareness Context**
    - The degree to which those who are involved are aware of and share information about dying.

Dying Trajectories

- No dying people move toward death in the same way and at the same speed.

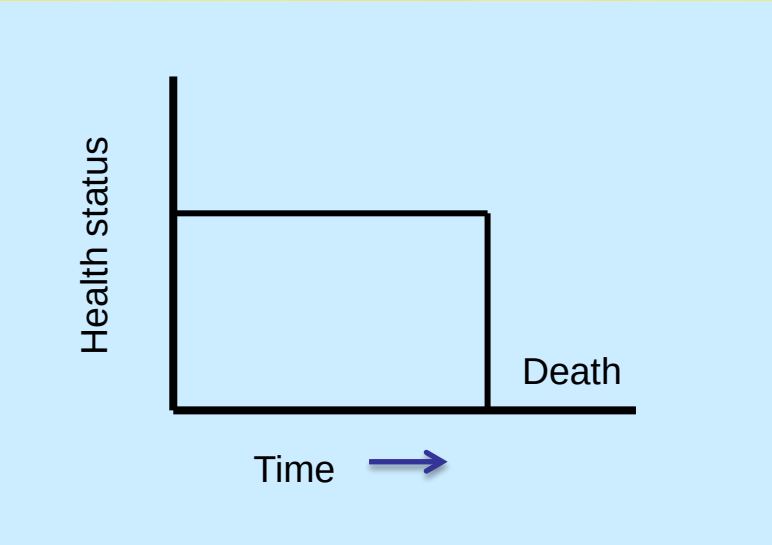
- Everyone have his or her own distinctive characteristics in the process of dying.
- The temporal pattern of the disease process leading to death has great impact on the experience of those involved in the dying process.

(Charles et al., 2009; University of Washington, 2011)

Dying Trajectories

- Two principal characteristics:
  - **Duration**
    - Refers to the time involved between the onset of dying and the time of death. This is coined as “living-dying interval”.
  - **Shape**
    - Refers to the course of the dying process, whether the process can be predicted and death is expected.

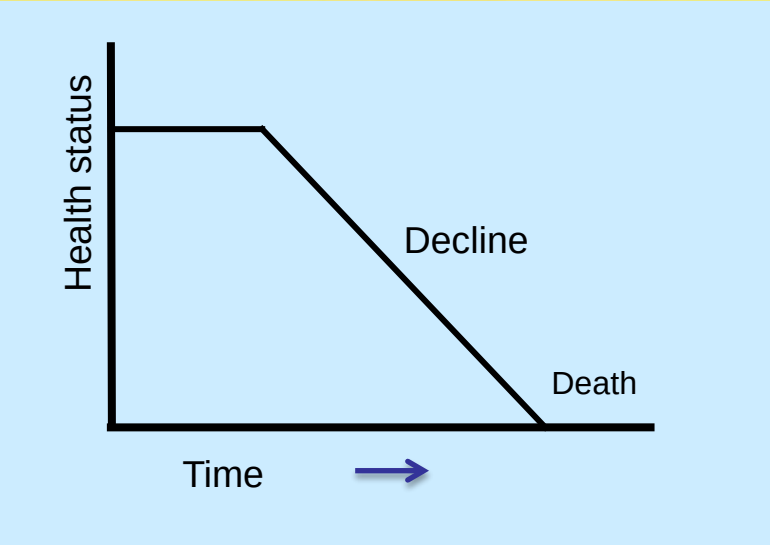
Example of common dying trajectories



- Usually related to trauma like a motor vehicle accident
- Sudden 'unexpected' death within the context of chronic disease, e.g.,
  - acute MI or fatal arrhythmia in the context of chronic heart disease
  - massive stroke in the context of chronic cerebral vascular disease

Example 1:
sudden death without prior warning

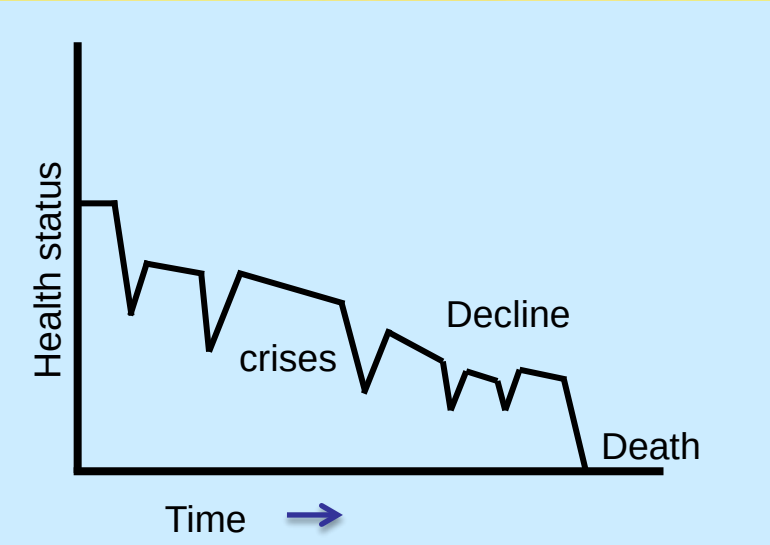
Example of common dying trajectories



Example 2:
steady decline with expected death

- A steady decline in health status over time and approaching death gradually.
- The steepness of the slope depends on the progress of the chronic disease.
- For example:
  - poor prognosis cancers, such as pancreatic cancer, lung cancer, metastatic colon cancer
  - neuro-degenerative diseases, such as Alzheimer's disease, Parkinson's disease

Example of common dying trajectories



Example 3:
steady decline with intermittent crises and unpredictable death

- After each crisis the patient's baseline drops.
- It is difficult to predict which crisis will cause death. Therefore, after several crisis *it is difficult for those involved to believe he or she won't survive the next one*.
- It is difficult to offer end-of-life care for these kind of patients.
- For example: advanced stage heart disease, end-stage liver failure

Dying Trajectories

- The concept of dying trajectories is helpful because:
  - this can assist in helping the patients and all others involved understand what they can expect.
  - This allows everyone involved, including ***patient, family, and health care professionals (HCPs)*** to have a common context for anticipating potential challenges and plan for them.

(University of Washington, 2011)

Awareness Contexts

- Glaser and Strauss (1965) argued that once a person is discovered to be dying, the relationships between that person and those involved in the dying can take at least into four basic forms of awareness contexts.
    - **Closed awareness**
    - **Suspected awareness**
    - **Mutual pretense**
    - **Open awareness**
- Each awareness context brings with it potential benefits and potential costs.

Awareness Contexts

Closed awareness	• The person who is dying does not realized the fact. • The family, HCPs and may be others know that the person is dying, but that information was concealed from the dying person, and the person does not suspect it.
Suspected awareness	• The person may begin to suspect that he or she has not been given all the information about his or her situation.
Mutual pretense	• The relevant information is held by all the individual parties, but not shared between each other. • This is a kind of communal drama in which everyone involved acts out a role intended to cover the truth. • This is a fragile situation, one fail can cause the entire structure collapse. • Mutual pretense requires constant vigilance. It is extremely demanding for everyone involved.
Open awareness	• The dying person and everyone involved realizes and willing to discuss the fact that death is near.

Awareness Contexts

- These four types of awareness contexts
  - are not steps in a linear progression from inhibition to openness.
- However, **open awareness** allows for honest communication, permits each involved person to participate in the dying process and unfinished business between the dying person and others can be addressed.

(Charles et al., 2009; DeSpelder & Strickland, 2005)

Coping with dying: a stage-based approach

- The best-known model of coping with dying is the stage-based model put forward by Dr. Elisabeth Kübler-Ross (1969).
- On her book *On death and dying* (1969), she reported the results of a series of interviews and developed model about the psychological reactions in persons who were dying: **five stages of death and dying**.

  - **Denial**
  - **Anger**
  - **Bargaining**
  - **Depression**
  - **Acceptance**

Five stages of death and dying

Stage	Typical Expression
Denial	***"not me!"***
Anger	***"Why me?"***
Bargaining	***"Yes me, but…"***
Depression reactive preparatory	Responding to past and present losses Anticipating and responding to losses yet to come
Acceptance	Described as a stage "almost void of feelings"

(Table ***Kübler-Ross's five stages in coping with dying***, pp. 138, Charles et al., 2009)

Five stages of death and dying

- This model regarded the dying people are people who are in a ***stressful situation***. And they develop a number of ***different ways of responding*** to the situation.

- Some of them may cope by withdrawing, by becoming angry, or by finding what has occurred in their lives up to now that might make death acceptable.

"Different people cope in different ways at different times and in difference contexts. " *(p.138)*

(Charles et al., 2009)

Five stages of death and dying

- Criticism of this model:
  - no evidence to show that these stages exist
  - no evidence to show that people do actually move from Stage 1 to Stage 5
  - the limitations have not been acknowledged
  - the line is blurred between description of what happens and prescription for what should happen
  - the wholeness of the person's life is neglected
  - the resources, pressures, and characteristics of the immediate environment are not taken into account

(Kastenbaum, 2006)

Five stages of death and dying

- Kübler-Ross argued for viewing the stages ***as fluid, not linear***, as people may re-experience various feelings in various situations.
- This model gives us a valuable premise for studying the experience of dying; however, this may not be adequate to fully understand dying individually.

Coping with dying: a task-based approach

- Coping involves more than an automatic or defensive reaction.

"Coping is, or at least can be, an active process, doing with a positive orientation that seeks to resolve problems or adapt to challenges in living."

(P.142)

- The dying person who is coping with dying is actually an actor, not just a reactor.

(Charles et al., 2009)

Coping with dying: a task-based approach

- Avoids metaphors that emphasise a passive or merely reactive way of coping with dying.
- Encourages the dying persons to see things from other individuals' point of view and to arrange or modify their efforts accordingly.
- Tasks are work that can be undertaken in coping with dying.

A task-based approach

Fours areas of task work in coping with dying	
Area of task work	**Basic types of task in coping with dying**
Physical	Aim to satisfy ***bodily needs*** and to minimise ***physical distress***
Psychological	Aim to enhance ***psychological security***, ***autonomy***, and ***richness***
Social	Aim to sustain and enhance those ***interpersonal attachments*** that are significant to the dying person, and to sustain selected ***interactions with social groups within society or with society itself***
Spiritual	Aim to address issues of ***meaningfulness***, ***connectedness***, ***transcendence*** and, finally to foster ***hope***

(Table ***Four Areas of Task Work in Coping with Dying***, pp. 143, Charles et la., 2009)

A task-based approach

- The aim of this model is to:
  - empower the dying person
  - encourage the dying person to participate in coping with dying
- The person should be allowed to decide which tasks are important to him or her.
- Even if some tasks can be completed, it is never possible to finish all the tasks that confront an individual.

(Charles et al., 2009)

Older people who are coping with dying

- Cook and Oltjenbruns (1998) have identified four specific needs of older people who are coping with dying:
  - maintaining a sense of self
  - participating in decisions about their lives
  - being reassured that their lives still have value
  - receiving appropriate and adequate health care

In order to promote good death and assists those who are coping with dying, two care models will be introduced.

Care for the dying

- ☺ Dignity-conserving care
- ☺ 2Ls + 3Ws

Dignity-conserving care

Defining Dignity

- Dignity is defined as ***"the quality or state of being worthy, honored, or esteemed"*** .

(Merriam-Webster's Medical Dictionary, 2007)

- The basic principle of palliative care could summarized as ***the goal of helping patients to die with dignity***.

- The term "dignity" provides an overall framework that guide the care at end-of-life.

(Chochinov, 2002)

- Geyman (1983) listed dignity as one of the five basic needs that must be fulfilled in caring for dying patients.

Why is dignity important in palliative care?

- For palliative patients, a sense of dignity ***is the feeling that they are respected, or worthy of respect, despite the physical deterioration of their bodies and the psychological distress.***
- The concept of dignity is important as it is
  - accessible and readily understood by patients in discussing the meaning and purpose in life and end-of-life care.
  - used and understood by caregivers and families when they try to assess the overall condition of the patients across various aspects of distress, physical, psychological, social and existential aspects. It includes the notion of good death and quality of life.

(Kissane, Treece, Breitbart, McKeen & Chochinov, 2009)

Dignity Model

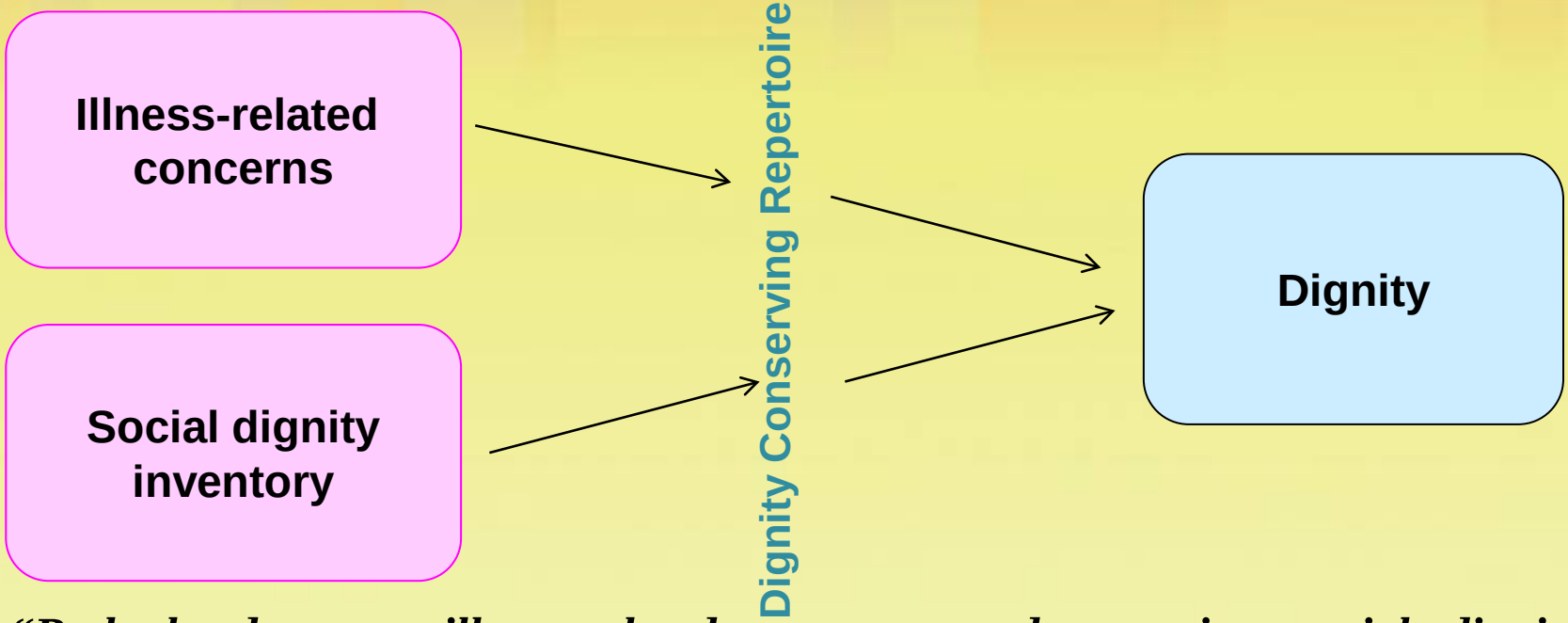
- Chochinov and colleagues (2002) performed a study

  'Dignity in the terminally ill: a developing empirical model'

  to determine how dying patients understand and define the term 'dignity', in order to develop a model of dignity for the terminally ill.

- '***Dignity Model***' was developed from the study.

Dignity Model: Inter-relatedness of the themes



"Both burdensome illness-related concerns and a taxing social dignity inventory are shown as having a deleterious effect on dignity. The model also show that negative influences might be buffered by a positive dignity conserving repertoire that includes dignity conserving perspectives and/or dignity conserving practices. In other words, the model shows that individuals with a limited dignity conserving repertoire would be more likely to have a diminished sense of dignity." (p.440-441)

(Chochinov, Hack, McClement, Kristjanson & Harlos, 2002)

Major Dignity Categories, Themes and Sub-themes of Dignity Model

Illness-related concerns	Dignity conserving repertoire	Social dignity inventory
Level of independence • Cognitive acuity • Functional capacity	***Dignity conserving perspectives*** • continuity of self • role preservation • generativity / legacy • maintenance of pride • hopefulness • autonomy / control • acceptance •resilience / fighting spirit	***Privacy boundaries*** ***Social support*** ***Care tenor*** ***Burden to others*** ***Aftermath concerns***
Symptom distress • Physical distress • Psychological distress – medical uncertainty – death Anxiety	***Dignity conserving practices*** •living 'in the moment' •maintaining normalcy •seeking spiritual comfort	

(Table ***Major dignity categories, themes and sub-themes,*** pp. 436, Chochinov, Hack, McClement, Kristjanson & Harlos, 2002)

For the details of each item, please refer to "Chochinov, H. M. (2002). Dignity-conserving care — a new model for palliative care. *JAMA, 287*(17), 2253-2260."

Validating the Dignity Model

- A cross-sectional, quantitative study was used to validate the model.
- 211 patients with end-stage cancer participated in the study over three years.
- From 22 items derived from the model, patients were asked the extent to which they believed these specific issues were or could be related to their sense of dignity.
- This study provides further evidence to valid the Dignity Model.

(Chochinov, Krisjansion, Hack, Hassard, McClement & Harlos, 2006)

Dignity-conserving care

- Dignity Model:
  - provides a direction for how to construct dignity-enhancing interventions for patients nearing death - dignity-conserving care
    - Dignity-conserving care questions
      - special questions may be used to elicit information
      - (for details of the questions, please refer to: Chochinov, H. M. (2002). Dignity-conserving care — a new model for palliative care. *JAMA, 287*(17), 2253-2260)
    - Dignity therapy

(Kissane, Treece, Breitbart, McKeen & Chochinov, 2009)

Dignity Therapy

- Chochinov (2002) has designed a novel intervention coined **Dignity Therapy**, to address existential distress among terminally ill patients.
- Patient is invited to address issues, memories, and reflections that they would wish to offer to those they are about to leave behind.
- Patient *shares her/her life stories*, *speaks to how they wish to be remembered*, *their most important accomplishments, hopes and dreams for loved ones*, *and advice or guidance for important people in their lives.*

- The therapy follows a framework of questions which evolved from the Dignity Model.
- The sessions are audiotaped and transcribed.
- The patient is given a copy of this 'generativity document' to keep and share with family and friends.
- And this also forms a legacy document, which aims to summarise the value and meaning of the life lived.
- This can be reread and shared by successive generations reinforcing the notion of generativity, and can engender a connection with an individual's core sense of self.

(Chochinov, 2002)

2Ls + 3Ws

Life review

Life meaning

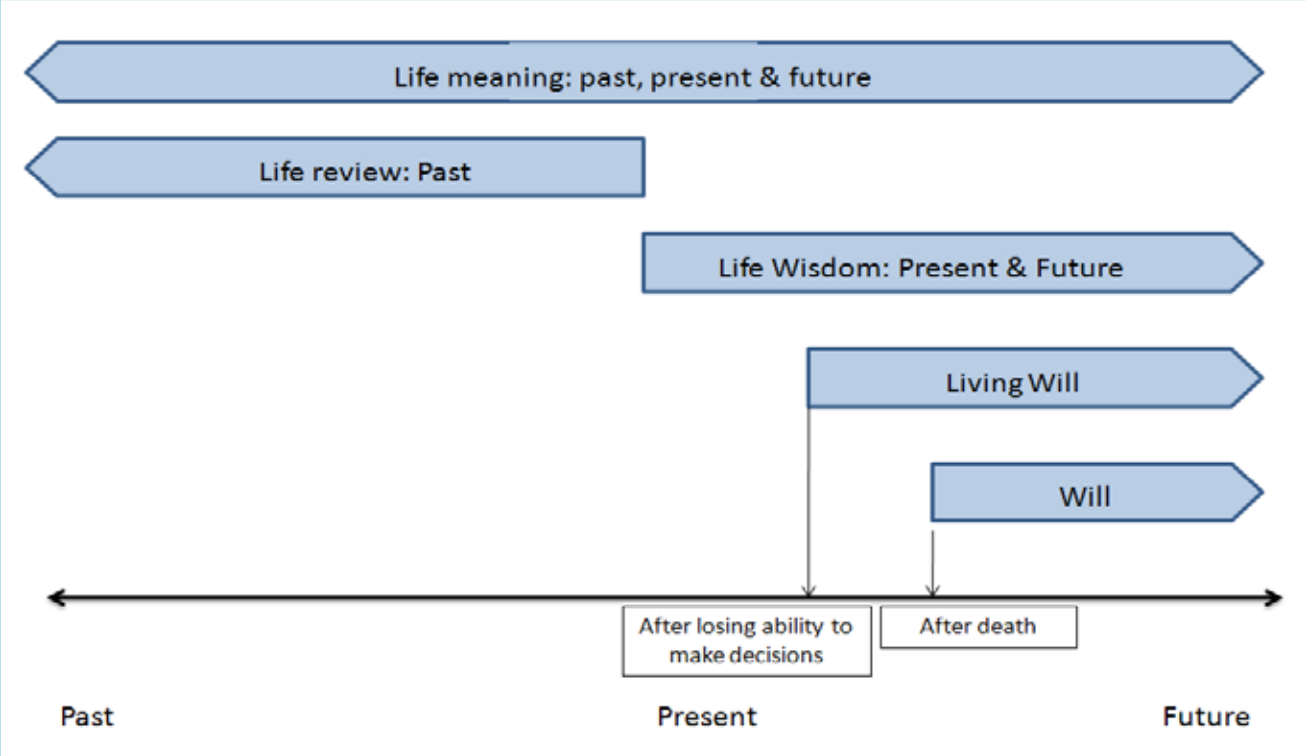
Living Will

Will

Life Wisdom

“2Ls + 3Ws”

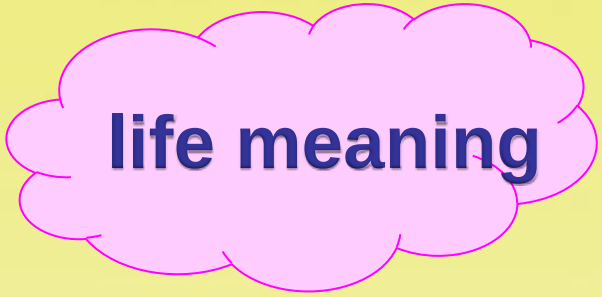
- This is a model proposed by Project ENABLE, the Centre on Behavioral Health, the University of Hong Kong, in order to promote **dignified death.**



(Table ***Illustration of the effective time frame for 2Ls+3Ws***, *In celebration of life. A self-help journey on preparing a good death and living with loss and bereavement, pp.29*. Hong Kong: the Centre on Behavioral Health, the University of Hong Kong)

2Ls

- The 2Ls denote



- The values of these 2 Ls from the basis of an individual life to which a person is anchored in integrating and making sense of the whole life.

Life review

- Black and Haight (1992) used a metaphor to describe the relationship between life and life review.

weaver

Life is made up of a mass of tangled threads without patterns

Life review is like a weaver that helps to form patterns and finally make the threads into a beautiful tapestry.

life review

- ***Life review*** is a psychoanalytically based intervention which ***critical analyze of one's life history*** with the goal to ***achieve ego integrity***.

- Life review is
  - a necessary part of **successful aging**,
  - and is a means of **deriving meaning from the past and resolving old conflicts**,
  - then in turns can prepare an individual on facing death and lessen one's fear.

(Haight & Haight, 2007)

Theoretical background

- Life review is theoretically grounded in the **life-stage developmental theory of Erikson**

- An individual must accomplish specific developmental tasks at each stage in order to traverse to the next stage effectively.

(Erikson, 1982; Haight & Haight, 2007)

Life review is theoretically grounded in the *life-stage developmental theory of Erikson*

Erikson's psychosocial crisis stages	Age range /life stage
1. Trust v Mistrust	0-1½ yrs / infant
2. Autonomy v Shame & Doubt	1-3 yrs/toddler
3. Initiative v Guilt	3-6 yrs /preschool
4. Industry v Inferiority	5-12 yrs /schoolchild
5. Identity v Role Confusion	11-18 yrs /adolescent
6. Intimacy v Isolation	18-40yrs/young adult
7. Generativity v Stagnation	30-65yrs/mid-adult
8. Integrity v Despair	**50+/late adult**

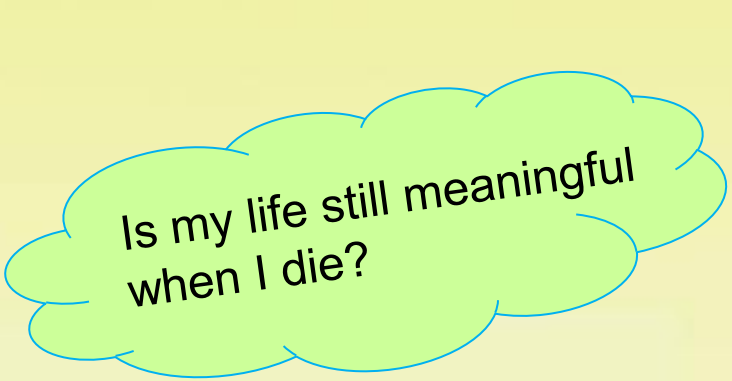
Erikson (1963) considered life review as a vital task in this stage, through which older people are allowed to reintegrate past experiences and value the present with an eye on the future. Hence, it promotes the attainment of ego integrity and therefore avoids despair in late adulthood.

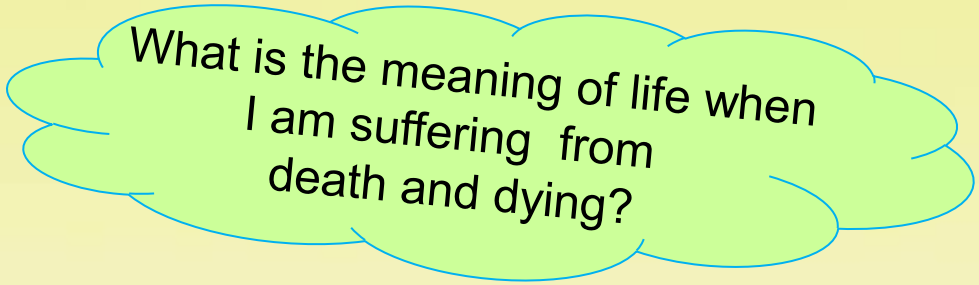
Life meaning

"Humans are fundamentally meaning-makers; their cognitive structures do not easily adapt to ultimate meaninglessness." (p.291)

(Dowd & Nielsen, 2006)

- When death is imminent, an individual is consciously aware of the limited time left; therefore the need to search for meaning in life becomes more intense.





(Chan, 2009)

- This is an individual task to search for life meaning in preparing for death.
- By enhancing the existential meaning and spiritual reframing or reconstruction of new life meaning to potential regret, an individual may better learn from present life experience and therefore live better and plan for the future.
- *Higher level of meaning in life* is found to be associated with *a lower level of fear of death*

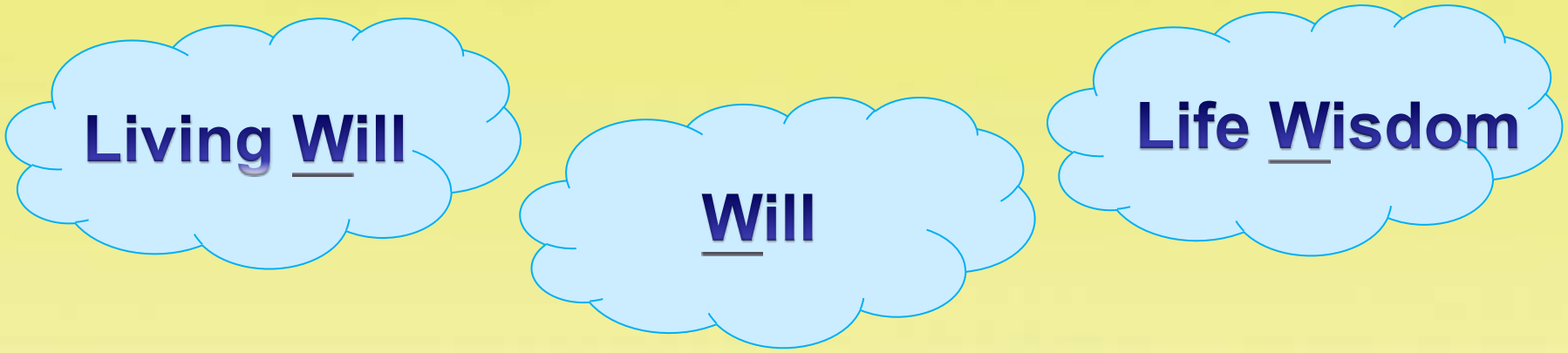
(Ardelt, 2008)

- A meaningful life may be a key to successful ageing.

(Wong, 2000)

3Ws

- The 3Ws denote



- The 3Ws are related to the future planning for a peaceful departure from the dying process.

(Chan, 2009)

Living Will

- Is actually a *medical care plan* which will come into effect when the individual loses cognitive decision-making ability.
- It is a way for an individual to let the health-care team and family or friends know how s/he feels about certain aspects of medical treatment and health-care service.

(Chan, 2009)

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)

Advance Care planning

- An advance care plan can consist of:
  - an advance directive
  - a do-not-resuscitate order

You may go to 003 module I Ch 10 for more details

Will

- Legally, a will is a document by which an individual regulates *the rights of others over his or her property* or family after death.
- However, in this model, the will includes wishes after death in addition to property arrangement. Including:
  - **Wishes for organ donation,**
  - **Insurance management,**
  - **Property/asset management**
  - **Burial/cremation instruction,**
  - **Service/funeral arrangements,**
  - **The way to be remembered by others, or**
  - **Gifts to others**

(Chan, 2009)

Life Wisdom

- Creating a legacy or imparting your life wisdom
- It is a channel of expressing heartfelt messages to an individual's loved ones.
- And can ease the anticipatory grief of the dying about leaving the loved ones behind.
- It just likes a love letter to the loved ones which may contains
  - **Important personal values and beliefs,**
  - **spiritual faith, wishes, hope and blessing for family, friends and the future generation,**
  - **Life lessons,**
  - **love and care,**
  - **concern,**
  - **messages of relationship reconciliation,** etc.

Life Wisdom

A letter to loved ones

Videotape diary

Make a VCD

Photos albums

Record an audiotape of memories and thoughts

Scrapbook with words and pictures

“2Ls + 3Ws”

- This is a local framework that proposes to promote a dignified death. Through this framework, many activities and exercises can be done in order to assist the dying person and his/her family and friends to prepare for death.
- For detail of the activities and framework you may browse the following web site:

  http://www.enable.hk/enable/tch/main/index.aspx

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The End of Chapter 1