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

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

Ch 8 - End-of-life Care: concept of palliative care, grief and bereavement care

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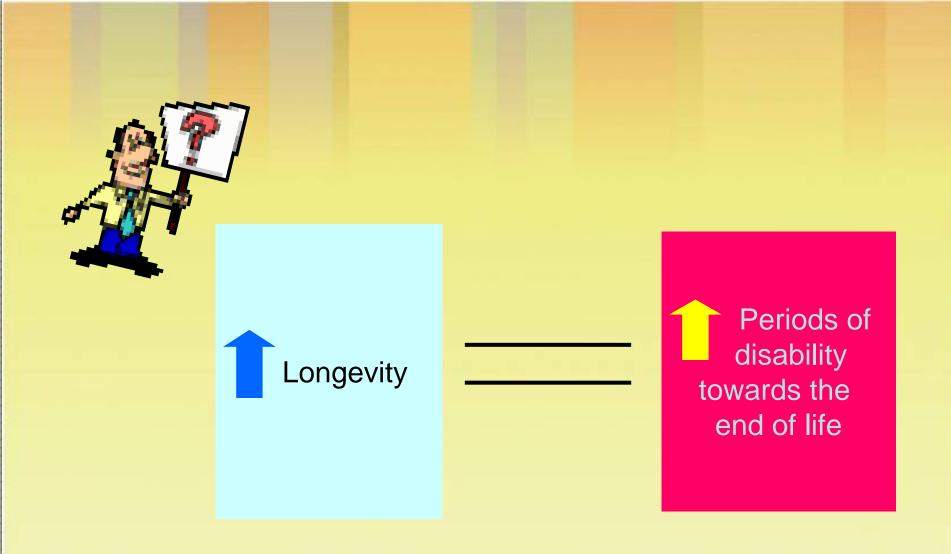
### Lecture Outline

- The demography of care
  - changing populations
- Concept of palliative care
  - palliative care (PC)
  - hospice care
- Palliative paradigm
  - bio-psycho-socio-spiritual paradigm
- Grief and bereavement care
- End-of-life service in Hong Kong
  - challenges for future development of PC in HK

## The demography of care: changing populations

- Population ageing
  - happening in European and other developed countries
  - longevity of people is increasing
  - proportion of population older than 65 years and surviving into very old age is increasing

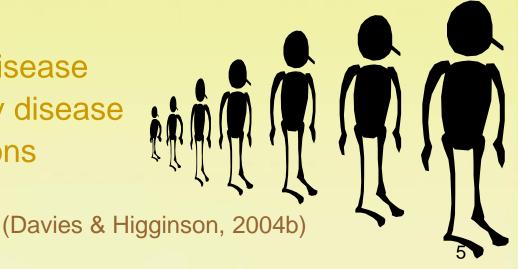
(Davies & Higginson, 2004b)

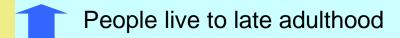


(Davies & Higginson, 2004b)

## Changing populations

- The changing pattern of disease
  - More people die through serious chronic diseases than through any other cause.
  - More likely to suffer multiple organ failure.
  - The top five predicted causes of death for 2020 will be:
    - heart disease
    - cerebrovascular disease
    - chronic respiratory disease
    - respiratory infections
    - lung cancer





Chronic diseases become more common with age



People die at late adulthood following illness due to serious chronic conditions which cause a wide range of physical, psychological and social problems.

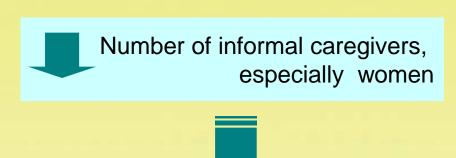


More people need help towards the end of life



## Changing populations

The changing social structure

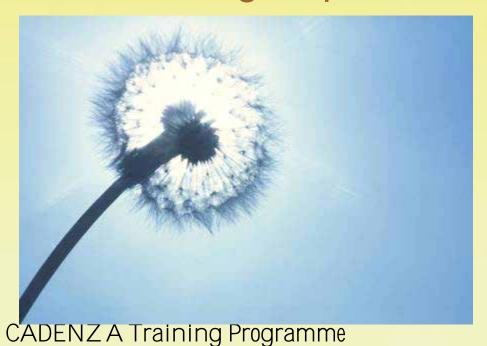




Health care systems need to provide effective and compassionate care at end-of-life for more people

### Therefore...

 Health care systems must be able to meet the needs of older people at the end-of-life by reducing their suffering, helping them to live comfortably and enhancing their quality of life for as long as possible.



(Davies & Higginson, 2004b)

### The need for palliative care

Older people commonly suffer from multiple medical problems

The combined effects of these medical problems are greater than any single disease and probably increase the need for care

Older people are more susceptible to adverse drug reactions and iatrogenic illness

Physical problems may a have psychological impact in older people.

## Concept of Palliative Care

- Definition of palliative care
- Difference between palliative care and hospice care

### **Palliative Care**

Defined in 2002 by the World Health Organisation as

"...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (p.84)

### Palliative care.....

- provides relief from pain and other distressing symptoms
  - 2 affirms life and regards dying as a normal process
    - intends neither to hasten nor postpone death
- 2 integrates the psychological and spiritual aspects of patient care
  - offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement

## (Cont'd) Palliative care.....

2 uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated

will enhance quality of life, and may also positively influence the course of illness

is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

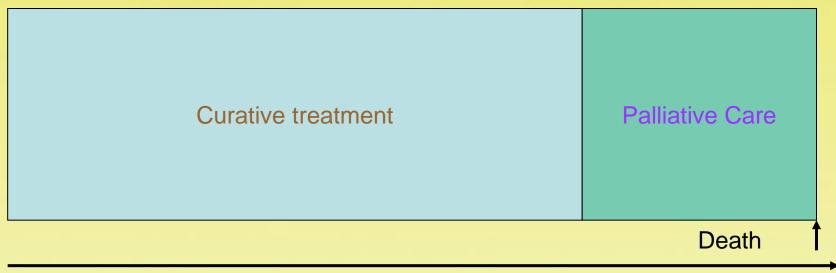
## Difference between Acute Care and Palliative Care

Acute Care  Quantity of care,	Palliative Care
Quantity of care,	O 114 (
	Quality of care
Curative, add days to life	Palliative, add life to days
Disease management	Symptom control
Lab values, investigation result	Patient discomfort and expectation
Curative rates, improved lab values, discharge to home	Free of pain and discomfort, peaceful death
Failure	Inevitable, natural
Patient	Patient, family and significant others
	Disease management  Lab values, investigation result  Curative rates, improved lab values, discharge to home  Failure

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(Smith, 2000)

## Traditional concept of palliative care

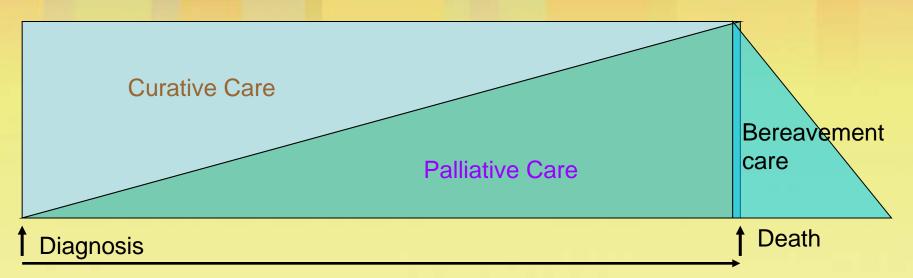


Disease progression

 Palliative care is relevant only to the last few weeks of life – when no treatments are of benefit to the patient.

(Lynn & Adamson, 2003)

### **New Concept of Palliative Care**



Disease progression

- Palliative care starts after the disease is diagnosed.
- •The involvement of curative treatment decreases as illness progresses, while that of palliative care increases with approaching end-of-life.
- •Support is provided to the family during the entire period.
- •Bereavement care is provided for the family and significant others after the death of the patient.

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## **Delivery of Palliative Care**

- Hospital in-patient
- Hospice in-patient
- Home care
- Outpatient
- Day care
- Palliative consultative services



(Hospital Authority, 2008)

## Palliative interdisciplinary care team members

- Core members:
  - patient and family

- Other important members:
  - doctors
  - nurses
  - clinical psychologists / counsellors
  - social workers
  - pastoral care workers
  - rehabilitation team PT / OT
  - dietitians
  - volunteers

### Palliative Care vs. Hospice Care

Are palliative care and hospice care the same?



## Hospice Care

- The term "hospice" is derived from the Latin root word *hospse*, mean "given to hospitality".
- In the past, it referred to a resting place for travellers along pilgrim routes, where those who were sick, poor ,and weary from travelling were taken in and received care.
- In modern-day society, hospice means a system of specialised care that provides shelter and comfort for those facing the difficult journey of death.

## Palliative Care # Hospice Care

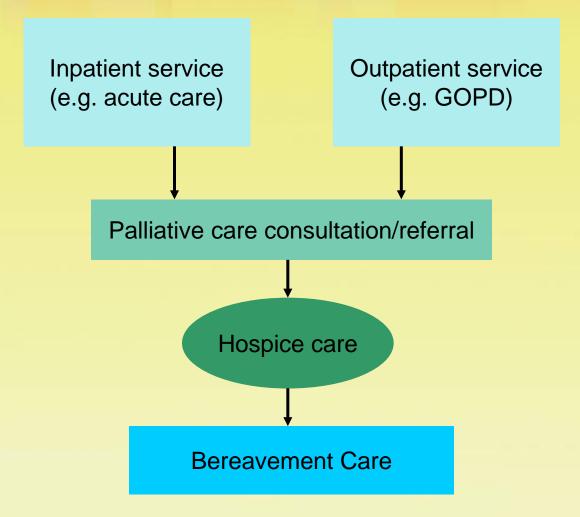
 Palliative care is associated with the hospice philosophy and extends the traditional hospice approach of care to a broader approach of services for the terminally ill in the modern health care system.

(Kuebler et al, 2002)

 Curative treatment can be obtained through palliative care, but not through hospice care.

(Wittenberg-Lyles & Sanchez-Reilly, 2008)

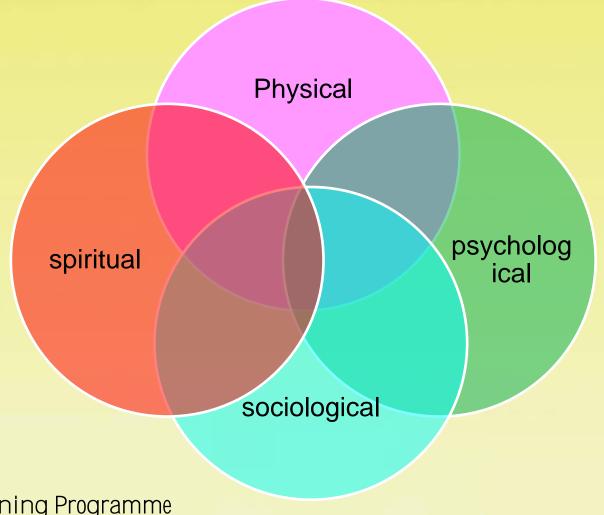
## Palliative Care vs. Hospice Care



(Wittenberg-Lyles & Sanchez-Reilly, 2008) 22

## Palliative Paradigm

## The palliative paradigm--Bio-psycho-socio-spiritual paradigm



## Physical care

 Discontinuing active curative treatment is not synonymous with saying,





"There is always something that can be done for the patient."

(Smith, 2000)



- symptoms control and relief of distressing symptoms as identified by the patient
- enhance comfort and quality of life.
- Good pain management is crucial to optimize quality of life and ease physical, social, and spiritual pain.

(Smith, 2000)

## Physical care

### Symptoms of patients in palliative care unit

- 1. Weakness
- 2. Fatigue
- 3. Weight loss
- 4. Anorexia
- 5. Dyspnea
- 6. Xerostomia
- 7. Cough
- 8. Pain



- 9. Anxiety
- 10. Dysphagia
- 11. Confusion
- 12. Depression
- 13. Constipation
- 14. Nausea
- 15. Insomnia
- 16. Vomiting



## Physical care

### Daily care

is also very important for the patient and could develop rapport during the care.



### **Grooming:**

- bathing everyday can provide comfort and refreshment, especially for bed-bound patients
- hair combing, shaving, etc. can also be done around bath time



(stoppain. org. Department of pain medicine & palliative care, 2005)

#### **Skin care:**

- Pressure ulcers often occur in remaining in one position for long periods of time.
  - check the patient's skin for reddened areas every day
  - assist the patient to change position frequently
  - keep the skin clean and dry
  - gently massage and apply lotions

(stoppain. org. Department of pain medicine & palliative care, 2005)
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#### **Mouth care:**

- Good mouth care helps to prevent sores and may improve the patient's appetite.
  - cleanse with a soft toothbrush or a cloth twice a day
  - refit or remove loose dentures to prevent mouth sores
  - moisturising the lips and corners of the mouth can prevent cracking



#### **Exercise:**

- Active or passive exercise.
- Bathing is also a good time for exercise.
   Exercise the patient's arms and legs during or after bath time.

## Psychosocial Care

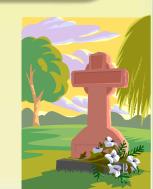
Conscious or subconscious fear

Uselessness

Psychological distress

Hopelessness

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## Psychosocial Care

Conscious or subconscious fear

The biggest fear is of death itself

- Not knowing what it will feel like;
- Not knowing how it will happen;
- Not knowing what to expect next.



## Psychosocial Care

• Symptoms like anxiety, anger, insomnia, depression, and other physical complaints may be exhibited.

 Dr. Elisabeth KÜbler-Ross identified five common reactions: denial, anger, bargaining, depression and acceptance. These are what she called the "stages of death and dying".

### Stages of Death and Dying

When people are dying, they go through a series of stages when certain feelings or emotions override all others. The stages are:

- denial
- anger
- bargaining
- depression
- acceptance



(Charles, Corr, & Nabe, 2009)

### Denial -- shock and disbelief

- Disbelief in the facts.
- May use another reason to "explain" the situation.
- Functions as a buffer for unexpected shocking news.

  (Smith, 2000)



## **Anger -- hostility and resentment**

- Rage, envy, resentment may appear.
- May often ask "Why me?".
- May displace the anger at random: doctors, nurses, family, God, and so forth.
- May result in outbursts and unreasonable demands.

  (Smith, 2000)



## Bargaining -- looking for a way out

- An attempt to defer the inevitability of death.
- Promises of good behaviour in order to bargain for longer life. Promises sometimes associated with *quiet guilt*.
- Often happens with God(s).



# Depression -- no longer able to deny, patients experience sadness and loss

- A normal reaction after realisation of great loss.
- Important to experience and express sorrow to facilitate the state of acceptance.



# Acceptance -- acceptance of the inevitability of death with peace and detachment

- Devoid of feeling.
- Diminished interest.
- Sitting in silence may be most meaningful communication with people at this stage.



# Psychosocial Care

- -Not all people will experience all five stages.
- The stages do not necessarily appear in sequence.
- -Stages may coexist or be revisited.

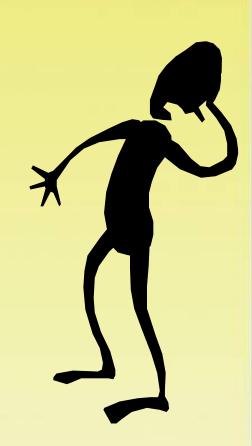


# Psychosocial Care

- Social distress
  - Usually involves very basic and practical matters.
  - Household and financial concerns are common.
    - e.g., a grandmother may worry about how the family will manage domestic affairs without her.
    - e.g., a husband may worry about how his wife will manage electrical issues without him.



- Source of distress
  - Loss of job, position, and control, etc.
  - not being able to function as his or her roles, like father or mother, husband or wife, or community member.



## Psychosocial Comfort

- Compassionate communication is essential at the end of life.

  (We will discuss more about communications at end-of-life in chapter 9.)
- Discussing issues frankly can facilitate psychological preparation for the patient. Issues include:
  - resuscitation orders
  - life support
  - arranging personal affairs

(stoppain. org. Department of pain medicine & palliative care, 2005)

# Spiritual needs # Religious needs

 Spirituality is a broader concept, reflecting more universal expectations.



- Spiritual needs are
  - highly <u>personal</u> and <u>salient</u> to many people at the end of life
- When approaching death, people may find themselves returning to an earlier faith or searching for answers about the meaning of life, suffering, and death.



- Some basic spiritual distress issues often reported by dying patients are:
  - Unresolved issues of forgiveness
    - e.g., forgiving or being forgiven
  - Love
    - e.g., to express love or know one is loved
  - Belonging
    - e.g., need for relationships



- Many patients will experience pain in their inner being, i.e. spiritual pains.
- Spiritual pains may magnify their physical pains.
- Spiritual pain is definitely a factor in total suffering.

# Spiritual Care Interventions

- For example:
  - present with the patient
  - religious support. Arrange visit by clergy as desired
  - perform spiritual life reviews
  - encourage expression of feelings
  - assist the patient in reframing personal goals.
  - prayers, music or meditation as desired.



(Smith, 2000; stoppain.org. Department of pain medicine & palliative care, 2005)
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## The palliative paradigm----

- Concerned with the individual holistically, as a whole, complete person.
- Holistic care approach
  - care for the patient and the family in a biopsycho-socio-spiritual approach
  - aims to improve their quality of life

# Grief and Bereavement Care

### Grief and bereavement care

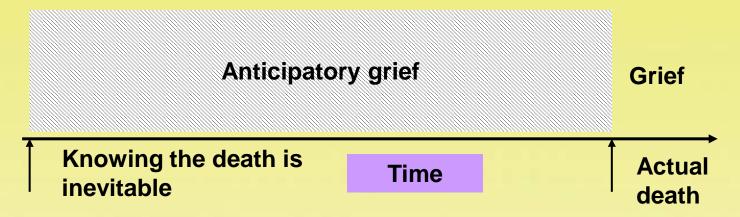
#### Grief

- is the normal process of psychological, social, and somatic reactions to perceived loss
- applies to any loss (e.g., divorce, job, selfesteem)
- death is generally viewed as the ultimate loss



### Grief and bereavement care

Anticipatory grief



- is normal, but may not always occur
- refers to grieving that occurs from the time between knowing death is inevitable and the actual death event
- offers chances to resolve conflicts or unfinished business

## Grief and bereavement care

### Mourning

 refers to cultural reaction to - or outward social expression of - the loss

#### Bereavement

- refers to state of deprivation following the loss of something held to be significant
- can be positive or negative



## Common responses to grief

# Psychological response:

- emotional outbursts
- frequent crying
- •guilt
- anxiety
- hostility
- depression
- irritability
- •helplessness
- social withdrawal

#### Physical reactions:

- palpitation
- •chest tightness
- gastrointestinal disturbances
- increase /decrease of appetite
- sleep difficulties
- dry mouth
- •fatigue
- •loss of sexual interest

#### Cognitive:

- preoccupationwith the deceased
- poor concentration
- dreams of the deceased
- Hallucinations
- •sense of presence of the deceased
- confusion

# Stages of Grief Resolution

- Four tasks of mourning
  - Task 1: to accept the reality of the loss
     (help actualise the loss)
  - Task 2: to experience the pain of grief
     (help the bereaved to identify & express feelings)
  - Task 3: to adjust to an environment in which the deceased is missing
  - Task 4: to emotionally relocate the deceased and move on with life
- May take place in any order

## 1. To accept the reality of the loss

- This task involves facing the reality that the person is dead and will not return.
- In order to assist the bereaved to fulfill this task, the bereaved:
  - should be encouraged to talk about the deceased,
  - Should attend the funeral and address the circumstances around the death.

## 2. To experience the pain of grief

- The bereaved need to allow themselves to feel the pain rather than suppressing their feelings.
   Suppression may lead to depression, physical illness, or aberrant behaviour.
- Encourage the bereaved to feel the pain and to know that it will pass.
- Caution:
  - not everyone's experience is the same; the intensity
     of pain may be different for different people

# 3. To adjust to an environment in which the deceased is missing

- The bereaved need to take up new roles formerly performed by the deceased
- The bereaved need to adjust to the changed dynamics in which the deceased is missing.

# 4. To withdraw emotional energy and reinvest it in another relationship

- Encourage the bereaved to form an ongoing relationship with the memories associated with the deceased, and continue with their own lives after the loss.
- Encourage the bereaved to reinvest their emotional energy in their present life.

(Worden, 2002; Behavioural Neurotherapy Clinic, 2005)

# A Dual Process Model (DPM) of coping with bereavement

 Stroebe & Schut (1999) discovered there are two types of stressors in coping with bereavement that the bereaved has to face:

- loss- orientated
- restoration-orientated

# A Dual Process Model (DPM) of coping with bereavement

 The bereaved may experience a process of oscillation between loss- and restoration-oriented coping.

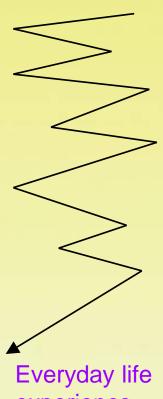
#### **Loss-oriented**

Grief

Breaking bonds with the deceased person

**Denial** 

**Avoidance** of restoration changes



experience

#### **Restoration-oriented**

Attending to life changes

Finding new interest

Distracting from grief

Developing new roles/ relationships

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(Stroebe & Schut, 1999)63

# A Dual Process Model (DPM) of coping with bereavement

 The process of oscillation is necessary for optimal adjustment after the loss.

 Each bereaved should find his/her own pace and oscillate between the loss- and restoration-orientation.

(Stroebe & Schut, 1999)

- In Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) abnormal grief reactions are referred to as "complicated bereavement".
- the intensification of grief to a level such that the person feels overwhelmed
- results in maladaptive behaviour,
- remains in a state of grief interminably without any progress towards completion









- There are four types of complicated bereavement:
  - chronic grief reaction
  - delayed grief reaction
  - exaggerated grief reaction
  - masked grief reaction

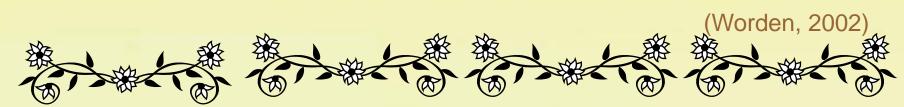
(Worden, 2002)



- Chronic grief reactions
  - in which the normal grief reactions continue for an excessive period of time without any progress towards completion
- Delayed grief reactions
  - in which the reaction occurs some period of time after the death



- Exaggerated grief reactions
  - in which a person is so overwhelmed by the symptoms of grief that major psychiatric disorders may develop
- Masked grief reactions
  - in which a person experiences <u>physical</u>
     <u>discomfort that may not at first appear to be</u>
     related to the loss



- There is no specific way to diagnose complicated grief.
- It is important to recognise when a person needs specialised help beyond the normal grief.
- Health care professional need to be alert to high-risk factors of complicated bereavement.



### Checklist for bereavement risk

- Situational factors
  - financial problems
  - poor social support
  - heavyresponsibilities
  - physical illness

- Relationship factors
  - dependence
  - ambivalence
  - multiple losses



### Checklist for bereavement risk

- Difficulty in coping
  - poor coping
  - mental illness
  - addiction
  - adult single child
  - having a child under15

- Circumstantial factors
  - suicidal death
  - sudden death
  - painful death
  - survival guilt

(Hospital Authority, 2008)









## Ten ways to help the bereaved

- 1. Be present and attentive.
- 2. Do allow silence.
- 3. Don't fill the conversations with a lot of outside topics.
- 4. Do listen in a non-judgmental and accepting way.
- 5. Don't use clichés such as 'Think of all the good times', 'Time heals all wounds', and so forth.

## Ten ways to help the bereaved

- 6. Do mention the deceased name and encourage talk about the deceased.
- 7. Do offer practical and emotional support e.g., looking after children or cooking a meal.
- 8. Do allow crying.
- 9. Reassure that grief may take years to work through.
- 10. Acknowledge anniversaries and dates of significance for the bereaved.



# End-of-life service in Hong Kong

 First set up in Our Lady of Maryknoll Hospital in 1982.

Society for Hospice Care set up in 1986.

- Bradbury Hospice (BBH), situated in Shatin, was built to house a specialist hospice unit in 1992
  - was transferred to Hospital Authority with effect from 1 April 1995
  - as at 31.3.2008, it has 26 beds
- The Society for the Promotion of Hospice Care is a charitable organisation founded in 1986





- Hospital Authority (HA)
- Non-governmental organisation (NGO)
  - Haven of Hope Holistic Care Centre
  - The Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre
  - Society for the Promotion of Hospice Care



 Referral network for inpatient palliative care in Hospital Authority (2/2008)

	Hospital	Bed no.
Kowloon (Central)	ВН	15
Kowloon (West)	OLMH	29
Kowloon (East)	UCH	15
	ННН	24
New Territories (East)	BBH	26
	SH	20
New Territories (South)	CMC	26
New Territories (North)	TMH	35
HK (East & West)	RHTSK	10
HK (South)	GH	44
	Total:	244

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- Hospital Authority standard referral form for palliative care
  - ~ mainly for cancer patients
  - Shatin Hospital pilots end-of-life programme for older people

HOSPITAL AUTHORITY		
Standard Referral Form for Palliative Care (Please read 'points to note' at the back side before you complete this form.	To: Hosp/Inst	
Patient's Particulars (Address and Tel no. is essential)  Name:  ID No.:  Tel No.:  Address:	Please either affix patient's gum label or fill in patient's particulars at the left.	
1.1 Referral for Palliative In-patient Care Palliative Home Care (Please specify the Palliative Out-patient Care Palliative Consultative Service	e expected date of discharge)  lospice Day Care	
1.2 Where is the patient at present?  Home Hospital	Others (please specify)	
2.1 Diagnosis: Primary:	Mctastasis:	
Diagnosis known to patient: Y N N N N N N N N N N N N N N N N N N	Diagnosis known to family: Y N N	
If yes, please specify      2.2 Medical History     Surgical Operation:     Chemotherapy given: Y	Date: Date of Next Appointment: Date of Next Appointment:	
3.1 Present Condition: (Please delete as appropriate) Mental State: Alert / Drowsy / Unconscious Orientated / Disorientated Mobility: Independently mobile / Mobile with air Feeding: Independent / Dependent / Tube-feedin	g	
3.2 Present Medication (+ Dosage)		
4.1 Reason for Referral Pain and Symptoms Control Psychos	ocial Care	
Others		
4.2 Will the referring unit continue to follow up the case If the answer is yes, please provide the date of next follo	Y	
4.3 Patient's consent for referral (Verbal): Y N		
4.4 Please enclose Pathology report/medical report/discha	rge summary/other confirming evidence.	
5. Remarks		
6. Referring Doctor:	(Block Letter)(Signature)	
Hospital/Unit: Tel & Fax No. of Re	ferring Doctor: (Tel) (Fax)	
Consultant of the Unit:	(Name) (Tel)	
For Palliative Care Unit:		
7.1 Date of referral received:		
7.2 Remarks:	Remarks: Sign:	

#### NGO

#### **Haven of Hope Holistic Care Centre**

- in-patient service
- home care service
- integrated rehabilitation service
- respite care
- bereavement counselling
- psycho-social spiritual care
- resources centre
- volunteer service

http://www.hohcs.org.hk/hcc.php

• NGO

# The Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre

- cancer rehabilitation wards
- out-patient
- pharmacy
- physiotherapy centre
- palliative care centre
- day care
- volunteers' centre
- traditional Chinese medicine centrehttp://www.jccrc.org.hk/Big5/About\_CRC.html

- Society for the Promotion of Hospice Care
- 贐明會 Comfort Care Concern Group
- Maggie's Cancer Caring Centres
  - hospice and palliative care
  - bereavement care
  - life and death education

# Self assessment of your beliefs about death and dying



http://www.thirteen.org/onourownterms/tools/index.html



Site Map

Credits

#### Dying: A Financial Guide

Can you cover the expenses of a loved one's final days? Get some tips on paying for

#### PATIENT TOOLS

Help Guide

- A Guide to First Steps
- A Guide to Advance
   Directives
- What Treatment Is Best For You?
- Taking a Spiritual
  Inventory

From the Series

• Self-Assessment of You
Beliefs About Death and
Dying

Talk About It

#### Requires From the Real Player



The Need to Plan: Program 1 Dr. Pat Caralis, University of Miami/Jackson Medical Center



Discussing Advance
Directives: Program 2
Dr. Diane Meier, Hertzberg
Palliative Care Center, Mt. Sinai
School of Medicine with Bill
Moyers



#### Hospice and Support: Program

Terminal Esophageal Cancer Patient Dr. Bill Bartholome and his wife, Pam Roffol Dobbies

- How to Share the Care
- How to Be with a Dying Person
- A Doctor's Guide to
   Diversity

#### Test Your Knowledge &

What do Americans fear most about death? What are the leading causes of death? Find out.

"Each person's dying is unique and we have to follow them.

They have to make the decisions..."

-- Frank Ostaseski, Director, Zen Hospice Project

Program 2: A Different Kind of Care

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# The End of Chapter 8

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