



Empowerment For Patient With Advance Illnesses & Their Family Caregivers

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Patient Empowerment

- Promote autonomous self-regulation
- Maximize individual's potential for health & wellness
- Begins with information & education
 - seeking information about one's condition
 - actively participating in treatment decisions
- Requires an individual
 - take care of one's self
 - make choices about care from among the options identified by the doctor



(Funnell et al, 1991)

Empowerment

**Meaningful
(Heart)**



**Power
(Strength)**

**Independence
(Mind)**

**Impact
(Might)**

Needs of patients with advanced illness & their family members

- Information
- Access to medical care
- Ability to make care choices
- Well-being of patients & family members
- Unmet needs

(Tallman et al, 2012)



Insufficient information

>50% patients reported that they were not communicated about

- Practical needs
- Choice of surrogate decision maker
- Spiritual concerns
- Emotional symptoms
- Life-support preferences
- Living wills
- Hospice

(Nelson et al, 2011)



Insufficient information

INFORMATION NEEDS

- Desire for information
- Point in time when require
- Type of information
- Reasons for needing information

INFORMATION BEHAVIOR

- Information sources
- Willingness to ask
- Responsibility for seeking information
- Using the internet
- Having other people informed



Access to medical care

- Seriously ill patients & their families required
 - timely access & coordinate medical care
 - symptom management
 - a trustful health professional
 - free of pain, symptoms & anxiety
 - avoid prolonged dying process
 - maintain mental alertness (Dy et al, 2008)
- Families reported
 - too few home visits from health professionals
 - inadequate symptom control (Bee et al, 2009)
- Various health system barriers were described by patients & families
 - multiple physicians
 - conflicting information from various teams
 - staff unfamiliar with issues related to the dying (Hudson, 2004)



Ability to make care choices

- Patients want
 - To consider their options
 - To have those choices honored (Morton et al, 2010)
- More frequent in advance care planning
- Shift invasive & life-sustaining treatment toward palliative goals as their illness progressed (Fried & O'Leary, 2008)



Well-being of patients & family members

- Patients wish
 - To avoid being a burden on family
 - To have conflict resolved
 - To know the family was prepared for their death
 - To have opportunity to say good-bye (Steinhauser et al, 2000)
- Value the presence of family members during advance care planning
- Information & support provided to caregivers are frequently been described as inadequate (Clayton et al, 2005; Dy et al, 2008 & Bee et al, 2009)
- Mortality risks of caregivers were 63% higher than non-caregivers (Schultz & Beach, 1999)



Needs of patients with advanced illness

Most important needs of terminally ill

- not suffering pain
- no difficulty breathing
- maintaining dignity
- having someone who listens
- receiving adequate nursing care

DON'T
FORGET!

(Natana et al, 2010)

Spiritual needs

- Identified spiritual needs
- Needs associated with relating to an ultimate other
- Need for positivity, hope, and gratitude
- Need to give and receive love
- Need to review beliefs
- Need to have meaning
- Needs related to religiosity
- Preparation for death

(Taylor, 2003)



Unmet needs

- Symptom control
- Decreased quality of life
- Illness related symptoms
- Needs of family caregivers
- Death deny society
- Unprepared to live with incurable illness
- Do not know what the information needs until crisis occurs
- Look for help & support to themselves & family
- Questions from extended family



Palliative nursing

- Holistic & patient-centered approach
- Address family members needs
- Helping patients reflect on their values
- Explaining care options
- Identify clear goals of care
- Managing symptoms
- Meeting psychological, social & spiritual needs of patients & family members
- Facilitate patient's family understand the underlying reasons of patient's choice
- Co-ordinate of care
- Support & improve the well-being of patient & family caregivers
- Supporting planning for future care



How to empower ?

- Knowledgeable & professional advice
- Empathy & active listening
- Positive attitude
- Good communication skills
- Effective counselling
- Timely delivery of information / information transition



Ms. P (Patient)

✚ **First encounter** (Nov 14): In-patient consultation

- Suffered from hereditary progressive muscular dystrophy & heart failure
- Admitted for respiratory failure participated by fluid overload
- Difficulty to express herself, but willing to communicate
- c/o insomnia since admission even eye closed
- Tearful while touch on family issues
- Act as patient's advocacy & follow up with parent team doctor & nurse

✚ **Pre-visit** (Nov 14): Phone consultation

- Patient refused nocturnal Bipap occasionally because of high-inspiratory pressure
- General advice & early home visit offered

Ms. P (Patient)

1st visit (Nov 14)

- Holistic assessment performed
- Fully aware of the diagnosis, but uncertain about the prognosis
- Good family support
- Facilitate mutual understanding between patient & adult daughter
- Empathic listening with acknowledgement & psychological support
- Practical advise on fall precaution & safety measures at home

2nd visit (Dec 14)

- Monitor patient's vital signs & functional ability
- Facilitate patient accept her limitation
- Patient enjoy travelling. Encourage outdoor activities with modification
- Energy saving technique introduced
- Discuss with daughter about the long-term care plan
- Plan appoint a maid for patient care

Ms. P (Patient)



✚ On-going visits (Jan - May 15):

- Monitor patient's vital signs & functional abilities as usual
- On nocturnal Bipap & slept well
- Mood improved after discharge
- Refer her sister (same disease) to HC nurse
- Increase acceptance of her limitation
- Increase dyspnea occasionally
- On & off shoulder & limbs pain. Analgesia taken with effects
- Decrease oral intake recently
- Enjoy family gathering with grandchildren
- Reinforce limbs exercise as tolerated & energy saving techniques

✚ Coming visits

- Prepare for the possibility of condition change
- Discuss future care planning

Mr. T (Bereaved) & his son

- ✚ Pre-visit (June 14): Urgent phone consultation
 - In-patient consultation provided by GH PMU nurse in parent hospital
 - Patient's family accepted the deterioration of patient in general after consultative services
 - Family reported distress emotion & behavior of patient's husband & son after visit
 - Referred to GH PMU for terminal care, but unfit for transfer
 - General advice given to deceased family by phone
- Patient dead (June 14)
 - Patient passed away in parent hospital
 - Refer to nurse clinic for bereavement support

Mr. T (Bereaved) & his son



First clinic visit (June 14): Mr. T & his son seen

- Deceased never seen
- Perform bereavement assessment
- Goals set
- Rapport building & seeding for child

7. Major health problem of family member(s)
☐ No ☐ Yes (please specify _____)

8. Relative chief concern(s)

 Conducted by: _____
 Date of assessment: _____

Part II: At the moment of death (please tick "x" where appropriate.)

1. ☐ Bereaved presence ☐ Chastity ☐ Restless

2. ☐ Expected death ☐ Bleeding observed ☐ Sudden deterioration

3. Mode of death & dying process ☐ Death by suicide ☐ Others _____

4. ☐ Eyes / mouth open ☐ Long dying process ☐ Crying

5. Relative's responses at death bed ☐ Numb ☐ Chanting

☐ Grieving ☐ Weeping ☐ Touching the body

☐ Realized dying ☐ Avoiding the body ☐ Banging own head

☐ Embracing the body ☐ Saying goodbye ☐ Injuring

☐ Talking incessantly ☐ Fainting ☐ Hyperventilation

☐ Denial ☐ Involve in last office ☐ Others _____

☐ Conflict among relatives

Part III: Risk Assessment (please tick "x" where appropriate.)

1. Level of risk

1.1 Psychological issues

- Has difficulty in believing the patient is seriously ill or is dying
- Has pre-existing or new psychiatric / psychological problems
- Reactions to impending loss are intense (stress, anxiety, withdrawal)
- Was very dependent on patient or vice-versa
- Was intense anger or cause undue friction with patient

1.2 Social issues

- Has other commitment (work, stress or illness)
- Has little or no social or family support
- Has young children / other dependents
- Has young or very old themselves (child / adolescent / elderly spouse)
- Is young or very old themselves (child / adolescent / elderly spouse)
- Works in healthcare

MR P1625 (2013-09)

Hospital Authority
 Grantham Hospital
 Bereavement Assessment Form

After patient's label if available
 Patient Name _____
 Hospital No. _____ HKID No. _____
 Sex / Age _____ Ward / Bed _____

Patient Diagnosis: _____
 Name of Relative: _____ Relationship: _____ Telephone: _____
 Relative Address: _____

Part I: Pre-Bereavement (Please tick "x" where appropriate.)

1. Date of diagnosis: _____

2. Date of death: _____

3. Genogram _____

4. Significant events during the process of illness

☐ Nil ☐ Uncontrolled symptoms ☐ Serious unhealed wound

☐ Unfulfilled wishes ☐ Unresolved conflict ☐ Resolved conflict

☐ Suicide attempt ☐ Others _____

5. Family relationship & social support

☐ Close relationship ☐ Supportive family ☐ Family dispute

☐ Supportive social network ☐ Doubtful ☐ No support

6. Relative Religion

☐ Nil ☐ Traditional Chinese ☐ Buddhist ☐ Taoism

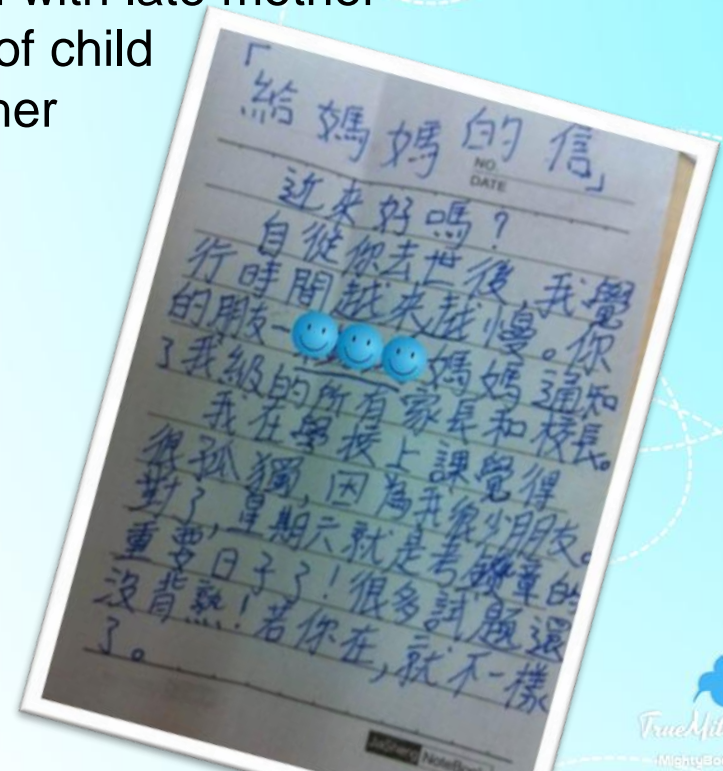
☐ Catholic ☐ Christian ☐ Others _____

MR P1625 (2013-09)



Mr. T (Bereaved) & his son

- ✚ **2nd session** (Jun 14): Child counseling with games
 - Invite father present during the whole process
 - Ground rule set
 - Prepare for the funeral
 - Facilitate the way of connection with late mother
 - Debriefing father in the absent of child
 - Bereavement counseling to father

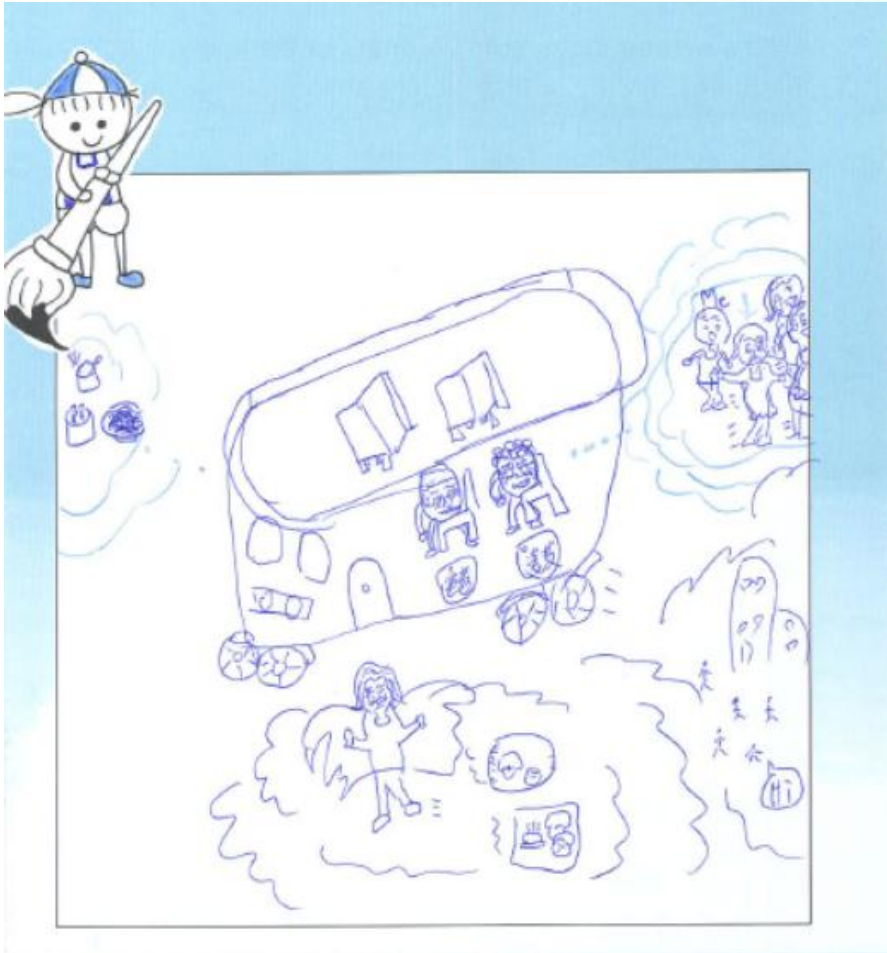


Mr. T (Bereaved) & his son



✚ Last session (July 14):

- Child counseling with games
- Reassessment after funeral completed
- At the present of his father
- Facilitate the way of connection with late mother
- Consolidation of the effective coping styles
- Debriefing father in the absent of child



可與他傾談癌症的人

可幫我解決問題的人

可傾訴心聲的人

可信賴的人

可幫我解決日常生活遇到問題的人

Information transition



Verbal
advice



Return
demonstration



Education
leaflet



Information

Information booklet & pamphlets



Information booklets



A practical
guide
何去何從



Bereavement
services for
adult
善別善生



Bereavement
services for
child
童心同行

Gift & grief workbooks



A special gift
for you
特别的你



Remembrance
for a loved one
新的一頁



An invisible
string
繫於無形

Five emotional love languages



- Words of Affirmation
- Quality Time
- Gifts
- Acts of Service
- Physical Touch

(Chapman, 1973)

Worden's four tasks of grieving

- To **accept** the reality of the loss
- To work **through** the pain of grief
- To **adjust** to a world without the deceased
- To find an enduring **connection** with the deceased in the midst of embarking on a **new life**

(Worden, 1991)



Outcomes



○ Paradigm shift ○○ Way of life ○○○ Informed decisions ○○○ Autonomous ○○○ Preferred care

Cultivate good palliative nursing practice



Aptitude + Attitude = Altitude