賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

BUILDING CAPACITY FOR END-OF-LIFE CARE IN HONG KONG

TRAINING KIT FOR HEALTHCARE PROFESSIONALS

策劃及捐助 Initiated and Funded by

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The Hong Kong Jockey Club Charities Trust
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CUHK Jockey Club Institute of Ageing

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Preface

Quality of death is one end of the spectrum of quality of life. However, there is an overemphasis on curative treatment and life prolongation rather than accepting life limitation and optimising quality of the remaining duration of life among healthcare professionals and members of the public. This quality gap is apparent in hospitals and the community. We need change, and the change agent is available.

The Jockey Club End-of-Life Community Care Project (JCECC) provided an opportunity to close this quality gap. The Chinese University of Hong Kong (CUHK) Jockey Club Institute of Ageing is one of the project partners. Our emphasis is put on nurturing healthcare professionals to provide end-of-life (EOL) care in hospitals and residential care homes for the elderly (RCHEs) so that the foundation for future service development by building a high quality and sustainable workforce can be established. This training kit compiles our training resources shared by different healthcare professionals in a series of training programmes for professional staff. It provides communication skills in EOL care and information of advance care planning (ACP), advance directive (AD), symptom management, etc. to raise competence among healthcare professionals to deal with death and dying.

On behalf of the Institute, I would like to express my sincere gratitude to the support by The Hong Kong Jockey Club Charities Trust. In particular, I would like to extend my appreciation to our training speakers for their time and effort. The Institute will continue to collaborate with various partners to contribute to EOL care in Hong Kong, thereby improving the quality of life of elderly patients.

Prof Jean WOO, MD, FRCP, FRACP
Director, CUHK Jockey Club Institute of Ageing
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About the Jockey Club End-of-Life Community Care Project

The population of Hong Kong is ageing rapidly. According to the Hong Kong Population Projections 2017–2066 conducted by Census and Statistic Department, the population aged 65 years or over is projected to rise from 1.16 million (16.6% of the total population) in 2016 to 2.37 million (31.1%) in 2036.[1] An increasing number of elderly people will suffer from various life-limiting conditions; thus the demand for end-of-life (EOL) care will be significantly elevated.

To address the evolving challenges, The Hong Kong Jockey Club Charities Trust earmarked HK$255 million to initiate the Jockey Club End-of-Life Community Care Project (JCECC) in 2016. The 6-year project aims at improving the quality of EOL care, enhancing the capacity of service providers and raising public awareness.

To help enhance EOL care in Hong Kong with special emphasis on the interface between social and medical systems, JCECC Project is a multidisciplinary, multi-institutional and cross-sectoral collaboration. Service models are being developed and shaped to provide holistic support to terminally ill elders in the community and elderly homes. The objective is to enable the elderly to improve their quality of life and have informed choices of care. The Trust's partners in JCECC include The University of Hong Kong Faculty of Social Sciences, CUHK Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, S.K.H. Holy Carpenter Church District Elderly Community Centre and St James' Settlement.

Partners:

Faculty of Social Sciences The University of Hong Kong 香港大學社會科學學院
香港中文大學賽馬會老年學研究所 CUHK Jockey Club Institute of Ageing
Hong Kong Association of Gerontology 香港老年學會
基督教靈實協會 HAVEN OF HOPE CHRISTIAN SERVICE 尊重生命‧改變生命
香港復康會 The Hong Kong Society for Rehabilitation
聖公會聖匠堂長者地區中心 S. K. H. HOLY CARPENTER CHURCH DISTRICT ELDERLY COMMUNITY CENTRE (由香港聖公會福利協會有限公司營運)
聖雅各福群會 St. James' Settlement

As one of the project partners of the JCECC Project, the CUHK Jockey Club Institute of Ageing has implemented a capacity building and education programme to address key issues in EOL care in light of medical ethics and to highlight the necessity of respecting the wishes of patients. Changing the mindset could complement new pathways and service models in hospitals, which are beneficial to patients and their relatives. We hope that the programme implemented in the community, RCHEs and the hospitals in the New Territories East Cluster (NTEC) of Hospital Authority (HA) will serve as a reference for other clusters.

Objectives of the Capacity Building and Education Programmes on End-of-Life Care

- To empower healthcare staff in hospitals and RCHEs settings in NTEC on the significance of quality EOL care
- To build capacity for the healthcare community and also patients, relatives and caregivers on quality EOL care, including medical ethics
- To implement quality EOL care models and practices in a hospital setting

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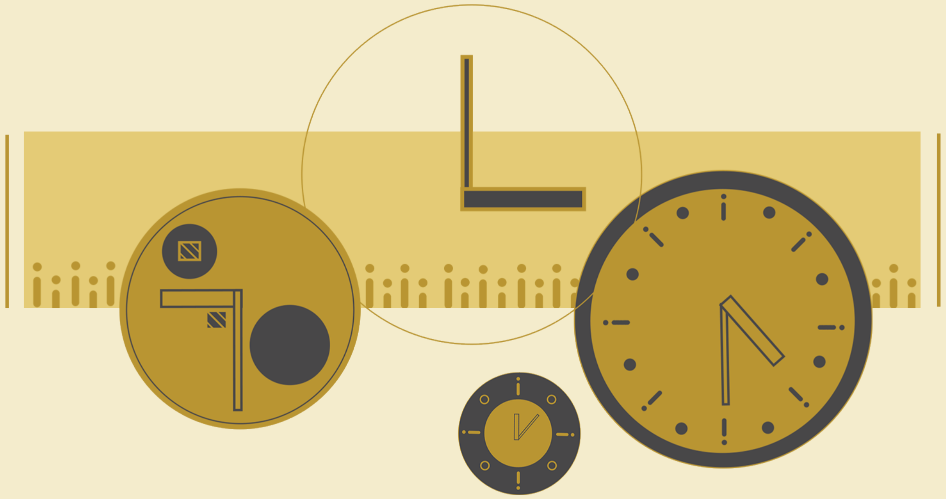
Abbreviations

ACP	Advance Care Planning
AD	Advance Directive
BiPAP	Bi-level Positive Airway Pressure
CGAT	Community Geriatric Assessment Team
COPD	Chronic Obstructive Pulmonary Disease
CPR	Cardiopulmonary Resuscitation
CUHK	The Chinese University of Hong Kong
DNACPR	Do-Not-Attempt Cardiopulmonary Resuscitation
EOL	End-of-Life
FEV1	Forced Expiratory Volume in One Second
HA	Hospital Authority
ICU	Intensive Care Unit
JCECC	Jockey Club End-of-Life Community Care Project
MDS-R	Moral Distress Scale-Revised
MRC	Medical Research Council
NLPRA	New Life Psychiatric Rehabilitation Association
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
NTEC	New Territories East Cluster
NYHA	New York Heart Association
RCHEs	Residential Care Homes for the Elderly
SICG	Serious Illness Conversation Guide
TENS	Transcutaneous Electrical Nerve Stimulation
UK	United Kingdom
US	United States
WHO	World Health Organization

Chapter 1



Introduction and Symptom Management of End-of-Life Care

1.1 Overview of End-of-Life Care in Hong Kong

In Hong Kong, acute medical and surgical wards in public hospitals are intended for acute curative management of ill patients and they are not generally well-designed for dying with dignity and privacy.[2] The Quality of Death Index by the Economist Intelligence Unit in 2015 showed that Hong Kong ranked 22nd in palliative care across the world in relation to quality, availability and affordability.[3] Hong Kong was way behind Western countries such as the United Kingdom (UK; 1st) and the United States (US; 9th), as well as other Asian neighbours, including Taiwan (6th) and Singapore (12th). This reveals that there is room for improvement and development of palliative care in Hong Kong and that most people have limited understanding about this topic.

	Rank / 80	Score / 100
Quality of Death overall score (supply)	**22**	**66.6**
Palliative and healthcare environment	28	50.4
Human resources	20	62.1
Affordability of care	=18	82.5
Quality of care	=20	81.3
Community engagement	=38	32.5

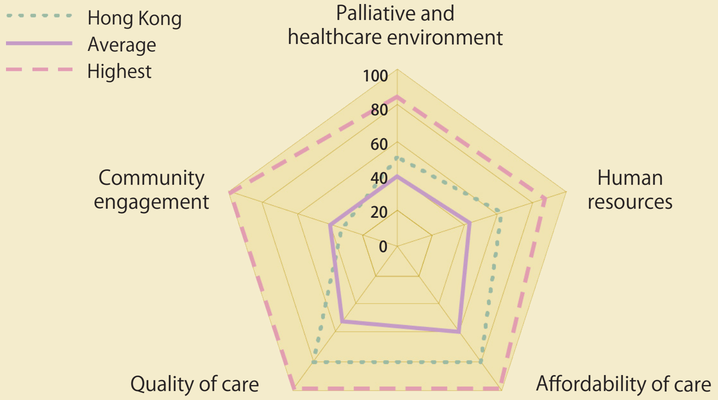


Figure 1. 2015 Quality of Death Index of Hong Kong

In view of increasing numbers of terminally ill patients requiring palliative and EOL care, the Hong Kong Government announced measures in 2017 Policy Address to improve the local palliative and EOL care services, such as raising the number of home visits by nurses, training staff in RCHEs and exploring the possibility to amend the law to enable dying in place.[4]

The HA issued Guidance for HA clinicians on Advance Directives in adults in 2010 and revised the guidance in 2014 and 2016.[5] They also published Guidelines on life-sustaining treatment in the terminally ill in 2015,[6] Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) in 2016[7] and Guidelines on Advance Care Planning in 2019.[8] Moreover, the HA Strategic Service Framework for Palliative Care was created in 2017 for guiding the enhancement of palliative care services over the next 5 to 10 years.[9]

However, lack of legislation on ADs in Hong Kong affects the development of EOL care. Although ADs are generally recognised under common law, they have not been legislated as part of the statute or case law in Hong Kong.[10] Members of public are not aware of ADs and do not prefer to make an AD due to a concern over a potential change of mind in the future;[11] in reality, they can actually change their preferred treatments at any time. From 2012 to 2018, only 5,561 patients with cancer or other advanced irreversible diseases signed ADs in public hospitals.[12] Private hospitals are also probably not provided with AD forms, which were designed by the HA and are only available in public hospitals.[10] In light of these concerns, the Government completed a three-month public consultation in December 2019 on the legislative proposal on ADs so as to improve the quality of EOL care in Hong Kong.

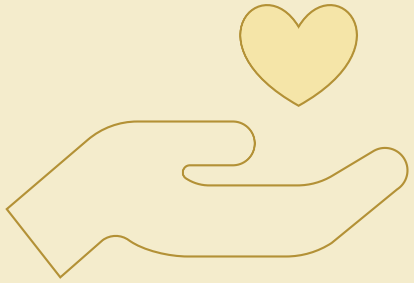
Besides, we are also facing a myriad of problems in this domain, such as overemphasis on curative treatment, lack of attention on EOL care for non-cancer patients, insufficient support for family carers and ineffective communication among patients, families and healthcare professionals. It is time to reflect on how we can improve the situation.

1.2 Basic Concepts of End-of-Life Care

Palliative care, EOL care and hospice care are common terms to describe care services for patients facing serious illness at the end stage of life. However, the emphases of these three terms are different.

Palliative Care

The World Health Organization (WHO) defines palliative care as an approach to improving the quality of life of patients, including adults and children who are facing life-threatening or life-limiting illness and their families/carers.[13] Palliative care aims at preventing and relieving the suffering of patients through early identification, assessment and treatment of pain and other physical, psychosocial or spiritual problems. The team approach in palliative care supports the patient in living as actively as possible and also supports the families/carers until bereavement. There is often a misconception that palliative care means EOL care and equals to 'giving up', and it is only for patients at the final stage of their illness.[9,11] However, palliative care should be provided alongside the curative treatment to support the patient at any stage of a serious illness and to relieve the symptoms of both the disease and the treatment (i.e. depression, pain, fatigue, dyspnoea, etc.).[9]

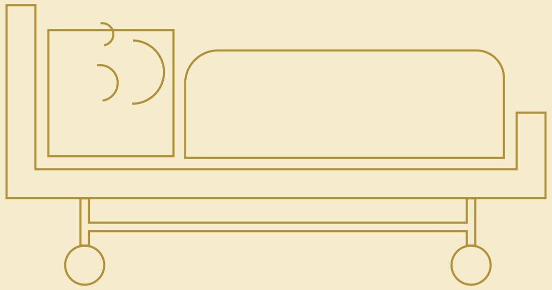


End-of-Life Care

EOL care is provided to people who are likely to die within the next 6 to 12 months, including those whose death is imminent (expected within a few hours or days) and those with:[14]

- Advanced, progressive, incurable conditions (e.g. advanced cancer, motor neuron disease)
- General frailty and co-existing conditions where patients are expected to die within 6 to 12 months
- Existing conditions where they are at risk of dying from a sudden acute crisis in their condition

EOL care aims at allowing a more peaceful and comfortable death during the patient's last journey and at improving the quality of life for patients/families through pain relief, symptom control, and psychosocial and spiritual support. It comprises a range of medical and social services, including disease-specific interventions as well as palliative and hospice care for those patients who are approaching the end of life.[15]



Hospice Care

Hospice care focuses on the very end-of-life period (i.e. generally with a prognosis of 6 months or less to live) or after curative care has been exhausted.[9] The goal of hospice care transfers from increasing life expectancy of patients to improving quality of life for patients at the end stage of life. Hospice care can include palliative care and comprehensive biomedical, psychosocial and spiritual support.[15] Hospice care also supports family members dealing with the complex consequences of illness, disability and ageing at the end of life.[15]

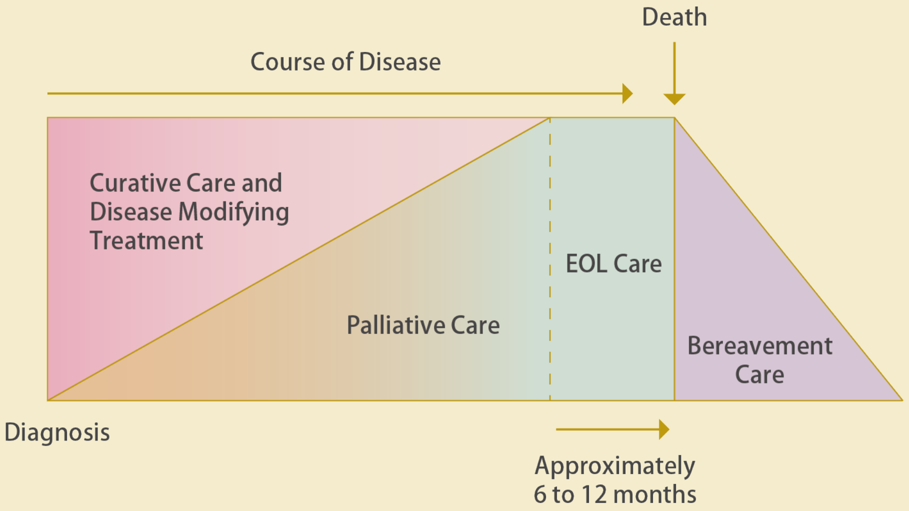


Figure 2. Course of Disease and Healthcare Needs

1.3 Symptom Management

Over the past years, symptom management has focused mainly on cancer patients, but little attention has been paid to patients with other life-threatening diseases, such as end-stage renal failure or advanced heart failure.[16] Similar to cancer patients, non-cancer patients also experience clinical symptoms, such as pain, delirium, cognitive impairment, depression, dyspnoea, fatigue, nausea, constipation and insomnia, as well as great suffering and distress.[16]

Lack of proper management of these symptoms can affect the quality of life of these patients and family members, and good symptom control for patients near the end of life is essential to reduce the negative impacts for patients and families/carers.

1.3.1 Principles of Symptom Management[17]

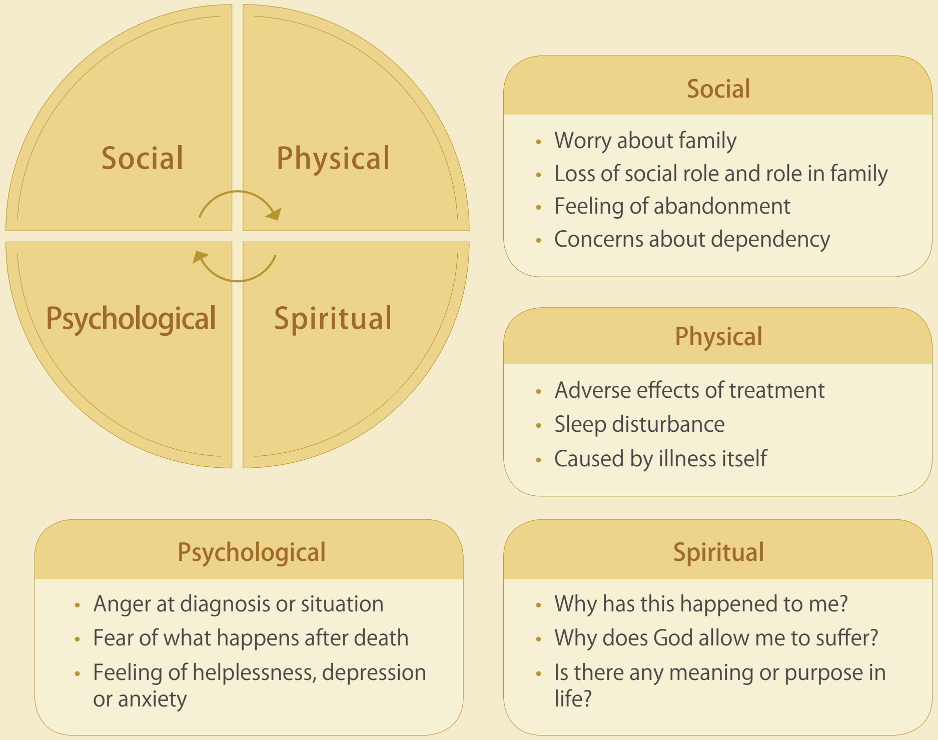
- Consider the 'whole patient'. Symptoms are not purely physical or psychological, and all symptoms and treatments have an effect on patients, their family and friends.
- Evaluate symptoms thoroughly and regularly. Consider potential reversible causes and causes other than the underlying condition. Also consider the impact of the symptom on the patient's quality of life.
- Communicate effectively. Explain in simple terms and avoid medical jargon. Discuss treatment options with patients and their families, and involve them in the management plan.
- Keep drug treatments as simple as possible.
- Consider non-drug treatments to help relieve symptoms, e.g. repositioning, complementary therapies, etc.
- Keep other staff informed. Establish good communication within the multidisciplinary team.

1.3.2 Pain Control

Pain is one of the most common symptoms for patients near the end of life. Pain can be cancer-related, treatment-related (e.g. mucositis or fibrosis post-radiotherapy), debility-related (e.g. muscle/joint stiffness or pressure sore) or from concurrent disorders (e.g. arthritis or gout).[18] It is a sensory perception and can be a subjective experience. Pain control can be challenging for healthcare professionals because it is difficult to evaluate without understanding the 'total pain' concept and the proper use of analgesics. If pain is inadequately treated, it can cause functional impairment and increase the risk of depression or anxiety.[19]

Total Pain Concept

Dame Cicely Saunders coined the term 'total pain'.[20] Pain can be understood as having physical, psychological, social, emotional and spiritual components (Figure 3). The combination of these elements is believed to result in a 'total pain' experience that is personalised and individualised to a patient's particular situation. The concept of 'total pain' can serve as a basis for pain assessment. A complete and thorough assessment of different dimensions can give an accurate picture of the patient's situation (Figure 4).



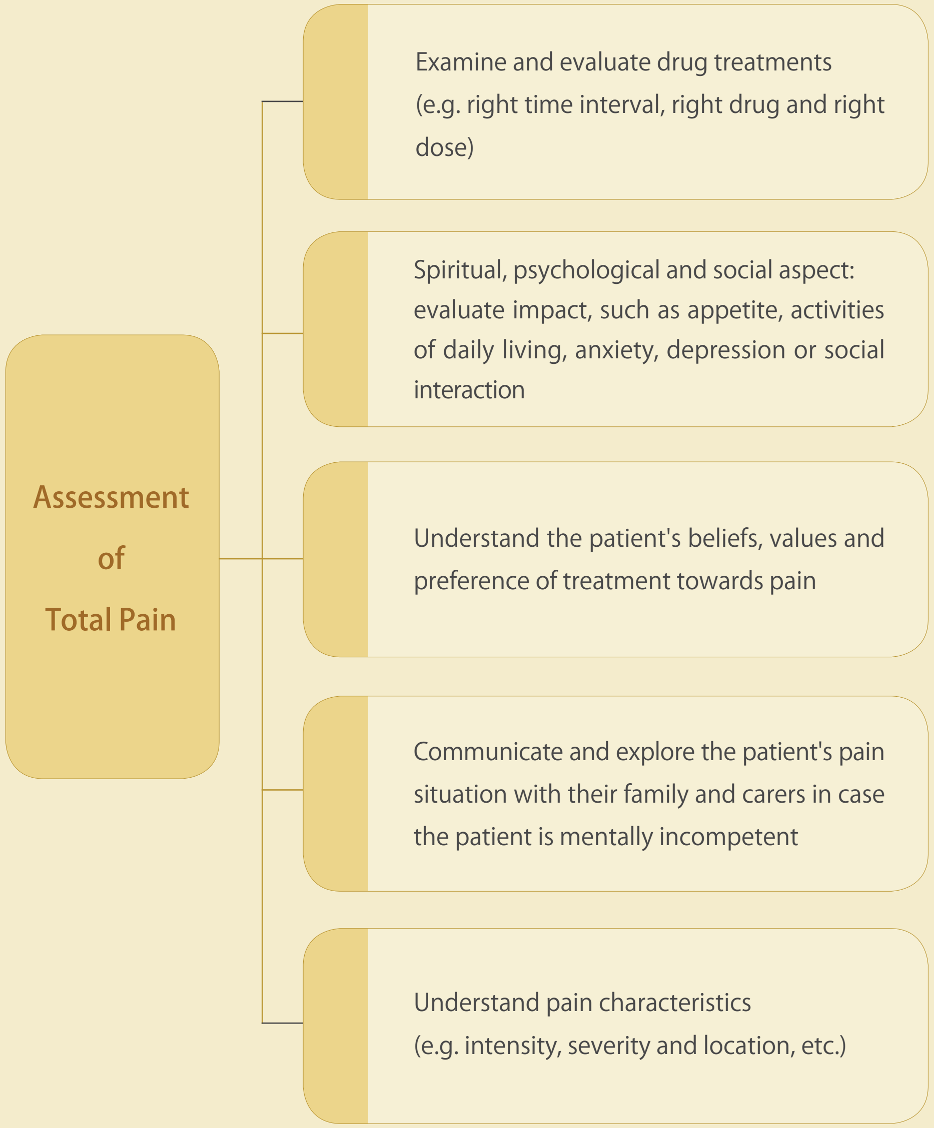
Social
- Worry about family
- Loss of social role and role in family
- Feeling of abandonment
- Concerns about dependency

Physical
- Adverse effects of treatment
- Sleep disturbance
- Caused by illness itself

Psychological
- Anger at diagnosis or situation
- Fear of what happens after death
- Feeling of helplessness, depression or anxiety

Spiritual
- Why has this happened to me?
- Why does God allow me to suffer?
- Is there any meaning or purpose in life?

Figure 3. Total Pain Concept



Assessment of Total Pain

- Examine and evaluate drug treatments (e.g. right time interval, right drug and right dose)
- Spiritual, psychological and social aspect: evaluate impact, such as appetite, activities of daily living, anxiety, depression or social interaction
- Understand the patient's beliefs, values and preference of treatment towards pain
- Communicate and explore the patient's pain situation with their family and carers in case the patient is mentally incompetent
- Understand pain characteristics (e.g. intensity, severity and location, etc.)

Figure 4. Assessment of Total Pain

Pain Assessment Tool

'OPQRST' to assess pain

OPQRST is a useful mnemonic to learn about the patient's pain and help assess the intensity, severity and location of the pain.[21]

- **Onset:** Ask "did the pain start suddenly or gradually get worse and worse?"
- **Precipitating or Palliating Factors:** Ask "does anything make the pain better or worse?"
- **Quality of Pain:** Ask "what words would you use to describe your pain?" or "what does your pain feel like?"
- **Region or Radiation of Pain:** Ask "point to where it hurts the most. Does your pain go anywhere from there?"
- **Severity:** Pain is subjective and differs for each individual. Ask "how would you rate your pain on a scale of 0 to 10?". Have an open mind for any response from 0 to 10 by adopting Wong–Baker Face Pain Rating Scale,[22] Numerical Rating Scale (Figure 5),[23] and Pain Assessment in Advanced Dementia Scale (Figure 6),[24] etc. Regular assessment and using a consistent tool is important.
- **Temporal Nature:** Ask "how long have you had the pain?"

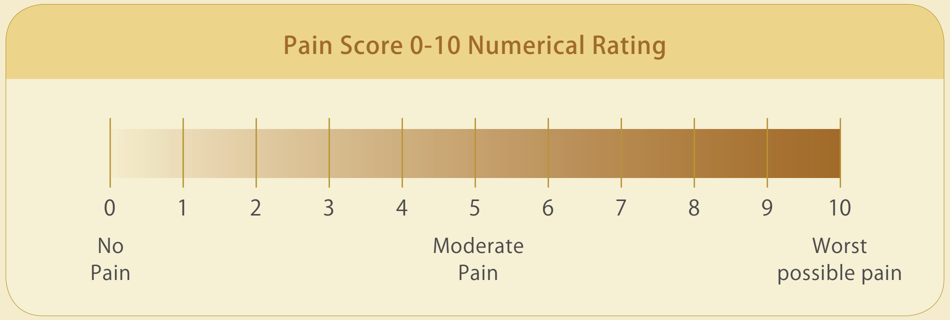


Figure 5. Numerical Rating Scale

Behaviour	0	1	2	Score
Breathing Independent of vocalisation	Normal	Occasional laboured breathing Short period of hyperventilation	Noisy laboured breathing Long period of hyperventilation Cheyne-Stokes respirations	
Negative vocalisation	None	Occasional moan or groan Low-level speech with a negative or disapproving quality	Repeated troubled calling out Loud moaning or groaning Crying	
Facial expression	Smiling or inexpressive	Sad Frightened Frown	Facial grimacing	
Body language	Relaxed	Tense Distressed pacing Fidgeting	Rigid Fists clenched Knees pulled up Pulling or pushing away Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
			Total Score	

Figure 6. Pain Assessment in Advanced Dementia Scale. Total score ranges from 0–10 (1–3=mild pain, 4–6=moderate pain, 7–10=severe pain).

Pain Management Options

There are a variety of pain relief options available to patients. Medications are important but there is more than one tool in pain management. Non-drug treatments, including relaxation techniques, music, acupuncture or massage, can all be useful in helping to manage pain as well as allowing patients to take less medication.

(i) Drugs Treatment

Upon completion of comprehensive pain assessment of patients, healthcare professionals can refer the WHO three-step ladder approach to pain management in people with serious illness (Figure 7).[25] If pain occurs, there should be prompt oral administration of drugs in the following order: (1) non-opioids, (2) mild opioids, as necessary and (3) strong opioids, until the patient is free of pain. Adjuvant drugs such as antidepressants and anticonvulsants should be used if necessary. To maintain freedom from pain, drugs should be given 'by the clock', i.e. every 3 to 6 hours rather than 'on demand'. However, opioids can have unwanted side effects, which are often treated with other medications. In addition, the three-step ladder approach is generally used for cancer pain. For patients experiencing chronic non-cancer pain, the healthcare professionals should note the followings:[26]

- Acquire informed consent prior to initiating opioid use for chronic non-cancer pain and discuss the potential benefits, adverse effects and complications to patients for making decision
- Monitor chronic non-cancer pain patients using opioid therapy for their response to treatment and adjust treatment accordingly
- Offer a trial of opioids to patients with chronic non-cancer pain only after the patients have been optimised on non-opioid therapy including non-drug treatments

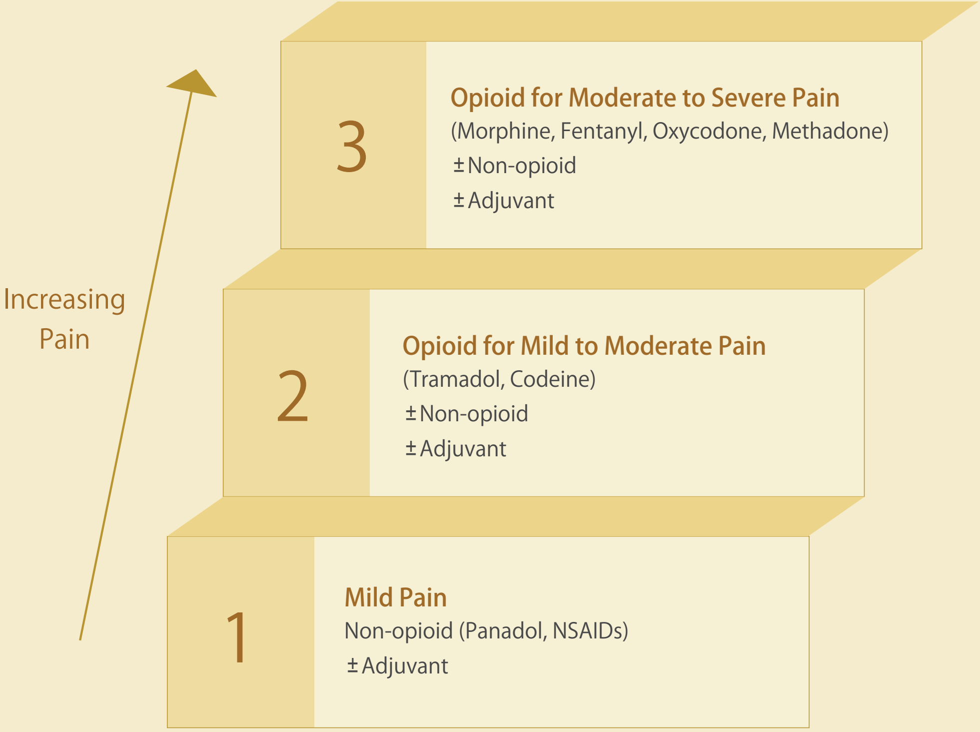


Figure 7. Three-step WHO Pain Ladder

Adverse Effects of Opioids[18]

Adverse effects	Management/remarks
Constipation	• All patients will require regular prophylactic laxatives, unless they have diarrhoea • Increase laxatives with increasing dose • Usually combine stimulant and softener laxatives
Nausea and vomiting	• Occurs in 30 to 50% of patients • Wears off within the first few days • Give antiemetics and reduce after few days
Drowsiness and confusion	• Consider lowering dose • Work up for other potential causes • Sleepiness wears off after 24 to 48 hours • Always comfort and reassure patients
Respiratory depression	• Very rare if doses titrated properly • Caution in frail elderly and renal/liver impairment • Safe in Chronic Obstructive Pulmonary Disease (COPD)
Other potential side effects	• Dry mouth, pruritus, sweating, urine retention, postural hypotension

Notes:

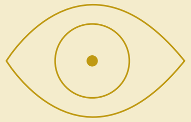
- Tolerance and physical dependence may occur to some extent but are not very common
- No evidence of addiction if used appropriately for relieving pain

Opioid Toxicity[18]

Opioid toxicity can occur with too rapid dose titration, renal impairment or pain which is not opioid-responsive.

Warning Signs

» Pinpoint pupils

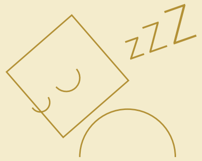


» Hallucinations (usually visual)

» Myoclonic jerks

» Slow respiratory rate

» Increasing drowsiness



Management

» Stop the opioid or reduce dose

» Rotate to alternative opioid

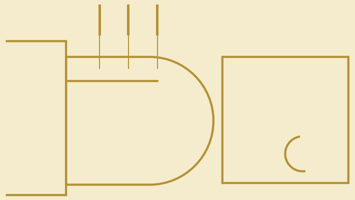
» Naloxone IV only if severe toxicity

Adjuvant Drugs[27]

Adjuvant drugs	Function	Adverse effects
Steroids (e.g. Dexamethasone)	Treat conditions such as arthritis, blood/hormone/immune system disorders, allergic reactions, certain skin and eye conditions, breathing problems, certain bowel disorders and certain cancers.	Gastrointestinal upset, headache, dizziness, trouble sleeping, increased appetite or weight gain, etc.
Anticonvulsants (e.g. Gabapentin, Epilim)	Prevent and control seizures. It is also used to relieve nerve pain.	Nausea, vomiting, drowsiness, dizziness, loss of coordination or tiredness, etc.
Antidepressants (e.g. Amitriptyline, Nortriptyline, Desipramine)	Treat mental/mood problems such as depression. It may help improve mood and feelings of well-being, relieve anxiety and tension, help sleep and increase energy level.	Drowsiness, dizziness, dry mouth, blurred vision, constipation, weight gain or trouble urinating, etc.
Anxiolytic (e.g. Ativan, Xanax)	Use to treat anxiety and panic disorders.	Drowsiness, sedations, confusion or dependence, etc.
Antispastic (e.g. Baclofen, Diazepam, Hyoscine)	Treat muscle spasms and help relax the muscles.	Drowsiness, weakness, tiredness or trouble sleeping, etc.

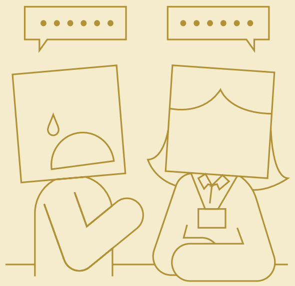
(ii) Non-Drug Treatments

- Palliative Radiotherapy
- Physiotherapy
    - Acupuncture
    - Massage
    - Transcutaneous Electrical Nerve Stimulation (TENS)
    - Heat / cold application



- Comfort Therapy
    - Companionship
    - Exercise
    - Meditation
    - Music, art, or drama therapy
    - Positioning

- Psychosocial Therapy
    - Individual counselling
    - Family counselling
    - Group counselling
    - Pastoral counselling



1.3.3 Dyspnoea

Dyspnoea, or shortness of breath, is the perception that the breathing is inadequate and difficult.[28] It is one of the most common symptoms for patients near the end of life. The possible causes of dyspnoea include:[18]

- Airway obstruction
- Bronchospasm
- Hypoxemia
- Pleural effusion
- Pneumonia
- Pulmonary oedema
- Arrhythmia
- Pulmonary embolism
- Thick secretions
- Anaemia
- Ascites
- Anxiety
- Collapse of lung

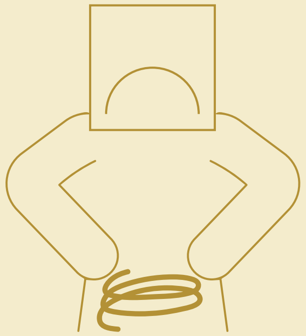
Recognition of Symptoms and Signs of Dyspnoea

Symptoms of dyspnoea can be reported by patient. Dyspnoeic signs can be detected through observing respiratory rate, oxygen saturation, blood gas and physical signs, including cyanosis, pursed lip breathing, wheezing, suprasternal notch retraction, restlessness and use of accessory muscles.

Management of Dyspnoea[18]

Treatment	Management/remarks
Oxygen	• Benefit hypoxic patients, but some functional breathlessness may have symptomatic benefit • Continuous use for COPD/lymphangitis • Intermittent use for exertion or panic
Opioids	• Established usefulness in breathlessness in malignant diseases • Tolerated in some COPD, with carbon dioxide retention if doses are carefully titrated • Small doses • Ethically acceptable
Benzodiazepines (Lorazepam)	• Slight benefit on the relief of dyspnoea for advanced cancer or COPD • Consider as a second-line or third-line treatment • More helpful if anxiety is present
Non-drug treatments	• Behavioural approaches, e.g. relaxation or distraction • Fan and flow of fresh air • Eliminate environmental irritants • Psychosocial counselling

1.3.4 Constipation



Constipation is very common in people living with a terminal illness. When someone is terminally ill, their eating habits, fluid intake, mobility and medications may change, all of which can contribute to constipation. It can be complex and cause emotional distress and physical discomfort. Signs of constipation can include opening the bowels less frequently than normal, passing hard stools or having to strain when passing stools.[29]

Constipation can lead to other symptoms or issues, including:[29]

- Nausea and vomiting
- Abdominal pain and bloating
- Overflow diarrhoea
- Faecal impaction (build-up of faeces in the rectum leading to blockage)
- Bowel obstruction
- Urinary retention
- Embarrassment and anxiety
- Confusion
- Restlessness and agitation

Causes of Constipation[18]

- Reduced appetite and fluid intake
- Lack of exercise and upright posture to promote colonic activity
- Poor abdominal/diaphragm/pelvic muscle strength
- Dehydration and fluid loss, e.g. due to vomiting
- Use of opioids
- Co-existing depression, neurological and metabolic problems

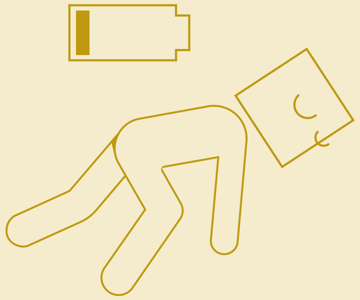
Management of Constipation[18,29]

- Encourage oral fluid intake
- Encourage the patient to eat regular meals. If appropriate, advise them to increase their fibre intake. High-fibre foods include fruit and vegetables, beans and pulses, and wholegrain cereals.
- Encourage exercise if it is appropriate for patient; even gentle activity can help to stimulate the bowel
- Massage the abdomen in a circular motion to encourage stimulation
- Record bowel motions regularly
- Increase laxatives if opioid doses increased
- Avoid blanket treatment (i.e. increasing softeners for already soft faeces)
- Make sure that patients have privacy in the toilet environment. If they need help going to the toilet, ask them how they would like healthcare professionals to help them and allow them as much privacy and dignity as possible.

Three Basic Questions in Management of Constipation[18]

1. Is the patient constipated?
2. Where is obstruction – rectum or colon?
3. Are faeces soft or hard?
   (a) Soft faeces in rectum
      - Add stimulant or bisacodyl (Dulcolax) suppository
   (b) Hard faeces in rectum
      - Use glycerine suppository or increase softener
   (c) Empty rectum
      - Confirm patient has true constipation
      - Examine for colonic loading
      - Increase stimulant, softener or enema

1.3.5 Fatigue



Fatigue is the most frequent distressing symptom associated with serious illness. Fatigue is a persistent, subjective feeling of tiredness, weakness or lack of energy related to advanced diseases and, despite often being under-recognised by healthcare professionals, it has effects on physical function, cognitive ability and social, emotional and spiritual well-being.[30] Moreover, fatigue can influence the patient's decision-making about future treatment and may lead to refusal of beneficial treatment.[30]

Causes of Fatigue[31]

- Anaemia
- Sleep disturbance
- Treatments
  (especially radiotherapy and chemotherapy)
- Medicines
  (e.g. opioids and antihistamines)
- Depression
- Poor nutrition
- Illness
  (e.g. cancer, heart and lung disease, kidney failure and hypothyroidism)

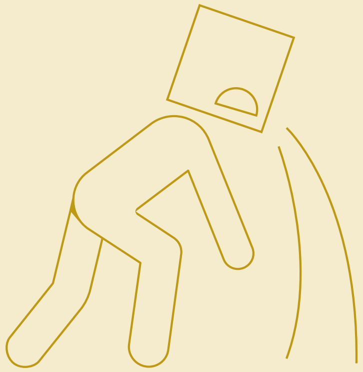
Assessment of Fatigue[32]

- Determine to what extent fatigue interferes with the patient accomplishing his/her daily activities
- Review all prescriptions and non-prescription medications
- Assess hydration and the patient's overall oral intake
- Assess for sleep disturbance and insomnia related to uncontrolled pain or other uncomfortable symptoms
- Determine whether the cause is reversible or irreversible
  - Reversible causes include medications (antihypertensives, cardiac medications, diuretics, etc.), dehydration, anaemia, electrolyte imbalance and disturbed nocturnal sleep
  - Irreversible causes are related to terminal disease process

Management of Fatigue[30,31]

- Use an activity/fatigue diary to identify precipitants and timing of symptoms
- Use energy conservation strategies for patients:
  - Consider a self-management plan, set priorities and delegate tasks
  - Pace activities and attend to one activity at a time
  - Schedule activities at times of peak energy and conserve energy for valued activities
  - Eliminate non-essential activities
  - Occupational therapy referral for advice on minimising energy expenditure and appropriate aids/equipment
- Physical activity and exercise:
  - Recommend an appropriate level of exercise to patients
  - Consider physiotherapy referral to ensure exercises are tailored to individual needs, particularly for those patients who have advanced disease or are experiencing effects of treatments (e.g. anaemia, osteoporosis/bone metastases, falls)
- Psychosocial interventions:
  - Stress/anxiety management
  - Relaxation/complementary therapy
  - Sleep pattern advice (e.g. hot drink at night and avoid stimulants)
- Can consider using medicines such as steroids to improve appetite and energy levels

1.3.6 Nausea and Vomiting



Nausea and vomiting are commonly associated with many advanced diseases and also may be the result of therapeutic interventions.[32] Nausea is expressed as an unpleasant subjective sensation as a result of stimulation of the gastrointestinal lining, the chemoreceptor trigger zone in the base of the fourth ventricle, the vestibular apparatus or the cerebral cortex.[32] Vomiting is an observable neuromuscular reflex that constitutes a final common pathway after stimulation of one or more of these regions.[32] Nausea and vomiting often occur together but they can be experienced on their own. Both symptoms can be very disruptive and distressing for patients and families.

Causes of Nausea and Vomiting[33]

- Constipation
- Anxiety
- Bowel obstruction
- Chemotherapy
- Inflammation or ulcers in the stomach
- Illness affecting the brain, such as metastases
- Metabolic causes (e.g. hypercalcaemia and kidney failure)
- Medicines, including opioids and non-steroidal anti-inflammatory drugs (NSAIDs)

Assessment of Nausea and Vomiting[33]

Nausea and vomiting can be assessed by physical examination and blood and urine tests. Healthcare professionals can also ask the patient or family for the following information:

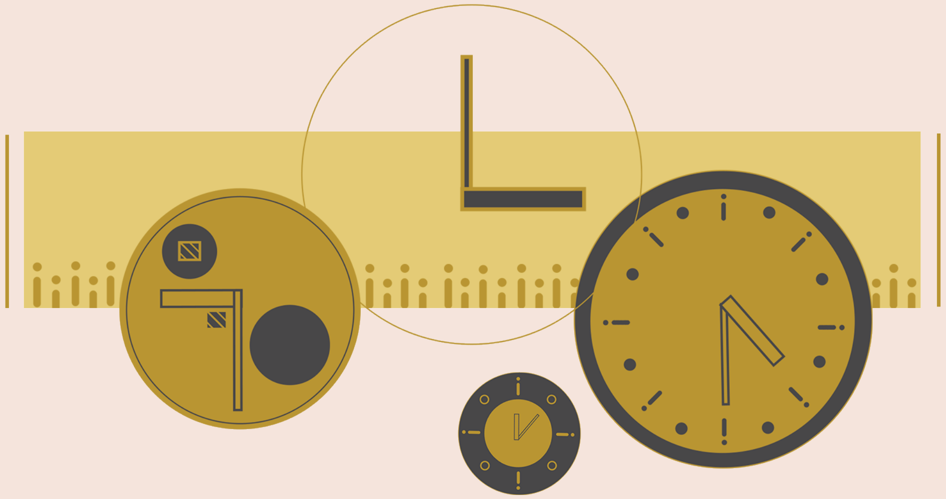
- How often do they feel sick or are being sick?
- Does anything make the nausea or vomiting better or worse?
- What medicines are they taking?
- What is their bowel habit like?
- How much do they manage to eat and drink?
- Do they have any worries or concerns that could contribute to anxiety?

Management of Nausea and Vomiting[33]

- Encourage eating small snacks rather than large meals
- Give antiemetics (e.g. Metoclopramide, Haloperidol, Prochlorperazine, etc.)
- Offer cool fizzy drinks
- Suggest eating cold food instead of hot food and avoid greasy or spicy food
- Provide a calm and reassuring environment
- Make sure the patient is positioned comfortably
- Encourage the patient to join in relaxing activities, such as listening to music or practising breathing exercises that can help manage anxiety
- Complementary therapy (e.g. acupuncture)
- Allow the patient to express any worries or concerns they may have

BUILDING CAPACITY FOR
END-OF-LIFE CARE
IN HONG KONG
TRAINING KIT FOR HEALTHCARE PROFESSIONALS

Chapter 2



Serious Illness Conversation

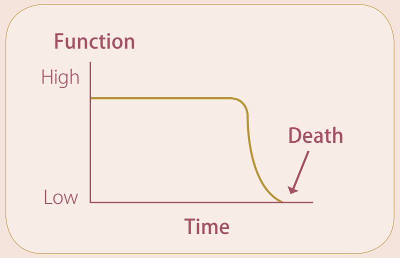
2.1 Identifying Patients Approaching the End of Life

Earlier identification of patients in final stage of life is important because it can lead to earlier anticipation of needs, better planning, reduced hospital admissions and tailoring care to patients' wishes.[34] This in turn can trigger specific active supportive care, such as clarifying patients' needs, and offering ACP discussions to ensure patients receive better coordinated care in their end stage of life.

The trajectories of illness below reflect the three main causes of expected death:[35,36]

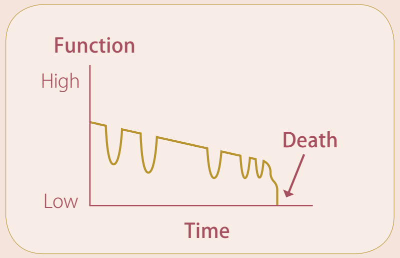
Rapid predictable decline

- **e.g.** cancer
- **Time:** often a few years, but decline usually over a few months



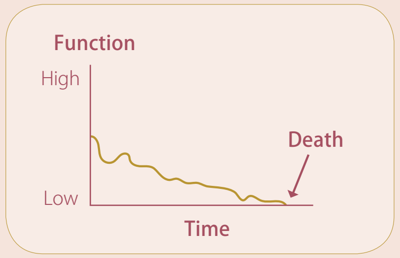
Erratic unpredictable

- **e.g.** organ failure (mostly heart and lung failure)
- **Time:** 2 to 5 years, but death usually seems sudden



Gradual decline

- **e.g.** frailty and dementia
- **Time:** quite variable (up to 6 to 8 years)



Proactive identification guidance enables healthcare professionals to identify earlier patients approaching the end of their life who may require additional supportive care.[34]

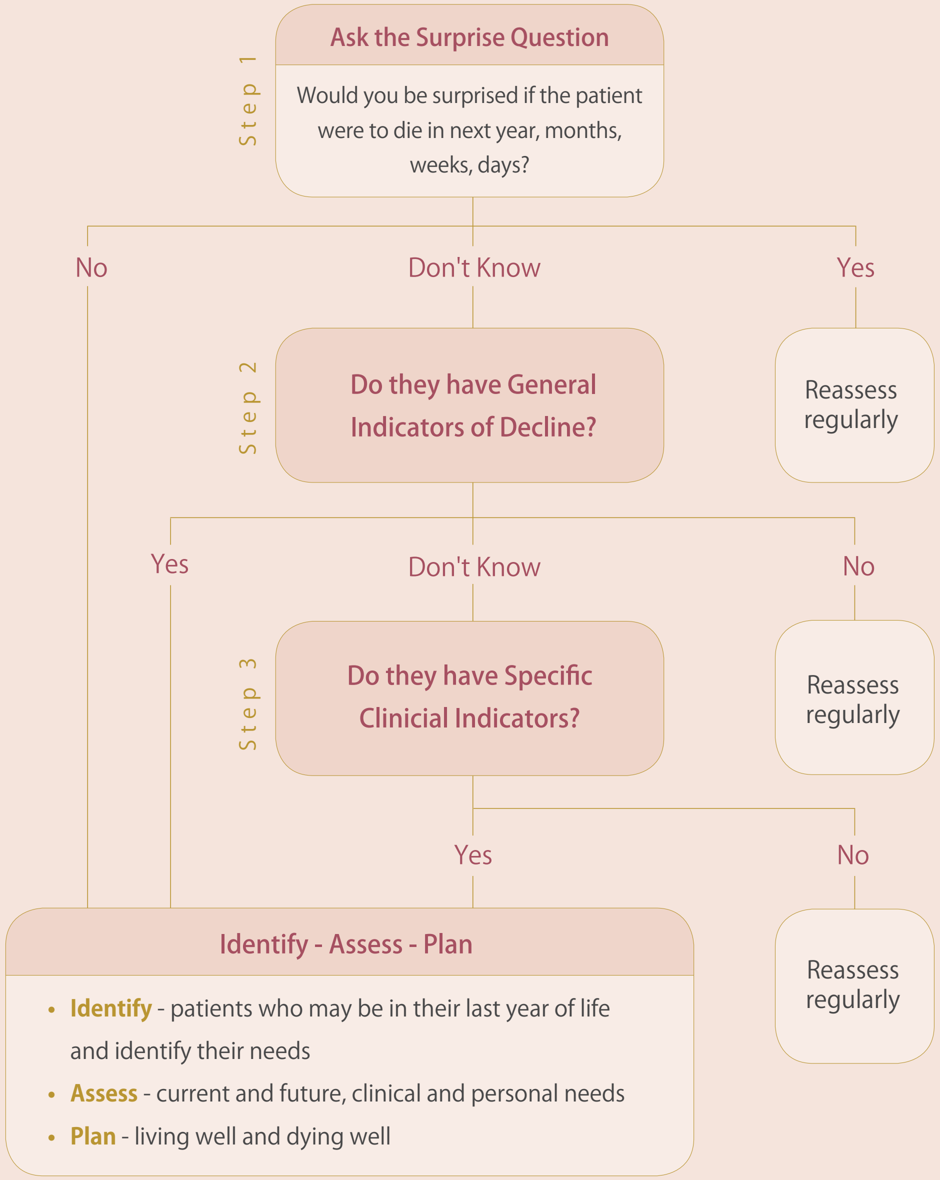
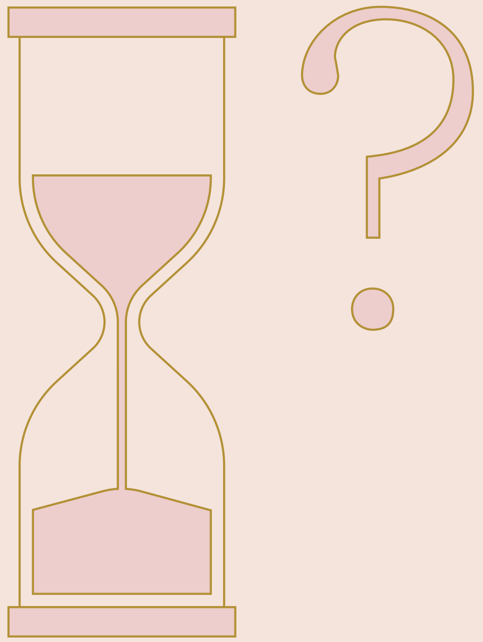


Figure 8. Proactive Identification Guidance

If the answer in question ‘would I be surprised if the patient were to die in the next 12 months’ is ‘No’ (Step 1), it means that the patient is frail or has advanced progressive disease. General indicators of decline (Step 2) and specific clinical indicators (Step 3) may include two or more unplanned admissions in the last 6 to 12 months, persistent symptoms despite optimal therapy, secondary organ failure arising from an underlying condition and poor performance status. Once identified, healthcare professionals can begin to assess the needs and wishes of patients.



Step 1

The Surprise Question[34]

To help answer the surprise question in Step 1, healthcare professionals can consider a range of clinical, social and other factors to obtain a whole picture of deterioration.

Step 2

General Indicators of Decline[34]

- Repeated unplanned hospital admissions
- General physical decline, increasing dependence and support
- Decreased response to treatments and decreased reversibility
- Patients choose no further active treatment and focus on quality of life
- Progressive weight loss over 10% in past 6 months
- Presence of significant multi-morbidities
- Advanced disease – unstable, deteriorating and complex symptom burden
- Decreased activity (e.g. in bed or in chair 50% day)

Step 3

Specific Clinical Indicators Related to Three Trajectories[34]

1. Cancer

- Persistent symptoms despite optimal palliative oncology
- Deteriorated functional ability and performance status due to metastatic cancer, multi-morbidities or not amenable to treatment (e.g. patients spending more than 50% of time in bed or lying down, prognosis is estimated to be in months)

2. Organ failure

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

At least two of the following indicators:

- Recurrent hospital admissions (at least three admissions in last year due to COPD)
- Fulfil criteria of long-term oxygen therapy
- Assessed to be severe (e.g. Forced Expiratory Volume in One Second (FEV1) <30% predicted, persistent symptoms despite optimal therapy, etc.)
- Medical Research Council (MRC) Grade 4 or 5 dyspnoea – shortness of breath after 100 metres on level
- Other factors (e.g. anorexia, right heart failure, cachexia, >6 weeks of steroids in preceding 6 months, etc.)

HEART FAILURE

At least two of the following indicators:

- Repeated admissions with heart failure (three admissions in last 6 months or a single admission aged over 75)
- Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy
- New York Heart Association (NYHA) Heart Failure Class III or IV with ongoing symptoms despite optimal heart failure therapy – shortness of breath at rest on minimal exertion
- Additional features include hyponatraemia <135 mmol/l, anaemia, declining renal function, etc.

KIDNEY DISEASE

Stage 4 or 5 chronic kidney disease where condition is deteriorating with at least two of the following indicators:

- Repeatedly unplanned admissions (more than three admissions within 12 months)
- Difficult physical or psychological symptoms that have not responded to specific treatments
- Patients with poor tolerance of dialysis with change of modality
- Symptomatic renal failure in patients who have chosen not to dialyse (e.g. nausea and vomiting, pruritus, anorexia or reduced functional status, etc.)

LIVER DISEASE

- Contraindication for liver transplantation
- Hepatocellular carcinoma
- Advanced cirrhosis with complications, including:
    - Encephalopathy
    - Refractory ascites
    - Other adverse factors (e.g. malnutrition, severe comorbidities or hepatorenal syndrome)

PARKINSON'S DISEASE

- Drug treatment is less effective or increasingly complex regime of drug treatments
- Psychiatric signs (e.g. depression, hallucinations, psychosis or anxiety)
- Reduced independence and need for help with daily living
- Dyskinesias, mobility problems and falls
- Similar pattern to frailty (see below)

GENERAL NEUROLOGICAL DISEASE

- Symptoms are complex and difficult to control
- Swallowing problems leading to recurrent aspiration pneumonia, sepsis or respiratory failure
- Speech problems such as increasing difficulty in communication and progressive dysphasia
- Progressive deterioration in physical or cognitive function despite optimal therapy

MOTOR NEURONE DISEASE

- Increased cognitive difficulties
- First episode of aspirational pneumonia
- Low vital capacity (e.g. below 70% predicted spirometry)
- Rapid decline in physical status
- Communication difficulties
- Mobility problems and falls
- Weight loss
- Significant complex symptoms and medical complications

3. Frailty and Dementia

FRAILTY

- Multiple morbidities
- Deteriorated performance score
- Weakness, weight loss, exhaustion
- Slow walking speed (e.g. take more than 5 seconds to walk 4 metres)
- Low physical activity

DEMENTIA

- Not able to walk without assistance
- Urinary and faecal incontinence
- No consistently meaningful conversation
- Low Barthel score
- Unable to perform activities of daily living
- Plus any of the following:
  - Weight loss
  - Urinary tract infection
  - Severe pressure sores – Stage 3 or 4
  - Recurrent fever
  - Reduced oral intake
  - Aspiration pneumonia

Finally...

After reviewing the triggers and identifying the patients approaching the end of life, healthcare professionals **can initiate serious illness conversation** to patients and their families.

2.2 Initiating Serious Illness Conversations with Patients and Family Members

2.2.1 Patient's Perspectives on EOL Care

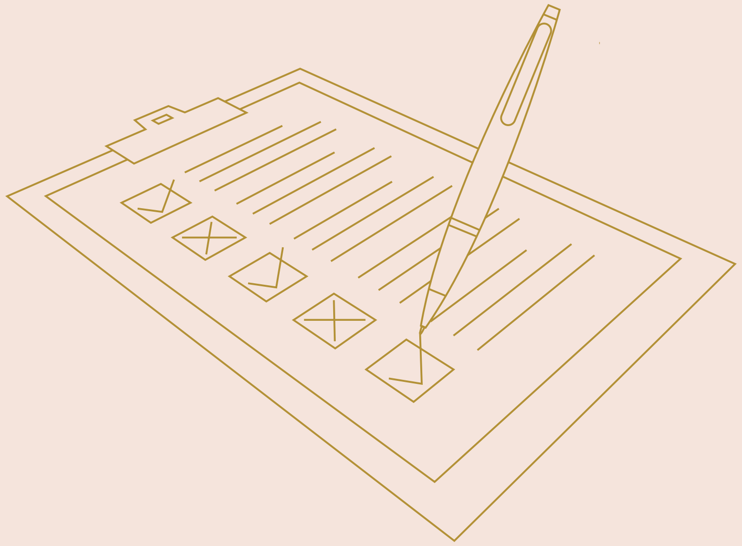
Good Death

Understanding the patient's and their family members' perspectives on 'good death' and identifying their most significant concerns can make it easier for healthcare professionals to initiate serious illness conversation. Previous literature has laid down the concept of a 'good death', which includes retaining control of what happens; having dignity and privacy; pain relief and symptom control; having access to spiritual or emotional support; having time to say goodbye; leaving when it is time to go instead of having life prolonged pointlessly; and knowing when death is coming and understanding what can be expected.[37] In Hong Kong, a survey on EOL care options in the community was conducted in 2011.[38] The results of 1,015 completed questionnaires showed that the five most important attributes of a 'good death' were:

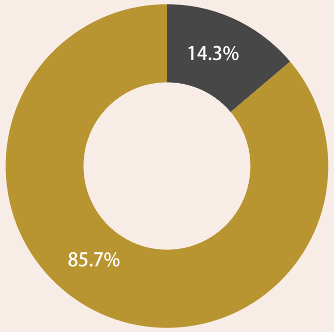
Priority	Attributes of a 'good death'
1	No acute suffering at the moment of death
2	Difficult symptoms under control
3	Knowing one's disease and prognosis
4	Not being a burden to family members
5	Allowing family members to prepare one's death

Knowledge, Attitudes and Preferences towards EOL Care

A population-based telephone survey of 1,067 adults regarding knowledge, attitudes and preferences of AD and EOL care was conducted by the Jockey Club School of Public Health and Primary Care of CUHK in 2016.[11] Study found that there was a great preference to have autonomy over their own EOL care among the Hong Kong general population despite low awareness and knowledge of AD. The general population also had a greater preference for receiving palliative care at the end stage of life that gives comfort and alleviates pain and discomfort, and not prolongation of life.



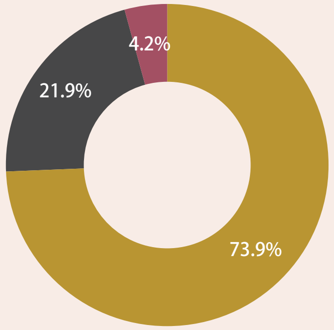
Knowledge, Attitudes and Preferences towards AD and EOL Care among the Study Participants



Heard of AD

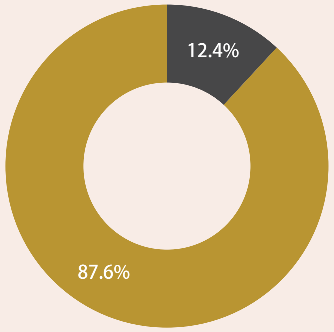
⬛ Yes

🟨 No



It is a good approach to make an advance decision when being diagnosed to be terminally ill on whether to continue life-sustaining treatment before becoming mentally incompetent

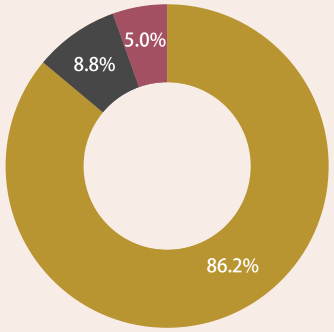
🟨 Agree ⬛ Not sure / Neutral 🟥 Disagree



If you were being diagnosed to be terminally ill, you would prefer to...

⬛ Prolong your life as much as possible even with pain, discomfort and suffering

🟨 Receive appropriate palliative care that does not necessarily prolong life but gives comfort

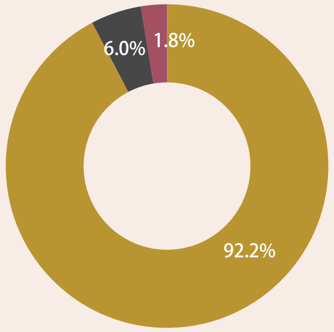


Patient's own wishes should determine what treatment he/she should receive

🟨 Agree

⬛ Not sure / Neutral

🟥 Disagree

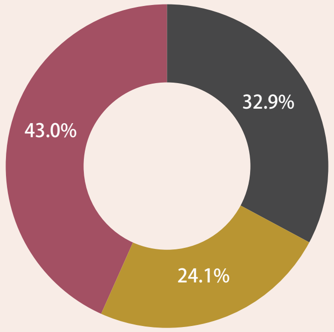


It is a good practice for medical staff to talk to the patient directly about their situation and EOL care arrangements

🟨 Agree

⬛ Not sure / Neutral

🟥 Disagree

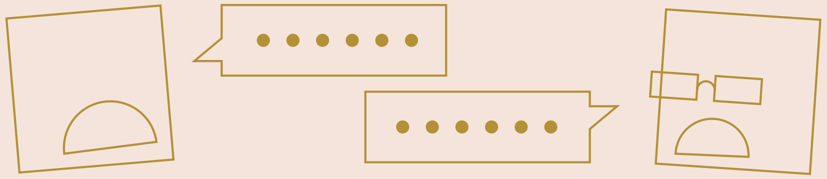


Doctors should generally try to keep their patients alive by any means (e.g. machines, intubation) for as long as possible, even if it means pain, discomfort, and suffering

⬛ Agree 🟨 Not sure / Neutral 🟥 Disagree

2.2.2 Serious Illness Conversation Guide

Conversations with terminally ill patients about their goals and values can be associated with a better quality of life, distress reduction and goal-concordant care. The serious illness conversation guide (SICG) supports healthcare professionals to conduct patient-centred serious illness conversations. This guide helps healthcare professionals explore a patient's view of illness, information preferences, goals, worries, views on trade-offs and wishes for family involvement. The ideal time to initiate the conversation of values and goals is when the patient is relatively stable and not in emotional or medical crisis.[39]



Principles of SICG[39]

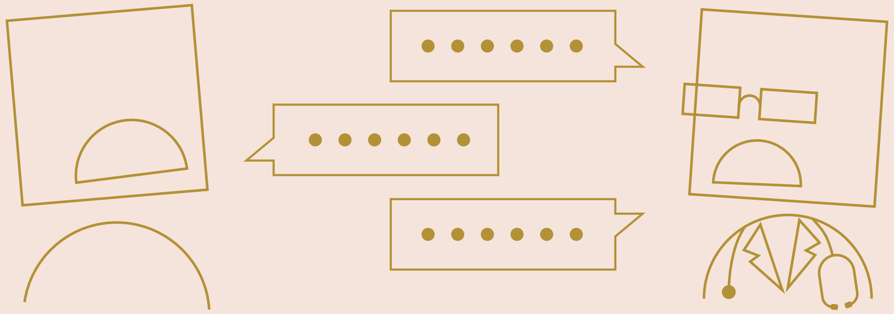
- Healthcare professionals would not harm the patient by talking about EOL issues
- Patients prefer the truth about prognosis
- Give patients a chance to express worries and fears
- Anxiety is normal for patients and healthcare professionals during the discussions
- Patients have goals and priorities besides living longer
- Titrate conversations based on patient's responses, especially anxiety

Practices[39]

	DO
✓	• Find a quiet location, private if possible • Allow silence • Give a direct and honest prognosis when desired by patient • Present prognostic information as a range • Focus on patient's quality of life, concerns and worries • Document conversation • Make a recommendation (e.g. "Based on current medical situation, treatment options and your goals and values, I recommend⋯") • Acknowledge and explore emotions
	DON'T
✗	• Focus on medical procedures • Provide factual information in response to strong emotions • Give premature reassurance • Use medical jargon

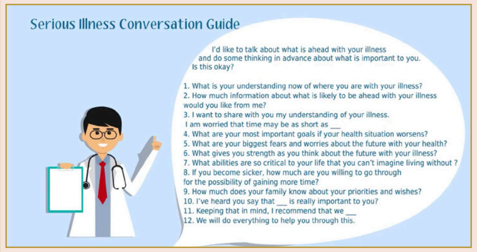
Conversation Flow[39]

Prompt	Purpose	Example
Set up the conversation	• Introduce the idea and benefits • Ask permission	• I would like to talk about what is ahead with your illness and do some planning in advance. • Is this okay?
Assess	• Assess illness understanding • Assess information preferences	• What is your understanding of your illness now? • How much information about your illness would you like to know?
Share prognosis	• Tailor information to patient's preference and response to emotion	• I am worried that your time may be limited.
Explore key topics	• Goals	• What are your most important goals if your health situation deteriorated?
	• Fears and worries	• What are your biggest fears and worries about the future with your health?
	• Sources of strength	• What makes you strong when you think about the future with your illness?
	• Critical abilities	• What abilities are important to your life that you cannot imagine living without?
Explore key topics	• Trade-offs • Tailor to patient's clinical situation • Explain treatment outcomes, likelihood of outcomes and treatment burdens	• If you became sicker, how much are you willing to go through for the possibility of gaining more time?
	• Family	• How much does your family know your wishes and priorities?
Close the conversation	• Summarise • Make a recommendation • Affirm commitment	• It sounds like __ is very important to you. • Given your goals and priorities and what we know about your illness at this stage, I recommend…. We are in this together.



Video on Serious Illness Communication

The CUHK Jockey Club Institute of Ageing produced a video on serious illness communication to demonstrate EOL conversations with a patient using SICG and to show the impact on the patient. Healthcare professionals can refer to the wordings and phrases used in the video to gain a better understanding of how to use the guide to explore a patient's goals and values.



Serious Illness Conversation Guide

I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you. Is this okay?

1. What is your understanding now of where you are with your illness?
2. How much information about what is likely to be ahead with your illness would you like from me?
3. I want to share with you my understanding of your illness. I am worried that time may be as short as ___
4. What are your most important goals if your health situation worsens?
5. What are your biggest fears and worries about the future with your health?
6. What gives you strength as you think about the future with your illness?
7. What abilities are so critical to your life that you can't imagine living without ?
8. If you become sicker, how much are you willing to go through for the possibility of gaining more time?
9. How much does your family know about your priorities and wishes?
10. I've heard you say that ___ is really important to you?
11. Keeping that in mind, I recommend that we ___
12. We will do everything to help you through this.

Link

https://www.youtube.com/watch?v=0h2rRoDG0eU&feature=youtu.be

QR code

Strategies for Common Scenarios[39]

Scenario 1

Patient says, "I don't want to talk about it"

Key ideas	Strategies
• Explore why the patient does not feel able to talk this issue. • Patient is ambivalent about receiving information. They may want to know, but are scared of the truth. Steadiness and calm of healthcare professionals can help them feel that talking about it is possible. • Patient needs more support (e.g. from family member) to address the issue. • Patient has intense fears about the future and dying that are overwhelming.	• Explore the patient's reasons for not wanting to discuss this: *"Could you help me understand the reasons you would prefer not to talk about this."* • If the patient is ambivalent, acknowledge or name the ambivalence. • Ask the positives and negatives of discussing the issues. • Remind the patient that the goal is to initiate discussion, not to make decisions. • Inform the patient that you will bring this up at the next visit or delay the conversation until more support is available.

Scenario 2

Patient is not ready to make decision

Key ideas	Strategies
• Patient needs more time to absorb and integrate information and also to prepare before making a decision. • Reassure the patient that decisions are not urgent and encourage them to talk with their family members. • Emphasise that decisions would be better made sooner if the patient is declining rapidly.	• Reassure the patient that there is time to think about the decision and let them know it will be discussed again. • Encourage discussion with family: *"These are difficult decisions and should involve your family. I recommend discussing with them first and we talk about it again next time."* • If the patient is declining rapidly, acknowledge this and focus on providing care aligned with the patient's wishes: *"I am worried your disease is getting worse. I would like to help you think through some of the decisions you may be faced soon."*

Scenario 3

Patient says, "I am going to beat this"

Key ideas	Strategies
• Explore the meaning of 'beating' this. • Help the patient focus on additional hopes beyond survival. • Consider strategies to reduce anxiety, such as relationship building, medication or encouragement from family members, which may make future discussions easier. • If the patient insists he/she may get better, it is often better to avoid addressing denial. Wait until the patient is in a less stressed frame of mind to address their denial.	• Acknowledge the patient's desire to beat their disease, but persist in exploring EOL issues and moving the conversation forward: *"We should hope for the best and prepare for the worst."* • Focus on the patient's strengths: *"I can see what a strong force you are for your family. I think there is a lot you can do to help them deal with this awful situation with your illness by helping to prepare them."* • Patient wants to be seen as a fighter by beating their disease. Show respect for the patient's fighting spirit: *"I think you have capacity to continue to be a fighter no matter what happens with your disease. Let's try to think together about what other things you could fight for if you can't beat the cancer."*

Scenario 4

Patient expresses anger

Key ideas	Strategies
• Healthcare professionals should stay calm. • Anger is usually related to the message that they are becoming sicker rather than directed at you personally. • Give the patient a chance to talk about their anger and respond non-defensively.	• Explore angry feelings, but use less intense language: *"I can see this is really frustrating. Could you tell me about frustrations you've been experiencing?"* • Respond non-defensively: *"I can understand why you feel that I let you down in not being able to find the right chemotherapy. I will still work hard to do my best for you."* • Encourage the patient to say what is on their mind. • Allow the patient an opportunity to explore what it means to them to be talking about EOL issues.

Scenario 5

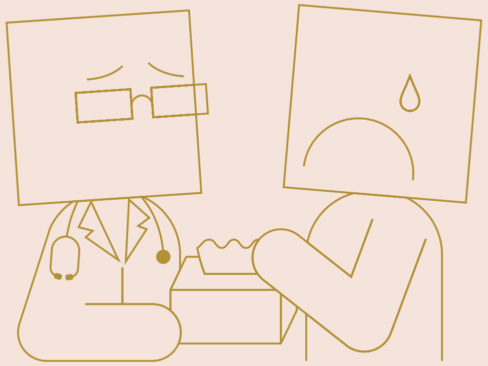
Patient expresses intense emotion (e.g. tears)

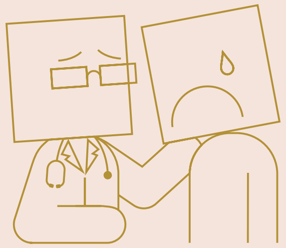
Key ideas	Strategies
• Tears and other emotions are natural while discussing serious illness issues. • Dealing with emotions is often a precondition for effectively addressing serious illness decisions. • When patients express strong emotion, it is therapeutic to listen even though we cannot 'fix' the situation. • Patients are frightened of alienating their clinician by crying – reassurance and staying present can mitigate this. • Titration based on patients' responses with gentle guidance allows forward movement without the patient being overwhelmed.	• Allow silence for the patient to express feelings. • Explore feelings: *"Tell me more."* • Avoid providing false or premature reassurance to contain the patient's distress. • Avoid offering information that is not explicitly sought. • Offer a break and proceed later: *"I can see that this a tough conversation for you. We will take a break today and talk about it next time."* • Explore whether a mental health referral would be needed if emotion is very intense and persistent.

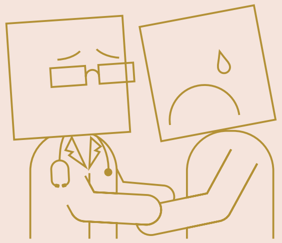
Responding to Emotion

- Respect
    - Acknowledge and validate the patient's experience
    - Listen to what the patient says and make them feel acknowledged
    - If the patient is disrespectful, they will either terminate the encounter or argue more strongly
- Empathy
    - Allow healthcare professionals to truly attend and connect with the patient
    - Appreciate the patient's feeling and situation
    - Facilitate the patient to engage in more open dialogue
    - Help the patient to initiate expressing additional fears and concerns

Non-Verbal Expressions of Empathy







NURSE Statement for Articulating Empathy[40]

	Example	Notes
Naming	"You seem worried."	This statement is useful even if you name the wrong emotion. The patient/family can correct you and explain what they are really feeling.
Understanding	"I can see how difficult this must be for you."	Try to put yourself in the patient/family's position, but stop short of suggesting you understand everything.
Respecting	"I can see you have really been trying to follow our instructions."	Try to praise patient/family.
Supporting	"Don't worry, I will be back soon to check on you."	Making this kind of commitment is a powerful statement and avoids feelings of abandonment.
Exploring (the emotion)	"Tell me what you're worried about now."	Ask a focused question about a statement just made to explore the emotion behind it.

This video on breaking bad news to a patient's family is made by the CUHK Jockey Club Institute of Ageing and demonstrates skills in handling the emotions of the patient and family using the NURSE statement.

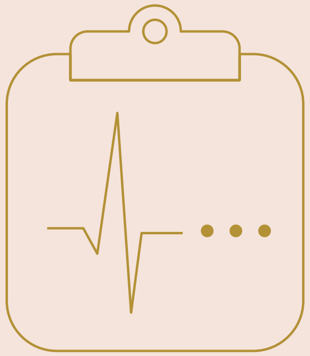
Breaking bad news with patients' family members

Link
https://youtu.be/UCzs56S7nSA

QR code

Discussion of Prognosis[39]

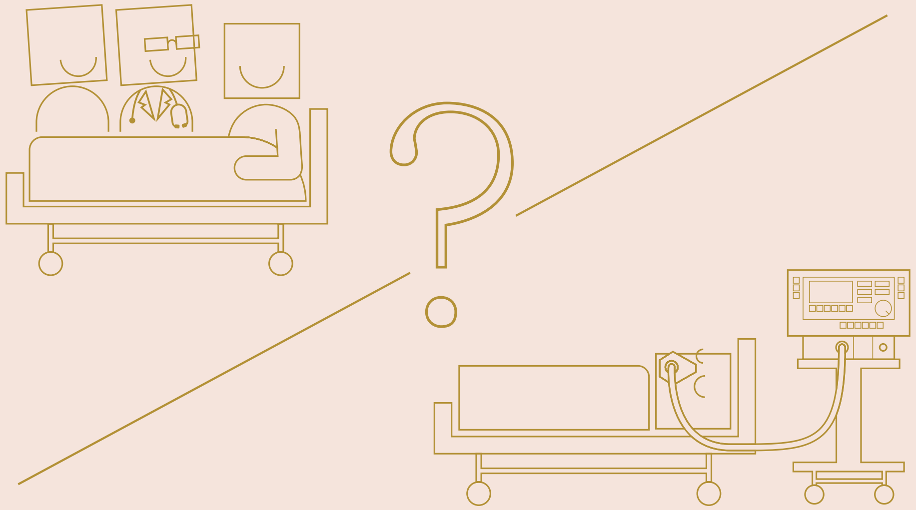
Prognosis	Key ideas	Strategies
Time-based	Most patients want a best estimation of how much time they may have in their stage of illness. Cancer has a more predictable prognosis, less so for lung, kidney or heart disease. Patients expect to be given time to prepare for what may come instead of expectation of precision.	Provide prognostic information as a range, without providing too much specificity: *"Days to weeks, weeks to months, months to years."* Support hope: *"I hope it will be on the long side of this range."* Acknowledge prognostic uncertainty: *"It may be shorter or longer."*
Functional	It is difficult to predict how much time a patient is likely to have, but it is possible to predict their level of function. It may provide them with useful information for planning and goal-setting. Outlining what is and is not likely to improve in the future can help them to understand what their lives will be and allow them to make trade-offs that will align with their values.	Support hope: *"I think that you can continue to have good times with family and take pleasure in small daily things."* Affirm commitment to optimise function: *"We are going to continue physical therapy to give your body the best chance possible to regain some strength. And we will keep looking for other options that help you feel well."* Provide information on what is likely or not likely to improve: *"I think your leg swelling may get better, but I think you will still need oxygen therapy."*
Unpredictable	If a patient has advanced heart and lung disease, it should be communicated to them that they can remain stable, slowly deteriorate over time or bring sudden and life-threatening crises. This allows patients and their families to consider their values and preferences within this context and to prepare for it.	Provide clear information about potential trajectories: *"Heart disease is unpredictable. Some patients can live well for years and some may deteriorate quickly. We need to prepare for a sudden event."* Hope for the best but plan for the worst: *"I hope you will have a lot of good time ahead and that doing some planning together can help you have a safety net in case things don't go as we hope."* Use hypotheticals: *"If your heart failure suddenly worsened, you may be unable to return to where you are now or you may need to be hospitalised or to consider intensive treatments."*



Discussion of Care Approach

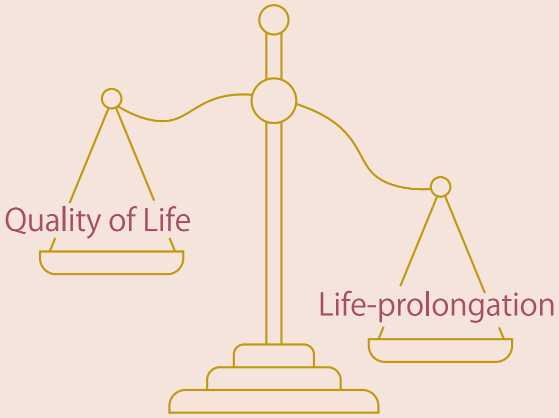
Life-prolonging care, comfort-focused care and conservative care approaches can help explain treatment outcomes, likelihood of outcomes and treatment burdens to patients and their family members.

Treatment burden may mean side effects or the need to be in a hospital and may reduce patients' time spent with family and friends. Each treatment approach represents a different trade-off between the desire of prolonging life versus the desire of maximising comfort. Acceptable outcomes for patients depend on personal values and goals. Patients’ trade-offs may change over time as the disease progresses. For instance, patients may accept more treatments at an earlier stage of the disease, but as the chance of living longer decreases or the treatment burden increases, they may switch to focus more on comfort care.



Life-Prolonging Care Approach

The goal of this approach is to prolong life. Patients would accept any available treatments that offer the best chance at keeping them alive, even if these treatments may cause discomfort or result in a poorer quality of life. Patients may require prolonged care in an intensive care unit (ICU).

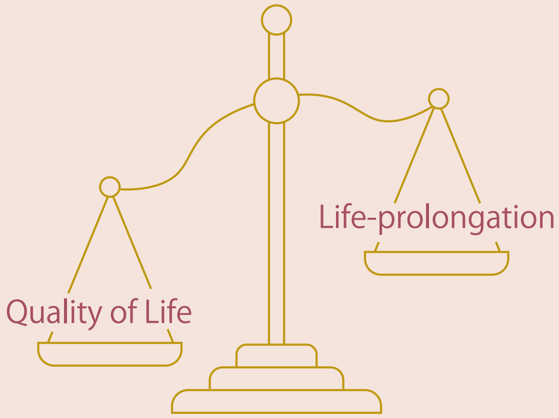


Example

“If your heartbeat or breathing were to stop, we would attempt to use cardiopulmonary resuscitation (CPR). This involves pressing on the chest and blowing air into the lungs. It may also involve delivering electric shocks to stimulate the heart. When the lungs cannot adequately deliver oxygen to the body, a tube will be inserted down your throat and connected to a breathing machine that pushes air into your lungs. You cannot talk or eat while on a breathing machine. A feeding tube is often inserted to provide artificial nutrition. Sedatives are often given to reduce the discomfort of being connected to a breathing machine. There is a small chance that patients may experience discomfort if the sedative effect is not deep enough. Some patients are able to be weaned off the breathing machine over time. Others may need the breathing machine permanently. Often in patients with advanced heart failure, CPR and other life-sustaining treatments do not work. When these treatments do extend life, patients are often unable to return to the level of function or quality of life they had prior to becoming hospitalised.”

Comfort-Focused Care Approach

This approach aims at maximising comfort and quality of life rather than at extending life. Patients who choose this approach do not want to undergo treatments that cause discomfort and they want to avoid hospitalisation as much as possible to spend more time with their family. They prefer letting their disease progress naturally to the end of their life. A multidisciplinary team including doctors, nurses, social workers, physiotherapists and spiritual care counsellors will work together to provide support to the patient and their family.

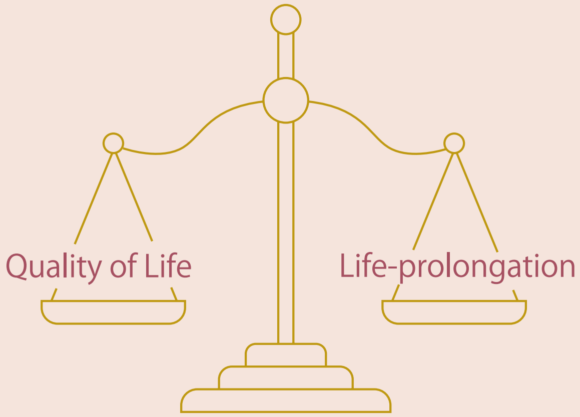


Example

"Treatments are used to provide symptom relief but not to hasten death. Medications and non-pharmacological strategies are used to treat symptoms such as breathlessness, anxiety and pain. When symptoms cannot be adequately relieved at home, you may be treated in the hospital or in hospice facilities."

Conservative Care Approach

This is a middle-ground approach. Prolonging life is still essential and treatments that cause some degree of discomfort are tolerated. If the discomfort is too significant or the treatments are unlikely to allow patients to return to an acceptable quality of life, this approach is not recommended.



Example

"You may go to hospital for treatable problems, such as an infection or to remove fluids from the lungs, as well as for symptom relief. Sometimes a large mask may be used temporarily to support the lungs. This mask is connected to a BiPAP (bi-level positive airway pressure) machine which helps the lungs exchange air. You cannot talk or eat while wearing the BiPAP mask and the tight-fitting mask may cause some discomfort."

Videos on EOL Conversations with Patients with Various Diseases

The CUHK Jockey Club Institute of Ageing produced three videos illustrating the different options for medical care. These videos aim at helping patients with advanced diseases, such as COPD, advanced heart failure and advanced dementia, to understand more about their condition and to help them think about their care preference in case they are not capable of making the decision in the future. Healthcare professionals can consider using these videos to help patients and their family members better understand their treatment options.

(i) Chronic Obstructive Pulmonary Disease

Goals of care options for patients with advanced COPD_ACP

Link

https://youtu.be/FEK0bpe9Cvg

QR code

(ii) Advanced Heart Failure

Understanding care decisions in advanced heart failure_ACP

Link

https://youtu.be/hCJ9aagZTLA

QR code

(iii) Advanced Dementia

End-of-life care for dementia patients

Link

https://youtu.be/Ay8SYK-1vNk

QR code

Tips for Managing the Conversation[39]

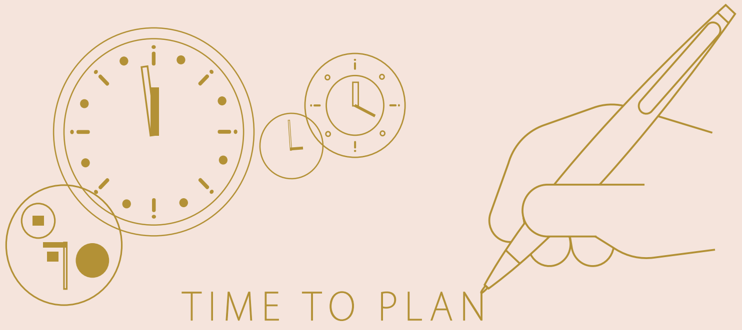
	Key ideas	Strategies
Keep patients on track	- Patients usually think that healthcare professionals have an agenda and need to fulfil it within a limited time frame. - Patients wander when they are anxious or have other high priority issues to discuss with healthcare professionals.	- Interrupt gently: *"We need to get back to the question about your goals if time is getting short."* - Remind time constraints: *"I wish we have more time to talk about your daughter, but I would like to get back to thinking about some future planning."* - Acknowledge this is a tough conversation and gently bring the patient back to the topic: *"I know it is hard to talk about, but I would like to see if we can clarify what your worries are for the future."*
Manage the time	- Some questions can be effectively handled by different healthcare professionals (e.g. social worker or nurse), but prognosis should be handled by clinicians. - The conversation can be effective when spread over several visits.	- Consider going through two questions per visit. - Delegate some questions to different team members as appropriate.
Document the conversation	- Avoid using the computer while discussing with the patient.	- Make frequent eye contact with the patient when taking notes.

2.3 Advance Care Planning

After starting a conversation about EOL care, patients may consent to these discussions being recorded as part of a more formal process of ACP.[41] ACP enables healthcare professionals to follow a patient's previously expressed wishes about their care and treatment preferences when they lose capacity in the future.[41] Options for recording an ACP range from a documented collection of values and preferences to a decision of making an AD to refuse life-sustaining treatments. In addition to discussing healthcare decisions, this is also an opportunity to explore wishes of organ donation and funeral arrangement.

Purpose of ACP[8]

- An overarching and preceding process for expressing preferences for medical and personal care
- During the process, the patient can:
  - Express beliefs, values and wishes
  - Make an AD refusing life-sustaining treatments
  - Express preferences for future medical and personal care
  - Assign a family member to be the key person for future consultation
- The patient and family can be better prepared emotionally for future deterioration of the patient's condition



Scope of ACP Discussion[8]

Disease	Anticipated progression and prognosis
Treatments	Available options, benefits and risks
Patient's preferences and values	Expectation from treatments Preferences for treatment limits Preferences for personal care Personal goals to accomplish
Family members	Family values and concerns Patient's prior wish or preference for incompetent patients
Other	May include funeral process or organ donation

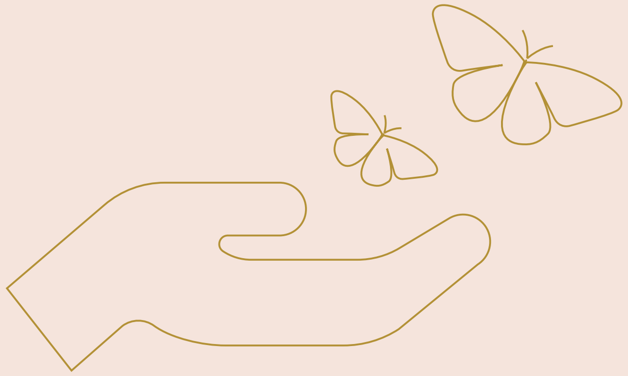
Notes of ACP Discussion[8]

- Depend on the state of disease and the readiness of the patient
- Are on a voluntary basis
- Should not be initiated simply as a routine procedure
- Can be initiated by healthcare professionals, patients as well as their family members
- Should not concentrate on decisions to withhold specific treatments. Healthcare professionals should focus on what will be helpful in achieving the patient's preferences, values and wishes in the context of a conversation about the illness.
- Are an ongoing process. Discussions do not have to be completed in one session.
- Are documented using an ACP form and it should not be treated as a checklist exercise.

Benefits of ACP[42]

- Respect patient autonomy
  - Patient can exercise autonomous decision-making by expressing in advance wishes about values and preferences and refusal of futile life-sustaining treatments through ACP
  - Respect patient's directive by medical team and family members if patient is not capable of making decisions in the future
- Avoid future disputes
  - Avoid disagreement and conflicts between family and healthcare professionals over decision-making in patient's terminal phase
  - Reduce family's burden and anxiety for future decision-making

- Exercise patient's right to know
    - Patient and family can gain in-depth understanding of the illness in the discussion
    - Patients have sufficient information of disease prognosis, benefits and burdens of life-sustaining treatments as well as clarifications on the meaning of withholding life-sustaining treatments before making an informed choice
- Promote family relationship
    - Patients express values and preferences to family, which may rarely be discussed at home, under encouragement and guidance by healthcare professionals
    - Let family know the patient's wishes and in turn shape the care for the patient
- Less suffering at the end of life
    - If the patients have decided to refuse futile life-sustaining treatments and prefer a natural and respectful death, this can reduce unnecessary suffering of the patient and relieve the grief of the family



Team Approach to ACP Conversation[8]

- Healthcare professionals act as facilitators in the ACP process
- Doctor is usually the core member among the facilitators. The process may be assisted or followed up by nurses or medical social workers as appropriate.

Before Conversation

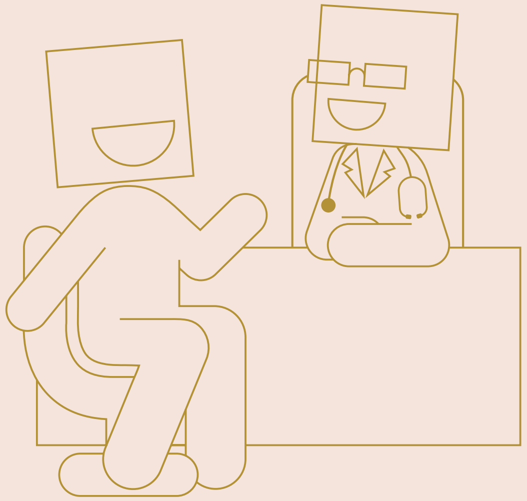
- Arrange interdisciplinary team meetings:
    - Clarify prognosis and treatment options
    - Understand patient's social background and decide who to invite to join the process
    - Plan the meeting, including timing and location, and identify meeting goals

During Conversation

- Provide appropriate and sufficient information about the disease and treatment in understandable terms
- Handle emotions and conflicts
- Build consensus with patient and family
- Respect patient's autonomy and confidentiality
- Practise active empathetic listening
- Be sensitive to assess the readiness of the patient in continuing the discussion
- Encourage the family to listen to the patient's concerns and elicit view from family

After Conversation

- Revisit the ACP
    - Timely review of ACP is required as patient's condition or preference changes
    - New ACP form should be filled in if there are any changes made
- Inform the patient's family, carers and relevant healthcare professionals of the plan
- Follow up if the patient chooses to complete an AD or DNACPR
- Details of the ACP discussion should be documented to facilitate continuity of care. Results of the discussion can be documented in the ACP form and include:
    - Patient's wishes, beliefs and values
    - Preferences for medical and personal care
    - Designated family member for future consultation
    - Overall preferences regarding limits on life-sustaining treatments; with preferences regarding specific life-sustaining treatments if any



Video on ACP

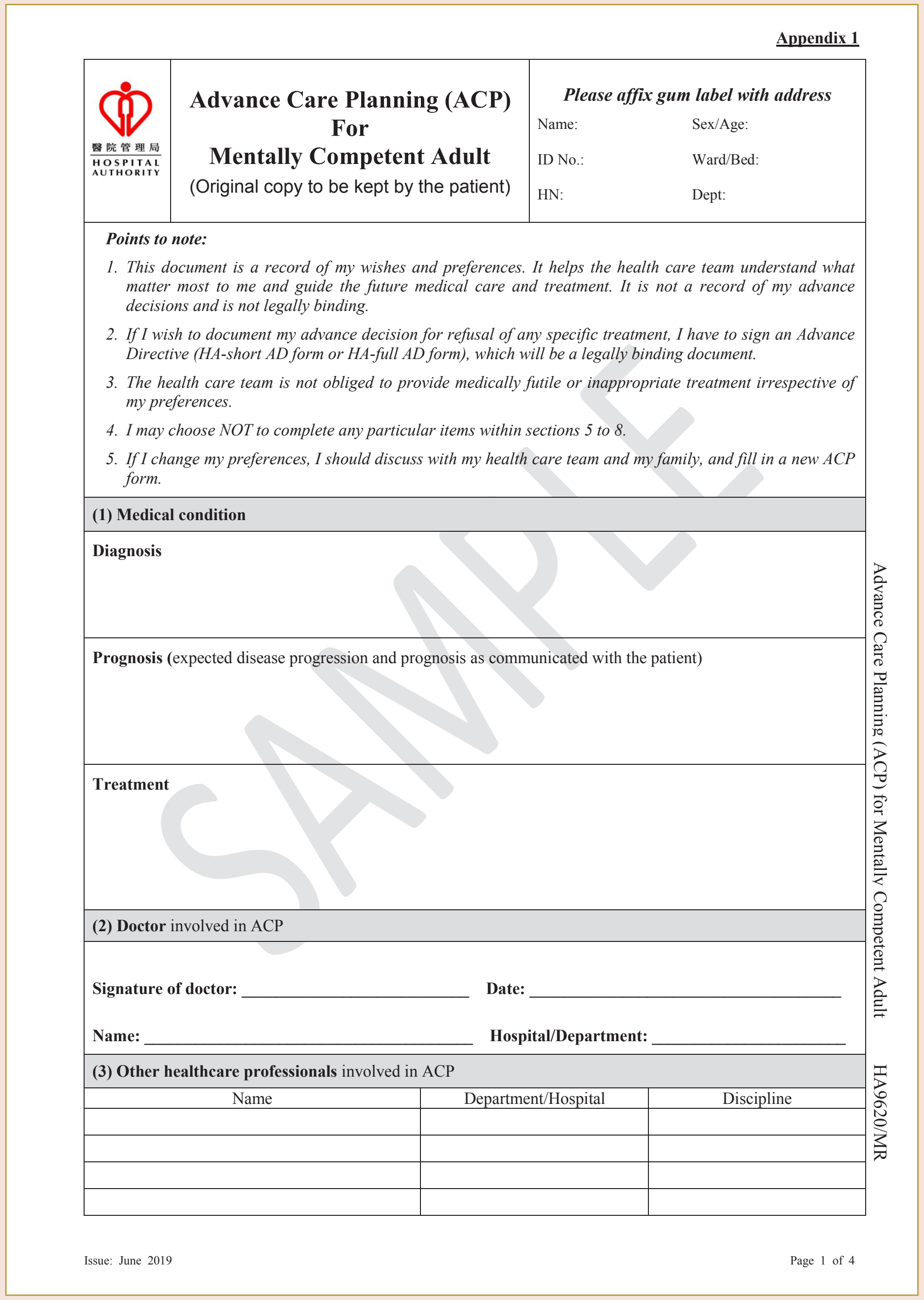
The video on ACP produced by the CUHK Jockey Club Institute of Ageing aims at enhancing communication skills on ACP among healthcare professionals. It provides practical tips for talking about ACP, challenges when talking with patients and relatives and how to handle them, and case sharing on ACP.

Link

https://youtu.be/lmTAn6JHW28

QR code

Sample of ACP Form



Appendix 1

醫院管理局 HOSPITAL AUTHORITY	**Advance Care Planning (ACP) For Mentally Competent Adult** (Original copy to be kept by the patient)	***Please affix gum label with address*** Name: Sex/Age: ID No.: Ward/Bed: HN: Dept:

Points to note:

1. *This document is a record of my wishes and preferences. It helps the health care team understand what matter most to me and guide the future medical care and treatment. It is not a record of my advance decisions and is not legally binding.*
2. *If I wish to document my advance decision for refusal of any specific treatment, I have to sign an Advance Directive (HA-short AD form or HA-full AD form), which will be a legally binding document.*
3. *The health care team is not obliged to provide medically futile or inappropriate treatment irrespective of my preferences.*
4. *I may choose NOT to complete any particular items within sections 5 to 8.*
5. *If I change my preferences, I should discuss with my health care team and my family, and fill in a new ACP form.*

(1) Medical condition

Diagnosis

Prognosis (expected disease progression and prognosis as communicated with the patient)

Treatment

(2) Doctor involved in ACP

Signature of doctor: ________________________ **Date:** ________________________

Name: ________________________ **Hospital/Department:** ________________________

(3) Other healthcare professionals involved in ACP

Name	Department/Hospital	Discipline

Advance Care Planning (ACP) for Mentally Competent Adult HA9620/MR

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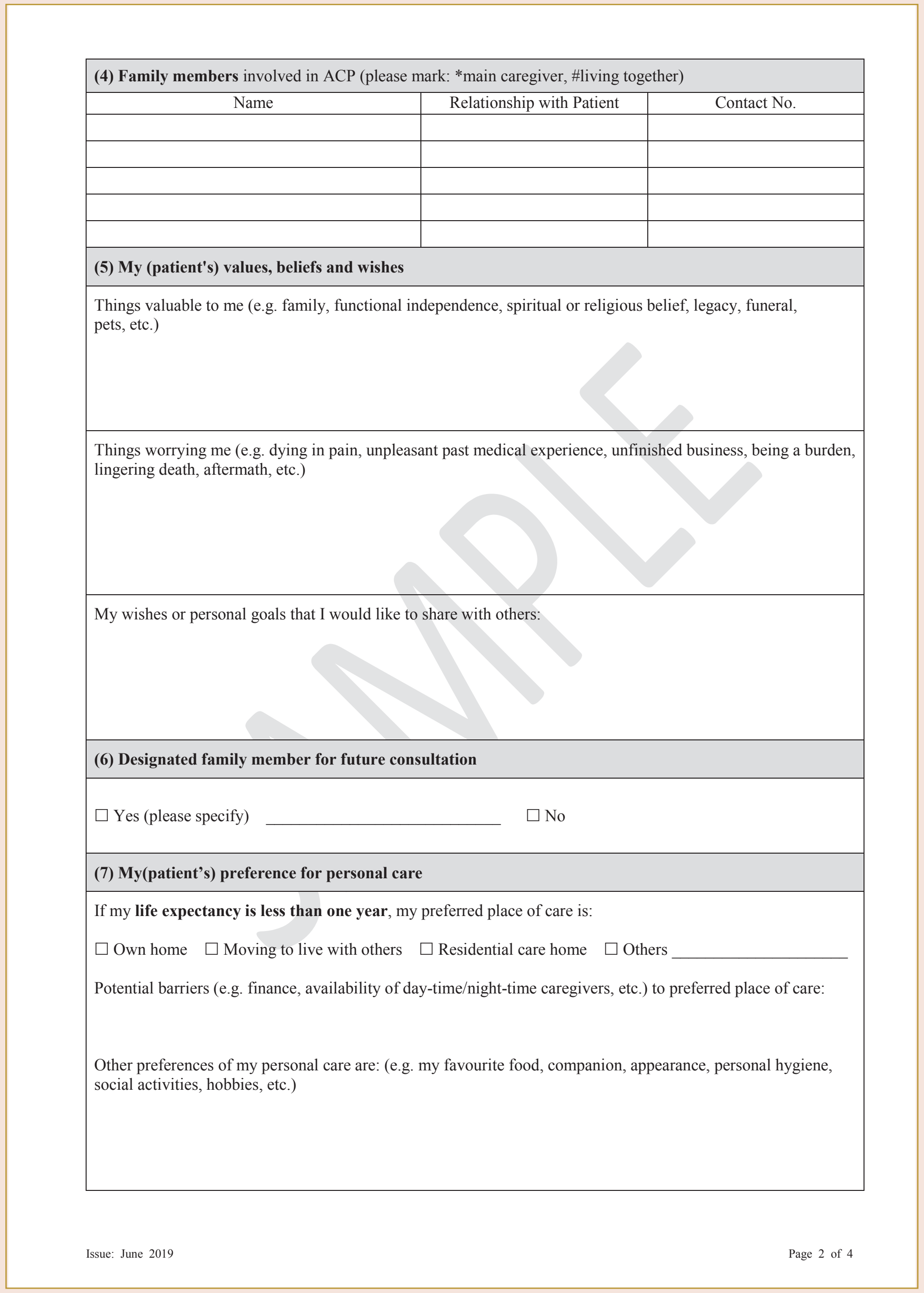

(4) Family members involved in ACP (please mark: *main caregiver, #living together)

Name	Relationship with Patient	Contact No.

(5) My (patient's) values, beliefs and wishes

Things valuable to me (e.g. family, functional independence, spiritual or religious belief, legacy, funeral, pets, etc.)

Things worrying me (e.g. dying in pain, unpleasant past medical experience, unfinished business, being a burden, lingering death, aftermath, etc.)

My wishes or personal goals that I would like to share with others:

(6) Designated family member for future consultation

☐ Yes (please specify) ________________________ ☐ No

(7) My(patient's) preference for personal care

If my **life expectancy is less than one year**, my preferred place of care is:

☐ Own home ☐ Moving to live with others ☐ Residential care home ☐ Others ________________

Potential barriers (e.g. finance, availability of day-time/night-time caregivers, etc.) to preferred place of care:

Other preferences of my personal care are: (e.g. my favourite food, companion, appearance, personal hygiene, social activities, hobbies, etc.)

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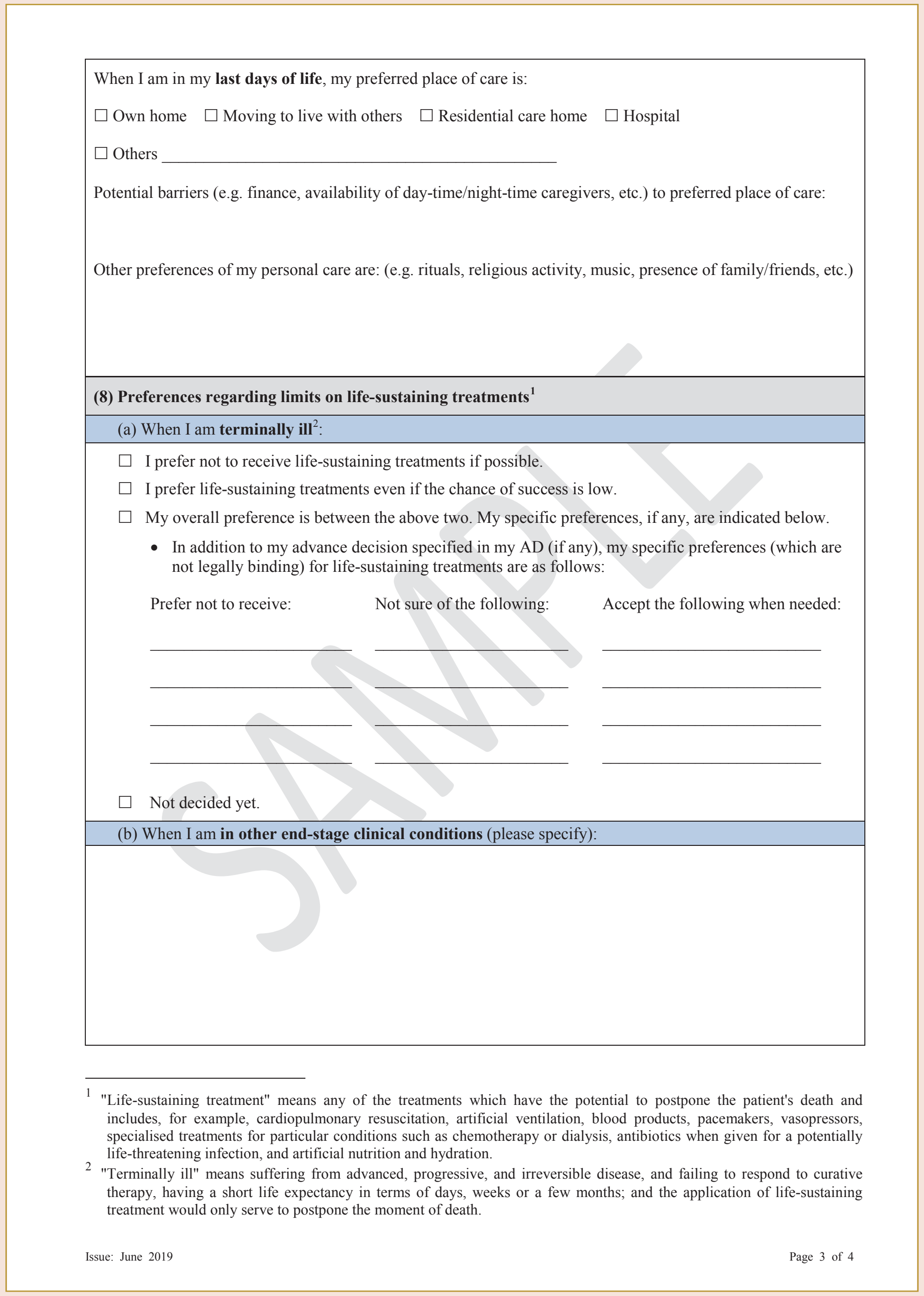


When I am in my **last days of life**, my preferred place of care is:

☐ Own home ☐ Moving to live with others ☐ Residential care home ☐ Hospital

☐ Others ____

Potential barriers (e.g. finance, availability of day-time/night-time caregivers, etc.) to preferred place of care:

Other preferences of my personal care are: (e.g. rituals, religious activity, music, presence of family/friends, etc.)

(8) Preferences regarding limits on life-sustaining treatments[1]

(a) When I am **terminally ill**[2]:

☐ I prefer not to receive life-sustaining treatments if possible.

☐ I prefer life-sustaining treatments even if the chance of success is low.

☐ My overall preference is between the above two. My specific preferences, if any, are indicated below.

- In addition to my advance decision specified in my AD (if any), my specific preferences (which are not legally binding) for life-sustaining treatments are as follows:

Prefer not to receive:	Not sure of the following:	Accept the following when needed:
____________________	____________________	____________________
____________________	____________________	____________________
____________________	____________________	____________________
____________________	____________________	____________________

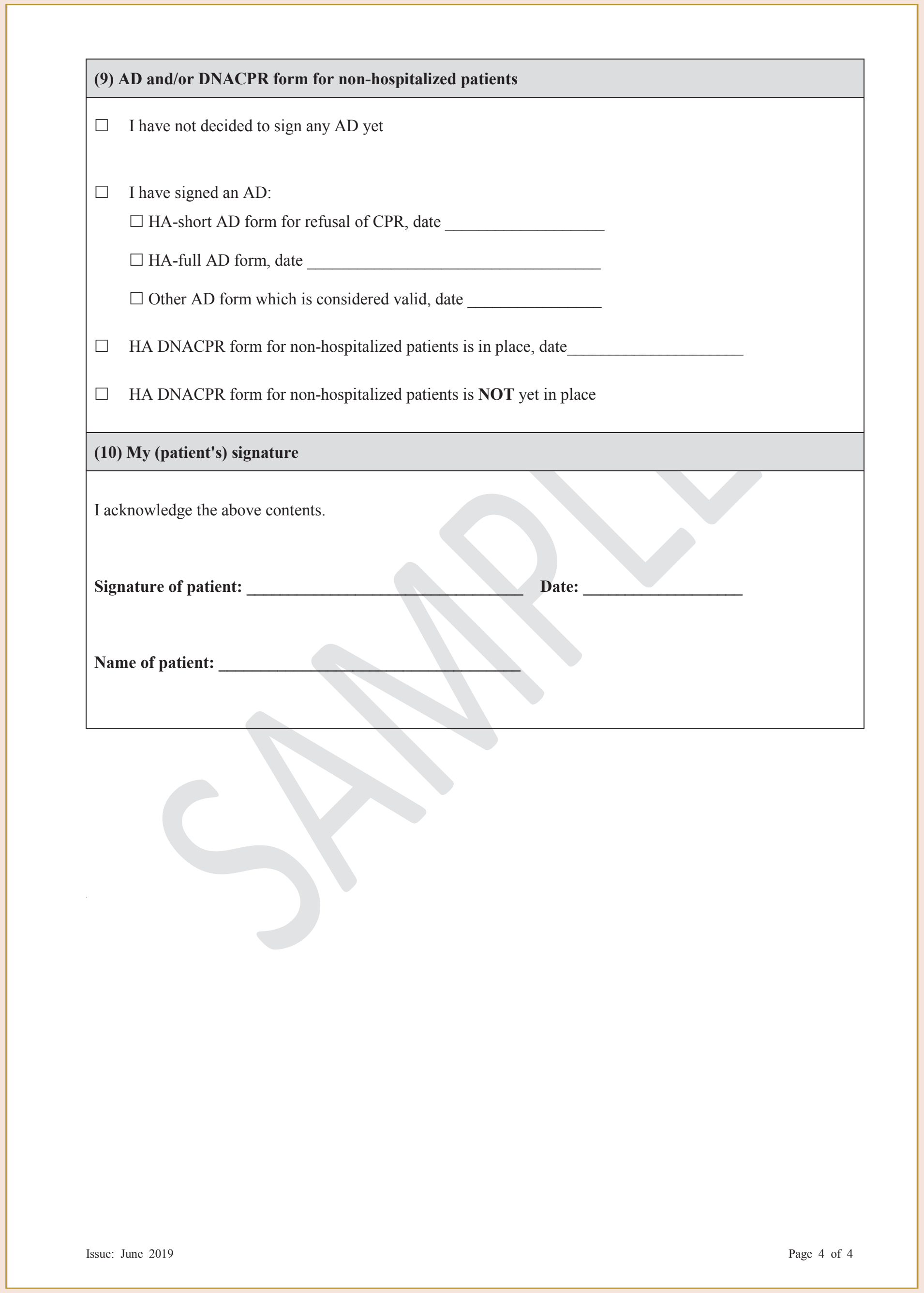
☐ Not decided yet.

(b) When I am **in other end-stage clinical conditions** (please specify):

---

[1] "Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, 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, and artificial nutrition and hydration.

[2] "Terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death.



(9) AD and/or DNACPR form for non-hospitalized patients

☐ I have not decided to sign any AD yet

☐ I have signed an AD:

☐ HA-short AD form for refusal of CPR, date __________________

☐ HA-full AD form, date ________________________________

☐ Other AD form which is considered valid, date _______________

☐ HA DNACPR form for non-hospitalized patients is in place, date____________________

☐ HA DNACPR form for non-hospitalized patients is **NOT** yet in place

(10) My (patient's) signature

I acknowledge the above contents.

Signature of patient: ______________________________ **Date:** __________________

Name of patient: ________________________________

Advance Directive[42]

A mentally competent and properly informed adult patient aged 18 years and over can make an AD for expressing his/her wish to refuse specific life-sustaining treatments in pre-specified conditions when he/she is in a terminal stage condition and is mentally incapable of making health care decisions. A valid and applicable AD is legally binding under common law.

The AD form is designed for patients covering the following situations:

Case 1

Terminally ill patients suffering from an advanced, progressive and irreversible disease

Case 2

In a persistent vegetative state or a state of irreversible coma

Case 3

Other end-stage irreversible life-limiting condition (e.g. end-stage renal failure, end-stage motor neuron disease or end-stage COPD)

Life-Sustaining Treatment[42]

A life-sustaining treatment is any treatment that may prolong the patient's survival. Some are invasive and may cause suffering and physical harm to the patient.

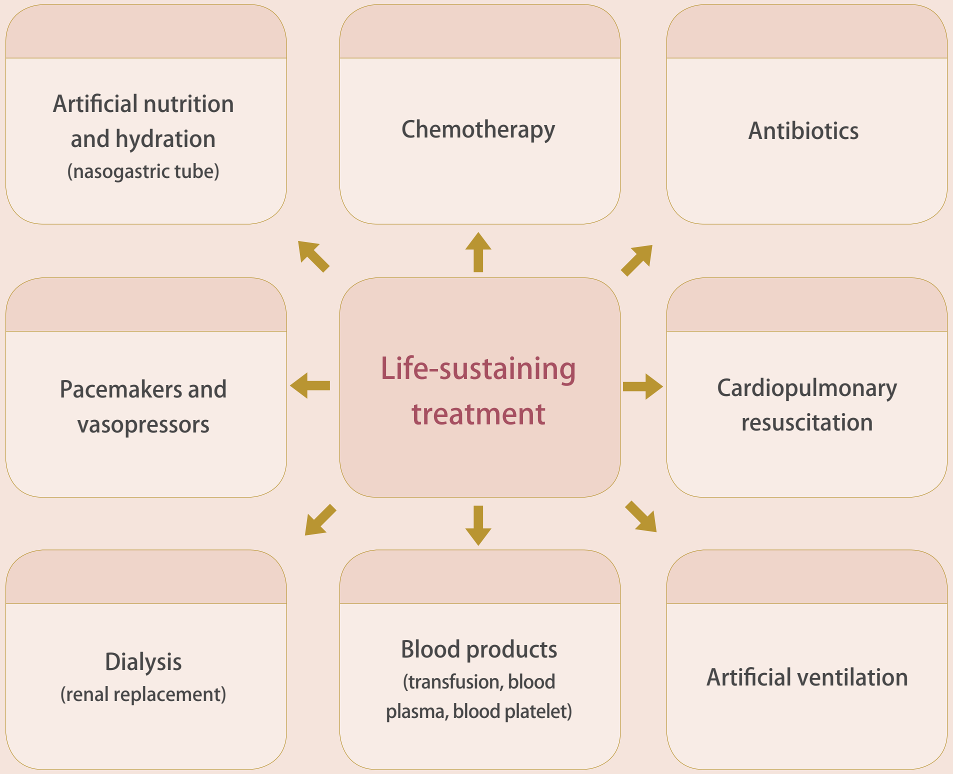
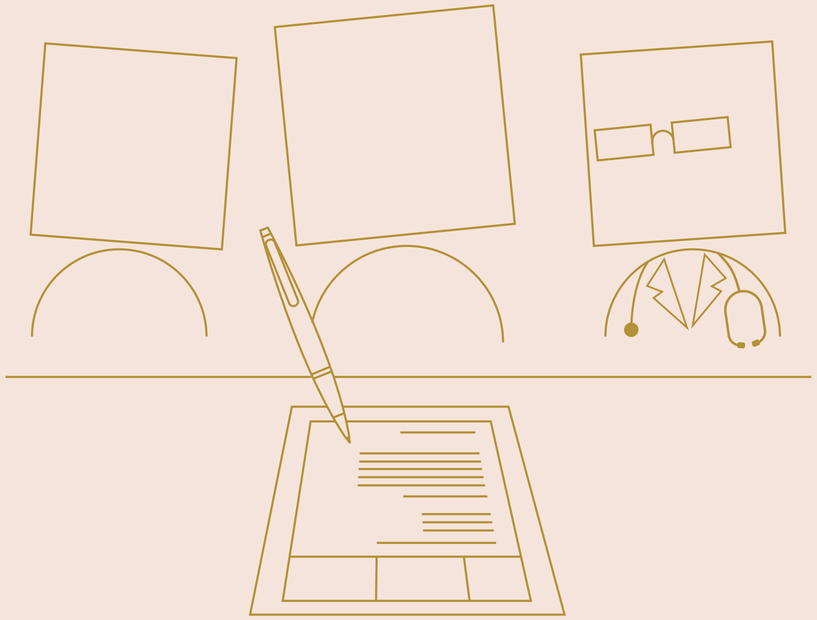


Figure 9. Examples of Life-sustaining Treatments

Notes for Making an AD[42]

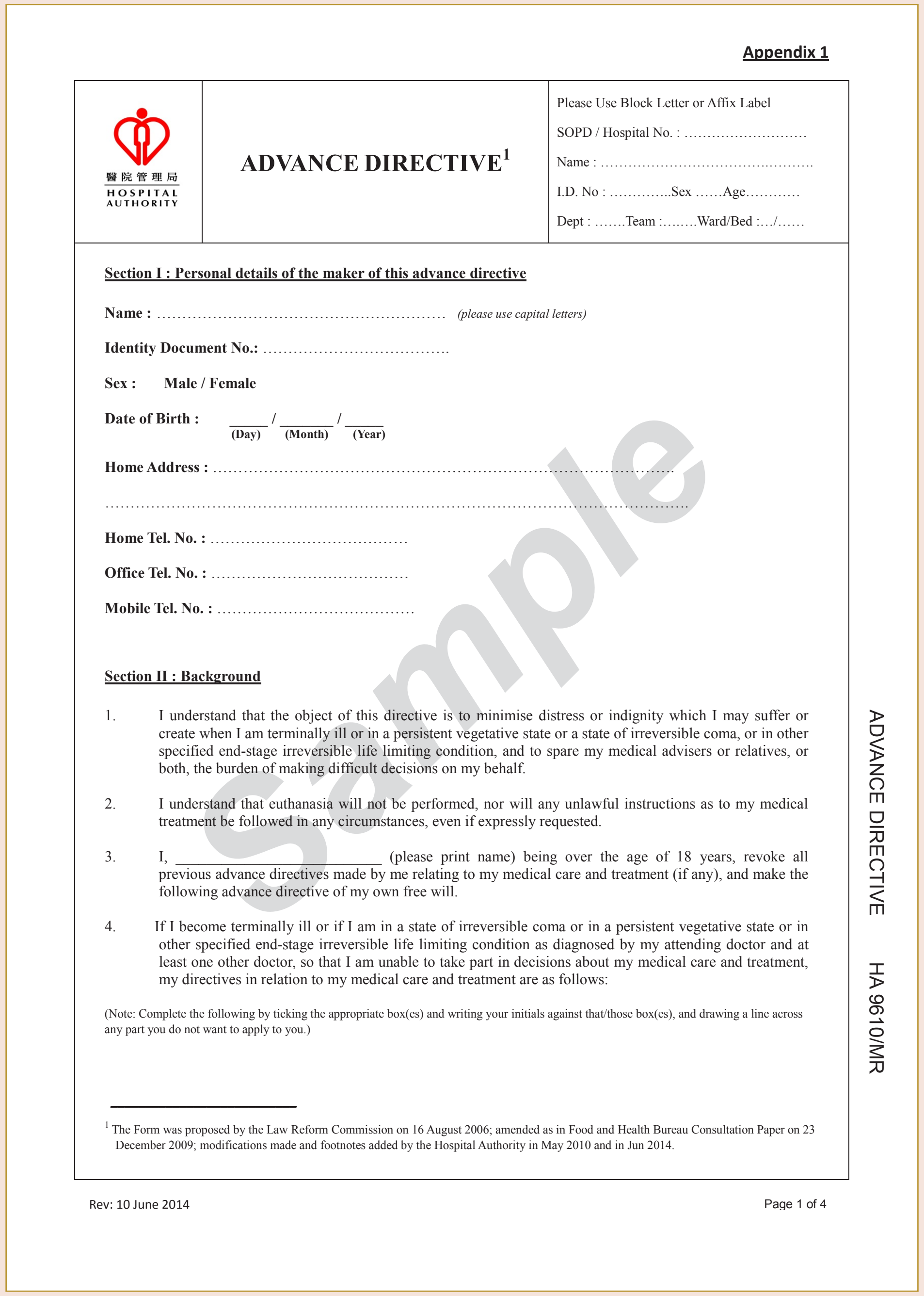
- Must be signed by the patient and two witnesses, two witness requirements must be fulfilled:
    - One witness must be a medical practitioner in Hong Kong
    - Neither witness should have an interest in the estate of the person making the AD



- The AD only comes into operation when the patient is no longer mentally capable of making decisions and they are confirmed by clinicians as suffering from the pre-specified conditions stated in AD. Clinicians can provide emergency treatment to the patient first if they think the applicability of the AD (e.g. the coma is caused by other factors) or validity of the document is in doubt (e.g. being damaged).

- Clinicians have the responsibility to follow the AD once it is applicable and valid. No one, including family members, can revoke the AD made by the patient.
- The original copy of the AD should be kept by the patient and their family and it should be presented to the clinicians on the patient's admission.
- Patients can change their mind after making an AD. The original copy held by the patient shall be deemed authentic in case there are different versions and discrepancies.

Sample of AD Form



Appendix 1

醫院管理局
HOSPITAL AUTHORITY

ADVANCE DIRECTIVE[1]

Please Use Block Letter or Affix Label
SOPD / Hospital No. : ………………………
Name : ………………………………………
I.D. No : …………..Sex ……Age…………
Dept : …….Team :……..Ward/Bed :…/……

Section I : Personal details of the maker of this advance directive

Name : ………………………………………………… *(please use capital letters)*

Identity Document No.: ………………………………

Sex : **Male / Female**

Date of Birth : _____ / ______ / _____
(Day) (Month) (Year)

Home Address : ……………………………………………………………………………

……………………………………………………………………………………………………

Home Tel. No. : …………………………………

Office Tel. No. : …………………………………

Mobile Tel. No. : …………………………………

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, or in other specified end-stage irreversible life limiting condition, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.

3. I, ________________________ (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.

4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state or in other specified end-stage irreversible life limiting condition as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my directives in relation to my medical care and treatment are as follows:

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

---

[1] The Form was proposed by the Law Reform Commission on 16 August 2006; amended as in Food and Health Bureau Consultation Paper on 23 December 2009; modifications made and footnotes added by the Hospital Authority in May 2010 and in Jun 2014.

ADVANCE DIRECTIVE HA 9610/MR

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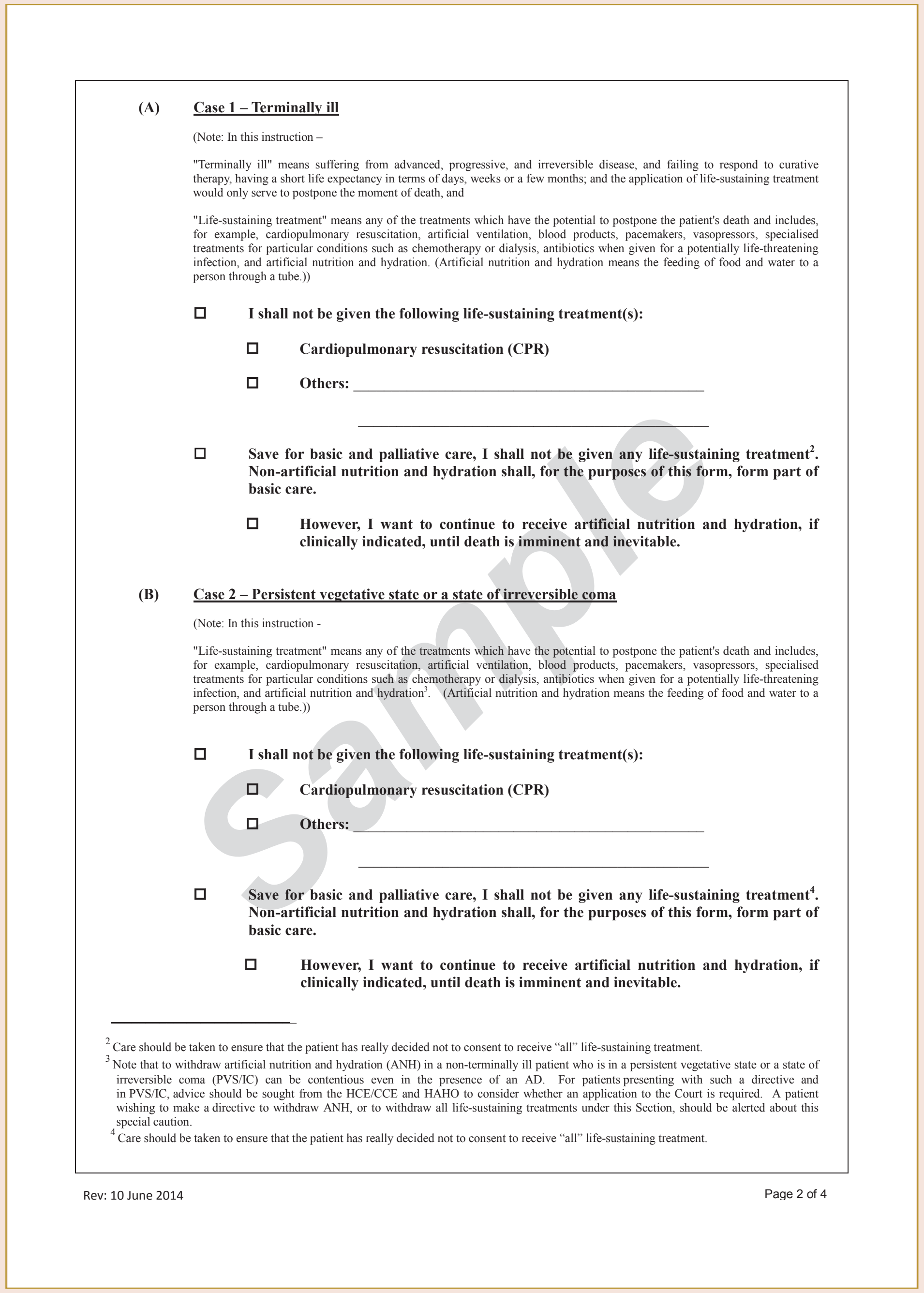

(A) Case 1 – Terminally ill

(Note: In this instruction –

"Terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, 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, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

  ☐ **Cardiopulmonary resuscitation (CPR)**

  ☐ **Others:** ____

  ____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[2]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

  ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

(B) Case 2 – Persistent vegetative state or a state of irreversible coma

(Note: In this instruction -

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, 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, and artificial nutrition and hydration[3]. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

  ☐ **Cardiopulmonary resuscitation (CPR)**

  ☐ **Others:** ____

  ____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[4]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

  ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

---

[2] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

[3] Note that to withdraw artificial nutrition and hydration (ANH) in a non-terminally ill patient who is in a persistent vegetative state or a state of irreversible coma (PVS/IC) can be contentious even in the presence of an AD. For patients presenting with such a directive and in PVS/IC, advice should be sought from the HCE/CCE and HAHO to consider whether an application to the Court is required. A patient wishing to make a directive to withdraw ANH, or to withdraw all life-sustaining treatments under this Section, should be alerted about this special caution.

[4] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

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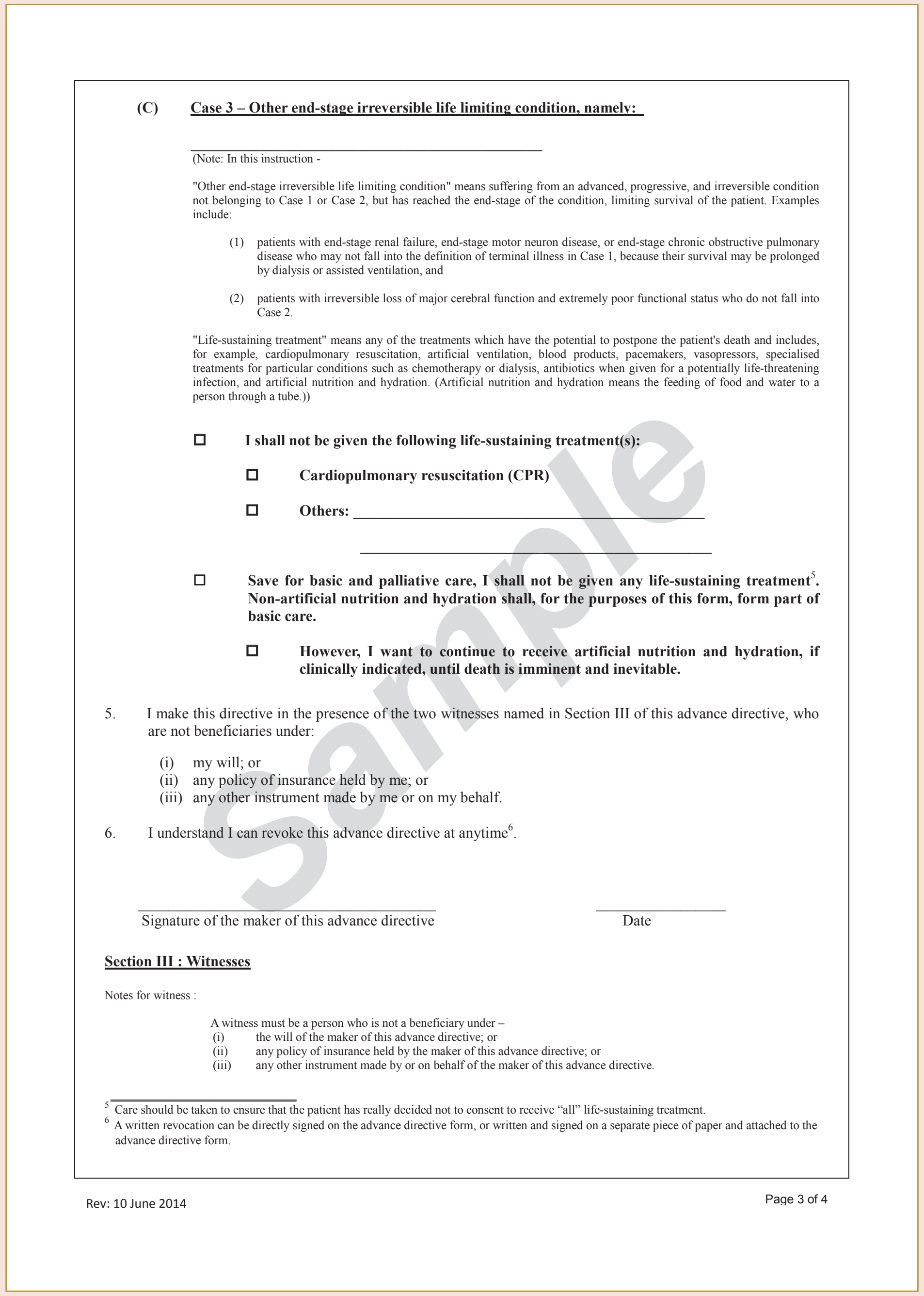

(C) Case 3 – Other end-stage irreversible life limiting condition, namely:

____

(Note: In this instruction -

"Other end-stage irreversible life limiting condition" means suffering from an advanced, progressive, and irreversible condition not belonging to Case 1 or Case 2, but has reached the end-stage of the condition, limiting survival of the patient. Examples include:

(1) patients with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease who may not fall into the definition of terminal illness in Case 1, because their survival may be prolonged by dialysis or assisted ventilation, and

(2) patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2.

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, 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, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

  ☐ **Cardiopulmonary resuscitation (CPR)**

  ☐ **Others:** ______________________________________

____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[5]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

  ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under:

   (i) my will; or
   (ii) any policy of insurance held by me; or
   (iii) any other instrument made by me or on my behalf.

6. I understand I can revoke this advance directive at anytime[6].

____
Signature of the maker of this advance directive

____
Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –
(i) the will of the maker of this advance directive; or
(ii) any policy of insurance held by the maker of this advance directive; or
(iii) any other instrument made by or on behalf of the maker of this advance directive.

---

[5] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

[6] A written revocation can be directly signed on the advance directive form, or written and signed on a separate piece of paper and attached to the advance directive form.

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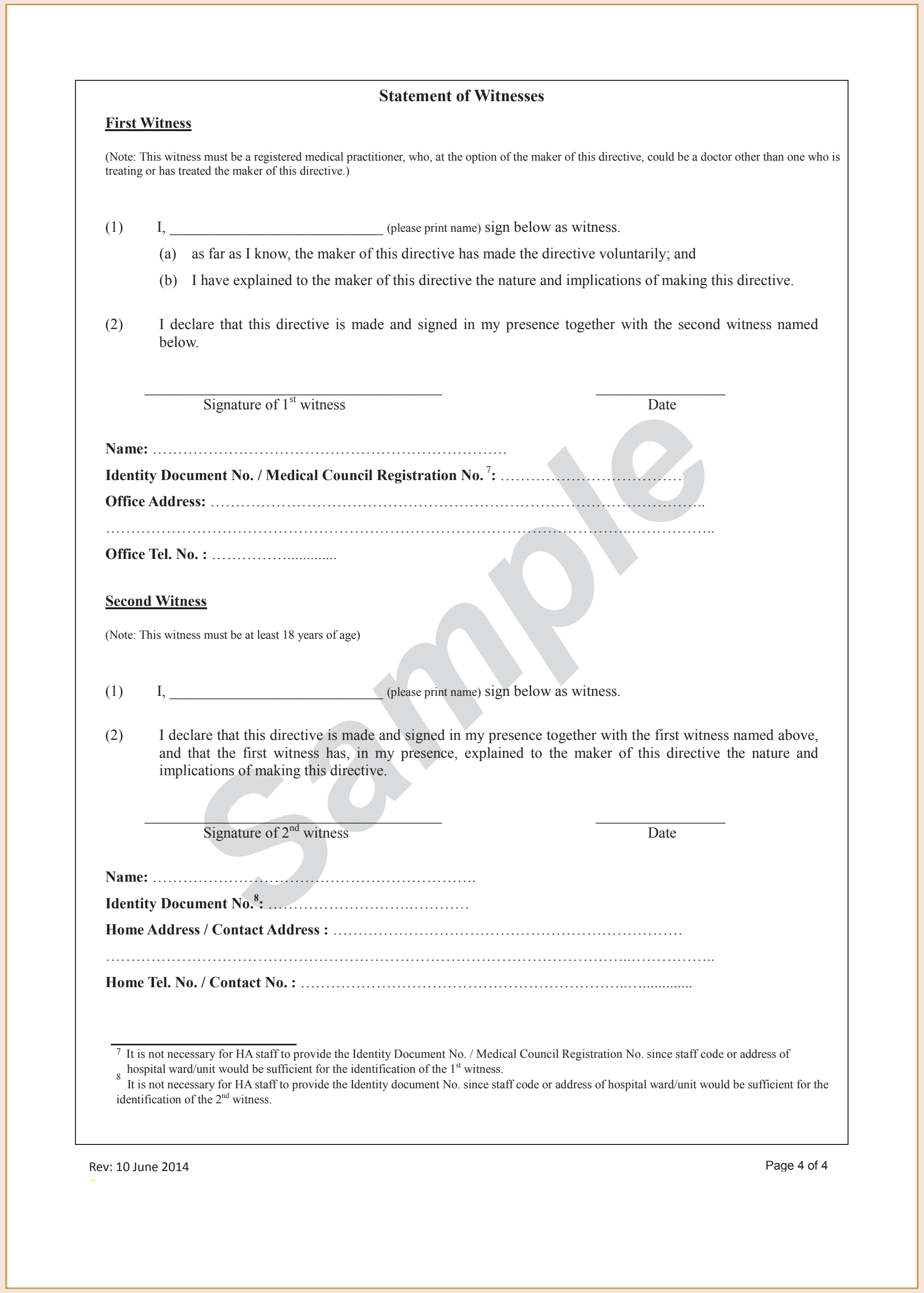

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

(1) I, _________________________ (please print name) sign below as witness.

  (a) as far as I know, the maker of this directive has made the directive voluntarily; and

  (b) I have explained to the maker of this directive the nature and implications of making this directive.

(2) I declare that this directive is made and signed in my presence together with the second witness named below.

____
Signature of 1st witness

____
Date

Name: ……………………………………………………………….

Identity Document No. / Medical Council Registration No. [7]: ……………………………….

Office Address: ……………………………………………………………………………………..

……………………………………………………………………………………………………..

Office Tel. No. : ……………............

Second Witness

(Note: This witness must be at least 18 years of age)

(1) I, _________________________ (please print name) sign below as witness.

(2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

____
Signature of 2nd witness

____
Date

Name: ……………………………………………………….

Identity Document No.[8]: ……………………………….

Home Address / Contact Address : ……………………………………………………………

……………………………………………………………………………………………………..

Home Tel. No. / Contact No. : …………………………………………………………..…...........

---

[7] It is not necessary for HA staff to provide the Identity Document No. / Medical Council Registration No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 1st witness.

[8] It is not necessary for HA staff to provide the Identity document No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 2nd witness.

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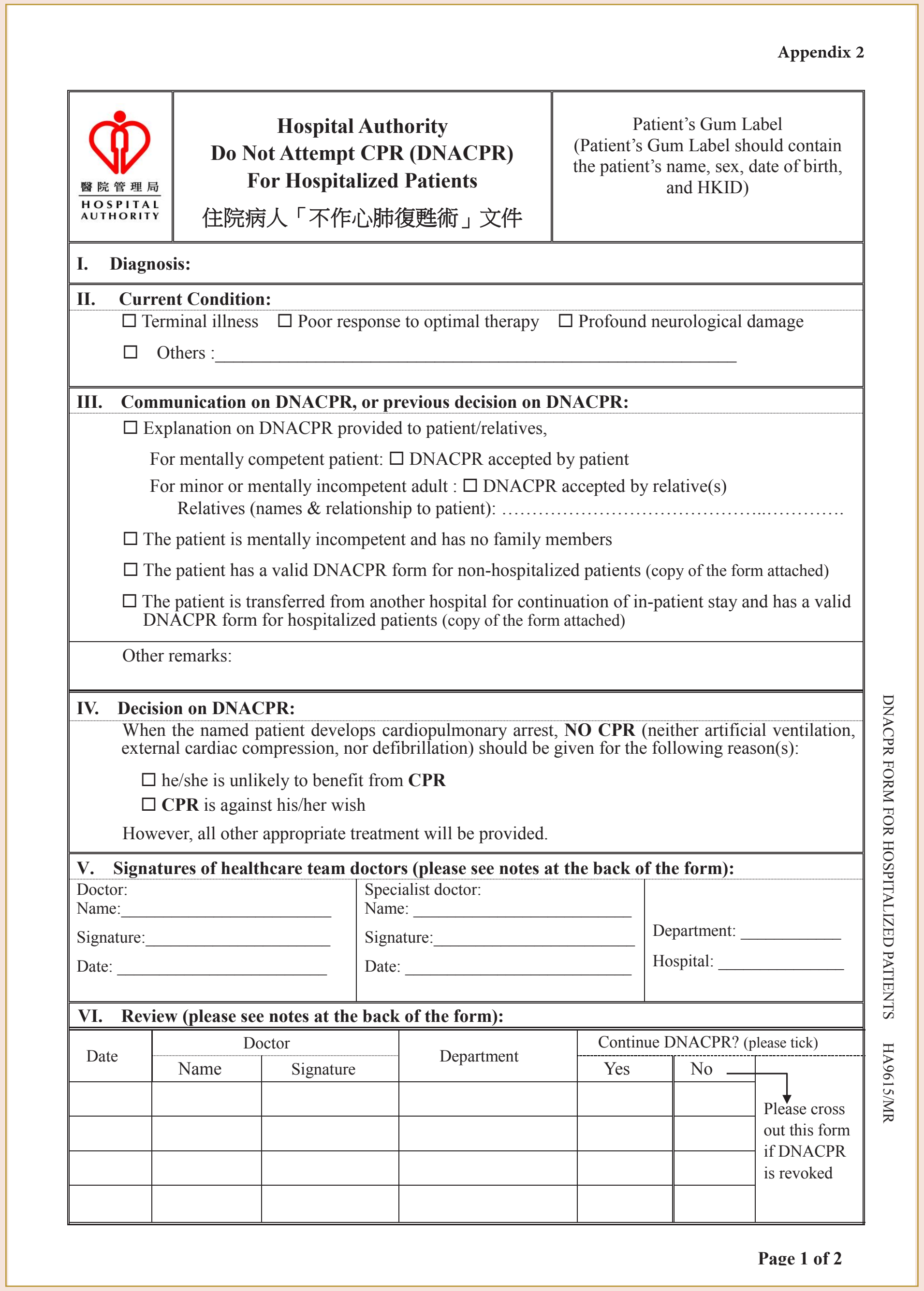
Sample of DNACPR Form for Hospitalised Patients



Appendix 2

Hospital Authority
Do Not Attempt CPR (DNACPR)
For Hospitalized Patients
住院病人「不作心肺復甦術」文件

Patient's Gum Label
(Patient's Gum Label should contain the patient's name, sex, date of birth, and HKID)

I. Diagnosis:

II. Current Condition:

☐ Terminal illness ☐ Poor response to optimal therapy ☐ Profound neurological damage

☐ Others :____

III. Communication on DNACPR, or previous decision on DNACPR:

☐ Explanation on DNACPR provided to patient/relatives,

For mentally competent patient: ☐ DNACPR accepted by patient

For minor or mentally incompetent adult : ☐ DNACPR accepted by relative(s)
Relatives (names & relationship to patient): ……………………………………..…………

☐ The patient is mentally incompetent and has no family members

☐ The patient has a valid DNACPR form for non-hospitalized patients (copy of the form attached)

☐ The patient is transferred from another hospital for continuation of in-patient stay and has a valid DNACPR form for hospitalized patients (copy of the form attached)

Other remarks:

IV. Decision on DNACPR:

When the named patient develops cardiopulmonary arrest, **NO CPR** (neither artificial ventilation, external cardiac compression, nor defibrillation) should be given for the following reason(s):

☐ he/she is unlikely to benefit from **CPR**
☐ **CPR** is against his/her wish

However, all other appropriate treatment will be provided.

V. Signatures of healthcare team doctors (please see notes at the back of the form):

Doctor:
Name:______________________
Signature:____________________
Date: ______________________

Specialist doctor:
Name: ______________________
Signature:____________________
Date: ______________________

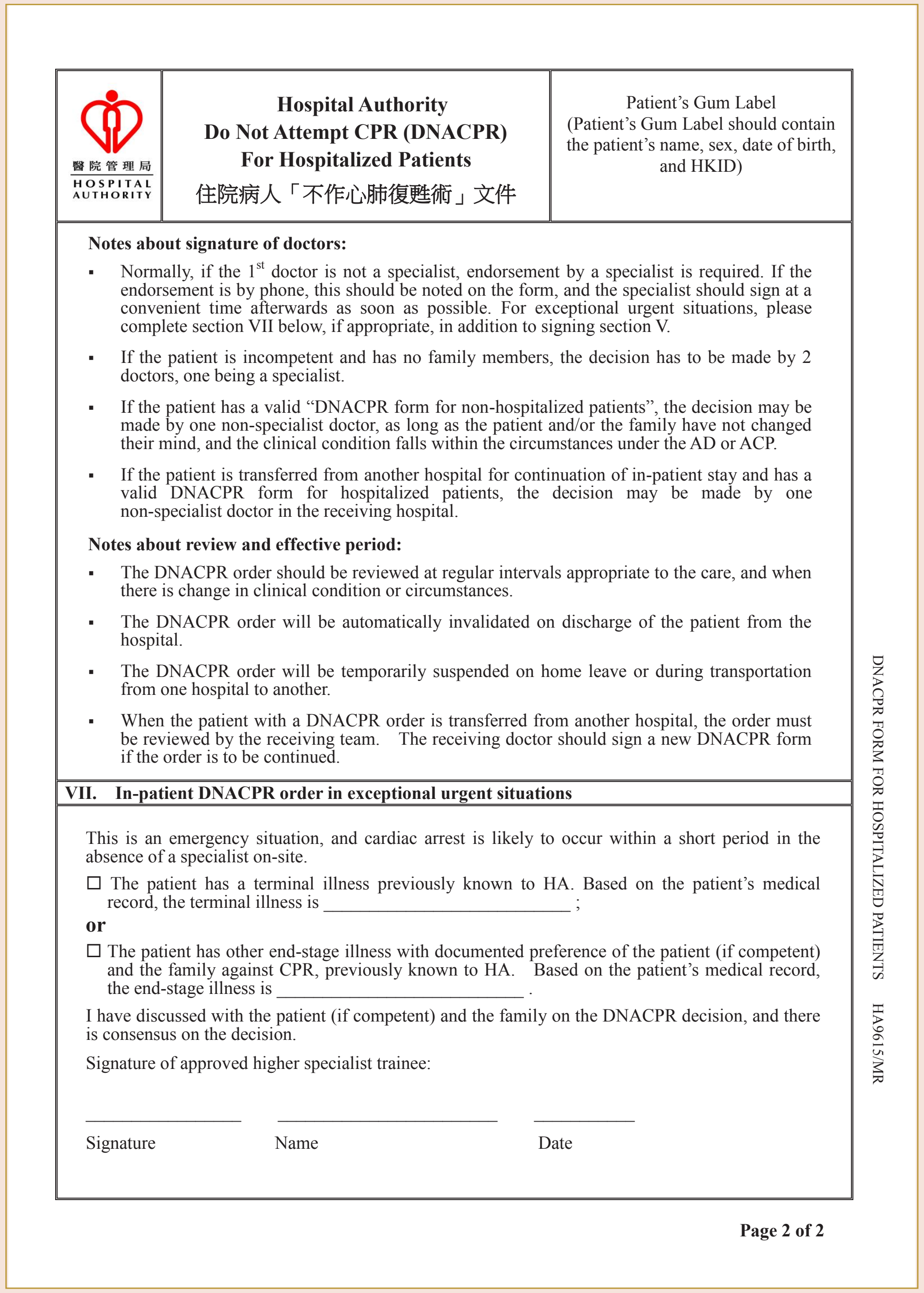
Department: ____________
Hospital: ______________

VI. Review (please see notes at the back of the form):

Date	Doctor		Department	Continue DNACPR? (please tick)		
	Name	Signature		Yes	No	
						Please cross out this form if DNACPR is revoked

DNACPR FORM FOR HOSPITALIZED PATIENTS HA9615/MR

Page 1 of 2



Hospital Authority
Do Not Attempt CPR (DNACPR)
For Hospitalized Patients
住院病人「不作心肺復甦術」文件

Patient's Gum Label
(Patient's Gum Label should contain the patient's name, sex, date of birth, and HKID)

Notes about signature of doctors:

- Normally, if the 1st doctor is not a specialist, endorsement by a specialist is required. If the endorsement is by phone, this should be noted on the form, and the specialist should sign at a convenient time afterwards as soon as possible. For exceptional urgent situations, please complete section VII below, if appropriate, in addition to signing section V.
- If the patient is incompetent and has no family members, the decision has to be made by 2 doctors, one being a specialist.
- If the patient has a valid "DNACPR form for non-hospitalized patients", the decision may be made by one non-specialist doctor, as long as the patient and/or the family have not changed their mind, and the clinical condition falls within the circumstances under the AD or ACP.
- If the patient is transferred from another hospital for continuation of in-patient stay and has a valid DNACPR form for hospitalized patients, the decision may be made by one non-specialist doctor in the receiving hospital.

Notes about review and effective period:

- The DNACPR order should be reviewed at regular intervals appropriate to the care, and when there is change in clinical condition or circumstances.
- The DNACPR order will be automatically invalidated on discharge of the patient from the hospital.
- The DNACPR order will be temporarily suspended on home leave or during transportation from one hospital to another.
- When the patient with a DNACPR order is transferred from another hospital, the order must be reviewed by the receiving team. The receiving doctor should sign a new DNACPR form if the order is to be continued.

VII. In-patient DNACPR order in exceptional urgent situations

This is an emergency situation, and cardiac arrest is likely to occur within a short period in the absence of a specialist on-site.

☐ The patient has a terminal illness previously known to HA. Based on the patient's medical record, the terminal illness is ______________________ ;

or

☐ The patient has other end-stage illness with documented preference of the patient (if competent) and the family against CPR, previously known to HA. Based on the patient's medical record, the end-stage illness is ______________________ .

I have discussed with the patient (if competent) and the family on the DNACPR decision, and there is consensus on the decision.

Signature of approved higher specialist trainee:

______________ ____________________ __________
Signature Name Date

DNACPR FORM FOR HOSPITALIZED PATIENTS HA9615/MR

Page 2 of 2

Sample of DNACPR Form for Non-Hospitalised Patients

To: Accident and Emergency Team

(Please fill in **either** English part **or** the Chinese part)

醫院管理局 HOSPITAL AUTHORITY

Do Not Attempt CPR
(DNACPR) Form
for Non-Hospitalized Patients
非住院病人「不作心肺復甦術」文件

Please Use Block Letter or Affix Label
SOPD / Hospital No.:..................................
Name:..
ID. No:................. Sex:.........Age:............
Dept::..........Team:........ Ward/Bed:..........

I. Diagnosis:

II. On the date of signing Part IV of the Form, we, the doctors of the certifying healthcare team (Please fill out either paragraph (A) or paragraph (B) below):

(A) ***For an adult with an advance directive (AD)*:**

have ascertained that the AD with a refusal of cardiopulmonary resuscitation (CPR) signed by this patient on _________________(date) is valid, and

hereby certify that this patient's clinical condition is that specified in the AD namely (please tick), he/she

- ☐ is terminally ill,
- ☐ is in irreversible coma or persistent vegetative state,
- ☐ has other end-stage irreversible life limiting condition: _________________________________, and

according to the AD, if this patient's condition falls within the circumstances under the AD and he/she suffers from cardiopulmonary arrest, neither artificial ventilation, external cardiac compression, nor defibrillation should be given.

(B) ***For a mentally incompetent adult without a valid AD or a minor*:**

certify that this patient (please tick)

- ☐ is terminally ill,
- ☐ is in irreversible coma or in a persistent vegetative state,
- ☐ has irreversible loss of major cerebral function and extremely poor functional status,
- ☐ in the case of a minor, has other end-stage irreversible life limiting condition,

and that

this patient's current clinical condition and advance care planning (ACP) have been discussed: (please tick)

- ☐ between the healthcare team looking after this patient and the family of this patient (who is a mentally incompetent adult)
- ☐ between the healthcare team looking after this patient and the parent(s) of this patient (who is a minor)

and that

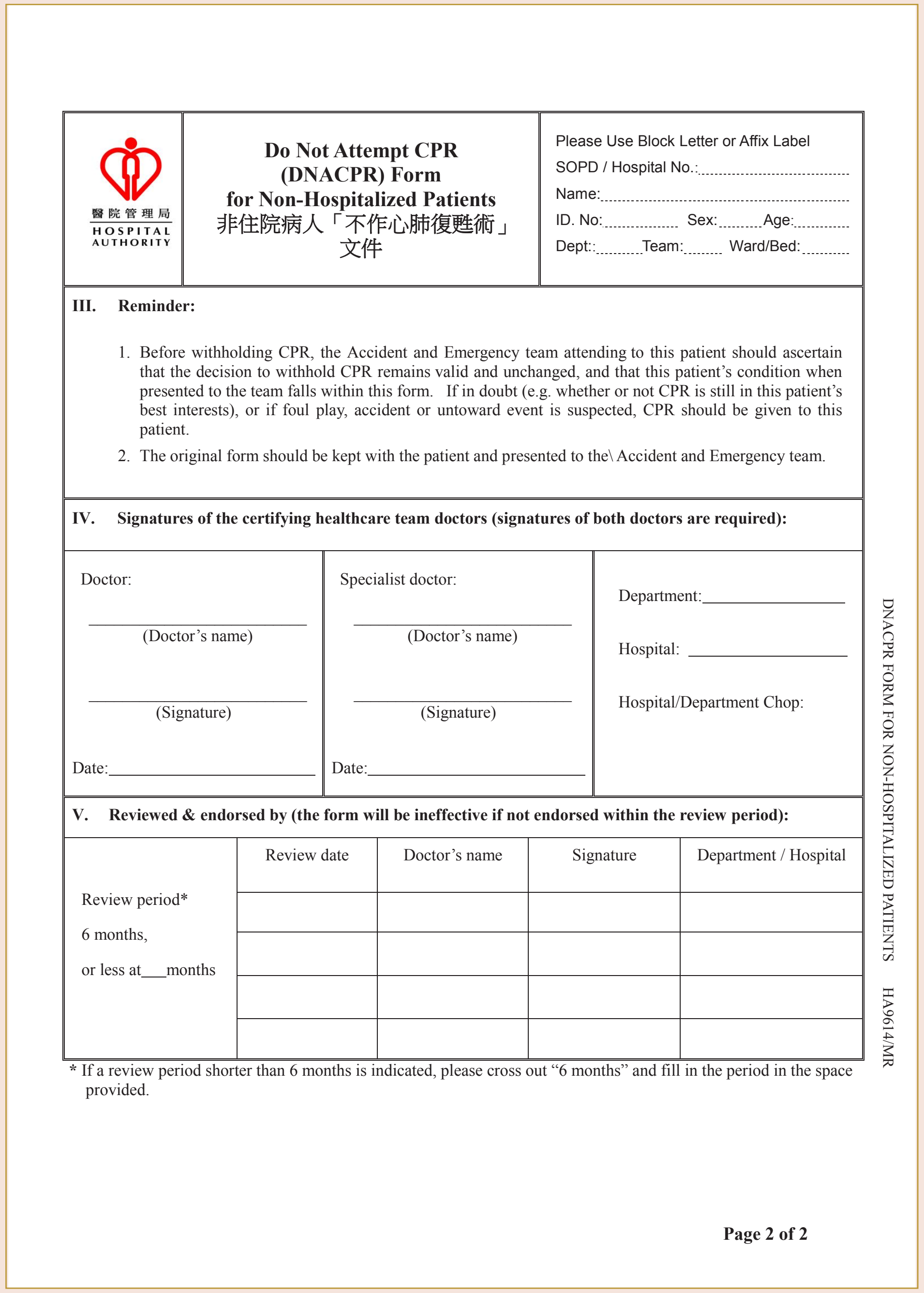
agreement has been reached that if this patient suffers from cardiopulmonary arrest, it would be in this patient's best interests that neither artificial ventilation, external cardiac compression, nor defibrillation should be given.

The family (or parents) of this patient confirms the agreement with the DNACPR decision (for paragraph (B) only).

Signature:_______________________________ Date: ________________________________
Name:__________________________________ Relationship with patient :_____________________

DNACPR FORM FOR NON-HOSPITALIZED PATIENTS HA9614/MR

Page 1 of 2



醫院管理局 HOSPITAL AUTHORITY

Do Not Attempt CPR
(DNACPR) Form
for Non-Hospitalized Patients
非住院病人「不作心肺復甦術」文件

Please Use Block Letter or Affix Label
SOPD / Hospital No.:..................................
Name:..
ID. No:................. Sex:.........Age:............
Dept::..........Team:........ Ward/Bed:..........

III. Reminder:

1. Before withholding CPR, the Accident and Emergency team attending to this patient should ascertain that the decision to withhold CPR remains valid and unchanged, and that this patient's condition when presented to the team falls within this form. If in doubt (e.g. whether or not CPR is still in this patient's best interests), or if foul play, accident or untoward event is suspected, CPR should be given to this patient.
2. The original form should be kept with the patient and presented to the\ Accident and Emergency team.

IV. Signatures of the certifying healthcare team doctors (signatures of both doctors are required):

Doctor:
____
(Doctor's name)
____
(Signature)
Date:_________________________

Specialist doctor:
____
(Doctor's name)
____
(Signature)
Date:_________________________

Department:_________________
Hospital: _________________
Hospital/Department Chop:

V. Reviewed & endorsed by (the form will be ineffective if not endorsed within the review period):

	Review date	Doctor's name	Signature	Department / Hospital
Review period* 6 months, or less at___months				

* If a review period shorter than 6 months is indicated, please cross out "6 months" and fill in the period in the space provided.

DNACPR FORM FOR NON-HOSPITALIZED PATIENTS HA9614/MR

Page 2 of 2

ACP Handbook

The CUHK Jockey Club Institute of Ageing published an ACP handbook to promote and enhance public awareness of ACP. The handbook provides concepts and information on ACP and AD and can be used to assist the public when considering their preferences of medical and personal care, expression of values and beliefs, and designated family member for future consultation if they become mentally incapable in the future. Healthcare professionals can use this handbook to facilitate ACP conversation with patients and their family members.

賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

晚晴照顧手冊

姓名：________　填寫日期：________

策劃及捐助 Initiated and Funded by
香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER
合作院校 Partner Institution
香港中文大學
The Chinese University of Hong Kong
CUHK Jockey Club Institute of Ageing

人生晚期照顧的意向

晚晴照顧手冊

當自己患上嚴重疾病或病情到了晚期，而須要作出醫療決定時，您會選擇：

□ 延長生命，即使有可能承受更多痛楚或不適

□ 紓緩痛楚及不適，即使有可能更快面對死亡／不能延長生命

10

To Download the ACP handbook

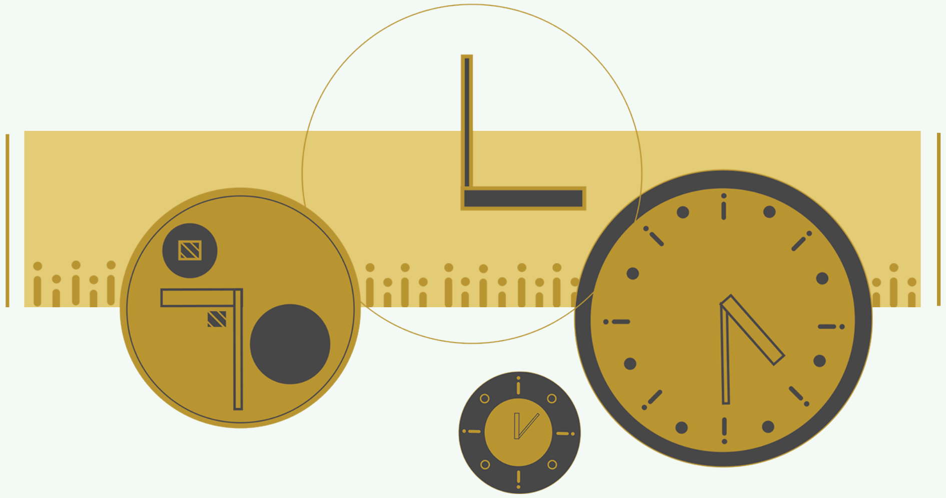
Link

https://www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/ACP-handbook.pdf

QR code

BUILDING CAPACITY FOR
END-OF-LIFE CARE
IN HONG KONG
TRAINING KIT FOR HEALTHCARE PROFESSIONALS

Chapter 3

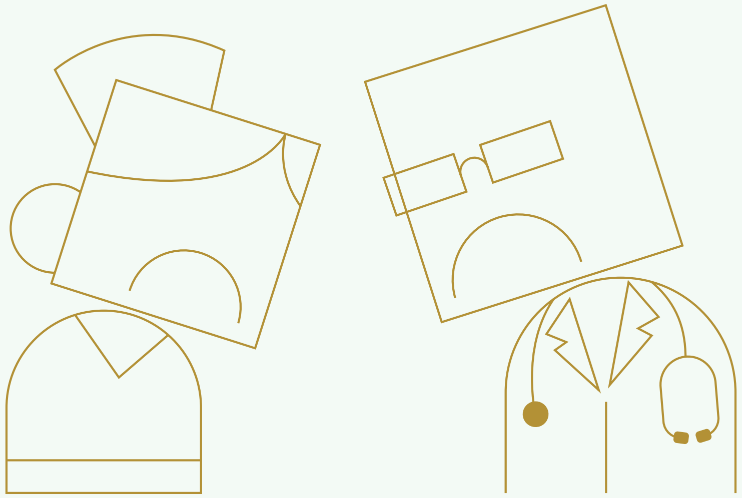


Bioethics of End-of-Life Care

3.1 Moral Distress Experienced by Healthcare Professionals

Moral Distress

Moral distress is a negative condition experienced by healthcare professionals when they know the right thing to do, but institutional constraints make it challenging to pursue the right course of action.[43] It differs from compassion fatigue and stress of work, although these may be experienced simultaneously.[44] Repeated and unaddressed situations of moral distress over time cause a gradual crescendo of moral residue, the lingering feelings of distress that may continue for months and even years after a morally distressing situation ends.[45] This 'crescendo effect' of repeated moral distress and build-up of moral residue undermines the professional commitment and integrity of healthcare providers.[46]



Prevalence of Moral Distress

Moral distress is a phenomenon affecting many healthcare professionals. Previous studies found that moral distress was present across various professions, including physicians, nurses, social workers, pharmacists and other allied health professionals.[47] It is also prevalent in medical students and junior practitioners.[48]

In Hong Kong, the CUHK Nethersole School of Nursing conducted a survey to examine the extent of moral distress experienced by nurses in the acute hospital setting in 2016.[49] The Moral Distress Scale-Revised (MDS-R) was used to measure the level of moral distress in the survey. MDS-R is a 21-item scale describing various ethically challenging situations and the resulting score based on the 21 items has a range of 0 to 336.[45] As shown in Figure 10, moral distress among nurses was reported across different specialties, including oncology, surgical, ICU and Accident & Emergency Departments.

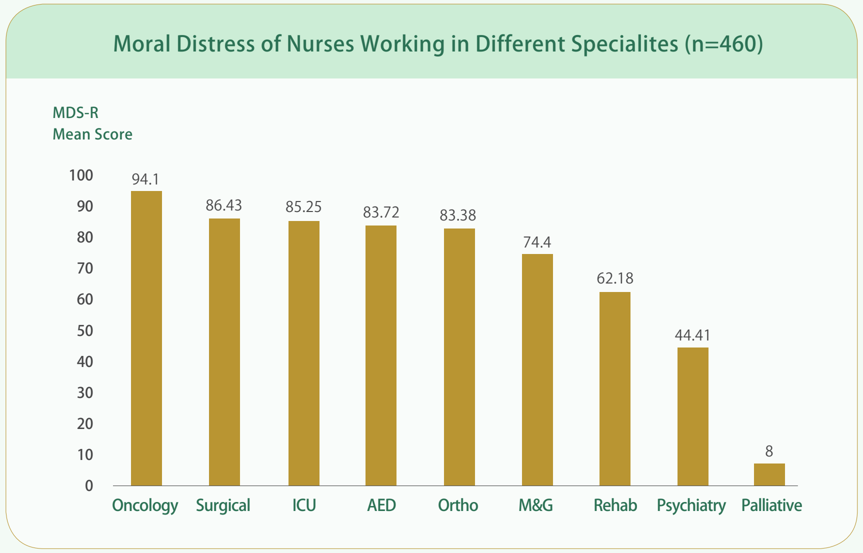
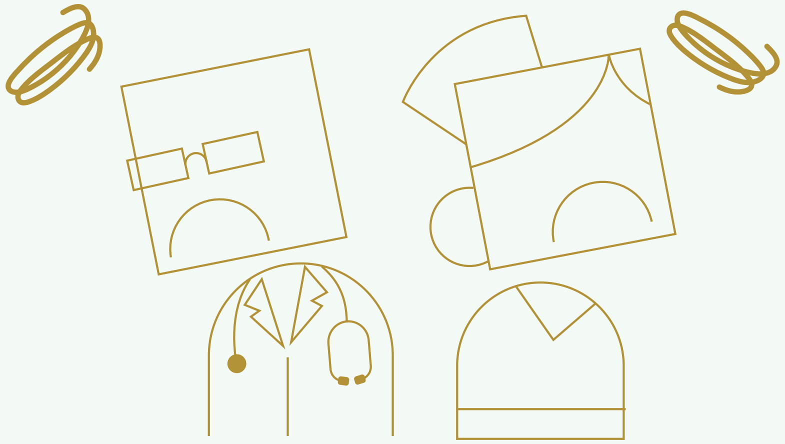


Figure 10. Moral Distress of Nurses Working in Different Specialties

Common Causes of Moral Distress[50,51]

- Continued life support, even though it is not in the best interest of the patient
- Inadequate communication about EOL care among healthcare service providers, patients and families:
  - Poorly defined treatment goals
  - Disregard for the patient's EOL wish
  - Incomplete/inaccurate disclosure of information
  - Lack of informed consent
- Objectification of patients
- Intra-professional conflict
- Lack of staffing or staff who are not adequately trained to provide the required care
- Inadequate pain relief measures provided to patients
- False hope given to patients and families



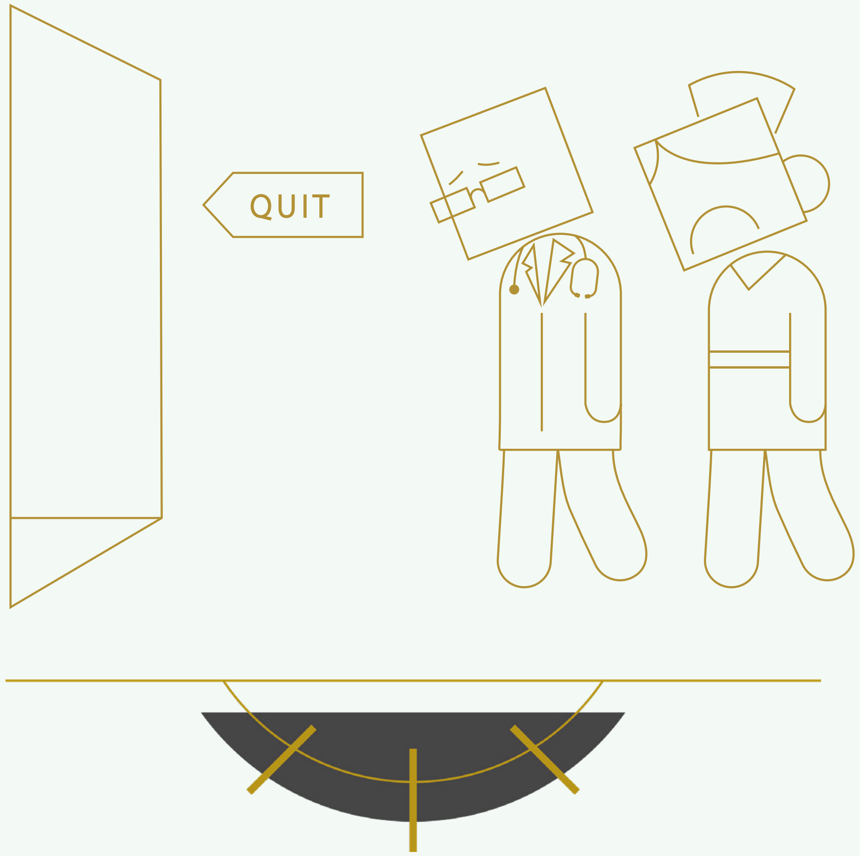
The survey conducted by the CUHK Nethersole School of Nursing in 2016 also examined the common causes of moral distress experienced by nurses in the acute hospital setting in Hong Kong.[49] The survey found that most of the MDS-R items with the highest scores were related to EOL care (Figure 11).[49,52] Moral distress arises when nurses perceived a gap between the provision of quality EOL care and the care that patients received in reality.[52]

Top five MDS-R item	
1	Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient.
2	Carry out the physician's orders for what I consider to be unnecessary tests and treatments.
3	Initiate extensive life-saving actions when I think they only prolong death.
4	Continue to participate in care for a hopelessly ill person who is being sustained on a ventilator, when no one will make a decision to withdraw support.
5	Work with nurses or other healthcare providers who are not as competent as the patient care requires.

Figure 11. Top Five MDS-R Items (n=460)

Impacts of Moral Distress[47,53]

- Emotional withdrawal from patients and co-workers
- Painful feelings, such as anger, guilt, depression and perhaps physical symptoms
- Causes poor job satisfaction, absenteeism and low workplace morale
- May be associated with poor staff retention because healthcare professionals perceive themselves as moral agents but fail to fulfil the moral obligations, resulting in compromised professional integrity



Addressing Moral Distress: Develop Ethical Competence

- Use the 4A Approach (Figure 12) to address and reduce moral distress[51,54,55]

Ask

Review the definition and symptoms of moral distress and ask yourself if you are experiencing moral distress. Are your colleagues exhibiting signs of moral distress as well?

Affirm

Affirm your feelings about the issue. What aspect of your moral integrity is being threatened? What role could (and should) you play?

Assess

Begin to put some facts together. What is the source of your moral distress? What do you think of the 'right' action and why is it so? What is being done currently and why? Who are the players in this situation? Are you ready to act?

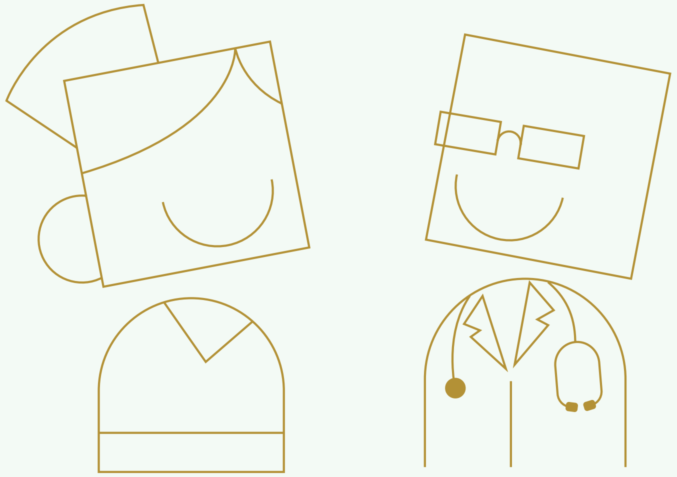
Act

Create a plan for action and implement it. Think about potential pitfalls and strategies to get around these pitfalls.

Figure 12. The 4A Approach to Addressing Moral Distress

Possible Strategies for Addressing Moral Distress[51]

Strategy	Implementation
Speak up	Identify the problem, gather the facts and voice your ethical concerns in a proactive way
Be deliberate	Know who you need to speak with and know what you need to speak about
Be accountable	Sometimes our actions are not quite right. Be ready to accept the consequences.
Build support networks	Find colleagues who support you or who support acting to address moral distress. Speak with one authoritative voice.
Participate in moral distress education	Attend forums and discussions about moral distress. Learn all you can about it.



- Understand and apply Moral Principles to serve as a basis for reason analysis of and justification for making a decision or taking an action[56]

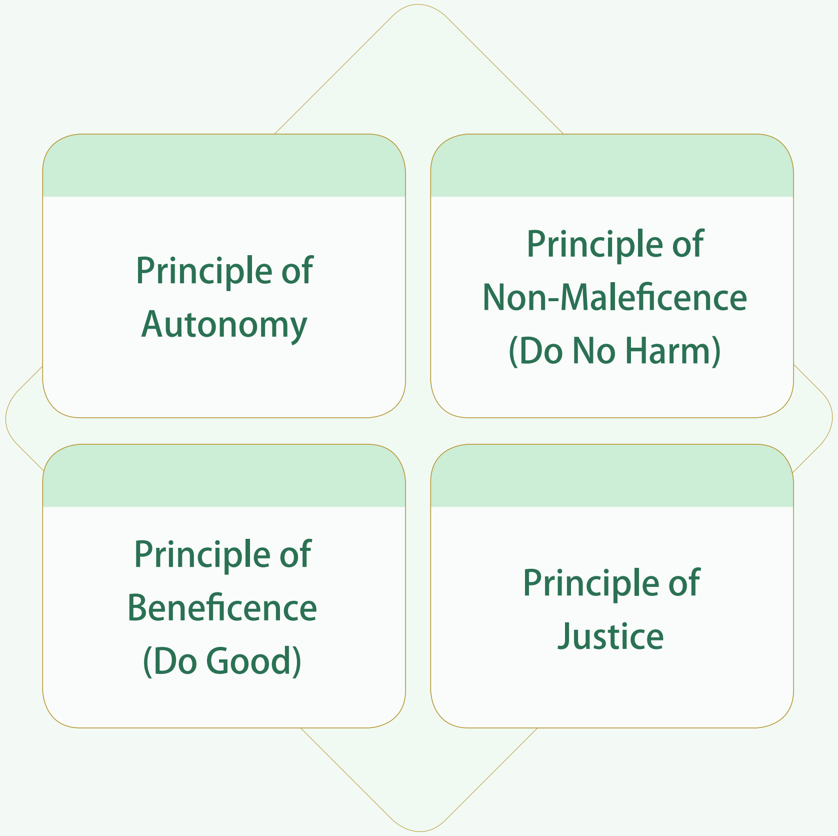
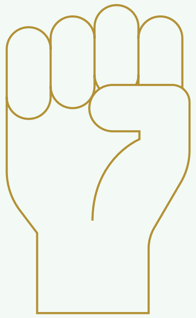


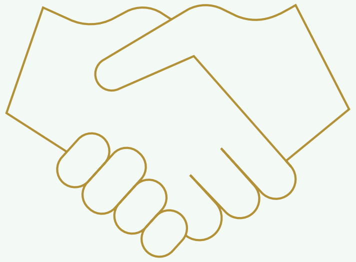
Figure 13. Four Moral Principles

Principle of Autonomy



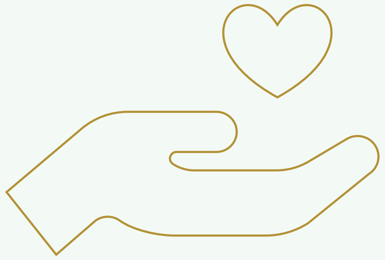
The Principle of Autonomy calls for the patient to be the decision maker. In other words, the patient has the right to self-determination. This presumes a decision maker who has the required information, capacity and circumstances to make rational decisions. Respect for autonomy requires the healthcare professionals to provide adequate information in an understandable language. Respect for autonomy underpins the concepts of informed consent, confidentiality and truth-telling about prognosis, treatment options and side effects. The patient's decisions must be respected by everyone, even if those decisions may not be in the best interest of the patient.

Principle of Non-Maleficence (Do No Harm)



The Principle of Non-Maleficence states that healthcare professionals should not inflict harm to the patient intentionally. Healthcare professionals should help the patient avoid any prolonged suffering due to futile interventions and they should fully consider the risks and harms of interventions. For example, a patient should not be provided futile treatment that is unlikely to benefit them if the treatment results in sustaining permanent unconsciousness.

Principle of Beneficence (Do Good)



The Principle of Beneficence states that healthcare professionals should advocate for what is the patient's welfare and interests, such as preserving life, relieving suffering and limiting disability.

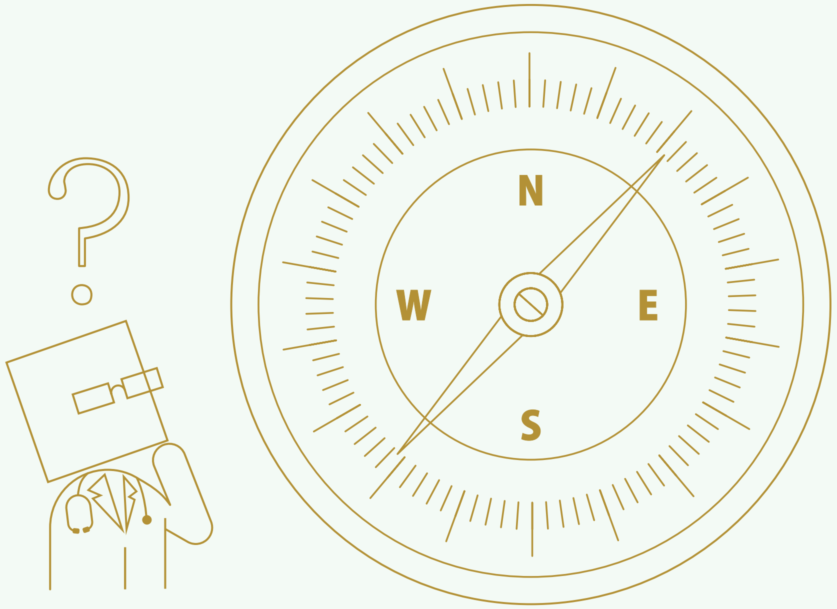
Principle of Justice

The Principle of Justice demands fairness in the delivery of healthcare service. It may apply on a societal level by assuring a just distribution of healthcare resources. It may also apply to an individual patient, who should not be unfairly treated (discriminated) based on disability, age, social status, etc. Moreover, an individual cannot claim unlimited right (e.g. to be treated at all costs) without consideration of the impact on other people or of the scarcity of resources.

It is sometimes not easy to make good use of the four principles.[57] They are not absolutely binding. Relevant principles have to be weighed and balanced in situations of conflict. Considerations are context-dependent and are related to the local legal and cultural situations.[57]

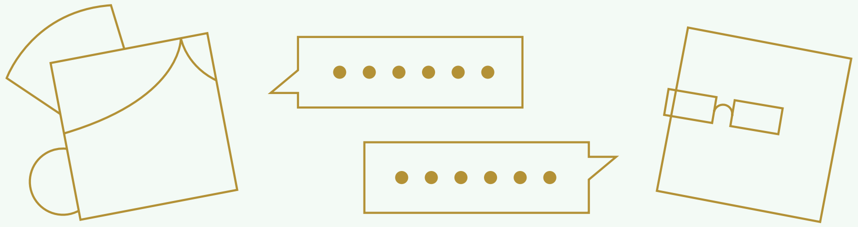
Examples of when to use the four moral principles[57]

- Example 1: a patient demands a medical treatment. If the treatment has minimal benefit, but will definitely cause a lot of harm, the Principle of Non-Maleficence may override the Principle of Autonomy.
- Example 2: a mentally competent patient refuses to receive a medical treatment. Respect for autonomy prevails over other considerations.
- Example 3: if the expected benefit of a treatment is minimal but the cost is very expensive. The Principle of Justice has to be considered in a public system.



Addressing Moral Distress: Discuss and Build Consensus with Colleagues

- Value judgements are often involved. Healthcare professionals should:
  - Stay open-minded
  - Build consensus
- Understand the goals to be achieved:
  - What is in the best interest of the patient
- When conflicts arise among different parties
  - Respect the values, opinions and responsibilities of other healthcare professionals
  - Clarify incorrect information and adjust unrealistic expectations
  - Be receptive to the values of the patient
  - Address relevant questions step by step



Addressing Moral Distress: Seek Organisational Support for Difficult Cases

- Refer to institutional guidelines as a backup to the healthcare professionals when facing challenges to the final decision-making
- Consult clinical ethics committees to clarify ethical concerns and moral obligations

3.2 Cases on Ethical Decision-Making in End-of-Life Care

The CUHK Jockey Club Institute of Ageing, in collaboration with the CUHK Centre for Bioethics, have developed the following cases, based on real-life scenarios, including ‘family requests to withhold the truth from a patient’, ‘disagreements over timings for ACP’ and ‘challenges experienced during careful hand feeding’. They are selected in consultation with healthcare and social care professionals serving older adults in hospitals, clinics and the community to present common, yet challenging, ethical situations that arise in Hong Kong. An expert commentary for each case provides a perspective on the ethical challenges and a practical clinical approach. Apart from the above three cases, healthcare professionals can also visit the following website or scan the QR code to read more cases on ethical decision-making in EOL care for reference.

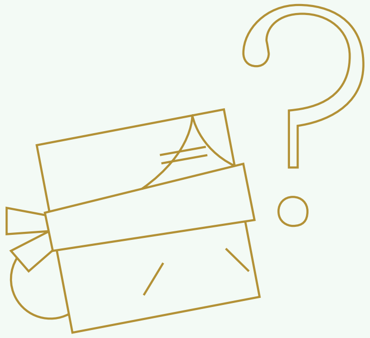
Link

http://www.ioa.cuhk.edu.hk/en-gb/casebook/cases

QR code

3.2.1 Family Requests to Withhold the Truth from Patient

Case Description



Mrs Kwok has been healthy her whole life. At the age of 88, she takes regular walks in her neighbourhood and does some cooking and light housework in the home. She lives with her husband and her eldest son’s family. She also has a younger son and a daughter and enjoys visits from her many grandchildren. About a week ago, she developed abdominal pain, nausea and vomited a few times. Her oldest son, Chung Man, brought her to the hospital and she was admitted to the medical ward.

A CT scan of her abdomen showed evidence of bowel obstruction from a mass in her colon. A nasogastric tube was placed for decompression and dark green bilious fluid immediately drained into the collecting container. A colonoscopy with biopsy was subsequently performed which confirmed the diagnosis of colorectal cancer. Upon seeing the biopsy report, the medical officer, Dr Leung, went to speak with the patient. He found the patient asleep in her bed while Chung Man sat beside her.

The doctor informed Chung Man of the diagnosis. Looking concerned, he asked, “What can be done, doctor? How can we let her eat? She can’t keep anything down now.” Dr Leung replied, “We’ll need to ask our surgery consultant to see your mother first before we know what treatment options would be best for her.”

Chung Man replied, “Ok. Doctor, please don’t tell my mother about the diagnosis. I don’t want to upset her and cause her to be overly anxious.”

Dr Leung nodded. He had wondered whether the patient has any cognitive impairment as she seemed to have some trouble with her memory and wasn't sure about her decision-making capacity anyway. He asked a geriatrics consultant to assess her cognitive status.

After a thorough evaluation, the geriatrics consultant thought Mrs Kwok has mild cognitive impairment but felt that she has capacity to make medical decisions about treatments for the cancer. The geriatrician then asked the patient whether she would like to find out from the doctors about her condition. Mrs Kwok shook her head. "No, I don't need to know. You should just tell everything to my son."

Then the geriatrician pressed on, "If you don't know about your condition, then you wouldn't be able to make good decisions about your care." To that, Mrs Kwok replied, "I want Chung Man to make all decisions for me. I'm too old. I don't know very much and these medical things are too complicated for me. I trust my son would know what to do."

The next day, the surgeon saw Mrs Kwok and recommended surgical resection of the mass to the team. However, when Dr Leung informed the surgeon that the patient does not know about her condition and prefers not to find out and defers all decision-making to her son, the surgeon was unwilling to comply. He responded, "How can we keep the truth from a competent individual, especially one who we may be doing surgery on? I do not feel comfortable cutting into the body of someone who did not agree to the surgery herself. What will happen when the patient wakes up and finds a big incision in the middle of her abdomen? We cannot lie to her!"

Dr Leung is unsure whether or not to tell the patient the truth.

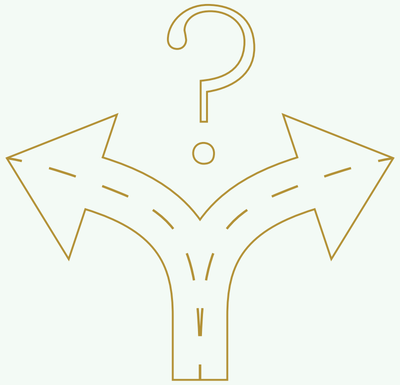
Commentary

Dr TSE Chun Yan, Chairman, HA Clinical Ethics Committee (2005–2017)

The Role of the Family in Decision-Making in Chinese Society

The case illustrated the importance of cultural factors in ethical dilemmas related to breaking bad news. Here, there was discordance between the view of the patient's son and the surgeon. Mrs Kwok's son did not want the patient to know in order to protect the patient from psychological harm. Such an attitude has been common in Chinese families, and ethicists have raised the concepts of protective truthfulness and family determination to justify deceiving a patient who wants to know the truth.

It is true that, in traditional Chinese culture, major decisions are often made by the whole family together. But this does not necessarily mean excluding the patient, and some have questioned whether the Principle of Non-Maleficence can really override the Principle of Autonomy in such a situation. However, in this particular case, the view of Mrs Kwok herself was in line with her son. She did not want to know, and wanted her son to make treatment decisions for her. In this case, can we simply follow the wish of the patient and her son?



Psychological Harm to the Patient

Firstly, let us look at psychological harm to a patient from truth disclosure in general. To balance the Principles of Non-Maleficence and Autonomy, we have to answer two questions:

a. Can non-disclosure actually avoid psychological harm?

There is little evidence that terminally ill patients who are not told the truth die happily in blissful ignorance. When the patients guess the diagnosis and prognosis themselves, psychological harm will still occur. There could be extra harm to patients who guessed the diagnosis themselves. A conspiracy of silence usually results in a heightened state of fear, anxiety and confusion. It undermines trust towards the clinical team, and breaks down communication with family members. Patients are unable to obtain information they want to know, express emotions after guessing the diagnosis, obtain appropriate psychological and spiritual support, or make suitable plans for their limited future with the family. Worse still, patients may pretend that they do not know in order to please family members.

b. Are there ways to reduce the harms of truth disclosure?

Experience, especially in palliative care, has shown that sensitive, skilled communication coupled with good psychological, social and spiritual support can reduce the harm of breaking bad news.

This would mean that if the patient wants to know, the doctor should disclose the truth in the aforementioned manner rather than deceive the patient and let the patient guess the diagnosis himself/herself.

Nonetheless, we still need to address the culture issue. We should respect the desire for family involvement in the communication and decision-making process. The approach must also be individualised. Although recent studies have shown that most Chinese patients want to know the diagnosis, there could be a small number of patients who do not want to know. We need to sensitively explore what the patient already knows and how much he/she wants to know. Those who do not want to know may have denial or avoidance as a defence mechanism, and we should not break the defence mechanism without appropriate support. To respect the patient, we may withhold information, but we should not lie. We also need to reassess the situation as the disease progresses.

Legal Reasons for Disclosure

Secondly, we need to know whether there are legal reasons why disclosure has to be made. For a mentally competent patient, it is a legal requirement that a doctor must obtain consent from the patient before providing medical treatment. According to the Hong Kong Medical Council Code of Professional Conduct, consent is valid only if (a) it is given voluntarily, (b) the doctor has provided proper explanation and (c) the patient properly understands. This implies that in order to proceed with the operation the patient has to be properly informed and to consent to the treatment. The decision cannot be delegated to the family. Does it mean that we should simply disregard the view of the patient and her son and disclose the bad news?

A Pragmatic Approach

In this particular situation, we can overcome the apparent dilemma by taking a step-by-step pragmatic approach.

Step 1:

We start off by discussing with the son about whether surgery should be done for the patient. There should not be a confidentiality problem because this was the request from the competent patient herself. If the son agrees to surgery, we then move onto step 2.

Step 2:

We then explain to the son sensitively that, legally, the patient has to be properly informed and consent to surgery before surgery can be done. We also explain that it is actually better to disclose the diagnosis and explain the operation to the patient sensitively, rather than have the patient find out herself what is wrong and what has been done. If the son agrees, we then move onto step 3.

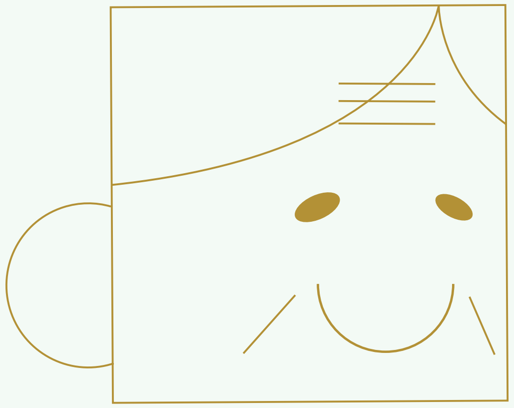
Step 3:

We then explain to the patient sensitively that the doctor has followed her request to discuss with her son and her son has decided that surgery should be done for her condition. However, she needs to consent to the operation herself, and thus the doctor has to discuss with her directly. If the patient agrees, we then move onto step 4.

Step 4:

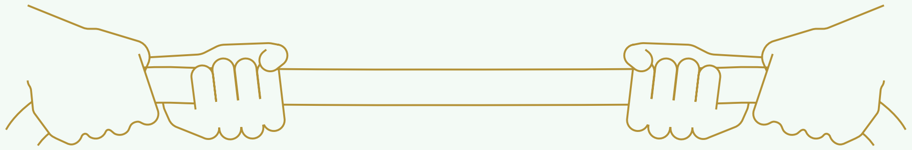
We then break the bad news to the patient sensitively and discuss the treatment plan to obtain a proper consent. Appropriate support to the patient should be given along the way.

Going through these steps and with agreement from the son and the patient, the disclosure does not violate any ethical principles. If the son does not agree, or if the patient still does not want to discuss the illness, further discussions should involve a senior clinician with good knowledge and skills in breaking bad news. One should try to explore the concerns of the son and the patient, to assess any misconceptions, denial and anxiety, and to provide clarification and support. At the end, one should be able to succeed.



3.2.2 Disagreements over Timing for ACP

Case Description



Mr Chau is a 75-year-old man who lives at home with his wife and his son's family. He was a former smoker and suffered from COPD for many years. Over the past year, he has become more easily short of breath with routine activities like walking around his home, dressing himself or taking a shower. He has also experienced more frequent exacerbations that led to several hospitalisations. In the last 6 months, he's already been admitted three times. Each time, he was put on a BiPAP machine for several days before his condition improved.

Last week, Mr Chau was admitted again for another exacerbation of his COPD. After a week of treatment in the respiratory ward, he was finally able to come off the BiPAP mask. However, when the food tray was delivered to Mr Chau, he pushed the food away. Ms Leung, a registered nurse in the ward, saw this and recognised Mr Chau from previous admissions. She approached Mr Chau to ask why he didn't want the food.

Mr Chau answered, "What's the point of eating? Just to keep coming back like this and be put on that mask? I'm as good as dead!"

Concerned, Ms Leung asked Mr Chau, "Is something wrong? I thought you'd be glad to come off the mask today."

Mr Chau said, "Well, it's just temporary. I know how bad things are with my lungs. It's just a matter of time. I just don't want to go through the same ordeal over and over again, in and out of the hospital. Then one day, game over. If I'm going to die anyway, I don't want to be strapped to that mask up the final moment! You know how awful it is to be on the mask? You can't eat. You can't talk. It just blows air into your face!"

"It sounds like you're really concerned about being put on that mask again," Ms Leung said.

"Yeah. I don't ever want to wear it again! Just let me go without making me suffer through all that! I've had enough!"

"Have you told your family how you feel?" asked Ms Leung.

"I tried. But my wife and son...they won't listen. They don't want me to talk so negatively. They said that I should just listen to the doctor. The doctor barely even has time to talk to me!"

Feeling that Mr Chau is probably correct about the advanced stage of his lung disease and that he's reasonable to prefer to be comfortable at this point, Ms Leung decides to discuss Mr Chau's concerns with Dr Kam, the doctor-in-charge. She suggested that Dr Kam should hold a family conference to explain his poor prognosis with his wife and son and to sign an AD for Mr Chau.

However, Dr Kam disagreed. "It's too premature to sign any AD and discuss EOL care issues. Mr Chau's condition can still be relieved by the current treatments. He's ready for discharge soon!"

Ms Leung felt powerless and does not know how she can help Mr Chau.

Commentary

Dr Derrick AU Kit Sing, Director, CUHK Centre for Bioethics

We may discuss this case as a scenario of moral distress in which the nurse Ms Leung felt powerless for being unable to do what she considered the right thing for the patient, as the doctor-in-charge held a strong opposite view on what was right.

Ms Leung's suggestion was to hold a family conference to explain the poor prognosis to the family, and to sign an AD for the patient.

Before considering her moral distress, it is useful to take a step back to ask a few questions.

How does Ms Leung know that her suggestion is the right thing for the patient?

One point is in Ms Leung's favour – Mr Chau has tried but failed to get his family to talk about this issue. We can therefore be quite certain that a dialogue is what he wants. Note that the patient's readiness is an important consideration in deciding on the timing for ACP.

Was the doctor-in-charge Dr Kam wrong?

Dr Kam seemed to have bundled 'discussing EOL issues' with 'signing AD'. In discussing EOL care issues and allowing the patient to express his/her wishes and values, the ACP process may or may not end up with signing an AD. In a fast-paced hospital operation, squeezing in the signing of AD into the short pre-discharge window may indeed be undesirable, but it is a reasonable time to initiate a dialogue with the patient and the family. Key decisions on withholding life-sustaining treatment such as BiPAP do not have to be forced into one session, but encouraging family members to listen to the patient may be achievable.

Note that in this case the nurse Ms Leung apparently also fell into the same trap of bundling EOL care planning with the immediate decision to sign an AD. Had she put forth the suggestion to initiate a dialogue rather than immediately holding a family conference to sign an AD, she might have had a better chance of getting her suggestion supported.

Was it just about the BiPAP mask?

Mr Chau was particularly vivid in articulating the burden of BiPAP, but he also questioned the point of eating, and expressed in general that he did not wish to go through the same ordeal over and over again, in and out of the hospital. It would be valuable to explore more about Mr Chau's perspectives on medical care. Rather than narrowing the focus on his dislike of BiPAP, the clinical team can find out what medical care Mr Chau considers too burdensome or intolerable and what he hopes the care to focus on, to develop a plan that honours his wishes appropriately.

Some assessment of his mood may also be called for. Depressive state is not uncommon in patients with advanced organ failure, if significant it may cloud the patient's judgement and perceptions on care plans. Without adequate background exploration and assessment, going directly into a family conference to make an AD may be undesirable.

On moral distress

As separately reviewed by Prof Helen Chan, 'moral distress' was first defined by Jameton (1984) as the negative experience among health professionals when they know the right thing to do but cannot pursue that course of action due to institutional constraint. Much of the literature on this subject focus on moral distress in nursing. The definition of moral distress by Jameton may be disputed. A professional in moral distress is not always right. Moral intuition ('knowing the right thing to do') should go hand-in-hand with moral reflections and openness to ethical reasoning. Is the 'institutional constraint' real or perceived? If a nurse feels powerless, is it due to a culture of medical dominance (nurses expected to follow doctor's orders), or is it due to the individual nurse's lack of confidence to effectively articulate her case? Nonetheless, it should be fair to say that in some healthcare institutions, the ethical climate is clearly unfavourable for a 'speak-up' culture, and unsupportive of staff in moral distress.

What can the nurse do?

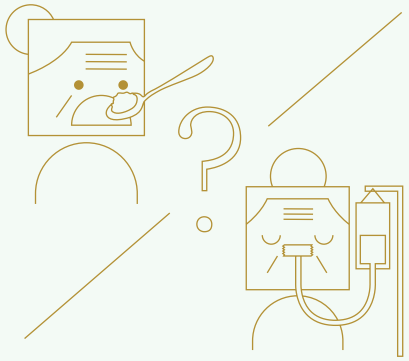
Ms Leung may feel less distressed if she can explore the patient's wish further. The patient did not ask for a family conference to immediately sort out EOL issues and AD. What does he really want? As a first step, she may try to ascertain whether Mr Chau does indeed wish healthcare professionals to mediate a dialogue with his family members concerning his future care. She may then relate such a wish to the wife and son, and at the same time provide them with initial information on the value of the ACP process. Mr Chau is probably a long-term follow-up case. Once such initial exploration has taken place; further dialogue may be possible.

This may be a pragmatic approach to overcome a deadlock. One may argue that taking the pragmatic approach does not always work, and there may well be other scenarios where institutional constraint is undisputable and even unfair. In some circumstances, a healthcare professional may need to bring up the issue of concern to hospital management, or raise conscientious objection to unethical practice.

In this particular case, it would appear that there is room for further assessment of the patient, positive communication within the team, and dialogue with the patient's family.

3.2.3 Challenges in Careful Hand Feeding

Case Description



Mrs Yeung is an 87-year-old woman with advanced dementia. She is widowed and has been living at an elderly care home for the past 5 years. Over the last couple of years, she has become bedbound and non-verbal. She no longer recognises her daughter Karen who visits regularly. She requires assistance with feeding and had lost over ten pounds in the last year due to poor oral intake.

Over the last week, Mrs Yeung was admitted to the hospital for increased lethargy. She was found to have a urinary tract infection and was treated with antibiotics and intravenous fluids. While she became more alert after a couple of days of treatment, she had failed her swallowing evaluation. The speech therapist documented that she was at high risk for aspiration and recommended non-oral feeding.

The doctor on the geriatrics ward discussed the question of nasogastric feeding tube insertion with Karen. He explained that Mrs Yeung's reduced food intake and swallowing difficulties are part of her advanced illness and suggested careful hand feeding as an alternative.

Karen replied, "Mom has already suffered enough. She doesn't recognise me anymore and she can't communicate. She just lies there. Putting in a feeding tube would be torturing her more." Karen opted for careful hand feeding. Her decision was documented in an ACP document which was sent back to the elderly care home when Mrs Yeung was discharged.

Man Yi, a personal care worker at the home, found it very difficult to continue to feed Mrs Yeung. She is very weak and could only take in a few spoonfuls of food at a time. Mealtimes would take over an hour and Man Yi cannot afford to take that time when she has many other residents to care for. Besides, noting the speech therapist's assessment, she is concerned that she would cause Mrs Yeung to have an aspiration episode while feeding her. She raised her concerns with the nursing supervisor.

The nursing supervisor replied, "Let's have a talk with her daughter then. If she doesn't want to insert a feeding tube like everyone else, then she needs to either come herself to assist with her meals or arrange for someone who can. What if she chokes? Then the responsibility would fall on us. Besides, this ACP document belongs to the hospital. I'm not sure if we're obligated to follow this anyway."

During the meeting, Karen was surprised and upset upon hearing the elderly care home's refusal to continue careful hand feeding. She exclaimed, "At the hospital, they said that she can continue to be fed by the staff here! I work full time at the post office and can't come to feed her myself. I cannot afford to hire a maid!"

Man Yi felt at a loss for what to do. She recognises the daughter's wish to keep Mrs Yeung comfortable but she cannot manage her workload if it takes so long to feed Mrs Yeung. Her nursing supervisor suggested that they should send Mrs Yeung back to the hospital. It seems that they don't have another option.

Commentary

Dr KONG Tak Kwan, Honorary Consultant Geriatrician/Clinical Associate Professor (Honorary)/Clinical Lecturer (part-time), Department of Medicine & Therapeutics, Prince of Wales Hospital, The Chinese University of Hong Kong

1. What are the pros and cons of careful hand feeding versus tube feeding in advanced dementia patients with swallowing problems?

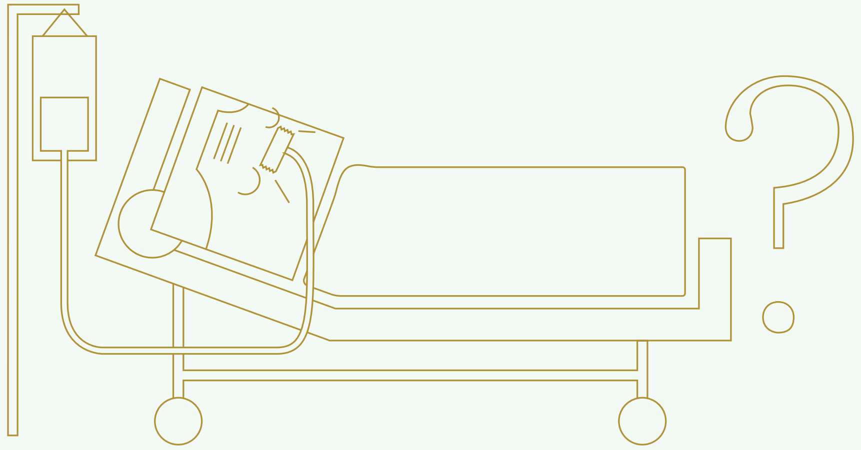
	Careful hand feeding	Nasogastric tube feeding
Pros	• Pleasure of eating/drinking • Comfort, companionship, intimacy	• Fast technique of bypassing the swallowing process in the provision of nutrition or hydration, and administration of oral medication
Cons	• Staff concern on aspiration risk with medico-legal consequence • Difficult to implement quality feeding without adequate resources (human presence, time, patience), ending up in poor feeding and dehydration, and consequent repeated hospitalisations • Distress related to eating/drinking, e.g. choking	• Aspiration pneumonia is not prevented (as reflux of gastric contents and aspiration of saliva continue with tube feeding), and may even be increased • Distress from tube insertion or its complications (irritation, blockage, dislodgement) • Immobilisation and agitation from increased use of hand restraints

2. How should ACP be done for advanced dementia patients with unsafe swallowing?

For a patient who has a serious illness, planning on future medical and personal care at the end of life can be done via an ACP process involving the patient, family and healthcare workers and takes into consideration factors such as disease prognosis, benefits and burdens of treatment, values and preferences of the patient. Usually ACP is a process of communication intended for mentally competent patients. In the HA of Hong Kong, the term ACP extends beyond communication with mentally competent patients to include that with family members of mentally incompetent patients. Decision-making regarding the patient's future medical or personal care should be done by consensus-building among members of the healthcare team and with the patient's family, based on the best interests of the patient.

Mrs Yeung suffered from advanced dementia, could not communicate and was judged by the geriatrician as lacking mental capacity to consent, but her wish may still be implied and understood from her body language (e.g. repeatedly pulling out the nasogastric tube). While her daughter, Karen, cannot insist on, or consent to, a treatment on behalf of the patient, her views help to understand Mrs Yeung's previously expressed views on EOL decisions. The decision-making process on dysphagia assessment and management in advanced dementia patients is complex and is ideally a combined effort of the multidisciplinary team. The speech therapist documented that Mrs Yeung was at high risk for aspiration and recommended non-oral feeding. However, dementia patients may under-perform on formal swallowing tests because of distress, unfamiliar test environment (e.g. tilt-table) and distasteful artificial barium-modified food. The observations of the usual swallowing ability of

Mrs Yeung during meal time by nurses and family members should also be considered when assessing the safety of oral feeding. Geriatricians have a role to diagnose and treat conditions impairing swallowing, e.g. delirium, depression, oral candidiasis and discontinue medications causing dry mouth and impairing swallowing (e.g. antipsychotics). In the ACP process, it is important to consider the context, including the available support systems and resource availability. Although the geriatric ward where Mrs Yeung stayed had the appropriate support and resources to practise careful hand feeding, the elderly care home where Mrs Yeung was subsequently discharged to did not and this may result in rebound hospitalisations. Careful transitional care planning and collaboration between hospital and elderly care home staff are important for success of smooth transfer of care from hospital to the community. The pros and cons of careful hand feeding versus tube feeding (see earlier) should therefore be carefully reviewed and discussed before drawing up an individualised ACP that is practicable.



3. How to optimise clinical ethical decisions when faced with ethical and legal dilemmas in the care of advanced dementia patients?

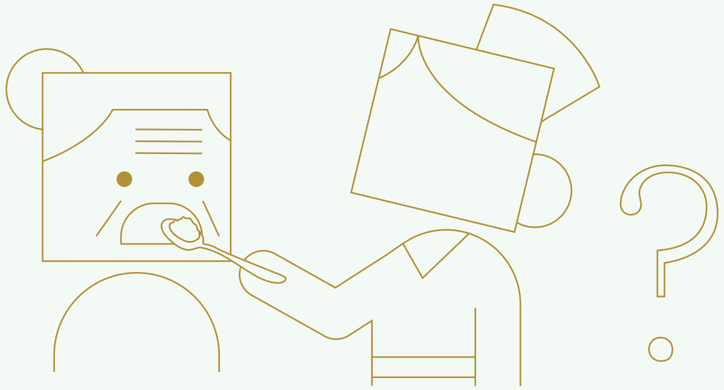
The ethico-legal dilemmas in this case are that while the hospital multidisciplinary team (experts) recommended careful hand feeding in their ACP (not legally binding) for an advanced dementia patient whose swallowing was judged unsafe by the speech therapist, the elderly care home staff (frontline) did not have the supporting practice (education, operational policy and human resources) and expressed litigation concern. A common argument for not starting tube feeding in this situation is that the burden of tube feeding is high and the intervention adversely impacts on the quality of life of terminally ill patients. Although Mrs Yeung is in an advanced stage of dementia, she has just been recovering from an acute illness (urinary tract infection), and it is thus arguable to label her as terminally ill. Moreover, Mrs Yeung had lost over ten pounds in the last year due to poor oral intake, and was probably suffering from malnutrition, which reduced her immunity and made her susceptible to infections. Tube feeding, on a short-term basis, may be a quick treatment to restore her nutrition and body weight and optimise her condition. However, quality studies are lacking to address whether or not tube feeding can improve nutritional status for advanced dementia patients. The British Geriatrics Society and the Royal College of Physicians recommend that, if in doubt, a trial of nasogastric feeding with clear agreed objectives may be appropriate in managing dysphagia in older people towards the end of life. Tube feeding should then be withdrawn if failing to achieve the objectives.

There are many ways of thinking about ethical issues in geriatrics that help to reduce our short-sightedness in order to benefit patients and ourselves. In addition to the usual ‘mainstream’ ethical approach (based on the ethical principles of autonomy, beneficence, justice, non-maleficence), there are also narrative approaches that take into consideration values and expectations, limitations/uncertainties and concerns, and the context (patient–doctor–family–care worker, hospital–community). This requires active listening and dialogue, with a commitment, compassion and courage to approach the ethical dilemmas in caring for elderly people. How certain is Mrs Yeung terminal prognosis and without any remediable cause(s) for her impaired swallowing? Do we know what is valued by Mrs Yeung? What is the expectation of her daughter Karen and can she be involved as an informal carer? Does Karen have a similar fear of unsafe swallowing as the elderly care home care worker Man Yi so much so that Karen is reluctant to hand feed her mother to avoid the guilt of causing her mother to choke to death? How can the elderly care home nursing supervisor and the hospital team give support to Man Yi and Karen?

4. Guidance for hospital and elderly care home staff presented with a similar situation

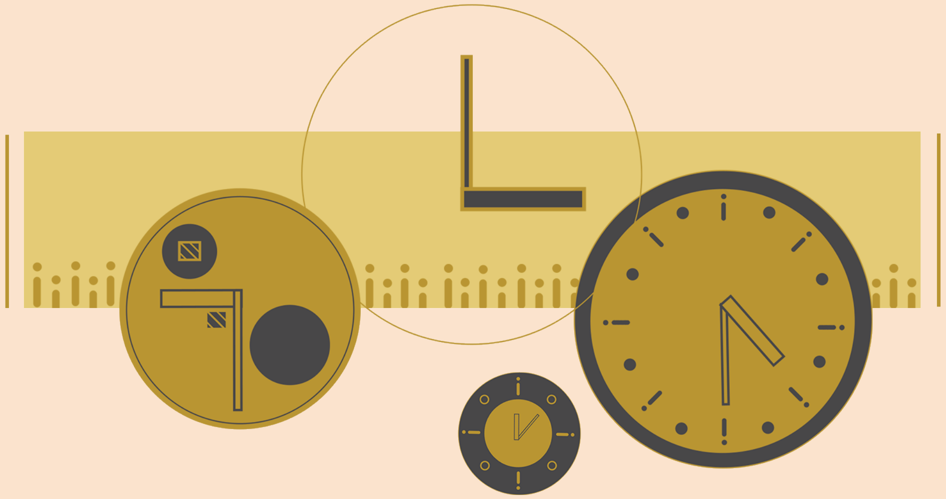
Ideally, this situation may have been prevented by collaborative discharge planning between providers/carers in the hospital and community setting. Short of this, the following tactics may be of help:

- Close liaison between the hospital outreach community geriatric assessment team (CGAT) and the elderly care home staff for post-discharge patients, e.g. review of oral intake of Mrs Yeung soon after discharge by CGAT; education of elderly care home staff on safe swallowing techniques and postures; a helpline accessible to elderly care home staff to call for help and advice by CGAT.
- Attitude of moving away from risk-centred medicine to person-centred care. Since the focus on risk-centred medicine (unsafe swallowing, aspiration risk) has created anxiety, fears and defensiveness in elderly care home staff, and probably also the hospital team and the patient's daughter, it may be reassuring if the speech therapist acknowledges 'relative' rather than 'absolute' swallowing risk, and avoids recommendation of 'non-oral feeding' in documentation, which may be seen as expert opinion with litigation consequences. The speech therapist and CGAT team can teach Karen on safe hand feeding techniques, diverting the focus from aspiration to human touch, and encourage Karen to try to come to the elderly care home after work and hand feed her mother carefully. Karen can also consider asking friends and neighbours to provide careful hand feeding for her mother at the elderly care home.
- ACP is not a one-off but rather an ongoing process of discussion and review as the patient's condition or preferences change. If Mrs Yeung is distressed (e.g. due to choking) despite careful hand feeding and continues to lose weight, CGAT can discuss with her daughter the option of short-term tube feeding and assess for any improvement and tolerability. If Mrs Yeung's condition improves after short-term tube feeding, careful hand feeding can be reintroduced.



BUILDING CAPACITY FOR
END-OF-LIFE CARE
IN HONG KONG
TRAINING KIT FOR HEALTHCARE PROFESSIONALS

Chapter 4



Self-Care for the Healthcare Professionals in End-of-Life Care

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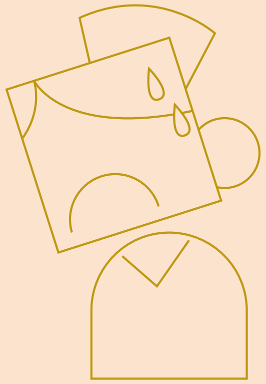
4.1 Burnout and Compassion Fatigue Experienced by Healthcare Professionals

4.1.1 Burnout



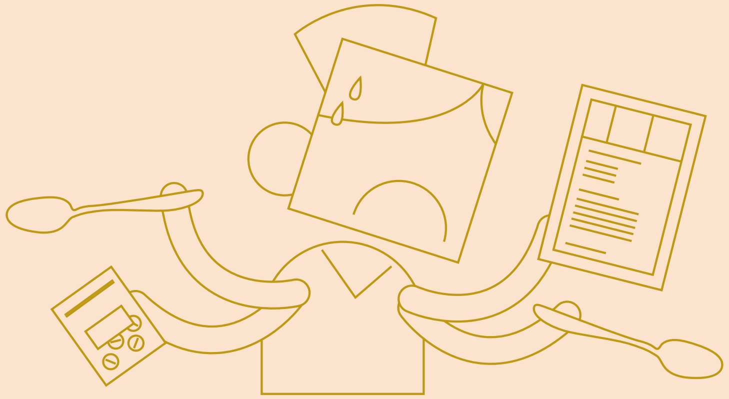
Healthcare professionals providing care for people who are dying face significant risk of burnout because their jobs are intensely emotional in nature and confront difficulties of coping with death. Burnout can have negative effects on physical and mental health of an individual, quality of care provided to the patient and relationships with colleagues, family and friends. Burnout means progressive loss of idealism, energy and purpose experienced by people in the helping professions as a result of the conditions of their work.[58] It is further defined by three key characteristics: (1) physical and emotional exhaustion, (2) cynicism and (3) inefficacy.[58]

Indicators of burnout are:[59]

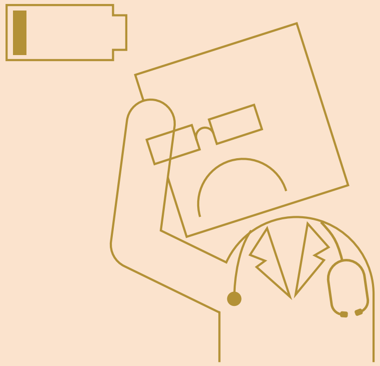
- Negative or cynical attitudes about patients and their needs
- Negative attitudes to work, the workplace or colleagues
- Pervasive feelings of dissatisfaction and unhappiness related to work
- Physical and emotional symptoms (e.g. fatigue, boredom, headaches and weight loss, etc.), which can be associated with absenteeism

Factors for Burnout[59]

Work overload (e.g. large patient volumes, insufficient resources, or feeling poorly managed)	**Lack of balance between home and work life**
Inadequate training (e.g. communication and management skills)	**Conflict and interpersonal issues in the workplace**
Personality and coping style	**Mismatch between motivations and expectations, and the actual reality of day-to-day work**



4.1.2 Compassion Fatigue



In addition to burnout, healthcare professionals may experience compassion fatigue. Compassion fatigue is used to describe the final result of a progressive and cumulative process caused by prolonged, continuous and intense contact with patients, the use of self and exposure to stress.[60] Compassion fatigue is the emotional residue or strain of exposure to working with those suffering from the consequences of traumatic events.[61] It can occur as a result of exposure to one particularly traumatic case or due to a cumulative level of trauma.[61] Those suffering from compassion fatigue become physically, mentally and emotionally exhausted. Healthcare professionals providing EOL care are highly susceptible to compassion fatigue due to their constant exposure to death, dying and suffering.

Impacts of compassion fatigue:[61]

- Has a negative effect on the ability of an organisation to provide services
- Leads to high turnover rates
- Reduces productivity
- Affects capacity to enjoy life
- Influences personal and professional relationships

4.1.3 Reducing Burnout and Compassion Fatigue

(i) Developing a Self-Care Plan

Given the negative consequences of burnout and compassion fatigue, it is crucial to develop strategies to help mitigate loss. One key approach is to encourage self-care. Self-care is defined as a cadre of activities performed independently by an individual to promote and maintain personal well-being throughout life.[58] Developing a self-care plan can help the healthcare professionals identify activities and practices to support their well-being, enhance health and manage stress.

Aspects of Self-Care

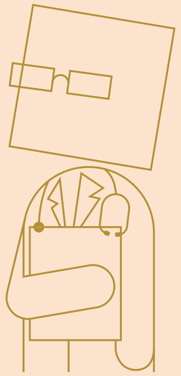
Self-care is a personal matter and everyone's approach can be different. It is related to personal goals and professional commitments. Figure 14 shows the multiple aspects of self-care, followed by examples of strategies that may be useful.[62]

Figure 14. Multiple Aspects of Self-care

Workplace or Professional Self-Care

Workplace or professional self-care involves the activities that help you work consistently at the professional level expected by yourself. For example, you can:

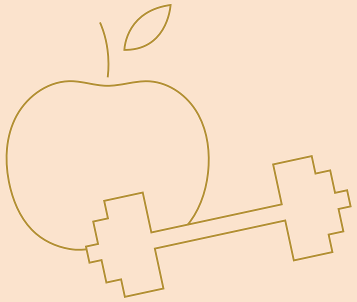
- Engage in structured clinical supervision or consult with more experienced colleagues who are familiar with clinical supervision
- Develop a network of peers and mentors
- Regularly appraise all aspects of work life
- Pursue reflective writing
- Attend professional development programmes



Physical Self-Care

Physical self-care involves the activities that help you stay fit and healthy and help you maintain enough energy for your work and personal commitments. For example, you can:

- Develop a regular sleep pattern
- Aim for a healthy diet
- Take lunch breaks
- Go for a walk at lunchtime
- Get some exercise before/after work regularly
- Take a vacation



Psychological Self-Care

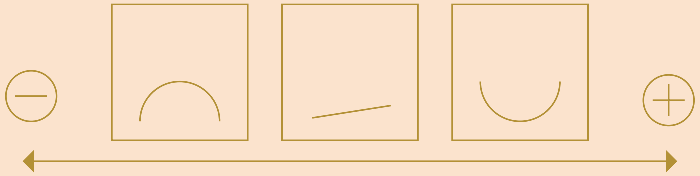
Psychological self-care involves the activities that help you feel clear-headed and allow you to intellectually engage with professional challenges. For example, you can:

- Foster recreational activities and hobbies
- Turn off your email and work phone outside working hours
- Make time for relaxation
- Make time to engage with positive friends and family

Emotional Self-Care

Emotional self-care allows you to safely experience your full range of emotions. For example, you can:

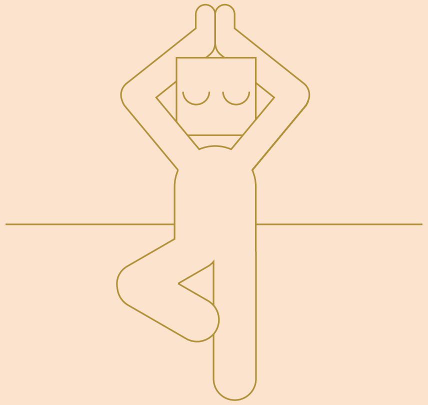
- Call on others for help when you start to feel overwhelmed
- Accept your true feelings, both positive and negative
- Take a few deep breaths, especially before expressing your feelings
- Learn to say ‘no’ and look after yourself first
- Talk to your friends about how you are coping with work and life demands



Spiritual Self-Care

Spiritual self-care involves the rituals or practices that allow you to further connect with your inner self. Your inner self is who we truly are as an individual, the real you. For example, you can:

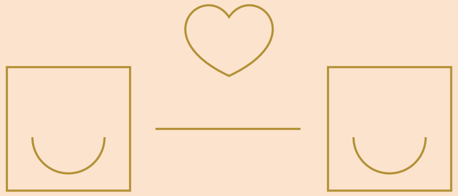
- Engage in reflective practices such as mindfulness
- Practise yoga
- Engage in religious practices
- Read spiritual materials
- Spend time in nature
- Pursue a reflective journal



Relationship Self-Care

Relationship self-care involves maintaining healthy and supportive relationships with others. It ensures you have diversity in your relationships, so you are not only connected with colleagues. For example, you can:

- Prioritise close relationships in your life (e.g. family and children)
- Attend special events of your family and friends



A Self-Care Manifesto[63]

A Self-Care Manifesto

1. I deserve to lead a joyful, whole life.
2. My work does not define me.
3. I am not the only one who can help dying and bereaved people.
4. I must develop healthy eating, sleeping and exercise patterns.
5. I must maintain boundaries in my helping relationships.
6. I am not perfect and must not expect myself to be.
7. I must practise effective time-management skills.
8. I must practise setting limits and alleviating stress I can do something about.
9. I must listen to my inner voice.
10. I should express the personal me in both my work and play.
11. I am a spiritual being.

4.1.3 Reducing Burnout and Compassion Fatigue (Continued)

(ii) Cultivating Self-Awareness

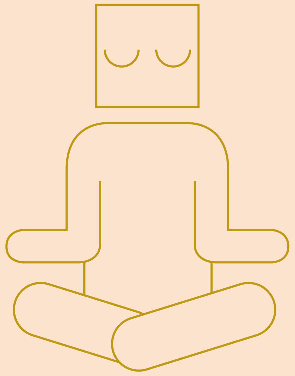
The importance of developing self-awareness deserves particular attention as a realm of self-care.[58] Psychologist Daniel Goleman defined self-awareness as knowing one's internal states, preferences, resources and intuitions.[64] It is the ability to monitor our inner world, our thoughts and emotions as they arise. Greater self-awareness among healthcare professionals may lead to greater job engagement and compassion satisfaction, enhanced self-care, and improved patient care and satisfaction.[58] On the contrary, healthcare professionals with lower levels of self-awareness have a greater likelihood of compassion fatigue and burnout.[58]

Ways to Cultivate Self-Awareness[65]

Create some space for yourself

Stay away from digital distractions and spend some time with yourself alone (e.g. reading and writing) to connect with yourself in the morning or half an hour before sleep.

Practise mindfulness

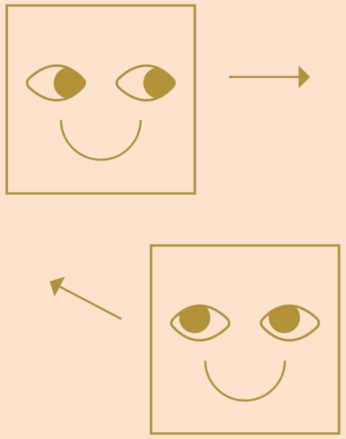


Mindfulness is important for self-awareness. Mindfulness is defined as developing purposeful attention in the present moment and cultivating a kind, non-judgemental attitude towards self and others.[66] Through mindfulness practice, you will be more present with yourself, allowing you to 'be there' to observe what is going on inside and around you. It is not simply about sitting cross-legged or suppressing your thoughts; it is about paying attention to your inner state. You can practise mindfulness at any time through mindful listening, mindful eating or walking.

Write a diary

Writing can help us process our thoughts and make us feel connected and at peace with ourselves. You can use a diary to record your inner state. Through the diary, you can pay close attention to your inner world, such as what you are feeling and what you are saying to yourself. You may be surprised about what you write down!

Gain different perspectives



We all have blind spots. Asking for feedback is helpful to gain a different perspective to see a fuller picture of ourselves. Sometimes we can be too afraid to ask what others think of us. Although some feedback may be biased or even dishonest, you will be able to differentiate them from real, genuine and balanced the feedback, and hence you can learn more about yourself and others.

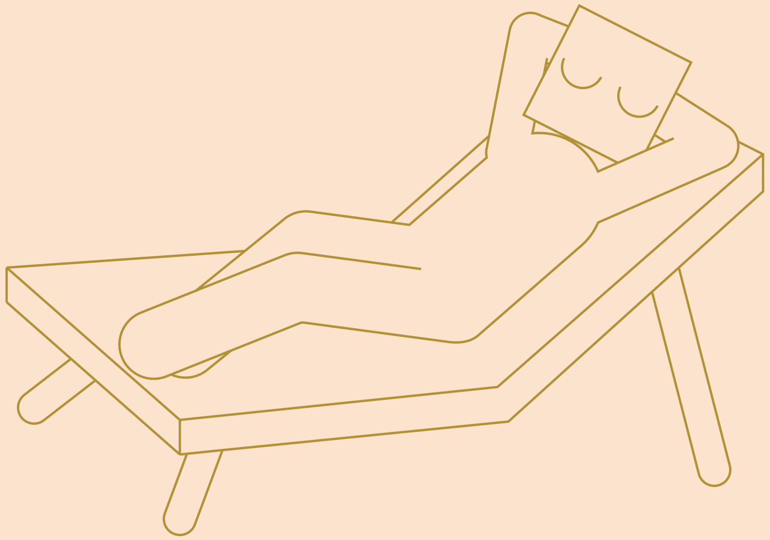
Practise being a good listener

Listening is not the same as hearing. Listening is related to being present and paying attention to other people's emotions, body movements and language. It is about showing empathy and understanding without constantly evaluating or judging. When you become a good listener, you will also be better at listening to your own inner voice and become the best friend of yourself.

4.2 Relaxation Exercises

Practising relaxation exercises can help reduce everyday stress, boost your energy and mood, and improve your mental and physical health. Guided relaxation exercises have been developed by the Jockey Club TourHeart Project – Emotion GPS (eGPS), which jointly involves the New Life Psychiatric Rehabilitation Association (NLPRA) and the CUHK Department of Psychology.[67]

Practise these exercises to fully relax your whole body and ease your mind.



(i) Breathing Exercise

Link

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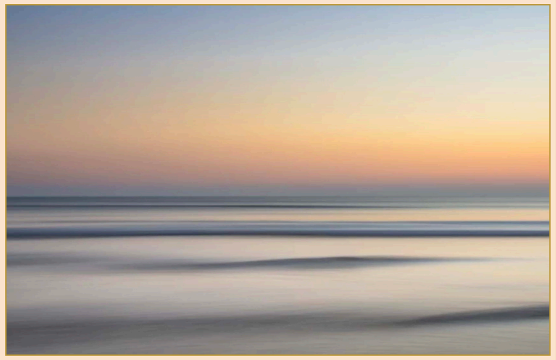
(ii) Muscle Relaxation Exercise



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(iii) Relaxation Exercise

Link

https://www.youtube.com/watch?v=bBrXsTHx04E

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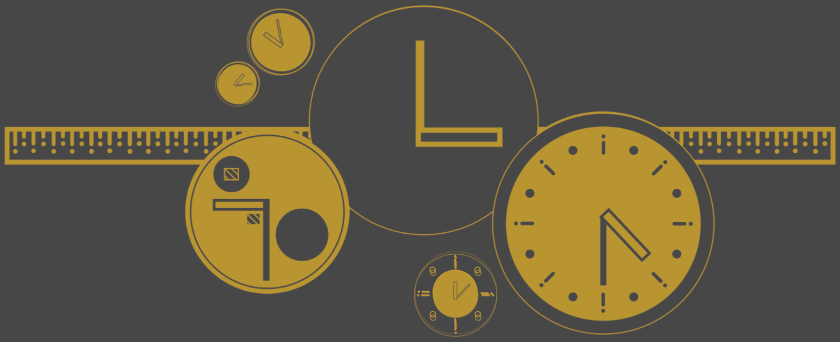

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