

NANYANG
TECHNOLOGICAL
UNIVERSITY
SINGAPORE

CC0007 Science and Technology for Humanity

Navigating the End of Life With Advance Care Planning

Assoc Prof Andy Hau Yan Ho, NTU



Death is the only constant
in life filled with uncertainties.



Changes in Mortality

Context	1900	2020
Age of death	47 years	83 years
Usual place of death	Home	Hospitals
Coverage of medical expenses	Family	Public fund/insurance/out-of-pocket savings
Disability before death	Usually not much	2–3 years on average
Support before death	Family, friends, neighbours, communities	Usually not much

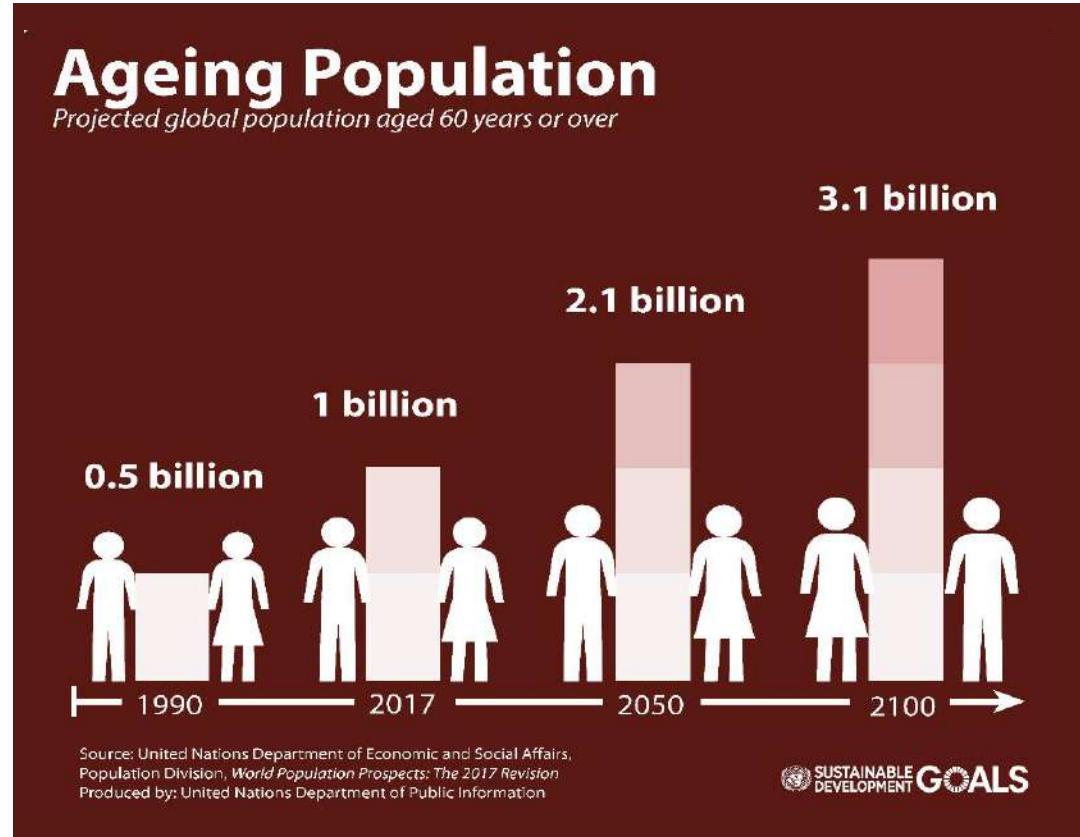
! Changes in the Leading Causes of Death Around the World

Rank	1900	2000 (High Income Countries)	2019 (High Income Countries)
1	Pneumonia	Ischaemic heart disease	Ischaemic heart disease
2	Tuberculosis	Stroke	Alzheimer's disease and other dementias
3	Diarrhoeal disease	Trachea, bronchus, lung cancers	Stroke
4	Heart disease	Chronic obstructive pulmonary disease	Trachea, bronchus, lung cancers
5	Liver disease	Lower respiratory infections	Chronic obstructive pulmonary disease
6	Injuries	Colon and rectum cancer	Lower respiratory infections
7	Stroke	Alzheimer's disease and other dementias	Colon and rectum cancer
8	Cancer	Kidney diseases	Kidney diseases
9	Senility	Diabetes mellitus	Hypertensive heart disease
10	Diphtheria	Hypertensive heart disease	Diabetes mellitus

World Health Organization. (2020, December 9). *The top 10 causes of death*. <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>

Epidemiologic Transition

- Redistribution of deaths from the young to the old
- Risk of dying from infectious diseases at young age decreased
- Most people survive into older ages but suffer from chronic life-limiting illnesses
- All together with low fertility rates and medical advances had resulted in **ageing population**

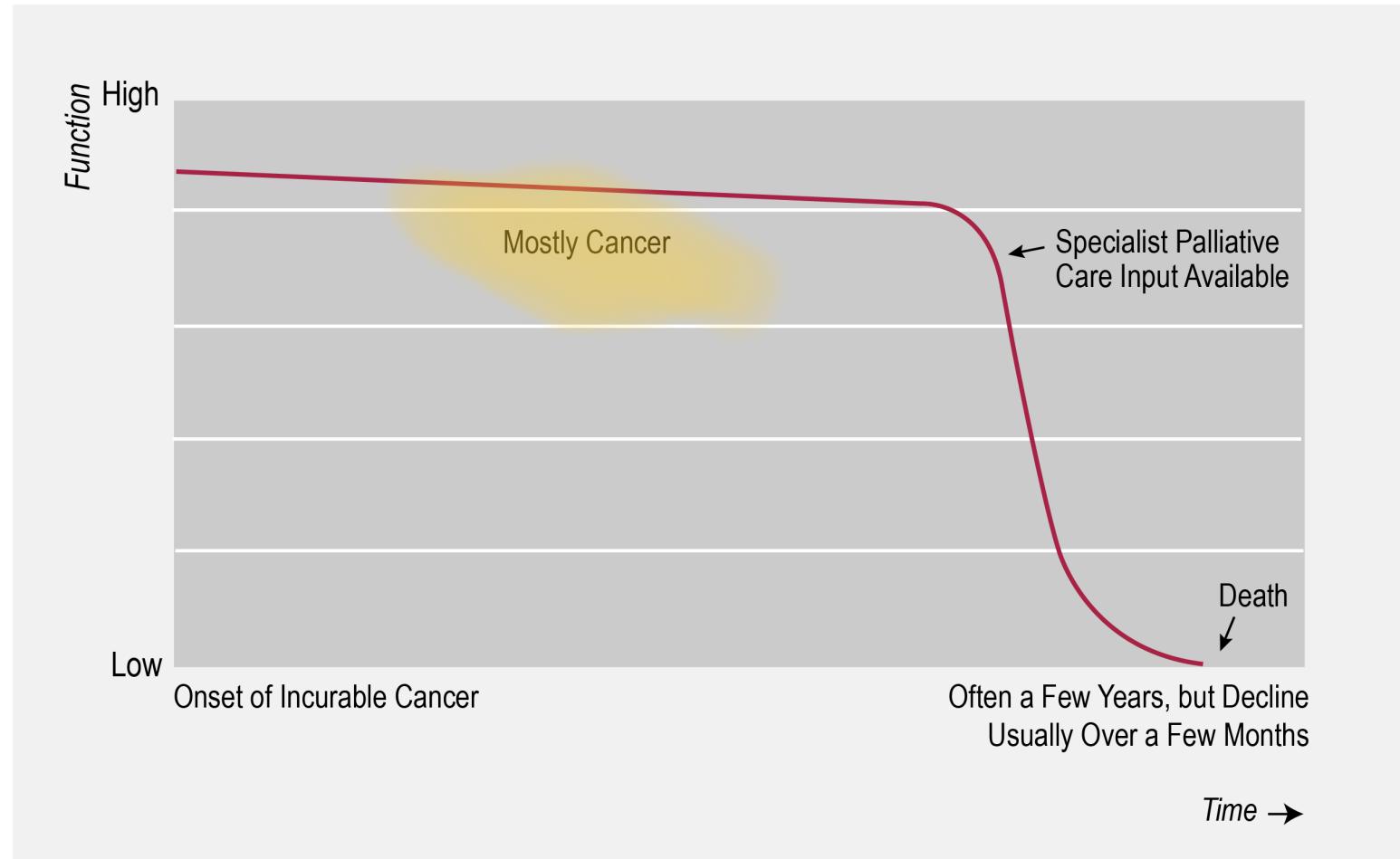


Towards Life's End



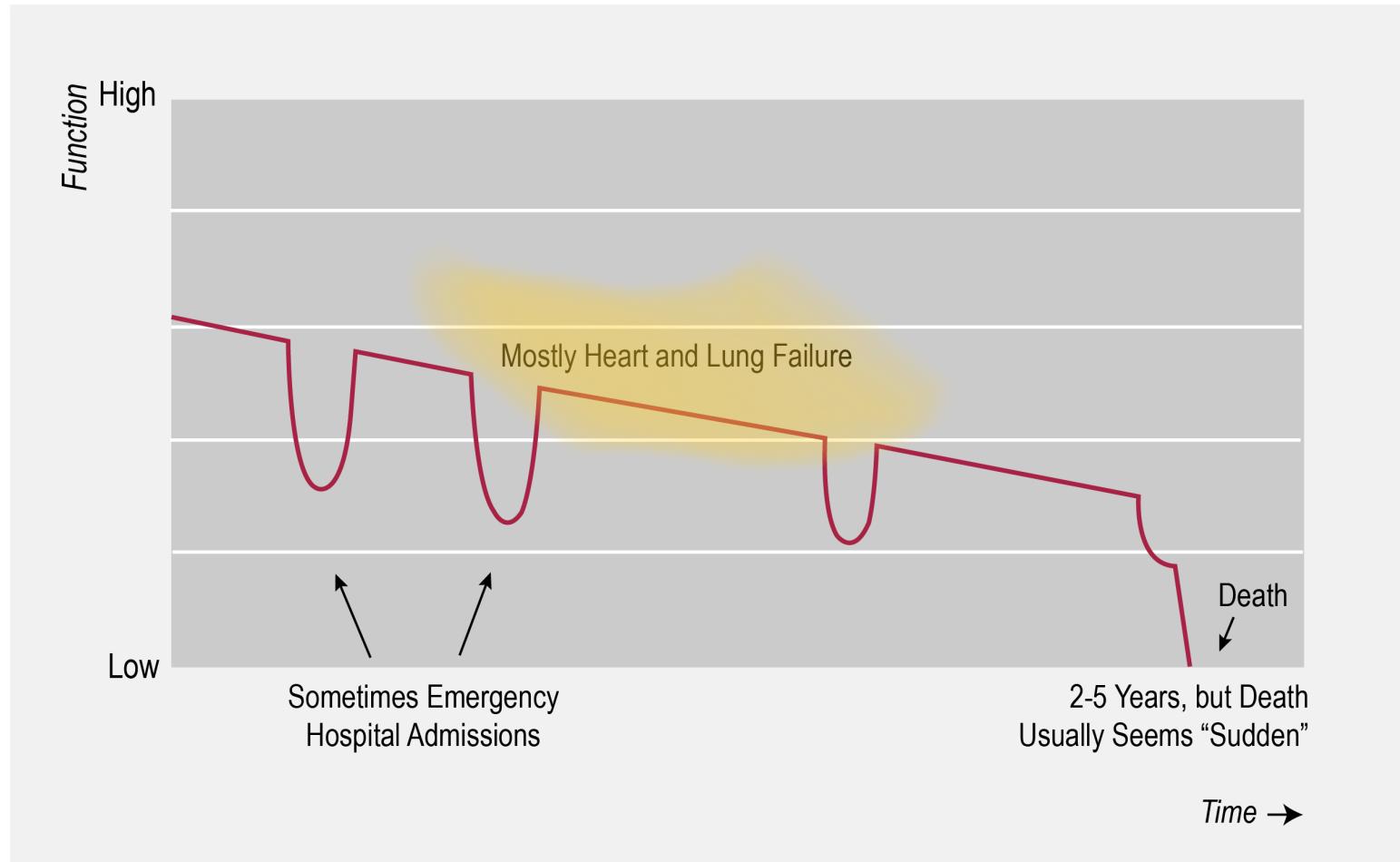
Typical Illness Trajectories for People With Progressive Chronic Illness

Short Period of Evident Decline



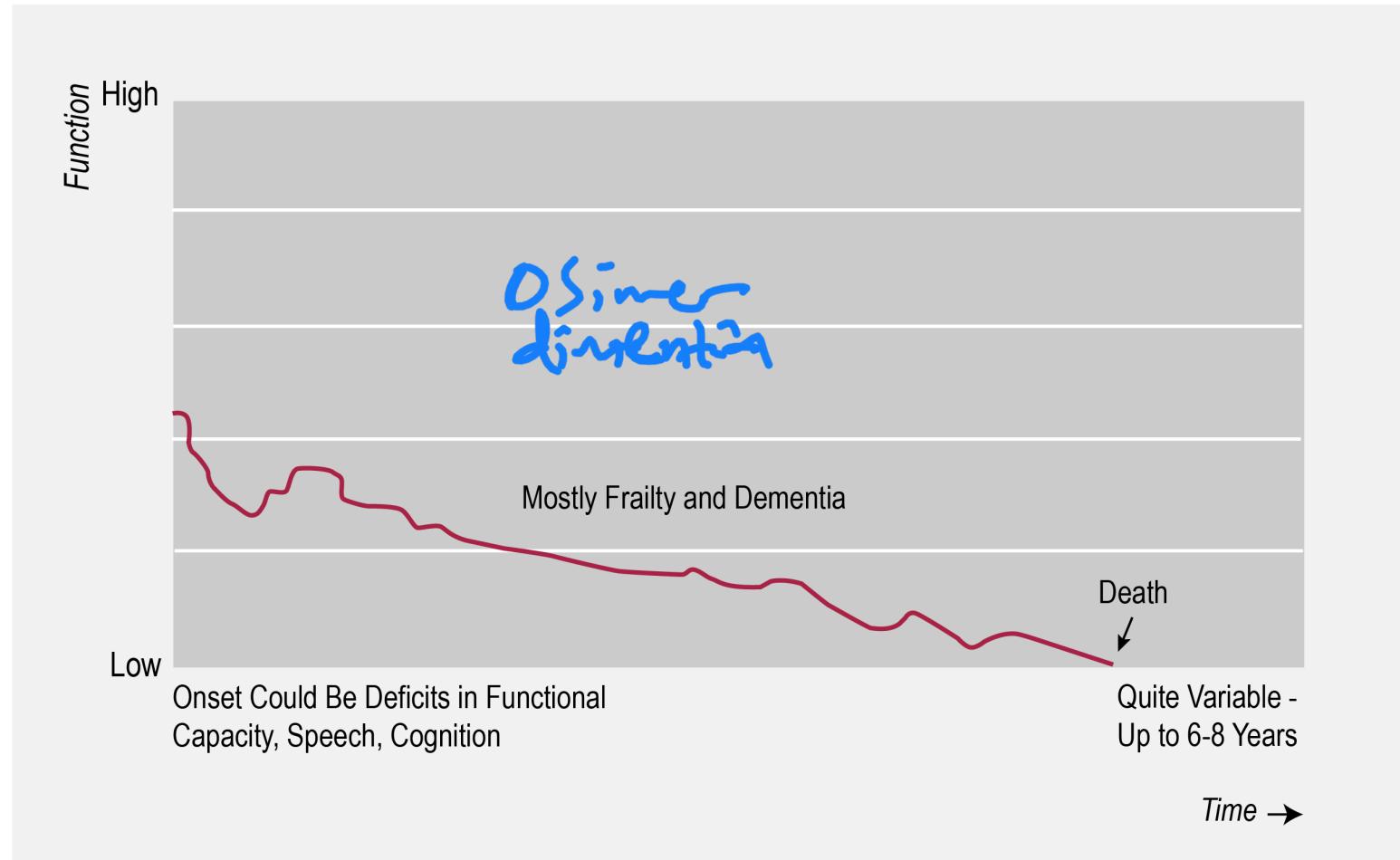
Typical Illness Trajectories for People With Progressive Chronic Illness

Long Term Limitations
With Intermittent
Serious Episodes



Typical Illness Trajectories for People With Progressive Chronic Illness

Prolonged Dwindling



Murray, S.A., Kendall, M., Boyd, K.J. & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, 330, 1007–1011. <https://doi.org/10.1136/bmj.330.7498.1007>

A Difficult Journey for Patients and Families

- The dying process is demanding on the patient, family members, as well as health care professionals
- Physical symptoms, pain, fatigue, suffering and dependency
- Strong sense of emotional frustration and inadequacy



A Difficult Journey for Patients and Families

- Uncertainties and fears of the journey of death
- Feelings of powerlessness and hopelessness
- Yet, many decisions need to be made amidst the existential chaos of mortality

anxiety ~ depression



When decisions arise concerning the treatment of dying patients, these options present complex ethical dilemma. These decisions—regarding their own care or the care of a dying loved one—confront people from all walks of life.

Betsy Carpenter,
Volunteer Counselor, Stanford Medical Center



End-of-Life Decisions

- Withholding or withdrawing medical treatment
- Medical futility
- **Advance medical directive**
- **Advance care planning**
- Terminal sedation
- Euthanasia and physician-assisted suicide



back in 1900

Beginnings of Advance Medical Directive (AMD)

- “Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable”
(Schloendorff v. Society of the New York Hospital, 1914)
- “The law provides that a patient may not be subjected to treatment without his consent... a living will... a declaration determining the termination of life”
(Kutner, 1969)
- “The Directive allows you to instruct your doctor not to use artificial methods to extend the natural process of dying”
(Natural Death Act, 1976; In re Quinlan v. State of New Jersey, 1976)

Patient Self-Determination

- In the United States, the **Patient Self-Determination Act (PSDA, 1990)** encourages everyone to decide now about the types and extent of medical care they want to accept or refuse if they become unable to make those decisions due to illness.



Patient Self-Determination

- Advance medical directive aspires to:
 - Protect patients' autonomy and respect their wishes and preferences in care
 - Help patients plan for the end of life through making informed care decisions before becoming incapacitated
 - Designate a dual power of attorney to help patient make care decisions when he/she becomes incapacitated
 - Avoid unnecessary and futile treatments which would cause more harm than good
 - Permit peace of mind



Advance Medical Directive and Quality Palliative Care

- Advance medical directive is a cornerstone to quality palliative care:
 - Establishes a personalised end-of-life care plan
 - Integrates the psychosocial and spiritual aspects of care
 - Reduces hospital admissions and likelihood to die in a hospital
 - Maintains and enhances patients' quality of life



Advance Medical Directive and Quality Palliative Care

- However, in most research that examined the effectiveness of AMD, QoL is measured solely with quality metrics or performance metrics such as hospital admission, hospice enrolment, usage and deaths.
 - This can potentially create a checkbox exercise that undermines the real needs and concerns of patients.
 - More research is needed to assess holistic care outcomes such as quality of life and quality of death.



From Advance Directives to Advance Care Planning (ACP)

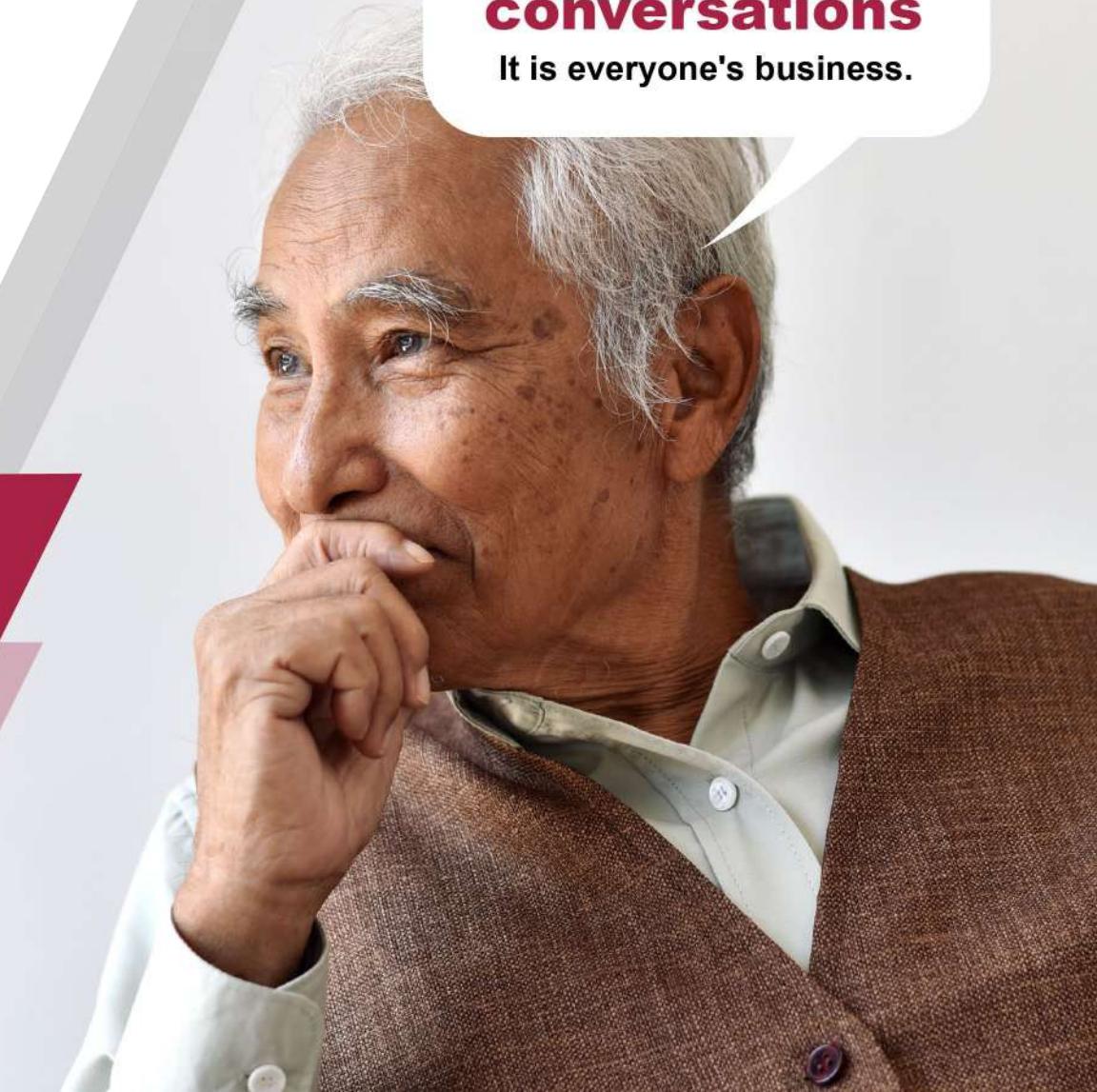
- ACP is the process of planning for future healthcare options through a series of voluntary, non-legally binding conversations with one's family and doctors.
- In an ACP discussion, patients are guided to understand, reflect upon, and discuss their goals, values and beliefs; then led to indicate their preferences with regard to future healthcare treatments.
- ACP also involves nominating a “substitute decision-maker” who can make decisions on the patient’s behalf. The documented discussion provides guidance for the medical team in making decisions when crisis strikes, and the patient is no longer able to communicate.



Key Decisions of ACP

- Cardiopulmonary resuscitation (CPR)
- Do not resuscitate (DNR) order
- Artificial nutrition and hydration
- Do not intubate (DNI) order
- Preferred place of care
- Preferred place of death
- Durable power of attorney for healthcare

**Start
end-of-life
conversations**
It is everyone's business.



National Advance Care Planning Programme

Singapore's Ministry of Health (MOH) and the Agency for Integrated Care (AIC) had launched a National Advance Care Planning programme in 2011, namely "Living Matters", to empower all members of the public with greater autonomy and self-determination in negating the complexities of mortality, especially those facing the end of life.

The screenshot shows the Living Matters website. The top navigation bar includes links for Healthcare Professionals, About Living Matters, Contact Us, Home, Advance Care Planning, Your Stories, and Start the Conversation. Below this, there are three main tabs: About ACP, How To Make A Plan, and FAQ. The 'About ACP' tab is active. The main content area features a heading 'What is Advance Care Planning?' followed by a paragraph explaining it as the process of planning for future health and personal care. It lists three steps: Share your personal values and beliefs, Explore how your values and beliefs affect your healthcare preferences in difficult medical situations, and Think about who among your loved ones can be your voice if you become very ill one day. A sidebar on the right titled '4 Simple Steps to Carrying out Advance Care Planning' provides a summary of these steps with icons. The bottom of the page has a call-to-action: 'By making your wishes known, your loved ones and caregivers do not have to guess what you might want or not want.' The right side of the image also shows a 'How do I begin?' section with a paragraph and a photo of two people looking at a document.

However, take-up rate remains low despite numerous public campaigns and advocacy efforts.

ppl are not
 ready to talk
 or die

Beyond ACP: What Do People Want as They Approach the End of Life?

- What type of care do people want?
- What are their worries, concerns and fears?
- What do they want to accomplish before they die?
- What type of legacy do they want to leave behind?
- What are important to them at the end of life?
- What are important to their family members?
- **How can we make use of technology, virtual company, online platforms and mobile apps to enhance people's acceptance of and willingness to take up ACP?**



I have a healthcare directive not because I have a serious illness, but because I have a family.

Dr. Ira Byock,
*American physician,
author and advocate for palliative care*



No part of this video shall be filmed, recorded, downloaded, reproduced, distributed, republished or transmitted in any form or by any means without written approval from the University.