



**Making Difficult Decisions with Patients and Families**

[www.bioethicscasebook.sg](http://www.bioethicscasebook.sg)

# THE ONLINE CASEBOOK PROJECT

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[www.bioethicscasebook.sg](http://www.bioethicscasebook.sg)



Centre for Biomedical Ethics  
Yong Loo Lin School of Medicine



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# History: Part I



Mr Manimaran Kanniah, 46, has motor neuron disease, a typically fatal illness that sees patients dying within two to five years. It was to get insight into the situation of patients like Mr Kanniah, as seen from the doctor's perspective, that led Dr Jacinta Tan (left) and Professor Jacqueline Chin to conduct the study What Doctors Say About Care Of The Dying.

Available in English and Chinese at <http://www.lienfoundation.org/publications.html>

# What Doctors Say about Care of the Dying

## The Lay Report

### **Topic 1: The concept of the end-of-life and its significance**

**1.1 The definition of 'end-of-life'**

**1.2 The significance of 'end-of-life'**

**1.3 The role of the doctor at the end-of-life**

**1.4 Religious influences at the end-of-life**

**1.5 Societal attitudes to the end-of-life**

# **Topic 2: Family cultures at the end of life**

**2.1 The discrepancy between Singapore law and medical practice**

**2.2. Family patterns of disclosure and decision-making in elderly patients**

**2.3 Family patterns in making decisions for younger patients**

**2.4 The practical consequences of not involving families in decisions**

**2.5 The role of finance in family decisions**

**2.6 The issue of whose interests are foremost**



# **Topic 3: Care of the dying in the Singapore healthcare system**

- 3.1 The current healthcare institutional structure**
- 3.2 Finance and the healthcare system in Singapore**
- 3.3 Caregiver burdens**

# **Topic 4: The law and the end of life**

**4.1 Doctors' attitudes to Singapore laws in general**

**4.2 Doctors attitudes towards the law relevant to consent and confidentiality**

**4.3 Doctors' attitudes to the Mental Capacity Act and Advance Medical Directive Act**

**4.4 Doctors' attitudes to withholding and withdrawing treatment**

**4.5 Doctors' views on euthanasia and physician-assisted suicide**

# Media Coverage of the Report



Mr Kanniah, who has a motor neuron disease, has signed a form stating that he does not wish to be resuscitated if his heart stops.

**无法接受母患癌命危 女坚持要医生 对母隐瞒真相**

【本報記者中心專訊】一名患有癌症的母亲，因病情危重，生命垂危，但其子女却坚持要求医生对母亲隐瞒真相，以便她能安心度过最后的日子。

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**病人无法 做临终安排 不知真实病情**

【本報記者中心專訊】一名患有癌症的母亲，因病情危重，生命垂危，但其子女却坚持要求医生对母亲隐瞒真相，以便她能安心度过最后的日子。

**因迷信和怀疑 医生与病人及家属 很难讨论临终课题**

【本報記者中心專訊】一名患有癌症的母亲，因病情危重，生命垂危，但其子女却坚持要求医生对母亲隐瞒真相，以便她能安心度过最后的日子。

# History: Part II

What the doctors said spoke of the difficulties they, their patients, and patients' families face, and also their *moral distress*.

## Examples:

- Day-to-day conflicts

- Resource issues

- Policies/law vs practice

- Existing healthcare structures and supports

# Birth of a Casebook

Strategy:

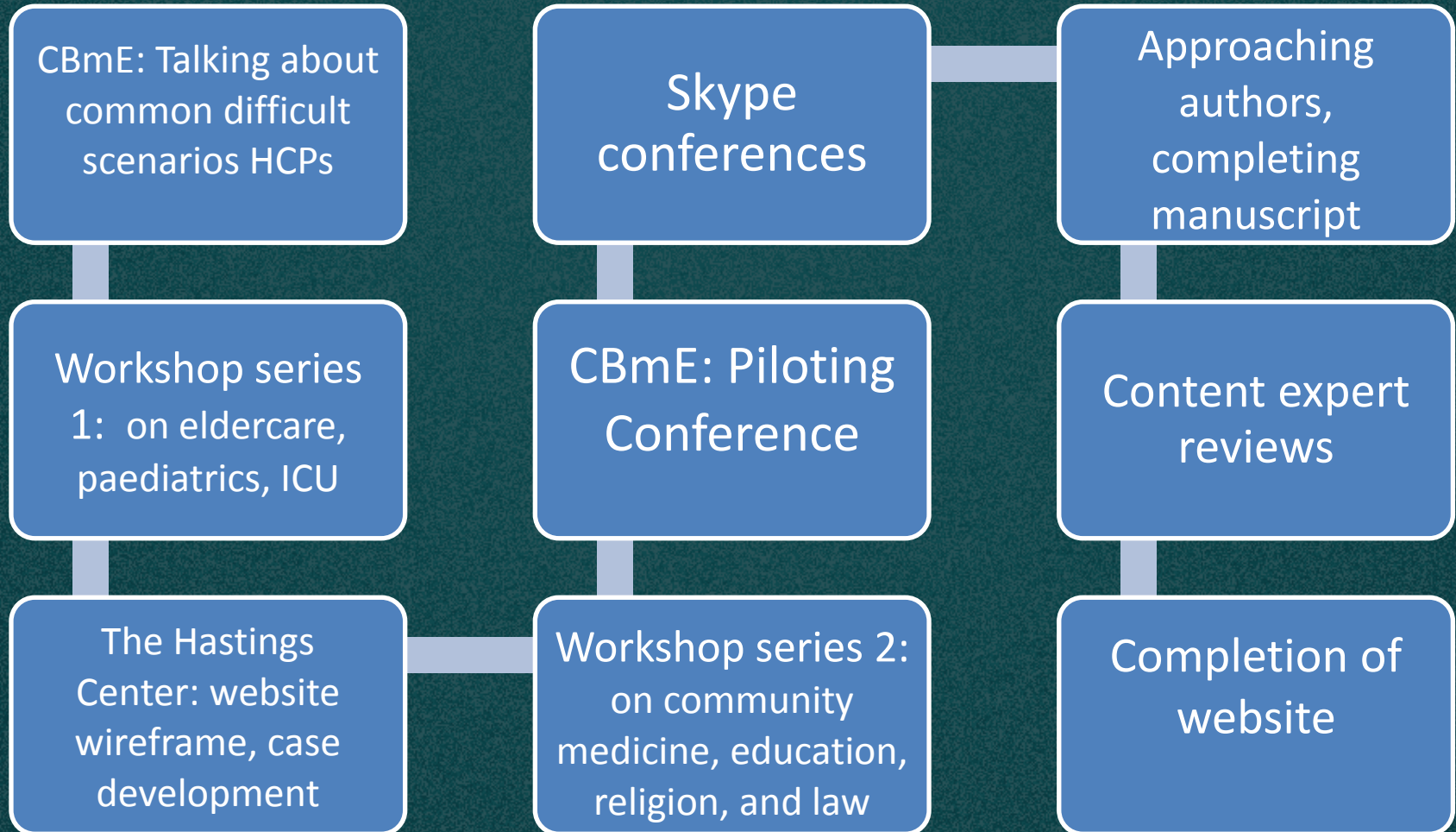
Deepen the analysis of the ethical issues and challenges

Engage healthcare professionals  
(in co-creating and authoring an open-source, open-access online teaching casebook with top bioethics expertise)

Acknowledge the difficulties

Educate for change and the future

# Creating the Casebook



# Spread of Cases

## I. Children and Young Persons

- Child with recurrent leukemia, parents refuse conventional treatment [tertiary care]
- Neonate with an uncertain diagnosis [tertiary care]
- Young person with brain injury and recurrent hospitalisations for infection [tertiary care and home care]

# Spread of Cases

## II. Adults (single, divorced and with family needs)

- Setting the goals of care (end-stage cancer) [tertiary care]
- Withholding futile interventions [tertiary care and home care setting]
- Chronic illness [polyclinic setting]
- Addiction and rehabilitation [GP setting]
- The 'difficult' patient [tertiary care and outpatient setting]



# Spread of Cases

## III. Elderly

- An Alzheimer's patient's advance care plan to refuse tube feeding [nursing home setting]
- Frail elderly patient with hip fracture [tertiary care]
- Elderly man with increasing memory loss and co-morbid condition [GP and specialist care setting]

## IV. Foreign Domestic Worker

- Healthcare needs [tertiary care]

# Structured Ethical Reflection



## Making Difficult Decisions with Patients and Families

### CASE STUDY

## Mr Shi

This case conce...  
has long been co...  
Alzheimer's dise...  
preferences abo...  
son, and who ha...  
problems. Whe...  
medical conditio...  
His son and othe...  
decision-making...  
should proceed.

### Case description

Mr Shi is an 80-year-old...  
Alzheimer's disease late...  
developing the disease h...  
his eldest son Jonathan, I...  
losing my marbles – you...  
don't want anything extr...  
want you to do anything...  
on." Jonathan, who was r...  
his father, said, "Sure, Da

Two years ago, Mr Shi's b...  
remembering how to ma...  
employees at holiday gat...  
these subtle changes. She...  
you tell if someone has d

"Are you worried about y...  
forgetting where you lef...  
what keys are for, that's o

Life-sustaining  
treatment

Impaired decision-  
making capacity

A physician's  
perspective



### Topics Covered

## Questions for Reflection

- It can be challenging for families to talk about end-of-life preferences when an aging person is relatively healthy. How can healthcare professionals who care for relatively healthy older people in the outpatient setting help their patients to have 'difficult conversations' within their own families? How does out-patient decision-making differ from decision-making in the in-patient context?
- Many people experience problems with memory as they age. How should healthcare professionals balance the rights of patients to receive health information and to make informed healthcare decisions with concerns about a patient's ability to process or retain information?
- What special ethical considerations are involved in decisions about cardiovascular implantable electronic devices, including decisions about deactivating or removing devices?

Here is a step-by-step approach to framing an ethical argument:

## Step 1: Confirming whether your question is an ethical question

Ethical questions are concerned with what we should do when there are reasons for more than one course of action, when no course is clearly 'right'. (Sometimes, the ethical course of action is not a clear option.)

"What should I do?" is an ethical question. This question is

- What am I legally permitted to do?
- What do policies or regulations require of me?
- What do most people think I should do?
- What does the clinical evidence suggest?
- What is the way we are accustomed to act in this situation?

It can be difficult to completely separate ethical questions from legal, policy, or clinical questions; good ethics depend on clarity about relevant facts. The reflection questions that follow the cases in this casebook include both ethical



# The Teaching and Learning Guide

## Continuing Ethics Education

# Baby Arun



This case concerns an extremely premature, critically ill newborn. It explores prognostic uncertainty in the neonatal ICU setting, and the challenge of communicating frequently-changing medical information while providing support to the baby's parents and other concerned relatives.

# Faizal



This case concerns an undergraduate whose traumatic brain injury results in locked-in syndrome. His doctors, nurses, and home caregivers must meet the challenges of understanding his wishes, while coping with repeated hospitalisations.

# Lina



This case concerns an adolescent with recurrent leukemia, and physician-parent conflicts over her treatment plan. It explores the rights of the adolescent patient and the possibility, consequences and ethics of seeking judicial intervention in the best interests of a child.

# Mr Bok



This case concerns a middle-aged professional and single parent whose multiple health problems are exacerbated by his smoking and alcohol use, and who is viewed as a 'difficult' patient by hospital and clinic providers. The patient's health problems could be alleviated by transplant surgery, but the hospital staff is uncertain whether this patient will adhere to the post-transplant regimen.

# Ms Khoo



This case concerns a single parent with a previous history of drug addiction who has completed a programme of drug rehabilitation and is working in a halfway house. The patient is seeing her GP periodically as follow-up to specialist treatment for hepatitis. The patient's mother, who helps with childcare while her daughter is at work, phones the GP with a problematic request.



# Mrs Kuan



This case concerns a middle-aged professional and parent with metastatic cancer for whom potentially beneficial, highly expensive treatment has failed. It explores clinical uncertainty over how to discuss the goals of care when few options for effective treatment exist.

# Mr Lim



This case concerns a middle-aged hawker's assistant with severe and progressively worsening arthritis who relies on steroids and other anti-inflammatory medications to enable him to continue to work, but is suffering from the chronic and potentially life-threatening side-effects of the long term use of these drugs. His polyclinic doctor is challenged to understand the coping strategies of her patient and how best to advocate for him.

# Ms Mendez



This case concerns a foreign domestic worker hospitalized for diagnosis and treatment of suspected pneumonia. Her health insurance coverage is likely to run out before she can be safely discharged, and her doctors are uncertain about this patient's options and their responsibilities as advocates.

# Mdm Lee



This case concerns an elderly nursing home resident with advanced Alzheimer's disease who, while she was competent, completed an advance care plan (ACP) that documented her explicit refusal of artificial nutrition and hydration. Confusion and family conflict arise after a staff member makes an ad hoc decision to insert an NG tube.

# Mr Shi



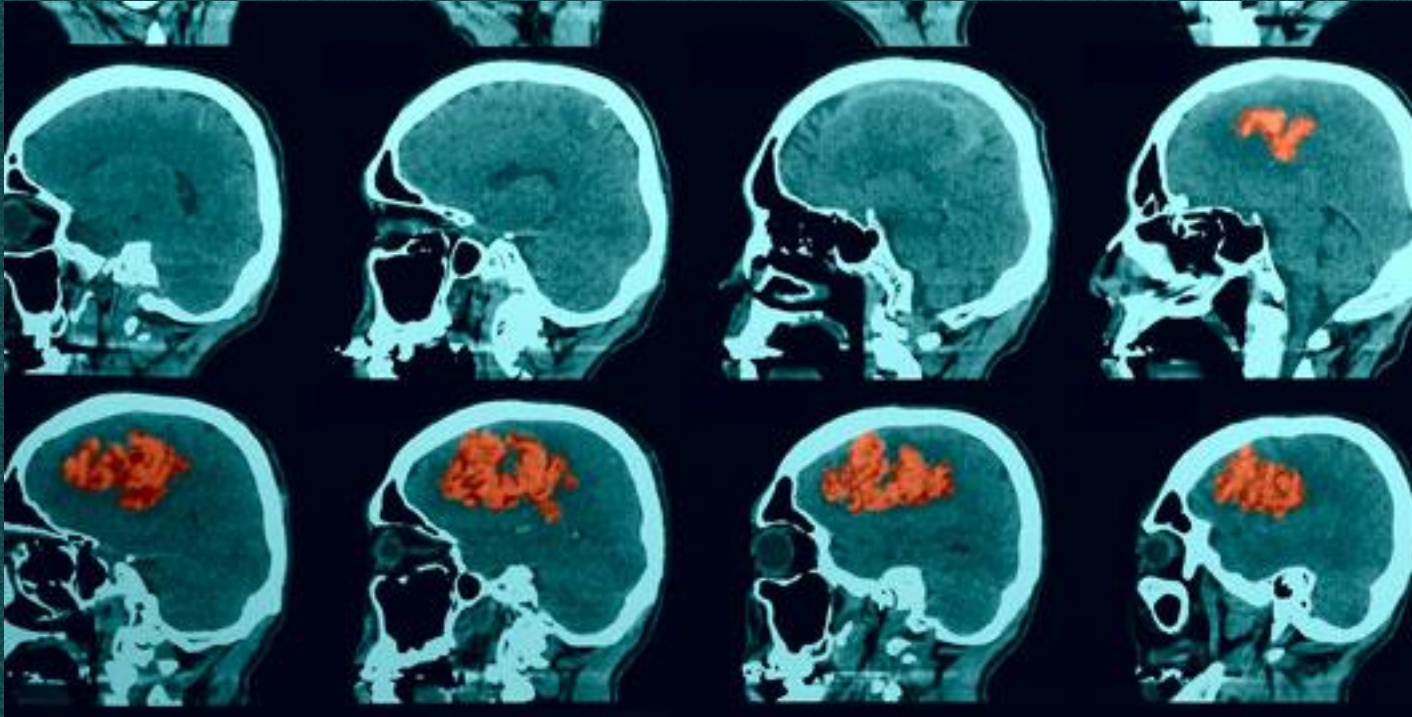
This case concerns an elderly retired businessman who has long been concerned that he would develop Alzheimer's disease, who had expressed general preferences about his future medical care to his eldest son, and who has now developed some memory problems. When the patient's GP diagnoses a comorbid medical condition, the patient is referred to a specialist. His son and other family members are uncertain how decision-making about treatment for this condition should proceed.

# Mdm Wu



The case concerns an elderly retired teacher with decision-making capacity who leaves decision-making to her eldest son after she declines surgery to repair a fractured hip. Conflict erupts between the eldest son, who lives overseas, and his sister, who is their mother's main caregiver. The healthcare team must resolve the conflict while addressing the caregiver's concerns about whether the care plan reflects an informed decision.

# Mr Yung



This case concerns a middle-aged professional and parent in a minimally conscious state, his wife's emotional and practical challenges in making decisions on behalf of her catastrophically injured spouse, family conflict, and the responsibilities of the healthcare team.

The process is the product.

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Centre for Biomedical Ethics at the Yong Loo Lin School of Medicine

# Making Difficult Decisions with Patients and Families

## A Singapore Casebook



*Making Difficult Decisions with Patients and Families: A Singapore Casebook* is a free and open-access online casebook for continuing professional education in healthcare ethics for doctors, nurses, and allied healthcare staff. Each case is supported by expert commentaries highlighting ethical issues and a clinical perspective by a healthcare professional offering practical insight. Additional support is provided by informational backgrounders, questions for reflection, and further online resources.

*The characters that appear in the Casebook are fictitious and modelled for teaching and learning purposes on the basis of common clinical encounters described by healthcare professionals, and do not refer to specific, real individuals, living or dead. Any individuals appearing in photographs depicting these characters bear no relationship or connection whatsoever to the stories ascribed to those characters.*

### Quotes from Physicians

*"The casebook is particularly useful as a learning tool to increase our exposure to these difficult situations in the local setting, and help to prepare as well as instil confidence in tackling such problems."*  
—Dr Lisa Anne Wong, Medical Resident in Paediatrics

### Editor's Introduction

The project team's aim is to promote learning, teaching, discussion and reflection among healthcare professionals in Singapore about ethical issues in clinical practice. To that end,

## Making Difficult Decisions with Patients and Families