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MINISTRY OF HEALTH MALAYSIA

ADVANCE CARE PLANNING

A GUIDE FOR HEALTHCARE PRACTITIONERS IN MALAYSIA

“Honoring Patients’ Wishes and Improving Quality Care Towards the End-of-Life”

Medical Development Division
Ministry of Health Malaysia

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"HONORING PATIENT'S WISHES AND IMPROVING QUALITY CARE TOWARDS THE END-OF-LIFE"

This document was developed by Medical Services Unit, Medical Development Division, Ministry of Health Malaysia and the Advance Care Planning Guidance Working Group.

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FOREWORD

Director General of Health

Health, as defined by the World Health Organisation is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. As the Ministry of Health continues to strive towards providing better health to the nation, it behoves us to remember that we cannot achieve this by merely increasing access to more medical technology and advanced medical interventions alone. The key to better health lies in understanding the needs of the person who is our patient.

The COVID-19 pandemic has certainly taught us many valuable lessons. It has demonstrated how fragile life can be and how often we might take our health for granted. It has also shown us how important it is to be prepared at all times in the event of something unexpected and how important it is to constantly communicate with our loved ones so they understand our preferences and aspirations for care. Consequent to this, it is indeed timely for the Ministry of Health to step up its focus on person-centred care and to increase the skills and competencies of health professionals in areas of ethics and communication that are fundamental to the practice of whole person medicine. This 1st edition of the National Advance Care Planning (ACP) Guidance is certainly an important step forward in that direction.

ACP is the practice of discussing the values and preferences of an individual regarding their future care in anticipation of the time when they may no longer be able to express these things due to deterioration in their physical and / or mental condition. The practice of ACP is certainly not something new and has been part of clinical medicine worldwide since the 1970s. As modern medicine evolves, it is increasingly understood that medical paternalism is no longer an acceptable practice and that shared decision-making is the most ethical and acceptable practice. ACP therefore allows individuals to retain some degree of autonomy in decisions about their care even when they are unable to express themselves.

As healthcare continues to advance, medical technologies do improve patients' survival to some degree. This has improved life expectancy throughout the world and today, more and more people are able to live beyond their 70s, 80s and even become centenarians. However, there are times when even though a person may have a longer duration of life, that does not mean they have a longer duration of health. This is where health professionals may find themselves in a dilemma when trying to decide if a certain medical intervention, that may potentially prolong a person’s survival, is in line with that person’s choices for care especially when that person is unable to speak and is already very ill. While doctors have a sworn duty to preserve life, they also have a duty to do no harm and to reduce suffering. The unfortunate truth however is that many life-sustaining treatments can often cause a lot of pain and suffering.

In this regard, I am delighted to congratulate the MOH for taking steps to formally promote a greater awareness of ACP and its practice. I hope this guidance will serve to increase the knowledge and skills of health practitioners throughout Malaysia and create a healthcare system where open communication, ethical decision-making and respect for the individual person will always be the norm at the forefront of patient care.

DATUK DR. MUHAMMAD RADZI BIN ABU HASSAN
DIRECTOR GENERAL OF HEALTH MALAYSIA

FOREWORD

Deputy Director General of Health (Medical)

Having served in the MOH for so many years now, I am indeed proud to see how much we have achieved until today. There has been so much development in terms of health facilities, services, specialties and subspecialties. We have advanced so much in terms of our technology and medical interventions. Life expectancy has increased significantly for Malaysians and many people now live longer and better. It is with all this in mind that I am delighted to see the publication of this 1st edition of the National Advance Care Planning Guidance by the Ministry of Health.

In a world where things are progressing at a tremendous rate with digital technology and artificial intelligence thrusting us into a new era of life, it is comforting to know that there are clear efforts to maintain ethical balance to ensure our human dignity. The efforts put into the guidance clearly show how clinicians in Malaysia have not forgotten the importance of upholding a patient's rights and autonomy, respecting a person's dignity and promoting a caring and compassionate profession. All these are values embedded in the mission statement of the Ministry of Health and I am delighted to see how this demonstrates our conviction towards these objectives.

Recent data from the Department of Statistics showed that in 2022, over 70% of medically certified deaths in Malaysia were due to non-communicable diseases. Many of these non-communicable diseases tend to have chronic and progressive courses of illness and while medical technology may help to prolong that course of illness, patients eventually deteriorate and suffer from complications of the disease. At that point, it is important to understand what a person really wants in terms of their care and what the goals of their care are. Advance care planning helps us achieve this so that we will always think about what is best for an individual based on their right to autonomy. This guidance has therefore come at a most opportune time as we are at the precipice of an increasingly aging population and a rising incidence of non-communicable diseases.

To all the contributors and reviewers of this guidance, thank you for the excellent work done. I would also like to congratulate the medical development division for a job well done and for supporting this initiative to implement advance care planning in our healthcare system. I look forward to seeing more developments in the areas of advance care planning, palliative care and clinical ethics in the near future.

DATO' INDERA DR. NOR AZIMI BINTI YUNUS
DEPUTY DIRECTOR GENERAL OF HEALTH (MEDICAL)
MINISTRY OF HEALTH MALAYSIA

FOREWORD

Director of Medical Development Division,
Ministry of Health, Malaysia

Over the past few decades, medical science and technology have grown tremendously. We are now able to treat conditions and improve survival in many patients who in the past would have been unlikely to survive. The modern intensive care units of today with their advanced technology and increasingly sophisticated techniques, can sometimes bring a person back from the brink of death and help them recover to live an active and productive life. While it is indeed the intention of the Ministry of Health to ensure that the Malaysian population has access to state-of-the-art technology and clinical expertise to improve health and survival, it is important that we also understand and consider the limitations of these interventions.

Time and time again, we hear stories of how families find themselves in terrible dilemmas because their loved ones who have terminal illnesses are now faced with very acute problems and they are torn between deciding to have aggressive but often painful interventions performed on the person versus taking a more conservative approach and focusing more on comfort and dignity. While such dilemmas will always exist in clinical practice, an important approach to reducing and hopefully preventing them is to promote better communication between health professionals and patients, as well as their families. Open and clear communication between health professionals and patients is the key to good healthcare delivery. This cannot be overemphasized and all health professionals must recognise this as part of the therapeutic process and a duty that we should all feel responsible for. Patients should also be encouraged to have open and honest communication with their family and loved ones to inform them about their feelings, values, concerns and preferences in terms of their future care.

I am indeed pleased that the MOH Medical Development Division along with key clinicians from various disciplines, divisions and universities have managed to come up with this first edition of the National Advance Care Planning Guidance which will serve as a foundation for the development of a national ACP programme and the strengthening of a culture within the healthcare system that emphasises open communication and respect for patient choices.

I sincerely hope that as time goes on, the Malaysian public and health professionals alike, will come to understand the importance and role of advance care planning and see this as a norm in society. It must be understood however that although discussions are had and preferences may be documented, the role of an ACP is mainly to provide essential information to assist decision making for patients who are unable to express their choices contemporaneously. It does not however, absolve the clinician from assessing and determining an individualised management plan. Neither does it absolve the clinician from having open discussions with the family and loved ones, and practise shared decision-making. It is also important to note that preferences stated in an ACP are not legally binding and clinical decisions should always be made based on the best interests of the individual patient.

I would like to thank the members of the team that have worked hard to develop this guidance and congratulations on a job well done.

DATO' DR. MOHD AZMAN BIN YACOB
DIRECTOR OF MEDICAL DEVELOPMENT DIVISION
MINISTRY OF HEALTH MALAYSIA

FOREWORD

Head of Palliative Medicine Subspecialty, Ministry of Health, Malaysia

It is with deep gratitude and a humble heart to see the launch and endorsement of this National Advance Care Planning Guidance which I hope will bring significant change to the healthcare system and to the people of Malaysia. For too long, doctors and patients along with their families have found themselves in various dilemmas surrounding the issue of difficult decision-making particularly when patients may have a very poor prognosis. While clinicians always try to do their best for patients, it can be very difficult to know exactly what is best and whether the interventions applied are in accordance with the preferences of the individual. I am therefore very grateful to the higher administration of the Ministry of Health for their resounding support for this initiative and the development of a nationwide advance care planning programme.

ACP is something that is applicable to all, be it the sick, healthy, young or old. It is something that everyone should become familiar with and all clinicians should incorporate into their practice. Even when patients seem relatively well, it is still relevant to have such discussions as nobody can predict what the future holds. This is the precise reason why ACP is so important.

It is hoped that with this guidance, more clinicians will become familiar with the concept and process of ACP, applying it in an appropriate manner. The guidance therefore attempted to provide both general information on ACP, alongside some more specific issues for patients with various disease processes.

One thing we all must note however, is that while ACP is indeed a very useful process, it is not a one-off solution for all medical decisions. ACP is a concept that has been very much evolving throughout time and it will continue to evolve as medicine and medical technology continue to evolve. Thus, things we may clearly decide upon today, may not be so clearly decided upon in the future. This is why the practice of ACP must be seen as a continuous process and clinicians must never think of ACP documentation as an absolute decision.

The main purpose of ACP is to allow a process where open communication can occur. For many patients, especially those who have serious illnesses, open conversations about how they feel and what they would want when things become worse are often seen as a taboo. So the ACP discussion is a process to allow the “elephant in the room” to be more openly recognised and to enable family and healthcare providers to know how patients feel about their situation. When we know how they feel and what they value, we will then know how to make decisions for them.

I would like to extend my deepest appreciation to the entire team that has worked hard to bring this document together and who will continue to develop the national ACP programme over the years to come.

DR. RICHARD LIM BOON LEONG
HEAD OF PALLIATIVE MEDICINE SUBSPECIALTY
MINISTRY OF HEALTH MALAYSIA

LIST OF CONTRIBUTORS

Advisors

Datuk Dr. Muhammad Radzi bin Abu Hassan
Director General of Health, Malaysia

Dato' Indera Dr. Nor Azimi binti Yunus
Deputy Director General of Health (Medical), Malaysia

Dato' Dr. Asmayani binti Khalib
Ex-Deputy Director General of Health (Medical), Malaysia

Dato' Dr. Mohd Azman bin Yacob
Director of Medical Development Division
Ministry of Health

Dr. Norhayati binti Ibrahim
Senior Deputy Director
Medical Services Development Section
Medical Development Division
Ministry of Health

Chairperson

Dr. Richard Lim Boon Leong
Senior Consultant Palliative Medicine Physician
Hospital Selayang
Head of Palliative Medicine Subspecialty
Ministry of Health

Sub-group Leads

Chapter 1:
Dr. Richard Lim Boon Leong
Senior Consultant Palliative Medicine Physician
Hospital Selayang

Chapter 2:
Dr. Ng Wan Jun
Palliative Medicine Physician
Hospital Queen Elizabeth, Kota Kinabalu

Chapter 3:
Dr. Liew Kean Yew
Palliative Medicine Physician
Hospital Ampang

Chapter 4:
Dr. Tan Hui Siu
Paediatrician
Lead, Hospital Ethics Support Services (HESS)
Hospital Ampang

Chapter 5 (5A):
Dr. Lee Chee Chan
Paediatic Palliative Paediatrician
Hospital Tuanku Azizah Kuala Lumpur

Chapter 5 (5B):
Dr. Chern Phei Ming
Consultant Rehabilitation Physician
Hospital Rehabilitasi Cheras

Chapter 5 (5C):
Dr. Lim Liang Yik
Palliative Medicine Physician
Hospital Pulau Pinang

Chapter 5 (5D):
Dr. Rizah Mazzuin binti Razali
Internal Medicine Physician and Geriatrician
Hospital Kuala Lumpur

Chapter 5 (5E):
Dr. Liew Houng Bang
Senior Consultant Cardiologist
Hospital Queen Elizabeth, Sabah

Chapter 5 (5F):
Dr. Rafidah binti Abdullah
Consultant Nephrologist
Hospital Putrajaya

Chapter 6:
Dr. Navin Francis a/l Susinadan
Palliative Medicine Physician
Institut Kanser Negara

Chapter 7:
Dr. Teo Aik Howe
Consultant Emergency Physician
Hospital Pulau Pinang

Chapter 8:
Dr. Richard Lim Boon Leong
Senior Consultant Palliative Medicine Physician
Hospital Selayang

Members:

Palliative Medicine Subspecialty

Dr. Saiful Adni bin Abd Latif
Palliative Medicine Physician
Institut Kanser Negara, Putrajaya

Dr. David Paul Capelle
Palliative Medicine Physician
University Malaya Medical Centre

Emergency Medicine Specialty

Dr. Kwanhathai Darin Wong
Consultant Emergency Physician
Hospital Pulau Pinang

Dr. Tan Wan Chuan
Emergency Physician
Hospital Raja Permaisuri Bainun, Ipoh

Dr Wan Nor Aida binti Wan Mohd Shukri
Emergency Physician
Hospital Kuala Lumpur

Dr. Cecilia Anthonysamy
Emergency Physician
Hospital Sultan Idris Shah, Serdang

Prof. Dr. Mohd Idzwan bin Zakaria
Academic Unit Emergency Medicine
Faculty of Medicine
Universiti Malaya

Dr. Hafizah binti Zainal Abidin
Emergency Physician
Universiti Sains Islam Malaysia

Internal Medicine Specialty

Dr. Cheah Wee Kooi
Consultant Internal Medicine Physician
and Geriatrician
Hospital Taiping
Head of Internal Medicine Specialty MoH

Dr. Yoon Chee Kin
Internal and Acute Medicine Physician
Hospital Pulau Pinang

Dr. Vijayan a/l Panirselvam
Internal and Acute Medicine Physician
Hospital Tengku Ampuan Rahimah, Klang

Nephrology Subspecialty

Dr. Azrini binti Abdul Aziz
Nephrologist
Hospital Kuala Lumpur

Dr. Nor Fadhlina binti Zakaria
Lecturer/ Nephrologist
Faculty of Medicine and Health Science,
Hospital Sultan Abdul Aziz Shah, UPM

Geriatric Medicine Subspecialty

Dr. Rosmahani binti Mohd Ali
Internal Medicine Physician and
Geriatrician
Hospital Kuala Lumpur

Dr. Ling Jia Nee
Internal Medicine Physician and
Geriatrician
Hospital Umum Sarawak

Cardiology Subspecialty

Dr. Abdul Muizz bin Abdul Malek
Consultant Cardiologist
Hospital Sultan Idris Shah, Serdang

Gastroenterology and Hepatology Subspecialty

Datuk Dr. Hajjah Rosaida binti Md Said
Senior Consultant in Gastroenterology and Hepatology
Hospital Sultan Idris Shah, Serdang

Dr. Tan Soek Siam
Senior Consultant Hepatology
Hospital Selayang

Respiratory Medicine Subspecialty

Dr. Lam Yoke Fong
Respiratory Physician
Hospital Raja Permaisuri Bainun, Ipoh

Dr. Azza binti Omar
Respiratory Physician
Hospital Raja Perempuan Zainab II, Kota Bharu

Dr. Ng Khai Lip
Respiratory Physician
Hospital Melaka

Hematology Subspecialty

Dr. Mandy Yap Yee Yee
Hematologist
Hospital Ampang

Neurology Subspecialty

Dr. Rose Izura binti Abdul Hamid @ Abdul Razak
Neurologist
Hospital Raja Perempuan Zainab II, Kota Bharu

Radiotherapy and Oncology Specialty

Dr. Chan Ming Jun
Clinical Oncologist
Hospital Kuala Lumpur

Psychiatry Specialty

Dr. Sapini binti Yacob
Consultant-liaison Psychiatrist
Hospital Kuala Lumpur

Dr. Ahmad Rostam bin Md Zin
Consultant-liaison Psychiatrist
Hospital Sultanah Bahiyah, Alor Setar

General Surgery Specialty

Dato’ Dr. Fitjerald a/l Henry
Senior Consultant of General Surgery and Colorectal Surgery
Hospital Selayang
Head of General Surgery Specialty MOH

Datuk Dr. Hanif bin Hussein
Senior Consultant of Vascular Surgery
Hospital Kuala Lumpur
Deputy Head of General Surgery Specialty MOH

Dr. Poobalan a/l Kandasamy
General Surgeon
Hospital Kuala Lumpur

Anesthesiology and Intensive Care Specialty

Dr. Shanti Rudra Deva
Past Head of Intensive Care Subspecialty
Hospital Kuala Lumpur

Dr. Zarina binti Abu Kassim
Senior Consultant Anaesthesiologist
Head of Department
Department of Anaesthesiology and Critical Care
Hospital Kuala Lumpur

Dr. Louisa Chan Yuk Li
Sessional Consultant of Anesthesiology and Intensive Care
Hospital Kuala Lumpur

Dr. Kang Ker Cheah
Intensivist Anesthesiologist
Head of Intensive Care Unit
Department of Anaesthesiology and Critical Care
Hospital Sungai Buloh

Dr. Nor Airini binti Ibrahim
Lecturer of Anesthesiology
Faculty of Medicine and Health Science,
Hospital Sultan Abdul Aziz Shah, UPM

Obstetrics and Gynaecology Specialty

Dato' Dr. Wan Ahmad Hazim bin Wan Ghazali
Senior Consultant Obs & Gyn
Putrajaya Hospital
Head of Obs & Gyn Specialty MOH

Paediatric Specialty

Dr. Zulaiha binti Muda
Senior Consultant in Paediatric Hemato-Oncology
Hospital Tuanku Azizah Kuala Lumpur

Dr. Elaine Wong Ee Lane
Neonatologist
Hospital Tuanku Azizah Kuala Lumpur

Dr. Nickson Tai Boon Khean
Paediatrician
Hospital Umum Sarawak

Rehabilitation Medicine Specialty

Dr. Tan Chee Jiun
Rehabilitation Physician
Hospital Melaka

Family Medicine Specialty

Dr. Ho Bee Kiau
Consultant Family Medicine Specialist
Klinik Kesihatan Bandar Botanik, Klang

Dr. Ranjini a/p Ambigapathy
Consultant Family Medicine Specialist
Klinik Kesihatan Sungai Dua Timur Laut, Pulau Pinang

Dr. Nik Suhaila binti Zakaria
Consultant Family Medicine Specialist
Klinik Kesihatan Labok, Machang, Kelantan

Dr. Teoh See Wie
Family Medicine Specialist
Klinik Kesihatan Salak, Sepang

Dr. Junita Harizon binti Aris
Family Medicine Specialist
Klinik Kesihatan Batu 14, Hulu Langat

Medical Development Division, MOH

Dr. Shahanizan binti Mohd Zin
Head of Medical Services Unit
Senior Principal Assistant Director
Medical Services Unit
Medical Development Division

Dr. Ezaty Dalila binti Adil
Senior Principal Assistant Director
Medical Services Unit
Medical Development Division

Dr. Puteri Aida Alyani binti Mohamad Ismail
Senior Principal Assistant Director
Medical Services Unit
Medical Development Division

Dr. Nur Shaheera binti Shaharuddin
Senior Principal Assistant Director
Medical Services Unit
Medical Development Division

Dr. Mohamad Kairul Aneeza bin Zakaria
Senior Principal Assistant Director
Emergency Services & Disaster Management Unit
Medical Development Division

Dr. Sangeeta a/p Subramaniam
Senior Principal Assistant Director
Obs and Gyn and Paediatric Services Unit
Medical Development Division

Dr. Muhammad Al-Amin bin Safri
Clinical Support Unit
Medical Development Division

Dr. Praveen a/l Nadarajah
Surgical Services Unit
Medical Development Division

Dr. Samha Bashirah binti Mohamed Amin
Senior Assistant Director
Medical Services Unit
Medical Development Division

Medical Practice Division, MOH

Dr. Theeban a/l Suntherasegarun
Senior Principal Assistant Director
Medico Legal Section
Medical Practice Division

Datin Dr. Syahiran binti Mohamad
Senior Principal Assistant Director
Medico Legal Section
Medical Practice Division

Family Health Development Division, MOH

Dr. Sheleaswani binti Inche Zainal Abidin
Public Health Medicine Specialist
Elderly Health Sector
Family Health Development Division

Dr. Muhammad Firdaus bin Ujang
Public Health Medicine Specialist
Adolescent Health Sector
Family Health Development Division

Nur Baizura binti Januri
Health Education Officer
Family Health Development Division

Public Health Development Division, MOH

Dr. Normaslina binti Mustaza
Senior Principal Assistant Director
Public Health Policy and Services Branch
Public Health Development Division

Institute of Health Behavioural Research, MOH

Sheikh Shafizal bin Sheikh Ilman
Senior Assistant Director (Health Education)
Institute of Health Behavioural Research

Universiti Malaya

Prof. Dr. Lai Siew Mei Pauline
Department of Primary Care Medicine
Universiti Malaya

EXTERNAL REVIEWERS

Dato' Dr. Patrick Tan Seow Koon
Consultant, Anaesthesia and Intensive Care
University Malaya Medical Centre

Professor Dr. Letchuman a/l Ramanathan
Professor of Medicine
Clinical School Monash University Malaysia

Dr. Lam Chee Loong
Senior Lecturer and Palliative Medicine Physician
Faculty of Medicine
Universiti Malaya

Associate Professor Dr. Sharon Kaur a/p Gurmukh Singh
Senior Lecturer
Faculty of Law
Universiti Malaya

LIST OF FIGURES

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ABBREVIATIONS

ACP: Advance Care Planning

AMD: Advance Medical Directive

MOH: Ministry of Health Malaysia

WHO: World Health Organisation

NCD: Non-Communicable Disease

ADL: Activity of Daily Living

EOL: End of Life

POLST: Preferences for Order of Life-Sustaining Treatment

LSTL Life Sustaining Treatment

DNR: Do Not Resus

DNI: Do Not Intubate

NFR: Not for Resuscitation

DNAR: Do Not Attempt Resuscitation

ICD: Implantable Cardioverter Defibrillator

VT: Ventricular Tachycardia

VF: Ventricular Fibrillation

AD: Advance Directive

SQ: Surprise Question

GOC: Goals-of-Care

CKD: Chronic Kidney Failure

CCF: Chronic Cardiac Failure

COPD: Chronic Obstructive Pulmonary Disease

CHD: congenital heart disease

MS: Multiple sclerosis

MND: Motor neuron disorder

ESLD: End-stage Liver disease

CLD: Chronic Liver disease

CKD: Chronic Kidney Disease

MASLD: metabolic dysfunction-associated steatotic liver disease

KRT: Kidney Replacement Therapy

ICU: Intensive Care Unit

PICU: Paediatric Intensive Care Unit

HCP: Healthcare Provider

CFS: Clinical Frailty Scale

NYHA: New York Heart Association

MELD: Model for End-Stage Liver Disease

MDAC: Medical Dental Advisory Committee

MAC: Medical Advisory Committee

CEC: Clinical Ethics Committee

MMC: Malaysian Medical Council

MMA: Malaysian Medical Association

AMM: Academy of Medicine Malaysia

MSIC: Malaysian Society of Intensive Care

ACT/ RCPCH: Association for Children's Palliative Care and the Royal College of Paediatrics and Child Health

PaPaS Scale: Paediatric Palliative Screening Scale

ED: Emergency Department

AYA: adolescents and young adults adolescents

VCC: verbal confidentiality contract

CRET: confidentiality, rapport, empathy and trust

NIV: Non-Invasive Ventilation

PEG: Percutaneous Endoscopic Gastrostomy

FVC: Forced Vital Capacity

VFSS: Video Fluoroscopic Swallowing Study

FEES: Fibreoptic Endoscopic Evaluation of Swallowing

NG tube: Nasogastric Tube

PWD: Person with disability

CFO: Comfort feeding only

MAGGIC risk score: Meta-Analysis Global Group for Chronic Heart Failure risk score

COPD-BODE index: Chronic Obstructive Pulmonary Disease-Body mass index, airflow Obstruction, Dyspnoea, and Exercise index

PAH-ESC/ERS risk stratification score: Pulmonary Hypertension/ European Society of Cardiology/ European Respiratory Committee

IPF- GAP Index: Idiopathic Pulmonary Fibrosis- Gender Age Physiology index

BSI: Bronchiectasis Severity Index

FACED score: FEV1, Age, Chronic Colonisation, Extension, Dyspnoea score

KRT: kidney replacement therapy
eGFR: estimated glomerular filtration rate

CPS: Child Pugh Score

SBP: spontaneous bacterial peritonitis

AKI: Acute Kidney Injury

REMAP framework: **R**eframe, **E**xpect emotion, **M**ap out patient goal, **A**lign with goal, **P**ropose a plan

UHC: Universal Health Coverage

CPR: Cardiopulmonary Resuscitation

ACE-I: Angiotensin-converting enzyme inhibitor

Upper GI bleeding: upper gastrointestinal bleeding

CPG: Clinical Practise Guideline

PRN: pro re nata (as required)

IV: intravascular

s/c: subcutaneous

ON: omni nocte (every night)

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EXECUTIVE SUMMARY

1. Introduction

Advance care planning (ACP) is a process whereby a person communicates his or her values and preferences regarding his or her future care with family members and healthcare providers which are then documented in order to facilitate important decision making at a future time when the person may be unable to speak or express these views.

As Malaysia progresses into a developed and high-income nation, it is necessary for society to evolve and progress so that ethical balance is also maintained in the ever-advancing healthcare milieu. ACP is a process that needs to become embedded in the healthcare system so that as the nation becomes more aged, people will still have the opportunity to receive care that is in accordance with their wishes and family members will have clearer directions when making decisions for their loved ones towards the end of life.

While it is often assumed that Asian societies typically consider it a taboo to talk about death and dying, numerous studies have demonstrated that the majority of Malaysians are interested and agree with the concept of ACP. It is also an acceptable practice as seen in the view of Islamic values and law.

This document serves as a guidance for healthcare practitioners in Malaysia to understand important aspects of ACP and to promote its practice within the healthcare system.

2. Fundamentals of Advance Care Planning

a) Concept of ACP

Advance care planning is a broad term that refers to a process whereby a competent individual of consenting age discusses their values, life goals and preferences towards future medical care. There are many different terms such as advance directives, durable power of attorney, POLST, DNR and living will, all of which are potential components of an ACP discussion. Some of these components require legal statutes in order to be considered legally binding. At the present time, Malaysia does not have any legal statutes to enforce legally binding advance directives or durable power of attorney however this may develop in the near future.

Adults at any age or stage of health can have an ACP discussion. In particular, individuals with chronic life limiting illnesses should be prioritized as they will likely have frequent encounters with life-sustaining treatment that may or may not be aligned with their goals and preferences. This would include the following:

- People facing the prospect of deteriorating health due to long term conditions or progressive life limiting illnesses, e.g. dementia, frailty, kidney, heart or liver failure, lung disease, progressive neurological conditions, incurable cancer.
- People with declining functional status, increased burden of illness or persistent physical or mental health symptoms
- People facing key transitions in their health and care needs, e.g. multiple hospital admissions, shifts in focus of treatment to a more palliative intent, moving into a care home, etc.
- People facing major surgery or high-risk treatments, e.g. bone marrow transplant.

ACP can be discussed at any time but preferably when a person is stable and well enough to consider their values and preferences clearly. It is a continuous process and should be updated often especially when there are changes in their health status or life views.

b) Principles of decision making in the seriously ill

Decision making in the seriously ill can be complex and requires clinicians to understand and apply principles of medical ethics with prognostication while recognizing the importance of considering a patient's values and preferences along with input from the family.

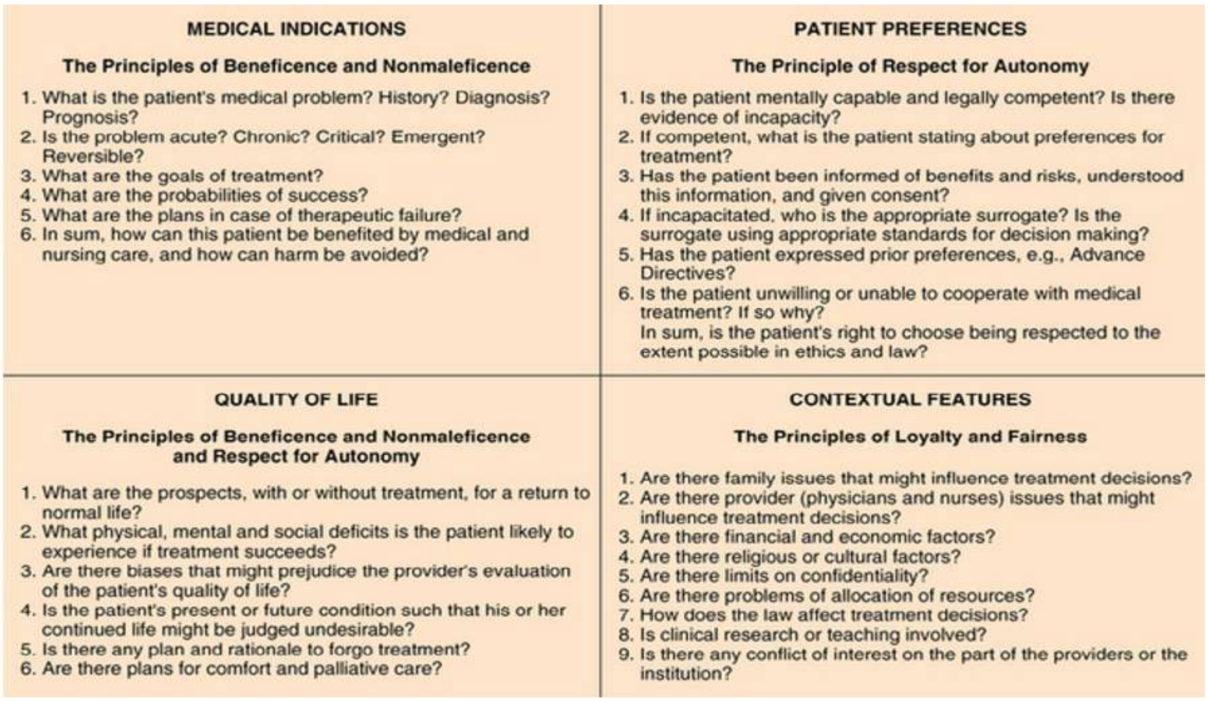
While medical interventions have been developed to improve a patient's survival, society needs to be aware of the limitations of these interventions and recognize situations where treatments may be considered inappropriate (futile).

The basic principles of bioethics include autonomy, beneficence, non-maleficence and justice. These need to be considered equally when deliberating on the appropriateness of any medical intervention. These principles may also be considered by using the "Four Box Method" which looks at medical indications, patient preferences, quality of life and contextual features surrounding any medical decision.

In situations where medical therapies are deemed to be inappropriate or non-beneficial in a patient with extremely poor prognosis, it is reasonable and ethical to consider withholding and even withdrawing such medical therapies.

Patients and families may feel vulnerable as they lack medical knowledge and are dependent on healthcare providers for information about their condition and treatment options. This is where shared decision making plays a vital role to empower patients and families to assert their autonomy in decision making.

Decision making however is only valid when a person is deemed competent and has capacity to make these decisions. They must be able to first understand and appreciate the information provided. Following this they must have the reasoning and communicative ability to discuss their choices. As decision making capacity is very often lost during serious illness, ACP and goals of care discussions are vital to help this shared decision process.



MEDICAL INDICATIONS	PATIENT PREFERENCES
The Principles of Beneficence and Nonmaleficence	**The Principle of Respect for Autonomy**
1. What is the patient's medical problem? History? Diagnosis? Prognosis? 2. Is the problem acute? Chronic? Critical? Emergent? Reversible? 3. What are the goals of treatment? 4. What are the probabilities of success? 5. What are the plans in case of therapeutic failure? 6. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?	1. Is the patient mentally capable and legally competent? Is there evidence of incapacity? 2. If competent, what is the patient stating about preferences for treatment? 3. Has the patient been informed of benefits and risks, understood this information, and given consent? 4. If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making? 5. Has the patient expressed prior preferences, e.g., Advance Directives? 6. Is the patient unwilling or unable to cooperate with medical treatment? If so why? In sum, is the patient's right to choose being respected to the extent possible in ethics and law?
QUALITY OF LIFE	**CONTEXTUAL FEATURES**
The Principles of Beneficence and Nonmaleficence and Respect for Autonomy	**The Principles of Loyalty and Fairness**
1. What are the prospects, with or without treatment, for a return to normal life? 2. What physical, mental and social deficits is the patient likely to experience if treatment succeeds? 3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life? 4. Is the patient's present or future condition such that his or her continued life might be judged undesirable? 5. Is there any plan and rationale to forgo treatment? 6. Are there plans for comfort and palliative care?	1. Are there family issues that might influence treatment decisions? 2. Are there provider (physicians and nurses) issues that might influence treatment decisions? 3. Are there financial and economic factors? 4. Are there religious or cultural factors? 5. Are there limits on confidentiality? 6. Are there problems of allocation of resources? 7. How does the law affect treatment decisions? 8. Is clinical research or teaching involved? 9. Is there any conflict of interest on the part of the providers or the institution?

Jonsen AR, Sieglar M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine[8]. Sixth ed. New York: McGraw Hill, 2010.

c) Ethical, legal and sociocultural considerations in advance care planning

From an ethical perspective, ACP is highly justifiable as it aims to uphold the principle of respect for an individual’s autonomy as well as the principle of beneficence and person-centered care.

At times there can be conflict between a person’s preferences as stated in an ACP and their best interests. This is because preferences stated in an ACP may be unclear or inapplicable due to unique circumstances or changes over time. Hence it must be understood that the content of an ACP is merely to guide and help the attending doctor understand what is best for the person during critical moments and is not meant to be legally binding. If there is uncertainty or in an emergency where information is lacking, it is ethically appropriate for physicians to treat the person according to their best clinical judgement. If a person still has capacity to make decisions, their current preferences will always take precedence over the past ones even when stated in an ACP.

From a legal perspective, Malaysia has not yet passed any legal statutes regarding advance directives or legal proxies however there is a plan for a mental capacity act to be tabled in the near future. Good medical practice however should always apply principles of bioethics, professionalism and the best interests of the person with legal recourse being a last resort.

Clinicians should use a personalised approach to explore decision making, considering cultural and religious dimensions but without making assumptions based on religious or cultural stereotypes.

3. Advance Care Planning in Specific Situations and Disease Processes

ACP is generally applicable for all individuals regardless of age or health status. The scope ranges from those who are still young and healthy to those who are frail and elderly with multiple comorbidities. While discussions are often conducted in an open-ended manner to allow the individual to determine the pace, direction and depth of the discussion, there are unique situations in certain disease processes that healthcare providers should be aware of.

a) ACP in Paediatrics

ACP in paediatrics is appropriate only to those distinct target groups of children with life-limiting conditions. Prognosis in childhood life-limiting illnesses can be very uncertain thus a parallel planning approach to ACP discussion is useful to enable various options for care to be considered in response to a range of potential outcomes.

While children under 18 years old are not legally able to consent to preferences discussed in an ACP, it is important to include the child in the discussion and respect their views if this is appropriate. Ethical issues unique to paediatric palliative care should be considered during any ACP discussion with a child and family.

b) ACP in Adolescents and Young Adults

Adolescents who are developing into their adult being undergo physical, cognitive and social changes that can be seriously impacted by life-limiting illnesses. Evidence suggests that the majority of adolescents and young adults (AYA) want to have end-of-life discussions and avoiding this by parents and older adults leads to fear and isolation.

Involving parents and trusted elders in the ACP discussion can help to provide emotional support, facilitate communication, and contribute to understanding the adolescent's wishes. Open and honest communication must begin right from the start emphasizing rapport, confidentiality, empathy and trust.

AYAs should be assessed for readiness to discuss ACP and should be given the right to opt out rather than to earn the privilege to opt in to discussions.

c) ACP In Dementia and Cognitively Impaired Frail Elderly

ACP discussions in persons with dementia (PWD) need to be initiated as early as possible after the diagnosis of dementia as decision-making capacity may be lost early on in the disease trajectory.

In PWD who lack decision-making capacity, ACP can be conducted through supported decision making or through a substitute decision maker who applies substituted judgement and best interest to make decisions on behalf of the PWD.

Important areas of discussion for PWD in relation to the stage of dementia include ceilings for active medical treatments and issues regarding feeding. Evidence suggests that tube feeding does not provide any survival advantage over careful oral hand-feeding. Oral feeding is a basic human right and should always be offered as long as it does not cause distress.

d) ACP in Neurodegenerative Diseases

ACP is essential in neurodegenerative diseases as cognitive, functional and communicative impairments are common in advanced disease. Important issues that should be discussed include artificial hydration/nutrition, ventilatory support and withholding specific life-sustaining treatments when it is no longer in the person's best interest.

Artificial hydration and nutrition should be discussed in a balanced manner considering the potential benefits and harms without making reflexive assumptions.

Issues of ventilatory support should be discussed early to avoid patients presenting with respiratory failure in an acute emergency setting. Non-invasive ventilation should be introduced early as respiratory function declines.

e) ACP in Chronic Organ Failure

Many chronic organ failure patients including heart failure, chronic lung diseases, chronic liver disease and chronic kidney disease have trajectories of progressive gradual deterioration over several years interspersed with episodes of acute deterioration which can result in recovery or death thus making prognosis very unpredictable.

ACP is a process that should begin early and continue to be revisited throughout the trajectory particularly when there is a change in condition or an acute episode of deterioration.

In advanced heart failure, issues of using inotropic support and also the role of ICDs, pacemakers and cardiac resynchronisation devices should be discussed.

In severe chronic lung disease, the role and type of mechanical ventilation as well as ceilings of its use should be discussed.

ACP in chronic kidney disease should include discussions on choices for kidney replacement therapy (KRT) or conservative non-dialytic therapy which is an acceptable approach especially in patients where KRT may not be beneficial. All patients on KRT will encounter more complications with longer dialysis vintage and ACP must be revisited to check if KRT is still in a patient's best interest.

For those with end-stage-liver-disease (ESLD), ACP discussions should include preferences for treatment in the event of common complications such as upper GI-bleeding, hepatic encephalopathy and acute kidney injury.

4. Practical Aspects of Advance Care Planning

a) Communication Skills

The practice of ACP is generally an exercise in open discussions between a patient +/- their family and healthcare providers regarding their values and preferences for future care. All healthcare providers should learn to apply good communication skills to navigate ACP discussions.

Some key elements to successful and effective ACP discussions include recognising the appropriate timing and readiness of a patient to have an ACP discussion. It also requires some understanding of prognosis and disease trajectories of various life limiting conditions and generic communication skills to build rapport, handle emotions and manage conflict.

Common scenarios that may need to be handled include breaking bad news, discussing prognosis and goals of care including preferences for using life-sustaining treatments.

General principles to follow when conducting an ACP discussion are as follows:

- Build rapport and trust
- Use plain and understandable language
- Practice active and reflective listening
- Ask open-ended questions
- Explore the person’s values and goals
- Provide information and education
- Respect cultural and individual differences
- Address emotions and fears
- Document and summarise discussion
- Encourage collaborative decision-making

b) ACP Documentation

Although not compulsory, some means of documenting a person's wishes of any advance care plan is preferred so that it can be shared with other family members and loved ones, can be communicated to healthcare providers, and can be recalled, altered or even removed totally if or when needed. A surrogate decision maker may also be identified to speak on behalf of the person when they are unable to do so.

It is important to understand that a documented ACP is **legally persuasive but not legally binding.** This means that the role of the ACP documentation is not to rigidly instruct healthcare providers to do or not to do specific medical interventions but to provide insight for the family and healthcare providers on the person's preferences for certain forms of medical care. It should not prevent healthcare providers from applying clinical judgement to recommend the best treatment possible to a patient's immediate health issues. Hence, the main role is to assist those who care for the person to make decisions on his/her behalf based on advance knowledge of his/her values and preferences.

In general, most ACP documentation should include the following areas:

- Individual perception to quality of life
- Statement of wishes / Expression of concerns
- Naming a surrogate decision maker
- Outlining preferences for life sustaining treatment and other interventions
- Spiritual and cultural considerations
- Preferences for social support
- Preferences for care setting

5. Palliative Care and Supporting Patients at the End of Life

When people make choices in their ACP to withhold or to withdraw certain medical interventions that are deemed not to be in their best interest, they are essentially making a choice to forgo aggressive treatments and are explicitly choosing the alternative to be more comfortable and to have more dignified care. That alternative is defined as palliative care. Therefore, if people are made to believe that they have such choices available to them during an ACP discussion, it is imperative that the option of palliative care should be made accessible to every person who expresses this choice.

The development of an ACP programme within a healthcare system, must always be accompanied with the development of universal access to palliative care. This is in keeping with the WHO definition of Universal Health Coverage (UHC).

Basic components of end-of-life care:

a) Prognostication and Diagnosing Dying

Clinicians must first be familiar with disease processes and their natural trajectories so as to understand the overall prognosis of a patient and recognize when a person is in the dying phase. Good end-of-life care can only be provided when healthcare providers recognize a person is facing the end of their life. Failure to recognize this results in inappropriate management because of unrealistic expectations for both healthcare providers and family members.

b) Compassionate Communication with the Family

Once a patient has been diagnosed to be dying, it is essential that an appropriate and compassionate explanation regarding this diagnosis is broken to the family. Often, even when doctors diagnose a patient to be in the dying phase, there is a reluctance to explain this to the family for fear of making them emotional. This however leads to even more shock and distress when the patient ultimately passes on as the family were not forewarned to anticipate the death. Therefore, if a healthcare provider recognises that a patient is dying, it is imperative that they ensure the family recognises it as well.

c) Symptom Management in the Terminally Ill

Common physical symptoms that need to be addressed at the end of life include pain, dyspnoea, nausea/vomiting, delirium/restlessness and terminal respiratory secretions. It is important that there is access to essential medications to address these symptoms and clinicians are knowledgeable on how to prescribe these medications in an appropriate manner. These medications usually include:

Symptoms	Treatment
Pain and dyspnoea	s/c Morphine (dose depends on prior 24H dose)
Nausea / vomiting	s/c Haloperidol 0.5-1mg prn
Restlessness / agitation	s/c Midazolam 2.5-5mg prn s/c Haloperidol 0.5-1mg prn
Death rattle / secretions	s/c Buscopan 20mg prn s/c Glycopyrollate 200mcg prn

d) Ethical Decision Making at the End-of-Life

Even at the end-of-life, it is very important to be mindful of the principles of biomedical ethics to ensure that patients are always treated in an appropriate manner. Clinicians may sometimes struggle with issues regarding withholding and withdrawing certain life-sustaining treatments such as artificial hydration/nutrition or ventilatory support. Also, the use of sedative medications and opioids at the end of life can sometimes be confused as an act that intends to hasten death. Therefore, all healthcare providers must be aware about the ethical basis of these actions and interventions that make them ethically permissible at the end of life.

It is equally important to be clear of that which is NOT ethically permissible, in particular, the act of euthanasia. Euthanasia is defined as the **intentional killing** of a dependent human being for his/her alleged benefit upon their competent and voluntary request. The key element that defines euthanasia is that the **intent is to cause death** and for euthanasia to be successful, immediate death of the patient must occur. In Malaysia such an act is clearly illegal.

In ACP, while patients are given the right to express their wishes, they **CANNOT** request for an intervention that is illegal and unethical. Hence an **ACP cannot include an advance request for euthanasia.**

6. Conclusion

It is imperative that advance care planning conversations become the norm in the Malaysian healthcare system as it is a highly ethical and person-centered approach to care which characterizes a mature and progressive society that respects individual autonomy as well as the overall wellbeing of the nation.

SECTION A
UNDERSTANDING ACP

CHAPTER 1: INTRODUCTION

Key Learning Points:

- Majority of Malaysians want to be involved with decision making regarding their medical care and agree with the concepts of ACP.
- ACP is a recognised process in healthcare systems around the world and is recommended as a quality indicator of good care by the WHO.
- ACP is very relevant in Malaysia as the population ages and the incidence of non-communicable diseases increases.

1.1 ACP AND PATIENT AUTONOMY IN HEALTHCARE DECISIONS

Advance care planning (ACP) is a process whereby a person communicates his or her values and preferences regarding his or her future care with family members and healthcare providers which are then documented in order to facilitate important decision making at a future time when the person may be unable to speak or express these views.

Autonomy has long been recognised as one of the foundational principles of bioethics and a characteristic of human nature which is often very closely linked to an individual's ability to enjoy his or her quality of life and spiritual wellbeing. While societies in the past may have practised significant degrees of paternalism within families, current evolution of societal norms have moved generally to recognise the value of respecting individual autonomy and a person's right to self-determination particularly if they are deemed competent, above the legal age to provide consent and take individual responsibility over their decisions and choice of actions.

In the medical setting, patients are frequently faced with situations where important decisions need to be made and current practice emphasises the need to involve the individual in their own health and medical decisions. Informed consent is one of the foundations of medicolegal statutes and the frequent saying, "Nothing about me without me" is a familiar battle cry for the right of every single individual to be able to express what they do or do not want in terms of their medical care [1-2].

Several studies in Malaysia have consistently demonstrated how patients in Malaysia prefer to be involved in making decisions regarding their medical care and frequently express how they appreciate healthcare providers who respect their views and practice shared decision making [3-4].

1.2 WHY IS THERE A NEED FOR ACP IN HEALTHCARE DECISION MAKING?

While obtaining informed consent and having shared decision making with patients who are alert and competent is currently the norm in clinical practice, the present challenge in the healthcare system is determining a patient's preference for care at a time when they may be incapacitated or cognitively impaired to the point where they are unable to express their preferences clearly or competently[2].

A common scenario is when an elderly person who has multiple life-limiting conditions comes into the emergency department with loss of consciousness and is critically ill. At this point, a decision must be made as to whether the doctor should take all necessary measures to prolong the patient's life and whether this would be in line with the person's individual preferences and goals of care. Family members are then left to make difficult decisions and this often leads to psychological distress and even conflict within the family as different family members may have differing opinions as to the best approach to care.

While medical science has developed interventions to improve the survival of an individual, some of these interventions may be futile and increase suffering when patients approach the terminal phase of life. It is with this understanding that many countries around the world now promote ACP in order to safeguard a person's autonomy and to promote better care at the end-of-life [5].

The World Health Organisation (WHO) has acknowledged the importance of ACP and has recommended it as a quality indicator in the Global Dementia Observatory Reference Guide[17]. Most recently, WHO had also listed the existence of a policy/guideline addressing ACP for medical decisions and end-of-life care as an international quality indicator of palliative care development[18].

While the concept of ACP has been well established in the Western world, many Asian countries have also embraced it such as in Singapore, Thailand, Taiwan, South Korea, India and Hong Kong where there are clear policies and legislation on ACP. It is therefore important that Malaysia begins to develop clear policies and guidance for health professionals in this area in order to promote better communication and more appropriate decision making for its people towards the end-of-life[6].

1.3 WHAT IS THE MALAYSIAN PUBLIC OPINION ON ACP?

At present, the concept of ACP is neither well known nor well embedded in routine clinical practice in Malaysia. This has been postulated to be due to the religious and cultural sensitivities of the topic which involves end-of-life issues. For Muslims, the perception and decision-making on ACP may differ from the western perspective as a patient's autonomy must be confined within the limits of Sharia law [7]. Islam however does not forbid the use of advance medical directives as a method to honour the wishes of a Muslim patient at the end-of-life and emphasises the importance of seeking consent of the patient before any medical procedures [8].

Another important characteristic of many Asian cultures is the family-oriented approach to decision making which is frequently emphasised and may even override the need to uphold individual autonomy [9,10]. The practice of ACP among such cultures therefore must also consider the involvement of the family during discussions.

In Malaysia, several studies have looked at the knowledge and attitudes of the Malaysian public regarding the concept and practice of ACP. In all these studies, it was very clear that the majority of the Malaysian public were not aware of the concept of ACP and were unfamiliar with the term ACP. The largest study of 1227 participants revealed that although 31.6% of participants had heard of ACP, only 8.7% (107) actually knew what it was about, suggesting that public awareness on ACP in Malaysia is currently very poor [11-15].

More importantly however, is that in all these studies, while the awareness of ACP was low, majority of participants in these studies later stated that after the concept had been explained to them, they agreed that it was indeed an important discussion and would consider having an ACP themselves (70-88.6% of participants). This suggests that in general, the Malaysian population does have a positive attitude towards ACP and there is a need for this concept to be promoted and practiced more widely among the Malaysian public [11-15]. It is also apparent that there is a desire among the Malaysian public to be able to express their autonomy and practice shared decision making with regards to their health and care towards the end-of-life.

1.4 WHY IS IT SO IMPORTANT TO PROMOTE THE PRACTICE OF ACP?

As Malaysia continues to advance towards being a developed and high-income nation, some of the key indicators of this include life expectancy, health, quality of life and education. Hence, as the nation progresses, we are already seeing increasing life expectancy as a result of better health care and education. Unfortunately, as life expectancy increases, we also see an increase in non-communicable diseases which will always be one of the main challenges of the healthcare system. The prevalence of conditions such as cancer, stroke and end-organ-failure are on the rise. In the 2018 National Health and Morbidity Survey on the elderly, it was reported that the prevalence of dementia among Malaysians over the age of 60 was 8.5% which amounted to over 260,000 individuals[16].

Individuals with severe and late stage non-communicable diseases (NCD) will at some point be required to make decisions regarding their medical care. For those who are well enough to express their choices this would still be possible, however given the nature of end-stage NCDs, patients are often too unwell to focus and understand the choices offered to them, let alone express their preferences. This is why it is imperative that the concept and practice of ACP is promoted and implemented throughout the nation.

In becoming a developed nation, the key ambition is to promote better quality of life among the population. Quality of life encompasses not only physical aspects of the person but also the psychological, social and spiritual aspects. Hence, quality of life must always include quality at the end-of-life because of the impact this has on psychological, social and spiritual wellbeing. ACP can help to achieve this by:

- Improving population health as a result of person-centred care.
- Improving bereavement experiences of families by reducing stress, anxiety and depression following the death of a loved one.
- Enhancing patient and family satisfaction with end-of-life care and understanding what to expect in the dying process.
- Reducing moral distress among critical care healthcare professionals.

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CHAPTER 2: WHAT IS ADVANCE CARE PLANNING?

Key Learning Points:

- In Malaysia, ACP is **NOT legally binding** and serves as a process to discuss and document a person's values and preferences for future care which will be used to assist decision making at a time when the person is unwell and incapacitated.
- ACP is a continuous process that is relevant throughout the life-course of an individual.
- ACP is relevant for any person at any age or stage of life and should be prioritised particularly in those with chronic life-limiting conditions.
- ACP can be discussed at any time but preferably when a person is stable and well enough to consider their values and preferences clearly.

2.1 DEFINITION OF ADVANCE CARE PLANNING (ACP)

ACP is defined as "a **process** that enables a **person regardless of their age and health status** to define and discuss their **personal values, life goals, and preferences** toward **future** medical care with their family and healthcare providers, and to review and record these preferences if appropriate".[1]

Extended Definition

Advance care planning enables individuals who have **decisional capacity** to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the **physical, psychological, social, and spiritual** domains. It encourages individuals to **identify a personal representative** and to record and regularly review any preferences, so that their preferences can be considered should they, at some point, be unable to make their own decisions.

ACP discussions should be **voluntary**, when the patient and/or family is ready to engage in the conversation. **Cultural sensitivity** and **shared decision making** need to be given emphasis.

ACP is part of the continuum of the care planning process which also includes **in-the-moment care planning**. ACP focuses more on a person's values, goals and preferences in "what if" situations; whereas in-the-moment care planning requires careful balancing of contextual factors (e.g. clinical uncertainty, reversibility of acute deterioration, family coping).

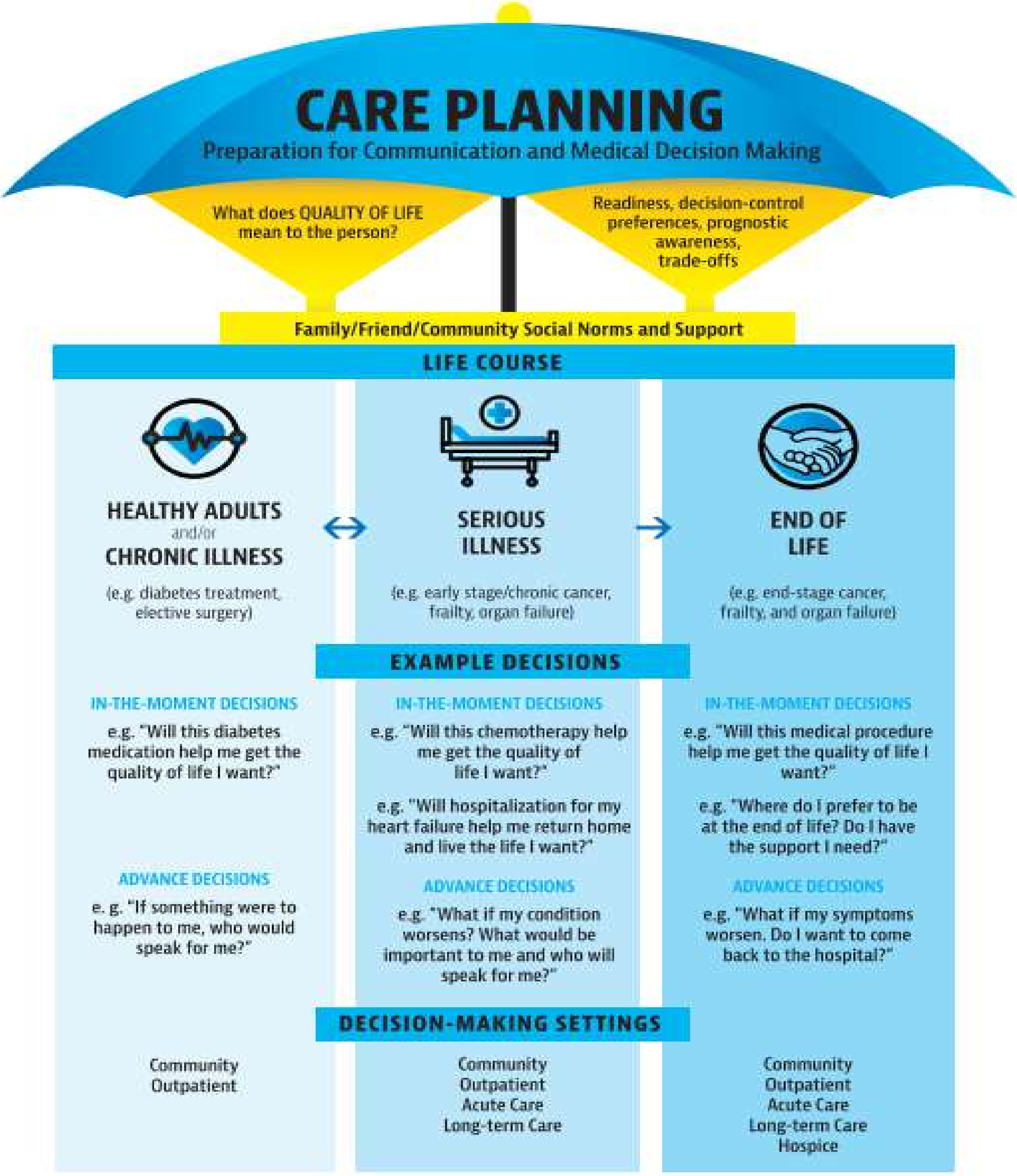


Figure 2.1: Overview of the continuum of advance care planning throughout life course[2]

2.2 DEFINITION OF OTHER RELATED TERMS[3]

ADVANCE DIRECTIVE

Advance directive (AD) (also known as advance care directive or advance medical directive (AMD) in some countries) is a legal document which records a person's preference for medical treatments, end-of-life decisions, and appointment of surrogate decision-makers ahead of time before he or she is incapacitated. Although the implementation and legislation on AD may vary between states or countries, AD generally comprises two main elements which function as the instruction directive commonly known as "living will" and a proxy directive or "durable power of attorney for healthcare". It is a legally binding document in countries with the relevant legal framework. **There is no such legal statute in Malaysia**, although the Malaysian Medical Council Guideline on Consent for Treatment of Patients endorsed the use of AD.

LIVING WILL

"Living will" also known as "advance decision" in the United Kingdom is a legally binding, written document detailing a person's preference regarding future medical treatment before he or she has lost the ability to communicate or make such decisions. A living will serve to "provide instruction" on the type of medical care a person would want or not want to receive (such as life-sustaining treatment, artificial nutrition, dialysis, management of implantable cardioverter-defibrillator, etc.) when the person has lost the decision-making capacity. A living will would only take effect when the person who wrote the living will (also known as the principal) has been determined to be in an incapacitated state.

DURABLE POWER OF ATTORNEY

A durable power of attorney for healthcare (also referred to as "medical power of attorney", "healthcare power of attorney", "lasting power of attorney for health and care decisions", "health care proxy, enduring guardian" or "enduring power of attorney" in various states or countries) legally designates a specific individual or proxy (also referred to as a surrogate decision-maker, representative, healthcare attorney or health care agent) to make medical decisions on behalf of a person at times when he or she is incapacitated. The durable power of attorney for healthcare can be used for medical or psychiatric emergencies to decide on starting or stopping of medical treatment or procedures. "Successor agents" that are a second or third decision-maker can be selected as back-up if the main surrogate decision-maker could not be reached during emergencies. Currently there is **no legal provision for durable power of attorney in Malaysia.**

PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

POLST is an acronym with various names depending on the country or region practising ACP (eg. Portable orders for LST, Pennsylvania orders for LST etc.). In general, POLST refers to a documentation which serves as a form of guidance to healthcare professionals to ensure provision of medical care that is consistent with the patient's preferences in an **acute medical emergency**. POLST commonly covers several specific key medical decisions such as cardiopulmonary resuscitation, ventilator support, intensive care, use of artificial nutrition and hydration, and the desired level of medical intervention during medical emergencies.

DO NOT RESUSCITATE ORDER

A do not resuscitate (DNR) order, also known as allow natural death (AND) or not for resuscitation (NFR) order is a document which informs healthcare providers specifically about the patient's desire to forgo futile resuscitation during emergencies. There are other similar documents related to DNR such as a do not intubate (DNI) order (which is used to express a patient's wish of not being ventilated), and a non-hospital DNR order which is used to inform emergency medical services personnel to avoid unwanted resuscitation during a medical crisis on the way to a hospital.

2.3 BENEFITS OF ACP

ACP discussion is a platform that will allow clinicians to elicit patients' understanding of their illness, their rationale in care preferences to enable an informed, shared decision-making process. Essentially, ACP is about good communication between an individual and the healthcare system.

Potential benefits of ACP discussion:[4-5]

- Empowers patients to set goals for future care so as to better cope with uncertainty.
- Prepares patients and families to make informed contingent care decisions when the need arises and reduces burden on proxy decision makers.
- Reduces decisional conflict and incongruence in care preference between patient and proxy decision maker.
- Reduces the rate of futile invasive life sustaining interventions.
- Enables more patients to die in their preferred place of dying
- Increases patient and family satisfaction with better communication and end of life care.
- Decreases patient/family anxiety, depression and complicated grief.

2.4 WHO SHOULD CONSIDER ACP?

Adults at any age or stage of health can have an ACP discussion. In particular, individuals with chronic life limiting illnesses should be prioritized as they will likely have frequent encounters with life-sustaining treatment that may or may not be aligned with their goals and preferences.

A simple screening question for patients with chronic life limiting illnesses is the **surprise question (SQ):** “will I be surprised if the patient dies in the next 12 months?” If the answer is no, then the patient should be prioritized for ACP discussion.

Examples of patients who should be prioritized for ACP discussion:

- People facing the prospect of deteriorating health due to long term conditions or progressive life limiting illnesses, e.g. dementia, frailty, kidney, heart or liver failure, lung disease, progressive neurological conditions, incurable cancer.
- People with declining functional status, increased burden of illness or persistent physical or mental health symptoms
- People facing key transitions in their health and care needs, e.g. multiple hospital admissions, shifts in focus of treatment to a more palliative intent, moving into a care home, etc.
- People facing major surgery or high-risk treatments, e.g. bone marrow transplant.

2.5 WHEN TO DISCUSS ACP?

Timing of initiating ACP discussions can be opportunistic, by anyone who recognizes the need.

Completion of comprehensive ACP discussion +/- documentation should be conducted by healthcare professionals who have preferably undergone training in ACP facilitation.

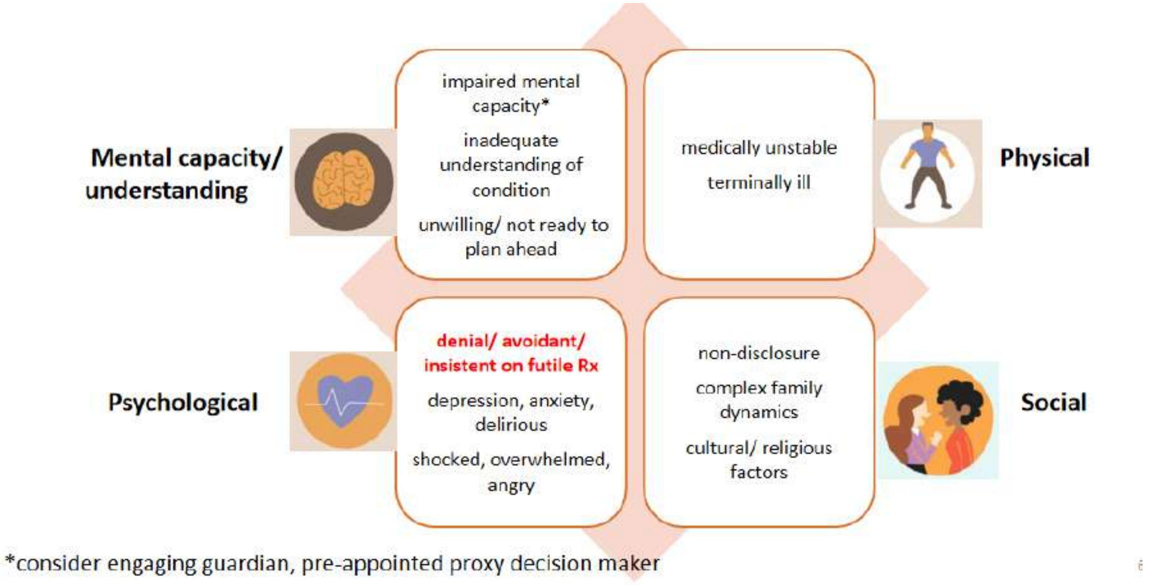
Generally, patients are most likely to consider ACP discussion when unwell and in hospital. Evidence however suggests that patients prefer to engage in ACP discussions when they are better and have recovered from their acute illness.

Trigger points to initiate ACP discussion include:[6]

- Routine review in clinic when patient express readiness
- Event-driven milestones:
    - Increased symptom burden requiring increment of diuretics, or decrement of neurohormonal medications
    - Recurrent hospitalizations
    - Significant functional decline with loss of ADLs
    - First or recurrent ICD shock for VT/VF, or initiation of intravenous inotropic support
    - Other important comorbidities: new cancer
    - Major life events e.g. death of a spouse

The fluidity of ACP and need for revisiting goals

Choice instability for life sustaining treatment is a contributing factor to discordance between documented preferences in ACP and actual care.[7] Therefore, individuals can, and should be advised to review their ACP regularly with their doctors and family members, to ensure clarity, specificity and currency of their goals or preferences.



**for patients with dementia, please refer to chapter 5c on how to determine mental capacity in cognitively impaired elderly*

Figure 2.2: Circumstances where ACP discussion is not appropriate, and unlikely to be productive

2.6 WHAT SHOULD BE DISCUSSED IN AN ACP?

Depending on illness trajectory and readiness of the individual, the range of topics covered can include:

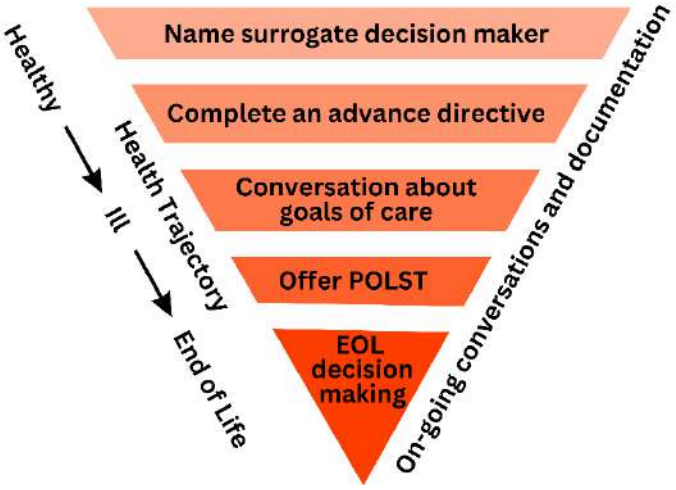


Figure 2.3: Continuum of advance care planning discussion[8]

Common themes often discussed in ACP:

1. **Explaining concept of ACP**
2. **Nomination of proxy decision maker**
3. **Checking understanding of disease and care options**
4. **Exploring information needs, preference level of autonomy decision making**
5. **Explore values of what living well means**
6. **Explore fears, worries and what is considered unacceptable suffering**
7. **Explore sources of support**
8. **Preferred goals of care**
9. **Preference for specific medical interventions**
10. **Preferred place of care and dying**

Table 2.1: Common themes often discussed in ACP

2.7 HOW DOES ACP IMPACT ON PATIENT CARE?

The five outcome domains that ACP impacts on include: process, action, quality of care, health status, healthcare utilization.[9] The impact of ACP on patient care is dependent on the effectiveness of every step along the ACP chain.

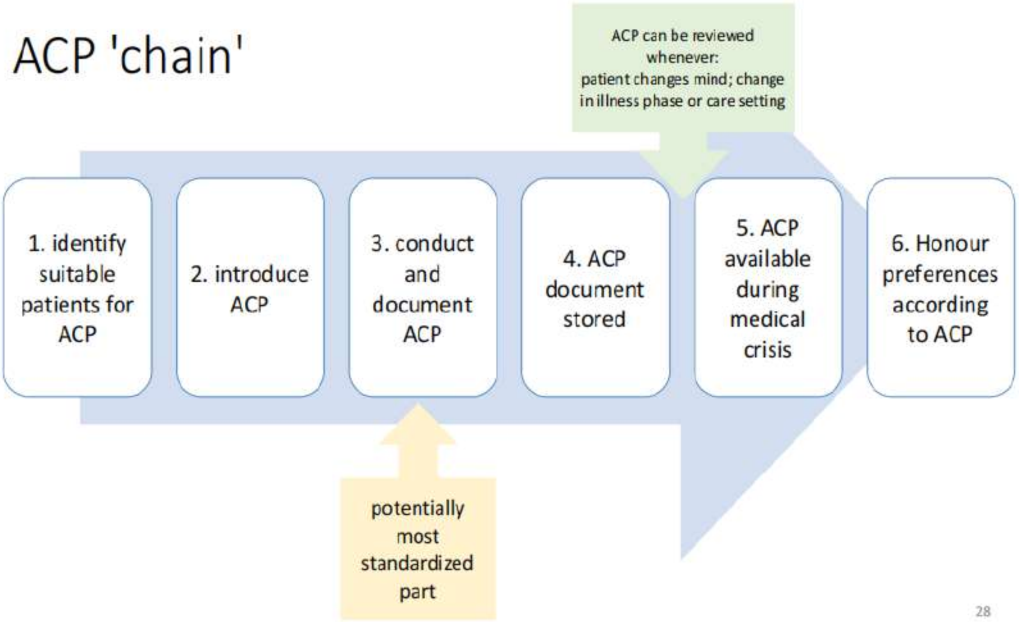


Figure 2.4: ACP Chain

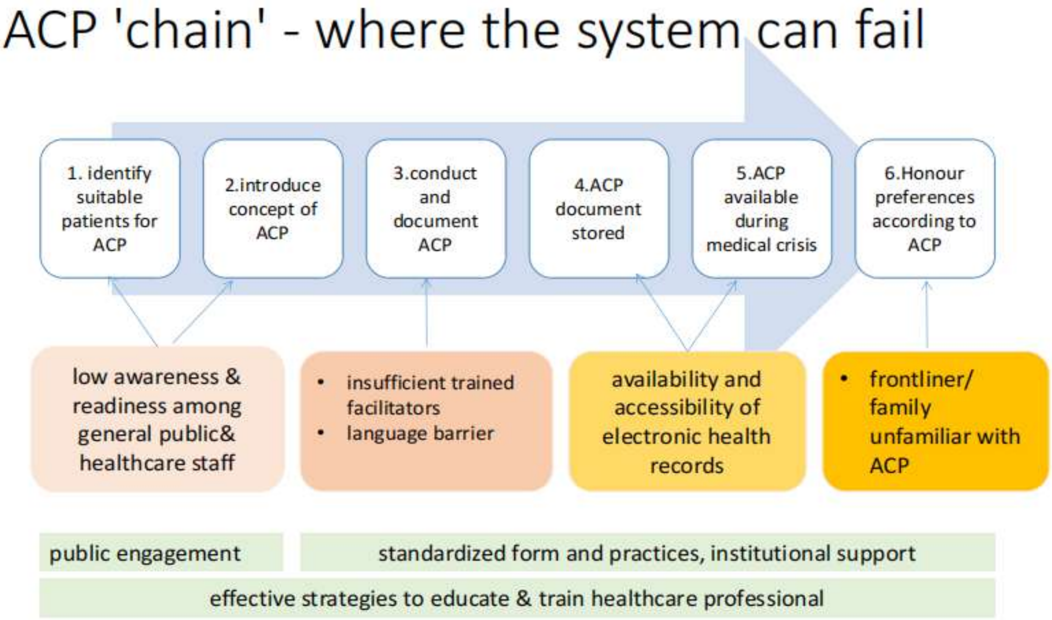


Figure 2.5: ACP 'Chain': Where the System Can Fail

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CHAPTER 3: PRINCIPLES OF DECISION MAKING IN THE SERIOUSLY ILL

Key Learning Points:

- Decision making should always attempt to consider a patient's values and preferences, with the input of next-of-kin, while contemplating the prognosis and treatment options provided by healthcare experts.
- A Goals-of-care (GOC) discussion is an essential part of care in the seriously ill and applies the 4 bioethical principles of medicine to promote shared decision making.
- Withholding and/or withdrawing life-sustaining interventions is morally and ethically permissible when the intervention is deemed inappropriate or non-beneficial.

3.1 RECOGNISING SERIOUS LIFE-THREATENING ILLNESS

Decision making for the seriously ill patient with poor prognosis is complex[1]. Inability to recognise serious life-threatening illness results in suffering, unrealistic expectations and institution of inappropriate treatments[2].

While the principle of sanctity of life is the main priority in critical care medicine, clinicians must also practice ethical decision making and act in the best interest of all patients. This requires recognising the limitations of medical interventions when a patient's pathology is irreversible and where aggressive life-sustaining therapy[3] (LST) may be deemed inappropriate.

Situations in which patients may be considered to have very poor prognosis include:

- When burdens of treatment clearly outweigh the benefits for example:
    - Multiple surgeries in uncontrolled intra-abdominal sepsis with multi-organ failure
- Imminent death
    - Severe acute illness not responding to optimal therapy, for example septic shock with multiorgan failure.

- Patients with progressive terminal diseases incompatible with survival longer than 3-6 months, for example:
    - End stage respiratory disease on long term home oxygen therapy with severe community acquired pneumonia
    - End stage cardiac, respiratory, liver disease with no options for transplant
    - Metastatic cancer unresponsive to treatment[2]

- Severe and irreversible conditions impairing cognition and consciousness with expected survival of less than 12 months and may have a pre-existing DNR order.
    - Post cardiac arrest patients in persistent vegetative state
    - Severe dementia
    - Severe stroke with poor cognitive recovery

- Poor functional status due to chronic organic dysfunction
    - Multiple comorbidities (CKD, CCF, COPD etc) with deteriorating physical performance

- Severe frailty[4] which can be defined as:
    - An ageing-related syndrome of physiological decline over months or years involving multiple body systems
    - An end-of-life state characterised by marked vulnerability to adverse health outcomes

- Advanced progressive neurodegenerative diseases such as
    - Motor neuron disease with rapid decline in functional status
    - Severe Parkinson's disease with reduced independence and needing assistance in activities of daily living

- Escalating medical needs or increasing hospital admissions
    - Recurrent hospital admissions (≥2 in the 3 months before current admission) or recent ICU admission (≥1 ICU admission in 3 months before current admission or recurrent ICU admission during single hospital stay.

- Any deteriorating patient who has stated his/her wish against initiation or continuation of life support therapy

3.2 PROGNOSTICATION

Deciding a patient's prognosis may be difficult. Where there are multiple teams involved in management, consensus should be reached with regards to the overall prognosis and goals of care of the patient. The following can be used to guide HCPs:

- Complete history, physical examination and review of investigations
- Use prognostication tools as adjunct (examples include CFS frailty, NYHA, Bode Index, MELD and many others). Kindly note there are independent factors for each disease and refer to Disease Specific Sections
- The "Surprise Question" (refer chapter 2)

3.3 APPLYING ETHICAL PRINCIPLES TO DECISION MAKING

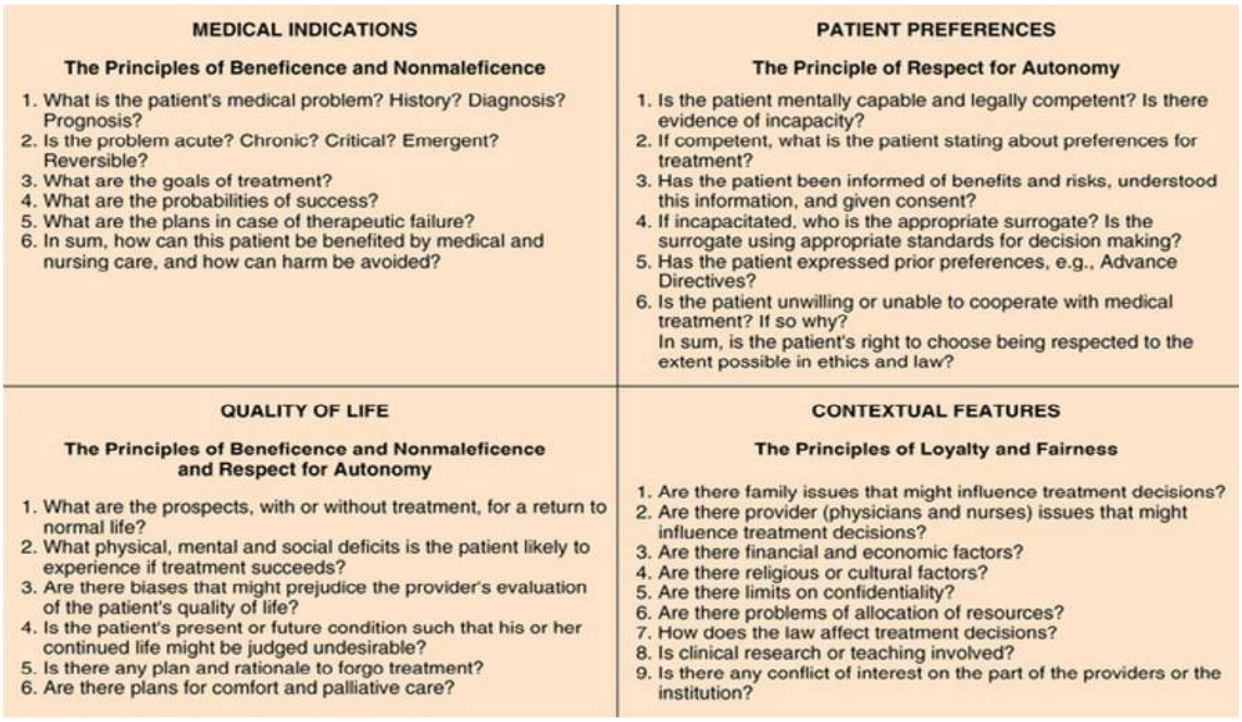
The ethical considerations of seriously ill patients include: respect for autonomy[7], beneficence, non-maleficence and distributive justice.

In a seriously ill patient, the burden of interventions is often high, benefits are marginal and the quality of life markedly diminished. Thus, the principle of nonmaleficence forms the basis of care options.

At times, principles may be conflicting for example:

- **Autonomy vs beneficence** (eg. a terminal cancer patient who insists all LST to be provided although it will not benefit him.)
- **Beneficence vs justice** (eg. providing invasive mechanical ventilation in a patient with decompensated heart failure who has had multiple hospital admissions in the last 6 months and is dyspnoeic at rest versus allocation of ICU bed for a patient with severe asthma.)

Where ethical dilemmas arise the Jonsen 4 Box model[8] can be used as a guide to assist in decision making. This framework was designed for ethical analysis based on 4 core areas:



MEDICAL INDICATIONS **The Principles of Beneficence and Nonmaleficence** 1. What is the patient's medical problem? History? Diagnosis? Prognosis? 2. Is the problem acute? Chronic? Critical? Emergent? Reversible? 3. What are the goals of treatment? 4. What are the probabilities of success? 5. What are the plans in case of therapeutic failure? 6. In sum, how can this patient be benefited by medical and nursing care, and how can harm be avoided?	**PATIENT PREFERENCES** **The Principle of Respect for Autonomy** 1. Is the patient mentally capable and legally competent? Is there evidence of incapacity? 2. If competent, what is the patient stating about preferences for treatment? 3. Has the patient been informed of benefits and risks, understood this information, and given consent? 4. If incapacitated, who is the appropriate surrogate? Is the surrogate using appropriate standards for decision making? 5. Has the patient expressed prior preferences, e.g., Advance Directives? 6. Is the patient unwilling or unable to cooperate with medical treatment? If so why? In sum, is the patient's right to choose being respected to the extent possible in ethics and law?
QUALITY OF LIFE **The Principles of Beneficence and Nonmaleficence and Respect for Autonomy** 1. What are the prospects, with or without treatment, for a return to normal life? 2. What physical, mental and social deficits is the patient likely to experience if treatment succeeds? 3. Are there biases that might prejudice the provider's evaluation of the patient's quality of life? 4. Is the patient's present or future condition such that his or her continued life might be judged undesirable? 5. Is there any plan and rationale to forgo treatment? 6. Are there plans for comfort and palliative care?	**CONTEXTUAL FEATURES** **The Principles of Loyalty and Fairness** 1. Are there family issues that might influence treatment decisions? 2. Are there provider (physicians and nurses) issues that might influence treatment decisions? 3. Are there financial and economic factors? 4. Are there religious or cultural factors? 5. Are there limits on confidentiality? 6. Are there problems of allocation of resources? 7. How does the law affect treatment decisions? 8. Is clinical research or teaching involved? 9. Is there any conflict of interest on the part of the providers or the institution?

Jonsen AR, Sieglar M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine[8]. Sixth ed. New York: McGraw Hill, 2010.

Table 3.1: Jonsen 4 Box model[8]

3.4 SHARED DECISION MAKING AND GOALS OF CARE DISCUSSION

An important aspect of decision making in patients facing serious illnesses with poor prognosis is a goals of care (GOC) discussion. It is a discussion that helps to determine 'in the moment' decision making and is an iterative process that is revisited at various points in a person's care throughout their illness.

The aim of the discussion is to:

- Align patient's values with medical treatment goals
- Incorporate ceilings of care
    - determine the highest level of intervention deemed appropriate by the medical team(s), aligning with patient and family wishes, values and beliefs.
- Create a platform for shared decision making

When the patient lacks capacity, the family will often act as the surrogate decision maker. The family members should understand the patient's clinical condition, prognosis, wishes, beliefs, priorities and preferences. This is where a prior ACP discussion on values and preferences may help to inform family members.

3.5 DECISION MAKING CAPACITY

Decision Making Capacity is a functional assessment determined by a clinician. It describes a person's ability to make a decision; utilising information about an illness and proposed treatment options. Thereafter, making a choice that is congruent with one's own values and preferences. Conditions that can cause impairment in decision making include:

- Severe active mental illness
- Severe intellectual disability
- Acute substance intoxication
- Medical conditions affecting cognition: delirium, moderate to severe dementia
- Impaired consciousness

How to assess decision making capacity

The 4 key components to address capacity evaluation[12] includes

- Understanding
- Appreciation
- Reasoning
- Expressing a choice defined by personal set of values

Decision-making ability	Definition	Sample questions
Understanding	The ability to state the meaning of the relevant information (eg. diagnosis, risks and benefits of a treatment or procedure, indications, and options of care).	After disclosing a piece of information, pause and ask the patient: "Can you tell me in your own words what I just said about fill in the topic disclosed?"
Expressing a choice	The ability to state a decision	Based on what we've just discussed about [insert the topic], what would you choose?"
Appreciation	The ability to explain how information applies to oneself.	To assess appreciation of diagnosis: "Can you tell me in your own words what you see as your medical problem?" To assess appreciation of benefit: "Regardless of what your choice is, do you think that it is possible the medication can benefit you?" To assess appreciation of risk: "Regardless of what your choice is, do you think it is possible the medication can harm you?"
Reasoning	The ability to compare information and infer consequences of choices	To assess comparative reasoning: "How is X better than Y?" To assess consequential reasoning: "How could X affect your daily activities?"

adapted from UpToDate Grisso T., & Appelbaum P. S. (1998). Assessing competence to consent to treatment: A guide for physicians and other health professionals[12]. New York: Oxford University Press.

Table 3.2: The 4 key components to address capacity evaluation[12]

If a person lacks decision making capacity, the clinician should refer to the families/surrogate decision maker. If surrogate decision maker is not available, a consensus between treating clinicians should be sought regarding prognosis and further goals of care. Failing this, clinicians should refer to the Medical Dental Advisory Committee (MDAC). In situations where consent is required, kindly refer to the “Guide on Consent Process Ministry of Health Malaysia”.

3.6 WITHHOLDING AND WITHDRAWING THERAPY IN THE SERIOUSLY ILL PATIENT WITH POOR PROGNOSIS

The goals of medical therapy and life sustaining interventions are to return patients to a reasonable quality of life with minimal disability[13]. If these goals are not possible, and the family agrees that this is not in keeping with the patient’s wishes, then compassionate care can be instituted to allow death with dignity.

Withholding and withdrawing life-sustaining treatment (LST) is a process where various medical interventions are either not initiated or ceased. There is no ethical or moral difference between withholding or withdrawing life-sustaining treatment.

Medically inappropriate or non-beneficial treatment

This was previously known as medical futility. The term medical futility however is complex, situation-specific and value-laden leading to uncertainty. There is no valid definition or clear consensus on this term. Hence, it is better served by the term medically inappropriate or non-beneficial treatment.

In general, it refers to treatment that will not be in the patient's best interest, will not achieve its purpose and is of no benefit to the patient. Each medical treatment should be assessed individually based on a patient's unique conditions.

3.7 DEALING WITH CONFLICTS IN DECISION MAKING

Conflict is described as an inability to arrive at a consensus on management, goals of care and extent of therapy[13]. This is a common problem especially when difficult decisions need to be made at the end-of-life. Several studies looking at conflict between family/surrogates and clinicians regarding decision making in the critical care setting showed that this can occur in up to two-thirds of serious illness communication.[14]

Often when conflicts occur, clinicians may perceive the family as being in denial, unrealistic or just difficult. Very often in these situations, clinicians tend to use a content-oriented approach whereby repeated explanations and justifications for decision making are given however this often creates even more conflict.[16]

An important approach to dealing with conflict is to first understand the reasons as to why conflict is occurring. Recognising the common fears and dilemmas that families face when dealing with a loved one who is seriously ill helps provide a more empathic approach that can help resolve conflict.

Issues, fears and dilemmas of family members / surrogate decision makers[14-16]

- Uncertainty of diagnosis and prognosis
    - Families often feel unclear about the seriousness of a diagnosis as this can be very unfamiliar to them and it may take time to understand.
- Uncontrollable emotions
    - Facing a loved one who is seriously ill is a very emotionally charged situation and there can be various personal feelings of shock, fear, guilt, anger and overwhelming sadness. This may lead to behaviour that is perceived as difficult.

    - Family members may perceive staff as lacking compassion as staff often follow strict protocols on information giving and may have poor communication skills lacking empathy. This may lead to poor rapport and trust.

- Limited health literacy
    - Those with poor literacy may misinterpret information provided and have challenges in understanding the situation.
    - They may have unrealistic expectations of the healthcare staff as their expectations may be influenced by idealised portrayals of healthcare from media/television.

- Disproportionate burden of responsibility
    - Certain family members may feel a disproportionate responsibility for the patient and therefore unable to bear the burden of allowing death to occur.
    - There may also be undue family pressure to continue life-sustaining treatments even though they feel this is not what the patient would want.

- Contentions about what is perceived as best interest for the patient
    - When doctors say that life-sustaining treatments may cause poor quality of life, family members feel that loss of quality of life is a small price to pay if it prolongs survival.
    - When faced with decisions of high-risk interventions versus certain death, the majority of families would see this as an obvious choice for interventions as death cannot be seen as a good option. Physicians on the other hand, not knowing the patient personally, do not see death as such a great loss and tend to normalise it.
    - When a family requests for a 2nd opinion, healthcare staff may see this as a threat and do not want to share confidential medical details with a 3rd party physician. This in turn leads to mutual distrust and further conflict.

Strategies to prevent the development of conflicts

- Establish open and consistent communication early.
- Build rapport and trust with family by using an empathic approach.
- Establish clear and reasonable goals of care.
- Review and evaluate treatment goals periodically with regular updates to family.
- Guide surrogate decision-makers on their responsibilities.
- Educate and train HCP on communication skills.
- Advocate health care policies on advance care planning with public education.

Approaches to resolve conflicts

- Early recognition of the issues and apply effective communication and listening.
- Use an empathic approach to acknowledge and validate how a family feels about the situation. (refer to section on communication)
- Time-limited trial of therapy may be undertaken to:
    - allow time for the family to adjust and accept that continuing medical treatment may be inappropriate.
    - clarify prognostic uncertainties among HCPs.
- Treatments which are to be commenced or continued, need to be stated with target goals and a time frame for review.
- Allowing a second medical opinion from doctors with relevant expertise, independent from the treating team.
- Mediation by a knowledgeable and neutral third party, of sufficient seniority and standing.
- Transfer of care to another suitable treating clinician within the same institution or to another institution.
- MDAC consultation.

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CHAPTER 4: ETHICAL, LEGAL & SOCIOCULTURAL CONSIDERATIONS OF ADVANCE CARE PLANNING

Key Learning Points:

- ACP upholds a person's autonomy and promotes person-centred care by informing decision-makers of the person's values and preferences which are then considered along with their best interest and substituted judgement by the surrogates/family during decision making.
- In an emergency when there is uncertainty regarding preferences, it is appropriate to treat a person according to the clinician's best judgement until more information is available.
- Clinicians should use a personalised approach to explore decision making, taking into account cultural and religious dimensions but without making assumptions based on religious or cultural stereotypes.

4.1 ETHICAL JUSTIFICATION OF ACP

1. ACP upholds the principle of respect for persons and their autonomy/self-determination to medical decision-making and end-of-life care.

Respect for persons commonly means,

"a kind of respect that all people are owed morally just because they are persons, regardless of social position, individual characteristics or achievements, or moral merit."[1]

Respect for persons' autonomy recognises that persons with decision-making capacity have the right to make decisions regarding their care. Autonomy requires both "independence from controlling influences and capacity for intentional action"[2] and should include the right to say yes, no, or to defer to others, e.g., physician or family member.[3,4,5] An expansion of the concept of autonomy includes the recognition of **relational autonomy** - that the free, self-governing agent makes decisions shaped by their relations to others.[6]

Advance care planning extends persons' self-determination to medical decision-making and end-of-life care following their goals, values, and preferences. It is invoked in the event of incapacitation.[7]

2. **ACP upholds the principle of beneficence and person-centred care, and aligns with surrogate-physician decision-making.**

"The goals of advance care planning is to help others know what matters to a patient and thereby increase the probability that the treatment provided is aligned with the patient's goals, values, and preferences should he or she not be able to express those because of a loss of decision-making capacity"[8]

These preferences include what medical interventions a person would be willing or unwilling to accept; how and by whom these decisions should be made; and how and where care (including end-of-life care) could be provided. Advance care planning extends the principle of beneficence and person-centred care. It guides how care recommended by the medical team could be provided concordant to the person's goals, values, and preferences.

Advance care planning takes the burden of decisions off surrogates. By having a preferred surrogate decision-maker or health proxy, advance care planning resolves the issues with multiple surrogates and guides medical decisions (e.g. prefer doctors to decide when it comes to resuscitation). Recognising the person's goals, values, and preferences can align physician-surrogate shared decision-making in life-sustaining interventions and end-of-life care.

4.2 ETHICAL CONSIDERATIONS IN ACP

1. Managing the conflict between a person's (past) preferences and their best interests

A person may have preferences expressed in an advance care plan, but with a decision that may conflict with their best interests.

Best interest's standard is a promoted beneficence framework, often used for critical decision-making. It considers the benefits, harms, and burdens of care, prognosis, and quality of life. It may also cover known values and a person's life goals.[9]

In the event of permanent incapacitation, an informed and shared decision-making process with the surrogates should be based on the best interest's standard given the current circumstances guided by the person's goals, values, and preferences as stated in the advance care plan.

When there is **uncertainty or in an emergency**, it is not wrong, ethically and professionally, for physicians to treat the person according to their best clinical judgment[10] while awaiting more information regarding the current diagnosis, reversibility of the condition, and the person's goals, values, and preferences.

A person's preferences may be unclear, inapplicable, unrealistic, or change over time.[11] The process with advance care planning is ultimately a learning process for the persons to think about their own values and know themselves better as decision-makers. Thus, medical decision-making will not only rely on the relevance and validity of any documented wishes[10], but also on the overall understanding and respect of the person's dignity and individuality.[12]

Initial management, especially with active resuscitation, does not preclude the opportunities for a revision in the goals of care in the following hours or day.

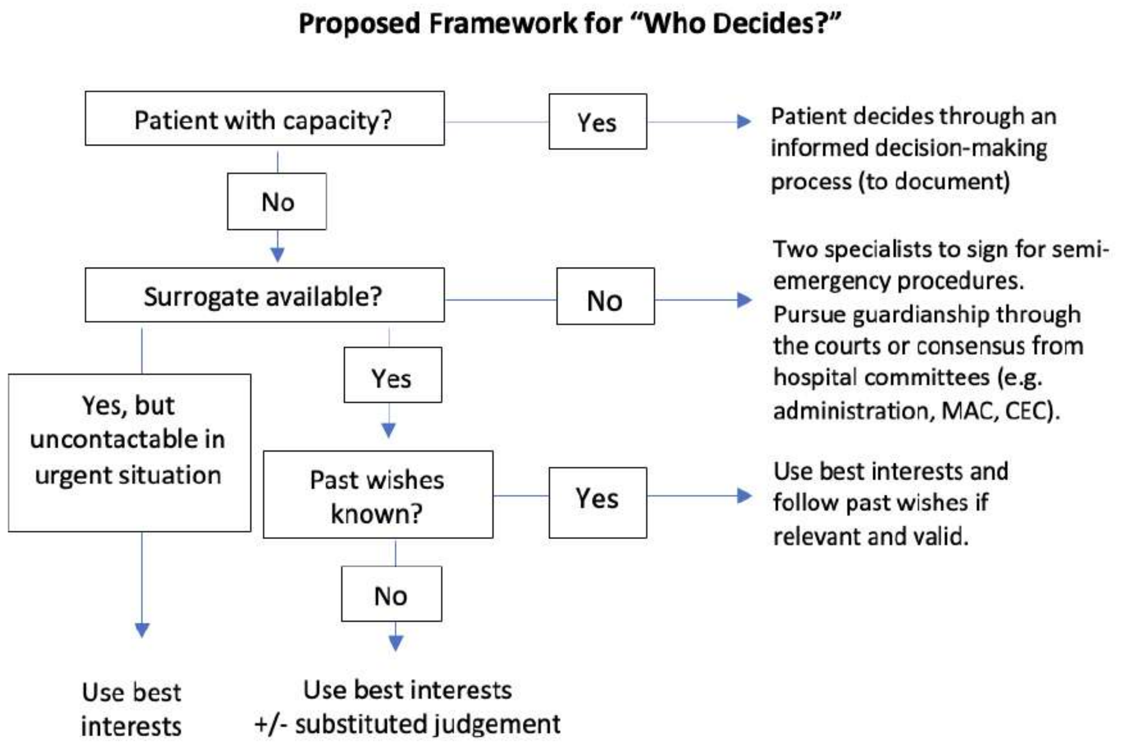
Thus, it is crucial to understand that the content of advance care plans guide and help the attending doctors to understand what is best for the person during critical moments. It is not legally binding and should be treated as a supportive document on what the person may prefer or is unwilling to accept.

2. Managing the conflict between a person's values and preferences of the past and current.

A person may have wishes previously expressed in an advance care plan, but with a decision that may be in conflict with their current preferences.[14] Thus, when a person with capacity[15] can make decisions, their current preferences take precedence over the past ones.

However, when a person no longer has the full capacity to make decisions, it would be appropriate to respect, when valid and relevant, the persons previously expressed autonomous wishes.[2]

Unless in exceptional circumstances, when the person may be in a very different (sometimes better) condition than what they might have anticipated (e.g. a currently happily incompetent person[2], or a person who was under informed or short-sighted on the benefits of modern medical advances etc), that a previously stated preference may be overridden. In these scenarios, together with best interests' standards, other frameworks such as substituted judgement, care ethics[16], and the notion of dignity and individuality[12] could be applied to reach a decision. Further ethical deliberation may also be needed.



Notes:

- Capacity: C - communicate a choice, U- understand the relevant information, R - reason about treatment options, A - appreciate consequences.
- Patient could decide to consent, refuse, or defer to others (e.g. family member or physician).
- Past wishes: through verbal, or written evidence e.g. advance care plans or resuscitation plans, goals of care discussion note.
- Best interests: promoted beneficence, which considers the benefits and harms/burdens of care, prognosis, and quality of life. It may also cover known values and the patient's goals.
- In the event of emergency, consent is not required.
- MAC: Medical Advisory Committee; CEC: Clinical Ethics Committee.

Figure 4.1: Proposed Framework for "Who Decides?"

4.3 LEGAL AND PROFESSIONAL CONSIDERATIONS AND BOUNDARIES

Legal provision and boundaries

Advance care plan (ACP) guidelines have always been in discussion among healthcare practitioners, especially in the discipline of palliative medicine and geriatrics. At present, the Medical (Amendment) Act 2012 and Medical Regulations 2017 do not include any reference to advance care planning.

Many of the available regulatory documents are related to advance directives (AD) or advance medical directive (AMD), i.e. specific interventions that patients do not wish to receive. For example, in the Malaysian Medical Council (MMC) Consent for Treatment guideline Clause 18 mentions:

> *"A medical practitioner should refrain from providing treatment or performing any procedure where there is an unequivocal written directive by the patient that such treatment or procedure is not to be provided in the circumstances which now apply to the patient ("Advance Care Directive"). However, this does not apply where the patient's directive contains instructions for illegal activities, such as euthanasia or the termination of pregnancy."*

Illegal activities is related to the Malaysian Penal Code - Section 304A that states,

> *"If any person dies by doing any rash or negligent act, shall be punished with imprisonment for a term which may extend to two years, or with fine, or with both. According to this section, if any patient dies due to any negligence of the doctor, he or she will be convicted under this section. Moreover, a doctor can be convicted under section 301,302 and 304 of the Penal code. For example, if a doctor commits any miscarriage without the consent of the woman, he or she will also be liable under this Act.7".*

Also, MMC Consent to Treatment guideline (as below) recommends doctors consider the validity and applicability of the AD, where such AD exists. When doubts or conflicts arise, additional actions are required, such as verification with the patient or appointed family members as per the AD. Seeking additional assistance and guidance from fellow practitioners when making decisions on AD is advised. This recommendation sheds light on how doctors may navigate treatment decisions in the light of doubtful AD.

> *"Should there be an Advance Care Directive, the medical practitioner should consider whether it is sufficiently clear and specific to apply to the clinical circumstances which have arisen. The medical practitioner should also consider the currency of the directive, whether it can be said to be made in contemplation of the current circumstances (for example, whether the directive was made before or after the diagnosis of the current illness). Whether there is any reason to doubt the patient's competence at the time that the directive was made, or whether there was any undue pressure on the patient to make the directive, are factors that should be considered."*

> *"In an emergency, the medical practitioner can treat the patient in accordance with his or her professional judgment of the patient's best interests, until legal advice can be obtained on the validity or ambit of any Advance Care Directive that may have been given by the patient. Where there are concerns about the validity or ambit of an Advance Care Directive in a non-emergency situation, the medical practitioner should consult the patient's spouse or next of kin or legal guardian and the medical practitioner should also consider the need to*

> *seek legal advice and to discuss the issue with his or her Colleagues, or other clinicians involved in the patient's care. Such discussions should be documented in the patient's medical case notes."*

Professional guidelines

Malaysia does not yet have a Law on advance care planning. This could be due to the challenge of fitting various dilemmas, such as ideal bioethics practice and socio-cultural norms in Malaysia.

Doctors in daily practice often face ethical dilemmas pertaining to end-of-life care and do-no-resuscitation (DNR) status. A few professional and medical guidelines related to this subject provide information for doctors facing ethical dilemmas in practice.

From Malaysian Medical Association (MMA), Code of Medical Ethics, 2001, page 12:

> *"5. The Dying Patient*
>
> *Where death is deemed to be imminent and where curative or life-prolonging treatment appears to be futile, ensure that death occurs with dignity and comfort. Such futile therapy could be withheld, withdrawn or one may allow irreversible pathology to continue without active resuscitation. One should always take into consideration any advance directives and the wishes of the family in this regard. In any circumstance, if therapy is considered to be life-saving, it should never be withheld."*

Other medical guidelines, such as the Handbook of Palliative Medicine, 2015 (Academy of Medicine of Malaysia, AMM), and ICU Management Protocols, 2019 (Malaysian Society of Intensive Care, MSIC) have outlined several ethical considerations that aid in critical decision-making.

More often than not, bioethical principles are the most practical and applicable values that can benefit the decision-making process in clinical practice. Principles such as respect for autonomy, beneficence, non-maleficence, and justice, when considered with several other factors such as disease progression, prognosis, and goals of care, help doctors advise patients and relatives on the next course of action or treatment.

Legal and Professional Resources for Malaysian Health Care Professionals:

1. Malaysian Medical Council Code of Professional Conduct (2019). https://mmc.gov.my/wp-content/uploads/2019/12/CODE-OF-PROFESSIONAL-CONDUCT-2019-Amended-Version.pdf
2. Laws of Malaysia: Act 574 - Penal Code (revised in 1997) (https://ccid.rmp.gov.my/Laws/Act_574_Panel_Code_Malaysia.pdf
3. Malaysian Medical Council Guideline - Consent for Treatment of Patients by Registered Medical Practitioners (2019). https://mmc.gov.my/wp-

content/uploads/2019/11/Consent_Guideline_21062016.pdfMalaysian Medical Association Code of Medical Ethics (2001) - http://www.bhanot.net/MMA/EthicsCode.pdf
4. Academy of Medicine of Malaysia - Handbook of Palliative Medicine (2015). https://www.researchgate.net/publication/284166633_Handbook_of_Palliative_Medicine_in_Malaysia/link/564d53d808ae4988a7a43b6a/download
5. Malaysian Society of intensive Care - ICU Management protocols (2019). https://www.msic.org.my/download/ICU_Protocol_Management.pdf

4.4 SOCIOCULTURAL CONSIDERATIONS IN ADVANCE CARE PLANNING.

The supportive and substituted roles of family members in ACP discussion

The discussion of advance care planning may include family members, either for a supportive or substitute role in medical decision-making.[17]

Advantages of including family members during the discussions of ACP:

- It is consistent with the local and Asian values.
- They have a better understanding of the persons' goals, values, and preferences.
- They are the preferred surrogate decision-maker in the event of incapacitation and should be aware of the content of the advance care plan.
- Family members fulfil the practical dimensions of a person's autonomy and preferences.

In some cases, however, family members may have a conflict of interest, may be poorly informed, and can be estranged from the person or non-committal to the person's welfare and interests.[2] In other cases, family members may be emotionally affected, overpowering or over-protective of the persons. An ACP may help address issues in these situations by having a named surrogate decision maker who clearly understands the person's preferences.[18]

Religious Perspectives and Traditions

Malaysians are culturally diverse and may depend on spiritual and religious guidance for decision-making related to life, health, and end-of-life matters. Below are the general views held by several religious traditions regarding medical decision-making and end-of-life care. They are not exhaustive, and variations may exist within the different schools or branches of the religion.

While it is useful for clinicians to be aware of the general religious perspectives in Malaysia, they must not stereotype and make assumptions regarding what values a person may or may not have based on their religious background.

4.4.1 ISLAMIC PERSPECTIVES[22,23,24,25]

Islam has the largest following within the population of Malaysia. It is also the official religion, as stated in the Malaysian Constitution. Therefore, it plays a significant role in shaping the country's cultural, legal, and social landscape.

According to the Islamic framework, advance care planning would be categorized as medical consent (idhn al-ṭibb). The Islamic jurisprudence defines consent (idhn) as 'permission granted to someone to carry out an action that was initially forbidden'. This means that medical procedures can only be performed on a patient when permission or approval has been obtained from the patient.

Refusal of treatment in Islam

The principles of anticipatory refusal can be derived from a hadith where the Prophet Muḥammad refused to take the medicine which was forced by his companions against his wish. The situation is similar to the principles intended through advance care plans where patients are empowered to make decisions and determine their preference in future healthcare. The Sunni schools of Islamic law (Ḥanafī, Mālikī, and Shāfi'ī) also agreed that it is permissible to abandon treatment, especially when the efficacy of the treatment is questionable.

However, Islam prohibits refusal of medical treatment if it is done voluntarily to cause death which taints the sanctity of life.

Patient autonomy

Islam does not prohibit anyone from holding views, making choices, and taking actions based on their values and beliefs. These actions are made before fully realizing the situation and understanding the consequences that may follow. Islam recognizes patients' preferences in their treatment, and the patient's rights should be respected.

The concept of wali (guardian) applies to underaged patients and those not of sound mind, regardless of gender. The wali should act based on the best interest of the patient.

Special Note:

a. The five foundational goals of the Maqasid al Shari'ah is the protection of religion, life, lineage, intellect and property.
b. The jurisdiction of Syariah court is confined to Islamic family law, Islamic inheritance law and Islamic criminal law.
c. It's important to note that Islamic perspectives on medical decisions vary among scholars and individuals, and interpretations may differ on specific cases or circumstances. Therefore, consulting with religious scholars or authorities regarding this issue is advisable.

4.4.2 BUDDHIST PERSPECTIVES[26,27,28,29]

There are two main branches in Buddhism – the Theravada and the Mahayana traditions, which predominate in South and South East Asia, and in North Asia, respectively. Under the Mahayana tradition – the Vajrayana school has distinct traditions from the Tibetans. In general, Buddhists do not believe in a God. The teachings of the Buddha, called Dhamma, are mainly from the earliest texts in the Theravada Pali canon, with different variations by the branches.

The practitioners of Buddhism in Malaysia may remain in the tradition they learned or grew up with, or practice the other traditions as well. However, many still follow the local culture practices and customs to a significant extent in their daily lives.

Buddhist teachings are encapsulated in the **Four Noble Truths** – 1) The life is imperfect and unsatisfactory with sufferings (dukkha); 2) the causes are craving and ignorance; 3) there exists a state free from all deficiencies (nirvana); 4) the way is by following the Eightfold Path.

The themes of **virtues of benevolence and compassion, impermanence, non-self, and karma** are recurring in Buddhist literature. In Asian cultures, Buddhism is identified as the authority on matters pertaining to death.

Respect for life and do not kill

There are five precepts which apply to all Buddhist, the first and foremost being respect for life and do not kill. This belief in the "sanctity of life" should not be taken that life must be preserved at all costs – but as an idea that intentional killing represents a failure to respect the dignity of living creatures.

Therefore, physician-aid in dying or euthanasia is wrong as it is unethical for a physician to assist in a suicide and for a person to commit suicide.

Death and Dying

Buddhist traditions assert that the universe is fundamentally impermanent (anicca), and death is an inevitable outcome. Attempts to postpone death suggest a fear of death and self-centric attachment to life.

Peaceful death

Buddha "taught that all beings experience the continual cycle of rebirths (samsara) and the suffering (dukkha) that ensues." Rebirth is influenced by karma, the natural consequence of their actions. Buddhist traditions emphasise the importance of meeting death mindfully since that last moment, along with their karmic merit, can influence the type and quality of the rebirth.

Potential issues concerning ACP and end-of-life conversations

A Buddhist and their family may have the concerns with decisions of refusing or withdrawing/ withholding life-sustaining treatment and the use of pain relief at the end-of-life due to:

- The violation of the first precept of "Do not kill", and
- The karmic consequences to both the patient and a family member.

But at the same time, Buddhist accept and respect the inevitability of death as part of the impermanence of life. Merely prolonging the dying process may only create "unnecessary grasping, anger, and frustration" and not helping with a peaceful death or spiritual progress and thus:

- With compassion, these decisions have the potential of relieving suffering, promoting a peaceful death, and allowing the person to enter rebirth to experience the fruit of their karma.

It will be prudent for the healthcare professionals to acknowledge and explore their views on these concerns and seek Buddhist monks or Dhamma teachers for further guidance.

4.4.3 CHRISTIAN PERSPECTIVES[30,31,32]

Christian traditions believe that the sick person should be treated with the utmost respect, dignity and compassion, that medical technologies should not obscure what should be transcendent and grace-filled moments when dying: "attending to spiritual needs, healing broken relationships, and saying goodbye to loved ones".

In general, the themes of the **sanctity of life, the redemptive nature of suffering, and the role of pastoral care are** recurring in Christian traditions concerning end-of-life care and advance care planning.

On human life

Christians believe that human life is a precious and inviolable gift from God. The Church emphasises that human life has meaning and "affirms the incomparable value of every human person." It is always wrong to intentionally bring about one's death or the death of another innocent person. The Gospel of Life holds that "euthanasia is a grave violation of the law of God since it is the deliberate and morally unacceptable killing of a human person" (n. 65, original emphasis).

Role of pastoral care

Christian traditions believe in addressing emotional and spiritual suffering. It is often necessary to consult psychiatrists, psychologists, or counselors to provide the appropriate intervention for clinical depression during serious illness. Those who are seriously ill should, apart from medical experts, also seek the help of pastors, and chaplains who can offer them pastoral care.

Redemption through suffering

Christians believe “suffering and death can take on a positive and distinctive meaning through the redemptive power of Christ’s suffering and death.” This truth does not reduce the pain and fear but gives confidence and grace for coping with the suffering rather than being overwhelmed by it. Therefore, some Christians may prefer to control their use of painkillers to accept some sufferings voluntarily and thus “associate themselves in a conscious way with the sufferings of Christ crucified”. However, this is not the general rule – still the use of medicines capable of suppressing pain is encouraged, even though these may cause reduced consciousness.

On life-sustaining treatment

Christians believe that one of the most critical moral distinctions in end-of-life care is between what is morally obligatory and what is morally optional. Generally, a medical procedure or intervention that carries little hope of benefits and is burdensome is considered “extraordinary” and is not obligatory. Whether an intervention is excessively burdensome to a person is a clinical and moral question that may require the input and advice of others. In other words, medical interventions that offer hope of benefit (proportionate) are morally obligatory, and medical interventions that are excessively burdensome or offer little hope (disproportionate – sometimes called “extraordinary”) are morally optional.

On advance medical directives

Christians believe that difficult decisions about the use of medical technology at the end of life may be made easier if wishes are expressed before severe illness begins. However, it is understood that the usefulness of an advance directive is limited because of its inflexibility. Therefore, one should “focus on general goals and concerns rather than specific medical procedures.”

The issue of quality of life should also be avoided. The “focus should not be on whether someone’s life has enough “quality” to it (quality will always be diminished during sickness or disease), but rather on whether a proposed medical treatment would be unduly burdensome and insufficiently beneficial for his or her particular circumstances.”

4.4.4 HINDU PERSPECTIVES[33,34]

Hinduism is the world’s oldest religion, with its culture and customs going back more than 4000 years. Also known as Sanata-dharma, today, with more than 1 billion Hindus, it's one of the largest religions in the world. Most schools within Hinduism share the common belief of a single founder, central religious establishment, or sole authoritative scripture. Two of these foundational concepts are the oneness of existence and pluralism. These two concepts mean they believe in the single God “Brahman” but recognize other Gods and Goddesses. Some fundamental principles in Hinduism include the existence of “Athman” or Soul, “Samsara” (beliefs in the continuous cycle of life, death, and reincarnation), which is influenced by “Karma” (the universal law of cause and effect).

Bioethics in Hinduism

Unlike secular bioethics principles on rights, Hinduism emphasises duty-based ethical consideration. Therefore, decision-making and advice will be shared in the greater context of family, culture, and environment. As a result, family members can strongly influence medical decision-making. Hindus believe in maintaining a lifestyle conducive to mental and physical well-being. Therefore, a more holistic approach of including family members with permission from the patient can smoothen the informed consent of the medical decision-making process.

Advance care planning

As duty is the main principle of bioethics in Hinduism, the intricate planning of an advance care plan will require advice from patients to include next of kin or family members. It is an obligation in Hinduism for the next of kin to care for the elderly or sick. Healthcare providers should keep this in mind when developing advanced care directives.

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CHAPTER 5: ACP IN SPECIFIC DISEASE PROCESSES

5.1 INTRODUCTION

Advance care planning is generally applicable for all individuals regardless of age or health status. The scope ranges from those who are still young and healthy to those who are frail and elderly with multiple comorbidities.

While discussions are often conducted in an open-ended manner to allow the individual to determine the pace, direction and depth of the discussion, there are disease processes that have unique situations that may be important for the healthcare professional to be aware of when engaging in ACP discussions with patients with specific conditions.

This chapter highlights some of the specific disease processes and the unique issues that may require consideration during an ACP discussion.

For purpose of this guidance, the following sub-chapters will be discussed:

- ACP in Paediatrics
- ACP in Adolescents and Young Adults
- ACP in Cognitively impaired frail elderly
- ACP in Neurodegenerative diseases
- ACP in Cardio-respiratory diseases
- ACP in advanced kidney/liver disease

CHAPTER 5A: ACP IN PAEDIATRICS

Key Learning Points:

- ACP in paediatrics is appropriate only to those distinct target groups of children with life-limiting conditions.
- Prognosis in childhood life-limiting illnesses can be very uncertain thus a parallel planning approach to ACP discussion is useful to enable various options for care to be considered in response to a range of potential outcomes.
- While children under 18 years old are not legally able to consent to preferences discussed in an ACP, it is important to include the child in the discussion and respect their views if this is appropriate.
- Ethical issues unique to paediatric palliative care should be considered during any ACP discussion with a child and family.

5A.2 THE DIFFERENCE BETWEEN ACP IN CHILDREN AND ADULTS

- **Distinct target groups**: ACP is only offered to a select group of children with life limiting conditions. It may not be relevant for the vast majority of children who access paediatric health services and should not be a standard process across general paediatric care as most children will recover and go on to live a full life.[1]
- **Prognostic uncertainty**: The course of many life-limiting childhood illnesses may be rare and difficult to predict. Parallel planning will be valuable in this situation as it enables various options for care in response to a range of potential outcomes to be considered and written down in advance. [2,3]
- **On-going discussion throughout disease trajectory**: Care plans in ACP may change in accordance to the child's different phases of illness and its trajectory. Hence, ACP can be an on-going discussion with the emphasis on different aspects of care for different phases of illness. ACP is recommended to be reviewed 6 to 12 monthly with the child's best interest being the main consideration for every care plan.
- **Goals in life**: Children’s priorities and goals in life differ from adults eg. educational achievements and social priorities are paramount to children. It is important to set realistic goals within the limitation of their condition while ensuring good quality of life.[4]
- **Legal differences**: Children under 18 years old have no legal status to create their own ACP. Meanwhile, it is important to solicit, consider and respect the views of children and

their families.[1,2] Shared decision making between patients, both parents and health providers should take place to formulate a care plan that is in the child's best interest.

- **Developmental understanding of serious illness and death**: Children have evolving information, recreational and educational needs as well as various coping mechanisms in accordance to their changing developmental milestones.[5]
- **Personnel involved**: Treating paediatricians tend to lead advance care planning in the paediatric setting due to the rarity and complexity of life-limiting illnesses affecting children.[1]

5A.2 CHILDREN FOR WHOM ACP IS NEEDED

Three ways of identifying the child who may need ACP discussion:

1. **The child fulfils any of the criteria for ACT/RCPCH categories for life-limiting or life threatening conditions[6]:**

ACT/RCPCH categories for life-limiting or life-threatening conditions:
Category 1 - Life-threatening conditions for which curative treatment may be feasible but can fail. Examples: cancer, irreversible organ failures of heart, liver, kidney.
Category 2 – Conditions in which premature death is inevitable. Examples: cystic fibrosis, Duchenne muscular dystrophy.
Category 3 - Progressive conditions without curative treatment options. Examples: Batten disease, mucopolysaccharidoses.
Category 4 - Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.

2. **When Paediatric Palliative Screening Scale (PaPaS Scale) score ≥ 15**

(Refer Appendix 1 for PaPaS score)

3. **The presence of a life-limiting condition with one or more of the following triggers:**

   Answer of “No” to the surprise questions:

“Would I be surprised if this child dies within a year?”
“Would I be surprised if this child is not expected to live beyond 18 years old?”

Plus, one of the following:

- Family or staff recognise the decline of current condition.
- Increasing intercurrent illness and failing to recover to baseline condition.
- 3 unplanned hospital admission in the past 12 months.
- Previous PICU stay for more than 1 week.
- Unsuccessful attempt to wean off ventilatory support.
- Previous prolonged hospital admission > 3 weeks.
- Multi-organ impairment.
- Invasive infectious disease.
- Initiation of palliative therapy.
- On-going palliative therapy with new progressing symptoms.
- Difficult symptom control.
- Conflict between parents and clinical team regarding use of life-sustaining medical therapy.
- Child or family members wish to have ACP discussion.

5A.3 TIMING OF ACP DISCUSSION IN CHILDREN

The right time to introduce discussion about ACP varies. Before any ACP discussion, it is important to consider:

- **Phase of illness**: ACP discussion should preferably be done during the stable phase of the disease as it gives the personnel involved space to reflect on the conversation which can be challenging during a crisis.
- **Early ACP discussion** offers the greatest opportunity to explore the different possibilities that may happen as the child's illness progresses.
- **The preparedness and willingness** of the child/parents and physician to discuss.

In view of possible prolonged trajectory of most childhood life-limiting conditions, ACP should be revisited and reviewed every 6-12 months.

5A.4 DISCUSSING ACP FOR CHILDREN

A. Discussion workflow

Step 1: Introduction of ACP

- After the treating doctor identifies the need of ACP discussion for a child, an introduction to the discussion will be given and a time and venue set for the next meeting.

(Refer Appendix 2a and 2b for ACP patient information - English and BM version)

Figure 1: ACP discussion workflow for children

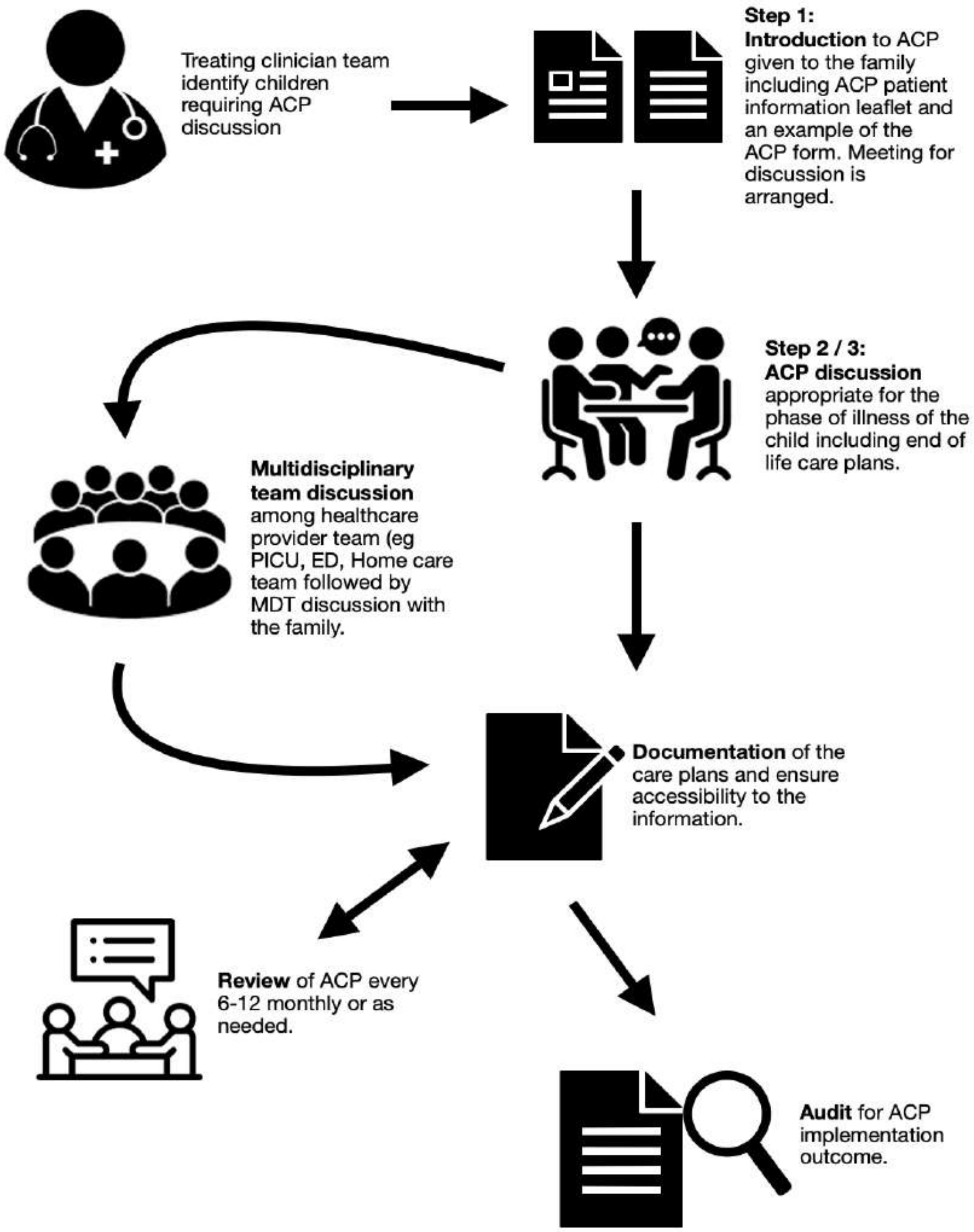

Figure 5a.1: ACP Discussion workflow for children

Step 2: Discussion and Documentation of Goals of Care and Personal Resuscitation Plan

- The ACP discussion should be carried out between the treating clinician, the child (as appropriate) and the parents.
- Discussion should be navigated by the readiness of the patient and/or parents and the phase of illness.
- At all times, children should be allowed a safe and protected platform to express their preferences. Any communication with children about their ACP should be handled with care.
- Consider using facilitated communication e.g. Button game, sand play, picture books, play therapy.

Step 3: Discussion on End of Life care

- End of life care plans should be discussed and documented when the child is evidently deteriorating into a dying phase or child / parents are ready and wish to discuss it at any point of the disease course.
- End of life care plans include preferred place of care, funeral arrangements, memory making, bereavement support for the family.

Any care plans, after the discussion should be documented in a standardised form.

(Refer Appendix 3 for Template of ACP form)

As accessibility of the care plans varies based on the local patient data management system, a copy of the form with the latest care plans is kept with the patient. Family should be advised to show the care plans to any future doctors attending to the child.

B. ACP discussion for children in different phase of illness

At diagnosis

- Explore values and goals of the child (where possible and appropriate) and the family. Discussion focuses on the “good” days of the disease.
- The questions you may wish to ask are:
    - *What do you (or does your child) enjoy?*
    - *What do you (or does your child) find most difficult about their illness and treatment?*
    - *As you think of the future:*
    - *What is most important?*
    - *What are your hopes?*
    - *What are your fears? What are the things that keep you awake at night?*
    - *What are your goals?*

Current or potential future deterioration

- Explore their hopes and fears as they apply the values and goals in possible future scenarios. Discussion guides the parents to talk about the potential "bad days" in the future
- Example phrases:
  - *'If time were shorter than we all hoped …' or 'if it looked like (child) was approaching the end of their life …'*
  - *What would be most important to you and (child)?*
  - *Have you had any thoughts about where you would like to be — home, hospital, hospice?*
  - *Is there anything you particularly wish to avoid?*
  - *Is there anything you would want to do?*

Goals of care

- Builds on the understanding of the values and goals of the child and the family previously discussed and defines the overall goals of care with the family.
- This usually falls into one of the following categories:
  - *focus on sustaining life*
  - *primary goal is to sustain life but with some limits*
  - *primary goal is comfort but some interventions to sustain life are considered appropriate exclusive focus on comfort*

End-of-life care

- Understand how to prepare for the final stage of the child's care.
- Questions you may wish to ask are:
  - *Where would you hope to be at this time? (For example, 'Some families have a very strong wish to be at home. Others think they would feel safest in a hospital or hospice'.)*
  - *Is there anywhere that you would hope not to be? (For example, 'Some parents worry that it might happen in an ambulance, emergency department, or intensive care unit'.)*
  - *Are there any spiritual or cultural needs you would like us to know about?*
  - *Are there any other special wishes you would like us to know about?*

5A.5 DECISION MAKING AND ETHICS IN ACP FOR CHILDREN

Ethical issues:

a) Disclosure of diagnosis or prognosis to the child

Ethical Principle(s)	Explanation
Autonomy Beneficence Non-maleficence	Parents may wish to withhold the diagnosis or prognosis from their child to protect them from the suffering [16]. However, many children do have some capacity to understand their condition [17]. Discuss with the parents the pros and cons of disclosing diagnosis and prognosis to the child. Disclosure of such information should be done appropriate to the child's cognitive development and understanding.

b) Preferences for place of death (home vs hospital)

Ethical Principle(s)	Explanation
Autonomy Beneficence Non-maleficence	Patients may prefer to die at home, however feasibility of home death may be limited by the availability of community support system and readiness of the parents [18]. Caregivers should be given information about the pros and cons of various locations where end of life care is provided. Parents should also be offered contingency plans e.g. admission back to the hospital should parents have difficulty coping with end of life care at home.

c) Conflict between child's and parents' preferences

Ethical Principle(s)	Explanation
Autonomy Best Interest Principle	Parents may have preferences that are conflicting with the child. Family conferences should be done in an attempt to reconcile the preferences. Should conflict persist, parents' preferences take precedence due to the Child Act which states that children <18 years old are under the care of their parents or legal guardians. It is important that any decisions made should be in the child's best interest. Besides medical interests, children's social, psychological and emotional interests should be considered as well.[14,15]

d) Conflict between treating team and parents' preferences

Ethical Principle(s)	Explanation
Autonomy Best Interest Principle Zone of Parental Discretion	There may be conflict of interest between parents and doctors, however, the role of the doctor is to ensure the decision made does not cause harm to the child.[19] Parents have the ethical right to make medical decisions for their children, based on their own perception of what is good for their child. The limit to parental authority lies at the point where significant harm is likely to be caused to the child.

5A.6 PERINATAL ACP

Criteria for Perinatal Palliative Consult & ACP discussion

Pregnant mother with foetus diagnosed with:

- Very likely lethal conditions (e.g. anencephaly, bilateral renal agenesis)
- Probably lethal conditions with some hope of longer life (e.g. Trisomies 13 / 18)
- Possibly lethal conditions with complex clinical course (e.g. Hypoplastic left heart, congenital diaphragmatic hernia)
- Any conditions likely to have a complex and/or chronic clinical course (e.g. multiple congenital anomalies, rare chromosomal conditions, brain anomalies, extreme prematurity, severe intrauterine growth restrictions)

Personnel involved in discussion

- Foetal medicine specialists, obstetricians, neonatal service providers, maternity services, including midwives and those working in the children's palliative care team.

Special consideration

- It is important to acknowledge the possibility of **multiple grief** such as the anticipatory grief at diagnosis, the grief for loss of the 'hoped-for baby' they were expecting and actual loss of the baby. In some hereditary conditions, parents may be dealing with the death of more than one child with the same condition.
- During the discussion, the baby's mother may have health needs of her own. Families often struggle to take in information and are torn between the needs of their baby and the mother.

Components of antenatal anticipatory ACP:

- Input from a foetal medicine specialist / obstetrician including the discussion regarding continuing the pregnancy and details of the diagnosis and its prognosis.
- **Birth plan**: place and timing of delivery, mode of delivery, monitoring during labour and people to be present at delivery.
- Anticipatory **care plans at delivery** including the extent of neonatal resuscitation.
- Details of **postnatal care for the bab**y in accordance with what is important for the family, including parents' wishes for skin to skin contact / breastfeeding, memory making, transition to home care etc.
- Care plans should be summarised in a standardised document as a record.

Figure 2: Perinatal ACP discussion work flow

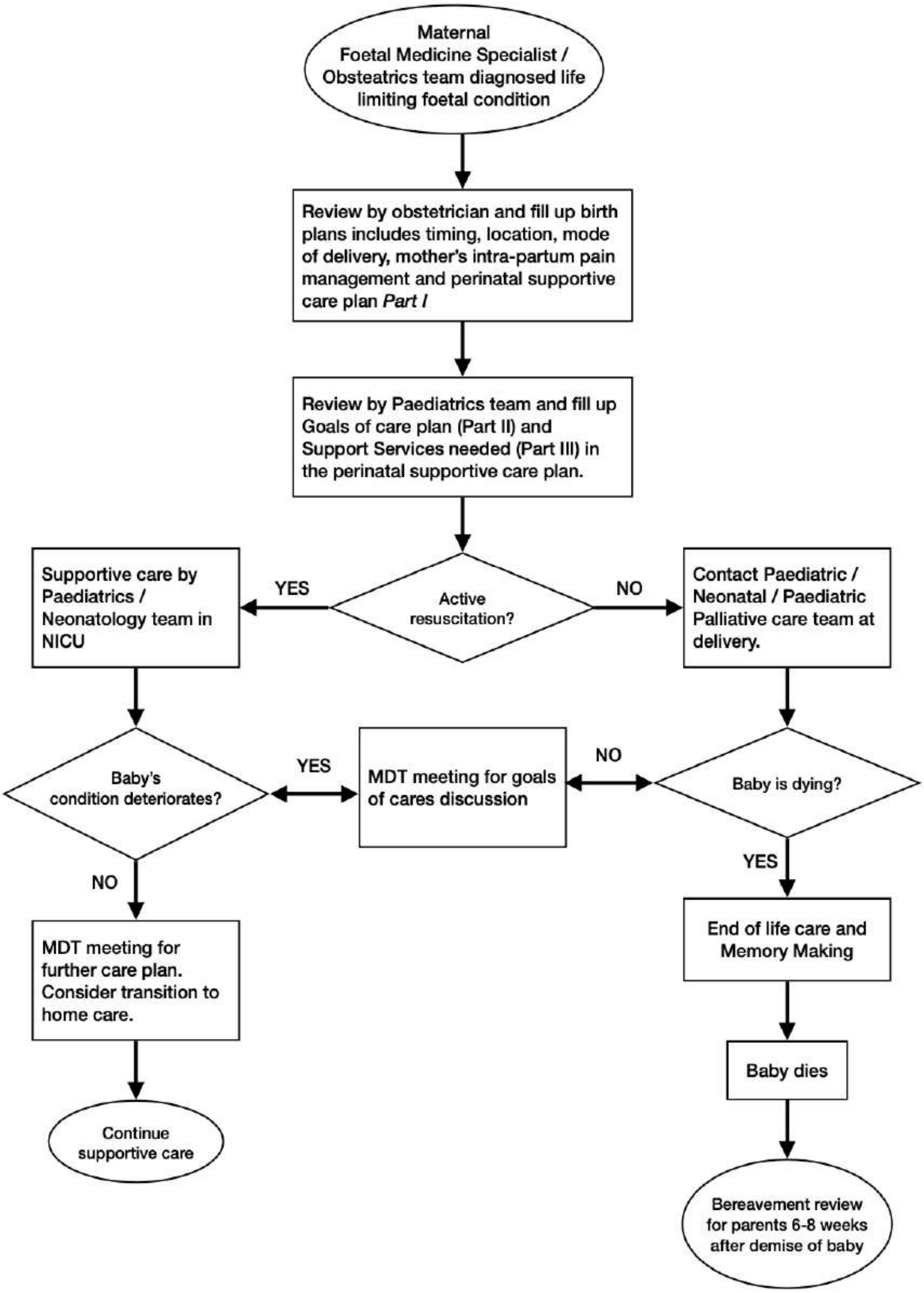

Figure 5a.2: Perinatal ACP discussion workflow

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CHAPTER 5B: ACP IN ADOLESCENTS AND YOUNG ADULTS

Key Learning Points:

- Adolescents who are developing into their adult being undergo physical, cognitive and social changes that can be seriously impacted by life-limiting illnesses.
- Evidence suggests that the majority of adolescents and young adults (AYA) want to have end-of-life discussions and avoiding this by parents and older adults leads to fear and isolation.
- Involving parents and trusted elders in the ACP discussion can help to provide emotional support, facilitate communication, and contribute to understanding the adolescent's wishes.
- Open and honest communication must begin right from the start emphasizing confidentiality, rapport, empathy and trust. AYAs should be assessed for readiness to discuss ACP and should be given the right to opt out rather than to earn the privilege to opt in to discussions.

5B.1 INTRODUCTION & DEFINITIONS

WHO defines 'Adolescents' as individuals in the 10-19 years age group and Youth as the 15-24-year age group. While 'Young People' covers the age range 10-24 years. Even though adolescents under the age of 18 are typically classified as minors, they still possess the right to be informed about their medical condition and allowed to participate in decisions regarding their own health.

Perkara 24 Konvensyen Mengenai Hak Kanak-Kanak:

> *Negara-Negara Pihak mengiktiraf hak kanak-kanak untuk menikmati standard kesihatan yang boleh dicapai yang paling tinggi dan kepada kemudahan rawatan bagi penyakit dan pemulihan kesihatan. Negara-Negara Pihak hendaklah berusaha untuk memastikan bahawa tiada kanak-kanak dilucuthakkan aksesnya kepada perkhidmatan jagaan kesihatan sedemikian.*

Adolescence is a period characterized by rapid physical, cognitive and social changes, including sexual and reproductive maturation; the gradual building up of the capacity to assume adult behaviours and roles involving new responsibilities requiring new knowledge and skills. While adolescents are generally a healthy population group, the period of adolescence also presents new challenges to health and development due to their inherent vulnerability and societal pressure, including peer influence, to engage in risky health behaviours. These challenges encompass the development of an individual identity and exploration of one's sexuality. The dynamic transition to adulthood is typically a period of positive changes, driven by adolescents' remarkable ability to learn quickly, embrace new and diverse experiences, engage in critical thinking, exercise their freedom, nurture creativity, and socialize.

Children may have a limited understanding of death by the age of 2-5 years old and begin to develop a more concrete understanding of death at the age of 5-9 years old. By 9-12 years old they have a more mature understanding of death. However, the understanding of death is not solely dependent on age but is also influenced by other factors such as cultural, religious belief, family, previous exposure to death related events and personality traits.

5B.2 THE IMPACT OF SERIOUS ILLNESS ON ADOLESCENTS AND YOUNG ADULTS

Due to the physical, cognitive, emotional and social changes occurring in all adolescents and young adults and how these changes are elemental to their development of their adult being, a diagnosis of a life-threatening diagnosis can have a significant impact to the AYA. [9,10,11,15]

- **Independence:**
  As a young person grows, they develop increasing autonomy and independence from parents and family in order to explore their emerging sense of self. When serious illness occurs, it demands the need for increased physical and emotional support. This results in a loss of independence and privacy.

- **Identity:**
  An individual's identity often develops based on perceptions of the future and dreams of opportunities with endless possibilities. Serious illness then brings the threat of disability and mortality which may shatter those dreams and with it, the identity of the young person.

- **Relationships:**
  For the young person peer group relations are essential for development of the adult identity. The young person will often choose a peer group that has an appearance and a way of life that sits well with them. Serious illness unfortunately may result in restricted freedom to socialise in school, college or go to group activities. Some illnesses may impact on body image and they may not be able to immerse in the culture and pre-occupations of the group. This results in a loss of sense of belonging.

- **Sexuality:**
  As the young person grows through puberty there is an inherent need to explore their sexuality and personal relationships. Serious illness may prevent the young person from expressing their sexual thoughts and feelings which can be frustrating and cause feelings of guilt or shame. Body image issues and disability may lead to feelings of anxiety about attractiveness and the lack of opportunities for personal relationships.

- **Financial:**
  For a young adult who is just starting a career, financial freedom is a common ambition as there is the prospect of personal income with relatively few financial commitments. Young adults at this stage may hope to travel and explore new experiences with whatever they are able to budget with. Serious illness however may not only result in loss of employment but also increased financial constraints due to medical costs.

- **Autonomy in decision making:**
  As the young person grows they develop a sense of responsibility by making their own choices. Often young adults learn by making occasional mistakes which later helps them develop wisdom. In a serious illness, some decisions may be very critical with no room for making mistakes. This is when parents and older adults may try to override the younger person's decisions. For those under the age of consent, parents and guardians may not consider the young person’s opinions for fear of making wrong choices.

5B.3 THE IMPORTANCE OF ACP IN ADOLESCENTS AND YOUNG ADULTS (AYA)

Many of the challenges faced by adolescents and young adults diagnosed with serious life-threatening illnesses stem from a desire to grow and to be acknowledged for their individual identity. It is therefore all the more important that the AYA faced with serious illness be afforded appropriate dignity and respect by allowing them adequate autonomy over their care.

Commonly there is a tendency for parents and older adults to protect the AYA from bad news and open discussions about end-of-life as there is a fear that this will lead to loss of hope for the patient. Evidence however clearly shows that: [12,14,15]

a. Majority of AYAs are interested in having end-of-life discussions.

b. They want to be able to choose and record: [14]
   i. the kind of medical treatment they want and do not want
   ii. information for their family and friends to know
   iii. how they want to be remembered

c. Avoidance of end-of-life discussions by older adults around them creates a sense of isolation, fear and anxiety. [12]

d. AYA and parents appreciate open honest communication and often feel resentful and later fearful when open discussion is avoided. [13]

e. When parents are aware of what the AYA wants it can be a great relief to them.[12]

ACP is therefore very important particularly in the AYA group of patients as it provides many important benefits to the wellbeing of the patient and family including:

- **Autonomy:** It promotes the autonomy of the AYA recognising their right to be involved in decisions about their own healthcare.
- **Shared decision making:** It facilitates shared decision-making between the young person, their family or caregivers, and healthcare providers.
- **Communication:** It encourages open and honest communication, ensuring that all parties are actively involved in discussions about the young person's healthcare goals, treatment options, and end-of-life preferences.
- **Preparation for critical situations:** It prepares young individuals, their families, and healthcare providers for critical situations that may arise due to their underlying health conditions or medical treatment. By discussing potential scenarios, ACP helps individuals and their families make decisions in advance, reducing potential distress and conflict during crises.
- **Family support:** It helps family members understand and respect the young person's autonomy while providing guidance and support during difficult decision-making processes.

5B.4 SPECIAL CONSIDERATIONS IN DISCUSSING ACP WITH ADOLESCENTS AND YOUNG ADULTS (AYAS)

Key points to consider:

1. **Developmental stage**: Adolescents and young adults are still developing their cognitive abilities and may have limited understanding of complex medical decisions. Discussions need to be tailored to their age and maturity level using age-appropriate language and concepts.
2. **Privacy and confidentiality**: As identity and peer relationships are of significant importance to the AYA, privacy and confidentiality must be respected. Ensure that ACP conversations take place in a private setting where they feel comfortable sharing their thoughts and preferences. Assure them that their wishes will be kept confidential (adolescence verbal confidentiality contract (VCC) is applied).

3. **Autonomy and decision-making**: Allowing the AYA to be more involved in their health care decision-making processes, especially at the end-of-life, can help re-establish their burgeoning autonomy and sense of purpose. They have the right to know their diagnosis and their medical condition even though the parent requests not to disclose it to them. Most importantly, work alongside parents to encourage them to express their preferences, values, and goals for their future healthcare. Emphasize that their choices will be respected and honoured to the greatest extent possible. For those less than 18 years old, although the final decision falls on the parents / guardian, their wishes should be acknowledged and considered in the decision making.
4. **Support system**: Recognize the importance of involving supportive individuals, such as parents, guardians, or trusted adults, in the ACP discussions. They can provide emotional support, help facilitate communication, and contribute to understanding the adolescent's wishes.
5. **Cultural and religious considerations**: Be sensitive and respect the cultural and religious beliefs of the adolescent or young adult and their family incorporating these into the discussion. Culture may not only refer to ethnic culture but also the culture of the AYA and their peer affiliations.
6. **Communication**: It is crucial to approach ACP discussions with sensitivity, empathy, and a focus on the individual's well-being. Assess the adolescent and young adult’s readiness in discussing ACP with the help of Readiness Assessment Tools*. AYA should be given the right to opt out rather than having to earn the privilege of opting in to discussion.
7. **Trust:** Open and honest communication must begin right from the first meeting. Always emphasize confidentiality, rapport, empathy and trust (CRET) during communication with adolescents. Allow the AYA to revise their decisions as their values and circumstances evolve.
8. **Legal considerations**: According to Malaysian Law, the legal age to make a decision is 18 and above (Age of Majority Act 1971). According to the Act, those below 18 years old are considered as minors and the final decision falls on the parents/ guardian.

**refer to communication chapter*

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CHAPTER 5C: NEURODEGENERATIVE DISEASES

Key Learning Points:

- ACP is essential in neurodegenerative diseases as cognitive, functional and communicative impairments are common in advanced disease.
- Artificial hydration and nutrition should be discussed in a balanced manner considering the potential benefits and harms without making reflexive assumptions.
- Issues of ventilatory support should be discussed early to avoid patients presenting with respiratory failure in an acute emergency setting. Non-invasive ventilation should be introduced early as respiratory function declines.
- Withholding/withdrawal of life-sustaining treatment is a very important aspect of ACP in order to understand when a patient may consider certain interventions as burdensome or unwanted.

5C.1 INTRODUCTION

Neurodegenerative diseases are a heterogeneous group of disorders characterized by the progressive deterioration and dysfunction of neurons. These diseases primarily affect the structure and function of the nervous system, leading to a gradual loss of cognitive abilities, motor skills, and overall neurological function.

Neurodegenerative diseases have a variable impact on prognosis. Parkinson's disease and hereditary muscular dystrophies may be associated with a longer prognosis while motor neurone disease, spinocerebellar ataxia, Parkinson plus disease, and secondary progressive multiple sclerosis may have a shorter prognosis.

Cognitive decline, physical disabilities and eating difficulties are common in patients with neurodegenerative disorders. In some, such as motor neurone disease, respiratory failure is common.

Disease	Issues
MND	- Prognosis poor (median 30 months) - Respiratory failure and dysphagia common
Parkinson disease	- Patients may gradually decline, and advance care planning is often initiated late. [22]
Atypical parkinsonian disorders (Progressive supranuclear palsy, multiple system atrophy, cortico-basal degeneration)	- These are associated with a poorer prognosis and earlier decline in cognitive and physical function compared to Parkinson's disease.[16]
Multiple sclerosis	- Primary progressive and secondary progressive forms of MS are associated with a progressive trajectory. - In MS, respiratory failure is an uncommon feature, limited mostly to the primary and secondary progressive forms of the disease.[20] Given the relatively younger age of patients with these forms of MS the issue of ventilation may need to be explored.
Muscular dystrophies	- Respiratory failure may occur and signifies a poor prognosis. NIV may be helpful.[13]

Table 5c.1: Lists of a few neurodegenerative disorders and the common issues that arise

5C.2 ACP PROCESS IN NEURODEGENERATIVE DISEASES

Due to the high incidence of cognitive and communication impairments at the end of life in neurodegenerative diseases, the need for early advance care planning must be emphasised. The decline in the ability to self-care often leads to reliance on family members or carers, and decisions made regarding patient care often have an impact on them. Advance care planning should be started early in the disease trajectory, before cognitive impairment and communication difficulties sets in. It often encompasses many activities across the disease trajectory.[21]

Initially, early advance care planning may focus on attending to informational needs and supporting emotions. This is important in facilitating transitions in hopes and expectations that are in line with the progression of disease and promotes decision-making that considers the prevailing situation. Understanding of patient values may start initially with an understanding of broad life goals. Over time, patients may be more able to express their hopes, worries, thinking, and feelings about treatments like ventilation and artificial nutrition and hydration. Some patients may express health states that they might find unacceptable, and these may form the basis for the consideration of withdrawal of life-prolonging therapy.

Early sharing of the patient's expected disease trajectory and values with loved ones allows them to transition to appropriate hopes and expectations, and support appropriate goals at the end-of-life. Despite the need for early discussion, most discussions over treatment withdrawal and limitations in neurodegenerative disorders still occur late in the disease trajectory, often triggered by cognitive decline, functional decline, the terminal phase, or patient/family request.[22]

5C.3 ARTIFICIAL HYDRATION AND NUTRITION

Neurodegenerative diseases may make swallowing unsafe. This is contributed by muscle weakness or cognitive decline. Artificial hydration and nutrition may help prevent malnutrition, maintaining body weight and improving overall well-being. This can indirectly contribute to an improved quality of life and potential quantity of life.

Limited studies however have shown mixed results, with uncertainty about its effects on quality of life, function, survival and aspiration risk[2,23]. Artificial hydration and nutrition may be burdensome, possibly leading to hospital admissions, social intrusion, oedema and discomfort. Patients may value enjoyment from continued oral feeds and find tube feeding intrusive. Others may value the maintenance of caloric intake and the ease associated with tube feeding.

Hence, a reflexive or reactionary approach to the administration of artificial hydration and nutrition is inappropriate. Instead, the decision should be individualized, with discussion of uncertainty, alternative options to using artificial methods, and patient values/priorities.

PEG feeding

PEG feeding may be discussed as part of advance care planning in neurodegenerative diseases. While it is a useful technique for long-term feeding in patients with difficulty eating from neurodegenerative disease[6,7,11], it carries the risk of complications, especially when respiratory function has declined [4].

In MND, there are suggestions that PEG should be inserted before FVC drops < 50% [14,18]. Therefore, if early discussions indicate that PEG feeding is consistent with future goals of care, PEG should be placed early for optimal safety and efficacy. Patients and family may have preferences in terms of how the PEG tube is utilized, e.g. foods that are put through, amount and continued oral feeding with a PEG tube. Blended diet via feeding tube may be feasible [8,17].

PEG feeding may serve different goals. It may be used to enhance adequate calorie intake or promote comfort. How tubes are utilized for feeding depends on the prevailing goals in the care of the patient.

General supportive measures for patients with swallowing difficulties

Supporting patients regarding nutrition is not limited to the provision of artificial hydration and nutrition. Discussing general supportive measures aids balanced decision-making regarding nutrition.

Supportive measures may include referral to a speech therapist for compensatory and rehabilitative measures, attention to food consistency/texture and position during feed, and high-calorie foods [5]. If clinically appropriate and desired, investigative procedures like bedside swallowing test, VFSS (Video Fluoroscopic Swallowing Study) and FEES (Fibreoptic Endoscopic Evaluation of Swallowing) may be used to provide guidance to patients and families about appropriate food consistencies.

It is important to realize the psychological, social and spiritual aspects of feeding. Difficulty eating may bring about feelings of anxiety and loss, interfere with mealtimes with family and change how a person feels about their well-being. When supporting patients with difficulty in feeding, attending to these broader issues are also important forms of support. Interdisciplinary input can be useful in supporting patient feeding.

5C.4 RESPIRATORY SUPPORT

Respiratory involvement in neurodegenerative diseases is a marker of poor prognosis, especially in motor neurone disease where it is the most common cause of death[10]. While no curative treatments are available, there is a role for ventilator support, which needs to be explored. There are several points to clarify as part of advance care planning:

- **Goals of ventilator support:** will generally fall in two categories. Ventilation may serve to relieve distressing symptoms such as orthopnoea, dyspnoea, fatigue, or poor sleep and hence improve quality of life. Secondly, some evidence indicates that ventilation may modestly improve the duration of survival, albeit at a cost which notably includes financial and caregiving burdens[3].

- **Type of ventilator support:** An important point in advance care planning regarding respiratory support is the distinction between invasive, tracheostomy ventilation and non-invasive ventilation via a mask interface.
  i. **Invasive ventilation:** In the absence of advance care planning discussions, disease progression will often lead to a situation where respiratory failure presents as an emergency. As lengthy discussions are no longer possible at the point of crisis, invasive ventilation may often be embarked on, with subsequent weaning to tracheostomy ventilation at home. This usually requires continuous nursing care,

skills in the management of secretions and tracheostomy emergencies. This places a considerable financial and logistic challenge, where support is not available at this time in Malaysia at a wide scale. This may be a suboptimal outcome which may not reflect patient preference in most instances.

ii. **Non-invasive ventilation:** An early ACP discussion could address this issue and introduce the option of NIV as the first line ventilatory support. This has two key advantages. Firstly, a trial of NIV can establish whether the patient perceives a benefit from ventilation without having to commit to its use in the long term as in tracheostomy ventilation. Secondly the caregiving burden associated with NIV, while not negligible, is much lower in comparison.

    Modern BiPAP devices are portable allowing for better mobility and hence better quality of life. Notably respiratory support demands a multidisciplinary approach, involving chest, rehabilitation, palliative care, and neurology. It is to be noted that this approach needs a network of support and shared understanding.

5C.5 WITHDRAWAL OF LIFE-SUSTAINING TREATMENTS

Withdrawal of life-sustaining treatments in neurodegenerative diseases refers to the removal of NIV, tracheostomy ventilation, artificial hydration and nutrition, resuscitation, or other life-prolonging treatments. The issue of withdrawal may be considered when the quality of life is perceived to be poor, the burdens of treatment become unacceptable or continued treatment is thought to be futile. The progression of disease and change in life circumstances may make previously acceptable trade-offs between benefit and harm seem no longer appropriate.

Withdrawal of life-sustaining treatments are complex for several reasons:

- Trajectory and prognosis of neurodegenerative diseases are often unpredictable.[15]
- Many patients may have been relying on these treatments for prolonged periods and may have adapted to life fully dependent on these treatments, and report ongoing meaningful life despite physical decline.[1]
- While patients have the right to refuse/withdraw treatment, there is often difficulty in assessing their wishes and capacity at the time of decision-making due to speech problems.[19]
- During periods of transitions, different stakeholders, e.g., patients, family, and HCPs, may have differing viewpoints, necessitating effective communication to formulate a plan that considers the perspective of all.
- Having had early discussions and reflections about goals and values in the advance care planning process forms a good background to ease discussions at the point of decision-making.

- When at the point of discussing withdrawal of treatment, the patient's perspective, values, and goals should be elicited as much as possible if they maintain capacity to participate in decision-making. It should be realized that patients may retain cognitive abilities to participate in decision-making but have limited capacity for expression due to speech difficulties. Understanding their perspective may require an extra amount of time and the use of assistive methods to facilitate expression, such as support from speech and language therapists, language boards, eye trackers, gesture, and sign language.
- If a patient has lost capacity, early advance care planning should have facilitated understanding by surrogate decision makers and clinicians about the patient's values. These provide invaluable insights to be considered by family and clinicians when making best-interest decisions for patients.[9]
- In most cases, patients would develop symptoms immediately or within minutes of withdrawing ventilation. Since death may occur quickly after withdrawal of ventilation, a determination of the preferred place for withdrawal should be made.
- Sedatives, such as midazolam and levomepromazine are commonly used in withdrawal of ventilation[9]. This makes discussion about sedation, and its effects on feeding and communication important when considering withdrawal of ventilation.

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CHAPTER 5D: ACP IN DEMENTIA AND COGNITIVELY IMPAIRED FRAIL ELDERLY

Key Learning Points:

- ACP discussions need to be initiated as early as possible after the diagnosis of dementia as decision-making capacity may be lost early on in the disease trajectory.
- In PWD who lack decision-making capacity, ACP can be conducted through supported decision making or through a substitute decision maker who applies substituted judgement and best interest to make decisions on behalf of the PWD.
- Important areas of discussion for PWD in relation to the stage of dementia include ceilings for active medical treatments and issues regarding feeding.
- Evidence suggests that tube feeding does not provide any survival advantage over careful oral hand-feeding. Oral feeding is a basic human right and should always be offered as long as it does not cause distress.

5D.1 INTRODUCTION

As the population grows and turns into an aging population, the number of people with dementia (PWD) will increase. The World Health Organization (WHO) estimates that people living with dementia is 35.6 million in 2015 and is expected to double by 2030[31].

Improving the quality of life for PWD is important, and will require knowing their specific concerns and wishes about types of care and their preferred place of care. As their ability to make decisions will be lost as the disease progresses, an earlier or timely discussion is necessary to ensure better quality of care in the future.

There are multiple factors to consider when discussing ACP with PWD:

- **Patient Aspects**
    - PWD can be reluctant to engage in ACP. This can be due to fear of death, the person's own personality, lack of understanding or unacceptance/denial of diagnosis.[27]
    - Commonly, in Asian culture, older patients may entrust their children to make decisions and future plans. This will transfer the burden of decision-making to one who may not be completely privy or correct on personal preferences of care.[2]

- **Dementia Process**
    - Dementia may fluctuate and interplay with delirium when exacerbated by infections and non-infectious triggers. This can occur during an earlier stage of disease rendering decision making ability temporarily affected. Timing of assessment is therefore important.
    - In more advanced stages of dementia, conflicts may arise between previously expressed preferences and current behaviour, particularly in those with altered behaviour or personality. This may cause uncertainty in following a plan of care.
- **Family or surrogate's understanding of the disease**
    - Families may not fully understand the disease process, therapeutic options and problems that may arise. Family involvement in shared decision making therefore may occur late when the disease has worsened, leaving them unprepared to make end-of-life decisions. This may cause a sense of guilt which may lead to inappropriate life sustaining measures being requested.[5]
- **Healthcare professional's knowledge on ACP**
    - HCP may be confused on the legal status of ACP and terms such as advance directive, Do not Attempt Resuscitation (DNAR) and living wills are often used interchangeably. This may cause concerns about potential litigation if wishes are not followed. [19]
    - In a busy clinic or setting, time is often a barrier to exploring patients' willingness to start ACP discussions. [27]
- **Socio-cultural and religious concerns**
    - Families and caregivers in certain cultures may view it as a taboo to discuss life-and-death due to deep respect for the older person, especially when death does not seem imminent.
    - Discussions on planning for future deterioration and death may not be aligned with some religious beliefs.[2]

5D.2 DETERMINING CAPACITY FOR DECISION MAKING IN DEMENTIA

Dementia is a disease with several stages of severity: mild, moderate and severe. For people with dementia, **the diagnosis of dementia alone cannot be taken as an absolute reason for non-capacity in making decisions**.

A judicial declaration of incompetence may be global or limited to certain areas such as financial matters, personal care, or medical decisions. Decision-making capacity is task specific. Components of decision-making capacity include:

- ability to understand information
- appreciation of the relevance of that information to the situation
- ability to reason or weigh up the risks and benefits
- ability to express a choice

ACP in people who lack decision-making capacity

It is still possible to conduct advance care planning with individuals who have lost decision-making capacity through:

i. Supported decision making

In supported decision-making, a person with limited decision-making capacity can still be involved in advance care planning conversations. They may still be able to discuss certain aspects, such as their overall values and what they consider a reasonable outcome, even if they are unable to discuss specific things. A trusted person such as a family member, friend or professional may be selected as a supporter and should help the person navigate certain decisions by:

a. Gathering all relevant information for the person to make the decisions.
b. Inform the person about the range of choices that are available.
c. Explain the information in a way they can easily understand.

ii. Appointed substitute decision maker

If they have previously appointed a substitute decision-maker, with support of documents completed on the person’s behalf, the substitute decision maker may then be called to decide on issues for the person by considering the following approaches:

a. Substituted judgement
b. Best interests

<u>Substituted judgement</u>

Substituted judgment is about making decisions that the person would have made in the circumstances. This means 'to stand in the shoes' of the person who lacks decision-making capacity [24]. The decision-maker should use the following principles to assist with this:

- The decision-maker is required to fully consider the person’s views (current where appropriate, and previous - written or oral) and make the decision they truly believe the person would make in the current circumstances.

- The decision-maker needs to consider whether the outcomes of care and treatment, as they understand them to be, are consistent with the values and preferred outcomes that have been previously expressed by the person.

Best interests

The best interest standard of decision making requires decision-makers to make the decision that provides the maximum anticipated benefit to person and entails weighing the relative benefits and harms of different treatment options.[4]

This generally includes making decisions that provide maximum anticipated benefit to the person while minimizing restrictions; and that seek to optimize care and protection of the person. There is variation as to what should be included in a best interest decision-making standard.

5D.3 WHEN SHOULD ACP DISCUSSIONS OCCUR IN PWD?

ACP discussions need to be initiated as early after the diagnosis of dementia as decision-making capacity may be lost early on in the disease trajectory.

Dementia is progressive condition with various transition points where carers need to inform or directly make decisions on behalf of the person with dementia.

Relevant milestones which can act as triggers to engage in ACP [25]:

- **Transition points**
  i. Time of diagnosis of dementia
  ii. Changes to the health status of the family carer (illness, death, etc.)
  iii. Changes to setting of care (e.g. Transfer to acute care or residential care setting)

- **Healthcare events**
  i. Deterioration or decline in the PWD condition
  ii. PWD presenting with complex symptoms
  iii. PWD presenting problems with nutrition and hydration
  iv. Decreasing response to antibiotic treatment
  v. When the question of a need for further medical investigations or treatments arise
  vi. Discussions about attempting cardiopulmonary resuscitation

5D.4 IMPORTANT AREAS OF ACP DISCUSSION IN PWD WHO IS SERIOUSLY ILL

Avoiding overly aggressive, burdensome or medically inappropriate treatment

- Transfer to the hospital and the associated risks and benefits should be considered prudently in relation to the care goals and stage of the dementia.
- Medication for chronic conditions and comorbid diseases should be reviewed regularly in light of care goals, estimated life expectancy, and the effects and side effects of treatment
- Restraints should be avoided whenever possible.
- Hydration, preferably subcutaneous, may be provided if appropriate, such as in case of infection; it is inappropriate in the dying phase
- Permanent enteral tube nutrition may not be beneficial and should be avoided in advanced dementia; careful hand feeding is preferred
- Antibiotics may be appropriate in treating infections with the goal of increasing comfort by alleviating the symptoms of infection. Life-prolonging effects need to be considered, especially in case of treatment decisions around pneumonia

Feeding issues in severe dementia

- The common feeding issues in PWD:
  - i. Failure to recognise food
  - ii. Loss of normal physiological drivers of appetite and satiety
  - iii. Refusal of food
  - iv. Apraxia (affect ability to use cutlery)
  - v. Physical difficulties and failure to manage food bolus once it is in the mouth (oral phase dysphagia)
  - vi. Aspiration when swallowing (pharyngeal phase dysphagia) [9]

- When the patient’s desire for food and drink becomes less, it is an indication that the person is entering a terminal phase of illness.
- There is little evidence that hunger or thirst are perceived significantly at this time.
- Such patients may even resist the efforts by carers to offer food or fluids. This results in the dilemma of whether to ‘force feed’ such patients by mouth or to artificially feed them.

- In general, careful hand feeding is preferred and gastrostomy should not be offered in advanced dementia as there is no evidence to support PEG feeding in advanced dementia as it has not been shown to alter mortality or improve survival. [3,9]

- In observational studies, tube feeding has not been shown to prevent aspiration, heal pressure ulcers, improve nutritional status or decrease mortality in persons with advanced dementia.

- Tube feeding is associated with substantial burdens, including recurrent and new-onset aspiration, tube-associated and aspiration-related infection, oral secretions that are difficult to manage, discomfort, tube malfunction, use of physical and chemical restraints and pressure ulcers.

- The appropriate intervention for this is to provide good mouth care rather than attempting to feed the patient and to consider the appropriateness of continuing PEG or NG feeding if this has previously been carried out.

5D.5 ETHICAL ISSUES IN DECISION MAKING REGARDING FEEDING IN PWD

When nutrition is withheld, death will follow. The duration between withholding nutrition and death can be as long as 10 weeks but when hydration is also withdrawn, the duration may be shorter at 3-14 days. Therefore, clear reasons should be identified for withdrawal of nutrition and hydration instead of blind adherence to a protocol.

The intention of withdrawal of artificial feeding should not be to hasten death but to avoid the suffering or burdens associated with feeding therapies.

As research consistently demonstrates that survival in older adults with advanced dementia is not better in tube fed compared to those who are not, it can be concluded that tube feeding does not provide any survival benefit in PWD who are no longer able to eat or drink naturally.

The right to food is protected by the Universal Declaration of Human Rights Article 25, adopted by the General Assembly of the United Nations. Therefore, food and drink must not be withheld from any incompetent person who is still willing and able to eat. Therefore, even if a patient previously expressed he/she did not want any medical interventions such as artificial feeding tubes and parenteral fluids, hand-feeding is still appropriate as this is not a medical procedure. [16]

Can surrogate request or decide on voluntary stopping eating and drinking for a PWD?

- A surrogate can choose to forgo medical procedures on the patient's behalf, but because hand-feeding is not a medical procedure, failure to offer food to an incompetent patient could be viewed as neglect.
- There is currently no accepted mechanism by which a surrogate can refuse "oral" food and drink on behalf of an incompetent patient in legal frameworks for ACP across different countries.
- If the surrogate insists that the patient would not want even hand-feeding, consider a family conference with other family members and offer comfort feeding only (CFO). In CFO, hand-feeding can be continued as long as the patient remains comfortable and to be ceased if they show any sign of distress.

"Old" Self vs. "Now" Self: Which Self Should Be Honored?

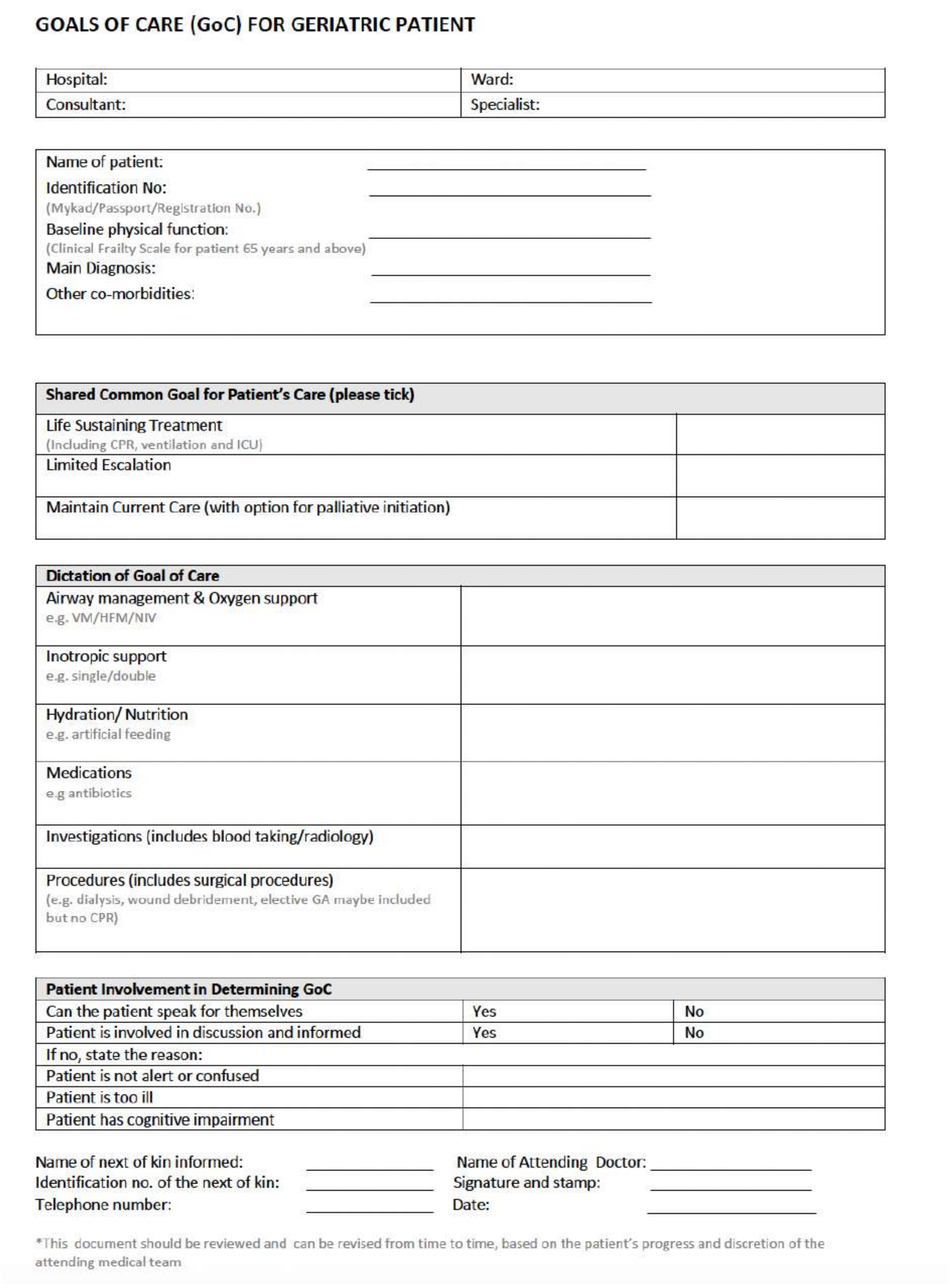
- Dementia progression might change the wishes and directive made earlier on while mental capacity was still intact (old self).
- Although the patient's "old self" expressed refusal of medical interventions to prolong life, as long as there is no distress and the patient seems to cooperate during oral feeding, it would still be ethically justifiable to honor the "now" self. [32]

5D.6 GOALS OF CARE IN FRAIL ELDERLY

In situations when an elderly patient (with or without cognitive impairment) is acutely ill and admitted to the hospital with serious medical conditions, the goals of care discussion (refer Chapter 3: Shared Decision Making and Goals of Care (GOC) Discussion) may assist in the direction of current treatment or care.

Goals of care conversations require physicians to effectively communicate complex information about a medical diagnosis and prognosis to the patient and family, elicit information about patient preferences, provide support and make shared decisions, and ensure treatments and outcomes are aligned with patient and family preferences.

Proper documentation of goals of care is crucial and should be readily available for the attending health care providers for the patient. An example of the Goals of Care document is found in below.



GOALS OF CARE (GoC) FOR GERIATRIC PATIENT

Hospital:	Ward:
Consultant:	Specialist:

Name of patient: ______________________

Identification No: ______________________

(Mykad/Passport/Registration No.)

Baseline physical function: ______________________

(Clinical Frailty Scale for patient 65 years and above)

Main Diagnosis: ______________________

Other co-morbidities: ______________________

Shared Common Goal for Patient's Care (please tick)	
Life Sustaining Treatment (Including CPR, ventilation and ICU)	
Limited Escalation	
Maintain Current Care (with option for palliative initiation)	

Dictation of Goal of Care	
Airway management & Oxygen support e.g. VM/HFM/NIV	
Inotropic support e.g. single/double	
Hydration/ Nutrition e.g. artificial feeding	
Medications e.g antibiotics	
Investigations (includes blood taking/radiology)	
Procedures (includes surgical procedures) (e.g. dialysis, wound debridement, elective GA maybe included but no CPR)	

Patient Involvement in Determining GoC		
Can the patient speak for themselves	Yes	No
Patient is involved in discussion and informed	Yes	No
If no, state the reason:		
Patient is not alert or confused		
Patient is too ill		
Patient has cognitive impairment		

Name of next of kin informed: ______________

Identification no. of the next of kin: ______________

Telephone number: ______________

Name of Attending Doctor: ______________

Signature and stamp: ______________

Date: ______________

*This document should be reviewed and can be revised from time to time, based on the patient's progress and discretion of the attending medical team

Figure 5d.1: Goals of care (GoC) for Geriatric Patient

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CHAPTER 5E: ORGAN FAILURE I (CARDIAC & RESPIRATORY DISEASES)

Key Learning Points:

- Many chronic organ failure patients including heart failure, chronic lung diseases, chronic liver disease and chronic kidney disease have trajectories of progressive gradual deterioration over several years interspersed with episodes of acute deterioration which can result in recovery or death thus making prognosis very unpredictable.
- ACP is a process that should begin early and continue to be revisited throughout the trajectory particularly when there is a change in condition or an acute episode of deterioration.
- In advanced heart failure, issues of using inotropic support and also the role of ICDs, pacemakers and cardiac resynchronisation devices should be discussed.
- In severe chronic lung disease, the role and type of mechanical ventilation as well as ceilings of its use should be discussed.

5E.1 INTRODUCTION

Cardiac diseases such as heart failure, chronic cardiac ischemia, pulmonary hypertension, and adults with congenital heart disease (CHD) are progressive conditions with high mortality. Similarly, respiratory diseases, mainly chronic obstructive pulmonary disease and interstitial lung diseases are also characterised by progressive reduced lung function, limiting basic daily activities and may require additional support for a long period of time.

The American Heart Association, the European Society of Cardiology and the European Association for Palliative Care recommend ACP for people with advanced cardiac disease, including those with heart failure[1,2,3]. The Global Initiative for Chronic Obstructive Lung Disease guidelines also recommend ACP as an essential part of management in severe COPD[4]. Many clinicians however still report feeling uncomfortable when discussing end of life care with patients.[5]

The timing of ACP discussions in cardiorespiratory diseases remains a challenge because patients and clinicians may incorrectly perceive that the initiation of ACP discussions as a transition to cessation of life prolonging treatment while the prognosis in these patients remains very difficult to predict.

5E.2 DISEASE TRAJECTORY

Both heart failure patients and patients with chronic lung disease share a common disease trajectory whereby there is a progressive and steady decline of performance status over many years interspersed with episodes of acute deterioration which with acute medical interventions may restore some health-related quality of life to the individual. The prognosis however is highly unpredictable.

In heart failure patients the course of illness can be interrupted by sudden cardiac death due to arrhythmia or an acute coronary syndrome, but more commonly ends in death from progressive pump failure.

In chronic lung disease patients, every episode of exacerbation can be life threatening and is associated with high mortality. The risk of death in patients with acute exacerbation of COPD increases to 10% during hospital admission, and the risk increases to 25% if the patient is on invasive mechanical ventilation. [7,8]

Patients with Idiopathic Pulmonary Fibrosis have a median survival of 2 to 3 years but may remain stable for longer periods of time. Most patients experience subacute worsening over a period of months, with a minority having more acute deterioration over a period of less than a month.[9,10]

Pulmonary hypertension has a highly variable clinical course depending on the type, functional class and co-morbidity. For PAH the median survival without treatment is 2.8 years.[11]

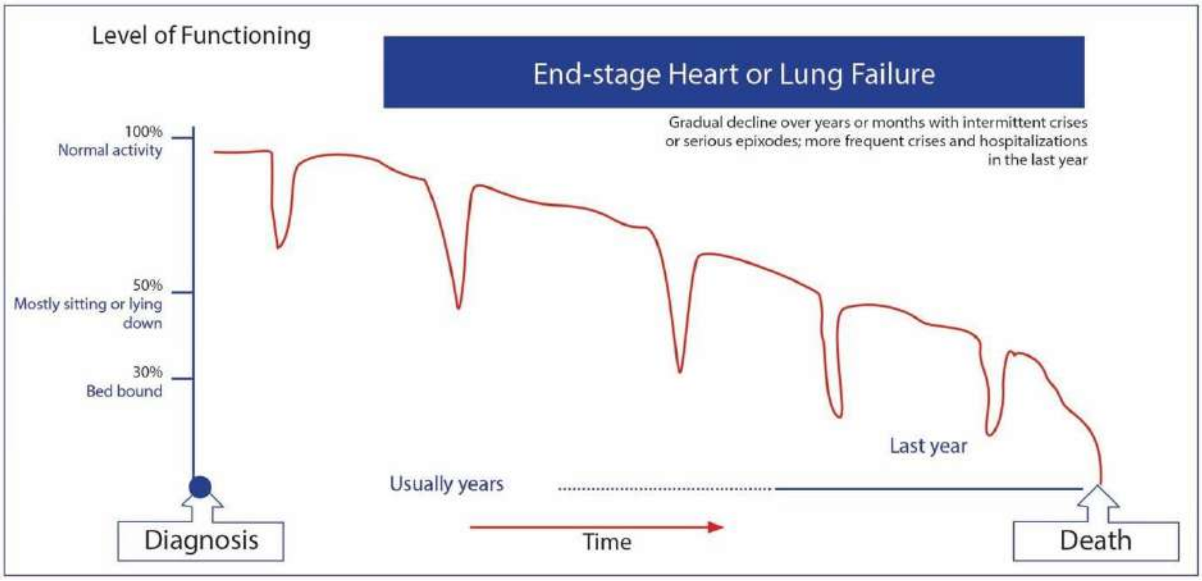

Figure 5e.1: End-stage heart or lung failure disease trajectory

5E.3 TIMING OF INITIATION OF ACP DISCUSSION

ACP should begin early in the disease process while the patient is still well enough to participate. Patients tend to underestimate disease severity and rarely initiate a discussion about palliative care or end-of-life planning[14,15]. Concerns about dying and fear of breathlessness or suffocation are highly prevalent but are scarcely discussed with their clinicians[16].

In patients with advanced heart failure, ACP should be initiated when the patient is on maximum medical therapy, and when there is clinical progression. In progressive chronic respiratory diseases, discussion on ACP should be initiated upon the time of diagnosis or first exacerbation attack, integrating it with disease modifying treatments throughout the course of disease.

Several transition points in chronic respiratory diseases have been identified that should serve to prompt a discussion about goals of care and advanced care planning[17-19]:

i. The start of new or different treatments, e.g: initiation of oxygen therapy
ii. Lack of further life-prolonging treatment options
iii. Functional decline
iv. Frequent exacerbation
v. Frequent hospitalizations/emergency room visits
vi. Referral for lung transplantation

One barrier to initiating a discussion of palliative care is lack of precision in determining prognosis in various cardiac and respiratory diseases

Several scoring systems can help to predict mortality, such as:

1. Heart failure – MAGGIC risk score[20]
2. COPD- BODE index[21]
3. PAH- ESC/ERS risk stratification score[22]
4. IPF- GAP index[23]
5. Bronchiectasis-BSI, FACED score[24]

However, as the disease course can be unpredictable, each patient should be evaluated on an individual basis.

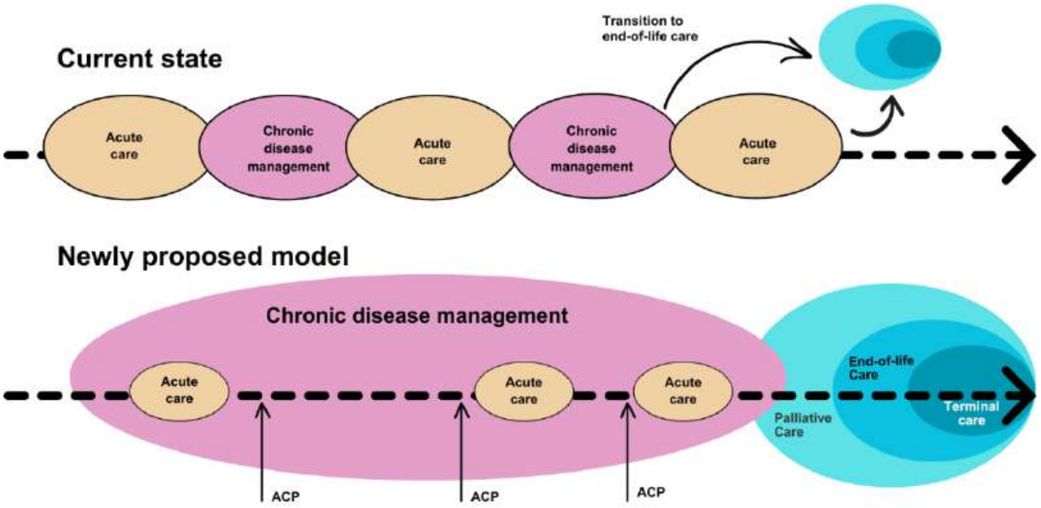

Figure 5e.2: Proposed model in the medical management of cardiorespiratory disease involving initiation of ACP early. (figure obtained from Professor D Robin Taylor)

5E.4 SPECIFIC ISSUES IN HEART FAILURE

Ethical dilemmas can arise when dealing with advanced heart failure patients as patients and clinician may have differing ideas regarding withholding or withdrawing life-sustaining treatments.

In general, treatments relevant for symptom management or prevention should be continued if well tolerated and the dose regularly reviewed.[28]

Inotropes

- The intermittent infusion of intravenous inotropes might sometimes be considered as palliative care intervention in inpatient institutions or even in-home care to improve both symptoms and quality of life. [30-32]
- Inotropic drugs should not be started or continued in patients who are actively dying as they usually no longer provide any symptomatic benefits in such situations.

Implantable cardioverter defibrillator

- The option of reprogramming the device at the end of life, to avoid potentially painful and usually futile shocks should be discussed in advance and, if agreed, performed timely[33,34].
- Anti-tachycardia pacing (ATP), which is generally well tolerated, can be left active if the patient does not wish to deactivate all anti-tachyarrhythmia therapies or if it might be in the patient's best interests.

Pacemaker

- Requests for pacemaker deactivation are more complex. Some patients fear that an active pacemaker can delay dying. However, this therapy neither delays dying nor causes symptoms, furthermore anti-bradycardia pacing can improve quality of life, even in patients who are dying, by preventing symptoms caused by low heart rate and/or pauses in heart rhythm (e.g. dizziness, pre- syncope, and breathlessness)[35-37].

Cardiac Resynchronization Therapy

- Discontinuing the re-synchronization component should be avoided, as the loss of pacemaker mediated synchronization can precipitate HF-related symptoms[38].
- A multidisciplinary approach should be considered including palliative care, cardiology, and ethics if needed, when patients or their caregivers request deactivation of anti-bradycardia or resynchronization pacing.

5E.5 SPECIFIC ISSUES IN RESPIRATORY DISEASE

Patients with chronic respiratory disease, death may be caused by progressive respiratory failure, an acute exacerbation of lung disease, intercurrent infection or a comorbid disease.

When given the opportunity, patients with chronic respiratory disease are able to indicate their preferences regarding life sustaining treatment based on their expected burden of treatment and expected outcome of treatment[39].

Disease specific triggers that help to prompt ACP discussions are:[40,41]

i. FEV1 or FVC <30% of predicted
ii. Oxygen dependence
iii. One or more hospitalization in prior year for exacerbations
iv. Weight loss or cachexia
v. Decreased functional status
vi. Increasing dependence on others
vii. Age greater than 70 years old
viii. Lack of additional treatment options

Mechanical ventilation

- COPD and IPF patients tend to have a poor prognosis after hospitalization and mechanical ventilation. They are associated with high inpatient mortality. It is important to include discussion on prognosis after resuscitation or mechanical ventilation and potential withdrawal of life support. [26,27,29,42]

- Making decisions about ventilatory support in the early stage of disease may be difficult for patients. “Time-limited trial” of ventilatory support may allow treatment of reversible processes such as pneumonia, but clinicians are allowed to withdraw ventilatory support if the patient does not improve based on a defined duration of therapy as guided by patient and or surrogates.

- It is important to establish the goals of care and the situation in which mechanical ventilation would be discontinued. Also, to provide other alternatives such as non-invasive ventilation or high flow nasal cannula if patients do not wish to be mechanically ventilated.

- It is appropriate to discuss withholding or withdrawing ventilatory support in situations such as:
    - When available medical interventions are unlikely to achieve the patient’s goal of care.
    - When duration or invasiveness of treatment to achieve a patient's medical goals is known to be unacceptable to the patient.

  More precise phrases should be used, such as “withdrawal of life support” or “withdrawal of the ventilator”.

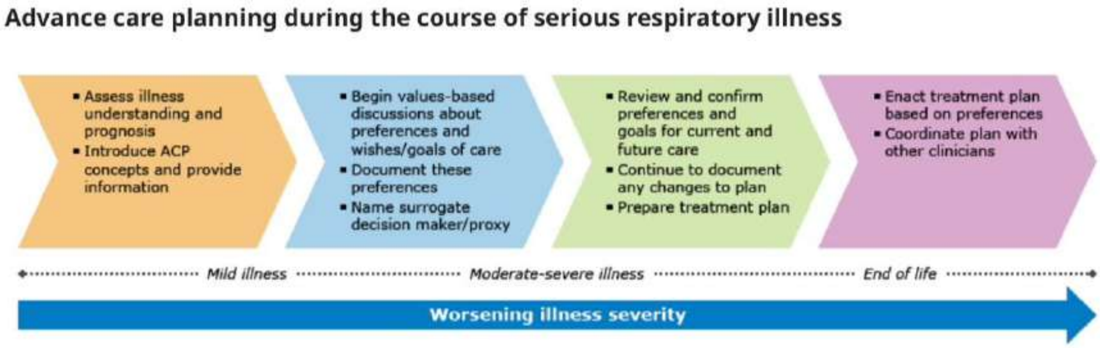

Figure 5e.3: Advance care planning during the course of serious respiratory illness[12]

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CHAPTER 5F: ORGAN FAILURE II (KIDNEY & LIVER DISEASE)

Key Learning Points:

- ACP in chronic kidney disease should include discussions on choices for kidney replacement therapy (KRT) or conservative non-dialytic therapy which is an acceptable approach especially in patients where KRT may not be beneficial.
- All patients on KRT will encounter more complications with longer dialysis vintage and ACP must be revisited to check if KRT is still in a patient's best interest.
- ACP in end-stage-liver-disease (ESLD) should discuss their preferences for treatment for common complications in ESLD including upper GI-bleeding, hepatic encephalopathy and acute kidney injury.

5F.1 INTRODUCTION

The incidence of chronic kidney disease (CKD) and chronic liver disease (CLD) are on the rise and this is very much associated with the large proportion of the Malaysian population who suffer from chronic non-communicable diseases such as type II diabetes, hypertension and dyslipidemia. While chronic liver disease has been often associated with viral hepatitis B and C infections in the past, at present, conditions such as MASLD (metabolic dysfunction-associated steatotic liver disease) are steadily on the rise and are predicted as the next major scourge of chronic liver disease and liver cancer.

The illness trajectory in both CKD and CLD takes on a course of steady deterioration over many years with episodes of acute decompensations which may recover to some degree but may also be unpredictable.

While interventions are available to manage these acute decompensations throughout the trajectory, as patients continue to decline over time, their ability to tolerate these interventions and the possibility of recovery from these episodes may be challenging with risks of poor outcomes. This is where ACP in these patients is very relevant and conversations to discuss goals and preferences for these interventions are so important.

5F.2 ACP IN CHRONIC KIDNEY DISEASE

ACPs in CKD patients need to be specific enough to direct clinical decisions on choice of kidney replacement therapy (KRT) options; but need to focus on broader goals of care as well.

Discussions about goals of care and advance care planning should be undertaken throughout CKD care regardless of whether or the patient is undergoing KRT. Important trigger points when ACP should be discussed include:

- When patients develop ESKD, estimated glomerular filtration rate (eGFR) < 15mL/min/1.73m^2
- During dialysis therapy
    a. Within the first year of commencement of dialysis
    b. Discussions to be repeated every 3 years
- When patients are faced with the end-of-life

ACP discussions with patients planning for KRT

It is difficult to decide on who will benefit from KRT (dialysis). ACP discussions should be performed in patients with low eGFR <15mL/min/1.73m^2. The discussions need to include:

- Choice of KRT
- Patient preferences of future care
- Shared-decision making process
- Goals of care

ACP discussions during KRT

ESKD patients experience a very high symptom burden. With longer dialysis vintage, there will be more complications increasing mortality and morbidity. Hence, ACP needs to be repeated in the future to check if KRT is still in a patient’s best interest.

ACP discussions with patient opting for comprehensive conservative care (non-dialysis) therapy

Non-dialysis therapy can be either chosen or medically advised in the following conditions:

- Advanced cancer with metastasis
- Elderly with multiple comorbidities
- Concomitant other advanced organ failures, such as liver and cardiac failure
- The patient is dying from sepsis with multiorgan system failure.

Comprehensive conservative care is a planned, holistic, person-centred care, which includes the following[6]:

- Provision of interventions to delay the progression of kidney disease and minimise the risk of adverse events or complications.
- Shared decision-making is a process through interactive communication between the managing nephrology team with the patients and their carers in an open, compassionate manner[7]. Risks, benefits, and uncertainties are discussed and viewed through individualised values and preferences. Patients and families/carers make informed decisions on treatment options, considering their current health, lifestyle, values and goals [7].
- Active symptom management
- Clear and concise communication, including advance care planning
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

ACP discussions when reaching end-of-life

ACP discussions need to be repeated when patients approach the end-of-life. This is defined as the last year of life or an expected prognosis of months. These may include[8]:

- Withdrawal of dialysis therapy
- Poor tolerance to pre-existing KRT and change of dialysis modality
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated KRT
- Recurrent hospital admissions (more than 3/year).

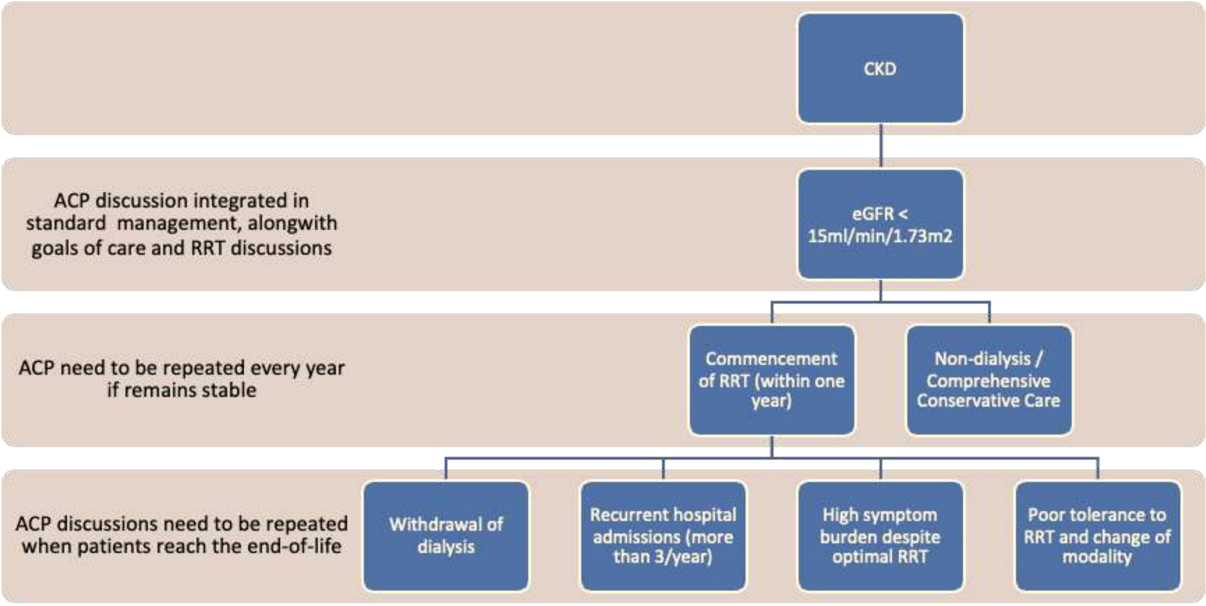

Figure 5f.1: Timeline for ACP discussions

5F.3 ACP IN CHRONIC LIVER DISEASE

Chronic liver disease accounts for over 1.32 million deaths worldwide of which 62.6% occur in the Asia-Pacific region. Over 50% of deaths due to chronic liver disease were related to hepatitis B[10,11]. The first liver transplant in Malaysia was performed in 1993 however till today, only a handful of liver transplants are performed annually. Therefore, while some patients may continue to hope for the option of a liver transplant, the majority of patients with chronic liver disease still continue to deteriorate and suffer from complications such as variceal bleeding, hepatic encephalopathy and spontaneous bacterial peritonitis (SBP). ACP is therefore an important part of the management of a patient with chronic liver disease especially when approaching the end-stage of the disease and when liver transplantation is not an option.

Prognostication in chronic liver disease can be aided by 2 commonly used tools which include the Child-Pugh Score (CPS) and the MELD (Model for end stage liver disease) Score. The CPS is less predictive for shorter term prognostication compared to the MELD however both are able to estimate a likelihood of surviving less than 6 months which is useful as a trigger to starting a conversation with the patient on ACP. [8,9]

Usual triggers for ACP discussion in patients with chronic liver disease includes:

- At initial diagnosis of end-stage liver disease or when first considering liver transplantation.
- At outpatient clinics after a recovery from acute episodes of illness.
- When considering a referral to palliative care.

Studies have shown that patients with chronic liver disease feel that ACP discussions are extremely important and want to have these discussions as well as information on their prognosis. Patients also state a preference to have ACP discussions when they are stable rather than when they are admitted for an acute illness.

Specific issues to discuss in chronic liver disease

- **Upper GI bleeding / Variceal bleeding**

i. As these patients may develop acute episodes of GI bleeding as a complication of chronic liver disease, it should be discussed regarding their views of endoscopy during such episodes.

ii. Some patients who are frail and have experienced extreme suffering from the procedure before may decide to forgo endoscopy however they may still consider conservative measures such as the use of somatostatin analogues and blood transfusions.

- **Hepatic encephalopathy**

i. In patients with end-stage liver disease, the occurrence of hepatic encephalopathy suggests a poor prognosis. While it is a common approach to search for reversible precipitating factors such as infection, SBP, hypoglycaemia and constipation, some patients may not want so many investigations or go through the process of intravenous drips and antibiotics.

ii. Patients who develop persistent hypoglycaemia may not want to undergo nasogastric tube feeding and frequent blood glucose monitoring.

- **Acute Kidney Injury**

i. AKI can occur from numerous reasons such as dehydration and loss of intravascular volume, sepsis or hepato-renal syndrome. In situations where IV hydration or an AKI albumin regimen fails to improve the renal function, clear goals should be set as dialysis in this case is seldom beneficial.

ii. AKI due to hepato-renal syndrome has an extremely poor prognosis where rapid deterioration is expected and dialysis would not be beneficial.

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SECTION B
PRACTICAL SKILLS IN ACP

CHAPTER 6: COMMUNICATION SKILLS

Key Learning Points:

- Develop effective communication skills to be adept at handling ACP discussions.
- Embody collaborative decision-making by actively involving patients and their families in the ACP process.
- Apply strategic timing and assess readiness to initiate ACP discussions.
- Exercise cultural sensitivity and patient-centred approach when discussing patients' values, beliefs, and personal goals.

6.1. INTRODUCTION

The practice of ACP is generally an exercise in open discussions between a patient +/- their family and healthcare providers regarding their values and preferences for future care. While this discussion is generally the responsibility of all healthcare providers, the task of conducting an ACP discussion would be daunting without the appropriate skills in navigating these conversations with patients.

Key elements for successful and effective ACP discussions:

Timing

- Recognizing the appropriate timing to initiate an ACP discussion is a key skill for healthcare providers.
- Training to recognize key trigger conditions and to use communication tools in starting conversations are vital to begin the ACP process.

Sensitivity and Readiness Assessment:

- Being sensitive to the individual's circumstances, preferences, and gauging their readiness to engage in ACP discussions is important.
- Assessing their readiness involves using open-ended questions to explore their understanding, concerns, and thoughts about future care.

Prognostication and Disease Trajectory

- Healthcare providers should also have proficiencies in prognostication and mapping out disease trajectories.
- This allows discussions to be aligned with the patient’s expected course and anticipated disease complications.

Communication Skills

- Good communication skills are absolutely important to ensuring ACP discussion success and includes rapport building, handling emotions and conflict management.
- Specific scenarios such as breaking bad news and discussing prognosis may be necessary in an ACP discussion.

6.2 GENERAL PRINCIPLES OF COMMUNICATION DURING ACP DISCUSSIONS

The following principles should be applied when facilitating ACP discussions:

1. **Building rapport and trust**
    - Rapport and trust should be actively built by engaging in open and honest communication, actively listening, showing empathy, and validating the emotions and concerns of patients and their families.
2. **Using plain and understandable language**
    - Communication should be done using plain and understandable language, avoiding the use of medical jargon and complex terminology.
    - This approach ensures that patients and families fully comprehend the information and actively participate in the decision-making process.
3. **Practicing active and reflective listening**
    - Listen actively by giving full attention to what patients and families express.
    - Reflect back on concerns and statements to ensure understanding and demonstrate that their perspectives are valued.
4. **Asking open-ended questions:**
    - Encourage patients and families to freely express their values, preferences, and concerns by asking open-ended questions.
    - This fosters deeper exploration of thoughts and feelings, facilitating more meaningful discussions.
5. **Exploring patient values and goals**
    - Engage in discussions about patients' values, beliefs, and personal goals to gain insight into what matters most to them regarding healthcare decisions and desired quality of life.
6. **Providing information and education**
    - Provide clear and accurate information about the purpose, benefits, and process of ACP.
    - Educate patients and families about available options, potential benefits, and risks associated with different treatment choices.
7. **Respecting cultural and individual differences**
    - Recognizing and respecting cultural, religious, and individual beliefs and values is essential.

- Communication approaches should be adapted to ensure cultural sensitivity and inclusivity that promotes effective dialogue.

8. **Addressing emotions and fears**
    - Acknowledge and address emotions, fears, and concerns that may arise during ACP discussions.
    - Provide emotional support and reassurance, ensuring that patients and families feel heard and supported throughout the process.
9. **Documenting and summarizing discussions**
    - Documentation of ACP discussions should be clear and accurate in capturing patients' preferences, values, and goals.
    - Key points discussed should be summarised to ensure that patients, families, and the healthcare team have access to this information for future reference.
10. **Encouraging collaborative decision-making**
    - Encourage collaborative decision-making by involving patients and families in the process.
    - Facilitate discussions, ensuring that patients have a clear understanding of available options and enable their active participation in decision-making.

6.3. ASSESSING READINESS TO DISCUSS ACP

An individual is said to be ready to have conversations of their values and preferences when they are able to speak realistically about their perspective on the end of their life while imagining themselves in future circumstances and reflecting on their emotions. Signs that indicate patients are not ready to participate in ACP discussions such as minimizing the seriousness of their illness, expressing a reluctance to consider ACP, steering away from talking about consequences of their illness, and avoiding thinking about their deterioration of health or death.

It is important to gauge an individual's readiness when intending to initiate ACP discussions although it should not be the only indicator and individual's need not be ready in all aspects of ACP for discussions to commence.

Just as goals of care may change during a course of the disease, readiness for ACP discussion and “re-discussions” should be reassessed regularly as well.

An example of a simple screening tool used particularly for younger people is shown below:

ACP Readiness Questions *(Wiener et al 2008)*

1. It might be helpful for me to talk about what would happen if treatments were no longer effective. (Yes/No)
2. Talking about medical care plans ahead of time to make sure my wishes are followed in the case that treatment options are limited or there are no more treatment options available would upset me very much (Yes/No)
3. I feel comfortable writing down or discussing what I want to happen to me if treatments were no longer effective. (Yes/No)

**if answer is Yes / No / Yes = patient is ready to discuss*

6.4. DOS AND DON'TS OF ACP FACILITATION AND DISCUSSION

Do	Don't
Do initiate the discussion early, preferably before the patient is critically ill, when the conversation will be easier.	Don't wait until the very end of life to have the conversation, when the situation is often chaotic and stressful.
Do create a safe and non-judgmental environment that encourages open and honest communication. This helps patients and their families feel comfortable expressing their values, preferences, and concerns.	Don't impose personal values or judgments on patients or their families during ACP discussions. Respect their autonomy and choices, even if they differ from your own perspectives.
Do actively listen to patients and their families, demonstrating empathy and understanding. Show genuine interest in their concerns, allowing them to express their emotions and facilitating meaningful dialogue.	Don't rush or pressure patients or families to make immediate decisions during ACP discussions. Allow sufficient time for reflection, understanding, and discussion among family members, if desired.
Do respect and consider the cultural and religious beliefs of patients and their families when discussing ACP. Recognize that these factors may influence their values and preferences regarding medical care and end-of-life decisions.	Don't use excessive medical jargon or technical terms during ACP discussions. Ensure that information is communicated in a clear and understandable manner to facilitate informed decision-making.
Do provide patients and families with clear and accurate information about ACP, its purpose, and its potential benefits. Use plain language and ensure that they understand the process and available options for future healthcare decisions.	Don't assume that patients fully understand the ACP process or its implications. Encourage them to ask questions and clarify any doubts they may have, promoting their active participation in the decision-making process.
Do be prepared to spend as long as necessary to discover and record the patient's wishes.	Don't enter these conversations cold.

Do start the conversation by asking if the patient has any documents already prepared, has talked to anyone else about advance directives, and would be comfortable sharing how they feel.	Don't skip the documentation.
Do practice what to say and well prepare for the conversation (for example, by role-playing with a colleague).	Don't rush the conversation.
Do document that the conversation was voluntary, summarize what you discussed, explain advance directives, record the length of the conversation, and note who was present.	Don't feel pressured to have this conversation with every patient. Don't force the conversation if the patient isn't ready or needs time to reflect.

Table 6.1: Dos and don'ts of ACP facilitation and discussion

6.5. NAVIGATING CHALLENGING CONVERSATIONS

Effective communication lies at the heart of Advance Care Planning (ACP), enabling healthcare professionals to engage patients and their families in open and honest discussions about their healthcare preferences and goals. Such conversations may require challenging areas such as breaking bad news or setting goals of care in someone who is seriously ill. The following serve as guides for clinicians to navigate these discussions.

Serious Illness Conversations

Conducting a serious illness conversation requires sensitivity, empathy, and effective communication skills. The following serves as a general outline for conducting conversations with patients having serious health issues.

Steps	Example Phrases
Set the Stage	"Thank you for meeting with me today. I understand this is a difficult and sensitive topic to discuss. I want you to know that I'm here to support you throughout this conversation."
Assess Readiness	"Before we begin, I want to check if you feel ready to discuss your illness. It's important to proceed at a pace that you're comfortable with. Would you like anyone else to be present during our conversation?"
Deliver the Information	"I have received the test results, and unfortunately, it indicates that you have been diagnosed with [specific diagnosis]. Based on the information we have, the prognosis is [discuss prognosis]. I understand this news may be overwhelming, and I'm here to provide support and answer any questions you may have."

Use Empathetic Listening	"I can imagine this news might be difficult to process. Please take your time, and feel free to share any thoughts, emotions, or concerns you have. I'm here to listen and support you."
Address Questions and Concerns	"What questions or concerns do you have about your diagnosis or treatment options? I'll do my best to provide you with the information you need to make informed decisions and address any concerns you may have."
Offer Support and Resources	"I want to ensure you have access to the support you need during this time. We have a team of counselors available who can help you navigate the emotional aspects of your illness. Additionally, there are support groups and organizations that can provide additional resources and assistance. Would you like more information on these options?"
Collaborate on Care Planning	"Moving forward, it's important for us to consider your treatment options and how they align with your goals. Let's work together to develop a care plan that reflects your preferences and priorities. What factors are most important to you in terms of your quality of life and the treatment options available?"

Table 6.2: General Outline for Conducting Conversations with Patients Having Serious Health Issues

Breaking bad news

Breaking bad news is one of the most important components of communication that need to be done well. At the same, it can be one of the most uncomfortable parts of the communication that need to be carried out by the healthcare providers. Without knowledge or training on how to do it systematically, it can complicate the communication process and worst still, it leads to communication breakdown.

There are various protocols that are used to make the conversation more structured and objective for the healthcare providers. Below is the most widely used and taught protocol for serious news discussions:

SPIKES Protocol

Approach	Elaboration	Example Phrases
S - Set up the interview	Plan ahead to ensure a private and comfortable setting for the conversation.	"Let's find a quiet and comfortable place to talk."
	Determine if the patient wants significant others involved in the discussion.	"Would you like any family members or loved ones to be present during our conversation?"
	Ensure minimal distractions, such as silencing your pager or phone, to give full attention to the patient.	"I've silenced my phone, so we can focus on our discussion without interruptions."
P - Assess the patient's perception	Begin by asking open-ended questions to understand how the patient perceives their medical situation.	"What do you understand about your current medical condition?"

	Correct any misunderstandings the patient may have and tailor the news according to their understanding and expectations.	"I can see there might be some confusion, and I'd like to provide you with accurate information about your diagnosis."
I - Obtain the patient's invitation	Inquire about the patient's preference for receiving detailed information about their diagnosis and prognosis. Fire a "warning shot" before giving the information	"How much information would you like to know about your condition? Are you comfortable discussing the prognosis?" "I'm afraid things are more serious than expected."
K - Give knowledge and information to the patient	Use plain language and avoid medical jargon when delivering information to the patient.	"I'm sorry to tell you that the cancer has spread to other parts of your body."
	Provide information in small amounts, using short sentences, and periodically checking for the patient's understanding.	"The tests showed that the cancer has metastasized. This means it has spread to other organs. We will explain the treatment options in a moment, but please let me know if you have any questions so far."
E - Address the patient's emotions with empathic responses	Identify the primary emotion the patient is experiencing and acknowledge their feelings.	"I can imagine how scary this must be for you. It's completely normal to feel overwhelmed right now."
	Express empathy and understanding towards the patient's emotional response to the information received.	"I understand this is difficult news to process. It's okay to feel upset, and I'm here to support you."
S - Strategy and summary	Present treatment or palliative care options, aligning the information with the patient's knowledge, expectations, and hopes.	"Based on your diagnosis, there are a few treatment options we can consider. Let's discuss them together and find a strategy that suits your preferences and goals."
	Provide a clear summary of the discussion, addressing the patient's concerns and reducing anxiety and uncertainty.	"To summarize, we have talked about your diagnosis, treatment options, and the potential outcomes. I want to ensure you understand the plan moving forward, and we can make any necessary adjustments based on your preferences. Does this summary align with your understanding?"

Table 6.3: SPIKES Protocol

Common pitfalls of breaking bad news

- Lack of preparation
- Poor communication technique
- Insufficient privacy or setting
- Lack of empathy and emotional support
- Lack of clarity regarding prognosis or treatment options
- Failure to assess the patient’s understanding
- Inadequate follow-up and support

Clinicians should be aware of these pitfalls, healthcare professionals can approach the process of breaking bad news with greater sensitivity and effectiveness, helping patients and their families navigate difficult situations with more support and understanding

Goals of care discussion

The Goals of Care discussion is an approach within Advance Care Planning (ACP) that plays a crucial role in guiding conversations and decision-making to set a patient's healthcare goals and preferences. These discussions are essential for ensuring that medical care aligns with the patient's values, wishes, and desired quality of life. The REMAP framework provides a practical and comprehensive approach to facilitate meaningful discussions between healthcare providers, patients, and their families.

REMAP framework

Approach	Elaboration	Example Phrases
Reframe	Shifting the conversation to focus on the current situation and the need to discuss goals based on the current circumstances.	"A lot has happened since we last met and I wonder if we can talk a bit about where things are at the moment and how things have changed with regards to your condition.”
Expect emotion	Recognizing and addressing the emotional aspects of the discussion	"I understand that this is a difficult conversation. How are you feeling about discussing your healthcare goals?"
Map out patient goals	Exploring the patient's goals and aspirations related to their health and well-being	"What are your hopes and goals when it comes to your health? What does a good quality of life mean to you?"
Align with goals	Discussing treatment options and aligning them with the patient's goals and values	"Based on what we've discussed, I believe [treatment option] what you are saying is very sensible and I completely understand your wish to

		focus on maintaining independence and minimizing discomfort."
Propose a plan	Presenting a care plan tailored to the patient's goals and preferences	"Considering your values and priorities, I propose a care plan that includes [specific treatments] to support your well-being."

Table 6.4: REMAP framework

Discussing Resuscitation Orders / Do-Not-Resuscitate Orders

Initiating discussions for Do-Not-Resuscitate (DNR) orders can be difficult for healthcare providers for many reasons. Some of the commonly reported barriers are listed below:

- Fear of taking away hope from the patient
- Medical culture is focused on cure and preventing death
- Inadequate training in communication skills
- Healthcare provider’s unresolved feelings about death and dying
- Fear of litigation and complaints

Although DNR discussions are challenging, there are methods of making these conversations more acceptable.

- Never discuss the issue of DNR in isolation. It should always be part of a wider discussion on prognosis and goals of care.
- Discuss broader treatment options with an emphasis that care will be ongoing and directed towards comfort, improving quality of life and maintaining dignity. DNR should never mean “doing nothing”.
- Include the participation of family and surrogate decision makers. Patient and family members felt better supported and satisfied with end of life care when included in DNR discussions.
- DNR discussions should preferably be done in non-acute or outpatient settings. This is to allow for a more conducive environment and at a time when the patient's condition is less vulnerable.
- The discussion should be preferably done by an HCP with whom they have a strong and trusting relationship.
- Conversation starters can be helpful to initiate conversation without feeling being confronted e.g. “When I take care of patients with advanced cancer, I like to talk with them about their wishes regarding resuscitation. Is that alright?”
- Avoid any form of jargon and use simple language.

Approach	Elaboration	Example Phrases
Exploration	● Begin the discussion with an introduction	"Today, we would like to discuss your current health status and future care."
	● Understand the patient's current understanding	"How would you describe your understanding of your medical condition?"
	● Inquire about existing advance care plans	"Have you documented any advance care preferences or directives?"
	● Review the current treatment plan	"Let's go through your current treatment approach to ensure we are all on the same page."
Explanation	● Correct any misunderstandings	"Based on your test results, it seems important to discuss the expected course of your illness."
	● Discuss benefits and burdens of resuscitation	"Resuscitation may not be recommended due to the advanced stage of your disease."
	● Explain alternatives for promoting comfort and quality of life	"Instead, we can focus on interventions that enhance your comfort and well-being."
	● Reassure the patient about the meaning of a DNR order	"Having a Do-Not-Resuscitate (DNR) order does not mean we will stop providing other necessary medical care."
Address Conflict	Facilitate open and respectful communication	"Let's take turns sharing our perspectives and concerns while listening attentively to one another."
Documentation	● Document details and outcome in patient's records	"I will make sure to accurately record our discussion in your medical file for future reference."
	● Share details with the medical team	"I will provide a summary of our conversation to ensure everyone involved in your care is informed."

Table 6.5: General Principles of DNR Discussion

Addressing conflict in family

Addressing conflict within families during Advance Care Planning (ACP) discussions can be challenging but important for ensuring that the patient's preferences are respected. There are some strategies for addressing conflict:

Strategies / Approaches	Elaboration	Example
Foster a supportive and neutral environment	Create a safe space for open communication, where family members feel respected and heard. Act as a neutral facilitator, encouraging everyone to share their perspectives without judgment.	"Let's create an environment where everyone feels comfortable expressing their thoughts and concerns. I will ensure that each person has an opportunity to speak and be heard without interruptions."
Clarify misunderstandings and concerns	Address any misunderstandings or misconceptions about ACP.	"It seems there might be some misunderstandings about ACP. Let's take the time to address any concerns and clarify any misconceptions that may exist. I am happy to listen”
Acknowledge and validate concerns	Allow each family member to express their concerns and fears, and validate their emotions.	“I can certainly see why something like this would upset you” “I can see how much you love your father and thinking about this can’t be easy”
Engage a neutral third party (4)	If conflicts persist, consider involving a trained mediator, social worker, or healthcare ethics consultant to facilitate the discussion and help find common ground.	"If we find it difficult to reach a resolution, we can invite a neutral third party, such as a trained mediator, who can provide guidance and help us navigate through any conflicts that arise."
Provide education and information (5)	Offer educational materials or information about ACP to help family members better understand its purpose, benefits, and importance. Share resources that explain different perspectives and options related to end-of-life care.	"Here are some resources that provide valuable information about ACP. They can help us gain a better understanding of the process and the various options available. Let's take the time to review and discuss them together."

Table 6.6: Strategies for Addressing Conflict Within Families During Advance Care Planning (ACP) Discussions

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CHAPTER 7: ACP DOCUMENTATION

7.1 INTRODUCTION

Although not compulsory, some means of documenting a person's wishes of any advance care plan is preferred so that it can be shared with other family members and loved ones; can be communicated to healthcare providers, and can be recalled, altered or even removed totally if or when needed.

The need for documenting a decision should never override the importance of having an advance care planning discussion. This is primarily because such decision often need time, further reflection or more consideration.

7.2 AREAS TO CONSIDER IN DOCUMENTATION OF ACP

Individual Perception to Quality of life

This involves the individual's perception of well-being and satisfaction in life. These relate to physical health, mental and emotional well-being, social relationships, material well-being, personal fulfilment, environmental factors and cultural and spiritual considerations.

Statement of wishes / Expression of concerns

A statement of wishes in an advanced care plan refers to a written document or section within an advance care planning (ACP) document where individuals express their personal preferences, values, and instructions regarding their future healthcare and end-of-life care.

Communication with healthcare providers

The statement of wishes can include instructions on how individuals want their preferences to be communicated and shared with their healthcare providers. They can specify whom they want to be involved in their decision-making process and designate a healthcare proxy or durable power of attorney for healthcare, if applicable.

Treatment options

Individuals can outline their preferences for various treatment options and interventions, including specific medical procedures, medications, resuscitation efforts, mechanical ventilation, artificial nutrition and hydration, and palliative care. They can indicate which treatments they would like to receive or avoid under different circumstances and this is called the Preferences for Life Sustaining Treatment (POLST).

Spiritual and cultural considerations

Different religions emphasize different principles, such as the sanctity of life, compassionate care, preservation of life, reducing suffering, and acceptance of the divine will. ACP discussions within religious contexts may involve considerations of medical interventions, palliative care, family involvement, spiritual support, rituals, and cultural customs.

Ultimately, ACP is about honouring an individual's autonomy, dignity, and wishes. By incorporating religious beliefs and values into the ACP process, individuals can find comfort, support, and spiritual guidance in making decisions that reflect their faith and provide a sense of peace and meaning during challenging times.

Social support

Individuals can consider their preferences for family involvement, support from friends, or engagement with social networks and community resources. Recognizing and honouring the individual's desire for companionship, visits, or communication can significantly contribute to their well-being. It would also be useful to have at least one or two named individuals as preferred contact persons.

Care setting

An individual preference for the location of care. This may involve decisions about receiving care at home, in a hospice facility, long-term nursing care facility or in a hospital. Considering the individual's comfort, safety, and access to the necessary support and services is essential when determining the most appropriate care setting.

7.3 DOCUMENT TEMPLATE

The document below is a sample template of an ACP documentation form that may be used for easy reference following an ACP discussion.

The section on POLST should be filled by a clinician while the initial area on values, strength, contentment and wishes may be filled by the patient or surrogate after a discussion has been facilitated.

The patient’s signature at the end does not make the document legally binding; however, it is a verification that the details in the document are truly that of the patient’s.

Advance Care Planning (ACP)

ACP Everybody for ME

Advance Care Planning Conversations and Documentations

Values, Strength and Contentment

[These are important for me; that give my life meaning]

[At this stage of my life, these give me strength]

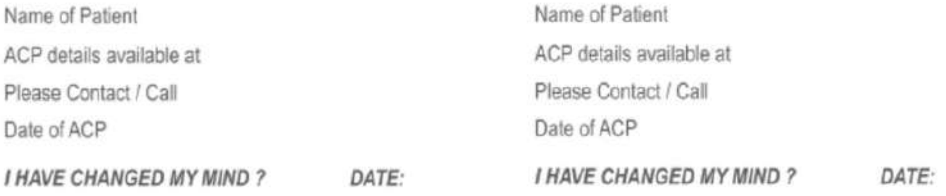
[These are situations that make me happy and content]

Preferences and Wishes

[These are worries that I concern me now]

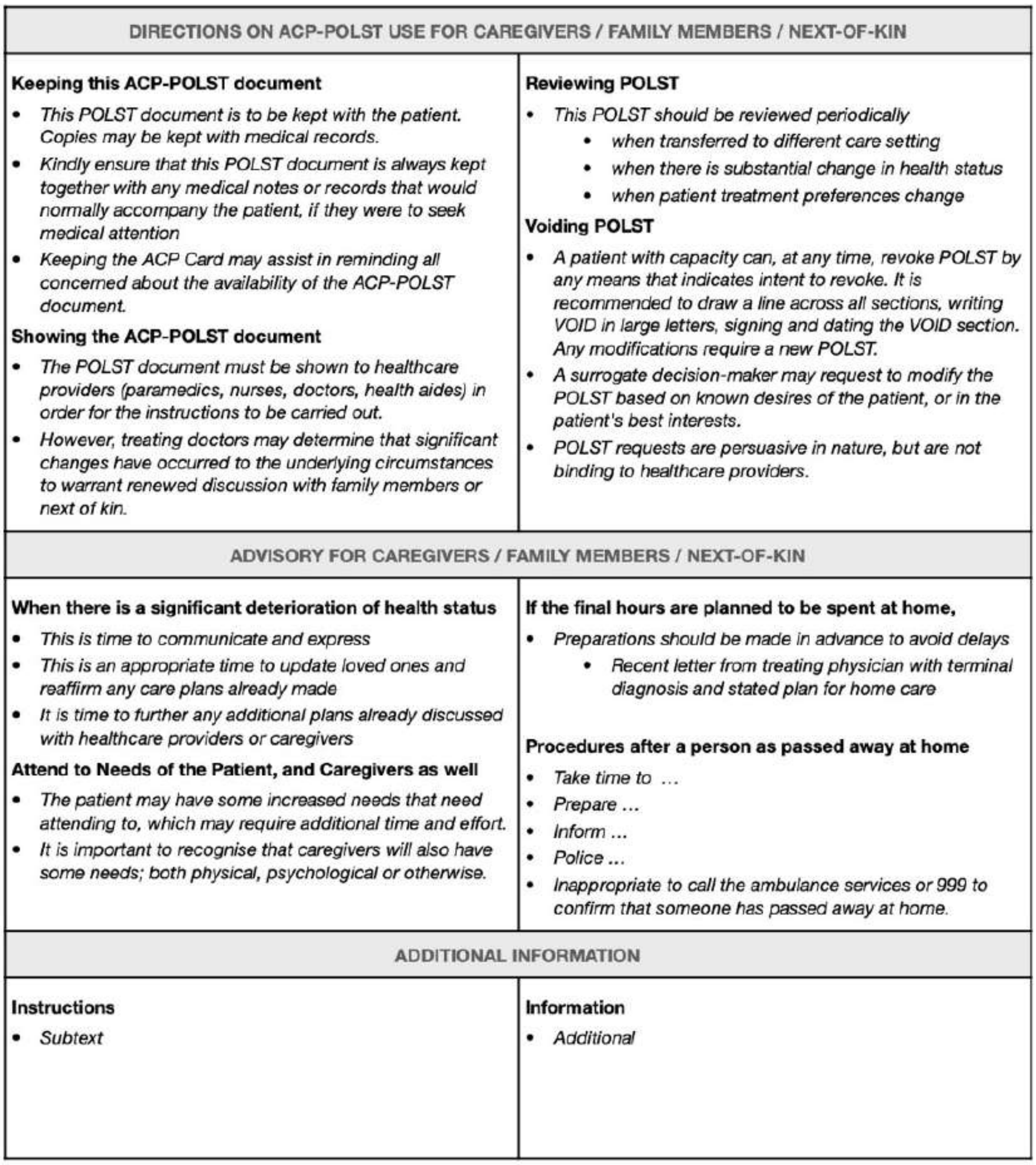
[These are situations which I would want to avoid, if possible]

[This is why I'm writing this down]



Name of Patient
ACP details available at
Please Contact / Call
Date of ACP
I HAVE CHANGED MY MIND ? ***DATE:***

Name of Patient
ACP details available at
Please Contact / Call
Date of ACP
I HAVE CHANGED MY MIND ? ***DATE:***



DIRECTIONS ON ACP-POLST USE FOR CAREGIVERS / FAMILY MEMBERS / NEXT-OF-KIN

Keeping this ACP-POLST document

- *This POLST document is to be kept with the patient. Copies may be kept with medical records.*
- *Kindly ensure that this POLST document is always kept together with any medical notes or records that would normally accompany the patient, if they were to seek medical attention*
- *Keeping the ACP Card may assist in reminding all concerned about the availability of the ACP-POLST document.*

Showing the ACP-POLST document

- *The POLST document must be shown to healthcare providers (paramedics, nurses, doctors, health aides) in order for the instructions to be carried out.*
- *However, treating doctors may determine that significant changes have occurred to the underlying circumstances to warrant renewed discussion with family members or next of kin.*

Reviewing POLST

- *This POLST should be reviewed periodically*
    - *when transferred to different care setting*
    - *when there is substantial change in health status*
    - *when patient treatment preferences change*

Voiding POLST

- *A patient with capacity can, at any time, revoke POLST by any means that indicates intent to revoke. It is recommended to draw a line across all sections, writing VOID in large letters, signing and dating the VOID section. Any modifications require a new POLST.*
- *A surrogate decision-maker may request to modify the POLST based on known desires of the patient, or in the patient's best interests.*
- *POLST requests are persuasive in nature, but are not binding to healthcare providers.*

ADVISORY FOR CAREGIVERS / FAMILY MEMBERS / NEXT-OF-KIN

When there is a significant deterioration of health status

- *This is time to communicate and express*
- *This is an appropriate time to update loved ones and reaffirm any care plans already made*
- *It is time to further any additional plans already discussed with healthcare providers or caregivers*

Attend to Needs of the Patient, and Caregivers as well

- *The patient may have some increased needs that need attending to, which may require additional time and effort.*
- *It is important to recognise that caregivers will also have some needs; both physical, psychological or otherwise.*

If the final hours are planned to be spent at home,

- *Preparations should be made in advance to avoid delays*
    - *Recent letter from treating physician with terminal diagnosis and stated plan for home care*

Procedures after a person as passed away at home

- *Take time to …*
- *Prepare …*
- *Inform …*
- *Police …*
- *Inappropriate to call the ambulance services or 999 to confirm that someone has passed away at home.*

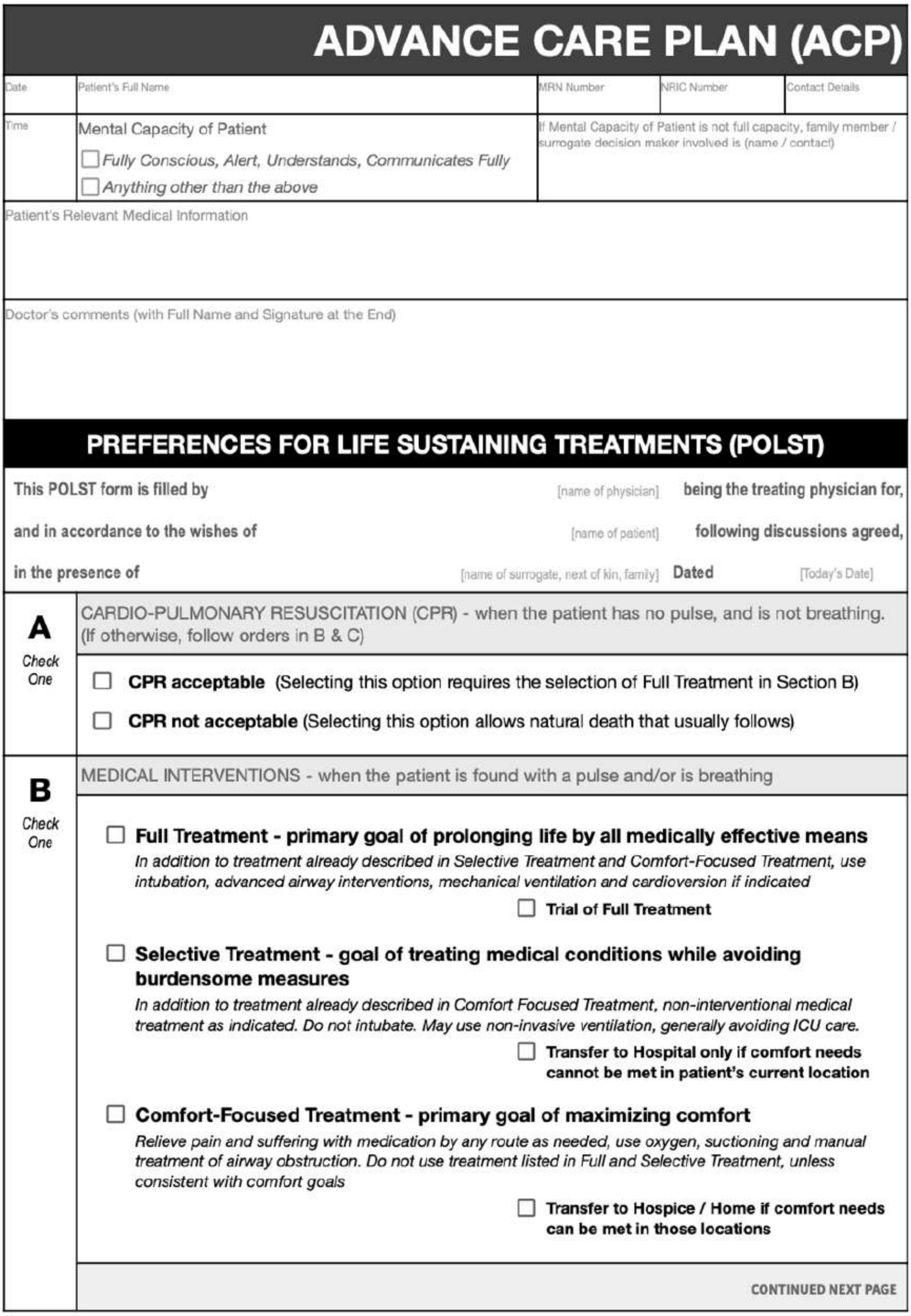
ADDITIONAL INFORMATION

Instructions

- *Subtext*

Information

- *Additional*



ADVANCE CARE PLAN (ACP)

Date	Patient's Full Name	MRN Number	NRIC Number	Contact Details
Time	Mental Capacity of Patient ☐ *Fully Conscious, Alert, Understands, Communicates Fully* ☐ *Anything other than the above*	If Mental Capacity of Patient is not full capacity, family member / surrogate decision maker involved is (name / contact)		

Patient's Relevant Medical Information

Doctor's comments (with Full Name and Signature at the End)

PREFERENCES FOR LIFE SUSTAINING TREATMENTS (POLST)

This POLST form is filled by [name of physician] **being the treating physician for,**

and in accordance to the wishes of [name of patient] **following discussions agreed,**

in the presence of [name of surrogate, next of kin, family] **Dated** [Today's Date]

A

Check One

CARDIO-PULMONARY RESUSCITATION (CPR) - when the patient has no pulse, and is not breathing. (If otherwise, follow orders in B & C)

☐ **CPR acceptable** (Selecting this option requires the selection of Full Treatment in Section B)

☐ **CPR not acceptable** (Selecting this option allows natural death that usually follows)

B

Check One

MEDICAL INTERVENTIONS - when the patient is found with a pulse and/or is breathing

☐ **Full Treatment - primary goal of prolonging life by all medically effective means**
In addition to treatment already described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation and cardioversion if indicated

☐ **Trial of Full Treatment**

☐ **Selective Treatment - goal of treating medical conditions while avoiding burdensome measures**
In addition to treatment already described in Comfort Focused Treatment, non-interventional medical treatment as indicated. Do not intubate. May use non-invasive ventilation, generally avoiding ICU care.

☐ **Transfer to Hospital only if comfort needs cannot be met in patient's current location**

☐ **Comfort-Focused Treatment - primary goal of maximizing comfort**
Relieve pain and suffering with medication by any route as needed, use oxygen, suctioning and manual treatment of airway obstruction. Do not use treatment listed in Full and Selective Treatment, unless consistent with comfort goals

☐ **Transfer to Hospice / Home if comfort needs can be met in those locations**

CONTINUED NEXT PAGE

<table>
<tr><td></td><td colspan="4">Medical Interventions that would be considered <u>unacceptable</u> (eg tube feeding, dialysis etc)</td></tr>
<tr><td>Outcome
Hospitalization
Interventions
Location of Care
Symptom Relief
Nursing Care
Others
Others</td><td colspan="4">PREFERRED PLAN OF CARE (condition-specific planned limits to medical interventions, as discussed and agreed with treating physicians) - <i>Signed and Stamped by Treating Physician at the End</i> -</td></tr>
<tr><td>Prognosis
Informing others
Ambulance
Home prep
Hospitalization ?
Prefer location
Symptom Relief
Care by ?
Others
Others</td><td colspan="4">If significant changes in medical status occurs, these plans as stated shall apply (discussed with treating and palliative physicians) - <i>Signed and Stamped by Physician at the End</i> -</td></tr>
<tr><td rowspan="2">X
<i>To VOID</i></td><td colspan="4">VOID or CHANGE OF MIND - Please check / mark to indicate change of mind or void this copy of the POLST form.</td></tr>
<tr><td>Discussed with (check at least one)
Name
☐ <i>Patient</i>
☐ <i>Surrogate / Next of Kin / Family Member / Loved one</i>
☐ <i>Healthcare Provider</i></td><td>Contact Details</td><td>Date (Mandatory)</td><td>Signature</td></tr>
</table>

Photocopies and faxes of signed POLST forms are valid. Healthcare providers may make copies for records.

DIRECTIONS FOR HEALTHCARE PROFESSIONALS

Completing ACP - POLST

- *This is generally meant for those with illness or frailty.*
- *Completing the POLST form is always voluntary.*
- *The POLST must be completed by a physician based on the medical condition and patient's preferences.*
- *POLST must be signed to be valid.*

Using POLST

- *A POLST can be regarded as a professional communication of the patient's wishes from a fellow healthcare provider to another.*
- *Although not legally binding, most consider an ACP legally persuasive.*
- *As long as mental capacity is not in question, the most recent POLST replaces all previous orders.*
- *In situations where the POLST itself is incomplete or vague, some guidance may come from surrogate decision makers, family members or portions of the ACP which communicate the intentions of the patient.*

Reviewing POLST

- *This POLST should be reviewed periodically*
  - *when transferred to different care setting*
  - *when there is substantial change in health status*
  - *when patient treatment preferences change*

Voiding POLST

- *A patient with capacity can, at any time, revoke POLST by any means that indicates intent to revoke. It is recommended to draw a line across all sections, writing VOID in large letters, signing and dating the VOID section. Any modifications require a new POLST.*
- *A surrogate decision-maker may request to modify the POLST based on known desires of the patient, or in the patient's best interests.*
- *ACP-POLST documents that are voided should be informed to healthcare providers, so that medical records that keep voided copies can be updated as void, and any new ACP-POLST documents are updated and kept.*

FORM IS KEPT WITH PATIENT - SEND COPIES WHENEVER TRANSFERRED OR DISCHARGED

Table 7.1: Practical approach on how to conduct ACP discussion in patients with chronic illness

Approach	Example of key Phrases and issues to discuss
Step 1: Introducing ACP and assessing readiness for discussion (This should be done after a conversation on the disease process and possible prognosis)	● "Given our earlier discussion, I wonder if you have any concerns, especially about your future care?" ● "Some patients find it useful to have a discussion about how they would want to be cared for in the future in case there is a time when they become too unwell to speak. Do you think you would find something like that useful?"
Step 2: Assess values, strength and contentment (This allows decision makers to understand a person's possible choices better)	● "Perhaps we can start by just thinking about what gives you meaning in life?" ● Prompt person to think of a) relationships b) meaningful activities c) religion/beliefs d) past memories ● "Think of a time in your life when you were down or having a lot of difficulties, what gave you strength to go on at that time?"
Step 3: Assess preferences and wishes (Ask about 1. Worries and concerns 2. Situations to avoid)	● "Given the fact that you have such an illness, are there any fears or worries you have in particular?" ● "What do you feel is most important to you at this point in your life?" ● Prompt person to consider: a) symptoms and comfort issues b) important events c) social/financial concerns d) family issues ● "In terms of your future care, if at some point you were very unwell to a point you were unconscious, are there any situations or particular procedures you would want to avoid?" ● Prompt with examples: Tube feeding, dialysis, invasive ventilation etc ● In general, this section could be filled up by the patient themselves once they understand what to reflect upon as it may be quite personal in nature.
Step 4: Discuss preferences for life sustaining treatments in acute medical events. (POLST) Part A & B (this follows further from discussion about situations to avoid)	● "So, if your illness were to get worse to a point where your heart became so weak to a point where it stopped beating, would you want doctors to attempt resuscitation/CPR?" ● "If you were to become more unwell to a point where you were unconscious and you are brought to hospital, would you want the doctors to do everything they can to make you survive even if your quality of life may be poor?" ● If a person does not want full treatment then explore if they are open to selective treatments with examples of IV antibiotics, IV fluids, non-invasive ventilation etc. (as you describe examples,

	if patient says no this can be recorded as unacceptable interventions. ● If a person says they want comfort measures only, then confirm that they would want minimum interventions including reducing injections and blood taking and only accept measures that provide comfort. ● Finally, “are there any other interventions that you would consider unacceptable if you were very sick to a point where you could not speak” (generally if a person is unsure if they would find an intervention unacceptable you should not document it as such.
Step 5: ● Preferred plan of care	● This section is meant to address care plans for the individual patient based on the unique circumstances of their health condition e.g. Discussion on ICD deactivation in cardiac disease or PEG feeding in motor neuron disease etc. ● Basically, this section outlines some broad goals of care and requires the clinician to discuss relevant issues that are commonly anticipated in a particular disease process. ● Towards the end of this discussion would be to explicitly ask about preferred place of care and possibly death if very ill eg. “If you were very ill and unconscious with slim chances of recovery, where would you prefer to be cared for? At home, hospital or nursing home ● “And if you were facing your last moments of life, where would you prefer to be as you pass on?”
Step 6: Naming a surrogate decision maker	● “While we have discussed quite a bit about your preferences, it is impossible to discuss every possibility that may occur in the future so it may be necessary for your doctors to still discuss your health matters with a family member or a close friend of yours who is able to speak on your behalf in case you are unable to do so yourself. Can you think of who you would like to be that person to speak on your behalf?” ● “And in case this person is unable to be reached at the time, can you think of a second person you would like to nominate to speak on your behalf?”
Step 7: Wrapping up	● “So, I have recorded our discussion here so that you can also let your family know about this and remember that this is merely a conversation about how you feel and it is not something that MUST be followed at all times. People change their minds all the time and situations are never exactly as we imagine it. What is important is that we have had this conversation and you have an idea now of how you feel.”

CHAPTER 8: PALLIATIVE CARE AND SUPPORTING PATIENTS AT THE END-OF-LIFE

Key Learning Points:

- Palliative and supportive care must always be provided when patients choose to forgo or are unable to undergo aggressive interventions towards the end-of-life.
- When a person is diagnosed to be dying, it is imperative that this information is conveyed to the family and loved ones compassionately.
- Pain, dyspnoea, restlessness/delirium, nausea/vomiting and terminal secretions are key symptoms to address at the end-of-life.
- Euthanasia is illegal in Malaysia and cannot be requested as part of an ACP.
- Use of sedation and withholding/withdrawing life-sustaining treatments is NOT an act of euthanasia and is ethically permissible.

8.1 INTRODUCTION

Advance care planning is a process of making individual choices for a future time when faced with serious illness. The reason for this process is because under certain circumstances particularly in people with life-limiting conditions and the frail elderly, aggressive medical interventions may not be in their best interest as it cannot be guaranteed that these interventions will provide a positive outcome and there are definite risks that some interventions may lead to increased suffering and poorer outcomes.

When patients make choices in their ACP to withhold or to withdraw certain medical interventions that are deemed not to be in their best interest, they are essentially making a choice to forgo aggressive treatments and are explicitly choosing the alternative to be more comfortable and to have more dignified care. That alternative is defined as palliative care. Therefore, if people are made to believe that they have such choices available to them during an ACP discussion, then it is imperative that the option of palliative care should be made accessible to every person who expresses this choice.

In summary, the development of an ACP programme within a healthcare system, should always be accompanied with the development of universal access to palliative care. This is in keeping with the WHO definition of Universal Health Coverage (UHC).

8.2 CARE NEEDS AT THE END-OF-LIFE

There are 4 basic components of care required for every person who is facing the end-of-life:

1. Prognostication and diagnosing dying
2. Compassionate communication with family
3. Symptom management in the terminal phase
4. Ethical decision making at the end-of-life

These components of care should be skills that all clinicians should be equipped with similar to how CPR is considered a basic skill that all healthcare professionals should know.

8.3 PROGNOSTICATION & DIAGNOSING DYING

Diagnosing dying is the process of prognosticating the last few days to 1-2 weeks of life. This is often possible when clinicians are familiar with disease processes and their natural trajectories along with recognising typical signs of dying. It is a key element in providing good end-of-life care as:

- **Allows appropriate communication regarding death and dying with the family**
  - To help them anticipate death and problems leading up to death
  - Reduce anxiety
  - Allow pre-emptive bereavement
- **Allows discussion on end-of-life choices**
  - Desired place of death
  - Avoiding medically futile interventions (CPR, ventilation)
- **Allows medical team to re-prioritise goals of care**
  - Ensure good symptom control
  - Minimise investigations, procedures and futile therapies

System / Function	Signs of dying
General performance	Reducing performance status ● Increasingly weak till bed-bound ● Generalised weakness in all muscles ● Unable to self-care
Cognitive functions	Decreasing cognition ● Increasingly lethargic ● May become confused and delirious ● Reversed sleep pattern ● Finally unresponsive.
Respiratory	Changes in respiratory pattern ● Cheyne-stokes breathing ● Deep sighing respiration ● Apnoeic phases ● Mandibular breathing ● Terminal secretions

Oral intake	Reducing oral intake till only able to take sips of fluid with frequent aspiration.
Circulatory system	Reduced systemic perfusion ● Cool peripheries ● Pulseless radial arteries ● Peripheral Cyanosis ● Mottling of skin

Table 8.1: Typical signs of dying

8.4 COMPASSIONATE COMMUNICATION WITH THE FAMILY

Once a patient has been diagnosed to be dying, it is essential that an appropriate and compassionate explanation regarding this diagnosis is broken to the family. Often, even when doctors have diagnosed the patient to be in the dying phase, nothing is explained to the family as there are fears that the family will become emotional. This however leads to even more shock and distress to the family when the patient ultimately passes on as family have no forewarning to anticipate death and pre-emptive bereavement does not happen.

If you know the patient is dying,
ENSURE that the family knows it as well.

Having a conversation with the family to inform them that their loved one is in a terminal phase is generally a breaking bad news scenario and a discussion about prognosis and goals of care all in one. The skills involved have been highlighted in the communication chapter.

Important points to remember when conducting such conversations:

- Always listen carefully for opportunities to discuss the patient's poor prognosis with the family, which may be when the family asks, "How is my relative/father/wife… doing?"
- Show empathy by using a serious but compassionate tone of voice and facial expressions that give a kind but sad impression.
- Use empathic statements such as "I know how hard it must be to see him like this" or "I know how much you love her and the thought of losing her must be so painful"
- When dealing with uncertainty use the "Hope – Worry" statement. E.g. "I hope he will respond to the treatments but I worry he is just too weak and will only get worse."
- When explaining that the patient is dying, be direct and use phrases like "I am sorry to have to say this but he is really sick enough to die."

8.5 SYMPTOM MANAGEMENT IN THE TERMINAL PHASE

In the terminal phase, the following are important principles of management:

- **Continuous symptom management** for pain, dyspnoea, nausea even when unresponsive.
- **Assessment using non-verbal cues**– facial expressions, respiratory rate and patterns, vomiting and bowel movements.
- **Minimise medications** - only essential drugs for comfort. Cease futile medications (ie. Aspirin, omeprazole, ACE-I)
- **Subcutaneous route** - Alternative route to administer medication as oral intake declines.
- **Frequent review** - drug chart and patient as things may change rapidly in the terminal phase.
- **Frequent communication** - update family as condition progresses and changes in treatment.
- **Anticipate problems** - forewarn family and tell them what they may expect.
- **Discuss issues early** - dispel misconceptions regarding drugs and issues of hydration/nutrition

There are 5 main physical symptoms to commonly address at the end of life. This includes:

1. Pain
2. Dyspnoea
3. Nausea / vomiting
4. Delirium and Restlessness
5. Terminal secretions

8.5.1 PAIN

Pain relief must be continued in all patients who were previously treated for chronic pain even though they are approaching the end-of-life and are less responsive. It is proven that even patients in a minimally conscious state will still feel pain and so pain relief must always be maintained till the end-of-life.

When patients are unable to swallow oral medications, alternative routes of administration must be applied. In the palliative care setting, the subcutaneous route is the simplest and safest route. The dose of morphine should be halved when converting from oral to injection morphine. Subcutaneous morphine may be administered as intermittent 4-6 hourly dosing or as a 24h continuous infusion. Alternatively, conversion to transdermal fentanyl may also be considered for patients who are unable to swallow oral medications.

*(*please refer to cancer pain CPG or Pain Free Programme guidelines for more details)*

8.5.2 DYSPNOEA

As patients approach the end-of-life, dyspnoea can occur for various reasons including poor perfusion, fluid overload, metabolic acidosis, weak respiratory muscles or progressive lung disease. Management of dyspnoea at this point may often involve using opioid medication such as morphine or fentanyl to relieve the sensation of dyspnoea.

The dose of morphine for dyspnoea may initially be lower than that used to treat pain. In opioid naïve patients' doses of morphine are as below:

- **Able to swallow:**
    - Aq morphine 2-3mg 6-8 hourly and PRN
    - Gradually titrate to 4 hourly and prn.
- **Unable to swallow or very ill:**
    - SC morphine 1-2 mg 6-8 hourly and prn. Gradually titrate to 4 hourly and prn.
    - May use continuous SC/IV infusion 10-15mg/24 hours
- **Renal impairment:**
    - Use SC fentanyl infusion 4 mcg/h with SC morphine 1 mg prn for severe renal impairment (eGFR < 30mL/min).
    - Increase fentanyl infusion by 2mcg/h every 6 hours till the patient is comfortable or till a maximum of 12 mcg/h.

8.5.3 NAUSEA / VOMITING

Nausea and vomiting may be experienced in the terminal phase for a variety of reasons such as gastroparesis, metabolic derangements, sepsis or uraemia.

It may not always be possible to address the underlying cause hence if patients are assessed to be distressed with symptoms of nausea or vomiting, antiemetic medications that cover the underlying causes broadly would be the choice of management.

- If gastroparesis is suspected, IV/SC metoclopramide 10mg prn would be an appropriate medication.

- For more persistent nausea and vomiting particularly from metabolic derangements or uraemia, SC haloperidol 1-3 mg as a single dose per day is often sufficient.

  **Low dose haloperidol acts on dopamine receptors in the vomiting centre of the brain which can reduce sensation of nausea and vomiting.*

8.5.4 TERMINAL DELIRIUM AND RESTLESSNESS

As a patient enters the terminal phase, the body generally deteriorates and begins to shut down. This process may lead to a decline in cognitive functions and patients may often develop delirium. Certain causes such as sepsis, hypoglycaemia, constipation, electrolyte imbalance and drugs may worsen delirium however the reversibility of these in the terminal phase may not always be feasible. In this situation, clinicians need to determine if the delirium is reversible or not and if it is not reversible, measures should be taken to keep the patient calm and relaxed if there are elements of hyperactive delirium leading to distress.

Family should be informed about what is happening to the patient as this can be a difficult situation for them to accept as the patient may be very confused, restless and behave oddly which may cause a lot of distress to the family seeing their loved one in this manner.

If the patient is confused and delirious which is distressing, the use of an antipsychotic such as haloperidol would be the choice of pharmacological management to address this:

- SC haloperidol 0.5 - 1 mg ON and prn every 30 mins till patient settles.
- Regular night dose may be increased by 1-2 mg depending on the number of prn doses.
- Most patients will not require more than 5mg in 24 hours.

When patients are very restless, sedatives such as midazolam would be helpful to reduce the restlessness and prevent complications such as seizures.

- IV midazolam 0.5-1 mg every 5-10 mins till calm.
- SC midazolam 2.5mg prn
- Consider continuous SC infusion when restlessness is persistent and distressing.
    - SC infusion midazolam 10-20 mg over 24 hours and 2.5mg prn

8.5.5 TERMINAL SECRETIONS

This is a condition also known as “death rattle”. It is a sign that inevitably heralds the last few days or short days of life. It commonly sounds like chesty secretions and may at times be mistaken for acute pulmonary oedema. Clinicians should know how to recognise this so as to prevent inappropriate management such as unnecessary chest x-rays, IV antibiotics and suctioning.

The key to diagnosing terminal secretions is to first diagnose dying hence the sound of such secretions in a patient diagnosed to be dying would likely be due to terminal secretions.

Family members are often distressed when they hear the sound of terminal secretions because they have the impression that this causes patients to be distressed and are "drowning" in their secretions. It is important to explain to them that this is a natural process of dying and it is due to a layer of secretions that pools in the airways and causes a noisy vibration as air passes through but does not cause dyspnoea to the patient. It is also important to explain that suctioning too deep will not help reduce the sound but will only cause distress in the patient.

Management of terminal secretions:

- Explanation and reassurance to the family.
- Gentle positioning of the patient may sometimes help.
- Pooled secretion in the oral cavity may be suctioned gently but avoid deep pharyngeal suctioning.
- If secretions persist, anticholinergic medication such as hyoscine butylbromide (buscopan) as a SC infusion of 60-240 mg over 24 hours may be considered. Alternatively, sc glycopyrrolate 200-400 mcg tds may also be used.

8.5.6 ANTICIPATORY MEDICATIONS FOR SYMPTOM CRISIS

As patients continue to deteriorate in the terminal phase, it is important to recognise that symptoms can at times escalate and anticipating these symptoms with a prescription of medications to be used when necessary is important to ensure continuous comfort till the very end of life. These medications which can be used in a crisis with escalating symptoms includes:

Symptoms	Treatment
Pain and dyspnoea	s/c Morphine (1/6 of 24h dose)
Nausea / vomiting	s/c Haloperidol 0.5-1mg prn
Restlessness / agitation	s/c Midazolam 2.5-5mg prn s/c Haloperidol 0.5-1mg prn
Death rattle / secretions	s/c Buscopan 20mg prn s/c Glycopyrollate 200mcg prn

Table 8.2: Anticipatory Medications for Symptom Crisis

8.6 ETHICAL DECISION MAKING AT THE END-OF-LIFE

When managing patients at the end-of-life, it is still very important to be mindful of the ethical principles of good medical practice and bioethics to ensure that patients are always treated based on the best ethical practices and appropriate decision making.

While one of the earliest principles of medical ethics includes the sanctity of life doctrine where it is said that all human life has worth and actions that end life directly or indirectly are wrong regardless of quality of life, in the era of modern medicine, the principle of preservation of life at all costs with no consideration to quality of life is questionable. This is where the practice of withholding and withdrawing life-sustaining treatments has already been discussed.

Another area of end-of-life care that must be clearly understood is regarding the role of hydration and nutrition in the dying patient and the role of opioids and sedating medications at the end-of-life. Clinicians may often struggle with these situations as they may have concerns that such management may hasten death and will approximate the act of euthanasia. This is where it is extremely important that clinicians are clearly informed about what is and is not considered euthanasia.

8.6.1 THE ROLE OF HYDRATION AND NUTRITION IN THE DYING PATIENT

In a Cochrane systematic review of assisted hydration and nutrition for adult palliative care patients, it was reported that at present there were no randomised control trials in this area to make evidence-based recommendations. It did however note that there were numerous non-controlled trials that had observed the role of artificial feeding using feeding tubes in the seriously ill.

Based on the evidence at hand, the majority of studies revealed that artificial nutrition did not provide any survival advantage for patients who were actively deteriorating and dying from serious illnesses. The survival advantage was only apparent in patients with neurological dysfunction in coma or with inability to swallow. In patients with organ failures or active deterioration from cancer or dementia, tube feeding generally does not provide a survival advantage.

It is known however that tube feeding in patients who are seriously ill may be associated with multiple complications which often lead to poorer quality of life and reduced survival as it can cause pain, nausea/vomiting, aspiration pneumonia and reduced dignity.

In fact, a syndrome documented as the tube feeding death spiral which is described as a triad of a dying patient with poor oral intake who is forced fed with a nasogastric tube which then leads to restlessness, the use of restraints and ultimately aspiration pneumonia, hypoxemia and death.

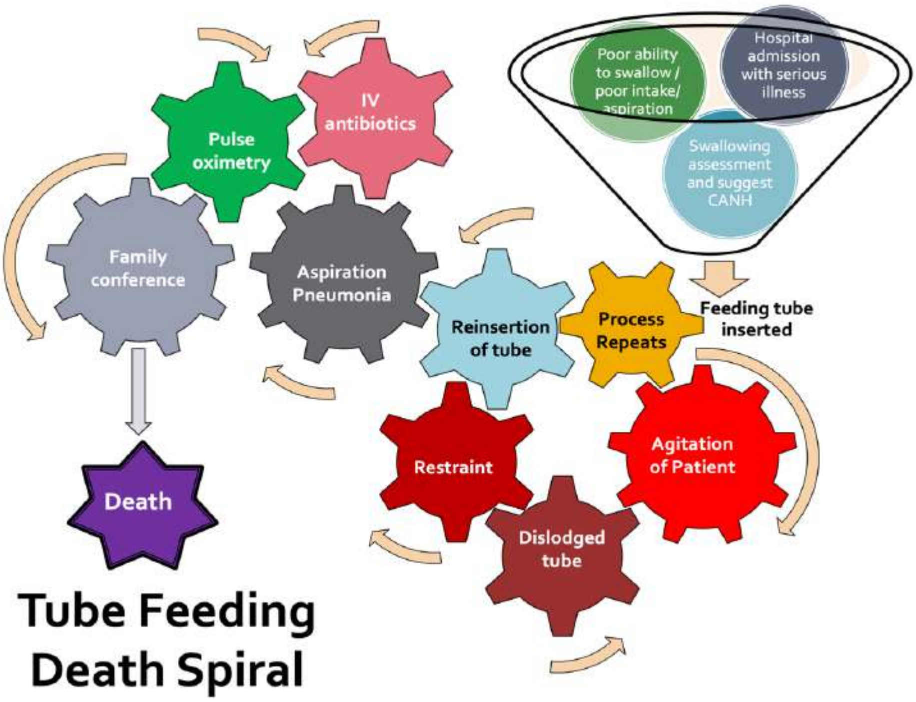


Figure 8.3: Tube Feeding Death Spiral

Generally, when a patient is at the last days to short weeks of life and has difficulty in feeding,

this is a marker of the dying phase and nutritional interventions do not play a significant role.

Explain the following to address family's concerns about nutrition and hydration:

- Patients in the dying phase would not feel hungry as often the gastrointestinal system is slowing down and they may actually feel more nausea with tube feeding.
- Patients do not deteriorate due to the lack of nutrition but due to the underlying disease. This is a natural process and more nutrition cannot reverse the process.
- Maintaining good mouth care for the patient provides relief from dry mouth and sensations of thirst.
    - Use a simple spray bottle filled with water to moisten the mouth regularly.
    - Ice-chips can be placed in the mouth to slowly melt.
    - Clean the mouth gently with a swab and sodium bicarbonate solution

8.6.2 USING SEDATION AT THE END-OF-LIFE

When patients are in a terminal state, restlessness and hyperactive delirium may occur. In such cases, the use of sedative medications may be necessary to provide comfort and dignity. Some clinicians may worry about side effects of sedative medication and concerns that it may hasten death and approximate to an act of euthanasia.

Based on the ethical principles of proportionality and double effect, the use of sedation at the end of life is **NOT** an act of euthanasia because of the following reasons:

1. The intention of sedating the patient is genuinely an act of goodness to relieve a distressing symptom.
2. The intention is only to bring about the good sedative effect and not to cause the harmful side effect. This is seen by the process of using small doses of sedation and titrating gradually till the desired effect.
3. The sedating effect of medications is not achieved by inducing the harmful side effects of the medications.
4. As the patient is in severe distress it would be acceptable to sedate the patient even though there is a potential risk of side effects.

As long as the intervention follows these general principles of proportionality and double effect, the act is permissible and is by no means considered the illegal act of euthanasia.

8.6.3 EUTHANASIA

Euthanasia is defined as the **intentional killing** of a dependent human being for his/her alleged benefit upon their competent and voluntary request. The key element that defines euthanasia is that the **intent is to cause death** and for euthanasia to be successful, immediate death of the patient must occur.

This is clearly illegal in Malaysia and as there is no specific law in Malaysia pertaining to euthanasia, any deliberate act to hasten death of a patient would amount to committing murder under section 300 of the Penal Code (Amendment) Act 1989. Even if a terminally ill patient consents to ending his/her life, this is still considered culpable homicide under section 299 of the Penal Code (Amendment) Act 1989.

Euthanasia is not ethically justifiable based on the principle of double effect because the intent is to cause death and it uses the bad effect of an intervention (namely death) as the means to provide relief of suffering.

In advance care planning, while patients are given the right to express their wishes, they CANNOT request for an intervention that is illegal and unethical.

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MEDICAL SERVICES UNIT, MEDICAL DEVELOPMENT DIVISION, MINISTRY OF HEALTH
MALAYSIA LEVEL 5, BLOCK E1, COMPLEX E, FEDERAL GOVERNMENT ADMINISTRATIVE
CENTER, 62590 FEDERAL TERRITORY OF PUTRAJAYA

MEDICAL SERVICES UNIT,
MEDICAL DEVELOPMENT DIVISION,
MINISTRY OF HEALTH MALAYSIA,
LEVEL 5, BLOCK E1, COMPLEX E,
FEDERAL GOVERNMENT ADMINISTRATIVE CENTRE,
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