ADVANCE CARE PLANNING: ADVANCED DIRECTIVES FOR HEALTHCARE

A GUIDE FOR HEALTHCARE PROFESSIONALS

College of Palliative Medicine of Sri Lanka
2024

ADVANCE CARE PLANNING: ADVANCED DIRECTIVES FOR HEALTHCARE

A GUIDE FOR HEALTHCARE PROFESSIONALS

College of Palliative Medicine of Sri Lanka

2024

Advance Care Planning: Advance Directives for Health Care

ISBN: 978-624-6511-12-8

Contributors

Dr Sashiprabha Nawaratne
Professor Samadhi Rajapaksa
Dr Janaki Vidanapathirana
Dr Ishanka Talagala
Dr Lalantha Senaratna
Dr Senitha Liyanage
Dr Kelum Palpola

External reviewer

Dr Marie Joseph
Consultant Lead, Palliative Medicine
East and North Hertfordshire NHS Trust
RCP Educator
University of Cambridge

Citation: College of Palliative Medicine of Sri Lanka. Advance Care Planning: Advance Directives for Health Care, The College of Palliative Medicine of Sri Lanka; Colombo: 2024

Message from the President of the College of Palliative Medicine of Sri Lanka

Advance care planning is an essential component of palliative care. It is a patient-centered initiative recognized worldwide that facilitates shared decision-making. It is based on respect for human autonomy and empowers individuals to choose their preferred quality of life for situations when they are unable to make or communicate their own decisions.

The College of Palliative Medicine of Sri Lanka, being the apex professional body that works towards enhancing palliative care services within the country, has taken the decision to develop a guideline for healthcare professionals to improve their awareness of the important aspects of palliative and end of life care.

The publication "Advance Care Planning: Advanced Directives for Healthcare" was developed by the College of Palliative Medicine of Sri Lanka with the aim of orienting and guiding healthcare professionals on advance care planning while introducing the key principles in a simple and understandable manner.

I hope this publication will be valuable for all healthcare professionals involved in the care of terminally ill patients or those with serious illnesses, in order to provide patient-centered, high-quality care.

Dr Janaki Vidanapathirana
President CPMSL

Preface

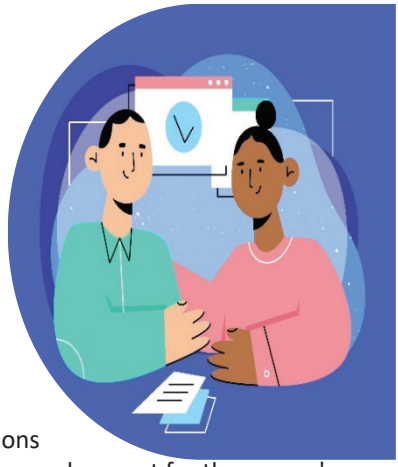
Advance care planning is crucial in providing high-quality end-of-life care, enabling healthcare professionals to align the care provided with the patient's priorities. Advance care planning empowers individuals to have greater control over their lives and lessens caregiver anxiety and depression. It also facilitates a personalised, holistic approach by helping patients better understand their preferences for care and treatment. Health professionals have an important role to play in supporting people to consider advance care planning.

Advance care planning is a continuous and dynamic process in which preferences and care goals must be reviewed and discussed throughout the course of the disease. Each complication or hospitalisation is considered, as well as the prognosis, which should be discussed whenever there is a change in the clinical course of the disease.

The purpose of this document is to introduce the principles of advance care planning for healthcare professionals in Sri Lanka. It aims to guide them in supporting and planning conversations with patients, and also to reduce the significant moral distress for healthcare professionals related to decision-making in end-of-life care. However, this guide is not intended to duplicate the many resources, detailed guidance, and training programmes that are already available in Sri Lanka on end-of-life care.

Table of Contents

What is Advance Care Planning (ACP)?



Advance care planning is a process that involves **discussing** and **preparing** for **potential future medical care decisions** in the event that an individual becomes **seriously ill** or **unable to communicate** their wishes.

Advance care planning guides the **patient's loved ones** and the **healthcare team** to make decisions in the **patient's best interest.**

This process entails multiple conversations over time and requires due consideration and respect for the person's wishes and emotions at all times. It should not be presumed that everyone desires to engage in ACP conversations when offered. Their wishes should be respected, and if individuals decline, this can be sensitively revisited at a later date.

What are the benefits of having an Advance Care Plan?

For the patient: promotes autonomy, strengthened relationships, enhanced communication, greater sense of being treated with dignity and respect, promotes coordination of palliative care and end of life care.

For the family/carers: can promote important discussions, • can make treatment decisions easier as the patient's wishes are known, • can help to reduce the likelihood of disagreements about the patient's care.

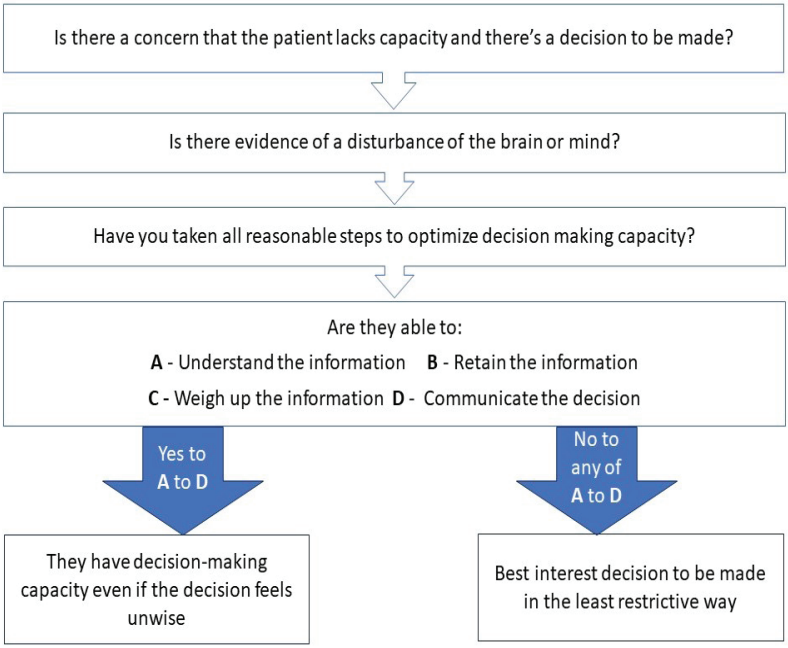
For healthcare professionals: helps to develop more constructive plans and create stronger doctor-patient relationships, • to improve communication, • for greater understanding of the patient's preferences to contribute to decision-making in the event that the patient loses the **mental capacity** to make his / her own decisions, • for better coordination of care.

What is mental capacity?

Mental capacity is the ability to make a decision or take an action that impacts a person's life. E.g Being able to decide on their own care and treatment.

How to assess mental capacity

When assessing whether the patient has the capacity to make decisions there are steps which need to be considered:



Source: British Medical Association, 2008. Assessment of Mental Capacity: Guidance for Doctors and Lawyers, 2nd Edition,

- ❖ The patient is presumed to have the capacity to make a decision unless there are good reasons to doubt this presumption. In general, capacity is assessed with respect to a specific decision at a specific time
- ❖ The patient's lack of capacity may be temporary, or fluctuating
- ❖ The capacity assessment is based on combination of relevant history, symptoms, behaviour observation, mental status examination and diagnosis. It is a clinical judgement of a clinician
- ❖ If possible, an assessment of capacity should be done when the person's condition has improved
- ❖ Do not assume someone is unable to make a decision based on their medical condition or disability
- ❖ The patient has the right to make a decision that you might disagree with or consider irrational or unwise. This doesn't indicate a lack of mental capacity but may reflect individual preferences or values
- ❖ The ability to make the decision is key; not the decision itself
- ❖ Decisions made or actions taken for or on behalf of the patient who lacks mental capacity must be made in their best interests

What is included in an advance care plan?

1. Living matters

By knowing what brings meaning to the patient’s life, their loved ones will understand what “quality of life” really means to them.

This may include important life values, relationships, activities, or hobbies.

2. Medical matters

Patient can express what treatments they wish to have, or prefer not to have. Topics that may be discussed include:

- Pain control options
- Resuscitation

- Life support treatments
- Organ donation
- Specific refusals of treatment

Principles of advance care planning

- Must always be a voluntary process
- ACP is done over time and regularly reviewed
- The person should have “sufficient mental capacity”
- ACP shouldn’t be a tick-box exercise
- ACP could be applied for anyone, and becomes important in those with serious or progressive illness
- The prepared ACP can be recorded in a summary and shared
- It may not be possible for patient wishes to always be honoured, but it may help guide decisions
- ACP may not be for everyone! (and that is ok)

What are Advance Health Directives (AHDs)?

Advance Health Directives are legal documents that provide instructions for medical care and only go into effect if a person cannot communicate his/her own wishes.

The most common advance directives for health care are;

1) The living will

2) The durable power of attorney for health care

1. The Living will

A living will is a legal document that **outlines a person's preferences for emergency medical treatment** in case they are unable to communicate their own decisions.

2. The durable power of attorney for healthcare

A durable power of attorney for health care is a legal document that designates a health care proxy to make health care decisions on behalf of a patient if they become unable to communicate their wishes.

Nominated healthcare spokesperson/ proxy

The patient can appoint up to two persons to be the nominated healthcare spokespersons. They should have the mental capacity and maturity to represent and articulate patient's care preferences, act in their best interest, and tell the doctors about the care they wish to receive when they lose mental capacity.

Who should need advanced health directives (AHD) ?

1. Terminal Illness: advanced cancer, end-stage organ failure, or advanced neurological diseases like Amyotrophic Lateral Sclerosis.

2. Chronic Progressive Illness: such as Parkinson's disease, Alzheimer's disease, or multiple sclerosis.

3. Advanced Age: Elderly individuals, particularly those with multiple comorbidities or frail health, may face complex medical decisions as they age.

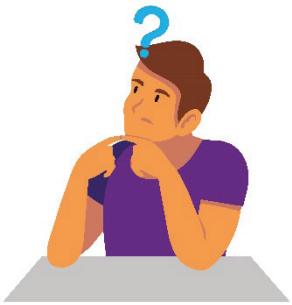
4. Mental Illness: such as schizophrenia, bipolar disorder, or major depressive disorder, who may experience fluctuations in decision-making capacity.

5. Dementia: Patients in the early stages of dementia may wish to create AHDs while they still possess decisional capacity.

6. Religious or Cultural Beliefs: Individuals with strong religious or cultural beliefs may wish to incorporate specific values, or practices into their healthcare decisions. (e.g Jehovah's Witnesses).

7. Desire for Quality of Life: People who prioritize quality of life over aggressive medical interventions may use AHDs to express their preferences for comfort-focused care, pain management, and symptom control, even in the face of terminal illness or serious medical conditions.

When should advance care planning be introduced?



Advance care planning conversations should be routine and occur as part of a person's ongoing health care planning. Better outcomes are experienced when advance care planning is introduced early as part of ongoing care. **When an advance care planning conversation is initiated, the patient should be medically stable, mentally sound, comfortable, and ideally accompanied by their substitute decision-maker(s), family, or carer.**

- Talking about future care plans can be emotional for the patient/carers and you as a healthcare professional
- If you're unsure how to approach, try talking to someone close to the patient, or other healthcare professionals involved in the care
- Do not force anyone into talking about advance care planning. Let them know you are there if they want to talk, whenever they feel ready

Opportunities for advance care planning conversations can include:

- if you would not be surprised if the patient were to die within twelve months
- when conducting a health assessment for a 75+ year old
- when there is a diagnosis of a life-limiting illness or organ failure indicating a poor prognosis
- when there is a diagnosis of early dementia or disease which could result in a loss of mental capacity
- when a patient or family member(s) asks about current or future treatment options

Making an ACP or AHD does not dictate all future medical decisions of the patient. Only if the patient lose the mental capacity to make medical decisions in the future, the medical team can take the ACP into consideration, and consult with the patient's loved ones to make decisions in their best interests

Talking about advance care planning

Listen for cues: The patient might give you some cues that they're starting to think about what happens if they become more unwell.

The main questions to ask and talk about are:

- What does the patient want to happen in the future?
- What does he/she not want to happen in the future?
- Who does he/she appoint to speak on their behalf if they cannot speak for themselves?

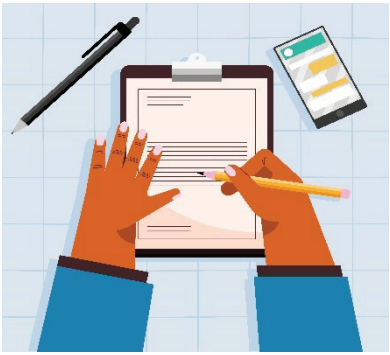
Be patient: Give the patient adequate time to consider the questions. Embrace silence as it may indicate the patient is carefully thinking about their response.

Be careful not to lead them into making any decisions they're not comfortable with. You do not have to talk about everything at once.

Give time to discuss with others: The patient should be given adequate time to discuss their plans with those important to them.

Be realistic and honest: Try to be open and honest with the patient/carer or those close to the patient.

Record the patient's wishes: It is crucial to diligently document all discussions regarding advance care planning in the patient's records (e.g shared care clinic record). This serves to create a record of the patient's preferences, providing a guide for other healthcare professionals to adhere to.



What happens in the absence of an advance care plan?

- If the patient does not have an advance directive and is unable to make decisions on their own, the law of the country will determine who may make medical decisions on their behalf (spouse if married, parents if they are available, or adult children)
- If the patient is unmarried and has not named a partner as their proxy, it's possible they could be excluded from decision-making
- If the patient has no family members, the treating physician(s) may act on the patient's best interests

Will an advance care plan guarantee that the patient's wishes are followed?

As a health care provider, you can do your best to respect the advance care plan, but there may be circumstances in which you cannot follow the patient's wishes exactly. E.g. In a complex medical situation where it is unclear what the patient wants).

There is also a possibility that you may have to refuse to follow the patient's advance care plan.

This might happen if the decision goes against:

- The healthcare provider's conscience
- The healthcare institution's policy
- Accepted health care standards

In these situations, the healthcare professional must discuss the situation with the other multi- disciplinary team members and inform the decisions to the healthcare proxy immediately.

Your role as a healthcare professional in advance care planning

- ✓ Identification (last year of life)
- ✓ Introduction
- ✓ Provide clear Information and support to ensure informed decision-making
- ✓ Communicate and Review
- ✓ Compassion and Reassurance

References

Advance Care Planning Australia. (n.d.). Factsheet for health professionals. Retrieved May 14, 2024, from https://www.advancecareplanning.org.au/__data/assets/pdf_file/0022/217642/fact-sheet-health-professionals.pdf

Marie Curie Hospice UK. (2024, February 27). *What is advance care planning? | Information for professionals*. Marie Curie. Retrieved May 14, 2024, from https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/advance-care-planning#types

MacLeod, R. D., & Van den Block, L. (2019). Textbook of palliative care. Springer.

Canadian Hospice Palliative Care Association (2024). Resources and Tools: Our directory of advance care planning resources. (2024). Advance care planning Canada. Retrieved May 20, 2024, from https://www.advancecareplanning.ca/resources-and-tools/

NHS England. (2022). *Universal Principles for Advance Care Planning (ACP)*. Retrieved June 10, 2024, from https://www.england.nhs.uk/wp-content/uploads/2022/03/universal-principles-for-advance-care-planning.pdf

Annexures

Example of an Advance Health Directive Form

Advance Health Directive (AHD)

This form is for Sri Lankan citizens who want to make an Advance Health Directive. To make an Advance Health Directive, you must be 18 years or older and have full legal capacity. Your Advance Health Directive is about your future treatment. It will only come into effect if you are unable to make reasonable judgements or decisions at a time when you require treatment.

Bar Code

Part 1: Patient details

Full Name

Date of Birth D D M M Y Y Y Y

Gender

Male	Female	Do not wish to say

Age

National Identity card number

Permanent Address

Date of completion D D M M Y Y Y Y

Part 2: Summary of relevant information for the Advanced Health Directive

Including diagnosis, communication needs, and the reasons for recommendations and preferences recorded

Other relevant details if any (e.g. advance planning, advance decision for refusal of treatment, decision on organ donation)

Part 3: Patients' personal preference to guide this plan

How would you like to balance the priorities of care? 3= most important, 1= least important)

Prioritise sustaining life, even at the expense of some comfort

Prioritise comfort, even at the expense of sustaining life

Part 4: Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment according to the guidance provided below

Clinician's Signature

Focus on symptom control according to the guidance provided below

Clinician's Signature

Clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts are **recommended**

Clinician's Signature

CPR attempts are **NOT recommended**

Clinician's Signature

Part 5: Witnessing

You must sign in front of two adult witnesses. One witness must be a registered medical practitioner. Neither witness can be a person who was appointed as the medical treatment decision-maker.

The signature of the person giving this directive	*Sign here*

Each witness certifies that:

- At the time of signing the document, the person giving this advance care directive appeared to have decision-making capacity in relation to each statement in the directive and appeared to understand the nature and effect of each statement in the directive; and
- The person appeared to freely and voluntarily sign the document; and
- The person signed the document in my presence and in the presence of the second witness; and
- I am not an appointed medical treatment decision-maker of the person

Witness 1 -Registered Medical Practitioner

Full name of registered medical practitioner:

SLMC Registration Number:

Signature and Date:

Witness 2 – Adult Witness

Full name of the adult witness:

National Identity Card Number:

Signature and Date:

You have reached the end of this form

It is recommended that you review your advance care directive every two years, or whenever there is a change in your personal or medical situation.

- Please keep your original advance care directive safe and accessible for when it is needed
- Ensure that your medical treatment decision maker (if any) has read and understood its contents
- Your advance care directive should be shared with your medical treatment decision-maker and relevant treating physician

Emergency Contact Information

Name	Relationship	Contact Number

For further technical assistance please contact:

College of Palliative Medicine of Sri Lanka

No.06 Wijerama House

Wijerama Mawatha,

Colombo 07

TP: 076 5469982

Email : officecpmsl@gmail.com

Web: www.cpmsl.lk