Advance Care Planning – How do we facilitate patient decision making

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Disclosure slide

Learning objectives

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1. Understand **definitions,** concepts and prerequisites for advance care planning.
2. Effectively consult published research to inform selection of advance care planning approach.
3. Interpret **how best** to use advance care planning.
4. Recognise **when** to offer patients opportunities to discuss advance care planning.
5. Understand the difference between advance care planning conversations and advance directives.
6. Independently learn and develop competencies in conducting advance care planning conversations.

Key messages

- Advance care planning enables patients to define **goals and preferences** for future medical treatment and care.
- Advance care planning addresses patients' concerns across the **physical, psychological, social and spiritual domains**.
- Advance care planning involves a **conversation** with the patient and their family and health-care providers, and is part of a **process, not a single event**.
- Goals and preferences may be recorded in a **written document**, and should be **regularly reviewed**.

Case study

Maria, aged 30 years, diagnosed with ALS. Her husband Carlos has started a new business in the UK, two children Dan 6 years and Elly 4 years. Her family live in Spain.

She has recently started to use a wheelchair and has difficulty managing to remember things. Her voice is weak and she struggles to talk for more than a few minutes.

What are the key decisions that Maria, her husband and health-care providers, will need to address?

Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care

Judith A C Rietjens, Rebecca L Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Droger, Agnes van der Heide, Daren K Heyland, Dirk Houttekier, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Jox, Ida J Korfage, on behalf of the European Association for Palliative Care

Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. We used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application. Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68–100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP based on the readiness of the individual; targeting ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. We present a list of outcome measures to enable the pooling and comparison of results of ACP studies. We believe that our recommendations can provide guidance for clinical practice, ACP policy, and research.

Lancet Oncol 2017; 18: e543–51

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Definition

Panel: Consensus definitions of advance care planning

Extended definition

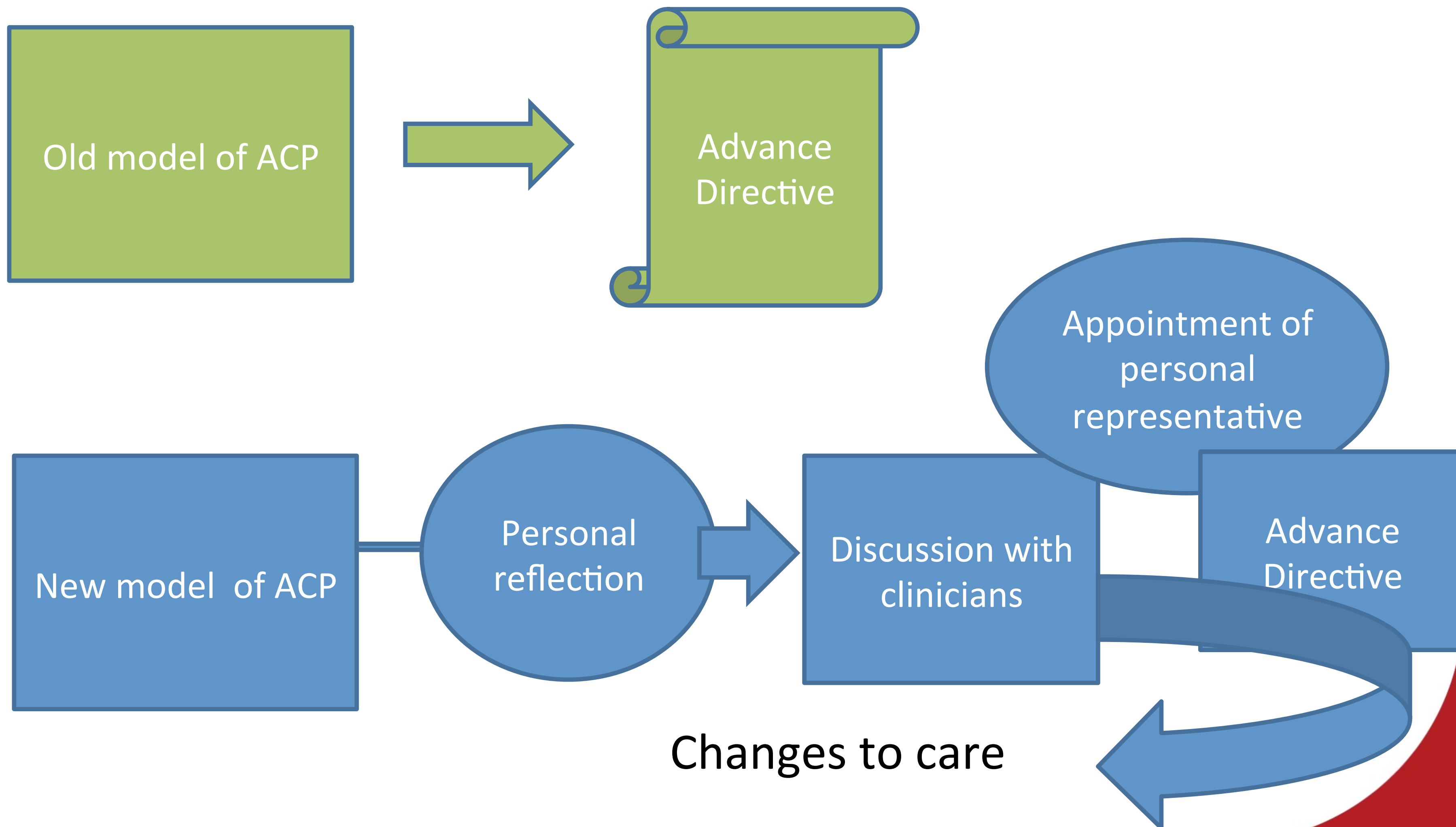
Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. 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 taken into account should they, at some point, be unable to make their own decisions.

Brief definition

Advance care planning enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate.

Rietjens JA, Sudore RL, Connolly M, et al *Lancet Oncology* 2017

ACP processes and outcomes



Prerequisites for advance care planning conversations - patients

- Mental capacity
- Health literacy
- Open disclosure of diagnosis, awareness of likely prognosis
- Coping styles
- Ability to express views (perhaps with assisted communication)

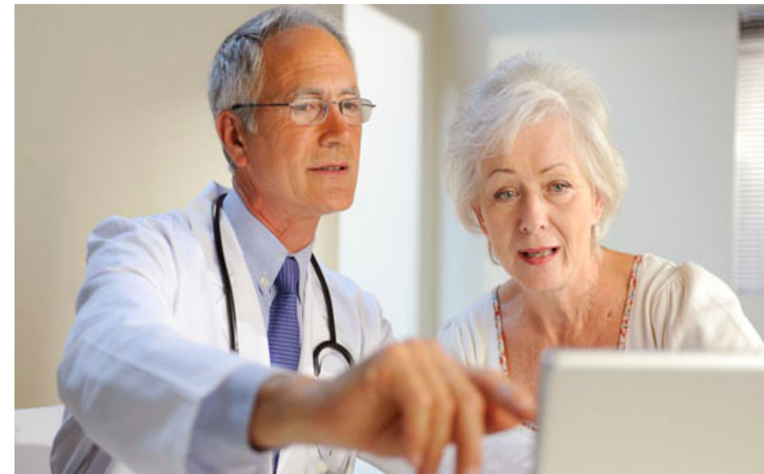
If the patient wishes:

- They can appoint a proxy decision maker, in the event that they lose mental capacity
- They can record their preferences in an advance directive.

Prerequisites for advance care planning conversations - clinicians

- Necessary communication skills
- Willingness to broach sensitive topics compassionately
- Sufficient time to undertake ACP conversations, and if patient wishes to record them in an advance directive
- Willingness to regularly review ACP decisions
- Willingness to comply with patient preferences (which may not be the same as the family)

ACP IS NOT A CHECKLIST



Prerequisites for advance care planning conversations - organisations

- Legal framework for advance care planning in your country

  What choices are permitted in your country?

Patients may be able to decline medical interventions but usually they can not compel physicians to provide medical treatments that are not regarded as clinically useful.

- Healthcare organisations support the use of ACP
- Ensure advance directives are available and ‘flagged’ in all care contexts eg emergency room
- All staff are informed of ACP choices, especially do not attempt resuscitation decision.

Who can conduct advance care planning conversations?

All people conducting ACP conversations require **training**.

- Physician
- Nurse
- Social worker
- Counsellor
- Trained volunteers

When can advance care planning conversations be offered?

- Any time during the disease trajectory but better early than late.
- There is never a perfect time.

'It is always too early, until it is too late.'

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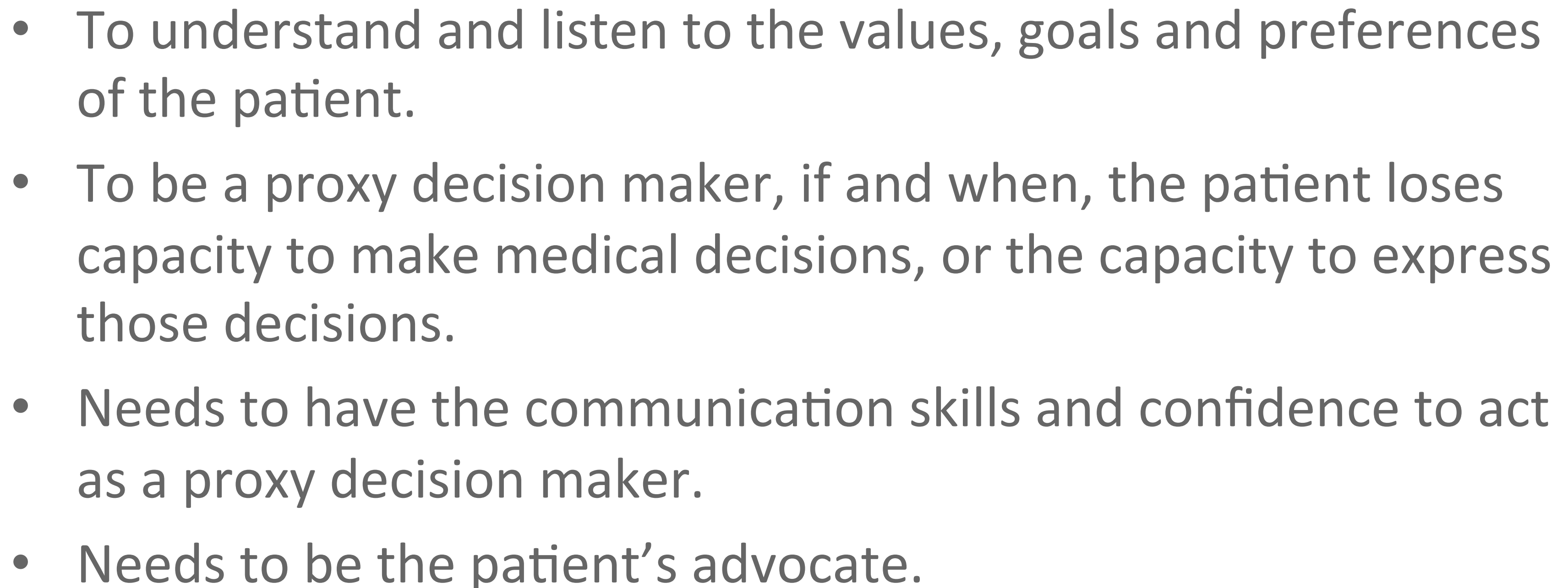
Role of personal representative



- To understand and listen to the values, goals and preferences of the patient.
- To be a proxy decision maker, if and when, the patient loses capacity to make medical decisions, or the capacity to express those decisions.
- Needs to have the communication skills and confidence to act as a proxy decision maker.
- Needs to be the patient’s advocate.

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How to conduct advance care planning conversations

All ACP programmes have been developed in the context of:

- a language (often English)
- a culture (often North American or Australian)
- a healthcare system (private medicine, insurance healthcare)
- norms of medical communication and practice.

There are some well developed ACP programmes such as:

'Respecting Choices' (https://respectingchoices.org)

'Serious Illness Conversation Guide' (Ariadne Labs: A joint Center for Health Systems Innovation and Dana-Farber Cancer Institute 2012)

Basic requirements for ACP

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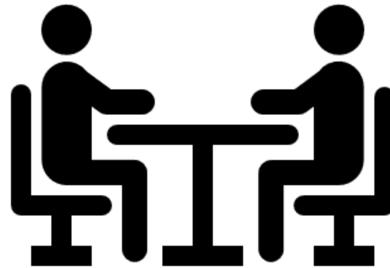

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Example of ACP guide 'Looking and Thinking Ahead'

- **Do you have any wishes that you would like to achieve in the near future?**
- **In the event of a gradual decline in health, is there anything that worries you (or, your family member), or that you (or, your family member) dreads happening?**
- **Are there any special wishes that you (or, your family member) would like us to know about when you approach the end of life?**
- **Do you (or, your family member) have a particular faith or belief system that is important to you (or them)? Would you like a priest or spiritual adviser to come and visit?**

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Example of ACP guide 'Looking and Thinking Ahead'

- **At the very end of life, where would you (or your family member) like to be cared for?**

- **Is there any specific ritual or religious practice that you wish to happen following the death that you (or, your family member) would like to make known? For instance: funeral details, burial/cremation**

- **Summary of any further discussion**

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Conclusions

- ACP formalising what a patient and family **do** want to happen which are statements about a person's preferences and wishes (i.e. where they would like to be cared for in the last days of life) which can be changed and re-discussed.

- ACP formalising what a patient and family **does not** want to happen. In some countries, an Advance Decision to Refuse Treatment is legally binding.

- Remember ACP is a choice and not everyone wants to be involved in medical decision making.

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