Government of **Western Australia**
Department of **Health**
WA Cancer and Palliative Care Network

Advance Care Planning

A step-by-step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life

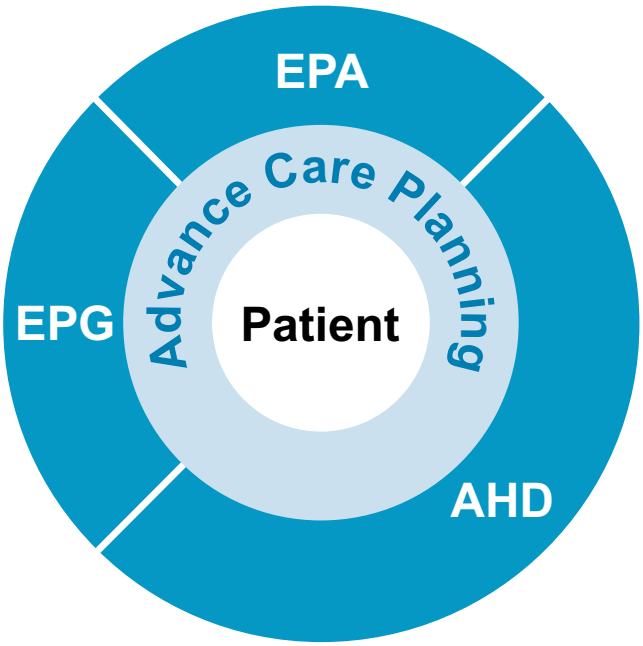
Contents

Introduction

Advance Care Planning (ACP) is an ongoing discussion between a patient, their carers/family and you, about their values, beliefs, treatment and care options. In particular, their wishes for future care should they no longer be able to communicate their decisions at the time they are needed.

ACP may assist in the development of an Advance Health Directive (AHD) and the appointment of an Enduring Power of Guardianship (EPG) or Enduring Power of Attorney (EPA). These are legal documents and the full requirements of these cannot be covered in this resource. A brief summary of each of these legal documents can be located in the glossary, pages 19-20. For more information, visit www.health.wa.gov.au/advancehealthdirective.

Advance Care Planning Process



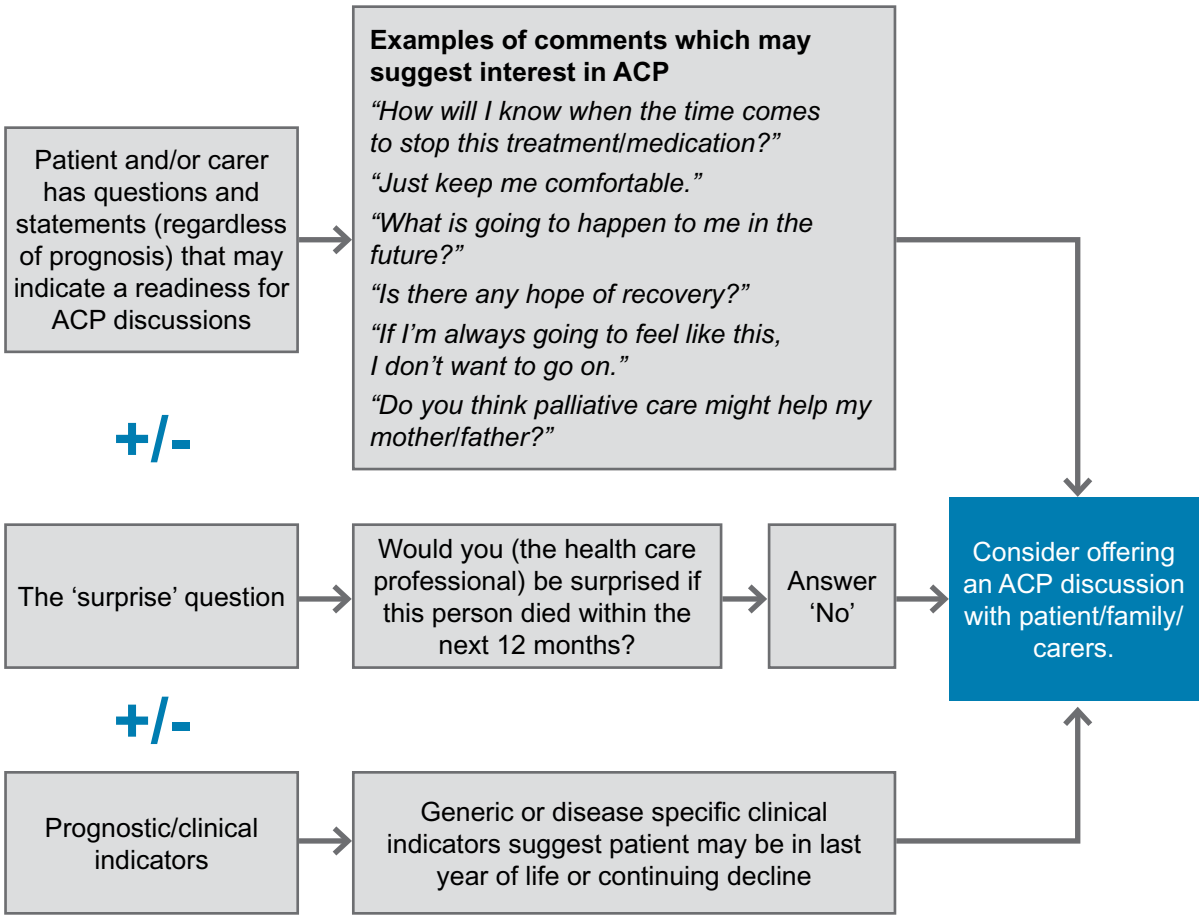
This resource focuses on the ACP conversation(s) and process. It will assist you in ACP discussions with your patients and help you identify those who may benefit from ACP discussions earlier in their illness.

The patient must have capacity to participate in these discussions. This Guide includes a *Mental Capacity Assessment,* which will help you to determine the patient's capacity to participate in the ACP process. Please refer to Appendix 1 for more information.

Many patients expect their health care team to initiate discussions; however**, not all patients will wish to engage in ACP discussions.**

Identifying patients for ACP discussions: triggers and prompts

Whether or not you are aware of the ACP process, patients may expect their health care team to initiate such discussions. It is therefore essential that health care professionals be sensitive to circumstances when it may be an appropriate time to offer ACP, and to identify when patients might be indicating their readiness to discuss. This section includes a list of triggers and clinical indicators to assist you in identifying those patients who may benefit from ACP discussions. It is designed to encourage ACP earlier in a patient's illness, when such discussions are likely to be more beneficial to the patient and their carer/family.



Identifying patients for ACP discussions: generic clinical indicators

These clinical indicators are designed to assist you to identify patients who may be ready for or who could benefit from the ACP process

They are not designed to provide patients with a prognosis or estimate how long they have to live.

Generic

Clinical Indicators

- Two or more admissions to hospital for a chronic or life-limiting illness within 12 months[1]
- Resident in a nursing home[2]
- Unintentional weight loss greater than 10% over 6 months
- Karnofsky Performance Status (KPS) ≤ to 50%[3]
- Deliberate non compliance with treatment
- Refusing food or fluids
- Frailty (patients who present with multiple co-morbidities with significant impairment in day to day living and deteriorating functional status).[4]

Initiating the discussion

This section provides an overview of the processes for facilitating ACP discussions and includes details for documenting and communicating ACP discussions with other health care providers.

Prior to holding the discussions:

- Do you have a private area with no interruptions?
- Who should be present?
- Does the patient and/or carer/family have the decision-making capacity to participate in the discussion?
- Ensure all relevant clinical information is available (review files/notes) and consult with other health care professionals involved with the patient's ongoing care.[5]

Remember, there is no recommended time frame for ACP discussions. These may be ongoing and can take place over several sessions or visits

ACP and communication skills

Communication skills are central to holding effective ACP discussions. For further information on communication skills in ACP and end-of-life discussions, refer to the Medical Journal of Australia supplement *"Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers"*.[5]

Examples of phrases to use (to initiate discussion)

- "Have you thought about the place where, or the type of care you would like to have, if you ever became too ill to care for yourself?"
- "Do you worry about what's going to happen to you when your heart/lungs/cancer gets worse?"
- "Would it help you to discuss this?"
- "Is there someone you would prefer to make decisions about your treatment if you were unable to make them for yourself?"
- "Some people have thought about what they want and document their wishes in what is called an Advance [Health] Directive or Living Will. Do you have an Advance [Health] Directive? Would you like to learn more about this?"

During the discussion:

If the patient is not interested in advance care planning discussions, ensure they are aware that they can revisit the topic at any time in the future. Offer to provide written information for the patient to take away if they are receptive.

Introduction

- Explain what ACP is and outline some of the reasons patients/carers/families etc may want to have the discussions.
- Check if the patient already has an Advance Health Directive/Living Will/Enduring Power of Guardianship, Enduring Power of Attorney or similar. If so, do they need to be reviewed?
- Discuss the role of a proxy/substitute person or Enduring Guardian for decision-making.

Identifying patient's goals and wishes

- **Identify issues that are important to the patient at that time:**
  - *"Think about what is most important to you in your life. What makes life meaningful or good for you now?"*[6]
  - *"At this point, given your medical condition, how could we (the health professionals) help you live well?"*[7]
  - *"Are there any special events/activities that you are looking forward to?" (e.g. birthdays, weddings, holidays etc.).*
- **What are the patient's values/goals for care?**
  - What is their understanding of their condition now and its prognosis?
  - *"If you have to choose between living longer and quality of life, how would you approach this balance?"*[7]
  - *"What, if any, religious or personal beliefs do you have about sickness, health-care decision-making, or dying?"*[6]

Issues to consider

- See disease specific issues to consider (pages 11 – 16)
- Identify the goals, benefits and burdens of other treatments and/or interventions the patient/carer/family may wish to discuss
  e.g. CPR, ventilation, dialysis, artificial nutrition and hydration, antibiotics
  (e.g. "*Are there any particular scenarios or interventions you would like to avoid?*")
- Does the patient wish to complete an AHD?
- Consider discussing referral to palliative care services (if appropriate) and preferred place for future care e.g. home, hospital, hospice etc.
- Is this an appropriate time to discuss organ and tissue donation?
- Are there other issues the patient, carer/family (if present) wants to discuss?

Closing the discussion

- Review/summarise discussion with the patient and others present.
- Clarify any inconsistencies or misunderstandings.
- Offer additional information if required (patient resources, information sheets, referrals etc).
- Document all details of the ACP process.
- Arrange further meetings if relevant and/or offer your contact details for future reference.

Documenting Advance Care Planning discussions

Health Care Professional Place written documentation in patient's file in a consistent and accessible section	**Patient Information**
▪ Details of all individuals present during discussions as well as others consulted in relation to this. ▪ Record details of topics discussed, including feedback from patients regarding what they consider acceptable treatment, along with specifics of any treatment decisions e.g. circumstances for cessation of treatments. ▪ Documenting presence of an AHD/EPG/EPA. ▪ Document any Not for Resuscitation (NFR) orders according to your organisation's policy. ▪ Include a note/flag in the patient's medical file to alert to ACP documentation.	▪ Provide a copy of the ACP document to the patient and their family/ carer. ▪ Obtain consent to forward copies of the ACP discussion to the patient's General Practitioner and other providers as consented to by individual/carer.

If/when the patient is transferred to another care setting(s), ensure copies of the ACP discussion are included in handover documents.

Reviewing Advance Care Planning discussions

There will be certain times in the patient's care when ACP discussions will need to be revisited and their Advance Care Planning, including their Advance Health Directive and Enduring Power of Guardianship reviewed.

When should an Advance Care Planning discussion, Advance Health Directive and/or Enduring Power of Guardianship be reviewed?

- When the patient and/or carer/ family requests or changes their mind about any previous decisions.
- Where the patient's medical condition or individual circumstances change (e.g. diagnosis of new illness, death of a carer/partner, change in location of care etc).
- When returning to hospital for any treatment.
- If treatment options or medical care available for the patient changes their needs in regards to ACP (for example, a new treatment for their disease, diagnosis of a co-morbidity etc).
- Patients can change or revoke their AHD or EPG at any time. Rather than make changes to an AHD / EPG, it is recommended that patients prepare a new one.

+/-

Reviewing "Not for CPR" (or similar) orders

Refer to your organisation's policy on documenting "Not for CPR" (or similar) orders.

Documentation

Staff

- Documenting all ACP discussion reviews and/or changes to AHD.
- All reviews and subsequent discussions should be documented and shared with relevant people (where consented to).

Patient

- Ensuring documents are distributed to all relevant people (in particular, those who received a copy of previous ACP documents).
- Discarding all previous ACP documents from circulation to ensure the most recent copy is available.

Identifying patients for ACP discussions: disease specific clinical indicators

Renal Disease

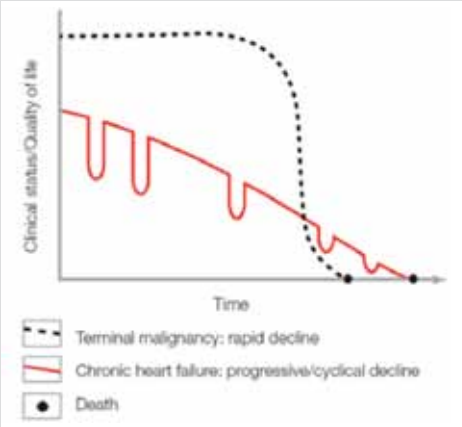
Clinical Indicators	Examples of issues to consider

▪ Commencement of dialysis in End Stage Kidney Disease patients with poor functional status.
▪ Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:[4]
  ▪ Patient for whom the surprise question is applicable (refer to page 4)
  ▪ Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
  ▪ Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
  ▪ Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload
▪ Failure of multiple vascular access and/or modalities for renal replacement therapy
▪ Deliberate non-compliance with treatment.
	▪ Is the patient aware of the stages of kidney failure (Stage 3 – 5)?
	  – Stage 3: moderate decrease in kidney function
	  – Stage 4: severe decrease in kidney function
	  – Stage 5: end stage kidney disease.
	▪ What does the patient know about the options for both haemodialysis and peritoneal dialysis?
	▪ Are they aware of the benefits and burdens of each choice?
	▪ Are patients aware that they may choose not to start dialysis and be conservatively managed instead?
	▪ Are they aware of what this will involve, how will they be managed, and what are the implications?
	▪ Dialysis:
	  – Does the patient know that they can withdraw from dialysis at any time they choose?
	  – What action would they want taken should their vascular access fail?
	  – What do they understand regarding the outcome when they opt either for not starting or withdrawing from dialysis?
	  – Has the patient been on home therapy that has now failed and does not wish to commence hospital haemodialysis?
	▪ Transplantation:
	  – Are they suitable for, or considering, transplantation?
	  – Is the patient's transplant failing and have they stated that they do not wish to return to dialysis treatments? What is their understanding of what will happen?

Chronic Lung Condition

Clinical Indicators	Examples of Issues to Consider
▪ FEV[1] < 25% predicted[8] ▪ Weight loss (Body Mass Index below 18)[8] ▪ Respiratory failure (PaCO2 > 50mmHg or 6.7 kPa)[8] ▪ Right sided heart failure[8] ▪ Worsening shortness of breath[8] ▪ Pulmonary hypertension.	▪ Does the patient have any co-morbidities associated with their Chronic Lung Condition (e.g. Ischaemic Heart Disease (IHD), osteoporosis, depression, diabetes, glaucoma and sleep disorders)?[4] ▪ What is their understanding of their quality of life, future care and treatment options? ▪ What type of treatment or care would the patient like during acute exacerbations of their Chronic Lung Condition? ▪ Where would they like to be cared for? (e.g. hospital/community)? ▪ Are they aware that there may be options other than hospital admission (e.g. Hospital in the Home (HITH), Hospital at the Home (HATH))? ▪ Are they aware of the option for ventilatory support (on exacerbation of Chronic Lung Condition)? ▪ Do they understand the difference between invasive and non-invasive ventilatory support during treatment for their Chronic Lung Condition? What are the patient's views on these types of ventilation? ▪ If the patient's breathing deteriorated to the point of needing ventilatory support, would they accept this? ▪ What are the implications for the patient's care if they choose to limit, withhold or withdraw ventilatory support in the future? ▪ What are the implications if they refuse admission to hospital?

Heart Failure

Clinical Indicators	Examples of issues to consider
▪ Heart failure with symptoms not responding to optimal therapy ▪ Repeated number of hospitalisations with heart failure symptoms[4] ▪ Experiencing multiple shocks from cardiac devices[2]  The typical trajectory of heart failure compared to a terminal malignancy.[9]	▪ What does the patient understand about the progression of heart failure? ▪ Are they and their family/carers aware of the unpredictability of this and how it may impact on decision-making? ▪ Where would they want to be treated in the event of an exacerbation? ▪ Sometimes all available medication/ therapy does not make the patient feel better or relieve the symptoms of their heart failure (and other co-morbidities). For example, shortness of breath, water retention and fatigue. What would be their goals for care at this time? ▪ Which symptoms bother them most? ▪ Electronic device implantations are sometimes used for patients diagnosed with heart failure. Would they accept such a device? What do they understand to be the benefits and burdens of these devices (e.g. the need for removal prior to cremation)? ▪ If the patient has an implantable device, are they aware of the impact this may have on their care at the end-of-life? For example, an Implantable Cardioverter Defibrillator (ICD) can be deactivated at the end of life to prevent prolonging the dying process.[10] Do they wish to discuss this with their specialist? ▪ Transplantation – this issue may be relevant for a small number of patients with advanced heart failure. Is this something the patient has thought about? Do they have any strong views on this?

Cancer

Clinical Indicators	Examples of issues to consider

▪ Metastatic Cancer[4]
▪ Deteriorating functional ability (if more than 50% time spent in bed/lying down <3 months[4,11]
▪ Cancer Prognosis tools available e.g. PiPs, Pap, PPI, PPS[4]
	▪ What is the patient's understanding of their cancer and their stage of disease?
	▪ Does the patient understand what is meant by primary and secondary/ metastatic cancer?
	  ▪ Metastatic cancer means the cancer has spread to other organs
	  ▪ Curing the cancer might now be more difficult
	▪ Does the patient know if their treatment is curative or palliative?
	▪ Does the patient think it more important to live long or to live well?
	▪ Does the patient know they can choose to stop treatment?
	▪ Do they understand what will happen if they choose to stop treatment?
	▪ Is the patient aware of the support available as their disease progresses?
	▪ What are their greatest concerns/fears?
	▪ How much control do they want to maintain over what happens to them?
	▪ Who can assist/support the patient with their decision making?

General Neurological Disease

Clinical Indicators

General Neurological Disease	Stroke	Dementia
• Progressive deterioration in physical and/or cognitive function despite optimal therapy • Predominantly bed-bound requiring assistance with ADL/ self care • Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure • Speech problems: increasing difficulty in communication, dysphasia. • Difficulties with nutrition/ hydration.	• Persistent vegetative or minimal conscious state or dense paralysis • Medical complications • Lack of improvement within 3 months of onset • Cognitive impairment/ post-stroke dementia.	There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:[4] Unable to walk without assistance and Urinary and faecal incontinence and No consistently meaningful conversation and Unable to do Activities of Daily Living (ADL) Barthel score >3. Plus any of the following: • Weight loss • Urinary tract Infection • Severe pressures sores – stage three or four • Recurrent fever • Reduced oral intake • Aspiration pneumonia.

Of all people experiencing a stroke, one third will die in the first 12 months[12]

Neurological Disease

Examples of Issues to Consider

General Neurological Disease, Stroke, Dementia

- What are the main fears or concerns (e.g. loss of communication, loss of body control)?
- How can they optimise their functional independence?
- Where do they want to live? What has to be done to address these wishes?
- Are they aware of available support (e.g. Home Help)?
- Carer issues – what will happen if the person's primary carer needs hospitalisation or is no longer able to assist with care? How can the person plan for this?
- What are the patient's views on artificial feeding and nutrition (e.g. nasogastric, PEG/gastrostomy insertion)?
- Do they have any opinions/thoughts on interventions related to treating complications such as pneumonia/chest infections or urinary tract infections (e.g. using intravenous antibiotics)?

It is vital that discussions with individuals living with dementia are started early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.[4]

Appendix 1: Mental Capacity Assessment

Central to the ACP process (and essential for creating a valid AHD or appointing an Enduring Guardian) is the question of capacity.

In WA, the legal position assumes that an individual aged over 18 years has capacity unless otherwise proven.

In the context of Advance Care Planning, capacity relates to the ability to make decisions about medical treatment now and in the future.

Some guiding questions which may assist in determining whether a person has capacity include:

- Does the patient possess adequate information processing skills (attention, absorption, intention and linear thinking) for the decision at hand?
- Is there understanding of the nature of the issue, why it's an issue and can they articulate this?
- Do they know the relevant facts?
- Is there understanding of options and the risks and benefits of each option?
- Is there ability to compare the choices at hand and arrive at a decision through a reasoned process?
- Is the patient able to communicate their decision and reasoning process?
- Is there an absence of coercion?
- Is there a mental disturbance which distorts thinking in relation to the specific matter in question?
- Is the patient depressed, in pain, or have other symptoms which may be altering their decision-making abilities?

Finally, it is also desirable but not essential if the patient demonstrates consistency of views over time.

Appendix 2: The Australia – modified Karnofsky Performance Status (AKPS)[13]

Score (%)	Australia-modified Karnofsky (AKPS)
100	Normal; no complaints; no evidence of disease
90	Able to carry on normal activity; minor signs or symptoms
80	Normal activity with effort; some signs or symptoms of disease
70	Cares for self; unable to carry on normal activity or to do active work
60	Requires occasional assistance but is able to care for most of his needs
50	Requires considerable assistance and frequent medical care
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast and requiring extensive nursing care by professionals and/or family
10	Comatose or barely arousable
0	Dead

	KPS ≤ 50%

Glossary

Advance Care Planning (ACP)

Advance care planning is an ongoing discussion between an individual, their carers/family and their health care team about their values, beliefs, treatment and care options; in particular, their wishes for future care should they no longer be able to do so at the time decisions are needed. Ideally these decisions should be documented in an Advance Health Directive.

Advance Health Directive (AHD)

An Advance Health Directive is a legal document that is completed using a form which contains a person's decisions about future treatment in anticipation of a time when they may be unable to make reasonable judgments for him/herself. A valid AHD is legally binding and documents treatment decisions in which a person consents or refuses consent to future treatment according to specific circumstances. A valid AHD must be in the form or substantially in the form prescribed by the regulations.[14]

Capacity

Capacity is the cognitive ability to understand and appreciate the context, choices and consequences of our decisions. It is also a person's performance on measures of decision making ability. On the other hand, competency is determined by courts and tribunals and is the judgement that a person's capacity is adequate to make the decision in question. Competency is a legal construct and capacity is a clinical one.

End-of-Life Care

Patients are 'approaching the end of life' when they are likely to die within the next 12 months, as described by The Gold Standards Framework, United Kingdom.[4] This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Enduring Power of Attorney (EPA)

An Enduring Power of Attorney is a legal agreement that enables a person to appoint a trusted person - or people - to make financial and property decisions on their behalf. An enduring power of attorney is an agreement made by choice that can be executed by anyone over the age of 18, with capacity.

Enduring Power of Guardianship (EPG)

An Enduring Power of Guardianship is a document in which a person nominates an Enduring Guardian to make personal, lifestyle and treatment decisions on their behalf in the event that they are unable to make reasonable judgments about these matters in the future.[14] An EPG is different from an Enduring Power of Attorney (EPA), which relates to financial and property matters.[14]

Palliative Care

Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of the early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.[15]

Proxy or Substitute

The individual the person nominates to assist in decision-making on his/her behalf in the future, should the person be unable to participate in the decision-making process themselves. The individual proxy or substitute does not have to be next-of-kin or a family member.

References are available at www.health.wa.gov.au/advancehealthdirective

References

1 Fischer S, Gozansky W, Sauaia A, Min S, Kutner J, Kramer A. A practical tool to identify patients who may benefit from a palliative approach: the CARING criteria. J Pain Symptom Manage. 2006 Apr;31(4):285-92.

2 Connolly M, Beattie J, Walker D, Dancy M. End of life care in heart failure: a framework for implementation. Leicester, UK: National Health Service Improvement and National End of Life Care Programme; 2010.

3 Stuart B, Herbst L, Kinzbrunner B, et al. Medical guidelines for determining prognosis in selected non-cancer diseases: the National Hospice Organization. Hosp J. 1996;11(2):47-63.

4 The Gold Standards Framework [Internet]. Shrewsbury, UK: GFS Centre CIC; 2012. GSF Prognostic Indicator guidance (4th ed.); 2011 September [cited 2012 Apr 23]; Available from: http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf

5 Clayton J, Hancock K, Butow P, Tattersall M, Currow D. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. MJA. 2007;186(12Suppl):S77-S108.

6 Karel MJ, Powell J, Cantor MD. Using a values discussion guide to facilitate communication in advance care planning. Patient Educ Couns. 2004 Oct;55(1):22-31.

7 Austin Health. Respecting patient choices: an Australian Advance Care Planning Program: consultant's manual. Western Australian Edition. Melbourne:Austin Health; 2006

8 Department of Health, Western Australia. Chronic Obstructive Pulmonary Disease model of care. Perth: Health Networks Branch, Department of Health, Western Australia; 2008.

9 Heart Foundation of Australia [Internet]. Canberra, ACT: National Heart Foundation of Australia; c2011. National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand (Chronic Heart Failure Guidelines Expert Writing Panel): guidelines for the prevention, detection and management of chronic heart failure in Australia; [updated October 2011; cited 2012 Apr 23]. Available from: http://www.heartfoundation.org.au/SiteCollectionDocuments/Chronic_Heart_Failure_Guidelines_2011.pdf

10 Beattie J, Connolly M. Managing the end-game: palliative care for advanced heart failure. Heart Improvement eBulletin [Internet]. 2009 May 5 [cited 2012 Apr 23];112. Available from: http://system.improvement.nhs.uk/ImprovementSystem/ViewDocument.aspx?path=Cardiac/National/Website/Heart/managing%20the%20end%20game%20article.pdf

11 Weissmen, D. Fast fact and concepts #13: determining prognosis in advanced cancer. (2nd ed.). End-of-Life / Palliative Education Resource Centre. [Internet]. 2005 June [cited 2012 Apr 23]; Available from: http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_013.htm

12 Department of Health Western Australia. Model of Stroke Care for Western Australia. Perth: Department of Health Western Australia 2012. http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Stroke_Model_of_Care.pdf
Department of Health, Western Australia. Motor Neurone Disease services for Western Australia. Perth: Health Networks Branch, Department of Health, Western Australia; 2008.

13 Abernethy A, Shelby-James T, Fazekas B, Woods D, Currow D. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. BMC Palliative Care [Internet]. 2005 Nov 12 [cited 2012 Apr 23];4(7). Available from: http://www.biomedcentral.com/1472-684X/4/7

14 Department of Health, Western Australia. A guide for health professionals to the Acts Amendment (Consent to Medical Treatment) Act 2008. Perth: Department of Health, Western Australia; 2010.

15 World Health Organization. [Internet]. Geneva, Switz. WHO; 2012. WHO definition of palliative care; 2012. [cited 2012 Apr 23]; Available from: http://www.who.int/cancer/palliative/definition/en/

This document can be made available in alternative formats on request for a person with a disability.

Produced by WA Cancer and Palliative Care Network

HP12505 OCT'12