A multidisciplinary guide to identify those who may benefit from advance care planning (ACP Quick Guide)

Triggers that suggest a person may benefit from advance care planning (ACP):

1. The "surprise question" – would you be surprised if the person were to die in the next year?
2. The person is experiencing symptoms and signs that indicate declining health
3. The person is experiencing indicators of decline related to their specific disease or condition
4. The person reaches or experiences a significant milestone e.g. advancing age (i.e. aged ›65 years or older, or ›55 years if an Aboriginal or Torres Strait Islander person), retirement, bereavement, admission to community or aged care facility
5. The person, family member or carer raises ACP with a health professional

Symptoms and signs of declining health:

- Advancing disease–unstable, deteriorating, complex symptom burden
- Decreasing response to optimal treatments, decreasing reversibility
- Repeated unplanned (emergency) hospital admissions
- General physical decline and often unwell; prolonged recovery periods
- Declining functional performance status (e.g. Palliative Care Outcomes Collaboration (PCOC) indicators (RUG-ADL, SAS and AKPS), reduced mobility, increasing dependence in activities of daily living
- Presence of other risk factors (e.g. social determinants of health – smoking, obesity, diabetes, depression)
- Resident of or about to enter Residential Aged Care Facility
- Presence of an increasing burden of comorbidities (comorbidity is regarded as the biggest predictor of mortality and morbidity)
- Deteriorating physical and mental status following a significant event, e.g. serious fall, retirement on medical grounds
- Choice to discontinue medical treatments and focus on quality of life
- Progressive unplanned unexplained weight loss in last 6 months (›10%) or failure to regain weight lost

Indicators of decline related to specific diseases/ conditions:

Cancer

- Diagnosis of malignancy
- Person is becoming less able to manage usual activities and symptoms getting worse
- Metastatic disease (spread to other organs)
- Persistent symptoms despite optimal therapy
- Refer to Cancer Prognosis tools for further information (e.g. PiPs, Pap, PPI, PPS)

Kidney disease

- Moderate to late stage (3b, 4 or 5) chronic kidney disease (eGFR ‹ 45ml/min)
- Kidney failure complicating other life-limiting conditions or treatments
- Non-compliance with recommended treatment
- Decision to withhold or withdraw dialysis, whether by patient or doctor, and in whatever circumstances

Lung disease

- Disease assessed to be moderate to severe (e.g. from GOLD II - FEV1 50-79% predicted to GOLD IV - FEV1 ‹30% of predicted)
- Recurrent hospital admissions (≥ 3 in last 12 months due to COPD)
- Fulfils criteria for long-term oxygen therapy
- MRC dyspnoea scale grade 3-5 (levels of breathlessness after activity)
- More than 6 weeks of systemic steroids for COPD in preceding 6 months
- Persistent symptoms despite optimal therapy, with surgery becoming more risky.

Heart and peripheral vascular disease

- Diagnosis of moderate to severe:
  - atherosclerosis
  - myocardial infarction
  - valvular heart disease
  - cardiomyopathy
  - lung disease
- Frequent ischaemic chest pain
- Short of breath when resting, moving or walking a few steps
- Increasing heart failure (HF) symptoms despite maximum tolerated HF therapy, including diuretics, ACE inhibitors and beta-blockers
- Intractable peripheral oedema
- Worsening or irreversible end-organ damage (including cardiac cachexia)
- Repeated hospital readmissions with deteriorating HF, ventricular arrhythmias or cardiac arrest
- Peripheral ischaemia (claudication)

Liver disease

- Deterioration in past year with complications such as:
  - ascites
  - hepatic encephalopathy
  - renal impairment
  - recurrent infections
  - oesophageal varices
  - spontaneous bacterial peritonitis
- Diagnosis of cirrhosis with one or more complications in the last year, including: diuretic resistant ascites, hepatic encephalopathy, hepatorenal syndrome
- Alcohol-related liver disease
- Liver transplantation options unlikely

Neurological disease including dementia

- Diagnosis of any progressive neurodegenerative disease, e.g. Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis, stroke or dementia.
  - deteriorating physical health or cognitive function
  - declining mobility or falls
  - deteriorating speech/communication
  - progressive dysphagia
- Recurrent aspiration pneumonia
- Residual paralysis following a stroke
- Inability to care for self without assistance
- Urinary and faecal incontinence
- Poor outcomes in PCOC indicators (e.g. SAS)
- Plus any of the following: weight loss, recurrent sepsis, pressure injury or reduced oral intake

Frailty

- Multiple co-morbidities with significant impairment in day-to-day activities and:
  - deteriorating functional performance status
  - combination of at least three of the following symptoms: weakness, slow walking speed, significant weight loss, exhaustion, low physical activity
- Decreasing appetite and oral intake
- Levels 6-9 using the Clinical Frailty Scale

[Adapted from: Gold Standards Framework. *Proactive Identification Guidance* (PIG) 6th Ed. 2016; University of Edinburgh. *Supportive and Palliative Care Indicators SPICT tools*; Alassaad A. Melhus et al. A tool for prediction of risk of rehospitalisation and mortality in the hospitalised elderly: secondary analysis of clinical trial data. *BMJ Open* 2015;5:e007259. doi:10.1136/bmjopen-2014-007259; Australian Commission on Safety and Quality in Health Care. *Safety and Quality of End-of-life Care in Acute Hospitals: A Background Paper*. Sydney: ACSQHC, 2013].

Please see reverse for purpose of this guide and recommendations for further steps to carry out ACP

Queensland Government

Identifying people who will benefit from advance care planning (ACP)

(Purpose of this guide and recommendations for further steps to carry out)

What is the purpose of the ACP Quick Guide?

The purpose of this multidisciplinary ACP Quick Guide is to assist clinicians to identify when a person may benefit from ACP earlier in the course of their illness. It may also assist to identify those who may be approaching the end of life before significant deterioration of their condition occurs.

Why do we need a guide to identify people who may benefit from ACP?

According to the Australian Commission on Safety and Quality in Health Care, "(C)linicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions, to increase the likelihood of delivering high-quality end-of-life care aligned with the patient's values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations."[1]

National and international research agrees that predicting mortality and the timing of decline can be difficult, even for experienced clinicians. A single page of broad indicators supports health professionals to identify whether the person in their care is approaching the end of their life and the potential for further decline. While it is never too early or too late to commence ACP, evidence is growing that people benefit most from carrying out ACP as early as possible in their disease trajectory. People who are identified as being at risk of deterioration are more likely to participate actively in their current and future treatment and care.

It is most beneficial for patients, their families[2] and the multidisciplinary healthcare team to commence ACP before the person suffers a loss of capacity and becomes unable to express and/or document their own preferences and choices about end-of-life care. Early identification of those who may benefit from ACP provides opportunities to actively involve the person and those closest to them in their current and future treatment and care.

Who can use the ACP Quick Guide?

Any healthcare professional who is looking for more guidance to identify those who will benefit from ACP can use this guide. While experienced clinicians may be aware of their patient's declining health, there are times when guidance is needed to make a more holistic assessment of whether the person may benefit from ACP. Caring for patients who are approaching the end of life offers opportunities for the multidisciplinary healthcare team to identify their patient's needs, coordinate and review their goals and plan of care, and consider how best to align care with their expressed values, goals and wishes.

Documenting decisions and potential decision-makers is also an important part of the ACP process, and the responsibility of all involved in the treatment and care of the person.

What happens when a person is identified by the ACP Quick Guide?

If a person is identified as likely to benefit from ACP, the range of health professionals involved in their care should initiate an appropriate ACP process leading to a multidisciplinary review of their treatment plans. After a more thorough clinical assessment of the person's condition, ongoing discussion, coordination and review with the multidisciplinary healthcare team can assist the person and their family to prepare for treatment and care when their condition deteriorates (refer to the *ACP Clinical Guidelines* or *ACP flip cards* for more information).

What happens if a person falls outside the purpose of the ACP Quick Guide?

A person may fall outside the purpose of these guidelines if they are well. It is never too early to undertake ACP and this can occur by following the six steps in the ACP process, as explained in the *ACP Clinical Guidelines*. Healthy people may decide to engage in ACP and this should be encouraged. Sometimes initiating ACP may be triggered by exposure to literature, posters and conversations that promote ACP in the well community.

Quality of life and comfort for the person and those closest to them will be the focus in the last days and hours of life through palliative care. The *Care plan for the dying person* (CPDP) is designed for those patients who are actively dying in the terminal phase of their disease. Most people who are near to dying should have been identified without the need to refer to the ACP Quick Guide; however that does not preclude their engaging in ACP for what may, in reality, be a limited range of choices.

When in doubt, it is best to initiate ACP in the context of a general discussion about the person's health and well-being. In this way, consent can be obtained and the ACP process followed. No harm can come from initiating ACP early. (Refer to the *ACP Clinical Guidelines* or *ACP flip cards* for more information, including the ACP process, clinician responsibilities, and legal issues around obtaining and documenting consent).

Where does the ACP Quick Guide fit with other ACP documents?

This guide is Appendix 2 in the *ACP Clinical Guidelines* and was developed to support the identification of those at or approaching the end of life, representing step 1 (identify) of the 6 step ACP Process.

1. Australian Commission on Safety and Quality in Health Care. *National Consensus Statement: essential elements for safe and high-quality end-of-life care.* Sydney: ACSQHC, 2015. p. 11.

2. Please note in this ACP Quick Guide the term family is used as the most likely support for the person identified as being at the end of life. Close family members are usually, but not always, substitute decision-maker/s. Where legal consent is required, ensure the person's decision-maker/s is consulted. Refer to the *ACP Clinical Guidelines* for further information.