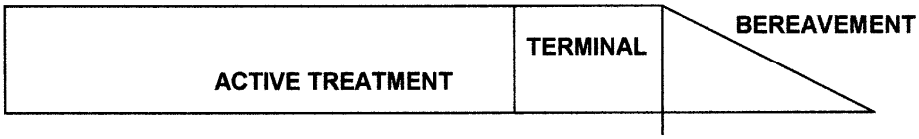
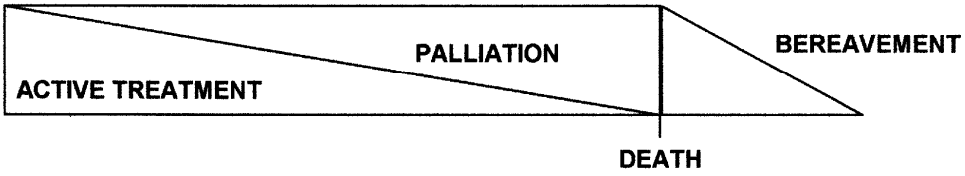
Definitions in Palliative Care

"Palliative care is specialist care provided for all people living with, and dying from a terminal condition and for whom the primary goal is quality of life." *Palliative Care Australia* http://pallcare.org.au/Default.aspx?tabid=1940

Traditionally, palliative care has been associated with the last few days or weeks of life. This was reflected in past education of health professionals and the delivery of palliative care services.



With the changing face of health care, the traditional paradigms of palliative care have also changed. As we improve health care, patients suffering from chronic illness including cancer diagnoses, can have a longer duration of illness and prognosis is often extended.



The palliative approach is now seen as a gradual transition from active treatment to comfort and symptom management. Early within a life-limiting disease process, we are called to consider questions such as advance care planning. Clinical management of chronic illness also undergoes gradual transitions, for example, the transition from inhaled steroids to the utilisation of opioids in COPD patients. This is reflected in the World Health Organisation's definition of the palliative approach (see left).

We therefore encounter patients who may be reasonably medically stable but are still receiving symptom management from a palliative paradigm. This raises interesting questions about the MBS items that we may be able to utilise for patients with a life-limiting illness. Team care arrangements, case conferencing, GP management plans and reviews are indeed appropriate item numbers to utilise for those faced with life-limiting illnesses, irrespective of prognosis. *(Steve Pitman RPCP Project Officer, Albury Wodonga GP Network)*

(Please see *AGPN document "Rural Palliative Care Project: enhancing efficient practice"* to highlight appropriate use of GPMP/TCA and Case Conferencing options in management of palliative patients and their families)

> *"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*
>
> *World Health Organisation's definition of palliative care*

Developed for the Rural Palliative Care Project funded by the Australian Government Department of Health and Ageing

Prognostic Indicator Guidance

"Earlier recognition of people nearing the end of their life leads to earlier planning and better care"

Guidance to enable better identification of patients who may need supportive/palliative care

Three triggers for supportive/palliative care are suggested.
To identify these patients, you can use any combination of the following methods

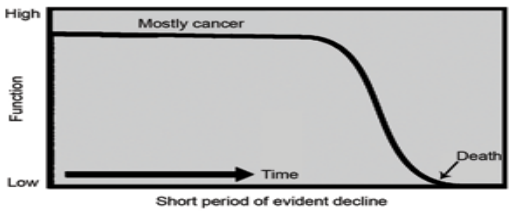
1. **The surprise question** 'Would you be surprised if this patient were to die in the next 6-12months' -an intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation for the dying stage. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions enabling the right thing to happen at the right time.

2. **Choice/need** - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care eg refusing renal transplant

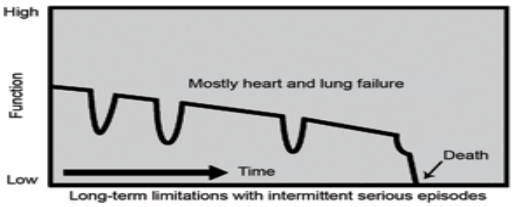
3. **Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia (see prompt pages following, regarding clinical indicators).

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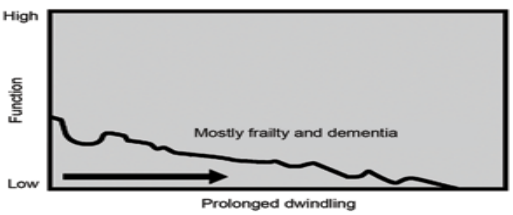
Typical Chronic Illness Trajectories



Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

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How to use this Guidance

This guidance document aims to clarify triggers for consideration of patients in need of supportive/palliative care. This is not attempting to answer the question 'how long have I got?' but more in answer to the question '**what can we do**?', and is in response to the common way of thinking 'Hope for the best but prepare for the worst'.

The main processes used in the Gold Standards Framework GSF are to **identify, assess, plan**, and at all times communicate about patient care and preferences. Use of this guidance might enable better identification of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better assessment and pre-planning e.g. holistic needs assessment, Advance Care Plans, and the appropriate management care plan and provision of supportive care related to their needs.

Specific clinical indicators of advanced disease

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual patient, but they **can help to alert clinicians to the need for extra supportive care**.
They have been drawn from a number of expert sources.
Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are only a very approximate guide to prognosis, these clinical indicators can act as a rough guide to indicate to those in primary care and in secondary services that patients may be in need of palliative / supportive care.

Co-morbidity is increasingly the biggest predictive indicator of mortality and morbidity. Also-

- Weight loss - Greater than 10% weight loss over 6 month
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status /ECOG/Karnofsky score (KPS) < 50%
- Dependence in most activities of daily living (ADLs)

Prognostication or Prediction of Need

Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators, and the trend is usually to over-estimate prognosis and to under-estimate planning for possible need, especially for those with non-cancer illnesses.

This work focuses more on pragmatically and instinctively improving prediction of decline, leading to better anticipation of need for support, and less on pure prognostication of time remaining.

In anticipating this possible deterioration, earlier discussions about preferences and needs can be initiated. Also, some practical measures could be introduced leading to prevention of crises and referral sought for extra help or advice.

The aim of such Advance Care Planning discussions, is to seek out particular unmet needs and preferences, sometimes previously unvoiced, enabling people to live out the final stage of life as they wish. We suggest a change towards instinctive, anticipatory and 'insurance-type' thinking, rather than pure prediction of likely timescale, so that appropriate support and care can be mobilised.
We know that some attempt to improve this prediction, however inaccurate, is key to beginning the process that leads to better end of life care for all.

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Functional scores

ECOG* Performance Status

0 Fully active, able to carry on all pre-disease performance without restriction
1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work
2 Ambulatory and capable of self care but unable to carry out work activities: upright more than 50% of waking hours
3 Capable of only limited self care, confined to bed or chair more than 50% of waking hours
4 Completely disabled, cannot carry on any self care, totally confined to bed or chair
5 Dead

As published in Am. J. Clin. Oncol.: *Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The *Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982* http://ecog.dfci.harvard.edu/general/perf_stat.html

Karnofsky Performance Status Score

100	Normal, no evidence of disease
90	Able to perform normal activity with only minor symptoms
80	Normal activity with effort, some symptoms
70	Able to care for self but unable to do normal activities
60	Requires occasional assistance, cares for most needs
50	Requires considerable assistance
40	Disabled, requires special assistance
30	Severely disabled
20	Very sick, requires active supportive treatment
10	Moribund

Triggers: A Karnofsky assessment of 60 or below may trigger a family conference to discuss functional status and disease progression see PCOC Assessment Tool Definitions: Karnofsky V1.2 December 2008

Specific clinical indicators of advanced disease

1. Cancer Patients

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.
More exact predictors for cancer patients are available elsewhere on the GSF website

2. Organ Failure Patients

2.1 Heart Disease - CHF

At least two of the indicators below:-

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steroids for COPD in the preceding 12 months

2.3 Renal Disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing renal replacement therapy. This may be from choice or because they are too frail or have too many co-morbid conditions.
- Patients with stage 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable i.e. overall you would not be surprised if they were to die in the next year?
- Clinical indicators:
- CKD stage 5 (eGFR <15 ml/min)
- Symptomatic renal failure -Nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload)
- Increasingly severe symptoms from co-morbid conditions requiring more complex management or difficult to treat

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2.4 Neurological Disease -

a) Motor Neurone Disease

- MND patients should be included from diagnosis, as it is a rapidly progressing condition
- Indicators of rapid deterioration include:
- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications e.g. pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry

b) Parkinson's Disease

- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis

Indications of deterioration and inclusion on register are:-

- Significant complex symptoms and medical complications
- Dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonias and recurrent
- admissions with sepsis and poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia
- Breathlessness may be in the terminal phase

3. Patients with Frailty and Dementia

3.1 Frailty

- Multiple co-morbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg EPOC/ Karnofsky
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, reduced weight loss, self reported exhaustion

3.2 Dementia

- Unable to walk without assistance
- Urinary and faecal incontinence
- No consistently meaningful verbal communication
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living

Plus any one of the following:

- 10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores e.g. stage III / IV, recurrent fevers, reduced oral intake / weight loss, Aspiration pneumonia

3.3 Stroke

- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / post-stroke dementia