Prognostic Indicators Guide

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)**

Prognostic Indicator Guidance Paper © National Gold Standards Framework Centre England 2005
Date: Sept 2008

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.

WHO/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

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

NB: Triggers: A Karnofsky assessment of 60 or below may trigger a family conference to discuss functional status and disease progression

NB: Reducing performance status / ECOG/Karnofsky score (KPS) < 50% is a predictor of mortality and morbidity

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 (Gold Standards Framework) 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 (RRT). 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 ie 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 comorbid conditions requiring more complex management or difficult to treat

NB. Many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT.

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 eg 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 comorbidities with signs of impairments in day to day functioning
- Deteriorating functional score eg ECOG/ 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, and
- Urinary and faecal incontinence, and
- No consistently meaningful verbal communication, and
- 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 eg 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
- Cognitive impairment / Post-stroke dementia