Prognostic Indicator Guidance

Revised Vs 5. Sept 08

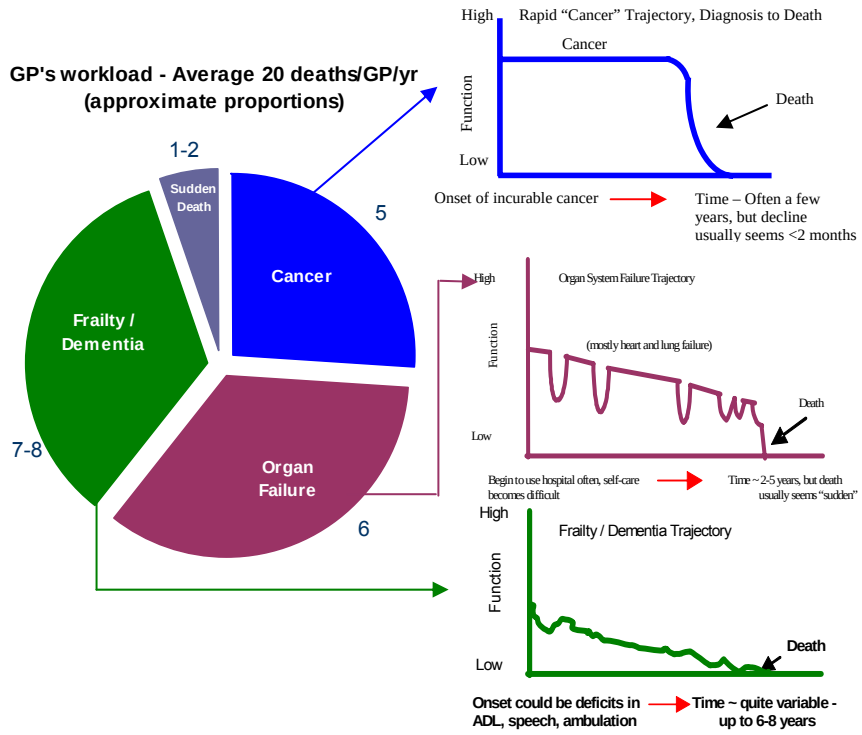
"Earlier recognition of people nearing the end of their life leads to earlier planning and better care"

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

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If predicted earlier, some supportive care measures could be introduced that would enable earlier discussion of their wishes, improve care aligned to their preferences and fewer crises. In short, if we could better identify these patients, we might be more able to provide better care for them as they approach the end of their lives. This guidance paper suggests which adult patients with any condition predicted to be in the final 6-12 months of life might be in need of supportive/palliative care. It was developed originally to support primary care teams using the Gold Standards Framework (GSF) and Quality Outcome Framework (QOF) to include more appropriate patients on their Palliative/Supportive Care Registers, and thereby to encourage better prediction of possible need and provision of care. The focus is more on improving prediction of need for support, rather than pure prognostication of time remaining. Though all prognostication is inherently inexact, and as people live longer with more co-morbid conditions, there can be disparity between levels of care provided to patients with different diagnoses. This guidance aims to help clinicians to support more patients nearing the end of life, whatever their underlying illness. It contributes to the development of accepted indicators for patients in the last months/year of life, which will aid identification of such patients and promote excellence in end of life care.

Three triggers for Supportive/ Palliative Care are suggested - to identify these patients we can use any combination of the following methods:

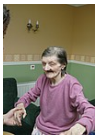
1. **The surprise question 'Would you be surprised if this patient were to die in the next 6-12months'** - an intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation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



Typical Case Histories

1) Mrs A - A 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired. Likely rapid decline

2) Mr B - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future



3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'. Likely slow decline, difficult to predict dying phase. Common picture in care homes

The Department of Health's new End of Life Care Strategy July 08 suggests development of a care pathway begins with the" identification of people approaching the end of life and initiating discussions about preferences for end of life care" (Exec.Summary 9 p.11). It also suggests use of this guidance to support such early identification "For many people suffering from a chronic illness a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately. The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened". (3.22)

Trigger 3 – 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 are. They have been drawn from a number of expert sources from the UK and abroad, and are updated regularly. Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore 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. Primary care teams may include these patients on their Supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such patients are included on the registers, if helpful.

Co-morbidities or other General Predictors of End Stage illness[1 / 2]

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

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

1. Cancer Patients

Cancer[3]

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 [4]

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 [5]

- 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 steriods for COPD in the preceding 12 months

2.3 Renal Disease [6]

- 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 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[7]

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 [8]

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register

- 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 [9]

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

Frailty [10]

- Multiple comorbidities 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

Dementia [11]

- Unable to walk without assistance, and
- Urinary and fecal 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

Stroke [12]

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

Functional scores- 1) Karnofsky Performance Status Score

The Karnofsky score, measures patient performance of activities of daily living. Score Function

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

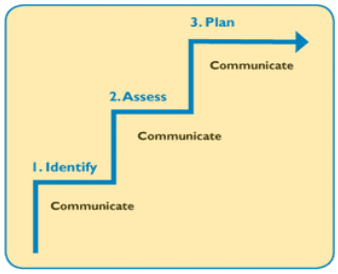
2) WHO/ ECOG Performance Status [13]

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

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. The aim of this paper is to enable better identification of patients who may need supportive/ palliative care. It 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, for which there is much more accurate guidance available (see GSF website)**.** In anticipating this possible deterioration, earlier discussions about preferences and needs can be initiated; 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 their particular unmet needs and preferences, sometimes previously unvoiced, enabling more 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.

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 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***.

For primary care teams, this is the first step towards developing a Supportive/ Palliative Care Register, now part of QOF palliative care points in the GMS contract. For more details of suggestions for claiming the QOF points, templates etc see the www.goldstandardsframework.nhs.uk/gp_contract.php. For those using the Gold Standards Framework (GSF), this might trigger inclusion of more non-cancer patients in the current Supportive Care Register. Of course, not all of these tests are performed in primary care, but GPs/DNs collate information from hospitals and, together with their own holistic assessment, form an overall view of a patient's likely prognosis. N.B: It can be much harder to predict whether patients in the third category of frail elderly patients are nearing end of their lives, as they are intrinsically more complex and vulnerable, with a more chronic variable illness trajectory. We do not suggest necessarily that all patients in this third category are included on the GSF Supportive Care Register, unless they fulfil the other criteria of co-morbidity, need or predicted decline, but we are suggesting that more non-cancer organ failure patients be included i.e. with Heart Failure and COPD, to the expected prevalence or to represent at least half the patients in the Supportive Care registers

For hospital teams, in addition to accessing supportive/palliative care services and consideration of supportive measures, it would also be helpful to notify the GP/Primary care team that this patient has advanced disease and could be included on their Supportive/Palliative Care Register.

For specialist palliative care/ hospice teams - Although traditionally focussed mainly on cancer patients, specialist palliative care now extends to patients with non-cancer illnesses. There is greater collaboration with other teams e.g. heart failure nurses, to provide best patient care, and these indicators may help clarify referrals.

For PCTs /Commissioners/managers etc - This could be used as part of an End of Life care strategic plan for the area, with improved provision of services for all patients nearing the end of life. **NB Long Term Conditions.** There is a strong overlap with care for patients with Long Term Conditions and prediction of unplanned admissions to hospital and that of patients with advanced disease in the last year of life. This is especially true for patients with heart failure or COPD. Close collaboration with Case Managers to support good end of life care is very important.

For Care Homes - Use of some broad prognostic indicators has been found to help identify patients most in need in some care homes, and help focus care and trigger key actions (see below and GSF Care Homes on website)

Examples of prognostic indicators used as part of patient needs assessment

Patients have differing requirements at varying stages of their illness. Some GPs categorise their patients on the Supportive Care Register according to estimated prognosis and need, and colour code them accordingly. Care Homes using the GSF for Care Homes Programmes have also found the intuitive grouping of their residents to be very helpful. Although only a rough guide, this helps teams 'awareness of patients' varying needs, focuses care to ensure that the right care is directed at the right time, ensures regular review, and triggers key actions at each stage. A needs/support plan is therefore developed. Suggested prognostic coding could be:

A - 'All'	**B -** 'Benefits' eg DS1500	**C -** 'Continuing Care'	**D** - 'Days'
Stable	Unstable / frequent exacerbations	Deteriorating	Dying / terminal phase
Years + prognosis	**Months prognosis**	**Weeks prognosis**	**Days prognosis**

The use of means of estimating approximate prognosis and need i.e. the intuitive 'surprise' question, needs/choice based care, and these clinical indicators, may help to ensure that patients with advanced illness receive higher quality proactive care and support as they near the end of their lives.

Development of this guidance paper. This paper was developed and later fully revised following wide consultation with a large number of specialist clinical bodies, special interest groups, national disease associations, Royal College of General Practitioners and major palliative care texts. We were helped also by considering prognostic indicators from other countries eg USA, used to trigger referral of non-cancer patients to hospice/palliative care. Since its first development in June 06, this 'PIG' paper has been widely used by clinicians nationally and internationally, by GPs in the UK (90% of whom now have supportive/palliative care registers), by care homes' staff, researchers and many others. We undertake regular reviews and would be pleased to receive any comments or ideas for improvements or example of usage. The accompanying Needs Support Matrixes are also in development for most conditions.

Further information and other prognostic guidance is available from www.goldstandardsframework.nhs.uk

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References

The 'Surprise question' was first developed and expounded by Prof Joanne Lynn, RAND Lecturer USA and senior advisor on end of life care.

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