



The information below is from the Hospice Friendly Hospital Programme's *Map for End-of-Life Care*

## Diagnosing Dying

### Recognising Where Death is Imminent – The 'Terminal' Phase <sup>1</sup>

Diagnosing that someone is dying is a *process* with significant implications and one which is best carried out by a team of professionals. It is important that dying is diagnosed as early as possible as this can ensure that the appropriate care and communication needed by patients and families is anticipated and provided. It also allows the clinical team to prioritise the goals of comfort and support based on the patient's preferences. Patients themselves may already be aware that they are dying, often before healthcare professionals.

There are a number of signals indicating that a patient is *actively* dying. It is likely that a patient with advanced incurable cancer with significant deterioration over recent weeks or months is entering into the dying phase when they have been deteriorating over a period of weeks or months and when two of the four criteria listed below apply.

*The patient is:*

- Bed bound
- Semi-comatose
- Only able to take sips of fluids
- No longer able to take oral medication

Such criteria may not be appropriate in patients who do not have cancer but may still provide a useful guide.

### The Surprise Question <sup>2</sup>

**'Would you be surprised if this patient died in the next 12 months?'**

This is an intuitive question that is helpful for clinicians to recognise when a patient with an advancing life-limiting illness may be near the end of his/her life. Earlier recognition of people nearing the end of their life leads to earlier planning and better care.

**The next question then is 'What do I need do now for this patient?'**

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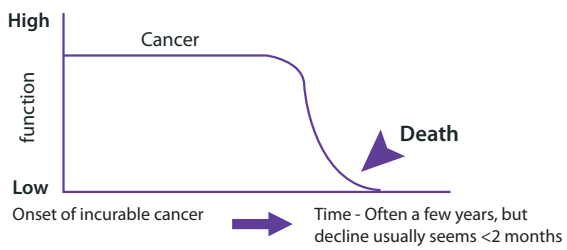
<sup>1</sup> *When a Patient is Dying* booklet, Hospice Friendly Hospitals Programme, 2008

<sup>2</sup> Lynn J., 2004. *Sick to Death and Not Going to Take it Anymore!*, University of California Press, Berkeley, CA: 2004.

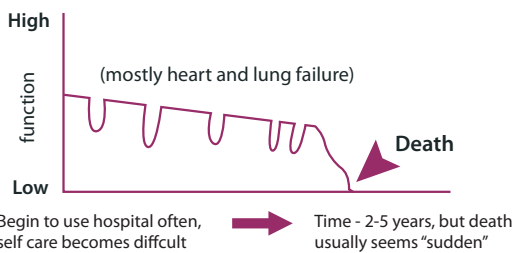
### Patterns of dying – dying trajectories<sup>2</sup>

Thinking about the different common patterns of dying allows us to anticipate particular needs for patients and families.

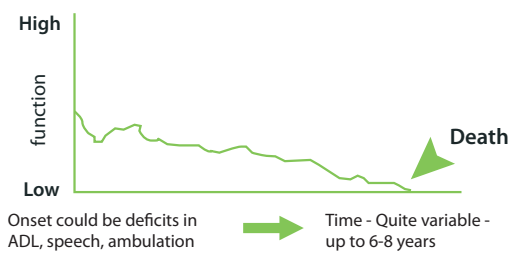
#### Cancer



#### Organ systems failure



#### Frailty/Dementia



<sup>2</sup> Lynn J., 2004. *Sick to Death and Not Going to Take it Anymore!*, University of California Press, Berkeley, CA: 2004.

## Recognising End of Life <sup>3</sup>

### Prognostic Indicators

The indicators below 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 should be interpreted with clinical judgement. When assessing patients, the focus is more on anticipating support needs rather than purely on time remaining.

### General Predictors of End Stage Disease

- Weight loss >10% over 6 months
- General physical decline
- Serum albumin <25g/l
- Dependence in most activities of daily living (ADLs)
- Reducing performance status e.g. spending more than 50% of time in bed

### Dementia

Unable to walk without assistance plus:

- Urinary and faecal incontinence
- No consistently meaningful verbal communication
- Unable to dress without assistance
- Barthel score <3
- Reduced ability to perform ADLs
- Plus any of: pyelonephritis/UTI, serum albumin 25 g/l, severe pressure sores, recurrent fevers, reduced oral intake/weight loss, aspiration pneumonia

### Frailty

- Multiple co-morbidities with signs of impairment in day-to-day activities
- Deteriorating performance status
- Combination of at least 3 symptoms of: weakness, slow walking, low physical activity, weight loss, exhaustion

### Cancer

Any patient whose metastatic cancer is no longer responsive to oncological treatments or is not amenable to treatment. The single most important predictive factor in cancer is performance status and functional ability – if a patient is spending more than 50% of time in bed/lying down, prognosis on average is unlikely to be more than 3 months.

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<sup>3</sup> Gold Standards Framework – Prognostic Indicator Guidance, September 2008

### 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

### Heart Disease – Chronic Heart Failure

At least two of the following indicators:

- CHF NYHA stage III or IV – SOB at rest or minimal exertion
- Patient thought to be in the last year of life - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure.
- Progressive physical or psychological symptoms despite optimal therapy

### Chronic Obstructive Pulmonary Disease

- FEV<sub>1</sub> <30% predicted
- Recurrent hospital admission (>3 admissions in 1 year for COPD exacerbations)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – SOB after 100 meters on the level or house bound through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV resistant organisms isolated, depression
- >6 weeks of systematic steroids for COPD in the preceding year

### Chronic Renal Disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing RRT 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 1 year 'surprise question' is applicable
- Clinical indicators:
  - CKD stage 5 (eGFR <15 ml/min)
  - Symptomatic renal failure (nausea, vomiting, pruritus, intractable fluid overload)
- Increasingly severe symptoms from co-morbid conditions that are difficult to treat
- Note: many people with Stage 5 CKD have stable impaired renal function and do not progress or need RRT

*For neurological prognostic indicators, refer to the Gold Standards Framework (UK), Prognostic Indicator Guidance.*

Insert  
hospital specific  
information