

## Why is it important to identify people nearing the end of life?

**'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'**

(GSF National Primary Care Snapshot Audit 2010)

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such as clarifying their particular needs, offering advance care planning discussions, prevention of crises, admissions and pro-active support to ensure they 'live well until they die'.

### Predicting needs rather than exact prognostication.

This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

### Definition of End of Life Care General Medical Council, UK 2010

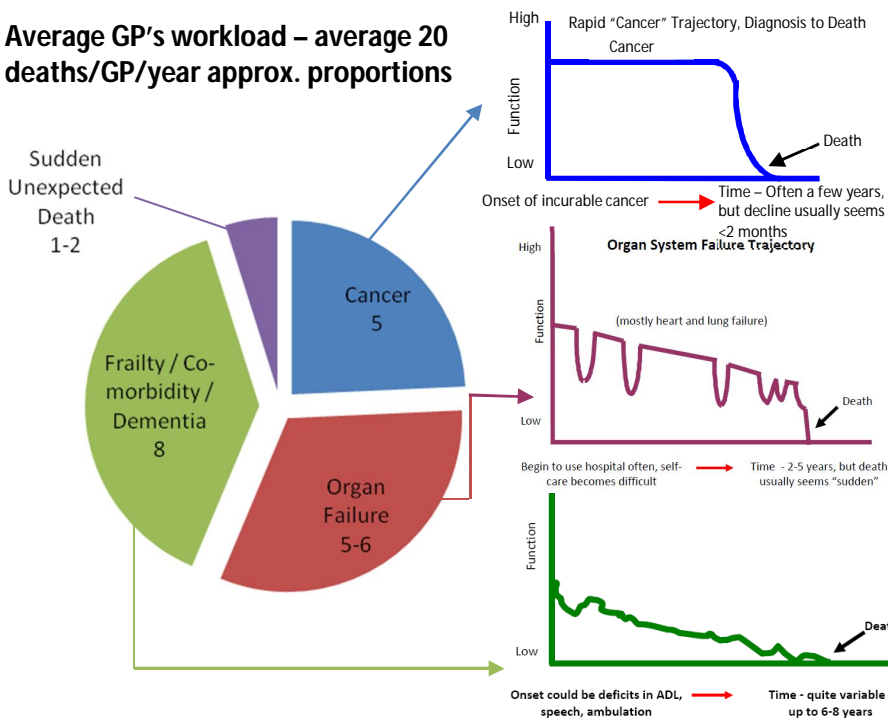
People are 'approaching the end of life' when they are **likely to die within the next 12 months**. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

## Three triggers that suggest that patients are nearing the end of life are:

1. **The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days?'**
2. **General indicators of decline - deterioration, increasing need or choice for no further active care.**
3. **Specific clinical indicators related to certain conditions.**

### Average GP's workload – average 20 deaths/GP/year approx. proportions



### Typical Case Histories



1) Mrs A - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline

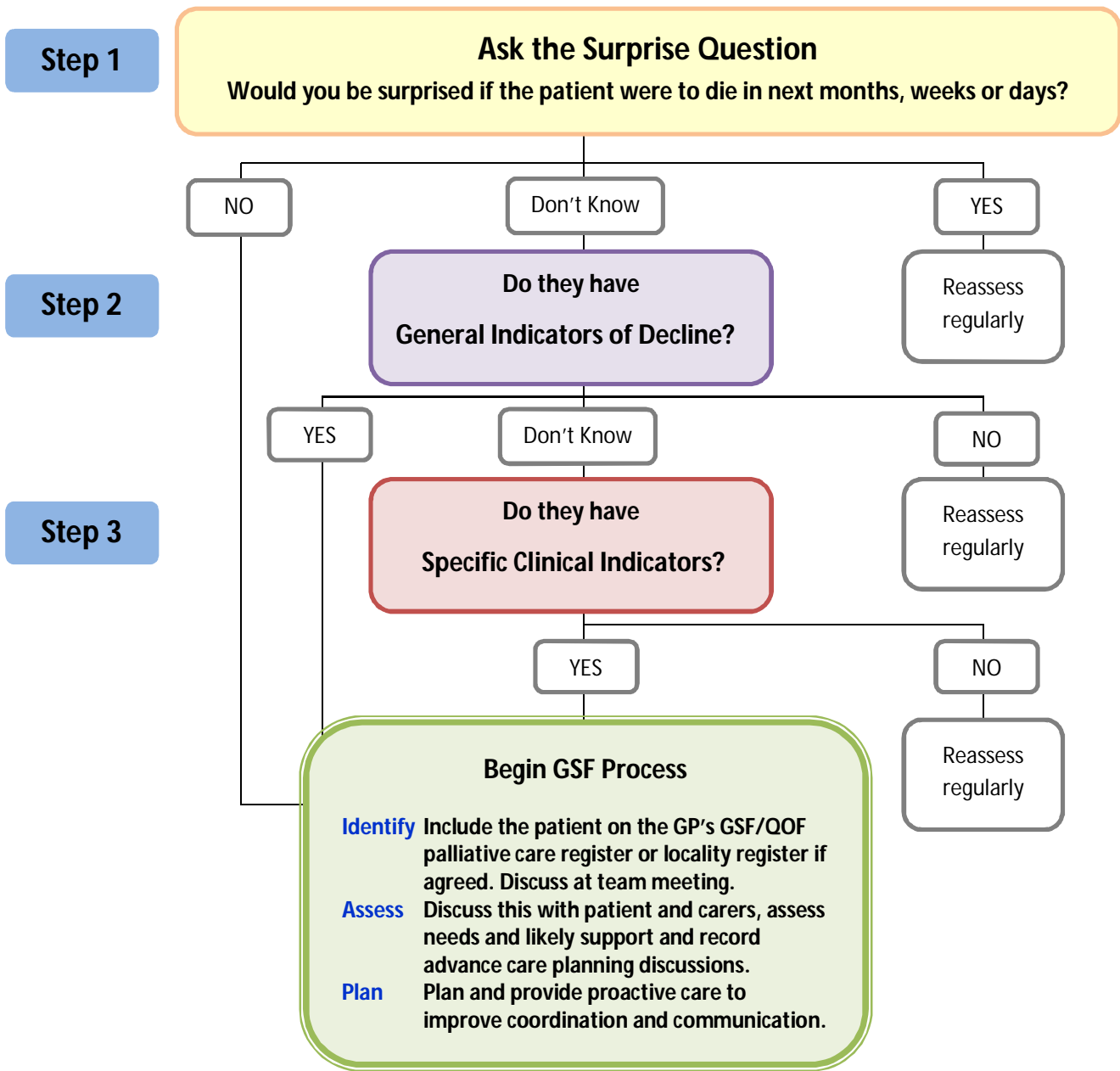


2) Mr B - An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline



3) Mrs C - A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline

Summary of suggested three steps for earlier identification



How to use this guidance – what next?

GSF Needs Based Coding



This guidance aims to clarify the triggers that help to identify patients who might be eligible for inclusion on the register (supportive/palliative care/ GSF/ locality registers). Once identified and included on the register, such patients may be able to receive additional proactive support, leading to better co-ordinated care that also reflects people's preferences. This is in line with thinking on shared decision-making processes and the importance of integrating advance care planning discussions into delivery of care. It is based on consideration of people's needs rather than exact timescales, acknowledging that people need different things at different times. Earlier recognition of possible illness trajectories means their needs can be better anticipated and addressed. Specific tasks for each stage are part of the GSF Programmes in different settings, to enable better proactive coordinated care.



## Step 1 The Surprise Question

**For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?**

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

## Step 2 General Indicators

### Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

### Functional Assessments

**Barthel Index** describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc .

**PULSE** 'screening' assessment - P (physical condition); U (upper limb function); L (lower limb function); S (sensory); E (environment).

**Karnofsky Performance Status Score** 0-100 ADL scale .

**WHO/ECOG Performance Status** 0-5 scale of activity.

## Step 3 Specific Clinical Indicators - flexible criteria with some overlaps, especially with Those with frailty and other co-morbidities.

### a) Cancer – rapid or predictable decline

#### Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc. 'Prognosis tools can help but should not be applied blindly'
- '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.

### b) Organ Failure – erratic decline

#### Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

#### Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

### Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

### General Neurological Diseases

- Progressive deterioration in physical and/ or cognitive function despite optimal therapy
- Symptoms which are complex and too difficult to control
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communications and progressive dysphasia. Plus the following:

#### Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

#### Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence, needs ADL help
- The condition is less well controlled with increasing "off" periods
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Similar pattern to frailty- see below.

#### Multiple Sclerosis

- Significant complex symptoms and medical complications
- Dysphagia + poor nutritional status
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive impairment notably the onset of dementia.

## c) Frailty / Dementia – gradual decline

### Frailty

Individuals who present with Multiple co morbidities with significant impairment in day to day living and:

- Deteriorating functional score e.g. performance status – Barthel/ECOG/Karnofsky
- Combination of at least three of the following symptoms:
  - weakness
  - slow walking speed
  - significant weight loss
  - exhaustion
  - low physical activity
  - depression.

### Stroke

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

### Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3.

Plus any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia.

It is vital that discussions with individuals living with dementia are started at an early to ensure that whilst they have mental capacity they can discuss how they would like the later stages managed.

**Prognostication  
or prediction of need.**

Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators. Most people tend to give undue weight to prognosis and too little to the importance of planning for possible need, especially for those with non-cancer illnesses, frailty and co-morbidities. In order to identify more accurately those patients who need additional pro-active supportive care, the focus should be on a pragmatic, even instinctive, prediction of the rate and course of decline. Some specific tools can help to predict accurately the time remaining for cancer patients but they should be used with caution (BMJ .2011; 343:d5171)

**Rainy day thinking.**



**“Hope for the best but prepare for the worst.”**

We suggest a move towards earlier consideration and more ‘rainy day thinking’ – bringing an umbrella just in case it rains. This instinctive, anticipatory and ‘insurance-type’ thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilised.

If you can anticipate possible deterioration, then you can begin discussions about preferences and needs at an earlier stage. The aim of such advance care planning discussions is to establish patients’ sometimes unvoiced concerns, needs and preferences, enabling more people to live out the final stage of life as they choose (see ACP Guidance on GSF/ EOLC web-sites). This also means you can introduce practical measures to prevent crises and make referrals for extra help or advice.

**Needs Based Coding - the right care at the right time**

Patients have differing requirements at varying stages of their illness. The use of needs-based or colour coding can be very helpful in prioritising need. Some clinicians in care homes, GP practices and hospitals use this system to identify their patients’ stage of decline and so predict at an earlier stage their future needs. Although only a rough guide, this helps us focus on giving the right care at the right time, with regular reviews built in to trigger actions at each stage. As a result a needs/support care plan can be developed for each individual.

**Needs Based Coding and Needs Support Matrices**

Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient

- **A – All – stable from diagnosis**      **years**
- **B – Unstable, advanced disease**      **months**
- **C – Deteriorating, exacerbations**      **weeks**
- **D – Last days of life pathway**      **days**

For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes contact the GSF Centre.

**Long term conditions.** There is a strong correlation between care for patients with long-term conditions and those with advanced disease nearing the end of life. This is especially true for patients with organ failure (heart failure, COPD). Close collaboration with case managers can reduce unplanned admissions and support good end of life care.

**Primary care teams.** Identifying patients, the first step of GSF, is key to developing a Palliative Care Register, which forms part of the QOF palliative care points in the GMS contract.

**The National Primary Care Snapshot Audit (2010)** in England demonstrated 3 key findings:

- Only about **25%** of patients who died were included on the GP’s Palliative Care/ GSF register
- Only **25%** of these had non-cancer conditions
- Most importantly, those patients identified early and included on the register received **better quality coordinated care**

Therefore this affirms the need for earlier recognition and identification of people nearing the end of life where possible, i.e. the 1% of the population who die each year, greater representation of patients with non-cancer, organ failure, and those with frailty and dementia is recommended, including those from care homes.

**Two helpful questions for practice teams to ask:**

- 1. What is your register ratio?** The number of patients on your palliative care register over the number who died in your practice (using the 1% rule as an approximation e.g. 5000 population = about 50 deaths/ year).
- 2. What is your non-cancer/cancer ratio on register?** What percentage of patients on the register has cancer or non-cancer conditions as their main cause of death?

For more details on the QOF points and guidance on Next Stage GSF in Primary care, see the GSF website.

**Care homes.** Use of the surprise question and this guidance has been found to help identify residents who are most in need in care homes. This can help focus care and trigger key pro-active support, thereby leading to reduced hospital deaths (e.g. halving of death rate in care homes using GSF in Care Homes Programme).

**Acute hospital teams.** About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there. Improved early identification of people in the final year of life helps reduce hospitalisation and accessing supportive and palliative care services. It is extremely helpful if hospital teams notify GPs that a particular patient has advanced disease and might be included on their register.

**Specialist teams.** Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care. These include those with dementia, care of the elderly, heart failure, etc. and this guidance may help clarify referrals.

**Commissioners/managers.** This guidance could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.

"It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time... However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need. **Identifying** patients in need of palliative care, **assessing** their needs and preferences and proactively **planning** their care, are the key steps in the provision of high quality care at the end of life in general practice."  
(Quality and Outcomes Framework (QOF Guidance) 2011/12 Guidance)

**'It is recommended that people approaching the end of life are identified in a timely way.'**  
(Draft Recommendation NICE Guidance in End of Life Care 2001)

**This is not attempting to answer the question that doctors often hear - 'how long have I got?' Rather, it responds to the underlying sometimes unspoken questions from people facing a new reality 'If I haven't got long, then what should I do and how can you help?'**  
(Thomas K GSF Centre 2008)

"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". (DH End of Life care Strategy 2008 England)

Identification of people with a life-limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgement and weighing up a complex mix of pathology, clinical findings, therapeutic response, co-morbidities, psychosocial factors, and rate of decline. (Glare P J Palliat Med 2008)

**"Using the GSF 'PIG' has helped us to identify these patients earlier than we previously did, especially those with non-cancer, thereby giving them earlier support as they face the end of their lives, leading to fewer crises and hospital admissions."** (GP using Next Stage GSF Training Programme 'Going for Gold')

**Development of this guidance paper.** This guidance was originally commissioned from the GSF Centre in June 2006 to support GPs include appropriate patients on their QOF Palliative Care Registers i.e. those considered to be in the final 12 months of life. It is regularly revised following extensive consultation with clinical and disease specialist groups, palliative care specialists and GPs in the Royal College of General Practitioners. Particular thanks go to the NHS End of Life Care Programme and University of Edinburgh team for their help. Since publication, this Guidance has been widely used by clinicians in many sectors in the UK and internationally. A list of detailed references is available on request. This is one of several tools available to support improvements in End of Life Care, and further details on best use, IT support and further developments can be obtained from the GSF Centre.

#### Resources and Further Reading :

National Gold Standards Framework Centre for End of Life Care- Primary care, care homes and other areas [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)  
National Primary care Snapshot Audit (2009/2010) DH report + Next Stage GSF Primary Care Training [www.goldstandardsframework.org.uk/GSFInPrimary+Care](http://www.goldstandardsframework.org.uk/GSFInPrimary+Care)  
NHS End of life care Programme [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)  
NHS Department of Health. End of Life Care Strategy (2008) P51, 3.22 <http://www.endoflifecareforadults.nhs.uk/strategy/strategy>  
GMC End of Life Care [www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf3](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf3)  
QOF Palliative Care - [www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract\\_2011\\_12\\_FL%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/QOFGuidanceGMScontract_2011_12_FL%2013042011.pdf)  
NICE Draft Quality standards in End of Life Care (for consultation- due Nov 2011) [www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp](http://www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp)  
National Audit Office. End of Life care Report Nov 08 [www.nao.org.uk/publications/0708/end\\_of\\_life\\_care.aspx](http://www.nao.org.uk/publications/0708/end_of_life_care.aspx)  
British Geriatrics Society. [www.bgs.org.uk/index.php?option=com\\_content...id](http://www.bgs.org.uk/index.php?option=com_content...id)  
The 'Surprise question': Lynn J 2005 Altarum Institute Center for Elder Care and Advanced Illness [www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf](http://www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf)  
Dying Matters- and the QIPP Find the 1% campaign - [www.dyingmatters.org.uk](http://www.dyingmatters.org.uk) or National Council for Palliative Care [www.ncpc.org.uk](http://www.ncpc.org.uk)  
Liverpool Care Pathway for the Dying Patient. <http://www.mcpcil.org.uk/liverpool-care-pathway/>  
QIPP Department of Health [www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention](http://www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention)  
Frameworks for Implementation (2010) from the End of Life Care Programmes - [www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework](http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework), [www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf](http://www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf), [www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia](http://www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia), [www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework](http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework)  
Renal advisory group of the NSF, British Renal Society, and British Transplant Society. [www.britishtrenal.org](http://www.britishtrenal.org)  
Barthel Score: Barthel's index of activities of daily living (BAI), [www.patient.co.uk/showdoc/40001654/](http://www.patient.co.uk/showdoc/40001654/)  
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SPICIT Guidance University of Edinburgh (2010). Supportive and Palliative Care Indicators tool (SPICIT) [www.palliativecareguidelines.scot.nhs.uk/careplanning/](http://www.palliativecareguidelines.scot.nhs.uk/careplanning/)  
SPOTLIGHT: Palliative care beyond cancer: Recognising and managing key transitions in end of life care: Boyd K, Murray S *BMJ* 341  
Watson M, Lucas C, Hoy A, Back I (2005) Oxford Handbook of Palliative Care. *Oxford University Press*

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