



Royal College of  
General Practitioners



Royal College  
of Nursing

# Matters of Life and Death



Helping people  
to live well  
until they die

General practice guidance for implementing  
the RCGP/RCN End of Life Care Patient Charter

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# Preface

Patients, their carers and the people close to them need special care and support through the natural process of dying. GPs and the primary healthcare team have a special relationship with not just their patients but also with the patients' carers and the people close to the patient. The GP and the primary healthcare team have the ability to coordinate good care and to help reduce some of the worry and stress when someone is at the end of his or her life. Key to this is having a guide to best practice. Patients, nurses, GPs, specialists and others from health and social care have worked together to develop this guidance. It will be revised over time based on feedback from patients, carers and primary healthcare teams, but we hope it will be a means to encourage and support best care for your patients nearing the end of life and their carers with bereavement.

The End of Life Care Patient Charter and this guidance were a collaboration between the Royal College of General Practitioners (RCGP) End of Life Care English Working Group, the RCGP Patient Partnership Group, the Royal College of Nursing (RCN) and specialists and others from

health and social care. This is a UK-wide web resource with signposts to guidance, policy, support and advice relevant to practitioners in Northern Ireland, Scotland and Wales.

This is about matters of life as well as death; it is about helping people and their families to live well until they die. *'Palliative care at home embraces what is most noble in medicine: sometimes curing, always relieving, supporting right to the end'* (Gomas 1993).

We hope that you will find this an invaluable resource.

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**August 2012**

# 1 Introduction

Caring for people nearing the end of life is one of the most important things we do, as doctors, nurses, clinicians, managers and, at a human level, as people. With the ageing population, primary care is at the front line in the increasing need for provision of care for this most vulnerable group of people. Although we undoubtedly care a great deal for our patients, things can still too often go wrong – and some of these things are preventable with better proactive teamwork and planning. We need to rethink our more reactive approach, which can sometimes by default lead to inadequate care, and start to identify people earlier and plan ahead. The time to do this is now!

Some of the needs and wishes of patients and their families have been expressed in the End of Life Care Patient Charter, developed by patient representatives from

the RCGP Patient Partnership Group in collaboration with GPs and nurses. This booklet and other resources aim to support and enable you to attain the kind of care that patients and their families are seeking through the charter. We are aware how hard this is, and that this is an evolving process, but we are committed in supporting you to provide the best-quality care for those that need it most.

Planning ahead involves considering our whole practice population, recognising those who might possibly be nearing the final year, months or weeks of life, and planning proactive, well-coordinated care in alignment with their wishes. This enables more to live and die as they choose and improves cost-effectiveness by reducing avoidable hospitalisation.

## 2 Definition of end of life care

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.

*Source: General Medical Council 2010.*

**Definition used by the GMC and NICE End of Life Care Working Group, [www.gmc-uk.org](http://www.gmc-uk.org).**

## 3 Context of end of life care

As people live longer, increasing numbers of our patients have long-term, advanced conditions requiring more complex support towards the final stages of life.

So, although there is good progress for many cancer patients, the majority of people who die have non-cancer conditions such as heart failure, chronic obstructive pulmonary disease (COPD), dementia, frailty and multiple co-morbidities. Recent reports confirm many patients may still not be receiving the best level of support and care as they near the end of life. This is in part because it is harder to identify them early enough, their course of decline is erratic, unpredictable or protracted, and they may require complex health and social care provision in a number of settings, crossing the boundaries of care.

*'You matter because you are you, you matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die'*

(Dame Cicely Saunders)

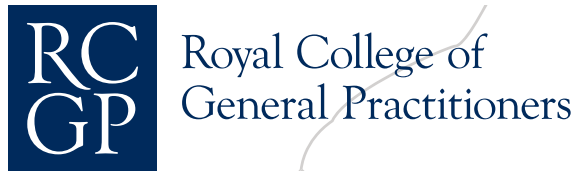
The statistics regarding end of life care also prompt us to review how we can improve the provision of this care.

- About 1% of the population die each year, with an estimated 17% increase from 2012.
- About 35% are home deaths (18% home, 17% care home) and 54% die in hospital.
- 40% of deaths in hospital could have occurred elsewhere (National Audit Office 2008).
- 60–70% of people do not die where they choose.
- 75% of deaths are from non-cancer conditions.
- 85% of deaths occur in people over 65.
- £19,000 per non-cancer patient (National Audit Office 2008).
- £14,000 per cancer patient is the average cost/patient/final year (National Audit Office 2008).
- On average each patient will have three crisis admissions in the final year of life, costing £3200 on average.

## 4 How to use the guidance

- We suggest that you discuss the Charter as a primary healthcare team. This includes working with community nursing, social care and palliative care teams. Seek views from your patient group and talk about it with patients and carers who you are supporting. They may be happy to help others and to share their experience.
- Decide whether you feel able to sign up to the Charter and add the name and contact number for the relevant person within your practice at the bottom of the Charter.
- Give the Charter to patients and the carers of people who are nearing the end of their life, e.g. those on the practice palliative care/Gold Standards Framework (GSF) register. It may lead to further discussion and a need for some clarification.
- Display the Charter in your waiting room and include it in your practice information pack.
- Use the Charter as a standard against which to review your care. Such review or audit could be included as one of the aspects of your own appraisal, revalidation or practice accreditation.
- If you feel you need help in implementing certain aspects of the Charter or require further training and support, discuss this with your local palliative care/end of life care team or facilitators. Visit the RCGP website at [www.rcgp.org.uk/endoflifecare](http://www.rcgp.org.uk/endoflifecare), the Gold Standards Framework (GSF) at [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk) or the National End of Life Care Programme at [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).
- Further information and guidance is available to download from the RCGP website at [www.rcgp.org.uk/endoflifecare](http://www.rcgp.org.uk/endoflifecare).

## 5 Patient Charter



### End of Life Care Patient Charter

**A charter for the care of people who are nearing the end of their life**

*"You matter because you are you, you matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die"* Dame Cicely Saunders

We want to offer people who are nearing the end of their life the highest quality of care and support. We wish to help you live as well as you can, for as long as you can. Therefore, if and when you want us to, we will:

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavour to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.
- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement.

We also invite your ideas and suggestions as to how we can improve the care and support that we deliver to you, the people who are important to you and others in similar situations.

*For more information from your Practice Team please contact*

Name .....

Phone Number.....

Leading the Way: High-Quality End of Life Care Through General Practice

Developed by RCGP English End of Life Working Group, Patient Partnership Group and Royal College of Nursing (2011)

## 6 Supporting information

The following information is to support your use of the guidance and the End of Life Care Patient Charter.



### The Gold Standards Framework programmes in end of life care

GSF programmes enable generalist frontline staff to deliver a 'gold standard of care' for all people nearing the end of life by improving the quality and organisation of care.

GSF is a systematic, common-sense approach to formalising best practice, so that quality End of Life Care becomes standard for every patient. It helps clinicians identify patients in the last year of life, assess their needs, symptoms and preferences, and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of

patients and their families, and encourages inter-professional teams to work together. GSF was developed originally for primary care and is now extensively used by GP practices throughout the UK, with 95% using foundation-level GSF throughout the Quality and Outcomes Framework (QOF). The GSF Care Homes Training Programme was developed from this in 2004 and is widely used. The GSF Acute Hospitals work is well underway and continues to spread to other settings in the UK and worldwide.

### Gold Standards Framework – three simple steps

1. *Identify* patients who may be in the last year of life and identify their stage. Use the surprise question + prognostic guidance + needs-based coding.
2. *Assess* current and future clinical needs and personal needs. Use assessment tools, advance care planning (ACP), etc.
3. *Plan*. Develop an action plan of care. Use 7 Cs key tasks, Needs Support Matrix, passport information, checklist and other tools, and develop action plan of care.

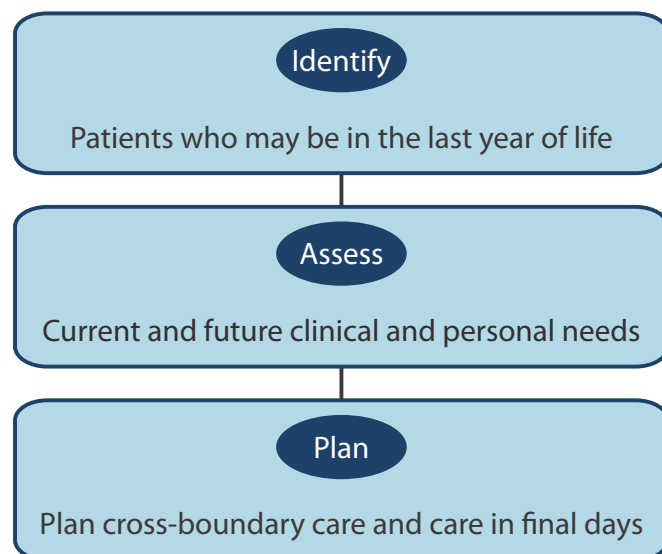
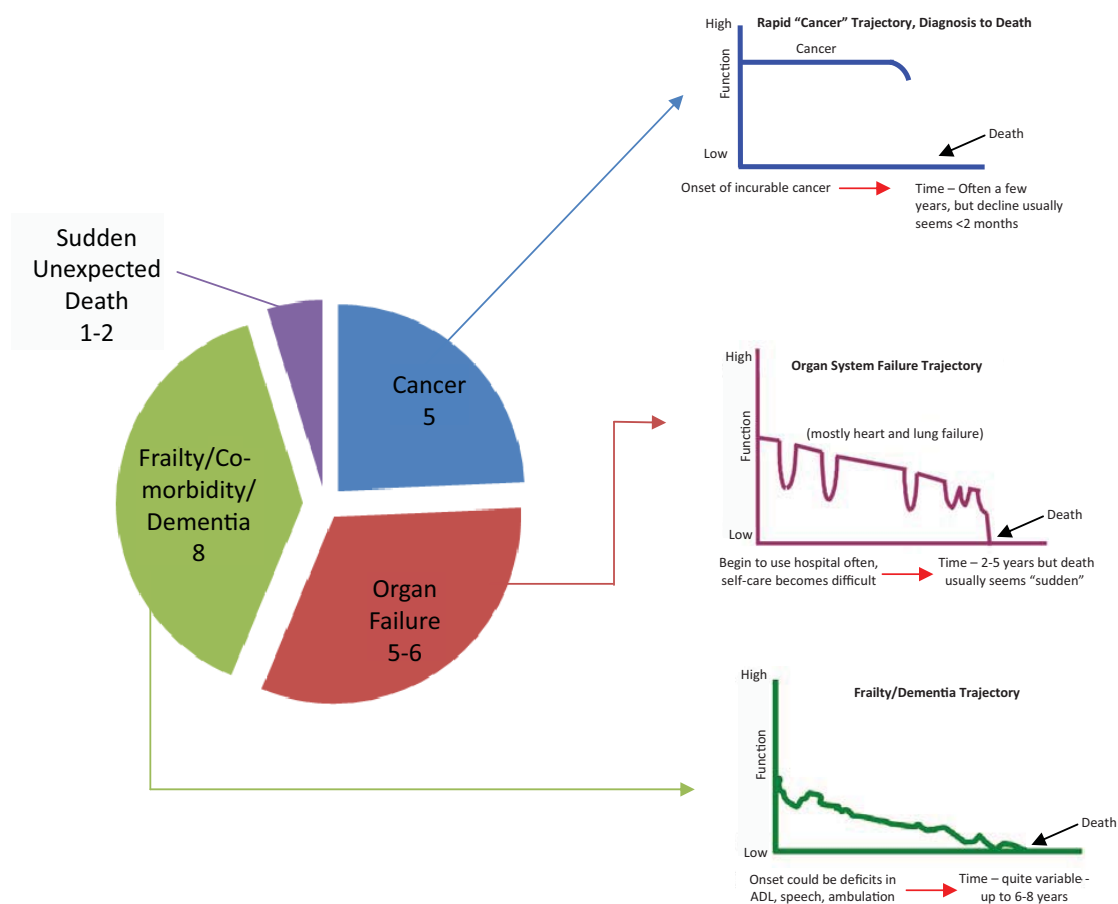


Figure 1: Three steps to the GSF

## Needs-based coding

For people at different stages of their illness trajectory, using the 'surprise question' to predict the likely stage of deterioration; to clarify their main needs and required support; to provide the right care at the right time for each person (see GSF Needs Support Matrices as part of GSF Programmes).



**Figure 2: Gold Standards Framework – three typical trajectories of illness and application to a typical GP caseload**

Source: Lynn 2005

GPs and the primary care teams play a key role in this area. A recent market research survey undertaken by the firm ComRes for the Dying Matters Coalition in 2011 revealed:

- 75% of GPs say that end of life care is important to them
- although most people have not discussed end of life care with their families, most (78%) think that it is the health professional's job to talk to them about these issues
- older people (85–89-year-olds) see their GP on average 14 times/year
- a fifth of hospital bed days are occupied by patients who would not wish to be there.



# 7 Identifying people nearing the end of their life

We need to identify which patients might be nearing the end of life. The first step is using the Patient Charter.

End of Life Care Patient Charter

Identifying those patients who may be nearing the end of life is the important first step in this process. Evidence suggests that, if patients are identified and included on the palliative care/GSF register, then they are more likely to receive proactive, well-coordinated care.

## Key question

How can you identify the 1% of patients nearing the end of life in your practice population?

If you use the working definition of end of life care of those being approximately in the final year or so of life, and you know that about 1% of the population die each year, we can estimate how many of our patients might be included on the register.

There are two key questions to help you identify who should be on your register.

## Two key questions

### 1. What is your register ratio?

- What is the approximate predicted annual death rate for your practice population, e.g. 1% of your practice population. If your practice consists of 8000 patients, this equates to about 80 deaths/year.
- How many patients do you have on your practice palliative care/GSF register in one year, e.g. 20 patients/year.
- What proportion of all people who died were on your palliative care register, e.g. in this example this is 20/80 or 25%.
- Now work out your practice figure.

- Is this good enough? What is a realistic figure and how can you improve?
- *Note:* in the National Primary Care Snapshot in End of Life Care this figure was 27%. Many find their proportion is lower and some higher. If they include more in nursing homes or with long-term conditions, or based on need, their prognosis might be longer.

### 2. What is your non-cancer/cancer ratio?

- About 25% die from cancers and 75% from non-cancer conditions of the patients on your palliative care/GSF register. How many have cancer and how many non-cancer conditions? What is your practice percentage?
- Is this good enough? What is a realistic figure and how can you improve this?
- *Note:* in the National Primary Care Snapshot in End of Life Care, only 23% of patients on the register had non-cancer conditions.

## Further questions to help you identify who should be on your register

### How can you include more patients on the Palliative Care Register?

- Use 'the surprise question' – would you be surprised if this patient were to die in the next year/months/weeks? If it would not be a surprise, what could be done to be prepared just in case this occurred?
- See guidance to increase chances of predicting these patients, e.g. the revised Prognostic Indicator guidance (GSF and RCGP websites – see later and RCGP microsite,

[www.rcgp.org.uk/end\\_of\\_life\\_care/home.aspx](http://www.rcgp.org.uk/end_of_life_care/home.aspx)), or other guidance.

- Consider all patients with long-term conditions or those patients on the QOF disease registers for cancer, heart failure, COPD, dementia, stroke and renal disease. What might lead you to think that they may be deteriorating or nearing the final months of life and require additional supportive and palliative care?
- Consider the residents within care homes in your area, especially those in nursing homes. With increasing complexity and decreasing length of stay in care homes, many residents may be in their final year of life, requiring good end of life care. They might be considered for your palliative care/GSF register.
- Those care homes having undertaken the GSF Care Homes Training Programme might be informing you of their estimated needs-based coding. Care home staff might well be aware of those in the final months/weeks of life.
- Invite members of your local hospice/specialist palliative care teams to join GSF meetings. They may be aware of patients who are approaching the end of life, referred from other sources.
- See the Dying Matters 'Find Your 1% Campaign' ([www.dyingmatters.org/gp](http://www.dyingmatters.org/gp)).

## What other patient groups could be considered?

### *Long-term/chronic conditions.*

Patients with long-term conditions or who are on the six key QOF registers (i.e. COPD, dementia, heart failure, cancer, stroke, and kidney disease) may be suitable for inclusion on the Palliative Care Register. In the same way, consider whether they are receiving optimal best-practice care.

### *Care homes*

Almost a fifth of all patients die in care homes, and of course this includes some of the most vulnerable – those with significant frailty, dementia and other life-limiting conditions. With more living at home longer, the average length of stay in nursing homes is decreasing and is now under a year, so many homes are very experienced with

caring for dying patients. Your role as GP is vital here. Some care homes, e.g. those using the GSF Care Homes Programme, use the needs-based coding system and will work with you to focus on the most needy. As with all end of life care, identifying, assessing, prioritising and planning can lead to better use of resources.

### *Patients with dementia*

Patients with dementia may die either *from* the condition or, more commonly, *with* the condition as part of a range of other illnesses. Usually, the dying trajectory is more prolonged and with a gradual decline. Their end of life care may present a number of challenges for primary care.

- *Assessment of pain/distress:* for people with advanced dementia, the assessment of pain and distress may require detailed observation from those caring for them, as they are often unable to directly communicate their needs. A range of assessment tools is available to help assess these symptoms, for example the Pain Assessment in Advanced Dementia (PAINAD) scale, but no one tool is currently recommended. It is available at [prc.coh.org/PainNOA/OV.pdf](http://prc.coh.org/PainNOA/OV.pdf).
- *Decision making:* this may be by proxy views from family carers unless the patient has made an advance statement prior to loss of mental capacity, which indicates their wishes. Where possible, best-interest decisions should be made, incorporating what the patient would have wanted with family and carer views.
- *Use of existing end of life tools and care pathways:* these will help assess when a patient requires more palliative care. End of life care pathways will help improve the quality of care at the very end of life, but because of the nature of dying may need to be used for longer than a few days.

## How can you best manage your register?

- Prioritise those with most urgent needs to be able to handle them proactively but bear the others in mind for later.
- See the needs-based coding (see Figure 3), and use the 'Needs Support Matrices' in the GSF Primary Care Programme; use a whiteboard or coding register to consider which patients require most help.
- Discuss these patients regularly, preferably at a monthly

team meeting, to ensure you are planning ahead for likely issues and that the care provided is in line with their stated wishes and preferences.

- Include patients based on their need as well as prognosis, e.g. those with difficult symptom control or coordination of care.

- A well-populated register gives each person put on it an advantage they did not previously have, in respect to their care.

# Identify – Needs-Based Coding

## Identify stage of illness – 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**



Figure 3: Needs-Based Coding

Source: Thomas K. *Prognostic Indicator Guidance (PIG)* (4th edn), 2011. Copyright © The National Gold Standards Framework Centre in End of Life Care CIC.

## Actions

Identify and make links with the appropriate local teams to ensure you are able to send and receive referrals when necessary.

Regularly review your practice population and update the register.

## Resources

- *GSF Prognostic Indicator Guidance*, 'Ask the Surprise Question' guide and Needs-Based Coding ([www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf](http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf)).
- Dying Matters 'Find Your 1% Campaign' ([www.dyingmatters.org/gp](http://www.dyingmatters.org/gp)).
- PAINAD – dementia pain assessment tool ([prc.coh.org/PainNOA/OV.pdf](http://prc.coh.org/PainNOA/OV.pdf)).

Following (Figures 4 and 5) is a summary of the suggested three steps for early identification, which is taken from the GSF *Prognostic Indicator Guidance*.

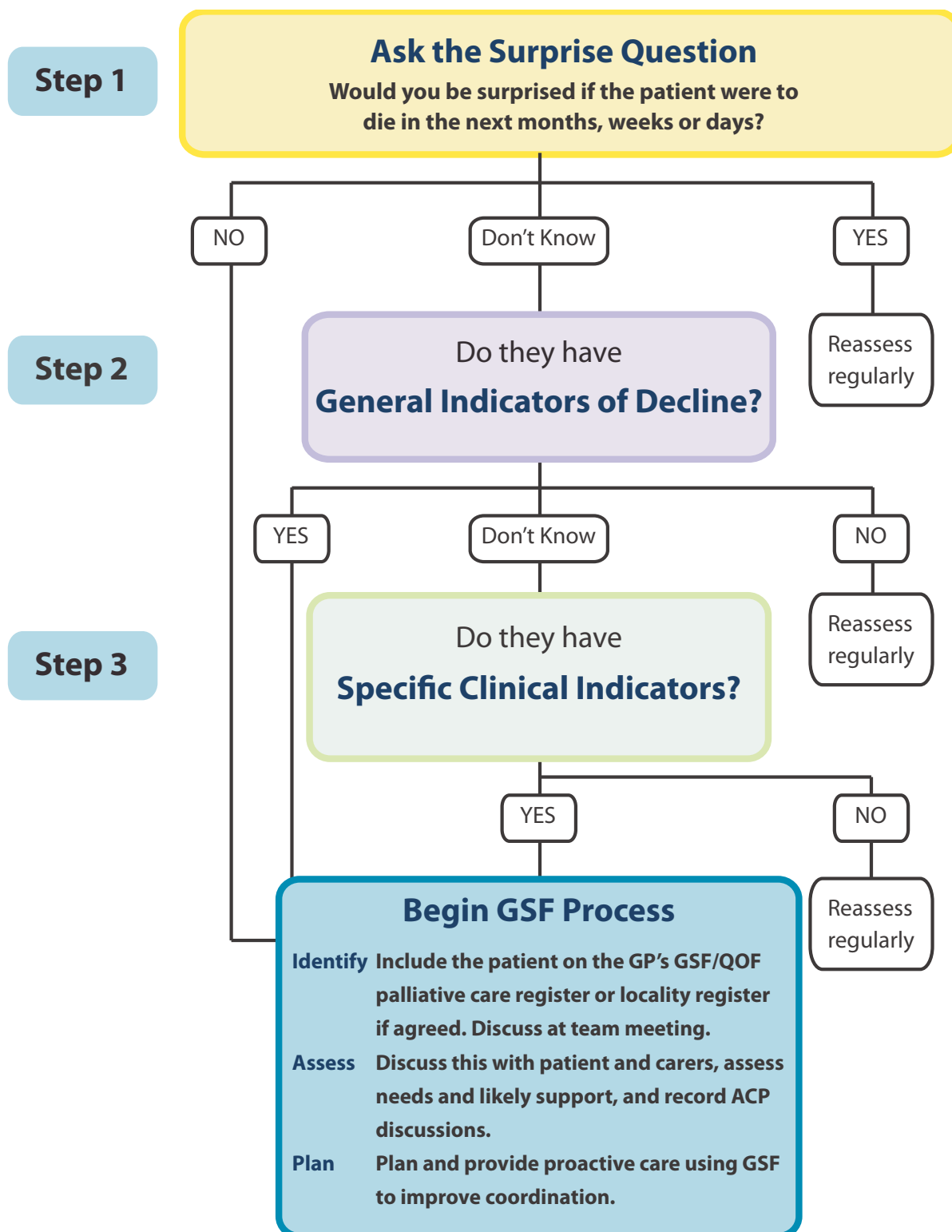


Figure 4: Summary of the three steps for early identification

Source: Thomas K. *Prognostic Indicator Guidance (PIG)* (4th edn), 2011. Copyright © The National Gold Standards Framework Centre in End of Life Care CIC.

## 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 a nursing home.
- Serum albumen <25 g/l.
- Considered eligible for DS1500 payment, i.e. prognosis under six months.

### 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

### 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.

### Dementia

There are many underlying conditions that may lead to degrees of dementia and these should be taken into account. Triggers to consider which 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 ADL
- Barthel score >3.

Plus any of the following:

- weight loss
- urinary tract Infection
- severe pressure sores – stage three or four
- recurrent fever
- reduced oral intake
- aspiration pneumonia.

Figure 5: The three steps

## 8 Assessing needs and wishes – advance care planning discussions

We will...

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavour to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.

From the Patient Charter

### Key questions

How well are you as a practice team able to listen to the needs and wishes of patients and those that care for them? How confident do you feel in having ACP discussions? Are you able to offer and record such discussions to every patient on the palliative care/GSF register?

We need to give patients the opportunity to say what they want to discuss. The challenge is how to give the opportunity for a discussion while not imposing one, and gently helping people come to terms with their new reality and its practical and emotional implications. GPs are very good at discussing difficult issues with patients once the conversations get going. Frequently the bottleneck is opening the door to the conversation that is there to be had.

We need to tread gently here in offering sensitive, open discussions and information to our patients nearing the end of life, only to the level that they seek. But there is some evidence that more patients would like to discuss their needs, wishes and preferences than are currently able to do so, through what are known as 'advance care planning' discussions. This does not always need to involve the GP, though for many this would be appropriate. Nurses, social

care professionals, clergy and volunteers in the community or in care homes can be involved in this process. It is especially important for patients with dementia to be able to have this discussion early before they deteriorate.

Your local hospice or specialist palliative care team may be able to help with such conversations in the event that they are difficult or will benefit from a specialist perspective.

Recent guidance from the Royal College of Physicians on ACP ([www.advancecareplanning.org.uk](http://www.advancecareplanning.org.uk)) recommends that these discussions are held mainly by someone with whom the patient has a longer-term relationship, such as his or her GP, nurse or carer in care home, etc.

### Example of questions to ask in ACP discussions

- Can you tell me about your current illness and how you are feeling?
- Could you tell me what the most important things are to you at the moment?
- Who is the most significant person in your life?
- What fears or worries, if any, do you have about the future?

- In thinking about the future, have you thought about where you would prefer to be cared for as your illness gets worse?

- What would give you the most comfort when your life draws to a close?

Source: Horne and Seymour 2006.

<i>Advantages of ACP and decision making</i>	<i>Disadvantages of ACP and decision making</i>
<ul style="list-style-type: none"> <li>• Respect the person's human rights.</li> <li>• Encourage full discussion about end of life decisions.</li> <li>• Doctors are more likely to give appropriate treatment.</li> <li>• Help difficult decision making.</li> <li>• Family/friends do not have to make difficult decisions.</li> </ul> <p>ACP may improve patients' quality of life by continuing to:</p> <ul style="list-style-type: none"> <li>• create mutual understanding</li> <li>• enhance openness</li> <li>• enable discussion of concerns</li> <li>• give hope</li> <li>• relieve fears about the 'burden' of decision making</li> <li>• strengthen family ties.</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulty in initiating discussion.</li> <li>• Anticipating the future and how an individual responds to such circumstances is complex.</li> <li>• Requires review and updates.</li> <li>• Availability of documentation for others and ensuring it can be interpreted.</li> <li>• Communication to others can be difficult. There are cultural and psychological challenges.</li> <li>• Sensitive to cultural interpretations.</li> <li>• Changing views over time.</li> <li>• Clash of viewpoints.</li> <li>• The impact of a 'bad news' interview.</li> <li>• A desire to 'live for the moment' or 'take one day at a time'.</li> </ul> <p style="text-align: right;">Source: Thomas and Lobo 2011, p. 10.</p>

**Table 1: Advantages and disadvantages of ACP**

## Assessing and managing symptoms

- Seek advice from your local specialist palliative care service, e.g. hospice, community CNS/Macmillan nurses.
- Consult your locally developed guidelines.
- See the RCGP end of life care website.
- PalliApp – available through iTunes App Store for £2.99 at <http://itunes.apple.com/gb/app/palliapp/id441961088?mt=8>.
- Seek specific courses or training in your area.

## Key questions

- What symptoms do you find hardest to manage?
- Where do you seek help and what could help you further?
- What assessment tools do you find helpful, e.g. holistic assessment tools, pain charts, dementias, depression, etc.?

## Actions

Consider if all staff that will be involved in ACP discussions have the confidence and competency to do so. Arrange training if necessary. If you feel you need further support seek advice from your local specialist palliative care service (e.g. hospice, community CNS/Macmillan nurses) and consult your locally developed guidelines.

## Resources

- Royal College of Physicians. *Advance Care Planning: national guidelines* (No.12 in the Concise Guidance to Good Practice Series) London: RCP, 2009, <http://bookshop.rcplondon.ac.uk/details.aspx?e=267>.
- PalliApp – available through iTunes App Store for £2.99 at <http://itunes.apple.com/gb/app/palliapp/id441961088?mt=8>.
- Advanced care planning guidance and support from the NHS End of Life Care Programme at [www.endoflifecareforadults.nhs.uk/publications/pubacpguidepdf](http://www.endoflifecareforadults.nhs.uk/publications/pubacpguidepdf).

## 9 Planning care and support

We will...

- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement.

Planning, providing and coordinating care

### Care and support for the patient

Some issues to consider when planning the care and support for your patient are:

- proactive planning and thinking ahead to consider likely anticipated needs and requirements including team meetings to focus on the future needs for patients on the register
- taking into account Locality Registers if you have them in your area and communicating to others involved, including cross-boundary care with hospitals, care homes, hospices, specialist palliative care teams and others
- ensuring out-of-hours and urgent-care services have the information they need, e.g. using the Handover Form for the Out-of-Hours Provider
- supporting carers, families and children before and in bereavement, and care in the dying stage, e.g. use of Liverpool Care Pathway.

The burden of poor health is not just a medical experience. The ability to manage at home can be supported by carer assessments, benefits reviews, carers' organisations, and comprehensive nursing and social care packages.

### Key questions

- What proportion of your patients die at home/care home/hospital?
- How are you ensuring that your patients are listened to, and their preferences and choices are respected, as they near the end of their lives?
- How do you support the family and carers of those nearing the end of life?

### Care and support for family and carers

Carers' assessment and support is a crucial area and one that will often require further specific efforts by primary care teams. It is one of the most important aspects of the care provided by primary healthcare teams. Carer breakdown is a key factor in prompting institutionalised care for dying patients. This is the experience of most healthcare professionals and is reflected clearly by carers themselves and in current research. If we are to enable more to live well and die well, supporting carers is a key factor.

For further information on supporting carers, see [http://www.rcgp.org.uk/professional\\_development/continuing\\_professional\\_devt/carers.aspx](http://www.rcgp.org.uk/professional_development/continuing_professional_devt/carers.aspx).



## Supporting carers in end of life care

- Acknowledge carers, what they do, and the problems they have.
- Flag the notes of informal carers so that in any consultation you are aware of their circumstances.
- Treat carers as you would other team members and listen to their opinions.
- Include them in discussions about the person they care for.
- Give carers a choice about which tasks they are prepared to take upon themselves.
- Ask after the health and welfare of the carer as well as the patient.
- Provide information about the condition the person the carer is looking after suffers from.
- Provide information about being a carer and support available.
- Provide information about benefits available.
- Provide information about local services available for both the person being cared for and the carer.
- Be an advocate for the carer to ensure services and equipment are appropriate to the circumstances provided.
- Liaise with other services.
- Ensure staff are informed about the needs and problems of informal carers.
- Respond quickly and sympathetically to crisis situations.

*Source: Simon 2001.*

**Measures GPs can take to improve the quality of life of informed carers**

# 10 Sources of additional help and support

## General

### RCGP End of Life Care

[www.rcgp.org.uk/endoflifecare](http://www.rcgp.org.uk/endoflifecare).

### RCGP – Supporting Carers

[www.rcgp.org.uk/professional\\_development/continuing\\_professional\\_dev/carers.aspx](http://www.rcgp.org.uk/professional_development/continuing_professional_dev/carers.aspx)

### NHS End of Life Care website (England)

The Department of Health End of Life Care Programme has a wide range of guidance and policy documents including links to events, publications, care pathways, tools, care settings, case studies, data and statistics.

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

### National Gold Standards Framework Centre

Enabling generalists in end of life care through training, resourcing and evaluation – used in primary care, care homes, acute hospitals, domiciliary care, etc.

[www.goldstandardsframework.org.uk/](http://www.goldstandardsframework.org.uk/)

### National Council for Palliative Care

The umbrella organisation for all involved in palliative care.

[www.ncpc.org.uk](http://www.ncpc.org.uk)

### General Medical Council

*Treatment and Care towards the End of Life: good practice in decision making*, 2010.

[www.gmc-uk.org/static/documents/content/End\\_of\\_life.pdf](http://www.gmc-uk.org/static/documents/content/End_of_life.pdf)

### QOF Palliative Care Points Guidance

*Quality and Outcomes Framework: guidance for GMS contract 2011/12*, 2011.

[www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract\\_2011\\_12\\_FL%2013042011.pdf](http://www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL%2013042011.pdf)

## Identification of patients

### GSF Prognostic Indication Guidance

Thomas K. *Prognostic Indicator Guidance (PIG)* (4th edn) Shrewsbury: GSF Centre CIC, 2011.

[www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf](http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/General/Prognostic%20Indicator%20Guidance%20%20Final%20Sept%202011.pdf)

### Palliative Care Guidelines Scotland

'Identifying patients for supportive and palliative care' – Supportive & Palliative Care Indicators Tool.

[www.palliativecareguidelines.scot.nhs.uk/documents/SPIC T.pdf](http://www.palliativecareguidelines.scot.nhs.uk/documents/SPIC T.pdf)

## Advance care planning

### Mental Capacity Act information booklets

[www.dca.gov.uk/legal-policy/mental-capacity/publications.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/publications.htm)

### Royal College of Physicians

*Advance Care Planning: national guidelines* is concise guidance to good practice.

Royal College of Physicians. *Advance Care Planning: national guidelines* (No.12 in the Concise Guidance to Good Practice Series) London: RCP, 2009.

<http://bookshop.rcplondon.ac.uk/details.aspx?e=267>

### NHS End of Life Care Programme

ACP guidance and support from the NHS End of Life Care Programme:

- a guide for health and social care staff – [www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3](http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet3)
- a volunteer training programme for ACP – [www.endoflifecareforadults.nhs.uk/education-and-training/acp-for-volunteers](http://www.endoflifecareforadults.nhs.uk/education-and-training/acp-for-volunteers)
- Preferred Priorities of Care, a tool for discussion and

recording end of life care wishes –  
[www.endoflifecare.nhs.uk/eolc/ppc.htm](http://www.endoflifecare.nhs.uk/eolc/ppc.htm)

- *Advance Decisions to Refuse Treatment: a guide for health and social care staff* is a guide to help health and social care professionals understand and implement the new law relating to advance decisions to refuse treatment, as contained in the Mental Capacity Act 2005. The 'My Advance Decision to Refuse Treatment' form is an example pro forma –  
[www.endoflifecareforadults.nhs.uk/publications/pubadrt/guide](http://www.endoflifecareforadults.nhs.uk/publications/pubadrt/guide)
- *The Differences between General Care Planning and Decisions Made in Advance* (11 March 2010) is a guide to show differences between ACP and Advance Decision to Refuse Treatment (ADRT) –  
[http://collections.europarchive.org/tna/20100509080731/http://endoflifecare.nhs.uk/eolc/files/NHS-EoLC-ACPADRT\\_Chart-Mar2010.pdf](http://collections.europarchive.org/tna/20100509080731/http://endoflifecare.nhs.uk/eolc/files/NHS-EoLC-ACPADRT_Chart-Mar2010.pdf).

### **The National Council for Palliative Care**

- *Planning for Your Future Care: a guide* (2009) is simple and easy to understand guidance for patients making advance care plans for their future. It may also prove to be relevant to family members and informal carers –  
[www.endoflifecareforadults.nhs.uk/assets/downloads/pubs\\_Planning\\_for\\_your\\_future\\_care.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/pubs_Planning_for_your_future_care.pdf).
- The Mental Capacity Act in practice is covered in *Good Decision Making: the Mental Capacity Act and end of life care* – [www.ncpc.org.uk/library?keyword=capacity](http://www.ncpc.org.uk/library?keyword=capacity).

### **The Gold Standards Framework for ACP**

A comprehensive resource for all aspects of ACP –  
[www.goldstandardsframework.org.uk/AdvanceCarePlanning](http://www.goldstandardsframework.org.uk/AdvanceCarePlanning).

The 'Thinking Ahead' paper is frequently used in care homes and includes general guidance and information on the use of ACP as part of the GSF programmes in end of life care in primary care, care homes, acute hospitals and other settings –  
[www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/ACP%20General%20version%20Feb10%20v20.pdf](http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/ACP%20General%20version%20Feb10%20v20.pdf).

See ACP section of the GSF website ([www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)). Also see ACP section of [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk).

### **Decisions Relating to Cardiopulmonary Resuscitation**

This is a joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing (2007).

It is a resource for decisions relating to cardiopulmonary resuscitation – [www.resus.org.uk/pages/dnar.pdf](http://www.resus.org.uk/pages/dnar.pdf).

### **Public awareness**

The Dying Matters campaign has information and resources to increase awareness and discussions about end of life care. See also the GP resource at [www.dyingmatters.org/](http://www.dyingmatters.org/).

The Dying Matters 'Find Your 1% Campaign' is led by the Department of Health's Quality, Innovation, Productivity and Prevention (QIPP) team. It encourages GP practices to find their 1% of people who die each year. See [www.dyingmatters.org/gp](http://www.dyingmatters.org/gp).

### **Hospices**

If you are not aware of the contact details of your local hospice, or for more general enquiries, contact Help the Hospices.

[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

### **Children**

Children and young people living with life-limiting illnesses have particular needs and concerns.

### **Children's Hospices UK**

ACT supports children and young people with life-limiting illnesses – [www.act.org.uk/](http://www.act.org.uk/).

The Association of Paediatric Palliative Medicine's Master Formulary 2011 – [www.act.org.uk/appmformulary](http://www.act.org.uk/appmformulary).

*Curriculum in Paediatric Palliative Medicine* – [www.act.org.uk/page.asp?section=169&sectionTitle=Curriculum+in+Paediatric+Palliative+Medicine](http://www.act.org.uk/page.asp?section=169&sectionTitle=Curriculum+in+Paediatric+Palliative+Medicine).

## Bliss

'For babies born too small and too sick.'

[www.bliss.org.uk/](http://www.bliss.org.uk/)

## International Society for Advance Care Planning and End of Life Care

This is a new society whose objectives include the promotion of:

- universal access to quality ACP
- excellence in care for people near the end of life
- the provision of physical, psycho-emotional and spiritual care in the context of ACP and end of life care.

[acpelsociety.com/](http://acpelsociety.com/)

## Clinical guidance

### Palliative Adult Network Guidelines (PANG)

'Adult Palliative Care General Guidelines.'

[www.wales.nhs.uk/sites3/Documents/489/NWCN%20Palliative%20Care%20guidelines%20Final%20draft%20%28July09%292.pdf](http://www.wales.nhs.uk/sites3/Documents/489/NWCN%20Palliative%20Care%20guidelines%20Final%20draft%20%28July09%292.pdf)

### Map of Medicine

'End of Life Care in Adults' – adult pathway.

[www.mapofmedicine.com/newsandevents/news/2010/endoflife](http://www.mapofmedicine.com/newsandevents/news/2010/endoflife)

### RCGP Practitioner with a Special Interest (PwSI) frameworks

*Guidance and Competences for the Provision of Services Using Practitioners with Special Interests (PwSIs): palliative care.*

[www.rcgp.org.uk/pdf/CIRC\\_PwSI%20Palliative%20Care.pdf](http://www.rcgp.org.uk/pdf/CIRC_PwSI%20Palliative%20Care.pdf)

## Other areas

### Liverpool Care Pathway for the Dying Patient (LCP)

[www.mcpcil.org.uk/liverpool-care-pathway/index.htm](http://www.mcpcil.org.uk/liverpool-care-pathway/index.htm)

## Marie Curie

[www.mariecurie.org.uk/en-gb/patients-carers/for-carers/end-of-life/](http://www.mariecurie.org.uk/en-gb/patients-carers/for-carers/end-of-life/)

## Macmillan Cancer Support

Many resources including that related to improving out-of-hours palliative care.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

## Health Talk Online – Living with Dying section

Formerly known as DIPEX, it has examples of patient experiences.

[www.healthtalkonline.org/Dying\\_and\\_bereavement/Living\\_with\\_Dying](http://www.healthtalkonline.org/Dying_and_bereavement/Living_with_Dying)

## The King's Fund

*Implementing the End of Life Care Strategy: lessons for good practice.*

Commissioning guidance for End of Life Care from the King's Fund.

[www.kingsfund.org.uk/publications/implementing\\_the\\_end.html](http://www.kingsfund.org.uk/publications/implementing_the_end.html)

## National Council for Palliative Care

*Commissioning End of Life Care: act & early to avoid A&E.*

<http://commissioning.rcgp.org.uk/wp-content/uploads/2011/07/AandE.pdf>

## Alzheimer's Society

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

## Dementia UK

[www.dementiauk.org](http://www.dementiauk.org)

# Appendix 1 Palliative care template codes and prompts for use in your practice computer system

NB: other specific codes may also apply.

## The GSF Read codes

8CM1	On gold standards palliative care framework
8CM10	GSF supportive care stage 1 – advancing disease
8CM11	GSF supportive care stage 2 – increasing decline
8CM12	GSF supportive care stage 3 – last days: cat C – weeks prognosis
8CM13	GSF supportive care stage 3 – last days: cat D – days prognosis

## Other codes

<i>Heading</i>	<i>Read code</i>	<i>Prompt</i>
Palliative care	ZV57C	Life-limiting illness, may be in their last 6–12 months of life. Refer to GSF guidance
Assessment of needs	389	Consider physical, psychological, emotional or PepsiCola
Medication Review done	8B3V	Rationalise medicines. Focus on symptom control, quality of life and patient's wishes
Benefits counselling	6743	Refer for benefits advice. Financial problems are common and reduce quality of life
DS 1500 Disability living allowance completed	9EB5	Complete if expect 6 months or less to live
Carer's details	9180	Name. Contact details. Do they live in the same place? Do they work? Are they a child?
Preferred place of (care) death		A rolling discussion. Circumstances may change. Their mind may change
Preferred place of death: home	94Z1	
Preferred place of death: nursing home	94Z5	
Preferred place of death: hospice	94Z2	
Preferred place of death: community hospital	94Z3	
Preferred place of death: hospital	94Z4	

Discussed with patient	8CN1	Create the opportunity and record the outcome. Do not insist on the discussion
Discussed with significant other	8CN0	Relatives, carers, nursing staff or other professionals
Is the patient for CPR?*		
For resuscitation*	1R0	Consider chances of success, post-CPR QOL, patient's wishes, advance directive
Not for resuscitation	1R0	
GP Out-of-Hours Handover Form completed	9e2	This facilitates patient choice and good care, reducing crises and unnecessary admission
Palliative care plan review done	8CM3	Record any additional discussion or points
Diary entry: palliative care plan review	8CM3	When setting the date consider, do they have days (red), weeks (amber) or months (green) left?

\*These codes need to be entered outside of the LV template so they can be saved as an active problem. The PCS template records these as active problems.

## Appendix 2 Quality and Outcomes Framework (QOF) guidance for GMS contract, 2011–12

<i>Indicator</i>		
<i>Records</i>		
PC3. The practice has a complete register available of all patients in need of palliative care/support irrespective of age	3	
<i>Ongoing management</i>		
PC2. The practice has regular (at least three-monthly) multidisciplinary case review meetings where all patients on the Palliative Care Register are discussed	3	

### Palliative care rationale for inclusion of indicator set

Palliative care is the active total care of patients with life-limiting disease and their families by a multi-professional team. The first National End of Life Care (EOLC) strategy was published in July 2008. It builds on work such as the NHS Cancer Plan 2000, NICE guidance 2004 and NHS EOLC programme 2005.

The way primary care teams provide palliative care in the last months of life has changed and developed extensively in recent years with:

- over 99% of practices now using a Palliative Care Register since the introduction of this indicator set
- specific emphasis on the inclusion of patients with non-malignant disease and of all ages since April 2008
- patients and carers being offered more choice regarding their priorities and preferences for care including their preferred place of care in the last days of life (evidence shows that more patients achieve a home death if they have expressed a wish to do so)
- increasing use of anticipatory prescribing to enable rapid control of symptoms if needed and a protocol or integrated care pathway for the final days of life
- identification of areas needing improvement by the National Audit Office (NAO), e.g. unnecessary hospital admissions during the last months of life.

The National EOLC Strategy and *Living and Dying Well*

suggest that all practices should adopt a systematic approach to end of life care and work to develop measures and markers of good care. They recommend the GSF and the associated After Death Analysis (ADA) as examples of good practice. Evidence suggests that over 60% of practices across the UK now use GSF to some degree to improve provision of palliative care by their primary care team.

The introduction of the GSF to primary care and its associated audit tool ADA are associated with a considerable degree of research and evaluation. The GSF provides ideas and tools that help practices to focus on implementing high-quality patient-centred care.

[www.goldstandardsframework.org.uk/](http://www.goldstandardsframework.org.uk/)

### Palliative Care (PC) Indicator 3

The practice has a complete register available of all patients in need of palliative care/support, irrespective of age.

#### Palliative Care 3.1 – Rationale

About 1% of the population in the UK die each year (over half a million), with an average of 20 deaths per GP per year. A quarter of all deaths are due to cancer, a third from organ failure, a third from frailty or dementia, and only one-

twelfth of patients have a sudden death. It should be possible therefore to predict the majority of deaths. However, this is difficult and errors occur 30% of the time. Two-thirds of errors are based on over-optimism and one-third on over-pessimism. Nevertheless, 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. This indicator set is focused on the maintenance of a register (identifying the patients) and in regular multidisciplinary meetings where the team can ensure that all aspects of a patient's care has been assessed and future care can be coordinated and planned proactively (National Audit Office 2008).

A patient should be included on the register if any of the following apply.

- 1 Their death in the next 12 months can be reasonably predicted. (Rather than trying to predict, clinicians often find it easier to ask themselves 'the surprise question' – 'Would I be surprised if this patient were still alive in 12 months?')
- 2 They have advanced or irreversible disease and clinical indicators of progressive deterioration, and therefore a need for palliative care, e.g. they have one core and one disease-specific indicator in accordance with the GSF Prognostic Indicators Guidance (see QOF section of GSF website).
- 3 They are entitled to a DS 1500 form. (The DS 1500 form is designed to speed up the payment of financial benefits and can be issued when a patient is considered to be approaching the terminal stage of his or her illness. For these purposes, a patient is considered as terminally ill if he or she is suffering from a progressive disease and is not expected to live longer than six months.)

The NAO *End of Life Care* report (November 2008) states: 'In one PCT 40 percent of patients who died in hospital in October 2007 did not have medical needs which required them to be treated in hospital, and nearly a quarter of these had been in hospital for over a month.'

The register applies to all patients fulfilling the criteria regardless of age or diagnosis. The creation of a register will not in itself improve care but it enables the wider practice team to provide more appropriate and patient-focused care.

## Palliative Care 3.2 – Reporting and Verification

The practice reports the number of patients on its Palliative Care Register.

Verification – in the rare case of a nil register at year end, if a practice can demonstrate that it had a register in year then it will be eligible for payment.

## Palliative Care Indicator 2

The practice has regular (at least three-monthly) multidisciplinary case review meetings where all patients on the Palliative Care Register are discussed.

## Palliative Care 2.1 – Rationale

The QOF monitors occurrence of the multidisciplinary meetings but it is up to the practice to ensure the meetings are effective. The aims of the meetings are to:

- ensure all aspects of the patient's care have been considered (this should then be documented in the patient's notes)
- improve communication within the team and with other organisations (e.g. care home, hospital, community nurse specialist) and particularly improve handover of information to out-of-hours services
- coordinate each patient's management plan, ensuring the most appropriate member of the team takes any action, avoiding duplication
- ensure patients are sensitively enabled to express their preferences and priorities for care, including preferred place of care
- ensure that the information and support needs of carers are discussed, anticipated and addressed wherever reasonably possible.



Many practices find use of a checklist during the meeting helpful, as it helps to ensure all aspects of care are covered, e.g. supportive care register (SCR) templates SCR1 and 2 and the assessment tools on the GSF website.

## **Palliative Care 2.2 – Reporting and Verification**

The practice should submit written evidence to the Primary Care Organisation describing the system for initiating and recording meetings.

# Appendix 3 Improving primary care management of end of life care

The King's Fund. *Transforming Our Health Care System: ten priorities for commissioners* London: King's Fund, 2011, [www.kingsfund.org.uk/applications/site\\_search/?term=transforming+our+health+care&searchreferer\\_id=0&searchreferer\\_url=%2F404.rm](http://www.kingsfund.org.uk/applications/site_search/?term=transforming+our+health+care&searchreferer_id=0&searchreferer_url=%2F404.rm).

## What is it?

Within primary care, improving the systematic identification of patients who are at the end of life, and then providing the appropriate support; in particular, improving the coordination of care, continuity, quality of communication, and the provision of bereavement care.

## Why is it important?

Two-thirds of people would prefer to die at home, but in practice only about one-third of individuals actually do (Higginson 2003).

The annual number of deaths in England and Wales is expected to rise by 17% from 2012 to 2030.

Further, the average age at death is set to increase markedly, with the percentage of deaths among those aged 85 or over expected to rise from 32% in 2003 to 44% in 2030. To respond to this, both in-patient and community care facilities must increase substantially.

The cost of caring for people at the end of their lives is estimated to run into billions of pounds (National Audit Office 2008). Care for the 27% who die from cancer is around £1.8 billion in the last year of their life, or £14,236 per patient (Hatziaandreu *et al.* 2008).

Wide variations exist in the quality of end of life care across England. Spending by primary care trusts (PCTs) on palliative care has varied from £154 to over £1600 per patient (National Audit Office 2008).

## What is the impact?

- Research by The King's Fund has identified many examples of how improvements in end of life care can have a high impact on patient experience as well as the experience of family members and carers (Addicott and Ross 2010).
- Some evidence suggests greater coordination of care can improve quality without incurring any additional costs (Addicott and Dewar 2008).
- There may be some scope to make cost savings, particularly through a reduction of unnecessary admissions into the acute setting, although research on this is limited.

## How to do it

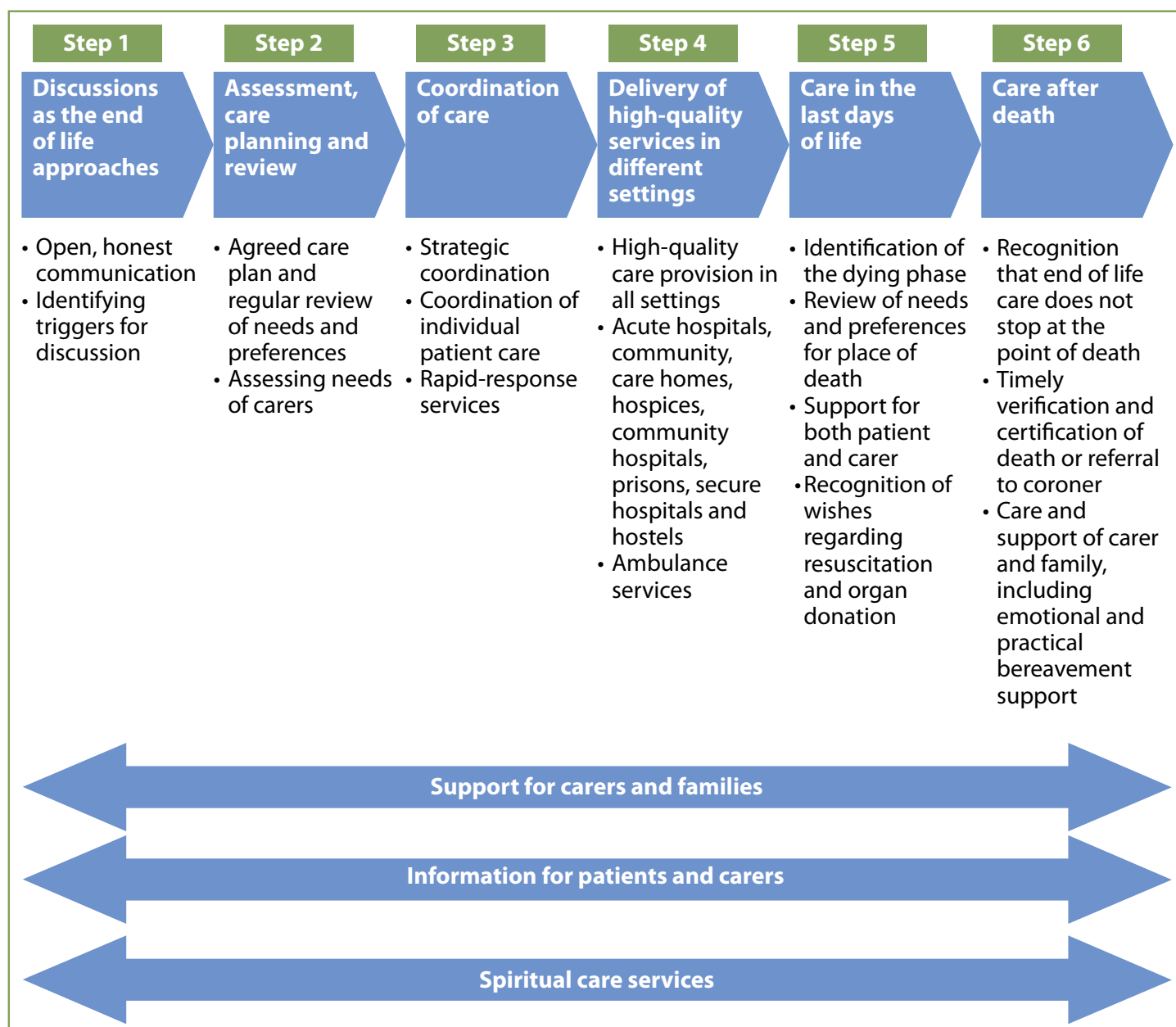
End of life care is provided in a variety of organisational settings by a range of health and social care professionals. To meet patients' needs a whole-systems approach is needed that coordinates care across professional and organisational boundaries (Addicott and Ross 2010). GPs will be in a central position to do this.

Commissioners should be driving a whole-systems approach that focuses on the availability of a range of services across the care pathway, such as:

- facilitation of discharge from the acute setting
- rapid-response services during periods out of hospital
- centralised coordination of care provision in the community
- guaranteeing 24/7 care.

It will also be important to ensure that end of life care features in any care pathway to ensure that we shift the focus beyond terminal cancer.

# Appendix 4 The End of Life Care Pathway NHS End of Life Care Strategy, July 2008



## Appendix 5 English policy developments in end of life care

- The End of Life Care Programme 2005–8 supported the use of three complementary best-practice models in end of life care.
- The GSF in Primary Care – care in final year/months of life – initially community focused.
- Liverpool Care Pathway for the Dying (LCP) – care in the final days/hours – initially hospital focused.
- ACP – Preferred Priorities of Care/other models, to encourage greater discussion and recording of patient wishes and choices.
- End of Life Care strategy for England (Department of Health), June 2008 (see below), and the National End of Life Care Programme to support the implementation of the strategy in England. New guidance produced on *The Route to Success in End of Life Care*.
- National Audit Office report, November 2008 – economic arguments for improving end of life care, reducing hospitalisation, greater community investment, improving training for generalist staff, etc.
- Mental Capacity Act 2005 and Mental Health Act 2007 and focus on ACP.
- *RCGP End of Life Care Strategy* (2009) – end of life care is a priority for the College – RCGP End of Life Care Working Group established UK-wide and four-country specific.
- GMC guidance on end of life care (2010) – *Treatment and Care towards the End of Life: guidance on good practice in decision making*.
- Current government white paper, Health and Social Care Bill, Palliative Care Funding Review, GP Commissioning and QIPP End of Life Care – under review.
- NICE ‘End of life care for adults quality standard’ published November 2011 ([www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp)).

**NICE end of life care for adults quality standard**

1	People approaching the end of life are identified in a timely way
2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences
3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment
4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment
5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible
6	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences
7	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences
8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences
9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences
10	People approaching the end of life who may benefit from specialist palliative care are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night
11	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication
12	The body of a person who has died is cared for in a culturally sensitive and dignified manner
13	Families and carers of people who have died receive timely verification and certification of the death
14	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences
15	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers
16	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support

This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

# Appendix 6 Gold Standards Framework training programme

## 4. Next Stage GSF Going for Gold Training Programme GSF Quality Recognition –

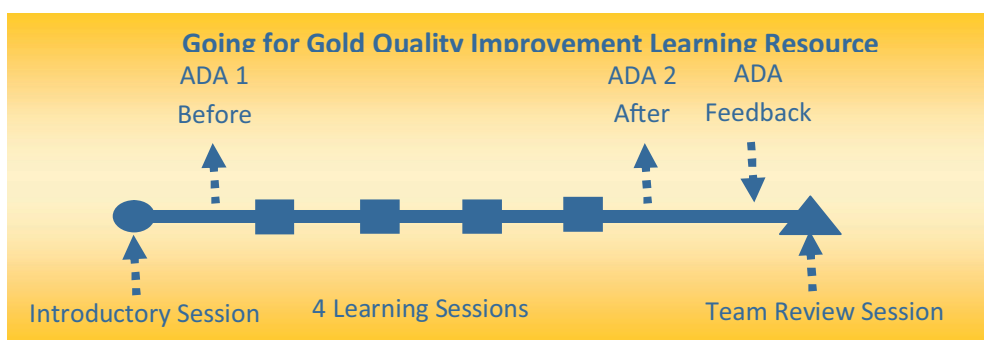
supporting the RCGP End of Life Care Patient Charter is part of the GSF Quality Recognition Process following the training

**Next Stage GSF.** Building on ten years of widespread use of GSF in primary care, mainstreamed into national policy and the Quality Outcomes Framework, there was a need to refresh and update GSF, to seek ways to enable primary care to best meet the challenge of the future. A full systematic review was undertaken, affirming the considerable success



of GSF but highlighting specific gaps in consistency of use, effectiveness, equity for non-cancer patients and quality of care. In response 'Next Stage GSF' was launched in June 2009, with this new training programme leading to quality recognition/accreditation plus updated tools, resources and other new developments.

**The new 'Going for Gold' GSF Training Programme** is designed to give a new impetus to delivering high-quality end of life care in primary care. It helps you attain local policy targets, DH End of Life Care Quality Markers, in line with the national strategies of the DH, the RCGP, the RCN and Transforming Community Services. It encourages cross-boundary working, linked to GSF programmes in care homes, hospitals and other areas. **Effective use of GSF enables more to live and die where they choose, and reduce hospital stays, and provides considerable value for money and cost-effectiveness to the NHS .**



### Step-by-step progress leading to excellence.

- This comprehensive step-by-step training programme supports best use of GSF and greater confidence in provision of care.
- Using ADA audit, reflection and action planning, this can lead to quality care for all those in the final year of life, especially the frail elderly with long-term conditions.
- It includes a special **Focus on Nurses**, supported by the RCN and in line with Transforming Community Services, encouraging the special role of nurses.
- This is supported as best practice by the RCGP and the RCN.

"The College is pleased to support GSF, as a major component of the new RCGP End of Life Care Strategy. It is clear that end of life care should be part of the core business of general practice, and GSF provides a standard against which we can measure our practice and a means to further improve it."

# Appendix 7 The National Primary Care Snapshot Audit in End of Life Care, England, 2009–10

How are we doing in primary care in England? Findings from the biggest national snapshot in community end of life care, supported by the Department of Health (DH) (England) End of Life Care Programme

Prof K Thomas,<sup>1,2</sup> Prof C Clifford,<sup>1</sup> Dr D de Silva,<sup>3</sup> H Corner,<sup>2</sup> H Bowden<sup>2</sup>  
<sup>1</sup>University of Birmingham, <sup>2</sup>GSF Centre CIC and <sup>3</sup>The Evidence Centre

## Aim

- The aim of the National Snapshot was to provide a national baseline assessment of provision of end of life care for the End of Life Care Programme and PCTs across England.
- The purpose was to assess gaps in service provision and areas requiring further improvement. Each area was benchmarked against national data, with reports to each practice, PCT and the DH, with specific suggested recommendations for improvement.

## Method

- The National Snapshot included every patient death for every practice in 15 PCTs for a two-month period (60% return rate).
- It involved use of the GSF After Death Analysis (ADA), a well-validated audit tool widely used within primary care, care homes and hospitals.
- It uses patient outcome data related to individual patients. This includes questions on dying in their preferred place of care, hospital admissions, use of services, advance care plan discussions etc.
- Over 4500 patient deaths' data, 502 GP practices, 15 PCTs, 90% Strategic Health Authorities (SHAs).

## Findings

Practices probably need more help identifying people near the end of life

- Unknown 17%
- On palliative care register 27%
- Not on register but predictable 15%
- Sudden death 42%

## Implications

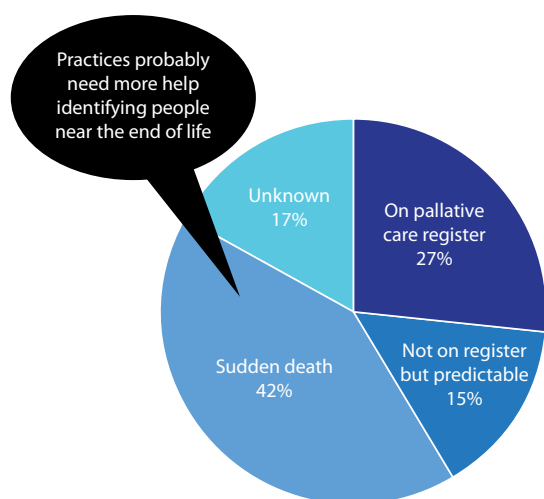
- This provided a valuable objective overview of the current state of end of life care in GP practices demonstrating key areas for further improvement.
- Conclusions - although an encouraging start, still too few patients were identified and included on the palliative/GSF Care Register, too few had non-cancer conditions and there were gaps in specific services such as out-of-hours care and bereavement support.
- Recommendations - focus on earlier identification of patients, some specific service specifications and improved training. The development of Next Stage GSF for Primary Care, to improve effectiveness, consistency, inclusion of non-cancer patients, and improve the overall quality of end of life care.

## Key Messages

1. Patients receive better coordinated end of life care if identified and included on the GP's Palliative Care / GSF Register.  
If patients were identified early enough and included on the palliative care register they received better coordinated care. Therefore we should try to identify earlier the patients who might be in the final year of life and require supportive/palliative care to enable consistent proactive provision.
2. We are still missing 75% patient deaths. 4500 patient deaths were analysed. About a quarter of all patient deaths were being identified and included on the register. This key proportion should be increased through earlier identification of dying patients.
3. Still not including enough non-cancer patients. Only a quarter of patients on register had non-cancer — whereas three quarters die from non-cancer, e.g. earlier identification of patients with heart failure, COPD, dementia, frailty etc.

## Findings of the National Primary Care Snapshot Audit

The National Primary Care Snapshot in End of Life Care was the biggest national snapshot as yet undertaken, part funded by the National End of Life Care Programme,



involving over 502 GP practices in 15 PCTs and data from about 4500 patient deaths (see GSF website).

So, one of the biggest inequalities in end of life care exists between those who are identified for the Palliative Care Registers and those who are not. Do clues exist that a patient might be suitable for such a register? You have the opportunity to give them an advantage, not least for all those non-cancer patients accounting for 75% of deaths but only 25% of those on a register.

Identification can be done opportunistically during a surgery or home visit consultation, during discussion of cases in practice/multidisciplinary team meetings, or in discussion with specialist palliative care and secondary care. This builds on the QOF and should maximise the use of the Palliative Care Registers.



# Appendix 8 The key role of nurses in end of life care



Lynn Young, RCN

*Working in partnership with the RCN, we have highlighted how important excellent nursing is to end of life care.*

We wish, therefore, to:

- promote the key role that all nurses have in delivering good end of life care
- recognise the specific role that district nurses, practice nurses and community matrons and specialist nurses have in end of life care in the community
- promote how important nurses in care homes are in looking after people as they approach the end of their lives, enabling more residents to be cared for and die in the care home, if that is the resident's wish
- promote the important work of specialist palliative care nurses in supporting primary care teams, patients and their carers
- inform nurses of the need to identify and assess using holistic assessment tools
- undertake ACP discussions and plan best care, thus ensuring a holistic approach with those in the last years of life
- affirm, recognise and celebrate the examples of best practice in the provision of individualised, person-centred care, particularly at end of life
- raise awareness with the public of the special role that nurses have in caring for and supporting patients and their families at end of life
- develop the knowledge and skills of nurses caring for those at end of life; utilising GSF and promoting the university-accredited coordinators and clinical course.

See the NHS End of Life Care Programme website for *Route to Success: the key contribution of nursing to end of life care* for guidance on care after death, guidance on care for patients with learning disabilities, etc. ([www.endoflifecareforadults.nhs.uk/publications/rts-nursing](http://www.endoflifecareforadults.nhs.uk/publications/rts-nursing)). See also the RCN's 'Principles of Nursing Practice' site at [www.rcn.org.uk/development/practice/principles](http://www.rcn.org.uk/development/practice/principles).

# Appendix 9 Mobilising the patient voice

## Encouraging Advance Care Planning Discussions using the RCGP UK End of Life Care Patient Charter



The Royal College of General Practitioners (RCGP), representing over 45,000 GPs in the UK, approved the RCGP End of Life Care (EOLC) Strategy in 2009, affirming that End of Life Care is a priority of the College. As part of its implementation the College worked with the RCGP Patient Partnership Group and the Royal College of Nursing to develop a Patient Charter 'for the care of people nearing the end of their life' (see right and how to use far right).

The End of Life Care Patient Charter describes in general terms the kind of care that patients say they would wish to receive for themselves or their families as they near the end of their lives (defined as final year of life by GMC in UK). It has seven key points - the first four of which relate to good listening, communication and involvement in decision making and the possibility of formalising this through advance care planning discussions.

**Media attention.** The charter was well reported in the media and was distributed to all UK GP practices via *RCGP News*. A Guidance leaflet (see below right) and dedicated microsite was launched to provide practical support and guidance for GPs and other primary health care professionals, with links to other resources such as the DH End of Life Care Programme and the Gold Standards Framework Training Programme 'Going for Gold.' Patient groups are encouraged to use the charter to help initiate such discussions with their GP and primary care team.

**Quality Recognition.** The RCGP Patient Charter forms part of GP and practice assessments e.g. Accreditation and Quality Recognition of GSF



### Next Steps

- Note and Increase the **key proportion** for each practice i.e. numbers on the register/all patient deaths (national average 2010 was 25% in National EOLC Audit), and numbers on register offered advance care planning discussions (NICE Guidance).
- Offer and record **Advance Care Planning discussions** to every patient on the GSF/Palliative Care Register.
- Ensure that appropriate information is updated on the register, the GP's register/Locality Register or Electronic Palliative Care Coordinating System.
- Use Patient Charter in hospitals, domiciliary care, and version in care homes.
- Discuss in Health and Wellbeing Boards and mobilise and encourage patient groups.
- Encourage further training in Advance Care Planning communication skills.

### Key message

A group of patients developed an End of Life Care Patient Charter in collaboration with the Royal Colleges of GPs and Nurses, describing the kind of care they would wish to receive from their GPs and Primary Care teams. The importance of listening, shared decision making and advance care planning discussions is emphasised. The charter received much media attention, was sent to all GP practices with Guidance, and is being used to stimulate discussion and encourage patients to initiate these issues with their GPs, primary care teams and others.

### Suggested uses of the Patient Charter:

- To stimulate discussion of team as to whether happy to sign up
- Display poster on surgery wall
- To use as a catalyst for discussion with patients & families on the practice's GSF/Palliative Care Register
- Discuss with practice patient group
- Discuss with care homes for their residents nearing the end of life
- Discuss training needs required
- Part of revalidation and audit
- Use as part of GSF 'Going for Gold' Accreditation Quality Recognition in Next Stage GSF Training (for more information on first stage and Next Stage GSF Training Programmes and other settings, see: [www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk))

**End of Life Care Patient Charter**  
A charter for the care of people who are nearing the end of their life

*"You matter because you are you, you matter to the last moment of your life and we will do all we can, not only to let you die peacefully, but to help you live until you die" Dame Cicely Saunders*

We want to offer people who are nearing the end of their life the highest quality of care and support. We wish to help you live as well as you can, for as long as you can. Therefore, if and when you want us to, we will:

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavor to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.
- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement.

We also invite your ideas and suggestions as to how we can improve the care and support that we deliver to you, the people who are important to you and others in similar situations.

Please signification from your Practitioner. *Time please indicate*

Name: \_\_\_\_\_ Title: \_\_\_\_\_

Leading the Way: High-Quality End of Life Care Through General Practice

Developed by RCGP English End of Life Working Group, Patient Partnership Group and Royal College of Nursing (2011)



**Matters of Life and Death**

Helping people to live well until they die

General practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter

**Prof Keri Thomas, National Clinical Lead GSF Centre, RCGP Clinical Champion for End of Life Care, The National GSF Centre in End of Life Care**

[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)  
[info@gsfcentre.co.uk](mailto:info@gsfcentre.co.uk)  
[http://www.rcgp.org.uk/end\\_of\\_life\\_care/patient\\_charter.aspx](http://www.rcgp.org.uk/end_of_life_care/patient_charter.aspx)

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