

The Gold Standards Framework is pivotal to palliative care



The new palliative care indicators are a stepping stone to providing optimum care at the end of life, as Drs Keri Thomas (left) and Amanda Free explain

The WHO describes palliative care as ‘the active, holistic care of patients with advanced, progressive illness’.¹

GPs are in an ideal position to provide and coordinate this care for a number of reasons:

- ▶ they have long-established relationships with their patients which are so important at this critical time in a patient’s life
- ▶ they are used to dealing with comorbidity and uncertainty
- ▶ they are trained to treat patients holistically which is central to the palliative care approach.

GPs have to be able to provide high quality, equitable care, and to work together effectively with specialist teams if they are to provide the best primary palliative care for all who require it.

There is an increasing imperative to be able to recognise the needs of all patients nearing the end of their lives, not just those with cancer, and

to be able to extend some of the developments in care provided for cancer patients to those with other illnesses, which constitute 75% of all deaths.

Proactive end of life care

In order to provide optimal care for any patient nearing the end of their

GPs are in an ideal position to provide and coordinate palliative care as they are trained to treat patients holistically which is central to the palliative care approach

life, i.e. not just in the terminal or dying phase, but in their last year, we need to be able to do three things:

- ▶ identify where a patient is on their illness trajectory – do they have years, months, weeks or days to live? This then allows proactive management, calmer planning and less ‘fire-fighting’ crisis management
- ▶ assess their needs, and those of their family/carers, in the light of their advance care plan
- ▶ plan (using a management plan) and then provide their care according to the patient’s preferences and varying needs, at different times.

There needs to be a better way to identify when patients are in their last year of life.

Up until now GPs have mainly considered cancer patients eligible for DS1500 attendance allowance as the criterion for inclusion on a palliative care register, but the new prognostic indicator guidance paper² is being

Table 1: Palliative care indicators and other indicators relating to the GSF

Disease/ indicator no	Clinical indicator	Points	Payment stages	
			Min (%)	Max (%)
PC 1	The practice has a complete register available of all patients in need of palliative care/support	3		
PC 2	The practice has regular (at least 3-monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed	3		
<i>Other indicators:</i>				
CANCER 1	The practice can produce a register of all cancer patients defined as a register of patients with a diagnosis of cancer excluding non-melanotic skin cancers from 1 April 2003	5		
CANCER 3	% of patients with cancer, diagnosed within the past 18 months who have a patient review recorded as occurring within 6 months of the practice receiving confirmation of the diagnosis	6	40	90
DEM 1	The practice can produce a register of patients diagnosed with dementia	5		
DEM 2	% of patients diagnosed with dementia whose care has been reviewed in the previous 15 months	15	25	60
EDUCATION 7	The practice has undertaken a minimum of 12 significant event reviews in the past 3 years which could include: – any death occurring in the practice premises – new cancer diagnoses – deaths where terminal care has taken place at home – any suicides – admission under the Mental Health Act – child protection cases – medication errors	4		
EDUCATION 10	The practice has undertaken a minimum of 3 significant event reviews within the past year	6		
RECORDS 13	There is a system to alert the out of hours service or duty doctor to patients dying at home	2		
MANAGEMENT 9	The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment	3		

Table 2: Read codes for palliative care

ZV57C	[V]Palliative care
8H7g.	Referral to palliative care service
8BAP.	Specialist palliative care
8BAT.	Specialist palliative care treatment – outpatient
8H6A.	Refer to terminal care consultant
8CMI.	On gold standards palliative care framework
8HH7.	Referred to community specialist palliative care team
8BJ1.	Palliative treatment
8BA2.	Terminal care
8H7L.	Refer for terminal care
8BAS.	Specialist palliative care treatment - daycare
9EB5.	DS1500 Disability living allowance completed
IZ01	Terminal illness – late stage

used as a way forward for primary and secondary care to identify these patients and initiate supportive care for them.

A key point is for all hospital and hospice clinicians who recognise that a patient may be in their last year of life to notify the patient's GP

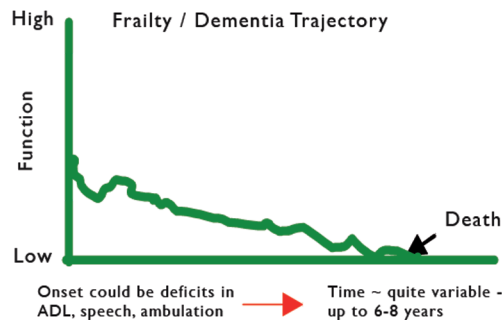
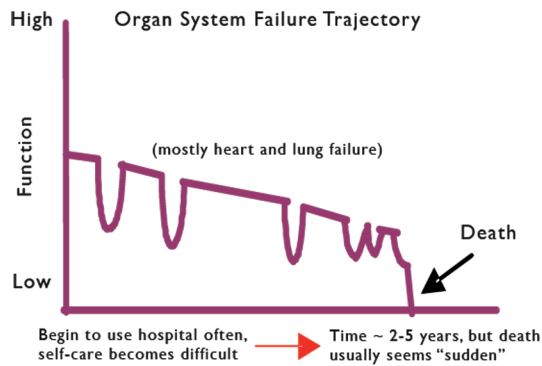
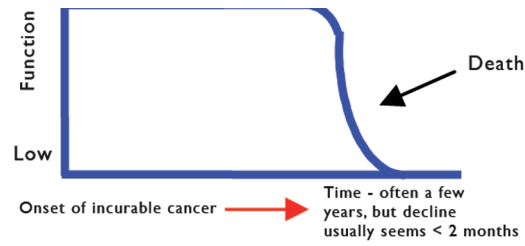
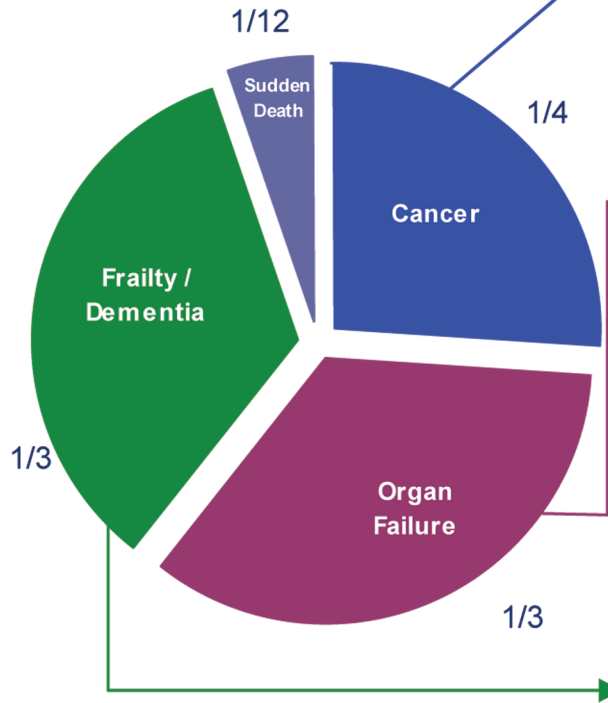
and recommend that the patient is added to the palliative care register.

QOF points

The recognition of the importance of palliative care is demonstrated by the addition of clinical indicators for palliative care in the revised QOF. This positive step will encourage good proactive palliative care in primary care. Although there are only six points for palliative care in the revised contract (which includes care for all patients estimated to be in the last year of life), when combined with cancer, dementia and other areas,

Figure 1: Illness trajectories

GPs' workload - Average 20 deaths/GP/yr (approximate proportions)



practices can claim up to 52 points if they are using the Gold Standards Framework (Table 1, p. 31).

For the first time good palliative care in primary care will be recognised and rewarded, but providing this best care for everyone at the end of their life is not always easy. However, considerable experience has been gained over the past few years, using tools such as the Gold Standards Framework (GSF), and we hope that by sharing this expertise we will enable all primary healthcare teams to undertake this rewarding task.

Palliative care is important to GPs and is an intrinsic and special part of the

job. So, despite its demands, many practitioners prioritise care of the dying and have made comments such as “it reminds us of why we came into medicine in the first place”, and “it brings us back to what matters, real patient care”.

The 1% rule

About 1% of your patients will die each year or, put another way, 1% of them are in their last year of life. We need to find ways of identifying these patients so that we can then assess their needs and preferences in order to plan for them and to provide the right services at the appropriate

time, e.g. send the handover form to the out of hours provider, ensure the DS1500 form has been completed and that arrangements have been made for respite for the carer and intensive support at home for terminal care. As healthcare providers we need to help give them the best care possible at each stage in that final year of life.

On average, each GP has 20 deaths per year: about one-quarter will die from cancer – these are the patients that have generally been thought of when initially discussing palliative care; about one-third will die from organ failure, e.g. heart failure and COPD; about one-third will die from

GP CONTRACT: QOF2

Table 3: The seven Cs of the Gold Standards Framework (GSF)

- C1 – Communication:
 - set up the register and meet regularly as a team
 - ensure that the patients have the information they need e.g. in home packs
- C2 – Co-ordination:
 - appoint a co-ordinator
- C3 – Control of symptoms:
 - pool knowledge and expertise to address physical, psychological, social and spiritual needs
 - use symptom assessment tools
- C4 – Continuity of care:
 - inform the out of hours service about the patients
 - work together with the secondary care teams
- C5 – Continued learning:
 - use audit (e.g. place of death) and significant event or after death analysis
 - identify and address knowledge gaps
- C6 – Carer support:
 - identify and address their emotional, practical and financial needs
 - extend care into the bereavement phase
- C7 – Care in the dying phase:
 - use a protocol for the last 48 hours of life, such as the Liverpool Care Pathway, for more information (www.endoflifecare.nhs.uk)

right across the UK. Teams report better quality of care for their patients, better organised care, fewer crises and unplanned admissions, and better team working.

The Department of Health publication *Building on the best: Choice, responsiveness and equity in the NHS*,⁴ published in 2003, demonstrated that patients and carers want more choice over care at the end of their lives.

The NHS End of Life Care programme (www.endoflifecare.nhs.uk) was set up in 2004 to address these issues and the GSF is supported by the programme. It is also supported by the NICE guidance on supportive and palliative care,⁵ available at www.nice.org.uk.

Its use is recommended by the RCGP, the Heart Improvement Programme in their document *Supportive and Palliative Care for Advanced Heart Failure*,⁶ and by the National Service Framework for Renal Services.⁷ Therefore the GSF has gained support from specialists and generalists alike.

multiple organ failure, frailty or dementia; and only about one-twelfth will die suddenly with little or no warning (Figure 1, p. 33).²

accordance with the GSF and/or

▶ they are the subject of a DS1500 form.

For the vast majority of patients we do have time to prepare and we need to be able to put plans in place to support them and to deliver the kind of care that they wish for.

Table 2, p. 31, covers the Read codes that can be used.

All the templates and tools needed to set up a palliative care register are available on the GSF website: www.goldstandardsframework.nhs.uk

There are three main steps in the GSF:

- ▶ identify the patients so that you can begin to provide some proactive rather than simply reactive care
- ▶ assess their needs and those of their carers
- ▶ plan their care:
 - plans must be made together with the patient and carer so that their wishes are taken into account
 - plans must be communicated to all involved, so that if for example a patient wishes to die at home, everyone including the reception staff know that that is the plan, and unnecessary ambulances and hospital admissions are avoided.

QOF points – how to claim and what to do

Palliative care 1 (PC1)

The palliative care register is prospective from 1 April 2006 and applies to adults over the age of 18 years. A patient should be included if:

- ▶ their death in the next 12 months can be reasonably predicted and/or
- ▶ they have clinical indicators of need for palliative care that are prognostic clinical indicators of advanced or irreversible disease and include one core and one disease specific indicator in

The programme³ has been running since 2001 and has led to real improvements in care for our patients with end-stage illness.

It is a programme for community palliative care designed to improve the organisation and quality of care that is offered to patients and their carers in the last 6-12 months of life. It provides primary healthcare teams with the tools needed to improve the planning of their palliative care.

It is now being used by approximately one-third of all primary healthcare teams in England, and is being used

Therefore, achieving all the palliative care points in the nGMS contract is

GP CONTRACT: QOF2

the first step towards the Gold Standards Framework.

▲

Achieving all the palliative care points in the nGMS contract ...

▼

It must be remembered that the palliative care register should include all those patients with advanced disease, not just cancer patients. Suggestions are available in the GSF prognostic indicators guidance paper on how best to identify these people, available on the GSF website, although prognostication will never be entirely accurate.

Clinical prediction of survival is not

an exact science with errors (defined as more than double or less than half of actual survival) noted 30% of the time. Two-thirds of errors are based on over-optimism and one-third on over-pessimism.⁸ However, there are considerable benefits in identifying these patients so that we can begin to address their needs earlier in their illness.

.....

Triggers for supportive and/or palliative care

We suggest using the following methods:

- ▶ the surprise question – would you be surprised if your patient were to die in the next 6-12 months? This is an intuitive question integrating co-morbidity, social and other factors
- ▶ choice/need – the patient with advanced disease may choose comfort care only rather than

‘curative’ treatment; they may also be in special need of supportive/palliative care

- ▶ clinical indicators of advanced disease – see prognostic indicators guidance paper.

The prognostic indicators guidance paper attempts to provide teams with the guidance necessary to identify those patients nearing the end of life, from any cause. It will be updated regularly and should be seen as an educational tool to be distributed widely among the team.

▲

... is the first step towards the Gold Standards Framework

▼

Indispensable information for medicines management



PAMMtrak

Pharmaceutical Advisors and Medicines Management Tracker

www.pammtrak.co.uk

The report of our second survey of medicines management in primary care is now available

For more information please go to www.pammtrak.co.uk, email info@pammtrak.co.uk or call Ramesh Patel on 020 8566 2127

GP CONTRACT: QOF2

However, teams new to the GSF may find it easier to begin with their cancer patients, and as they develop in confidence, they can extend their register to include their non-cancer patients.

Initially you could ask your specialist community palliative care nurse which patients they have on their list, but it is important to build on this and include more non-cancer patients, e.g. those with COPD and heart failure.

Appointing a member of the PHCT to act as a coordinator is recommended to coordinate the process and the patient's care. They can then ensure the register is kept up to date and can manage the multidisciplinary team meetings that will ensue.

The palliative care register

There are templates for the register on the GSF website.

The well tried and tested SCRI, or summary sheet of all palliative care patients, will act as a checklist to record, plan and monitor patient care. It reminds us to make sure that the DS1500 has been completed; that the out of hours service has been informed of the patient's needs; and to consider the patient's choice with regard to place of care and/or place of death.

Once the register is set up the regular multidisciplinary team meetings can be held to discuss those patients on the register.

Palliative care 2 (PC2)

Although the QOF points are awarded for 3-monthly meetings we recommend holding them monthly, as patients can deteriorate rapidly at the end of life. The register, or SCRI, can be used as a tool to facilitate dis-

cussion and care planning for these patients at the monthly multidisciplinary team meetings. This is a way to pool expertise and knowledge, ensuring that available resources are used in the most effective way possible.

▲

Initially you could ask your specialist palliative care nurse which patients they have on their list, but it is important to build on this and include more non-cancer patients

▼

The aims of the case review meetings are to improve the flow of information (particularly out of hours and between different teams) and to:

- ▶ ensure that each patient has a management plan as defined by the practice team, and that decisions are acted upon by the most appropriate member of the team
- ▶ ensure that the management plan includes preferences for place of care
- ▶ ensure that the support needs of carers are discussed and addressed wherever possible.

The essential personnel to invite to the multidisciplinary team meetings include GPs, district nurses, practice managers and preferably specialist palliative care nurses, social workers and a member of the administration team.

As the meetings become established teams may want to invite the respiratory nurse or the heart failure nurse, particularly once they start to identify

more of their non-cancer patients.

The information held on the register is also easily accessed to facilitate audit and significant event analysis. At each meeting reviewing deaths from the past month should become routine as the team will learn from this reflective practice.

Continuing the GSF

It is hoped that once teams see the benefit of working in this way they will want to extend this work, and to take on more of the principles of the GSF. There are seven key tasks in the programme, also known as the seven Cs, to work towards (see Table 3, p. 34).⁹

The QOF2 palliative care points cover C1 and C2.

Support and advice is available through local End of Life project leads, accessed via the Strategic Health Authorities; or from the GSF website.

GSF developments

We encourage the inclusion of more non-cancer patients, and of patients in other settings, in the GSF. There is a separate and very enthusiastic GSF in Care Homes Programme, involving more than 300 care homes, looking at how we can improve the care of our patients in this setting.

We also have GSF pilots in community hospitals, children and GSF 'in-reach' to hospitals.

Advanced care planning is an integral part of this process, enabling patients to express their wishes for future care, and we are developing tools to facilitate this.

Audit is an important part of the GSF from which we can all learn. We are developing tools such as the 'after

Prescribing Information

Refer to full Summary of Product Characteristics before prescribing

AVANDAMET Rosiglitazone/metformin HCl

Prescribing Information For Avandamet Use In Dual Therapy Only. Refer to full

Summary of Product Characteristics before prescribing. **AVANDAMET**

Rosiglitazone/metformin HCl Presentations AVANDAMET 2mg/500mg film-

coated tablets containing 2mg rosiglitazone with 500mg metformin HCl.

AVANDAMET 2mg/1000mg & 4mg/1000mg film-coated tablets containing

2mg or 4mg rosiglitazone respectively with 1000mg metformin HCl. **Indications**

Treatment of Type 2 diabetes mellitus patients, particularly overweight

patients: who are unable to achieve sufficient glycaemic control at their

maximally tolerated dose of metformin alone. **Posology & administration**

4mg rosiglitazone/2000mg metformin with food. Can be increased to 8mg

rosiglitazone/2000mg metformin if greater glycaemic control is required.

Elderly Renal function should be monitored regularly. **Children & adolescents**

Not recommended. **Contraindications** Hypersensitivity; history of cardiac

failure (NYHA stages I to IV); disease which may cause tissue hypoxia; hepatic

impairment, acute alcohol intoxication/alcoholism, diabetic ketoacidosis/pre-

coma; renal impairment; acute conditions that may alter renal function;

lactation; concomitant insulin. **Special warnings & precautions Lactic**

acidosis can occur as a result of metformin accumulation, primarily in patients

with significant renal failure. **Renal function** serum creatinine concentrations

should be determined regularly (see SPC). **Fluid retention & cardiac failure**

Rosiglitazone can cause dose-related fluid retention that may very rarely be

associated with rapid & excessive weight gain, & may exacerbate or

precipitate heart failure. Heart failure occurred uncommonly in double-blind

clinical studies with metformin (0.2%). Monitor signs & symptoms of fluid

retention. Discontinue if deterioration in cardiac status. Heart failure reported

more frequently when history of heart failure, elderly, or mild or moderate renal

failure, or when used in combination with insulin. Concomitant administration

with NSAIDs may increase risk of oedema. **Monitoring of liver function** Rare

reports of hepatocellular dysfunction; the incidence of all adverse events

relating to liver and biliary systems was <1.5% in any treatment group and

similar to placebo. Therapy should not be initiated when increased baseline

ALT levels (>2.5xULN), or other evidence of liver disease. Liver enzymes

should be checked periodically based on clinical judgement. **Weight gain**

Rosiglitazone can cause dose-related weight gain, which should be closely

monitored. **Anaemia** Rosiglitazone treatment can be associated with dose-

related reduction in haemoglobin; if levels low before initiation, risk of anaemia

increases. **Surgery** AVANDAMET should be discontinued 48 hrs before elective

surgery with general anaesthesia & not be resumed earlier than 48 hrs after.

Iodinated contrast agents Discontinue prior to/at time of tests & do not

reinstigate until 48 hrs after & only after renal function has been found to be

normal. **Others** By improving insulin sensitivity, ovulation may resume in

patients anovulatory as a result of insulin resistance. Be aware of risk of

pregnancy. Contains lactose. **Interactions** Caution when administering CYP2C8

inhibitors (e.g. gemfibrozil) or inducers (e.g. rifampicin), concomitantly. Caution

when administering cationic drugs eliminated by renal tubular secretion (e.g.

cimetidine). Monitor glucose control and consider dose adjustment or

treatment change. Increased risk of lactic acidosis in acute alcohol

intoxication. If needed adjust dosage when used with agents that effect blood

glucose levels e.g. glucocorticoids, beta-2 agonists, diuretics & ACE-inhibitors.

Pregnancy & lactation Do not use. Risk unknown. **Ability to drive & use**

machines No effects observed. **Undesirable effects** Suspected adverse

reactions reported in double-blind studies (frequencies: very common, >10%;

common, 1%-10%; uncommon, 0.1%-1%; rare, 0.001%-0.1%; very rare, 0.0001%-

0.001%): **Rosiglitazone+metformin** (AVANDAMET or as separate components):

Common: anaemia, flatulence, nausea, gastritis, vomiting, hypoglycaemia.

Uncommon: constipation, hyperlipidaemia, diabetes mellitus aggravated,

hypercholesterolaemia, weight gain, anorexia, oedema dependent. **Additional**

information on individual active substances Rosiglitazone Elevations of ALT

>3xULN were equal to placebo. Rare cases of elevated liver enzymes &

hepatocellular dysfunction post-marketing. In very rare cases fatal outcome

reported, but causal relationship not established. Rare cases of congestive

heart failure & pulmonary oedema; very rare cases of angioedema & urticaria.

Very rarely cases of rapid & excessive weight gain. **Metformin** GI symptoms

very common with metformin, most frequent at initiation of therapy, resolving

spontaneously in most cases. Metallic taste is common. Mild erythema

reported very rarely in hypersensitive individuals. Decrease of vitamin B12

absorption very rarely observed following long-term metformin. Lactic acidosis

is very rare. **Overdose** No data for AVANDAMET. Doses of up to 20mg

rosiglitazone well tolerated. A large overdose of metformin may lead to lactic

acidosis. Supportive treatment should be initiated, dictated by patient's clinical

status. Rosiglitazone not cleared by haemodialysis. **Basic NHS cost:**

AVANDAMET: 2mg/500mg - 112 film-coated tablets £52.45 (EU/1/03/258/006);

2mg/1000mg - 56 film-coated tablets £27.71 (EU/1/03/258/009); 4mg/1000mg - 56

film-coated tablets £52.45 (EU/1/03/258/012). **Marketing Authorisation holder:**

SmithKline Beecham plc, 980 Great West Road, Brentford, Middlesex TW8 9GS.

Legal category: POM. **Date of preparation:** April 2006. **Further information**

is available from: Customer Contact Centre, GlaxoSmithKline, Stockley Park

West, Uxbridge, Middlesex UB11 1BT; customercontactuk@gsk.com;

Freephone 0800 221 441. AVANDAMET is a registered trademark of the

GlaxoSmithKline Group of Companies © Reference: 1. Bailey CJ et al. *Clin Ther*

2005 Oct; 27(10): 1548-61.

June 2006 AVM/FPA/06/26172/1

In order to continually monitor and evaluate the safety of AVANDAMET, we

encourage healthcare professionals to report adverse events, pregnancy,

overdose and unexpected benefits to GlaxoSmithKline on 0800 221 441.

Please consult the Summary of Product Characteristics for full details

on the safety profile of AVANDAMET. Information about adverse event

reporting can also be found at www.yellowcard.gov.uk

GP CONTRACT: QOF2

death analysis' to standardise and facilitate this. They are available from the GSF team.

info@goldstandardsframework.co.uk,
www.goldstandardsframework.nhs.uk.

Conclusion

Although the task may seem daunting, we would urge primary health-care teams to get started and give the GSF a go.

▲

**The new QOF2
palliative care points
can be a real stepping
stone to making
significant practice
developments in this
vitaly important area
of end of life care**

▼

There are huge benefits, not just to our patients, but to healthcare professionals as well, in terms of job satisfaction and better team working. By organising palliative care better we may even be seeing a time saving for the team, with a reduced number of crises occurring.

The new QOF2 palliative care points can be a real stepping stone to making significant practice developments in this vitaly important area of end of life care.

Acknowledgement

All figures, tables and information are reproduced with permission of the Gold Standards Framework programme. For more information, please contact the GSF office: Tel: 0121 465 2028,

References

- (1) Cancer pain relief and palliative care. Report of a WHO Expert Committee. *World Health Organ Tech Rep Ser* 1990; 804: 1-75.
- (2) *Prognostic Indicator Guidance to aid identification of adult patients with advanced disease in the last months/year of life, who are in need of supportive and palliative care.* Version 1.24. Prognostic Indicator Paper vs 1.21. Birmingham: Gold Standards Framework Programme, 2006. www.goldstandardsframework.nhs.uk
- (3) Thomas K. *Care For the Dying at Home.* Radcliffe Medical Press: Oxford, 2003.
- (4) Department of Health. *Building on the best: Choice, responsiveness and equity in the NHS.* London: DoH, 2003.
- (5) NICE guidance on cancer services – *Improving supportive and palliative care for adults with cancer: research evidence.* www.nice.org.uk
- (6) NHS Modernisation Agency – Coronary Heart Disease Collaborative. *Supportive and palliative care for advanced heart failure.* London: NHS Modernisation Agency, 2004.
- (7) Department of Health. *National Service Framework for Renal Services - Part Two: Chronic kidney disease, acute renal failure and end of life care.* London: DoH, 2005.
- (8) British Medical Association. *Revisions to the GMS contract 2006-2007 Delivering investment in general practice.* London: BMA, 2006.
- (9) Ellershaw JE, Wilkinson S (eds). *Care of the Dying - A pathway to excellence.* Oxford: Oxford University Press, 2003.

Dr Keri Thomas is a GPwSI and National Clinical Lead, Palliative Care and the Gold Standards Framework in the NHS End of Life Care Programme
Dr Amanda Free is a Macmillan GP Facilitator and GP Associate, Gold Standards Framework team

If you would like to comment on any of the articles in this issue, please contact us by:

Post: Guidelines in Practice
The Chapel
Park View Road
Berkhamsted
Herts HP4 3EY
Fax: 01442 299220
Email: gip@mgp.ltd.uk