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 co-morbidity 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 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.

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

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 paper[2] 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		
Other indicators:				
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
8CM1.	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
1Z01	Terminal illness – late stage

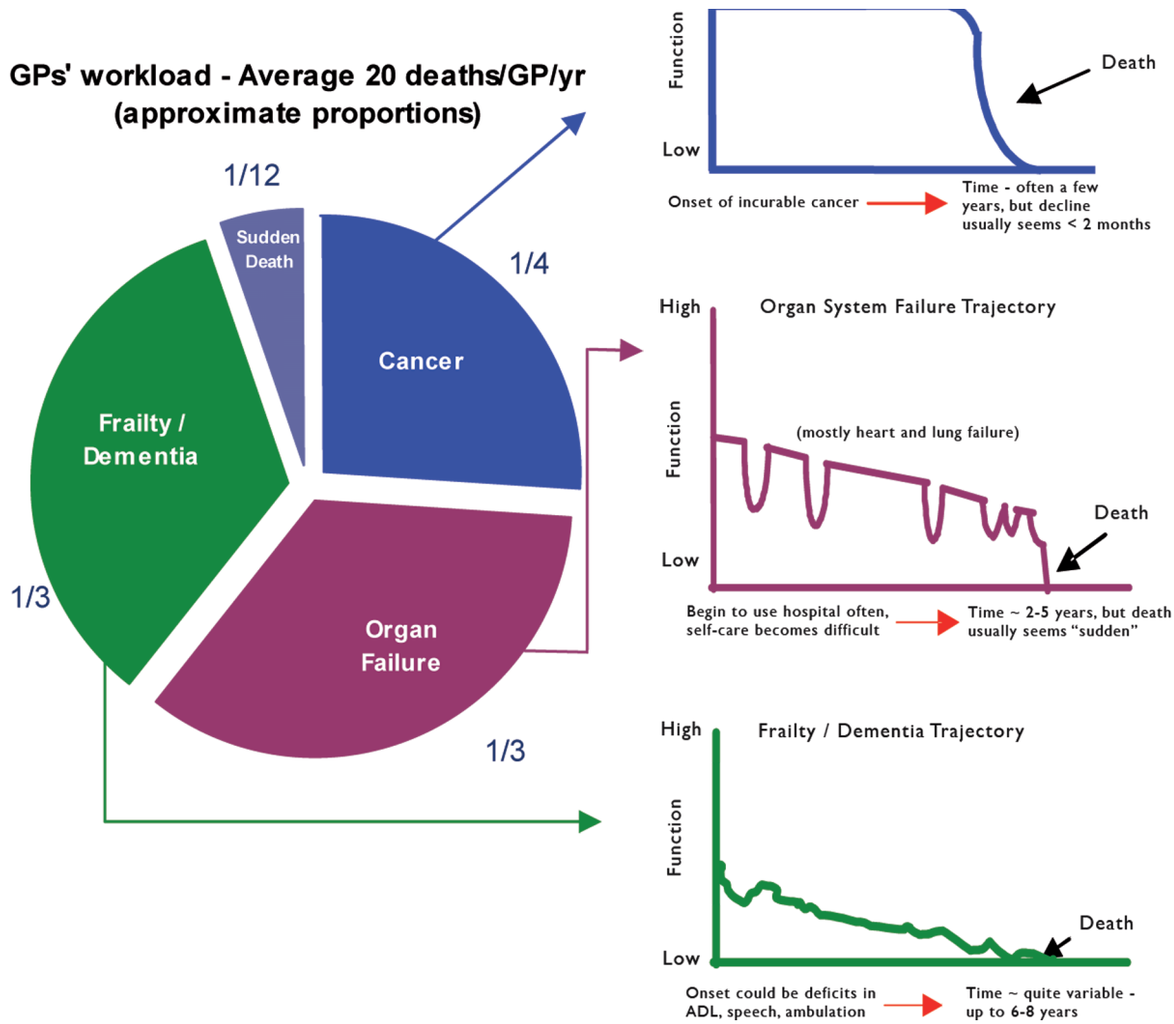
used as a way forward for primary and secondary care to identify these patients and initiate supportive care for them.

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



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

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**)

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

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.

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 accordance with the GSF and/or
- they are the subject of a DS1500 form.

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**

The programme[3] 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 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.

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.

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

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

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 SCR1, 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 SCR1, can be used as a tool to facilitate discussion 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

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

Conclusion

Although the task may seem daunting, we would urge primary healthcare 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 vitally 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 vitally important area of end of life care.

Acknowledgement

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