

# The Gold Standards Framework for palliative care in the community

It is important for pharmacists to consider their involvement in the provision of terminal care because the ready availability of medicines to treat terminal symptoms in the community will improve quality of life. In this article, **Clare Amass** describes the Gold Standards Framework, a model of best practice in palliative care that has been adopted by almost a third of GP practices in the UK



All patients faced with a chronic, progressive and terminal illness need high quality end-of-life care and this includes the choice over how they live and die. Research indicates that 56 per cent of dying patients prefer to remain at home. However, only 20 per cent do so.<sup>1</sup> Although much of the final year of life might be spent at home, many patients are admitted to hospital to die, when it may not be what they want.<sup>2</sup> A major factor contributing to these unmet wishes is insufficient support in the community setting. Poor co-ordination of round the clock care, poor communication, difficult symptom control and inadequate support for carers can all result in the breakdown of care in the community, making staying at home impossible.

The Department of Health strategy publication, "Building on the best: choice, responsiveness and equity in the NHS", published in 2003, demonstrated that patients and carers also want choice over care at the end of their lives.<sup>3</sup> To address these issues the NHS end-of-life care programme was set up in 2004.

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## Panel: The seven Cs of the Gold Standards Framework

### 1. Communication

- A supportive care register is compiled to record, plan and monitor patient care. This is used as a tool for discussion at health care team meetings.
- Regular primary health care team meetings are held to improve the flow of information.

### 2. Co-ordination

- A nominated co-ordinator (eg, a district nurse, practice manager or GP) is appointed to maintain a register of concerns and problems. The co-ordinator also organises team meetings for discussion, planning, case analysis and education.

### 3. Control of symptoms

- Patient symptoms are assessed, discussed and treated.
- Anticipatory prescribing is practised.

### 4. Continuity

- Palliative care patient details are passed on to local palliative care specialists with transfer of information to the local out-of-hours service.

- Patients and carers are given information about the contacts needed for out-of-hours advice.

### 5. Continued learning

- Meetings are organised to discuss patients' care and to share ideas and problems.
- Significant event analysis takes place to consider good examples of care and possible improvements for future work.

### 6. Carer support

- Carers are supported, listened to, encouraged and educated to play as full a role in the patient's care as they wish.
- A link with social services will be made to ensure that practical support is available.
- Health care professionals plan support for the carer when bereavement occurs.

### 7. Care in the dying phase

- The period when the patient is approaching the terminal phase (death is likely in the next two weeks) is recognised and this information is communicated to family and carers.
- Medicines for symptom control of all terminal symptoms is made available in the home.

This is designed to help health care professionals to improve end-of-life care, regardless of disease, and to widen the pool of staff trained in palliative care.<sup>4</sup> The main objectives of the end-of-life programme are:

- To offer greater choice for patients of place of care and place of death
- To have fewer emergency admissions of patients who wish to die at home
- To have fewer patients transferred from a care home to a hospital in the last week of life
- To improve skills among general staff in the provision of end-of-life care

Meeting these objectives requires close co-operation between health care professionals in the community, including pharmacists, together with a carefully planned approach. An example of how this can be achieved is provided by the application of the Gold Standards Framework (GSF).

## The Gold Standards Framework

The GSF is a systematic approach to optimising the service delivered to any patient nearing the end of life in primary care. It was started in West Yorkshire by Keri Thomas, a Macmillan GP facilitator and adviser.<sup>5</sup> The challenge was to bring the best of the advances made in hospice care into the community.

The primary aim of the GSF is to develop a practice-based system to improve the quality of palliative care in the community, so that more patients are able to live and die "well", where they choose. It developed from the need to prevent the out-of-hours crises in the community that cause many inappropriate hospital admissions.

The GSF provides primary health care teams with tools to improve the planning of palliative care. It ensures that palliative care patients are identified. Patients' needs are assessed and recorded (usually by nurses in GP practices) so that a plan of care is initiated and these needs are addressed — the GSF makes sure that no aspect is ignored or forgotten. The main goals of the GSF are:

- To enable patients to live well in the last stages of life with symptoms controlled as well as possible
- To allow patients to live and die (pain free and with dignity), where they choose, and with services shaped to their needs
- To provide security and support for patients (who have less fear and anxiety because information is well communicated), together with advanced care planning to avoid a crisis that may lead to hospital admission
- To make carers feel supported, informed and involved in patient care, with good communication, social or financial help and education available
- To increase the confidence of health care staff through improvements in teamwork, co-ordination and communication

To achieve these goals seven key aspects need to be developed. These are called the "seven Cs" and are listed in the Panel on p353. Nominated practice co-ordinators are given a toolkit containing templates of checklists and other forms, and guidance (eg, for developing practice protocols). Checklists include a PACA (problems and concerns assessment) scale and PEPSICOLA (explained below). Using the PACA scale gives an up to date overview of patients and carer's problems and concerns, including physical, social, psychological and spiritual issues. For example, patients are asked about pain, nausea and vomiting, constipation and insomnia.

Using PEPSICOLA ensures that physical (eg, symptom control), emotional (eg, depression), personal, social support, information, control (ie, choice and dignity), out-of-hours (eg, drugs and equipment), late (ie, terminal care) and after death (ie, bereavement and family support) issues are addressed. In addition, patients are given a home pack to enable better sharing of information. In particular, patients are asked about times they need help but do not receive any (ie, care gaps).

The goal of palliative care is the achievement of the best quality of life for patients and their families. Management of pain and other symptoms, with provision of psychological, social and spiritual support, is paramount. Practice review and audit is an integral part of GSF as are measures to improve consistency and dependability of care provision.

## Application in the community

When the GSF was first piloted in West Yorkshire in 2001, 12 GP practices took part. The framework induced the introduction of supportive care registers (see Panel, p353) and team meetings and these, in turn, improved patient care. Specific improvements were noticed in communication, teamwork, identification, assessment, planning and raised awareness. Indeed, from next month, having a register and holding meetings will be included in the Quality and Outcomes Framework of the general medical services contract.

In phase two of the pilot, eight practices using the GSF were matched with practices that were not using the GSF. Users believed there was more consistency of care, with a reduced likelihood that individual patients would "slip through the net". The most common concerns with the GSF related to the workload associated with the role of the framework practice co-ordinator.<sup>6</sup>

In the North Hertfordshire and Stevenage PCT area, a pilot study in 2003 had already demonstrated that anticipatory prescribing of palliative care medicines reduced hospital admissions and calls to the out-of-hours doctor.<sup>7</sup> This involved the use of "just in case" boxes to provide medicines to relieve pain, agitation, nausea and respiratory secretions. In July 2004, with help from the Mount Vernon Cancer Network, a GSF steering group was initiated by the North Hertfordshire and Stevenage PCT to provide support to GP practices wishing to become involved in GSF. A launch

meeting was held in November 2004 with GPs, nurses and pharmacists present, followed by presentations given to individual GP surgeries by a hospice pharmacist and hospice at home sister. To date, 18 GP practices out of a total of 20 have adopted the GSF. In addition, the "just in case" approach has been adopted by the practices within the Mount Vernon Cancer Network using the GSF.

In 2004, guidance for improving supportive and palliative care for adults with cancer, issued by the National Institute for Health and Clinical Excellence, endorsed the framework.<sup>8</sup> By January 2006, the GSF had been introduced to nearly a third of GP practices in the UK. It is currently being evaluated by Birmingham and Warwick Universities. Findings show more patients dying where they choose and more advanced care planning, together with improved co-ordination and communication. The GSF is now being adapted for other settings, such as care homes and community hospitals that are served by GPs, and for use for patients with non-malignant conditions.

## Conclusion

The Government's recently launched White Paper on health and social care in England calls for an expansion of the role of pharmacists in primary care. One of the ways in which pharmacists can contribute to the GSF is to ensure that medicines needed for terminal symptom control are always available. This will enable pharmacists to ensure that services are responsive to patient's needs.<sup>9</sup> Palliative care pharmacists who are supplementary prescribers working under a clinical management plan may also have a useful future role in terms of anticipatory prescribing.

For health care professionals, care of the dying is a challenging experience. The GSF for palliative care supports the need to aim for the best for patients, carers and health care professionals. A full summary of the framework can be found at: [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

## Reference

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