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. 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. 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. To address these issues the NHS end-of-life care programme was set up in 2004.

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.

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 (e.g. 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.

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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. 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 cooperation between health care professionals in the community, including pharmacists, doctors, nurses, and people with specific palliative care training, to work collaboratively with the patients and their families.

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 advances made in hospice care into the community, including pharmacists, to improve the planning of palliative care in the community, so that many inappropriate hospital admissions are avoided, and 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 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. The challenge was to bring the best of the advances made in hospice care into the community, including pharmacists, to improve the planning of palliative care in the community, so that many inappropriate hospital admissions are avoided, and 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.

To achieve these goals seven key areas 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 PEPSICO.LA (explained below). U sing the PACA scale gives an up to date overview of patients' problems and concerns, including physical, social, psychological and spiritual issues. For example, patients are asked about pain, nausea and vomiting, constipation, and insomnia. U sing PEPSICO.LA 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 the 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 plan of care 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. U sers believed there was more consistency of care, with a reduced likelihood that individual patients would "slip through the net". T he most common concerns with the GSF related to the workload associated with the role of the framework practice co-ordinator.

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. T his 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 North 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. 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 University. Findings show that patients dying where they choose and make advanced care planning together with improved 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. T hose GPs who now use the GSF will enable pharmacists to ensure that services are responsive to patients' needs. 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. T he 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

Reference

8. NICE Guidance in Supportive and Palliative Care. Available at: www.nice.org.uk