

Key messages

# Review of palliative care services in Scotland



Prepared for the Auditor General for Scotland  
August 2008

# Key messages

## Background

**1.** More than 55,000 people die in Scotland each year.<sup>1</sup> Many of these people need different kinds of palliative care including help with pain relief, nausea, depression and emotional and spiritual support. Palliative care aims to help patients and their families maintain the best quality of life throughout their illness and allow people to have 'a good death', where the wishes of the patient and their family are respected.

**2.** In the past, palliative care largely focused on end of life care, but in recent years it has been broadened to include the time from diagnosis of a life-limiting condition. It may continue through to bereavement support offered to families after someone has died. Palliative care should be an integral part of the support available to everyone who needs it.

**3.** People with different conditions will have different care needs. Specialist palliative care should be available to patients with complex needs while general provision should be available to all.<sup>2</sup>

**4.** Specialist palliative care can be provided anywhere. It focuses on people with complex needs and is provided by professionals who specialise in palliative care. The voluntary sector is a key provider of specialist palliative care services.

**5.** General palliative care is part of the routine care of patients and support for carers. It can be provided in the patient's home, a care home, in GP practices or as part of the general care provided in community or acute hospitals. It may be part of the work of a range of health and social care workers including GPs, district nurses, social workers or care assistants, as well as hospital staff.

**6.** Historically, palliative care near the end of life was mainly provided to cancer patients, but it is now recognised that it should be offered for a wider range of serious illnesses. Long-term conditions, such as dementia, chronic obstructive pulmonary disease (COPD) and heart failure account for around 60 per cent of all deaths.<sup>3, 4</sup>

## The study

**7.** This report is the first overview of activity, costs and quality of specialist and general palliative care in Scotland. It includes the views of almost 1,000 bereaved families and friends.

**8.** The study examined a range of issues including:

- access to palliative care services
- the quality of palliative care services and the extent to which these are joined up
- the extent to which the Scottish Government provides clear direction and promotes coordinated planning and delivery of palliative care

- local planning arrangements.

**9.** In the course of the study, we:

- analysed published and unpublished information
- surveyed all 14 NHS boards and all 15 hospices<sup>5</sup>
- carried out interviews with the Scottish Government, the Care Commission, NHS Education for Scotland (NES), NHS Quality Improvement Scotland (NHS QIS),

the Scottish Ambulance Service and the Scottish Partnership for Palliative Care (SPPC)

- interviewed staff in five NHS board areas, including representatives from boards, hospices, palliative care networks, and Community Health Partnerships (CHPs)<sup>6</sup>
- sent questionnaires to 500 district nurses of whom 85 responded (17 per cent)
- invited 5,249 bereaved families and informal carers to take part in a carers survey (997 responded – 19 per cent)
- spoke to 72 patients through focus groups and individual interviews.

## Key messages

**1** There is significant variation across Scotland in the availability of specialist palliative care services and how easily patients with complex needs can access these. People with a range of conditions need specialist palliative care but it remains primarily cancer-focused.

**10.** There are different models of delivering palliative care across the country with specialist services varying from board to board. This means that some patients will find it more difficult than others to access specialist care, particularly those in remote and rural areas.

**11.** There is a lack of information about the ethnicity, age and religion of patients getting specialist palliative care. This information is needed to ensure that patients receive care that suits their needs. Where this information is recorded, it shows that

1 GROS <http://www.gro-scotland.gov.uk/files1/stats/death-tab1-2006.xls>

2 *Palliative Care: the solid facts*, Copenhagen: WHO, 2004.

3 Long-term conditions last a year or longer, limit what a person can do, and may require ongoing medical care.

4 *Chronic disease management. A compendium of information*, Department of Health, May 2004.

5 Including the two children's hospices run by the Children's Hospice Association Scotland (CHAS).

6 NHS Borders, NHS Fife, NHS Greater Glasgow and Clyde, NHS Highland and NHS Shetland.

people over 75 years are less likely to receive specialist palliative care than people aged 45-74 years.

**12.** Around 90 per cent of specialist palliative care is delivered to patients with cancer although cancer accounts for less than 30 per cent of deaths. People with other conditions such as organ or respiratory failure and dementia may have complex palliative care needs but are less likely to get specialist palliative care (Exhibit 1). NHS boards do not have criteria for referring patients to specialist palliative care services.

**13.** Results from our carers survey showed that half of deaths (52 per cent) took place in hospitals, 20 per cent in a care home, 19 per cent at home or in the home of family or friends, and eight per cent in a hospice.

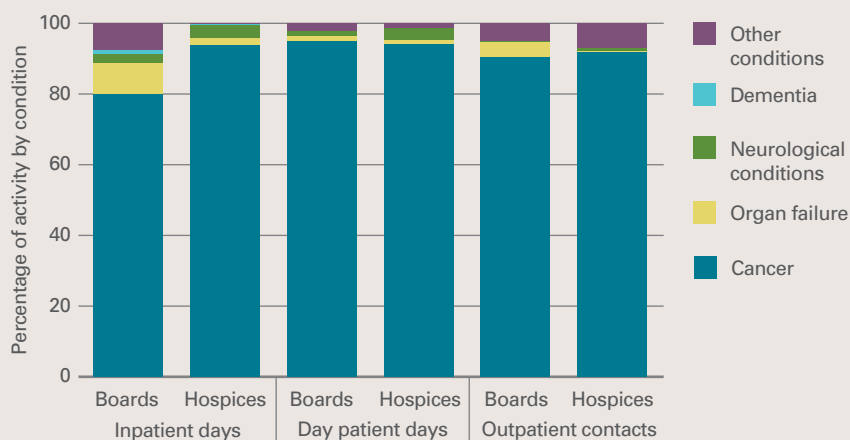
**14.** Eighty-one per cent of family and friends who completed our carers survey reported that they thought the place of death was the right one. The main reasons given for dissatisfaction with the place of death were: it was not where the patient wanted to be; the care received was poor; or it was too far away from family and friends.

**2** Most palliative care is provided by generalist staff in hospitals, care homes or patients' own homes. But palliative care needs are not always recognised or well supported. Generalists need increased skills, confidence and support from specialists to improve the palliative care they give to patients and their families.

**15.** We estimate that three-quarters of all people who die in Scotland could benefit from some form of palliative care (approximately 42,000 people per year).<sup>7</sup> However, only 5,000 patients in 2007 were included on GP palliative care registers. This suggests that around 12 per cent of people with

## Exhibit 1

The majority of specialist palliative care activity in local hospices and NHS boards is for cancer patients



Source: Audit Scotland NHS board and hospice surveys, 2007

potential palliative care needs had these identified and recorded by their GP.<sup>8,9</sup> The low number of patients on palliative care registers may be due to difficulties identifying when patients need palliative care, particularly for patients with a non-cancer illness.

**16.** There is a risk that failing to recognise when a patient could benefit from palliative care may result in a patient not getting appropriate care in the community or not being referred to specialist care when this is needed. Widening access to palliative care to all who need it requires both specialist and general staff trained to deliver high-quality care that meets patients' needs. NHS boards and hospices are starting to use education, training and good practice guidelines to support awareness of palliative care and earlier recognition of palliative care needs, but more should be done.

**17.** Towards the end of life patients may experience symptoms such as pain, breathlessness, anxiety, depression and nausea. Access to palliative care medicines is well organised through the national

community pharmacy scheme. Guidelines for managing physical symptoms have been developed and need to be applied consistently by both specialist and generalist staff. However, there are gaps in the provision of psychological, social and spiritual support.

**18.** NHS QIS and the Care Commission monitor the quality of care provided in voluntary hospices and care homes against national standards of care. But there are no national standards for general palliative care in hospitals or in the community.

**19.** There are a number of good practice frameworks which are being used in some board areas to support the delivery of good quality palliative care in hospitals, hospices and the community. These include:

- the Gold Standards Framework Scotland (GSFS)
- the Liverpool Care Pathway (LCP)
- Do Not Attempt Resuscitation (DNAR) policies.

<sup>7</sup> *The Palliative Care of Londoners: Needs, Experience, Outcomes and Future Strategy*, Higginson I, London Regional Strategy Group for Palliative Care 2001.

<sup>8</sup> Patients who are judged to be within their last year of life or who are registered on DS1500 form for disability living allowance should all be included on a palliative care register.

<sup>9</sup> In 2007, 56,000 people died in Scotland. If three-quarters of these people could have benefited from palliative care that would approximate to 42,000 people of whom only 5,000 were registered on a GP palliative care register.

**20.** The GSFS was introduced in 2003 and aims to raise the standard of care provided by GP practices to all people nearing the end of their lives.<sup>10</sup> Across Scotland, 75 per cent of GP practices are signed up to the GSFS but the key elements of this framework need to be used in all practices.

**21.** The LCP aims to ensure good quality of care for patients in the last days or hours of life once it has been confirmed that they are dying.

- Only one NHS board (NHS Dumfries and Galloway) has this in place in all acute and community hospitals.
- Twelve of the 13 voluntary sector hospices are using the LCP.
- Only a quarter of district nurses reported that they were currently using the LCP.

**22.** DNAR policies aim to reflect patients' wishes, clarify decision-making about resuscitation and improve communication between staff and with patients' families. All voluntary hospices have a DNAR policy in place and 12 boards have a DNAR policy in place in all acute and community hospitals. However, there is variation in the DNAR policies leading to uncertainty about which to apply if the patient is moved. This can cause confusion for staff and families involved in making decisions about patients who have been transferred between care settings and can make it more difficult to implement patients' wishes.

**3** Palliative care needs to be better joined up, particularly at night and weekends. Family and friends caring for someone also need support but this is not widely available.

**23.** Patients with more than one condition or who receive care in different places, such as hospital or in their own home, will get support from a wide range of staff but often this is not joined up. Sharing information is often slow which hinders continuity of care for patients. Communication among staff needs to get better and having a single person responsible for managing and coordinating a patient's care can help.

**24.** Transferring information about patients between staff working during the day and those working out of hours (evenings, nights and weekends) needs to improve. A lack of time and staff resources to address patients' needs out of hours may also lead to delays in patients getting the right care and can result in inappropriate admission to hospital.

**25.** Patients are entitled to a community care assessment to determine whether they need services and support in the community. Our carers survey highlighted that one in five patients cared for at home were not offered this assessment.

**26.** Carers often have needs of their own but our carers survey showed that two-thirds of those who looked after a family member or friend at home were not offered a carer's assessment. Patients and carers also reported difficulties in accessing respite care.

**4** In 2006/07, £59 million was spent on specialist palliative care. Almost half of this came from the voluntary sector. It is not possible to say how much is spent on general palliative care. NHS boards and their partners need to plan now to meet the predicted increase in demand from an ageing population.

**27.** In 2006/07, the total expenditure on specialist palliative care was £59 million. The NHS spent £15.5 million on specialist services and contributed £17.3 million to specialist services provided by the voluntary sector. The remaining £26.2 million was spent by the voluntary sector. It is not possible to say how much is spent on general palliative care because it is part of other services and not separately identified. However, this is likely to be much more than expenditure on specialist services.

**28.** There is little research on evaluating the effectiveness of different palliative care services. NHS boards do not routinely evaluate this and there is no information about the cost of general palliative care. NHS boards, CHPs and their partners need to work together to better plan and monitor palliative care services to meet local needs.

**29.** There is a risk that demographic changes, including the increasing numbers of people with life-limiting conditions such as dementia and COPD, could put pressure on palliative care services.<sup>11, 12</sup> NHS boards and their partners need to ensure that specialist and general palliative care are available in the future to meet these changing needs.

**30.** With the increasing pressure on services, the current dependence on voluntary sector funding is a potential risk to the sustainability of specialist services. The Scottish Government

<sup>10</sup> The GSFS focuses on the support of patients during the last year of life.

<sup>11</sup> *Managing long-term conditions*, Audit Scotland, 2007.

<sup>12</sup> <http://www.alzscot.org/pages/statistics.htm>

and NHS boards need to take this into account in their planning.

**31.** Palliative care is included in a number of national strategies but there is no overarching policy to coordinate planning and delivery across conditions or across settings.<sup>13, 14, 15</sup> The Scottish Government intends to publish an action plan in October 2008.

**32.** Twelve of the 14 NHS boards have a palliative care strategy though not all of these are up to date and not all boards with a strategy have a palliative care needs assessment. Each NHS board area has a palliative care network to coordinate planning and delivery of services. These aim to help integrate delivery of NHS, council and voluntary services. However, there is low representation of council partners on the networks and little evidence of CHPs providing a lead in coordinating health and social care services. Both these factors are barriers to developing joined-up care for people with palliative care needs.

### Key recommendations

The Scottish Government should:

- ensure that the palliative care action plan, due for publication in October 2008, addresses access issues; the balance between specialist and general palliative care; ways of joining up services for people with palliative care needs and their families; and the sustainability of services for the future
- work with NHS boards, primary care staff and the voluntary sector to develop consistent and evidence-based assessment criteria for all patients with life-limiting conditions. These are needed to support decisions about who goes onto a palliative care register. This should apply equally to patients with cancer and with other conditions.

NHS boards should:

- ensure they have an up-to-date strategy for delivering palliative care based on an assessment of the current and future needs of their local populations
- work with the voluntary sector to develop and agree protocols for primary care staff and non-specialist hospital staff to refer patients to specialist palliative care services
- apply service improvements such as the GSFS, LCP and DNAR in all care settings and ensure these are used appropriately.

NHS Education for Scotland should:

- work with NHS boards, CHPs and their council partners to ensure there is appropriate training in place for generalist staff to identify patients with palliative care needs and improve the quality of care provided.

Community Health Partnerships, including council partners, should work with palliative care networks to:

- ensure that there are clear management arrangements for palliative care across each CHP and develop a palliative care action plan to coordinate the involvement of NHS, voluntary sector and council partners in planning and delivering palliative care.

13 *Our National Health: A plan for action, a plan for change*, Scottish Executive, 2000.

14 *Cancer in Scotland: Action for change*, Scottish Executive, 2002.

15 *Coronary Heart Disease and Stroke: Strategy for Scotland*, Scottish Executive, 2002.

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