

Review of palliative care services in Scotland



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Summary



Good palliative care is not available to everyone who needs it.



Background

1. More than 55,000 people die in Scotland each year.¹ Palliative care should be an integral part of the support available to everyone who needs it in the last months, days or hours of life. It also includes help to live with a life-limiting condition. This report is the first overview of the activity, costs and quality of specialist and general palliative care across Scotland. It includes the views of almost 1,000 bereaved families and friends.

2. Palliative care is defined by the World Health Organisation (WHO) as the 'active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families'.² Palliative care can start from the point of diagnosis of a life-limiting condition and may continue through to bereavement support offered to families after someone has died.

3. Towards the end of life people may experience symptoms such as pain, breathlessness, fatigue, anxiety, depression and nausea.³ Palliative care may therefore involve a range of support including symptom control, psychological support, physiotherapy and complementary therapies as well as emotional support for patients and their families. This support 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.

4. This broad definition of palliative care encompasses both specialist and general palliative care. Specialist palliative care can be provided anywhere – in hospitals, hospices or at home – but focuses on people with complex palliative care needs, such as people needing complex pain management or psychological support. It is provided by professionals who specialise in palliative care (for example, consultants in palliative medicine and clinical nurse specialists in palliative care).

5. General palliative care forms 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 and district nurses, social workers or care assistants, as well as hospital staff.

6. Demand for palliative care services is likely to increase. The population is ageing, and more people are now living with the effects of serious chronic illnesses.⁴ Historically, palliative care near the end of life was mainly offered to cancer patients but it is recognised that it should now be offered for a wider range of serious illnesses.⁵ Long-term conditions, such as chronic obstructive pulmonary disease (COPD), dementia and heart failure, account for around 60 per cent of all deaths.^{6,7} In Scotland, it is estimated that around a million people have at least one long-term condition.⁸ Prevalence increases with age and the number of people in Scotland aged 75 and over is projected to rise by 75 per cent from 370,000 to 650,000 over the period 2004 to 2031.⁹ Palliative

care therefore needs to be developed across health and social care services to ensure specialist provision is available to patients with complex needs and general palliative care is more consistently provided to all.¹⁰

Setting the scene

7. Palliative care was developed as a new specialty in 1967 at the world's first modern hospice, St Christopher's Hospice in London. The number of hospices grew rapidly, with the voluntary sector opening around ten new hospices in the UK each year during the 1980s. The voluntary sector remains a key provider of specialist palliative care and is increasingly working in partnership with the NHS to plan and deliver services. We comment on the planning of palliative care in [Part 1](#).

8. Specialist palliative care was developed primarily as a means of providing support to people with cancer nearing the end of life, but has started to provide care for people at earlier stages of illness, including those with other illnesses.^{11,12} We comment on specialist palliative care in [Part 2](#).

9. Most people with palliative care needs receive care from generalist providers in their own homes, acute hospitals, long-stay hospitals, community hospitals and care homes. Lead cancer and palliative care GPs and palliative care clinical nurse specialists, often funded (at least initially) by the voluntary sector, have taken a key role in developing general palliative care in the community.¹³ We comment on general palliative care in [Part 3](#). Palliative care can involve specialists and generalists to support patients and their families in different settings ([Exhibit 1, overleaf](#)).¹⁴

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

2 *National Cancer Control Programmes: policies and guidelines*, Geneva: WHO, 2002.

3 *Palliative care services: meeting the needs of patients*, Royal College of Physicians, 2007.

4 *Drivers for change*, Kendrick S, Scottish Executive Health Department, 2004.

5 *Joined up thinking, Joined up care*, Scottish Partnership for Palliative Care, 2006.

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

7 *Preventing chronic diseases: a vital investment*, WHO, 2005.

8 *A health and well-being profile of Scotland*, NHSScotland, 2004.

9 *Managing long-term conditions*, Audit Scotland, 2007.

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

11 *From margins to centre: a review of the history of palliative care in cancer*, Clark D, *Lancet Oncol*, 2007.

12 *Continuity in Palliative Care. Key Issues and Perspectives*, Munday D, Shipman C, eds, Royal College of General Practitioners, London, 2007.

13 Lead Macmillan GPs are practising GPs with experience in palliative care who work with local primary care teams to promote high standards of palliative care. They act as a bridge between specialists and primary care to improve collaboration and coordination of services.

14 The names and illustrative examples are fictional and are based on what can happen when care works well.

Exhibit 1

Illustrative examples of how palliative care can work well

General and specialist palliative care at home

Sarah has advanced cancer with secondary tumours in her bones. She has severe pain and feels sick all the time, so she is not eating and is becoming very weak. Her GP is coordinating her care and the district nurses and homecare team visit twice a day. The GP is worried about increasing the amount of pain relief in case it makes her sickness worse and is not sure if Sarah can stay at home or should be admitted to the hospice, so calls the hospice for advice. A specialist in palliative medicine discusses the treatment and care options with the GP on the telephone and they try a new combination of drugs to manage her symptoms. Two days later, Sarah is distressed and agitated and the specialist agrees to visit her at home with the GP to work out what is best. Together, they decide the best combination of treatments to manage all Sarah's symptoms and discuss with Sarah where she would like care. She is sure she wants to be at home and her family agrees they can manage, so the district nurse organises a Marie Curie nurse to provide care at night. A week later, Sarah dies peacefully at home.

General and specialist palliative care in hospital

John has heart failure and has been admitted to hospital several times in the last year with severe breathlessness. John prefers to be in hospital when he is very breathless as he finds it frightening and feels more confident with hospital staff to look after him. One night, John becomes very breathless at home and calls an ambulance. After a few days of treatment, the ward staff realise that John is not going to recover. The ward nurse asks him what he thinks is going to happen and he tells her he doesn't think he has long left and is worried about how he will die. She asks the clinical nurse specialist from the hospital palliative care team to visit John and give advice on his care. She talks to John about the possibility of going home or to the hospice, but John says he knows and likes the cardiology ward staff and thinks that would be the best place to be cared for. The hospital chaplain met with John and his family during previous hospital admissions and continues to offer emotional support as well as helping them to talk about questions about life and death. John's treatment is adjusted to provide maximum comfort and the Liverpool Care Pathway is introduced. John dies in the ward as he wanted, with his family around him.¹

General palliative care in a care home

Mary has COPD, diabetes, osteoarthritis and is depressed. For many years, she has been seeing a respiratory consultant for her COPD, the practice nurse at her GP's surgery for her diabetes, and her GP gives her repeat prescriptions for pain medication and antidepressants. She lives alone but finds it increasingly difficult to look after herself. One day, her home carer finds her collapsed on the floor and she is admitted to hospital. She is malnourished, dehydrated and needs considerable help with all her care. The occupational therapist tries to organise a care package in preparation for her discharge home but finds it difficult to arrange all the care Mary requires as her needs are complicated. Eventually, Mary is discharged to a care home. The matron thinks Mary is on too many different drugs for all her different conditions and no-one has looked at all her needs together. She asks the GP and district nurse to visit. In discussing the situation with Mary, they decide that the focus of Mary's care should be palliative – managing her symptoms and keeping her comfortable – as she probably has only a few months to live. They use the Gold Standards Framework Scotland to ensure that Mary's needs are reviewed regularly, with monthly meetings of all relevant staff to discuss her care.² It is not clear how long she will live, but an advanced care plan ensures that everyone knows what to do should her condition deteriorate unexpectedly.

Notes:

1. The Liverpool Care Pathway is a quality improvement framework used to care for patients in the last days or hours of life once it has been confirmed that they are dying (see Part 4).
2. The Gold Standards Framework Scotland provides a means for improving the quality of care provided by primary care teams in the final year of a patient's life (see Part 4).

Source: Audit Scotland (The names and illustrative examples are fictional but are based on elements of real life examples)

10. Family and friends have traditionally been the main providers of palliative care. The unpaid care they provide includes help with dressing and bathing, domestic tasks like shopping and cleaning, emotional support, transport and help with medicines. They are also often the focal point for planning and coordinating care for individual patients.^{15, 16} We comment on the needs of family carers within a broader discussion of improving services in [Part 4](#).

Key messages

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

- 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.

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 on 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 Gold Standards Framework Scotland, Liverpool Care Pathway and Do Not Attempt Resuscitation policies in all care settings and ensure these are used appropriately.

NHS Education for Scotland should:

- work with NHS boards, Community Health Partnerships (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.

CHPs, 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.

11. Recommendations are made at the end of each section. These have been used to prepare a self-assessment checklist for NHS boards which aims to support them in monitoring progress against the recommendations ([Appendix 2](#)). We have also produced a separate document for NHS board non-executive directors, available from the Audit Scotland website www.audit-scotland.gov.uk

¹⁵ *Home based support for palliative care families: challenges and recommendations*, Hudson P, Med J Australia, 2003; 179: S35-37.

¹⁶ *Informal care and community care. The future for palliative care: issues of policy and practice*, Neale B, Open University Press, 1993: 52-67.

Our study

12. 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 for palliative care services.

13. In the course of the study, we:

- analysed published and unpublished information
- surveyed all 14 NHS boards and all 13 voluntary hospices and the two children's hospices to gather key information on palliative care activity, costs, planning and delivery arrangements¹⁷
- interviewed staff in a sample of five NHS board areas, including representatives from boards, hospices, palliative care networks and CHPs¹⁸
- 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)

- sent a questionnaire to 500 case-holding district nurses in the five sample NHS board areas, receiving 85 responses (a response rate of around 17 per cent)¹⁹
- invited 5,249 bereaved families and informal carers to take part in a carers survey.²⁰ 997 people responded to this survey (a response rate of 19 per cent). We gathered their views on, and experiences of, palliative care services, through a questionnaire based on the Views Of Informal Carers Evaluating Services (VOICES) methodology^{21, 22}
- spoke to 72 patients through focus groups and interviews to hear their experiences and expectations about palliative care.²³ These patients had a range of conditions.

17 A hospice provides palliative services in specialised inpatient beds, day care places or at home to people with advanced illness and their families in the form of physical, psychological, social and spiritual care.

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

19 Ninety-three per cent of these district nurses had palliative care patients and our analysis is based on their responses.

20 This work was carried out in four of the sample board areas. NHS Shetland was not included in this survey as the number of respondents was too small to ensure anonymity of responses.

21 This work was carried out by George Street Research using an adapted version of the VOICES tool with the permission of Julia Addington-Hall of Southampton University.

22 The VOICES survey measures the views of informal carers and is only a proxy measure of the actual views of patients.

23 This work was carried out by the Cancer Care Research Centre at the University of Stirling.

Part 1. Planning palliative care



The NHS and its partners need to work together to make sure that palliative care services meet patients' and carers' needs.

Key messages

- There is currently no coordinated national strategy for palliative care. The Scottish Government is working with NHS boards and the voluntary sector to produce a palliative care action plan in October 2008.
- Generalists and specialists should be working together to ensure that specialist palliative care is available to patients with complex needs while general provision is available to all. The needs of people with life-limiting conditions other than cancer are more difficult to predict but this should not make them any less of a priority for receiving palliative care.
- Every NHS board area in Scotland has a palliative care network to help coordinate services but there is low representation of council partners on these networks. CHPs do not play a lead role in managing the integrated delivery of palliative care by NHS, council and voluntary sector partners.

People with a range of conditions need access to palliative care

14. NHS specialist palliative care teams developed in the 1980s and 1990s, and at the same time GPs and district nurses began to take an interest in general palliative care. Palliative care is becoming part of mainstream healthcare and is provided to patients and their families in a range of settings.^{24, 25} More recently, care homes have been recognised as having an important role in providing palliative care.

15. Integrating palliative care into mainstream healthcare involves broadening access to patients with life-limiting conditions other than cancer, but this is not straightforward. The course of an illness due to cancer can often be predicted and this makes it easier to plan when specialist or general palliative support is likely to be needed. Other life-limiting conditions have less predictable patterns.²⁶ For example, people with organ failure may have several episodes where their health deteriorates significantly before recovering improved health again. People with dementia may have very poor health for a long period of time. The needs of people with these conditions are therefore more difficult to predict but this should not make them any less of a priority for receiving palliative care.²⁷

“Because I am stable now it doesn't necessarily mean I'm going to last out... I'm not sure what support needs I'll have or how to plan for the future.”

Patient interview, chronic heart failure

16. Generalists and specialists should be working together to ensure that specialist care is available to patients with complex needs while general provision is available to all.

17. People are living longer and the number of people living with long-term conditions is increasing (see Summary chapter). For example, it is estimated that between 59,000 and 66,000 people have dementia in Scotland this year and this is expected to rise by 75 per cent to between 102,000 and 114,000 by 2031.²⁸ Similarly, the number of people with COPD is predicted to rise by a third over the next 20 years.²⁹ Services not only have to develop to improve

access to palliative care for people with long-term conditions, but will also need to plan to meet the predicted increase in demand for these services associated with an ageing population.

The Scottish Government is developing a palliative care action plan

18. Palliative care is included in a number of national strategies but there is no overarching strategy to coordinate this:

- In 2000, in *Our National Health: A plan for action, a plan for change* the Scottish Executive Health Department (SEHD) stated that good palliative care must be available to all those who need it regardless of diagnosis.
- In 2001, *Cancer in Scotland: Action for Change* outlined the important role palliative care plays in cancer care while acknowledging the wider application of palliative care to non-cancer conditions. It stated that all NHS boards should undertake comprehensive needs assessments for palliative care, including the need for joint working across care sectors and agencies.
- In 2002, *Coronary Heart Disease and Stroke: Strategy for Scotland* outlined that palliative care services should be open to everyone with end stage heart failure.

19. In England, an end of life strategy has recently been published, which aims to promote high-quality care for adults approaching the end of life.³⁰ Scotland does not have a similar framework but in *Better Health, Better Care*, the Scottish Government committed to publishing a palliative care action plan in October 2008.³¹

24 *From margins to centre: a review of the history of palliative care in cancer*, Clark D, Lancet Oncol 2007.

25 *Continuity in Palliative Care. Key Issues and Perspectives*, Munday D, Shipman C, eds, Royal College of General Practitioners, London, 2007.

26 *Living well at the end of life: adapting health care to serious chronic illness in old age*, Lynn J, Adamson DM. Rand Health, Arlington, VA, 2003.

27 *The Solid Facts: Palliative Care*, WHO, 2004.

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

29 *Managing long-term conditions*, Audit Scotland, 2007.

30 *End of Life Care: Promoting high quality care for all adults at the end of life*, Department of Health, 2008.

This will set out how it will implement the recommendations of the SPPC report: *Palliative and End of Life Care in Scotland: the case for a cohesive approach*.³² The SPPC report stresses the importance of widening access to palliative care to patients with all conditions and the central role of general providers.

20. Earlier this year, the Scottish Government appointed a National Clinical Lead for palliative care and asked NHS boards and special health boards to identify a strategic lead at executive level for palliative care (for example, a medical director or director of nursing).³³

Not all NHS boards have palliative care strategies or needs assessments

21. To improve access for people with non-cancer illness, NHS boards should have palliative care strategies which ensure access for patients based on needs not diagnosis. Twelve NHS boards have palliative care strategies although not all of these are up-to-date. Not all NHS boards have a needs assessment of the palliative care requirements of their population and the level of detail and the conditions covered is not consistent (Exhibit 2).

22. Local clinical leadership plays an important role in driving change at both strategic and operational levels. We identified many examples where specialist and general palliative care staff – particularly consultants, clinical nurse specialists, GPs, district nurses and allied health professionals – have led initiatives to improve general palliative care. These include supporting staff in other specialties to learn palliative care skills, developing standards for pain and symptom management, and education for home care staff in palliative care. However, in the absence of a needs-based palliative care strategy, these may

Exhibit 2

Not all NHS boards have a palliative care strategy and a palliative care needs assessment

NHS board	Palliative care strategy	Year completed	Palliative care needs assessment
NHS Ayrshire & Arran	Yes	2004	No
NHS Borders	Yes	2007	Yes
NHS Dumfries & Galloway	Yes	2006	Yes
NHS Fife	No		Yes
NHS Forth Valley	Yes	2006	Yes
NHS Grampian	No		Yes
NHS Greater Glasgow & Clyde	Yes	2000/2005	Yes
NHS Highland	Yes	2007	Yes
NHS Lanarkshire	Yes	2007	Yes
NHS Lothian	Yes	1998	Yes
NHS Orkney	Yes	2004	No
NHS Shetland	Yes	2003	Yes
NHS Tayside	Yes	2007	Yes
NHS Western Isles	Yes	2007	Yes

Note: NHS Greater Glasgow and Clyde has two strategies, one for NHS Argyll and Clyde (2000) and one for NHS Greater Glasgow (2005).
Source: Audit Scotland NHS board survey, 2007

be ad hoc and not necessarily widely shared.

Local systems for delivering integrated palliative care services are not fully joined up

23. Every NHS board area in Scotland has a palliative care network to coordinate the planning and delivery of services, although the structure and membership varies among boards. These networks aim to help different providers work in partnership to manage resources and integrate the delivery of voluntary sector, council and NHS services. Palliative care networks provide local clinical leadership to develop strategy, support service development

and develop education to meet local needs. However, there is low representation of council partners on palliative care networks, which is a barrier to developing genuinely joined-up social and health care for people with palliative care needs and their carers. For example, none of the NHS boards reported any examples of joint teams involving specialist palliative care providers and councils providing support to patients and their families in the community.

24. Individual staff who can integrate the planning of services for individuals can make a big difference to the quality of care. For example, NHS Borders and Scottish Borders

31 *Better Health, Better Care*, Scottish Government, 2007.

32 *Palliative and End of Life Care in Scotland: the case for a cohesive approach*, SPPC, 2007.

33 Special health board executive leads have been identified from the National Waiting Times Centre, NHS 24, NHS QIS, NHS Health Scotland and the Scottish Ambulance Service, in addition to the NHS boards.

Council's social work department have a joint budget for palliative care patients in the last six months of life, providing single shared assessment and care management led by community nurses.

25. CHPs could play an important lead role in developing general palliative health and social care. But to date palliative care has not been a priority for CHPs and in most cases they have no specific budget or appointed lead for palliative care. Recent changes to local performance reporting by councils and their Community Planning partners, through Single Outcome Agreements, could provide a mechanism for CHPs and councils to further develop joint approaches to providing palliative care in people's homes and the wider community.³⁴

It is not currently possible to evaluate the efficiency and effectiveness of services

26. Historic arrangements, the involvement of the voluntary sector and geographical factors have resulted in a nationally diverse range of models for delivering palliative care across Scotland. This variation means it is difficult to make meaningful comparisons across boards:

- There has been no coordinating national strategy, local needs assessments are inconsistent and local needs are not always being met.
- There is no consistency in the extent to which palliative care services are delivered directly by specialist providers or by generalists who are supported by specialists.

- The level of specialist palliative care activity provided in hospitals is not recorded by NHS boards (see Part 2).
- The level of general palliative care activity and the associated costs are not recorded by NHS boards and it would be difficult to identify these fully, as they are part of mainstream services (see Part 3).

27. As a result it is not possible to fully describe the resources used to deliver palliative care and to draw robust conclusions on the cost-effectiveness of delivery. However, NHS boards and their partners need to ensure they are planning and delivering care in the most efficient and effective way to meet the needs of their local populations.

There is a lack of comprehensive and coherent information to support planning decisions

28. There are no specific national performance targets for palliative care and it is not explicitly monitored through national performance management arrangements. A number of different computer systems are used to monitor information and in some areas records are not computerised. There is no integrated data set that includes palliative care needs, provision and activity across the variety of settings, providers and NHS boards to ensure consistent monitoring of palliative care services.

29. NHS boards are required to gather user views on palliative care.³⁵ All do so, with eight boards gathering views at least quarterly (others gather views less frequently).³⁶ But there is little evidence of NHS boards using these to improve the planning or delivery of services.

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, councils, voluntary hospices and the Information Services Division (ISD Scotland) to ensure information is collected consistently across all services and used to improve planning. This would also help provide joined-up care for individual patients.

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
- develop methods to ensure that service improvements take full account of the views of patients and their families.

CHPs, including council partners, should work with palliative care networks to:

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

34 Single Outcome Agreements set out the outcomes which each council aims to achieve in line with the 15 key national outcomes specified by the Scottish Government in 2007.

35 *Patient Focus and Public Involvement*, Scottish Executive Health Department, 2001.

36 The eight NHS boards were NHS Ayrshire and Arran, NHS Forth Valley, NHS Grampian, NHS Lanarkshire, NHS Orkney, NHS Shetland, NHS Tayside and NHS Western Isles.

Part 2. Specialist palliative care



The availability of specialist palliative care varies across Scotland and is primarily focused on people with cancer.



Key messages

- The availability of specialist palliative care services and the ease with which these can be accessed by patients varies significantly across Scotland.
- Patients with cancer have access to a broader range of services and currently account for 90 per cent of specialist palliative care activity. Patients with other conditions do not have equal access to the same services.
- Hospices and NHS boards are not able to demonstrate that different ethnic and social groups have equal access to specialist palliative care services since they do not routinely monitor who receives these services.
- In 2006/07, £59 million was spent on specialist palliative care, £15.5 million of which was spent on services provided by the NHS. NHS boards commissioned £17.3 million of specialist services from the voluntary sector. The voluntary sector also contributed £26.2 million to the delivery of specialist hospice services in 2006/07. With increasing pressures on palliative care services, the current dependence on voluntary sector funding is a potential risk to the sustainability of services.

Specialist palliative care provision varies across NHS board areas

30. Each NHS board has its own way of delivering specialist palliative care services, but the way that specialist

services are currently distributed does not ensure equal access for people living in all areas of Scotland. Seven NHS boards have NHS hospices or specialist palliative care units, six have local voluntary hospices and two have no hospice or specialist palliative care units ([Exhibit 3](#)).^{37, 38, 39} Specialist palliative care for children is provided on a national basis by the Children's Hospice Association Scotland (CHAS) which has two hospices and a hospice at home service.⁴⁰ The voluntary sector provides more than half of all hospices and specialist palliative care units, and 44 per cent of the funding for specialist palliative care.

31. Nine NHS boards have hospital-based specialist palliative care teams.⁴¹ These teams do not have dedicated specialist palliative care beds but provide specialist services to patients in general hospital wards, outpatient clinics, day hospitals and in the community.

32. NHS Shetland does not have a hospice, a specialist palliative care unit or a specialist palliative care team. The board has arrangements to access specialist palliative care support from NHS Grampian and sends patients to Aberdeen for specialist inpatient care. In Shetland, and in other remote and rural areas, general services play a more prominent role in delivering palliative care.

Specialist palliative care is provided in different ways throughout Scotland

33. Hospices and NHS boards provide specialist palliative care in a number of ways. Staffed palliative care beds and specialist palliative care day care places are provided in voluntary and NHS hospices as well as in designated wards in acute and community hospitals. Day care is

provided for patients living at home who can benefit from access to specialist services such as symptom management, or from therapies such as physiotherapy or counselling.⁴²

34. In 2006/07, the majority of specialist palliative care beds (250 beds) and 72 per cent of day care places were provided by voluntary hospices.⁴³ Patients who took part in focus groups reported particular concerns about the availability of, and access to, day care services. This was consistent with the finding that 46 per cent of district nurses in our survey reported difficulties in accessing day care services for palliative care patients. Four boards had no day care provision.⁴⁴

35. Specialist palliative care teams also provide support to patients in hospital beds used by other specialties. This can be through providing care themselves or by supporting other clinicians to provide palliative care. NHS boards reported that a significant part of their palliative care provision is provided in this way but boards do not record the level of this activity.

36. The number of specialist palliative care staff working in the NHS and the voluntary sector per 100,000 population varies among boards, reflecting the different approaches to the provision of palliative care ([Exhibit 4, page 14](#)). In NHS Shetland, for example, the nearest specialist palliative care inpatient service is in Aberdeen. It therefore aims to strengthen its general palliative care services so more people can be cared for at home. The Macmillan Lead GP and the Clinical Nurse Specialist in cancer and palliative care provide regular training for generalist staff to improve their skills and confidence

37 A hospice provides palliative services in specialised inpatient beds, day care places or at home to people with advanced illness and their families in the form of physical, psychological, social and spiritual care.

38 NHS hospices may also be known as specialist palliative care units.

39 NHS Borders and NHS Shetland have no hospice provision or specialist palliative care units.

40 CHAS has a hospice at Rachel House in Kinross, a hospice at Robin House in Dunbartonshire and a hospice at home team based in Inverness.

41 NHS Ayrshire and Arran, NHS Borders, NHS Forth Valley, NHS Grampian, NHS Greater Glasgow and Clyde, NHS Highland, NHS Lanarkshire, NHS Lothian and NHS Tayside.

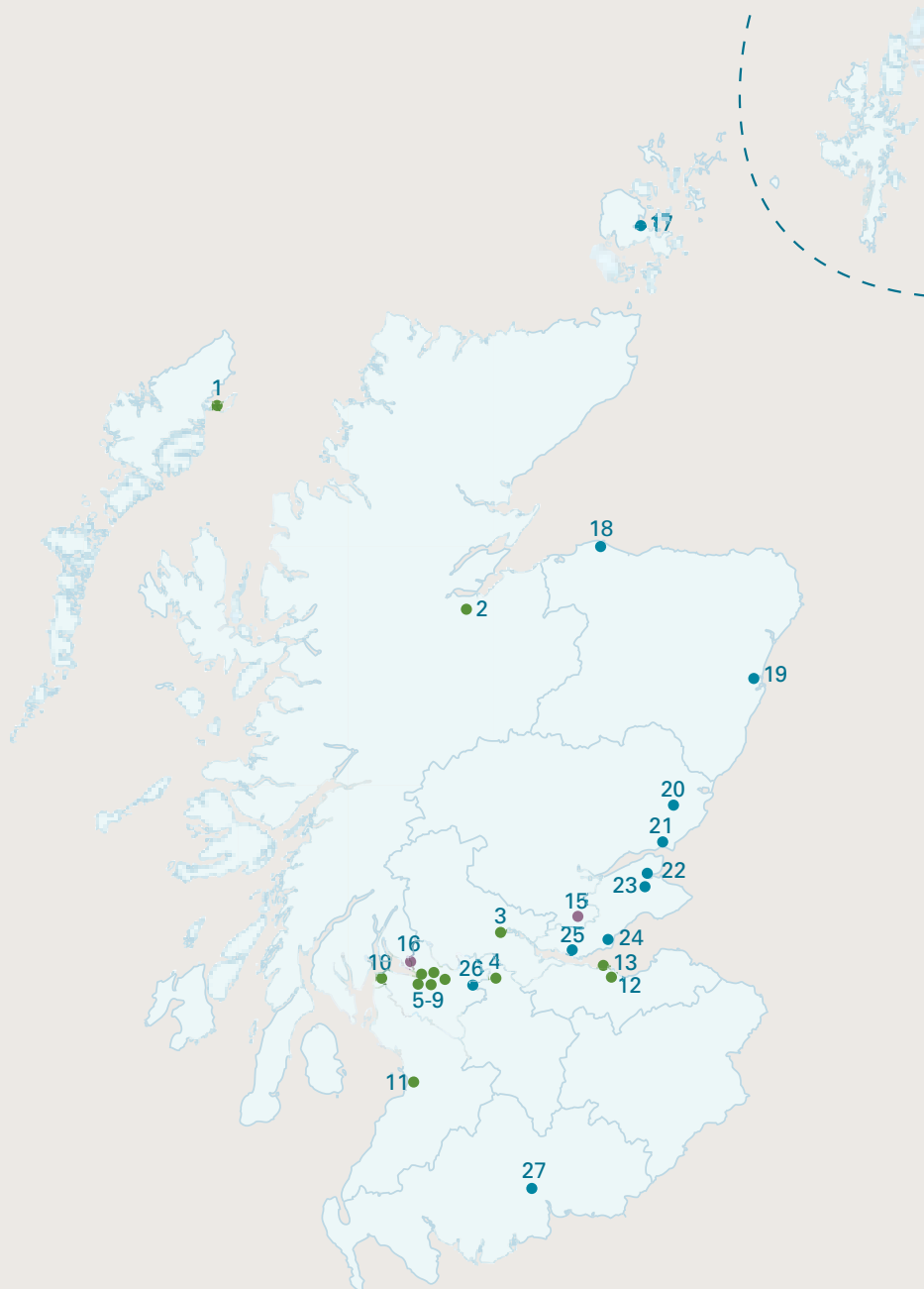
42 Symptom management can include providing relief from pain or controlling other symptoms such as loss of appetite or shortness of breath.

43 These figures include 13 local voluntary hospices and the two CHAS hospices.

44 NHS Borders, NHS Dumfries and Galloway, NHS Orkney and NHS Shetland did not have day care provision and NHS Western Isles did not provide this information.

Exhibit 3

Most hospices and specialist palliative care units are located in the central belt and there is limited access for remote and rural communities



- **Voluntary hospices**

- 1 Bethesda Hospice, Stornoway
- 2 Highland Hospice, Inverness
- 3 Strathcarron Hospice, Denny
- 4 St Andrew's Hospice, Airdrie
- 5 Marie Curie Hospice, Glasgow
- 6 Prince & Princess of Wales Hospice, Glasgow
- 7 St Margaret of Scotland Hospice, Clydebank
- 8 Accord Hospice, Paisley
- 9 St Vincent's Hospice, Johnstone
- 10 Ardgowan Hospice, Greenock
- 11 Ayrshire Hospice, Ayr
- 12 Marie Curie Hospice, Edinburgh
- 13 St Columba's Hospice, Edinburgh

- **National hospices**

- 15 CHAS, Rachel House, Kinross
- 16 CHAS, Robin House, Dunbartonshire

- **NHS specialist units**

- 17 Orkney Macmillan House, Balfour Hospital, Kirkwall
- 18 The Oaks Palliative Care Day Centre, Elgin
- 19 Roxburghe House, Aberdeen
- 20 Strathmore Hospice, Forfar
- 21 Roxburghe House, Dundee
- 22 Hospice Unit, Memorial Hospital, St Andrews
- 23 Hospice Unit, Adamson Hospital, Cupar
- 24 Victoria Hospice, Kirkcaldy
- 25 Queen Margaret Hospital Hospice Ward, Dunfermline
- 26 Dalziel Day Unit, Strathclyde Hospital, Motherwell
- 27 Dumfries Specialist Palliative Care Unit, Dumfries

Exhibit 4

There is variation across Scotland in specialist palliative care provision, staff and activity per 100,000 population

NHS board area	Model of specialist care provision	Provision per 100,000 population (2006/07)	
		Staffed PC beds	Day care places per week
NHS Ayrshire & Arran	1 voluntary hospice, 2 hospital-based specialist palliative care teams	5.5	21.8
NHS Borders	1 hospital-based specialist palliative care team, Macmillan services (including 1 day care unit)	5.4	0
NHS Dumfries & Galloway	1 NHS specialist unit, Macmillan services	15.5	0
NHS Fife	4 NHS specialist units	7.5	4.2
NHS Forth Valley	1 voluntary hospice, 1 hospital-based specialist palliative care team	9.8	39.2
NHS Grampian	2 NHS specialist units, 2 hospital-based specialist palliative care teams, Macmillan services	4.3	14.2
NHS Greater Glasgow & Clyde	6 voluntary hospices, 5 hospital-based specialist palliative care teams	8.4	27.5
NHS Highland	1 voluntary hospice, 3 hospital-based specialist palliative care teams, Macmillan services	3.3	12.7
NHS Lanarkshire	1 voluntary hospice, 1 NHS specialist unit, 2 hospital-based specialist palliative care teams, Macmillan services	4.1	24.2
NHS Lothian	2 voluntary hospices, 3 hospital-based specialist palliative care teams, Macmillan services (including 1 day care unit)	7.1	17.0
NHS Orkney	Macmillan services (including 1 day care and inpatient unit)	20.2	0
NHS Shetland	Macmillan services	0	0
NHS Tayside	2 NHS specialist units, 1 hospital-based specialist palliative care team, Macmillan services (including 2 day care units)	7.9	20.4
NHS Western Isles	1 voluntary hospice, Macmillan services	19.0	0
Scotland		7.3	19.5

Note: INA = Information Not Available.

Source: Audit Scotland NHS board and hospice surveys, 2007

Specialist palliative care staff per 100,000 population (2006/07)			Activity per 100,000 population (2006/07)			
Specialist palliative care staff	Nurses who work with specialist palliative care teams	Other	Inpatient days	Day patient days	Outpatient contacts	New referrals in the community
4.1	12.9	1.3	1,565	972	113	175
4.8	0	2.3	2,032	0	INA	490
4.8	11.0	1.4	1,894	0	360	382
4.7	12.2	3.0	2,001	626	61	278
7.1	13.6	2.8	2,269	1,539	209	245
4.4	5.1	1.2	1,198	57	110	201
7.3	14.4	2.8	2,399	871	207	230
11.2	2.0	1.9	1,003	287	81	INA
4.5	12.9	2.6	1,048	657	112	204
5.1	14.1	1.3	2,053	413	70	138
22.3	57.1	1.0	5,195	911	880	491
10.1	0	0	2,546	0	0	0
6.7	10.7	2.5	2,032	179	667	184
20.5	82.5	0.2	3,829	95	INA	INA
6.8	12.4	2.3	1,921	579	181	217

in core aspects of palliative care, such as symptom management and communication. Multidisciplinary training supports good understanding of roles and responsibilities. Telephone advice from specialists in Aberdeen is available 24 hours a day if needed. There are no voluntary hospices in NHS Fife and NHS Borders and services are provided by specialist palliative care units based in district general hospitals, with community hospitals providing additional general palliative care.

37. Specialist palliative care can be provided on an inpatient, outpatient or day patient basis, as well as through support offered in the community. Specialist palliative care activity varies among NHS board areas ([Exhibit 4](#)). In 2006/07, 70 per cent of inpatient activity across Scotland was in voluntary hospices.

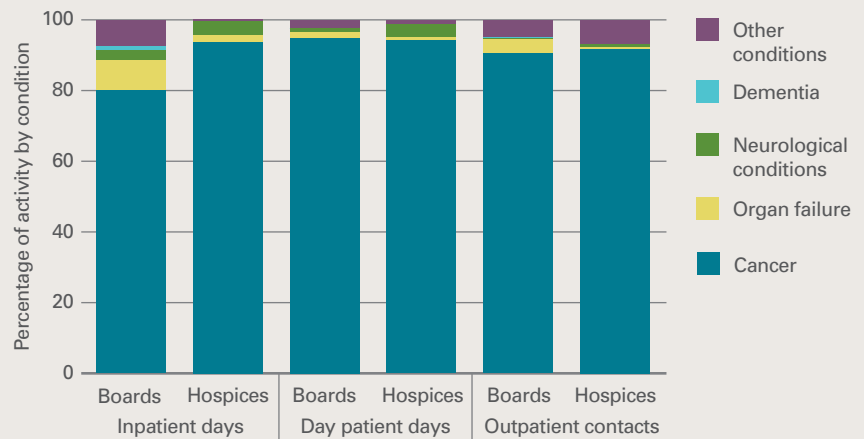
Specialist palliative care is not currently available to everyone who needs it

38. The Scottish Government has committed to the delivery of 'high quality palliative care to everyone in Scotland who needs it, on the basis of clinical need not diagnosis and according to established principles of equity and personal dignity.'⁴⁵

39. In 2006/07, 90 per cent of specialist palliative inpatient, day patient and outpatient care was delivered to patients with cancer but cancer accounts for less than 30 per cent of all deaths. Patients with other conditions may have complex palliative care needs but are less likely to receive specialist palliative care ([Exhibit 5](#)).

Exhibit 5

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

40. Patients with cancer who took part in our focus groups reported receiving specialist palliative care in hospices, palliative care wards and specialist support at home. This contrasted with comments from patients with other conditions who reported more limited access.

"Not enough help for people with motor neurone disease – if she had had cancer she would have been given all the services. I had to fight for the services."

Carers survey respondent

41. Our carers survey showed that when care was provided at home, patients with cancer were more likely than those with organ failure or neurological conditions (such as motor neurone disease) to receive support from a district nurse, Marie Curie nurse, Macmillan nurse or hospice nurse.^{46, 47} Patients with neurological conditions or organ failure were more likely than patients with cancer to receive support from a home carer ([Exhibit 6](#)).⁴⁸

42. Patients living in remote and rural communities face additional difficulties in getting specialist palliative care due to the distance from services and limited outreach capacity of specialist staff based in hospices and hospitals. For example, in the Highlands there is one hospice providing day care but this is only viable for people living within a reasonable travelling distance of Inverness. Remote and rural communities also face difficulties in accessing general services: 41 per cent of district nurses reported some difficulty in providing palliative care to patients in remote communities, in part due to the increased travelling distances which reduce the time available for patient care. Providers in Highland and Orkney are using new technology to improve patient care ([Case study 1](#)).

NHS boards need to do more to ensure equal access for everyone

43. NHS boards and hospices are not able to demonstrate that everyone has equal access to specialist palliative care services. Almost no data are gathered on access to

⁴⁵ *Better Health, Better Care: Action Plan*, Scottish Government, 2007.

⁴⁶ Marie Curie nurses offer expert home nursing care and emotional support to families affected by cancer and increasingly to those with other conditions at the end of life.

⁴⁷ Macmillan nurses are palliative care clinical nurse specialists who can be based in hospitals, hospices or the community.

⁴⁸ A home carer, such as a home care worker, home care aide or home help, is employed by the local council to support independence and help with everyday tasks such as dressing and personal care.

services by socio-economic group or ethnicity and the religion of patients is only recorded in ten voluntary sector hospices and five NHS boards. It is important that NHS boards and hospices monitor access by different groups to understand the needs of patients using the services and to

ensure equality in service provision. Some hospices have taken action to increase awareness among minority ethnic groups (Case study 2).

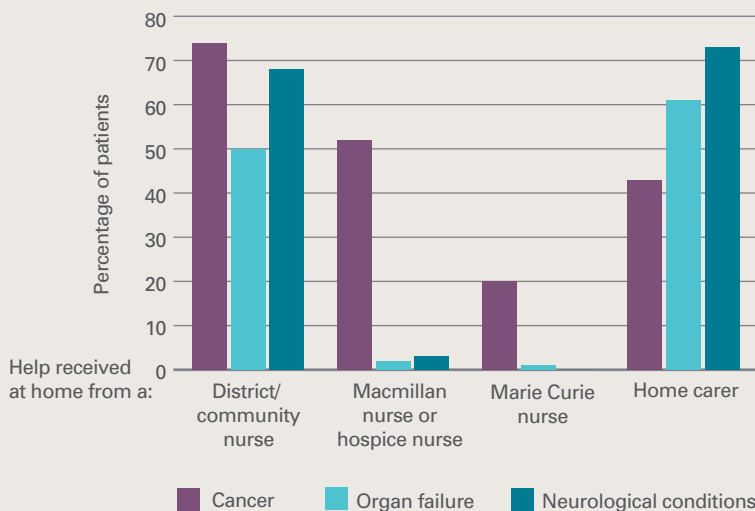
44. Only seven NHS boards reported the age of patients receiving specialist palliative care. Based on these boards,

the age profile of patients accessing specialist palliative care closely matches the age profile of patients with cancer. A higher proportion of the population who die aged 45-74 years receive specialist palliative care support than of those who die aged 75 years or more. This suggests that elderly patients may have less access to specialist care.⁴⁹ In our carers survey only seven per cent of patients aged over 75 years had stayed in a hospice during the last three months of life. This is significantly less than the 22 per cent of those aged 55-74 years and 34 per cent of those aged 18-54 years. The oldest patients may face a barrier to accessing inpatient specialist palliative care due to potential difficulties in finding appropriate services for patients to be transferred to once their complex needs have been resolved and the risk that it may take longer to discharge these patients.

45. Children's palliative care is significantly different to adult care and CHAS was established in 1992 to provide children's hospice support

Exhibit 6

The support available at home varies according to the condition of the patient



Note: This is based on 528 respondents who reported that the patient needed home care

Source: Audit Scotland survey of informal carers, 2007

Case study 1

Using new technology

NHS Highland

In remote and rural areas, new technology is improving access to palliative care for people who live a long way from hospices and hospitals. A telehealth pilot is under way in Bute for people with advanced respiratory illness using remote monitoring equipment at home and also with sheltered housing in Lochgilphead for people with all conditions.

Highland Hospice

Highland Hospice, NHS Orkney palliative care team and CCRC piloted the use of handheld computers and mobile phones provided to patients to enable them, if they feel unwell, to send information about their symptoms to hospice staff. Patients receive tailored self-care advice via their mobile phones directly related to the severity of their reported symptoms. If the doctor or nurse is concerned about the severity of the symptoms they can contact the patient by telephone to give advice.¹

Note: 1. The pilot was developed from work being led by the CCRC at the University of Stirling using an Advanced Symptom Management System (ASyMS ©).

Case study 2

Access for minority ethnic groups

The Prince and Princess of Wales Hospice in Glasgow and Strathcarron Hospice in Denny have both held open days for people from minority ethnic communities. These were organised jointly with Securing Care for Ethnic Elders in Scotland to raise awareness of the hospices and of palliative care and to hear about specific cultural needs. The Prince and Princess of Wales Hospice open day led immediately to three new referrals for patients from minority ethnic groups, more than had been received in the previous year.

Case study 3

Services for young people

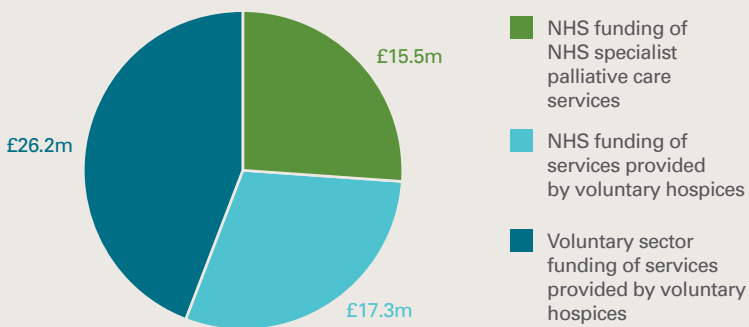
Children's Hospice Association Scotland

CHAS has recognised that young people will have palliative care needs which are particular to their age and stage of life. It organises themed teenage weekends five times per year which bring seven young people with life-limiting illnesses together in a safe, supportive environment. These weekends aim to: raise self esteem; provide peer support; give opportunities to discuss diagnosis and prognosis; establish friendships and relationships; introduce end of life care planning; and support young people to realise their potential.

As part of the hospice service, CHAS offers young people the opportunity to discuss the end of life and helps them to capture and communicate their wishes. It is working in local communities to reduce isolation and also runs young befriender projects, a young adult community support project and bereavement weekends for brothers and sisters of children who have died.

Exhibit 7

The total expenditure on specialist palliative care in 2006/07 was £59 million



Source: Audit Scotland surveys of hospices and NHS boards, 2007

Exhibit 8

NHS boards provided £15.5 million of specialist services in NHS settings

Expenditure by NHS boards on specialist palliative care (excluding voluntary hospices).

NHS hospices	4.47
Acute hospitals	6.57
Community hospitals	2.01
In the community (people's homes, care homes, health centres)	2.39
Service level agreement (with another NHS board)	0.05
Total NHS spend	15.49

Source: Audit Scotland NHS board survey, 2007

to children and their families across Scotland (Case study 3). CHAS normally takes referrals for children under the age of 16 years.

46. During our review, concerns were raised about access for adolescents who do not have age-specific care and can be inappropriately placed on child or adult wards.

47. Patients with dementia, learning disabilities, mental health problems and sensory impairments may also lack access to appropriate care.⁵⁰ Hospices reported that their services can be flexible enough to meet inpatient needs which may vary from the norm, but that arranging care on discharge for patients who require additional support is particularly challenging due to the complexity of care management and the cost of the care packages required.

In 2006/07, £59 million was spent on specialist palliative care

48. In 2006/07, total expenditure on specialist palliative care was £59 million (Exhibit 7).⁵¹ Almost half (44 per cent) of this funding came from the voluntary sector. The voluntary sector has played a key role in developing specialist palliative care and continues to be a major provider of these services. Therefore, there is a risk that a reduction in the contribution from the voluntary sector could have a significant effect on the capacity of current services to deliver specialist palliative care.

49. The NHS spent £15.5 million on its own specialist services (Exhibit 8).

⁵⁰ *Death, Dying and Social Differences*, Oliviere D and Monroe B, eds, 2004.

⁵¹ This does not include additional voluntary sector funding for specialist community services as detailed in paragraph 52.

Exhibit 9

Not all NHS boards are meeting the Scottish Government requirements for funding services from voluntary sector hospices NHS boards' contribution to voluntary hospice expenditure.

Hospice	Funding board(s)	Board funding of agreed hospice running costs 2006/07 (£m)	Total hospice agreed running costs 2006/07 (£m)	Percentage of agreed hospice funding provided by NHS boards (%)
Accord	NHS Greater Glasgow & Clyde	0.91	1.86	49
Ardgowan	NHS Greater Glasgow & Clyde	0.86	1.84	47
Ayrshire	NHS Ayrshire & Arran	1.78	4.00	44
Bethesda	NHS Western Isles	0.23	0.46	51
Highland	NHS Highland	0.97	2.35	41
Marie Curie, Edinburgh	NHS Lothian	1.57	3.60	44
Marie Curie, Glasgow	NHS Greater Glasgow & Clyde	1.77	3.76	47
Prince & Princess of Wales	NHS Greater Glasgow & Clyde	1.37	3.00	46
St Andrew's	NHS Lanarkshire	1.99	4.53	44
St Columba's	NHS Lothian	2.21	4.81	46
St Margaret's	NHS Greater Glasgow & Clyde	0.92	1.83	50
St Vincent's	NHS Greater Glasgow & Clyde	0.81	1.53	53
Strathcarron	NHS Forth Valley NHS Lanarkshire	1.66	3.54	47
	Subtotal:	17.04	37.10	46
CHAS	All NHS boards	0.29	2.09	14
	Total:	17.33	39.19	

Note: The national children's hospices are not included in the HDL guidance.

Source: Audit Scotland NHS board and hospice surveys, 2007

50. NHS boards are required to fund 50 per cent of the agreed annual running costs of independent voluntary hospices providing specialist palliative care within their area.⁵² In 2006/07, NHS boards funded between 41 and 53 per cent of the costs of voluntary sector hospices in their areas (Exhibit 9).

51. Commissioning arrangements between the NHS and the voluntary sector are improving but there remain difficulties in agreeing what should be included in the voluntary hospice funding allocation provided by boards. NHS boards hold annual meetings with their voluntary sector partners

to discuss the 50 per cent funding arrangements. These meetings are also used to review and agree the services they expect voluntary hospices to deliver. However, NHS boards do not currently evaluate value for money in the services they commission or provide.

52 Funding of specialist palliative care provided by independent voluntary hospices in Scotland, HDL(2003)18, SEHD, 2003.

The voluntary sector provides additional specialist services in the community

52. National charities such as Macmillan and Marie Curie provide significant funding for patient services other than hospices.⁵³ In 2006/07, Marie Curie spent £1.8 million of charitable funding and £1.7 million of NHS funding on Marie Curie palliative care nursing support. In 2007, Macmillan Cancer Support spent £1.7 million on clinical nurse specialists and £3.4 million on palliative care inpatient and day care. The provision of these services is agreed with NHS boards and has historically focused on patients with cancer although this is changing. For example, in 2007 Marie Curie changed its constitution to enable 49 per cent of its services to be available to patients with conditions other than cancer.

Recommendations

NHS boards should 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
- provide services that ensure equity of access for palliative care services in remote and rural communities
- record ethnicity, social demography, age and religion of all palliative care patients and monitor these to ensure equity of access. NHS boards should review provision and develop a range of strategies to promote equity of access to appropriate care
- put in place commissioning and monitoring arrangements to ensure value for money is achieved.

⁵³ Due to the large number of condition-specific charities which provide palliative care support as part of their work, it is not possible to get a complete picture of this level of funding.

Part 3. General palliative care



Most palliative care is provided by generalist staff in patients' own homes, care homes and hospitals.

Key messages

- Palliative care is an integral part of the care delivered by health and social care services. However, systems are not always in place to ensure patients and carers get access to the general palliative care that they need. Only 5,000 people are on GP palliative care registers and a fifth of patients looked after at home were not offered a community care assessment.
- Joint working between specialists and generalists allows both to use their knowledge and skills to help meet patients' needs. In order to widen access for patients with conditions other than cancer, generalists need increased skills, confidence and support from specialists to care for palliative care patients. Training and education need to be developed for health and social care providers to improve access to high-quality general palliative care.

Most palliative care is provided by non-specialist staff

53. General palliative care is delivered in a number of settings and by a variety of people (Exhibit 10). Those responsible for providing general palliative care do so as part of their general caring responsibilities and our work with boards identified examples of high-quality general palliative care, such as district nurses or GPs coordinating a multi-agency care plan to support patients to remain at home. However, there are competing demands on generalists' time and some reported little or no training in palliative care.

Recognition of palliative care needs in general settings could be better

54. Patients reported variation in the quality of general palliative care they received in hospitals and in the community. NHS boards reported that the main barriers to accessing palliative care for patients were: lack of awareness of palliative care among non-specialist staff; and difficulty recognising when palliative care should begin, particularly for patients with conditions other than cancer.

55. The points of transition from long-term condition management to palliative care and end-of-life care are poorly defined and recognised, particularly for patients with non-cancer illness. There is therefore a risk that patients in hospital, in care homes or living at home may not receive appropriate general palliative care. Hospices and NHS boards are starting to use education, training and good practice initiatives such as the Gold Standards Framework Scotland (GSFS) and the Liverpool Care Pathway (LCP) to raise awareness of the palliative care approach and support earlier recognition of palliative care needs (Part 4).

56. Recognising the need for palliative care can be a complex process as the course of an illness is often difficult to predict. In a hospital setting, where the culture is often focused on cure, palliative care may not be considered as an option until very late in the course of illness.⁵⁴ Identifying palliative care needs earlier means symptom management can focus on providing comfort and enable the patient and family to prepare for death. Delays in recognising the palliative care needs of patients looked after in hospitals can result in unmet needs for symptom control, psychological and social support for patients.^{55, 56}

57. Patients are entitled to an assessment of their needs in order to receive community services and support. This is called a community care assessment and may be undertaken by a range of professionals such as a district nurse, occupational therapist or social worker. Carers in our survey reported that one in five patients cared for at home were not offered this assessment.⁵⁷

GP systems are not always in place to ensure patients and carers get the care they need

58. Our carers survey indicated that three-quarters of the patients who died were visited by their GP during the last three months of their life. Our survey of district nurses found that 93 per cent of those who responded had palliative care patients as part of their caseload and that almost a third of their time was spent supporting palliative care patients. This highlights the importance of having effective general palliative care in place.

"I would have been unable to look after him at home without the support of the local GP and district nurse."

"Good homecare services enabled us to look after him for as long as possible before he was admitted to hospital."

Carers survey respondents

59. Palliative care needs vary for each individual. Some deaths occur very suddenly without any need for palliative care and others require only a short period of support in the final few days or hours of life. However, we estimate that approximately three-quarters of all people who die could benefit from some form of palliative care.⁵⁸ The results from

⁵⁴ *Care of the dying patient: the last hours or days of life*, Ellershaw J, Ward C, BMJ 2003; 326: 30-34.

⁵⁵ *Do hospital-based palliative teams improve care for patients or families at the end of life?* Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, Douglas HR, Norman CE, Journal of Pain and Symptom Management 2002, 23(2): 96-106.

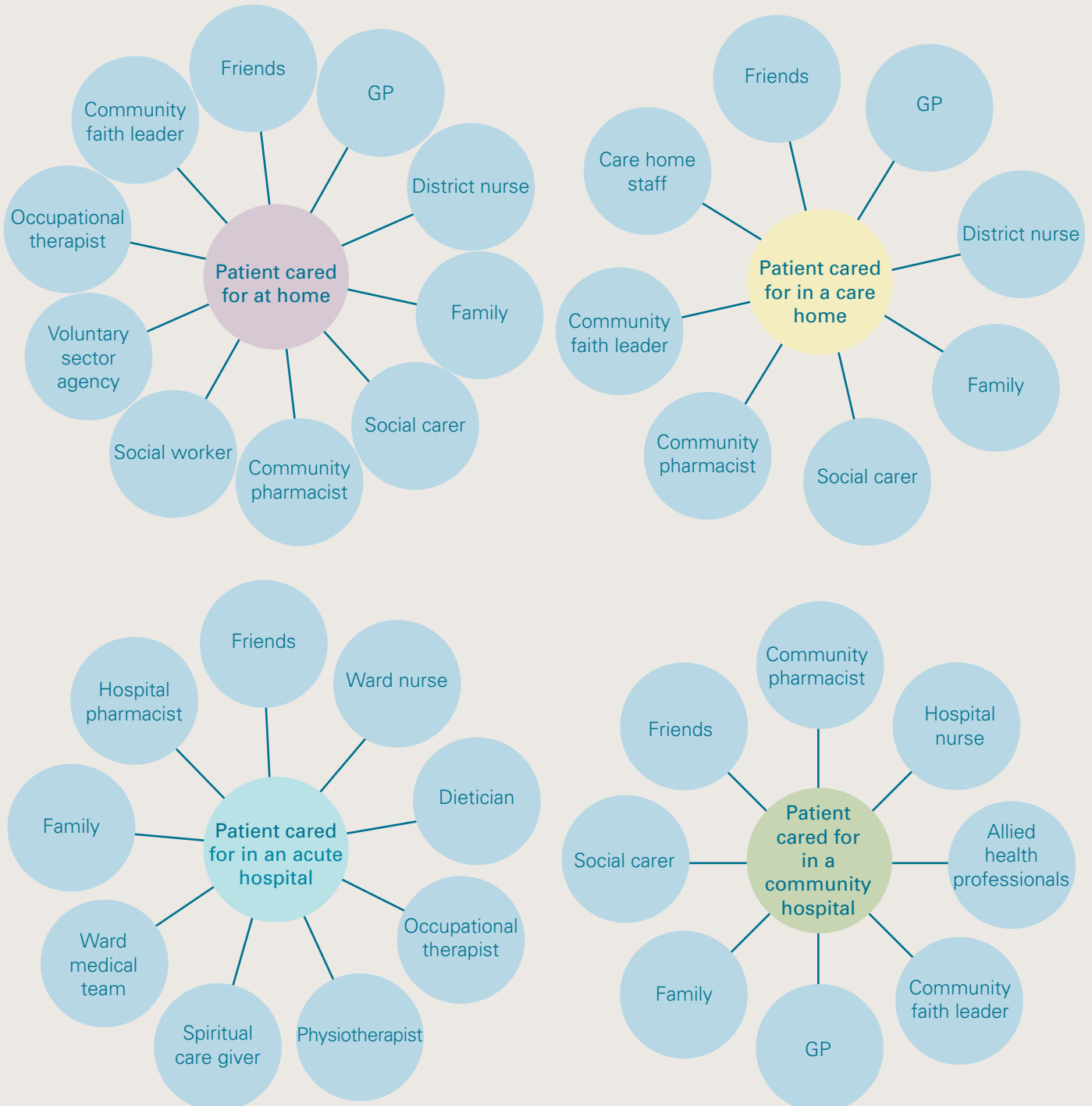
⁵⁶ *The SUPPORT Investigators. A controlled trial to improve care for seriously ill hospitalised patients*, JAMA 1995; 274: 1591-1598.

⁵⁷ Two-thirds of carers reported that patients had been offered a community care assessment and 12 per cent did not know or did not reply to this question.

⁵⁸ *The Palliative Care of Londoners: Needs, Experience, Outcomes and Future Strategy*, Higginson I, London Regional Strategy Group for Palliative Care, 2001.

Exhibit 10

Examples of varied provision of general palliative care



Source: Audit Scotland 2008

our carers and district nurse surveys show that primary care teams are providing a significant level of support to patients with palliative care needs. An accurate and up-to-date register of palliative care patients is necessary in GP practices to ensure that these patients have their needs assessed and a coordinated care plan put in place.

60. In 2007, 5,000 patients in Scotland were included on GP palliative care registers.⁵⁹ This indicates that only around 12 per cent of those with potential palliative care needs had these recorded by GPs.⁶⁰ 99.9 per cent of new General Medical Services practices across Scotland received Quality and Outcomes Framework (QOF) payments for satisfying the condition that their practice has a complete register of all patients in need of palliative care.⁶¹ The apparent inconsistency may be due to difficulties in recognising when it is appropriate to introduce palliative care. Recognising palliative care needs is essential for planning and delivering services but recognising these needs in patients with non-cancer illness is particularly difficult.

The cost of general palliative care is not known

61. NHS boards do not have specific funding to deliver general palliative care and the cost of general palliative care is not collected at a local or national level. Since it is not possible to identify how much is spent on general palliative care and there is little information about its effectiveness, it is not possible to measure whether these services are delivering value for money.

62. NHS boards reported that general palliative care can be resource intensive but it is not possible to accurately identify the costs involved due to:

- difficulties in recognising palliative care needs for non-cancer patients
- difficulties in differentiating palliative care from long-term conditions management, and from disease-specific care such as treatment for COPD or cancer
- monitoring systems that are not designed to record palliative care activity or cost.

63. Palliative care can form a large part of the workload of primary care teams and hospital staff. For example, our survey of district nurses found that on average one in ten people on their caseloads were palliative care patients, but around a third of their time was spent on palliative care.

64. Information on the cost of palliative care delivered through councils and their voluntary sector partners is also not collected as much of the support provided (eg, home care or respite) is not recorded as palliative care. Although the costs of general palliative care are not measured, there is a risk that the removal of ring-fenced funding for councils introduced through Single Outcome Agreements may lead to a tightening of funding available to the voluntary sector, causing potential restrictions on voluntary sector provision.

Education and training should improve the quality of general palliative care

65. Widening access to palliative care requires a shift in balance between specialist and general services, with specialist staff increasingly working with generalist services. Specialist provision should focus on people with the most complex needs (both physical and psychosocial), whatever the condition. Specialists can provide support, advice and education for

generalists who care for the majority of patients with less complex needs. But hospices and NHS boards reported variation in how easy it is for generalists to access this support from specialist palliative care colleagues.

66. Both specialists and generalists bring essential knowledge and skills to palliative care and joint working is the best way to ensure patients' needs are met. In order to widen access for patients with conditions other than cancer, generalists need increased skills, confidence and support from specialists to care for palliative care patients. Specialists in palliative care need increased skills and confidence in managing non-cancer illness. NES, hospices and NHS boards reported that multidisciplinary education and training supports clinical skill development and improves understanding of the different roles among staff in different care settings, helping to improve continuity of care for patients. Provision varies across Scotland and not all staff providing palliative care have access to palliative care training.

Education for specialist palliative care staff is well organised and funded, but generalists often have difficulty accessing training

67. Education for specialist palliative care staff is well established; there is a range of high-quality educational provision in higher education and in the workplace; and staff can access funding for training courses. However, NHS boards reported that education and training in palliative care for generalist staff is less well established and the core competencies needed to provide integrated palliative care are not defined. Generalists often have to attend education in their own time and fund this themselves. NHS Greater Glasgow and Clyde has created a dedicated palliative care training resource to support the development of better palliative care skills among primary care staff (Case study 4).

59 <http://www.isdscotland.org/isd/5057.html>

60 In 2007, 56,000 people died in Scotland. If three-quarters of these people could have benefited from palliative care then that would approximate to 42,000 of which only 5,000 were registered on a GP palliative care register.

61 <http://www.isdscotland.org/isd/5057.html>

Case study 4

Education in primary care teams

NHS Greater Glasgow and Clyde has dedicated Macmillan District Nurse Facilitators with district nursing backgrounds exclusively working within palliative care. These posts are based on the Macmillan GP facilitator model. They have a mainly educational remit – planning, developing and delivering education programmes – and have close links with higher education institutes. This education includes core training such as Syringe Driver Training and Verification of Expected Death, as well as symptom management and communication skills.

Case study 5

Mentoring and shadowing

In NHS Fife, GPs can receive locum cover while they are attached to one of the hospital specialist palliative care units for four sessions. They spend time with the specialist palliative care team, visiting patients in a range of settings, learning about the palliative care approach and symptom management, and finding out how the team works.

In NHS Lothian, the Palliative Care Education Project is a collaboration between the CHPs and hospices, which allows GPs and district nurses to shadow specialist palliative care colleagues to develop and update their palliative care knowledge, skills and confidence. Participants set their own objectives, with a mentor and educator, and follow the patient's journey from diagnosis to death, observing, reflecting on and discussing their care. The project was initially funded by the Big Lottery Fund and is now funded for a further three years by Macmillan Cancer Support.

NHS Fife has completed a palliative care education in care homes pilot project, which was funded for three years by the Big Lottery Fund. Forty-four care homes and 249 staff participated in a 'Foundations in Palliative Care' educational programme, supported by the Macmillan Cancer and Palliative Care Educator. The study days addressed topics such as managing confusion and dementia, and provided an introduction to service improvement tools such as the Liverpool Care Pathway and the Gold Standards Framework Scotland. Thirty-five nurses in care homes have been trained and appointed as 'key champions' in palliative care to support continued skill development among staff.

how care might be improved. NES uses web-based SEA for pharmacists as a way to support isolated practitioners.⁶²

Palliative care education is too reliant on short-term funding

70. Short-term funding of many educational initiatives from charitable sources creates difficulty sustaining programmes. NES reported that withdrawal of Macmillan and Marie Curie nurse education programmes has left gaps in provision, particularly for those who do not want to pursue degree-level education. Developing generalist staff's skills in this area will require training to be funded in a more sustainable way.

Recommendations

The Scottish Government should:

- 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 on who goes onto a palliative care register. This should apply equally to patients with cancer and with other conditions.

NHS boards should:

- work with CHPs, including their primary care, council and voluntary sector partners, to ensure that all patients on a palliative care register are offered an individual needs assessment and care plan, which is coordinated across providers and communicated to patients and their families.

Working alongside specialists improves generalist skills in palliative care

68. Shadowing, mentoring and secondment schemes to develop generalist skills by working with specialists for short periods are under way in boards such as NHS Fife and NHS Lothian (Case study 5).

69. Some staff are improving general palliative care by learning from real case studies. This is known as significant event analysis (SEA). In NHS Lothian, for example, specialist palliative care staff lead case discussions with primary care teams following the death of a patient, analysing what happened, why and identifying both good practice and

NES should:

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

NHS boards, CHPs and council partners should work together to ensure that:

- the local palliative care action plan includes health and social care provision and that community care assessments are offered to people with palliative care needs
- all staff providing general palliative care receive relevant training to identify and care for patients with palliative care needs. This includes staff working in primary and community care, hospitals and care homes.

Part 4. Improving service delivery



Good practice frameworks are not applied everywhere that patients receive palliative care.

Key messages

- Current arrangements do not always deliver coordinated care for patients. The quality of palliative care available out of hours does not always meet the needs and expectations of patients and their families.
- Users reported high satisfaction with the quality of care provided by hospices. However, most palliative care is provided at home, in care homes or in hospital by generalist staff and user experience of this care is more mixed.
- The Gold Standards Framework Scotland, Liverpool Care Pathway and Do Not Attempt Resuscitation policies aim to improve the quality of care available to patients and families but they are not yet consistently applied across all services.
- Respite care is not widely available and there are gaps in the provision of psychological, social and spiritual support for patients and their families in hospitals and the community.

The way services are currently delivered does not ensure coordinated care for patients

71. Patients with more than one condition or who are treated in different places will see several different service providers and may experience little joined-up care. A large number of people can potentially be involved in caring for a patient (Exhibit 10, page 23).

"The care system could not adapt quickly enough to meet his changing needs."

Carers survey respondent

72. Transferring information between different services can be slow and hinders continuity of care for patients.

Case study 6

Service integration

ACCORD hospice and the Royal Alexandra Hospital in Paisley have a joint consultant post. This aims to integrate specialist and general services and enable the same team of staff to follow patients as they move between care settings. The post was initially hospice-funded, before shared costs were agreed with NHS Greater Glasgow and Clyde. The consultant encourages joint working and a flexible approach to roles and boundaries in the wider multidisciplinary team. This allows specialist palliative care services which would normally only be provided in the hospice to be provided to hospital patients. For example, hospice staff can provide family support and bereavement counselling in the hospital setting; the hospice hairdresser provides support and advice as well as hair styling and wigs to people experiencing hair loss as a result of their treatment. Hospice-funded clinical nurse specialists, who are based in the community, liaise closely with the hospital-based Macmillan nurse. In complex cases, the hospital and community nurses jointly visit patients and their families, improving support at the time of discharge or at the end of life. The integration with the hospital also helps to raise awareness and skills in general palliative care among ward staff through the ready availability of specialist advice and support in managing individual cases, both for cancer and non-cancer illness.

A quarter of carers reported that health services could have made the end of life easier and identified poor communication as a key problem.

Paisley's Accord Hospice and Royal Alexandra Hospital have appointed a joint post to improve coordination of palliative care (Case study 6).

73. Patients reported that care was well coordinated when managed through a hospice or coordinated by a clinical nurse specialist. In the community, a key worker approach, where an individual member of staff takes responsibility for coordinating care, can also be effective. Such roles are often the responsibility of GPs or district nurses. Patients who did not receive this support reported fragmented care. A third of district nurses who responded to our survey reported that poor communication among agencies could be a barrier for patients.

"I have a good network of people working together. I feel comfortable with that. I feel sorry for those who don't have this."

Patient focus group, cancer

74. NHS Forth Valley has developed a resource pack to improve the quality of palliative care information across care settings (Case study 7).

75. Managing the acute episodes which are a frequent feature of non-cancer illness requires flexible health and social care services to support patients to remain at home and prevent unnecessary admission to hospital. Where this is not achieved, there is a risk of unnecessary hospital admissions – particularly out of hours.

76. Fifteen per cent of respondents in the carers survey reported that social services could have helped make the end of life easier for their family member or friend. The two main problems reported were lack of continuity of care 24 hours a day and difficulties in accessing equipment to enable patients to be cared for at home.

"She had to wait three weeks for equipment although her prognosis was only two to three weeks."

Carers survey respondent

Case study 7

Palliative care resource pack

NHS Forth Valley has developed a palliative care resource pack for use across all care settings that provide general or specialist palliative care. The aim is to ensure that a high-quality and equitable standard of information is available to all care settings involved in the care of palliative patients. The resource pack includes sections on symptom control, how to access local services, how to approach the last few days of life, how to deal with death, and bereavement support for relatives. A total of 240 copies of the pack were distributed locally. Although initially designed for local use, there has been significant interest in the pack from many care settings across Scotland and beyond, with over 50 electronic copies sent outwith Forth Valley. This includes distribution to various countries across Europe and further afield. The British Medical Journal asked the Forth Valley managed clinical network (MCN) to develop a palliative care learning module based on the resource pack, and this is now available online as an educational resource for health professionals. The module was accessed by over 1,000 users in the first year, making it one of the more popular topics accessed on the BMJ website. The BMJ module can be accessed at <http://www.learning.bmj.com/learning>

staff suggested that nationally consistent out-of-hours support for patients and families is needed.

82. Out-of-hours arrangements vary among boards. Ten boards have a special phone number for palliative care patients and carers out of hours, and 12 boards have a special number for professionals ([Exhibit 11, overleaf](#)).

83. NHS boards provided examples of anticipatory palliative care planning for patients whose needs are likely to change outwith normal working hours. Dedicated professionals try to ensure that provisional arrangements are put in place to deal with changes in care needs. NHS Borders has developed its local out-of-hours provision ([Case study 8, page 31](#)).

The quality of palliative care is variable

Specialist palliative care services are meeting national standards

84. In its review of national standards for specialist palliative care NHS QIS reported good quality care.⁶⁴ Four key areas for improvement were identified:

- The provision of specialist palliative care services funded by the NHS and the voluntary sector can be complex and clear planning arrangements are needed.
- Patients are not always prioritised by their needs and specialist resources are not always efficiently targeted.
- There is a shortage of nurses with specialist qualifications, particularly out of hours.
- There is a lack of evaluation of the different types of service configuration to inform planning decisions.

Continuity of palliative care over 24 hours needs to improve

77. NHS QIS developed national standards for specialist palliative care services and carried out reviews of these in 2003.⁶³ The reviews identified concerns about some aspects of out-of-hours palliative care services including:

- the demand for specialist medical care out of hours far exceeds the number of trained staff available to provide this
- specialist nursing care is not routinely available out of hours and there are not enough specialist nurses to support 24-hour advisory services
- there is limited and variable specialist knowledge amongst those providing out-of-hours GP services.

78. During our more recent fieldwork, NHS boards reported that these continue to be areas requiring attention.

79. Patients in the focus groups reported that access to out-of-hours care was not straightforward and often presented difficulties where systems did not share relevant information. This leads to delays in accessing appropriate care and can result in inappropriate admission to hospital. Respondents in the carers survey were more satisfied with out-of-hours services. Half had accessed out-of-hours services in the last three months of life and half of those were completely satisfied with the response from the out-of-hours service. However, one in ten were completely dissatisfied.

80. The information recorded for patients registered on a GSFS register can be linked to an Emergency Care Summary sheet available to out-of-hours providers, but this is not yet available on all GP practice IT systems.

81. NHS staff reported that 24-hour on-call telephone advice from palliative care specialists was usually available and effective, but specialist assessment and care were not universally available out of hours for patients cared for at home. Specialist

63 *National Overview: Specialist Palliative Care*, NHS QIS, 2004.

64 *National Overview: Specialist Palliative Care*, NHS QIS, 2004.

Exhibit 11

Provision of specialist palliative care out-of-hours support varies among NHS boards

NHS board	Out-of-hours support available	For patients, informal carers, family		For professionals	
		Special out-of-hours phone number	Normal out-of-hours number ¹	Special out-of-hours phone number	Normal out-of-hours number ¹
NHS Ayrshire & Arran	Yes	Yes	Yes	Yes	Yes
NHS Borders	Yes	Yes	No	Yes	No
NHS Dumfries & Galloway	Yes	Yes	Yes	Yes	Yes
NHS Fife	Yes	No	No	Yes	Yes
NHS Forth Valley	Yes	Yes	Yes	Yes	Yes
NHS Grampian	Yes	No	Yes	Yes	Yes
NHS Greater Glasgow & Clyde	Yes	Yes	Yes	Yes	Yes
NHS Highland	Yes	Yes	Yes	Yes	Yes
NHS Lanarkshire	Yes	Yes	Yes	Yes	Yes
NHS Lothian	Yes	Yes	Yes	Yes	Yes
NHS Orkney	Yes	Yes	INA	Yes	INA
NHS Shetland	Yes	INA	Yes	INA	Yes
NHS Tayside	Yes	Yes	Yes	Yes	Yes
NHS Western Isles	No	No	No	No	No

¹ The normal out-of-office hours number would include NHS 24.

Note: INA = Information Not Available.

Source: Audit Scotland NHS board survey, 2007

85. The findings in our review show that these areas for improvement remain. NHS QIS has no current plans to review palliative care services in its programme up to 2010.

86. The Care Commission inspects 15 voluntary hospices at least twice a year. It produces reports and makes recommendations based on the National Care Standards, codes of practice and recognised good practice.⁶⁵ Hospices attracted very few complaints and the Care Commission reported that its requirements are usually acted on promptly.⁶⁶

The quality of general palliative care could be improved

87. The NHS needs to do more to identify and meet the needs of all patients with palliative care needs as

early as possible. The carers survey showed that 71 per cent of those who were cared for in hospices reported that they had their pain relieved completely all or some of the time, compared with 53 per cent of those who received treatment in hospital. Similarly, 92 per cent of respondents reported that personal needs (such as bathing, dressing, help with eating and going to the bathroom) were met in hospices, compared with 66 per cent saying they were met in hospital.

“Excellent care on palliative care ward but initially placed in open general ward which was inappropriate for the stage of her illness.”

Carers survey respondent

88. During the course of the audit, concerns were raised about the standard of general palliative care in hospitals. These included failure to recognise palliative care needs; inappropriate referrals to specialists; poor environment for dying; competing priorities meaning insufficient time for palliative care; and poor discharge planning. More needs to be done to raise awareness among hospital staff of palliative care needs earlier in the patient's illness to ensure they get appropriate general palliative care and referral to specialist palliative care when required.

⁶⁵ *National Care Standards: hospice care*, Scottish Executive, 2002.

⁶⁶ *The Quality of Care Services in Scotland*, Scottish Commission for the Regulation of Care, 2007.

Case study 8

Out-of-hours palliative care in NHS Borders

NHS Borders has developed an out-of-hours palliative care service which has won an 'Evidence Into Practice' award. Led by the Lead Macmillan GP and Clinical Nurse Specialist in cancer and palliative care, with active support from social work, GPs and district nursing, the key features are:

- The service was designed from patient and carer experiences rather than being service-driven.
- A dedicated phone number is given to individual patients near the end of life and their carers to call, bypassing NHS 24; patients and carers are actively encouraged to call, and are given a leaflet about the service to reinforce this.
- The service is local and nurse-led with rapid response to calls, structured assessment of needs and records kept on advice given.
- Social care services are actively involved in planning and delivery.
- Palliative care training is provided for out-of-hours staff and clear guidelines for palliative care and protocols for referral have been established.
- Handover sheets from in-hours services give details of the patient's condition and care plan; handovers are usually completed by nurses and are completed for 80-90 per cent of patients at the end of life. Information about the patient is therefore usually readily to hand, so they do not have to repeatedly answer the same questions; and preferred place of care is recorded on the handover form.
- Effective pharmacy services enable rapid access to drugs when needed.
- The service is regularly monitored and audited and is continually developed in response to feedback from patients, carers and professionals.

Audits have shown benefits including low out-of-hours admission rates (one hospital admission from 150 contacts from November 2004 to April 2005), more robust processes such as pain assessment, and the popularity of the service with patients and primary care staff.

"The staff were helpful on the palliative care ward but on the general ward they were less friendly, and would not explain procedures."

Carers survey respondent

89. Community hospitals enable palliative care to be provided close to people's homes, particularly where patients need 24-hour nursing care but not specialist care, and the nurses

have some palliative care training. But there is variation in the extent to which community hospitals prioritise palliative care and in their criteria for use of palliative care beds. The level of palliative care training and skills varies among community hospital staff, as does the degree of complexity of palliative care they provide.

90. Many people with palliative care needs live in care homes – a fifth of deaths in the carers survey were in

care homes. The predicted growth in the older population suggests that care homes are likely to provide more palliative care in the future. The Care Commission inspects care homes using national care standards and good practice guidance for palliative care.^{67, 68} Audit Scotland has previously highlighted the concerns raised by the Care Commission and Help the Aged about the lack of GP services to care homes in some areas and indicated that this is an area which all NHS boards should review.^{69, 70} This variation in the services provided in care homes may affect the quality of general palliative care available to patients.

"Staff in the nursing home did not recognise her deteriorating condition."

Carers survey respondent

91. Sample boards reported that considerable educational initiatives are under way to improve palliative care in care homes, but they still have concerns about standards including: failure to recognise palliative care needs; poor symptom management; and high staff turnover making it difficult to provide training for staff.

Good practice guidance is improving the quality of palliative care

92. Three examples of good practice guidance are being used to help drive improvement in the quality of palliative care:

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

67 National Care Standards: care homes for older people, Scottish Government, 2007.

68 Making good care better: National practice statements for general palliative care in adult care homes in Scotland, Scottish Partnership for Palliative Care, 2006.

69 Review of the new General Medical Services contract, Audit Scotland, 2008.

70 My home life, Help the Aged, 2007.

The Gold Standards Framework Scotland has improved palliative care in primary care

93. There are no clinical standards covering palliative care delivered by generalists. The GSFS aims to raise the standard of care provided by primary care teams to all people nearing the end of their lives but is not externally monitored or regulated. It was introduced in 2003, in recognition of the volume of general palliative care being delivered by primary care teams. It builds on what many GP practices are already doing by using seven standards to improve communication within primary care teams, help proactive planning and raise the profile of carer support (Exhibit 12).

94. Where the GSFS is used, NHS boards identified a number of benefits including raised awareness of the palliative care needs of non-cancer patients, better use of standard documentation and guidelines, and more systematic care planning and organisation. Community nurses in GSFS practices were particularly positive about the improvements in multidisciplinary care planning, teamwork and communication, both within teams and between specialists and primary care. However, there remains variation in the extent to which patients with non-cancer illness are included on GSFS registers.⁷¹

95. The general themes to emerge from patient interviews carried out for an independent evaluation of the GSFS were:

- people feel supported and informed
- people are enabled to care
- proactive and ongoing contact is much appreciated
- general feeling that there is a team.⁷²

Exhibit 12

The seven gold standards of the GSFS

Communication: practices maintain a Supportive Care Register to record, plan and monitor patient care, which they use as a tool to discuss their patients at regular multidisciplinary team meetings.

Coordination: each primary care team has a nominated coordinator for palliative care to ensure good organisation and coordination of care in a practice, by overseeing the process.

Control of symptoms: each patient has their symptoms, problems, concerns (physical, psychological, social, practical and spiritual) assessed, recorded, discussed and acted upon, according to an agreed process. The focus is on the patient's wishes.

Continuity: practices will transfer information to the out-of-hours service for palliative care patients, for example, using a hand-over form and out-of-hours protocol. This builds in anticipatory care to reduce crises and inappropriate admissions.

Continued learning: using practice-based or external teaching, lectures, videos, significant event analysis or other tools, the practice and personal development plans as well as audits and appraisals are implemented.

Carer support: carers are supported, listened to, kept fully informed, encouraged and educated to play as full a role in the patient's care as they wish. They are regarded as an integral part of the team. Support is also given in bereavement.

Care of the dying: patients in the last days of life are cared for appropriately, for example, by following an integrated care pathway. This includes stopping non-essential interventions and drugs, considering comfort measures, psychological and religious/spiritual support, bereavement planning, communication and care after death.

Source: GSFS website <http://www.gsfs.scot.nhs.uk/overview.html>

Seventy-five per cent of GP practices are signed up to the Gold Standards Framework Scotland

96. Across Scotland, 75 per cent of practices are signed up to the GSFS. There is substantial variation among boards, ranging from no practices in NHS Shetland through to 88 per cent of practices in NHS Forth Valley (Exhibit 13). NHS boards reported that as well as variation in the numbers of practices which have signed up to the GSFS there is also variation in the

extent to which the components of the standards are used regularly to improve the quality of care within the participating GP practices.

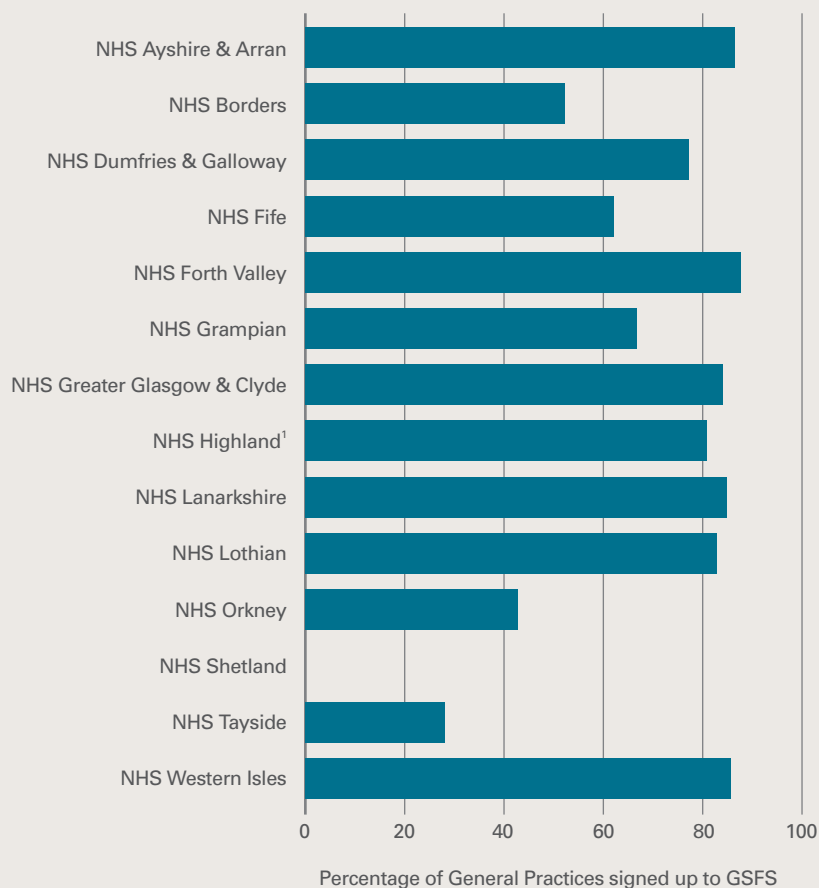
97. Participation in the GSFS is voluntary and requires some additional administration to set up and maintain the systems involved. The core principles of the GSFS, such as planned and integrated care, can be applied by practices which are not formally signed up to the scheme.

71 The GSFS register is not the same as the GP palliative care register (page 24).

72 <http://www.gsfs.scot.nhs.uk/documents/GSFS%20audit%20report%20Oct06.doc>

Exhibit 13

The percentage of general practices signed up to the GSFS varies among boards



1 Former Highland area only, not including Argyll & Bute.

Source: Audit Scotland NHS board and hospice survey, 2007

NHS Borders, for example, reported that its integrated palliative care system, recommended by the SPPC as a national model, was in place before the advent of GSFS.⁷³ There is significant overlap between the first stage of the GSFS and the palliative care elements in the QOF.⁷⁴ To avoid duplication the Scottish Government should review the use of both systems and identify any potential to link them to reduce administration and improve the quality of care.

The Liverpool Care Pathway is being used to improve the quality of palliative care services

98. The LCP was developed to take the best of hospice care into hospitals and other settings. It is used to care for patients in the last days or hours of life once it has been confirmed that they are dying. The LCP facilitates effective communication within the multidisciplinary team and with the patient and family, anticipatory planning including psychosocial

and spiritual care, and appropriate symptom control and bereavement care. The LCP has accompanying symptom control guidelines and information leaflets for relatives.

99. The pathway is not universally used. Only five NHS boards have the LCP in all acute hospitals, two boards have it in place for all community hospitals, and NHS hospices in two boards are also using it.⁷⁵ Twelve voluntary sector hospices are using the LCP and only a quarter of district nurses reported that they were currently using the LCP.⁷⁶ Some boards have appointed facilitators to roll out LCP to all care settings, including care homes and the community.

A consistent Do Not Attempt Resuscitation policy is not applied in all settings

100. Do Not Attempt Resuscitation (DNAR) policies aim to reflect patients' wishes, reduce inappropriate resuscitation attempts, clarify decision-making about resuscitation and improve communication among 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.⁷⁷ However, there is variation in the DNAR policies leading to uncertainty about which to apply if the patient is moved. The Scottish Ambulance Service reported variation in the policies applied by different boards and the extent to which they are implemented in practice. This can cause confusion for staff and families involved in making decisions about patients who have been transferred between care settings that have different DNAR policies and can make it more difficult to implement the patients' wishes.

73 *Palliative and End of Life Care in Scotland: the case for a Cohesive Approach*, SPPC, 2007.

74 <http://www.goldstandardsframework.nhs.uk/>

75 NHS Borders, NHS Dumfries and Galloway, NHS Forth Valley, NHS Greater Glasgow and Clyde and NHS Orkney use LCP in all acute hospitals. NHS Ayrshire and Arran and NHS Dumfries and Galloway use LCP in all community hospitals. NHS Orkney and NHS Tayside use LCP in all NHS hospices.

76 Ardgowan Hospice and CHAS do not use LCP.

77 NHS Shetland and NHS Greater Glasgow and Clyde do not have a DNAR policy in place in all community and acute hospitals.

Family and friends provide a significant amount of palliative care but often lack support for their own needs

101. Providing support for families, whether the patient is at home, in hospital or hospice, is a core principle of palliative care.⁷⁸ Palliative care in the last few days and weeks of life can be a 24-hour responsibility for family carers. Carers can be unprepared for the demands of caring for someone who is dying at home and are not always well-supported by services, especially out of hours.^{79, 80}

102. Patients in our focus groups reported that families provided a significant amount of care and support but that carers' needs were not always met. A carer's assessment is designed to identify the needs of the carer independently of those of the patient, but 66 per cent of carers who were looking after patients nearing the end of life at home reported that they were not offered one. This suggests that not everyone who has need for general support services, such as home care and respite, can access these.

103. There are also gaps in the provision of day care, respite care and support in the home to enable carers to have a break and bereavement support. A third of the district nurses who responded to our survey reported that they did not have enough time to meet the needs of the families of palliative care patients.

104. Patients' families and informal carers often need support around, and after, the death of a family member or friend. Bereavement support is most readily available where the patient has been cared for by specialist palliative care services, but provision is inconsistent. NHS Fife has made specific provision to look at the

Case study 9

Emotional, spiritual and family care

NHS Fife child and family support worker

In NHS Fife, the child and family support worker provides continuity for families from point of entry to palliative care to post-bereavement care as required. The service is holistic and tailored to family needs, so the level of support provided can range from minimal and occasional to intensive, depending on the family's needs. It is viewed as especially valuable for children with a dying parent in preparing them for the death. In situations where children need to take a role in caring for a family member, it ensures they receive adequate support and attention to their own needs. The child and family support worker liaises with numerous other agencies, including primary care, schools, nurseries, specialist palliative care, social work and social care, to ensure the child and family receive the care and services they need. She also acts as a resource for other staff, giving advice and support to enable them to manage complex family situations. The post was funded by Macmillan Cancer Support, but this funding has now ended.

NHS Fife spiritual and pastoral care

NHS Fife has a dedicated hospital chaplaincy service which can follow up patients after discharge from hospital into the community if needed. Although not specialised in palliative care, the chaplains are an integral part of the specialist palliative care team, have flexible role boundaries and view their service as providing pastoral, emotional, psychological and spiritual support as needed by patients and families. They are on call via pager 24-hours a day. The chaplains provide support for staff on a one-to-one or group basis as needed, for example, if ward staff have faced a series of deaths or a particularly difficult death. They also provide training courses for staff on topics such as breaking bad news and bereavement support; the courses are open to all staff and are over-subscribed.

emotional and spiritual care of patients and their families (Case study 9).

Respite care is not widely available

105. Informal carers are often elderly and may have health concerns of their own.⁸¹ Respite care provides them with a break by looking after the needs of the patient for a short period of time. However, in our survey of district nurses, 42 per cent reported that they could seldom or never get access to respite care for patients and their families when they needed it.

106. Fifty-five per cent of respondents to the carers survey reported that they had not needed respite care. A further seven per cent did not ask

for respite care because they did not know it was available.⁸² Only ten per cent of the carers in our survey had asked for respite care, nearly a quarter of whom did not get it and nearly one-in-five had to wait to get it.

"When I tried to ask for respite care I was told I had to arrange it myself with the care home. The care home said they could not do it as the request had to come from the care worker. I was back and forth. It was appalling."

Carers survey respondent

107. Hospices and NHS boards reported very limited availability of respite care. They recognised this as

78 Home based support for palliative care families: challenges and recommendations, Hudson P. Med J Australia 2003; 179: S35-37.

79 The NHS Cancer Plan, Department of Health, London, 2000.

80 Out-of-hours palliative care: a qualitative study of cancer patients, carers and professionals, Worth A, Boyd K, Kendall M, Heaney D, McLeod U, Cormie P, Hockley J, Murray S, B J Gen Practice, 2006; 56 :6-13.

81 Continuity in Palliative Care: Key Issues and Perspectives, Royal College of General Practitioners, London, 2007.

82 Twenty-seven per cent of carers did not reply to this question.

a gap in provision, with patients likely to be admitted to hospital if carers become exhausted or reach crisis point. Care homes and community hospitals offer limited respite care. Alternative forms of carer support, such as Crossroads support at home, are sometimes available, but provision of these types of respite varies.⁸³

108. Patients reported that the shortage of other services such as day care also affects their families and carers who would be able to get a break if day care services were available. They reported that if the support needs of their family and friends were not met, this added to their own anxiety.

“She (family member) never complains but I know she needs a break. I get day care two days a week. I enjoy it. And I enjoy it because it gives her a break.”

Patient focus group, Parkinson's disease

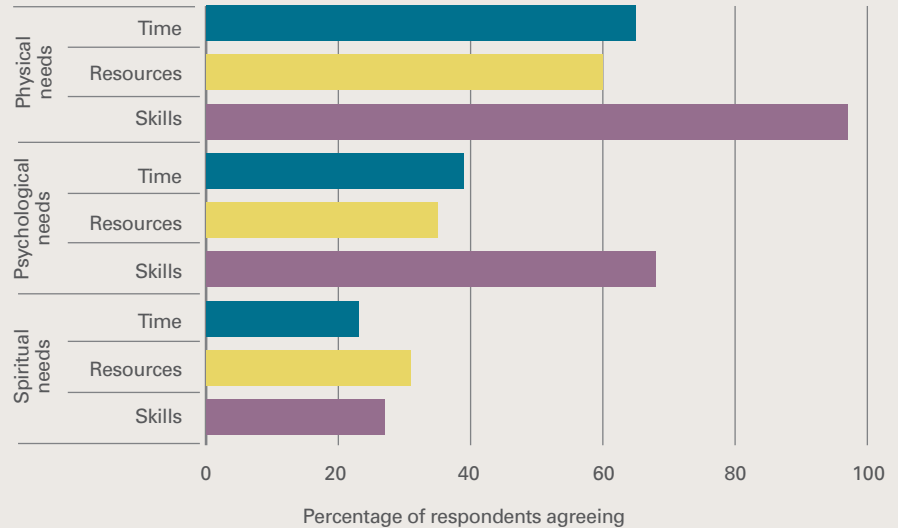
Physical, psychological, social and spiritual support are not available to everyone

Symptom control is well developed but is not applied in all settings

109. Hospices and NHS boards reported that local audits indicate that symptom management has improved. Symptom control tools have been developed by specialist palliative care teams and managed clinical networks, and guidelines (such as the Scottish Intercollegiate Guidelines Network (SIGN) guideline on pain management in cancer) are used to manage physical symptoms.^{84, 85} However, the results of our carers survey indicate that more needs to be done to improve the treatment and control of pain as this is such an important part of providing quality care.

Exhibit 14

District nurses reported that they had more time, resources and skills to meet patients' physical needs



1 District nurses who agreed that they have enough time, access to resources or the necessary skills to meet each type of need.

Source: Audit Scotland survey of district nurses in sample boards, 2007

110. Provision of palliative care medicines is an important part of controlling symptoms such as pain or nausea. NHS boards reported that provision was well organised through the national community pharmacy scheme.⁸⁶ Anticipatory care planning has led to 'Just In Case' boxes containing essential medicines being available in patients' houses or local health centres for easy access out of hours.

There are gaps in the provision of psychological, social and spiritual care

111. NHS boards reported that access to psychological care is variable. Generalist and specialist staff assess psychological and spiritual needs, and provide general psychological support, such as listening and discussing fears and emotions. Generalist and specialist medical and nursing staff reported that they lacked time and skills to provide complex psychological and spiritual care and the lack of local specialist psychology

or spiritual care services can mean they have no resources to which they can refer patients or their families.

112. District nurses reported that they were better skilled and had more time and resources to support the physical needs of their palliative care patients than their psychosocial or spiritual needs (Exhibit 14).

113. Where patients and families have problems with severe psychological adjustment, grief, or unresolved distress, specialist psychology services might be required. Seven NHS boards have psychologist staff working with their specialist palliative care staff and six NHS boards have specialist bereavement support provision in their hospitals or hospices.^{87, 88} Specialist psychological and bereavement support is largely hospice-based, so those who live a long way from a hospice are disadvantaged – hospices and NHS boards reported that phone and

83 Crossroads provides support to carers by giving them time to have a break from their caring responsibilities – <http://www.crossroads.org.uk>

84 Symptom control algorithms are step-by-step problem, solving guidelines for clinical staff.

85 *Control of Pain in Patients with Cancer*, SIGN, 2000.

86 The national community pharmacy scheme was not reviewed as part of this audit.

87 NHS Ayrshire and Arran, NHS Dumfries and Galloway, NHS Fife, NHS Forth Valley, NHS Grampian, NHS Lothian and NHS Tayside have psychologist support.

88 There are bereavement specialists in NHS Fife, NHS Greater Glasgow and Clyde, NHS Highland, NHS Lanarkshire, NHS Lothian and NHS Tayside.

new technologies are of limited benefit in psychosocial and family support. Almost a third of district nurses reported that they sometimes had difficulties getting access to psychological support for their patients.

114. Spiritual care is an integral part of the total care provided to a patient and family. Specialist spiritual and pastoral care is provided by hospital and hospice spiritual caregivers, who also offer support to staff, but specialist spiritual support is not always available to patients and families in the community. All boards have a spiritual care policy but three NHS boards reported that they did not have any chaplains working with either board or hospice specialist palliative care teams.⁸⁹ In our carers survey a fifth of respondents reported that the spiritual needs of patients were not addressed. The majority of respondents whose spiritual or emotional needs were met reported that these were met at home. NES is developing a capability framework for spiritual care which sets out the core skills that NHS staff should possess, and the Scottish Government is developing new guidance on spiritual care.

Four in five carers believe that their friend or relative died in the right place

115. A survey carried out for Marie Curie in 2004 reported on where people would choose to die if they became ill with a terminal condition: 64 per cent would prefer to die in their own home; 23 per cent in a hospice; and only four per cent in a hospital.^{90,91} Helping patients to make informed choices about the location of care and where they would prefer to die is an important part of palliative care. Hospices and NHS boards identified a number of issues which affect the level of choice available:

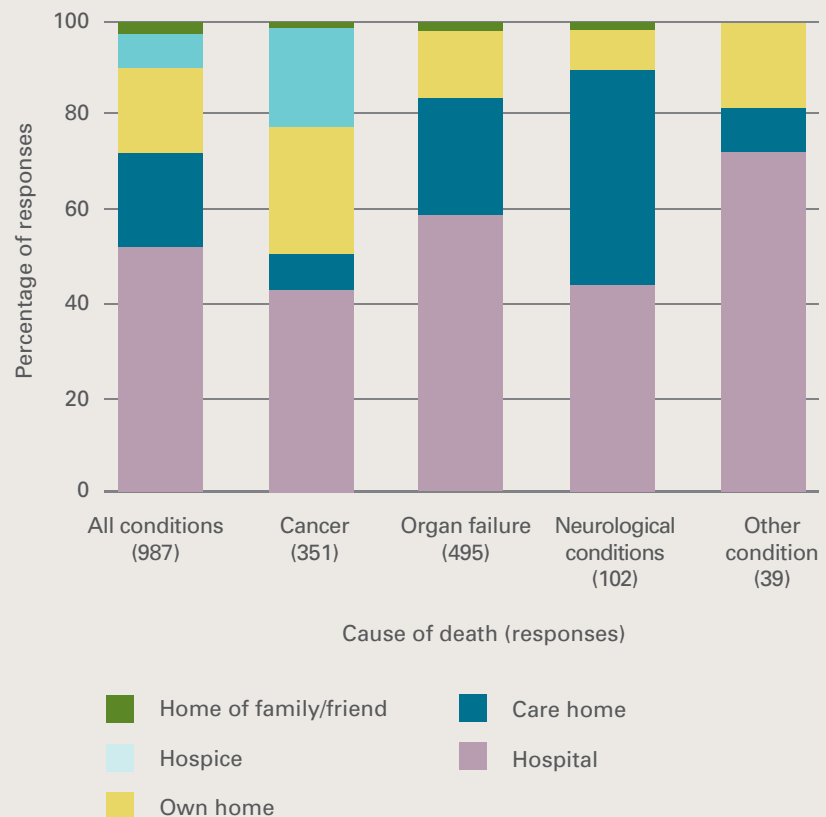
- Services, particularly social care and carer support, can be inadequate especially for people with non-cancer illness, meaning choice is restricted.
- Late referral to specialist care due to poor awareness of palliative care needs, particularly in non-cancer illness.
- People sometimes die at home or on general wards because specialist palliative care beds are unavailable.
- Death at home seems more achievable in rural or remote areas where there is no easy option of admitting people to inpatient care, but this can also be construed as lack of choice.

116. The results of our carers survey showed that the place of death varied according to the cause of death. People dying of cancer were more likely to be supported to die at home or in a hospice (Exhibit 15). People who died of organ failure were more likely to die in hospital and people with neurological conditions were more likely to die in a care home. Overall, almost three-quarters of people (72 per cent) died in a hospital or a care home.

117. Hospices and NHS boards also reported that not achieving the patients' preferred place of death did not necessarily constitute failure to offer choice or plan appropriately. The place of death will be affected by patients' changing needs and preferences as well as unexpected

Exhibit 15

The location of death varies by the cause of death



Source: Audit Scotland carers survey, 2008

89 NHS Borders, NHS Orkney, NHS Shetland (in addition, NHS Western Isles were not able to provide this information).

90 http://campaign.mariecurie.org.uk/England/press_centre/press_releases/press_releases_archive/marie_curie_cancer_care_launches_supporting_the_choice_to_die_at_home_campaign.htm

91 Seven per cent answered 'don't know', and two per cent answered 'other'.

deteriorations in condition and situations where the family may not be able to manage the death at home.

118. Four out of five carers who completed our survey reported that the place of death was the right one. The main reasons given by informal carers who reported that the place of death was not the right one 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.

Recommendations

The Scottish Government should:

- work with NHS boards, NHS 24, primary care and the voluntary sector to ensure that all IT systems in primary care include a palliative care page that automatically links directly to the Emergency Care Summary
- promote the use of the GSFS within primary care and care homes and review the potential to link this with the palliative care element in the QOF
- promote the use of the LCP in all care settings
- establish a consistent national DNAR policy.

NHS boards and CHPs should work with councils and the voluntary sector to:

- improve systems for transferring information across settings and between in-hours and out-of-hours services to provide better coordinated patient care
- ensure that family and friends who help provide palliative care at home receive a carer's assessment and have any additional support needs addressed

- review the provision of respite care and ensure it is available and appropriate to meet current and future needs
- review the provision of psychological, social, spiritual and bereavement care to ensure it is available and appropriate to meet current and future needs
- apply service improvements such as the GSFS, LCP and DNAR in all care settings and ensure these are applied appropriately.

NHS QIS should:

- work with NHS boards and the voluntary sector to develop standards for generalist palliative care in acute settings
- review its standards for specialist palliative care.

Appendix 1.

Project advisory group membership

Member	Organisation
Maureen Black	Senior Macmillan Development Officer, Macmillan Cancer Relief
Hilary Davison	Head of Standards Development Unit, NHS QIS
Richard Dimelow	Health Quality and Safety Branch, Scottish Government
Dr Elizabeth Ireland	National Clinical Lead for Palliative Care, Scottish Government
Dr Bridget Johnston	Senior Research Fellow, Cancer Care Research Centre, University of Stirling
Kate Lennon	Nurse Consultant for Palliative Care, NHS Greater Glasgow and Clyde
Elaine McLean	Professional Adviser Palliative Care, Care Commission
Susan Munroe	Director of Patient and Family Services, Marie Curie Cancer Care
Professor Scott Murray	St Columba's Hospice Chair of Primary Palliative Care and Macmillan Research Advisor, Primary Palliative Care Research Group, The University of Edinburgh
Dr David Oxenham	Medical Director, Marie Curie Hospice, Edinburgh
Craig Stockton	Vice-chair, Scottish Neurological Alliance, and chief executive of the Scottish Motor Neurone Disease Association
Patricia Wallace	Director, Scottish Partnership for Palliative Care
Dr Chris Ward	British Heart Foundation advisor on palliative care and heart failure in Scotland

Members of the project advisory group sat in an advisory capacity only. The content and conclusions of this report are the sole responsibility of Audit Scotland.

Appendix 2.

Self-assessment checklist for NHS boards

The checklist on the next few pages sets out some high-level statements about palliative care based on issues raised in this report. Boards (with their CHPs, voluntary sector and council partners) should assess themselves against each of the statements and consider which statement most accurately reflects their current situation:

- not in place and action needed
- not in place but action in hand
- in place but needs improving
- in place and working well.

This approach will enable boards to identify what actions need to be taken forward.

Issue	Assessment of current position				Comment to support or explain your statement
	No – action needed	No – but action in hand	Yes – in place but needs improving	Yes – in place and working well	
Are there agreed protocols in place (based on need not diagnosis) for referring primary care, care home, and acute care patients with specialist palliative care needs to specialist palliative care services?					
Are consistent assessment criteria for all patients with life-limiting conditions used to support decisions about who goes onto a GP palliative care register?					
Do all patients on palliative care registers have an individual needs assessment and a coordinated care plan in place?					
Is information on ethnicity, social demography, age and religion of palliative care patients recorded for all patients in boards and hospices?					
Is this monitored and action taken to promote equal access?					
Are IT systems in place that share information across providers (including out of hours) to ensure joined-up delivery of palliative care services?					
Has the provision of psychological, social, emotional, spiritual and respite care been assessed against the needs of palliative care patients and their families?					
Are plans in place to address any gaps in provision?					

Issue	Assessment of current position				Comment to support or explain your statement
	No – action needed	No – but action in hand	Yes – in place but needs improving	Yes – in place and working well	
<p>Has an up-to-date palliative care needs assessment been carried out?</p> <p>Is this used as part of a palliative care strategy to plan and deliver palliative care services?</p> <p>Is performance information monitored to assess progress against the strategy and improve services?</p> <p>Are user views gathered regularly and used to improve services?</p>					
<p>Do NHS specialist palliative care services ensure value for money?</p> <ul style="list-style-type: none"> Do you have arrangements to monitor use of resources and occupancy rates? Do you benchmark your services against other providers? <p>Does the board ensure value for money in the specialist palliative care services it commissions from other providers?</p> <ul style="list-style-type: none"> Is an agreed contract in place which specifies services and costs? Are services regularly monitored? 					

Issue	Assessment of current position					Comment to support or explain your statement
	No – action needed	No – but action in hand	Yes – in place but needs improving	Yes – in place and working well	Not applicable	
<p>Are referral protocols being used to link long-term conditions management, palliative care and end of life care? These should:</p> <ul style="list-style-type: none"> • identify needs • ensure appropriate referrals • provide appropriate care. 						
<p>Are service improvement initiatives consistently applied in all care settings (acute hospitals, community hospitals, hospices and care homes)?</p> <ul style="list-style-type: none"> • GSFS • LCP • DNAR 						
<p>Are arrangements in place to ensure that staff providing general palliative care have appropriate training?</p> <p>Is there sustainable training to support general palliative care?</p> <p>Is the board dependent on short-term funding from the voluntary sector to provide training?</p>						
<p>Does each CHP have:</p> <ul style="list-style-type: none"> • a palliative care action plan? • clear management arrangements for palliative care? • active involvement from NHS boards, the voluntary sector and councils in the joint planning of palliative care? 						

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