

# Review of palliative care services in Scotland

Report supplement: Patients' views



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# Part 1. Summary

## Background

1. Audit Scotland published its national report, *Review of palliative care services in Scotland*, on 21 August 2008. This report is available at [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk). As part of our review, we commissioned the Cancer Care Research Centre (CCRC) at the University of Stirling to carry out research into patients' views and experiences of palliative care. This supplement accompanies the national report and summarises the main findings from that research.
2. Palliative care provides support for people living with advanced, progressive or terminal conditions. Adopting a holistic approach, palliative care considers the whole person, and includes pain relief, symptom management and the provision of psychological, social and spiritual support.
3. In 2007, the Scottish Government published *Better Health Better Care: Action Plan* which states that *"palliative care is an integral part of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable disease. It is not just about care in the last months, days and hours of a person's life but includes support to enable someone to live with a life threatening condition and maintain, as far as possible, a decent quality of life for their families and themselves."*<sup>1</sup>
4. The research carried out in this study considers patients' perspectives on palliative care and includes the experiences of patients with a range of life-limiting conditions such as cancer, dementia, the frail elderly and older people, progressive neurological illness, chronic respiratory illness and chronic heart failure/heart disease.
5. This report focuses on the experiences of people receiving care and also those who may have palliative care needs for which they are not currently receiving direct services. The study considers the provision of palliative care by hospital based services, primary-care teams, hospices and voluntary organisations.
6. The report is organised into three parts: **Part 2** considers the availability of, and access to, palliative care services; **Part 3** examines the quality of palliative care services; and **Part 4** looks at the coordination of care to meet patients' needs.

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<sup>1</sup> *Better Health, Better Care: Action Plan*, Scottish Government, 2007.

## Key messages

- Patients reported inequalities in access to palliative care services.
- Patients want better access to information on their illness and appropriate services.
- Patients found it difficult to access appropriate out-of-hours care.
- Patients need support to deal with the emotional needs of life-limiting illness.
- Practical support should be considered as part of effective palliative care.
- Families and informal carers provide a significant amount of care but may have support needs of their own.
- Information and communication are key to ensuring that care meets patients' needs.
- Clinical nurse specialists have improved the coordination of palliative care for patients with conditions other than cancer.

## Methods

7. CCRC carried out this study for Audit Scotland using a combination of telephone interviews and focus groups held in a variety of NHS and voluntary sector care settings. The researchers used a semi-structured questioning format based on the focus group schedule included in **Appendix 1**. Responses to the questions and the related discussion were recorded and analysed alongside a written note taken by the researcher.
8. A total of 72 patients participated in this project. Patients were drawn from five NHS board areas identified as sample boards in the wider review undertaken by Audit Scotland (NHS Borders, NHS Fife, NHS Greater Glasgow and Clyde, NHS Highland, and NHS Shetland).<sup>2</sup> Participants comprised 41 per cent men and 59 per cent women. The ages of those participating ranged from 42 to 96 years. Participants had a range of chronic and life-limiting illnesses, including: breast cancer, bowel cancer, mouth cancer, multiple sclerosis, chronic obstructive pulmonary disease (COPD), Parkinson's disease, stroke and chronic heart failure/disease, dementia, frail elderly and learning disabled. Participants were identified in a number of different settings including hospices, day care centres (both voluntary sector and NHS), support groups (located both within the NHS and community-based settings) and wider voluntary sector day services aimed more specifically at caring for the frail elderly

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<sup>2</sup> A pilot focus group was also conducted in a hospice day care setting in NHS Forth Valley.

and those experiencing dementia. A more detailed description of the sample of participants is included in **Appendix 2**.

9. The methodology used was adapted to fit the needs and expectations of the participants. Palliative care is not a widely recognised term and does not have a universally agreed definition. **Appendix 3** gives a fuller discussion of some of the challenges faced when researching this topic and how these were addressed in this study.

# Part 2. Access to palliative care

## Patients reported inequalities in access to palliative care services

10. Many patients with cancer described receiving palliative care services in a number of settings. These included: in a hospice, hospital, palliative care ward, hospice day centre and at home with the support of specially trained staff. Some received care involving district nurses and many received care via palliative care nurse specialists. Other patients accessed similar services but less frequently.
11. For the frail elderly and dementia patients participating in this study, day care was available once or twice a week in a voluntary sector setting. This service was commended by all who received it and was seen as providing a vital social focus. However, many lacked the network of care and information provided to other patient groups receiving palliative care services.
12. There was unequal access to this type of specialist support as indicated by the following participant's reflection on their experience prior to the involvement of a clinical nurse specialist, and the continued experience of others in that position:

*“Utterly hopeless. Not all patients get a heart failure nurse ... only those with a hospital diagnosis ... generally older people are just not getting any advice, a lot of people don't even understand the medication properly.”*

**Patient interview, chronic heart disease**

13. Participants' main concerns about access focused on the availability of day care services. Day care was seen as a form of respite for family and friends as well as providing social contact for patients. Participants reported that access to day care was limited and some did not have access. They also held low expectations that access to day care was likely to improve.

*“I'm not so lucky..... I have a niece she does what she can but that's all ... she's there in an emergency ... they live quite different lives to me.”*

**Patient focus group, frail elderly**

14. The reports of some of the cancer patients illustrated the benefits of receiving more comprehensive local services. In this study, the difficulty experienced by non-cancer patients illustrated a less-developed network of service provision. Where patients were not supported by a coordinated network of care, many experienced anxiety, fear, isolation and difficulty in looking after their own care needs.

## **Patients want better access to information on prognosis and appropriate services**

15. Patients with cancer talked about the importance they placed on information about their own care needs and about services to address these. They made a direct link between their confidence in the system around them and heightened self-confidence, capacity to look after their own care needs and a sense of well-being. However, for patients with non-cancer chronic progressive illnesses, the absence of a clear clinical prognosis was linked to patients often being poorly informed about their palliative care needs or the help available to address these. Where there was a lack of information, this affected patients' understanding of possible end of life care requirements and led to a reduced likelihood of accessing appropriate end of life care.

*“Because I’m 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. Patients with cancer emphasised how sharing information should not be considered a one-off event occurring at the time of diagnosis. They reported that sharing information was unsatisfactory unless it was adjusted to different stages of illness. However, for other patient groups, this type of communication and information-sharing was not always available.

## **Patients found it difficult to access appropriate out-of-hours care**

17. Participants described a range of difficulties with out-of-hours service provision. Ineffective out-of-hours care could intensify feelings of uncertainty and anxiety. Poor experiences of these services led to reduced confidence in out-of-hours care. A number of participants held strong views concerning their experiences and described inappropriate care as a result of accessing services out-of-hours which failed to take their complex needs into account.

*“It was a lack of care and pure dirt ... you’re treated like cattle going to  
emergency.”*

**Patient focus group, cancer**

*“If a doctor came out to me again and said hospital I’d say no thank-you, I’ll take  
my chances in the house ... I would never, ever, ever go back again.”*

**Patient focus group, cancer**

18. Some participants reported that they had been encouraged to use NHS 24 for out-of-hours care. Some patients acknowledged that there would be limitations to this type of care and adjusted their expectations accordingly.

*“I’m no a doctor-botherer over the weekend ... I’d much prefer waiting to phone the ward on the Monday.”*

**Patient focus group, cancer**

19. However, a number of participants stressed the need for improved out-of-hours care. In particular there was a common concern that there should be better processes for sharing patient information, treatment and health records with out-of-hours services.

*“They take too long and ask too many questions and you can be really ill ... they take too long on the phone.”*

**Patient interview, chronic heart disease**

*“I was really struggling breathing and couldn’t answer all the questions”*

**Patient interview, chronic heart failure**

20. Only a few frail elderly and dementia patients used NHS 24 as an out-of-hours contact and most remained unaware of this service. Participants who lived in sheltered housing depended on warden support for out-of-hours care.



# Part 3. Quality of care

## Patients need support to deal with the emotional needs of life-limiting illness

21. Patients attending hospice day care emphasised the benefits of the hospice in getting emotional support from *“like-minded people, dedicated staff and people experiencing similar ill-health”* (patient focus group, cancer). This promoted a sense of well-being which helped to counter feelings of anxiety and depression.
22. However, many older people were reliant on family members for this type of support. Family members were often the first point of contact for both physical and emotional needs. When patients did not have family members to help in this way they did not receive the same level of support:

*“There was H. She was a volunteer who used to come and sit with me and talk to me and have a cup of tea. She lived up in S but had her own car. But she said she felt that I was getting dependent on her and had to stop coming so often. So I don’t see her much any more. She’ll drop in now and again, but I haven’t seen her for ages. It would be nice to have visitors that would come in for a blether and a cup of tea. If the weather’s bad and you can’t get about, or if you’re feeling a wee bit off, you just sit here for hours on end, looking out of the window. I do the crossword in the paper of a morning. If I can’t finish it, I cut it out and keep it. I used to have the dog, but she’s gone now. She was old, like me. She was good company and I could take her up to the park. But I’m not fit enough now to have a young dog.*

**Patient focus group, COPD**

23. Many participants, particularly those living with long-term conditions, emphasised the benefits of respite care as a means of easing the emotional and physical strains of day-to-day living both for patients and for informal carers.

*“It gives me a good break. But the big thing is – and she won’t say anything – it gives her a break too. Time to herself and get some normal things done. So it’s good for both of us.”*

**Patient focus group, Parkinson’s disease**

24. However, some participants had difficulty discussing their emotional needs and many used humour to make light of this. These needs may not be as obviously articulated as the physical needs of patients and there was low expectation amongst patients that their emotional needs would be met.
25. People who received specialist support gave positive reports of the emotional support available, but those who did not have access to specialist care struggled to deal with the emotional needs associated with their illness.

## **Practical support should be considered as part of effective palliative care**

26. Patients identified the benefits of other practical support such as help with transport. This was particularly important for patients living in more isolated areas where there was the need for more help getting out and about. Similarly, patients expressed a need for more financial information and guidance about how to manage the financial complexities caused by life-limiting illness. For example, the difficulties of navigating the benefits and assistance claim forms were indicated by the following participant:

*“Absolutely no-one gave me advice. What I’ve learnt I’ve learnt from the Internet ... for the whole of 2004 I was just too ill to do anything ... then I discovered there was Disability Living Allowance ... and the forms! You have to think through every page ... you actually have to feel quite well to get through them ... my friend who’s been near death a few times found it very depressing and it put her backwards ...”*

**Patient interview, chronic heart disease**

## **Families and informal carers provide a significant amount of care but may have support needs of their own**

27. The care of people with life-limiting illnesses is shared among family and friends and health and social care professionals. Patients identified a number of issues:
  - the importance of strong family and friendship networks
  - the difficulties of isolation and living alone
  - the sense of increased fear outside of extended family and friendship networks and without these types of support

- increased dependency on (sometimes sparse) formal services outwith close and extended family and friendship networks.

28. Many patients discussed the benefits of informal carer support, underlining this type of support as a key part of their care and integral to their well-being.

*“I like going to the stroke club and they can help you with stuff. The doctor’s handy down the road and my family can get me things. The district nurse always phones to see that I’ll be in when she comes, so that I know to expect her. My grand-daughter ... visits me nearly every week ... my son or daughter-in-law comes in every other day ... My two daughters when they’re able ... the older one phones me every Saturday morning to see how I am.”*

**Patient focus group, COPD**

29. However, patients were concerned about the impact that their illness had on partners and close family. While some confirmed their partners or carers had accessed some form of counselling or support, this depended on it being available. Many described how they felt partners and close family were keen to ‘*shoulder the burden*’ (interview with patient with cancer) but less keen, able, or willing to disclose their own needs because they did not feel it acceptable to do so.

30. The participants reported that informal carers are integral to patient care and well-being. Patient and carer needs were seen as interdependent and could not be considered or catered for in isolation. Patients were also clear that their informal carers may have unmet needs themselves and were anxious to see these addressed.

*“She 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**

# Part 4. Coordinating care to meet patients' needs

## Information and communication are key to ensuring that care meets patients' needs

31. Many patients with cancer reported positive experiences of both the quality and the coordination of their care. They received joined-up services in their community, at the local hospital and in hospice day care.
32. Many patients stressed the importance of different health professionals and services linking together and clearly sharing the same information

*"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**

33. This lessens the burden on the patient and increases their confidence in the system around them. Information sharing and clear communication are critical to both patient knowledge and patient confidence and well-being. A number of patients already receiving palliative care felt strongly about this. One patient described refusing emergency hospital admittance because of a lack of faith in the communication between different services and fear of potential delays in emergency treatment.
34. Patients described communication and information-sharing as central to their sense of well-being. Good communication was considered as more than simply being provided with written or verbal information but about a continuing and ongoing, interactive dialogue with patients, families, partners and carers. This type of communication was most often reported by patients with cancer.
35. Participants stressed the importance of knowledge gained through good communication and information exchange between health care professionals and patients. As well as sharing information between patient and healthcare provider, there was a need for good communication and information sharing with the extended network of patients, families, partners and carers
36. Many patients relied heavily on family networks for support and therefore described the importance of information-sharing with partners, families and carers. A number of older people described how their immediate or close family members tried to be directly involved in their care yet often lacked

information about their treatment and sometimes knowledge of (changeable) daily events. For older people in particular, this led to a sense of isolation and confusion over treatment and care plans.

## **Clinical nurse specialists have improved the coordination of palliative care for non-cancer patients**

37. As outlined above, palliative care faces challenges such as promoting equal access to services, improving out-of-hours care, and ensuring that care is coordinated between different providers. A number of participants in this study highlighted the invaluable support received from clinical nurse specialists in overcoming some of these difficulties. Those living with long-term life-limiting conditions over a number of years (in particular neurological disorders, chronic heart failure and heart disease) were able to reflect on service developments in this field, comparing their early experiences with current care.

*“I was then referred to [Lead Heart Failure Nurse Specialist] to monitor my progress... I was still feeling very tired and unable to do very much. She [Lead Heart Failure Nurse Specialist] was excellent and I felt safe with her. At last there was someone you could contact if you didn't feel well or were concerned about your health and wanted advice. She was like a Godsend to me! If I have any problems or concerns about my health she is only a phone call away. If this service had been provided years ago I know I wouldn't have had to go through as much as I did!”*

**Patient interview, chronic heart failure/heart transplant**

38. In cases where patients had access to a clinical nurse specialist, they perceived the clinical nurse specialist as a vital link in both treatment and care. Those with access to clinical nurse specialists describe this type of care as the critical link that strengthens their network of communication and care.

*“She [Lead Heart Failure Nurse Specialist] is my first point of contact now. Without her, I would have been at the GP a lot oftener and I would have seen the cardiologist a lot more.”*

**Patient interview, cardiomyopathy**

39. Participants outlined a number ways in which the involvement of a clinical nurse specialist had made a positive difference to their care:
- reduced isolation and an opportunity to share the burden associated with their illness

- improved information, knowledge and awareness
- better communication between acute, specialist and primary services and between patients and informal carers
- increased confidence in the health and social care system working around them
- increased confidence in their own abilities to look after their own needs by enabling the patient to assess his or her own condition
- reduced reliance on primary and acute services leading to reduced waiting times for consultation, information and advice
- improved support for patients and informal carers.

# Appendix 1. Focus group schedule

## Services and care

1. Can you tell me/us what services/people are most involved in your care and treatment at present?
  - Probe: what services and where (hospice, hospital, home, health/personal care)
  - Who would you contact first if you had a worry or problem?
  - Do you have services as well for other illnesses (such as heart/lung problems, diabetes)?
  - Do all the services you need work together well? Do different people involved in your care talk to each other? Do you sometimes find you get conflicting advice/information?
  - What works well in your care? What is it that makes it work so well?
  
2. Do you feel you have all the services you need?
  - Is there anything you would like/like more of that is not available?
  - Have you ever thought you needed to be in the hospital or hospice but were not admitted? For what reason?
  - [Social needs]: Do you feel you can get all the care and support you and your family need at home? (Prompts: personal care; day-to-day living; support with housework; getting out and about; financial support; family support)
  - [Emotional needs]: If you need someone to talk to other than family/friends about how you are feeling emotionally, is there someone you contact?
  - [Spiritual needs]: If you want to talk to someone about what the future holds for you, or about your faith, is there anyone you can talk to about these things?
  - [Probe for all the above: do you think services could be improved?]
  
3. Have you ever needed to contact services out-of-hours? Probe:
  - Was it clear who to contact and when?
  - What did you think of the way they dealt with your problems?
  - Is there anything that could be improved?

## **Information**

4. Do you feel you have the information you need about your condition, treatment and care?
  - Probe: If not, what more would you like? Is there a particular person who gives you information you find helpful? What is it about them/the information they give that you find particularly helpful?

## **Ending question(s):**

5. Is there anything else we haven't mentioned that works particularly well in the care you receive?  
What is it that makes it work so well?
6. Is there anything else you think could be improved?



## Appendix 2. Demographic data

Number of patients	Age	Diagnosis	Area, eg hospice voluntary centre	Focus group (FG) Telephone interview (TI)	NHS board
7	65-78	Mixed cancer group Multiple sclerosis	Hospice	FG	Forth Valley (pilot)
10	76-96	Frail elderly/ dementia Learning disabled Breast cancer/ dementia	Day care centre (voluntary sector)	FG	Fife
8	74-94	Chest/stroke group	Day care centre (voluntary sector)	FG	Fife
9	42-91	Mixed cancer group	Hospice	FG	Greater Glasgow & Clyde
11	69-91	Frail elderly Chronic heart disease MS COPD Stroke	Voluntary centre (community based)	FG	Greater Glasgow & Clyde
8	46-72	Parkinson's disease	Support group (hospital)	FG	Borders
10	46-72	Parkinson's disease	Support group (hospital)	FG	Borders
5	46-71	Chronic heart disease COPD Mixed cancer	Various	TI	Highlands
4	44-70	Mixed cancer	Various	TI	Shetland
Total = 72					

# Appendix 3. Researching palliative care

Current Scottish Government policy outlined in *Better Health Better Care: Action Plan (2008)* commits 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.*” This move towards a more equitable provision of palliative care is accompanied by a policy drive for “*patient centred care which is respectful, compassionate and responsive to individual patient preferences, needs and values.*”

Improving patient care requires working with patients, tapping into real-life experiences and using these to develop patient-centred care. CCRC identified two particular challenges in adopting this approach:

- Sensitivity - Exploring palliative care needs and experiences requires methodological sensitivity and should build on a growing bank of research expertise. The discussion of death and issues surrounding end of life can be uncomfortable and often distressing. Participants in this project are patients experiencing chronic and life-limiting illness, or requiring end of life care for the frail elderly. Many actively avoided talking about the subject of death and dying, or treated it humorously, focusing instead on the difficulties and concerns surrounding day-to-day living for themselves, and their families, partners and carers.
- Understanding and awareness of service provision - One of the earliest problems identified in this project was the difficulty recognising and understanding the term ‘palliative care’ outwith cancer-specific settings. For patients with cancer, the hospice movement has greatly influenced perceptions and understandings of palliative care services. For participants with cancer involved in this project, the term palliative care was a meaningful one. For patients with other life-limiting illnesses the term was unfamiliar and unclear. The lack of clarity of about the term ‘palliative care’ and of the services available was often accompanied by low expectations of this support.

# Review of palliative care services in Scotland

## Report supplement: Patients' views

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Audit Scotland, 110 George Street, Edinburgh EH2 4LH  
T: 0845 146 1010 F: 0845 146 1009  
[www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk)